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UNIVERSITY OF ALBERTA

UNDERSTANDING NURSING AND ITS PRACTICES

BY

BRENDA LEIGH CAMERON



A THESIS SUBMITTED TO THE Faculty of Graduate Studies and Research in partial fulfillment of the requirements for the degree of Doctor of Philosophy

DEPARTMENT OF SECONDARY EDUCATION

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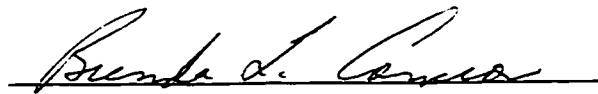
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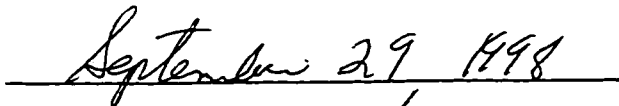
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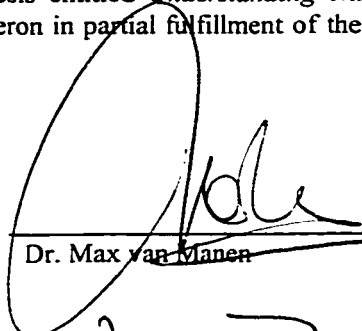
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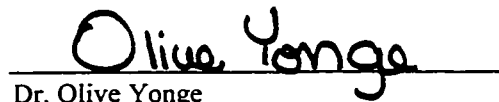
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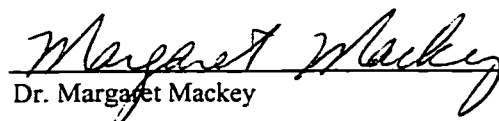
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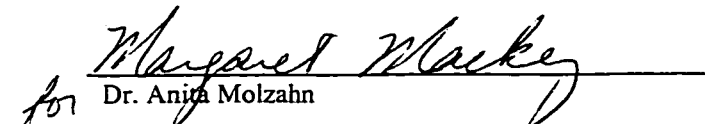
  
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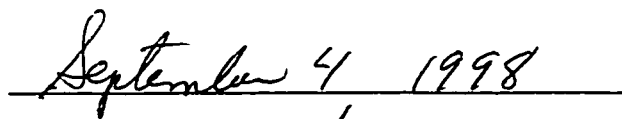
  
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## **ABSTRACT**

This is an inquiry into the nature of nursing practice. In particular this study addresses the question “what are the distinguishing qualities of the nursing relation as revealed in the practices of nursing?” A related question is “to what extent does the theoretical discourse of nursing approximate, inform, and present the practices of nursing?” Because this study took place in a cancer institution, the study gives insight into the qualities of nursing that are important to nursing people with cancer. In chapter one, differing descriptive “takes” on the experience of nursing are presented with a view to opening up the complexity of the research questions. This is followed by an elucidation of bathing as an integral nursing intervention written first in terms of research arguments and second, in terms of experiential narratives from nursing practice and literature. Chapter three aims to document how the knowledge base of nursing expresses an ongoing tension between representational and presentational forms. It is suggested that the more the knowledge base tips towards representational forms the more it tends to lose contact with the experiential reality of nursing. A review of hermeneutic phenomenology combined with direct description follows and shows an attempt to find ethical and linguistic means to retain as much as possible the vibrancy of the actual experience of nursing. Descriptions and interpretations gleaned from observation and participation in the lives of nurses and cancer patients along with audio-taped interviews, are woven together with the researcher’s own experiences in a particular narrative style revealing aspects of nursing practice that are often tacit and taken-for-granted. In the final chapter some assertions are listed in the form of theses statements based on the findings of the study for the profession of nursing in practice, education, and research areas. The study supports a better balance between the intellectualized forms of knowledge that serve primarily the more technical (cognitive) aspects of nursing and the felt (non-cognitive) forms of knowledge that may lie more at the very heart of nursing as a human caring-healing practice.

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Seeking the qualities of nursing as revealed in the practices of nursing has brought to light the qualities and gifts of individuals who have informed, sustained and supported myself and this work from its inception to its completion. And just as the qualities of nursing slumber until they are evoked in a certain moment in time, then remain forever as possibilities in the world, so too will the qualities in others summoned by this work not fade. They will live on in my life and the pages of this dissertation. These individuals have made the writing of this dissertation not only possible, but inherently worthwhile.

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on from preconceptions and distortions of things to clearly seeing the essence, the qualities inside myself as person, nurse, researcher and those qualities expressed inside nursing practice. I acknowledge Max van Manen for these generous and sincere gifts to me. In time, I hope to emulate his mentorship, his supervisory abilities with my own students.

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### *Seeking Nursing*

*"But what is nursing?" asked I.*

*"Nursing is encaptured and held in its theorizing. Seek there," replied the Theoried Ones.*

*I sought and did not find it there. Save replicas. No pulsing life did I feel.*

*"But what is nursing?" pursued I.*

*"Here it is; in these skills, look close; see this protocol. Hands On stuff, it's great," supplied the Skillologists.*

*I looked and saw templates, Step A, Step B, Step C...Imitations all. Devalued things I thought, they judge the value of the thing by the utility of the thing. No intrinsic judgment did I see. More replicas.*

*"And here," said the Outcome Specialists. "Read here and be certain what an application of nursing does for others; See here, in this map listed here, day one, day two..."*

*I looked and saw a dose of nursing delivered there; day two care when it was plain to see the person needed day one care and more; no deviation from pre-formed care did I see. Anathema I scream; worse than imitations; withholding care is what it is. Fabrication all. Practiced concealing of need.*

*They nurse the map I thought; the heart of nursing not at all, at all. All withers within this scheme.*

*"But what is nursing?" I ask with despair.*

*"Look among the wide awake" a daimon urges in my head.*

*"Seek in the nursing place, the commonplace, the ground well trod," whispers another.*

*I heard and looked and there I found the Nursed. And I see.*

*The answer softly comes...it is not a great knowing.*

*Rather it is like the simplest of things. Age old patterns come to view; moving the infirm off an aching hip, lifting a child to safety, spooning food into a drooping drooling mouth, sponging a sweating body, directing a crying baby toward a nipple, coaching a step-crutch-step walk to an injured one, injecting a body with pain relief.*

*"Here," I said, "Here it is. The practice of it begets the nature of it. The acts are the flesh, the bedrock of nursing, anew each time; taking into oneself another and making space for her.*

*(Cameron, 1998)*

## CHAPTER 1: THE QUESTION OF NURSING

*"My own body is in the world as the heart is in the organism: it keeps the visible spectacle constantly alive, it breathes life into it and sustains it inwardly, and with it forms a system"*

*(Merleau-Ponty, 1962, p. 203).*

I started the process of formal data collection by running alongside nurses. I had a luxury that most nurses don't. I could stand still, record, and "see" nursing happen. Because another nurse nursed, I was free to observe, to reflect, and help when needed; free to gain views on nursing acts. I was able to stand back and just see, hear, touch, smell and yes, even taste as some of the strong odours of chemotherapy, stem cell transplant solutions somehow ended up in a taste in the mouth.

In the beginning, I just wanted to run around and "fix" things. The overwhelming acuity of illness care, the immense amount of work the nurse must get through, the unplanned for events, a person's condition worsening, special procedures that must be done immediately, allied disciplines needing coordination, nurses melding together other departments mandates for patient care and more. The constant sense of being "Jannie on the spot" hit me at once. Yet the nurses went about their work seemingly oblivious to the complexity of what they did, seemingly unaware of the high level of integration and synthesis they demonstrate and practice. They would move from one situation to another, each one demanding different responses, vastly different interactions from the nurse and I wondered again with outside/inside eyes "what makes this all click, succeed, rather, what makes it work?"

### Nursing Take One: Air Hunger

Gwen cannot breathe. Her attempts to suck in gasps of air are audible. Her colour is poor. A pale circle surrounds her mouth. Her lips are not pink anymore. Her chest heaves and retracts with the effort of breathing. I know Gwen is close to a respiratory arrest. Her nurse immediately moves to her side, speaks to her while reaching for and replacing her nasal oxygen prongs with a mask and increasing the oxygen flow. I move to the other side of the bed, quickly assist with the removing of the prongs and the securing of the mask (the mask will increase the amount of oxygen taken directly into the lungs). Because I am new to this agency I scan the room for the equipment and other elements for dealing with respiratory and cardiac arrests. I look for a suction apparatus in the room. I look outside for location of the crash cart and emergency medications. I check how large the vein is that currently has an IV running in it. I look out the window for other staff. I look back at Gwen and wonder if there will be a mucous plug soon. We will need suction. I note all of this in split seconds and turn to Lynn the nurse. This is what I observe:

The nurse bends over to Gwen. She seeks eye contact. She speaks softly but firmly and tells Gwen how to breathe with simple directions. As she speaks she places her hand over Gwen's diaphragm to give emphasis to her words. Her other hand supports Gwen on her back and upper shoulders, gently pushes her forward to a more upright position. She alternately strokes and supports the spine. Her hand goes to Gwen's legs which reflexively jerk up and down in her anxiousness; flexed knee, extended leg, flexed again to her chest. The nurse guides these limbs into a crossed leg position and holds them firmly in place for a

few seconds. Gwen allows the nurse to do this and stills the movements of her legs and places her consciousness on her breathing, following the nurse's instructions.

This goes on for a seemingly endless time. The nurse coaches, supports Gwen sitting upright, encourages her to breathe from where her hand is placed. "Breathe down here Gwen, push my hand out, that's it, really good, now another one." I stand across the bed from the nurse. I look for signs of muscle flaccidity and fatigue to indicate a worsening condition. I see them. The arrest nears yet Gwen's nurse continues. I know this nurse is in control here.

The soothing tones of the nurse's voice and her utter calmness envelop nurse and patient. There are only two in this universe. Yet as, and even before Gwen's breathing slowly returns to approximating normal, I feel a calmness envelop me too. There will not be a respiratory arrest here. "They" have come through.

There is just as much a sense of relief in my nurse as in Gwen. They stand quietly together, a sort of celebratory together. I see my nurse adjust her postures, her breathing. Gwen breathes. I retrieve the oxygen saturation machine from the outside room to my nurse. She thanks me with her eyes and sets it up.

I know as clear as the dawn that a less experienced nurse would have called an arrest. Gwen would have been intubated, and would now be on a respirator as the hospital code team would carry out their mandate. I know too that this nurse brought her through with her finely tuned nursing judgments. At coffee break I tell my nurse what I observed during the "almost arrest." She replies:

You know if she had progressed to respiratory arrest and I know she was at that point, the fine moment where it could go either way I would have acted then as per the protocol for respiratory arrests. But to worry about that then would have taken me away from the actual moment. I had to be very present to her right then in order to just get her through it. Getting her through it was my foremost thought not treating what might happen. I didn't want her 'tubed' (intubated) with everything else that is going on for her.

Later on in the day, I hear the physician saying, "Good Lynn, we didn't have to intubate her, keep it up." I ask the physician about this while he runs to answer an urgent page from the next unit.

What you have here is skilled nursing judgment, don't mistake this for non-action or anything else. Another nurse would have called an arrest. Lynn knew what to do. She saved that person from much agony and another invasive

procedure. And then if we would have intubated her, it takes so long to get the person off it. I need these nurses like this. How health care thinks we can survive without them is ludicrous...

Later as I was still negotiating my role as researcher and still uncertain as the best way to come at nursing as lived, I tried to probe a little bit more about just what this nurse was doing on the inside. "Tell me about this situation", I asked the nurse, begged really, my zeal most apparent and probably written on my face. "How did you know what to do? What were you thinking when I saw you assessing her, what made you not call the arrest? What made you able to act in this way?"

I was just nursing Gwen. Gwen has mets to her lungs, she has fluid on her lungs, her haemoglobin is very low right now, so severe breathlessness is to be expected. Mind you that was more than severe breathlessness I know and more than we like to see. But I also knew she had the ability to overcome it. She was a dancer you know, she knew about breath control and bodily relaxation techniques at one time in her life. I just called on it, transferred it. I knew she had it within herself to come through on her own.

Then the nurse went on to speak of signs and symptoms of breathlessness; no new material here to me. I wanted her to speak of her judgment, her critical awareness. Mostly I wanted her to speak to the tacit intimacy of the moment and how that connects to her judgments; how her relational qualities as nurse to Gwen as patient, enabled and generated her nursing actions. Instead she began to translate her action into theory.

I asked Gwen, the patient, to describe this same situation. She spoke about how the nurse stood beside her and talked to her and gave her the confidence to breathe, to keep trying to breathe with whatever lung capacity she had.

I eventually focused on my breathing and her hand touching me on the front where she wanted me to breathe. It was funny. I knew she was asking me to do something that was really really hard at the time and I wondered if maybe this just might finally be it, dying. Yet she made me feel calm and gave me confidence. Her hand was rubbing my back, I remember that. It's hard to explain. It's just something I felt. She helped me stay in my body, I couldn't have done it by myself, I was past helping myself. Afterwards she taught me a few things too so I can recognize it coming on and control it better. She knows me better than I know myself sometimes.

And so I learned early in my participant periods to observe, to write, to record, and then to discuss these descriptions later in an audio-taped interview. And in the nursing tradition, we would talk in the hallway, the tub rooms, utility rooms, on the way to coffee, at coffee, while charting. Most often I wrote on scraps of paper, paper towels in the bathroom, anything I could get my hands on. My journals were always with me but in the report room on the station. I couldn't always get back to them quickly enough and I wanted to grasp the moment of lived

experience as soon as possible. For a while I tried a tiny tape recorder that fit in my pocket and I would go off and speak into it. But this proved not to be better than writing on the scraps of paper. Writing caught the description and moved me into reflection even for a brief moment.

### Nursing Take Two: Exhaling

#### *First Voice:*

Administrators these days want *predictable outcomes*. I used to be a head nurse, now I'm a business woman. We are no longer Nightingales at the sick's command, we have to understand business. I have to be able to prove that I need so many nurses for my floor. My lifelong nursing expertise and judgment of how much nursing care is needed and how many nurses I need to do it no longer cuts any mustard. I have to be able to use *criteria to justify* my requests, criteria that doesn't match nursing practice very well, if at all. Its about pre-planned patient care maps and pre-planned patient care outcomes. In my experience and just plain common sense tells me that people just don't fit into these things very well.

#### *Second Voice:*

Well if nursing is now supposed to be run as a *business*, what other business would be run like this? We have *human beings* not just a thing as a *commodity*. We are so short of supplies, we ran out of normal saline last night, something so basic to surgical care. There are no 2x2 (5 x 5 cm's) gauze pads on the unit right now; there is nothing to *cleanse* the wound. We need to save the 4x4's (10x10's) to *cover* the wounds.

#### *Third Voice:*

Last night we *received* a patient from Emergency who was on a medication that needed a pump (an infusion pump to regulate flow and dosage). Our floor was already short pumps and we had already been *calling* over the intercom for a pump for someone else that evening. The emergency nurse told me that she was *taking the pump back* to the Emergency Room. I told her to either leave the "patient and the pump" or take the patient back to Emerg. She was very angry at me. But I already had a patient who had to be *watched* every minute because of heparin running with no pump. That's just plain *dangerous* given what else I was doing last night.

#### *Second Voice:*



Nursing talks so much about *caring*. When people use the word caring and say nobody cared for this patient, I get angry. I care. But what I do is nurse and now I have to *nurse within a structure determined by economics and politics*. When they say nobody cared, it covers up other facts...like for instance that that day there was only one registered nurse to take care of the needs of 30 patients.

*Fourth Voice:*

As a patient, I believe you can't replace a nurse with someone who learns everything in the lab. I've had an occasion here to meet one of those nurses who has just learned in the lab. She came in to work with my lines and I could see she was having trouble. I asked her if she had done this before and she said, "Yes, I've done it in the lab." Well I had to tell her certain things about how to work with the lines, safety things. I thought to myself, "Heaven help us if all the nurses would be like that, a product of a lab! We need a Nightingale again.

*Fifth Voice:*

People look at me feeding a newborn and they think, "who has to be a nurse to do that?" But I'm doing many things, I'm evaluating his sucking reflex, swallowing abilities, his colour as he sucks to note cardiovascular status, his abdominal changes while he sucks and swallows, his fontanel, his skin, his comfort, all of these things and more. I once picked up a baby with a hypoplastic left heart that had already been discharged only because the baby was crying and I just sat down in the chair and held him and rocked him and settled him. At the end of 15 minutes I knew there was a serious cardiovascular problem going on and I got up and called the paediatric resident. He told me the baby had been discharged and that was that, and I told him to get up here right away. He came. This Mom and new baby were on their way down to the car having been discharged.

*Sixth Voice:*

I like my nurse to be with me when all these people came into my room, the doctors, the diet person, and lots of others. They talk and they ask me questions. I can't take it all in, and sometimes I can't understand it. And I don't like to look the fool you know. But later my nurse *explains things*. She *remembers* to ask my questions too, in case I forget, and I always do forget something. She asks too the questions I'd rather not ask, but need to.

### *Third Voice:*

I had a very ill patient the other night. My patient had a relapse after four years of being cancer free. She had a bone marrow transplant and was one year away from “cure.” And she was angry, very angry, and striking out at her husband and her mother especially. We had tubed her because she had a complete respiratory arrest and so she was angry at us for that now she could speak again. I knew I needed to sit down and speak with her and so I took 15 minutes to talk to her. Fifteen minutes is just a drop in a bucket with someone who has all of this going on, yet that fifteen minutes allowed me to learn some things, to explain some things, to find out what was going on and what she really wanted here. And in doing this, I am very aware that I am fifteen minutes behind in all my other work and others will say then, “this was not time well spent.” Later I was criticized by the doctor and some of the other nurses. The doctor wanted to know why I hadn’t started the blood. Physicians sometimes just expect you to go in there and do certain things because they need to be done. But blood was not a priority right then. Like this woman is yelling, “I don’t give a shit about anything!” And she yelled at her mother, “Get out of here you ----, it’s all your fault!” Do you think she cares how her haemoglobin is at this moment? And you know I had to give Benadryl (to prevent allergic reaction) first anyway before the blood could be started and as soon as I started it, she would have altered sensations. For this discussion she needed to be alert and she needed my undivided attention. She needed me sitting in front of her with direct eye contact.

Later the nurses criticized me for sitting down when they were running around “answering bells.” And so we start pitting ourselves against each other. You know, I don’t think nurses even appreciate nursing sometimes. I think it is partly because we don’t nurse very often these days with the budget cuts. We are very good technicians in the hospital and becoming better and better at it but feeling less and less fulfilled. That is why these good people are leaving.

### **Nursing Take Three: Inhaling**

When nurses reflect they tend to engage in specific descriptions and interpretations of practice.

There was a 19 year old boy who had a rapidly growing sarcoma. They thought it was appendicitis and when they opened him up saw this large growth. They removed it and transferred him to us for care and chemotherapy. His prognosis

was not looking good at this point. The mother was there every moment with him. This young man was demanding, obnoxious, and rude. Sad to see really. His mother was worse. She was always yelling at us each time we were in the room. Or giving us sarcastic remarks. The father refused to be involved with the son because of his own grief over this. The boy had a colostomy and the father could not be in the room when you changed it or even spoke about it. But the mother could.

Everything we did for this young boy was carefully scrutinized. To be honest and to give these two the benefit of the doubt, they had been transferred from another hospital where they did not receive good care, and this may have been the whole origin of the situation. We often have to do much rectifying work when patients who are very ill have been at other institutions during this time of downsizing. Or the nature of their cancer, their limitations, are not understood and so staff in other places look upon them as whiners or complainers, etc. And we also knew the obvious, the great fear of what is coming, whether there is a future, of facing death. We knew and understood this and so we acknowledged all of it and got on with it. We spoke with the young boy, with the mother, found out their expectations, fears. We explained everything we were doing, why, what, when, how. Often this helps those who are fearful and upset. We took the mother to coffee to get her out of the room and one of us stayed with him. We really rearranged all our schedules to accommodate this family. Nothing worked. We would be leaving the room and they would call us back and say that the overbed table needed to be a little bit closer to the boy. Or that the curtains weren't drawn just so. Usually this means that we need to address the fear more directly. So we decided to spend as much time as possible with them to allay their fears, to show them compassion, to encourage them to trust the treatment their doctors had given the boy. We gave them the same care as anyone else but it was more comprehensive in that we spent so much time with them and explained every act.

This went on for some time. Soon it came that as nurses we had to change our assignments every two days which was not good. But we could not take the nastiness of this family for more than two twelve hour shifts. Their doctors were

not anxious to see them either because of this and they made only very very short visits which was not helpful to the family or to us. This went on for some time.

We never did feel we were able to manage this young man even though we tried everything we could. It is so demoralizing to be constantly criticized and told our care is poor. We nurses were reported to the administration several times with accusations that were either untrue or trivial. But we still kept going in there, staying with them, giving them the best nursing we had to offer. We kept working through with them things they found difficult. We managed all his symptoms well and got him going again for a while. We wanted him well enough to go home while they decided on the best course of action for him in terms of chemo, radiation, whatever.

I don't think our care made a difference to them at all but it will down the road. I mean of course it did physically and I think emotionally too because the nursing care got him back on his feet. But I don't think they know it. We have a vision in mind for this young man and we will keep working toward it. He will come to see it, grow into it. And we are willing to wait. It was as if the boy was challenging us and saying, "the last place I want to be is with you nurses. See how nasty and unlovable I am when I am still not dying yet. Will you still care for me when I am really sick and dying?" I think he got his answer. We know he will be back soon. For people to have others give up on their life and their prognosis and withdraw from them before they are even dead is so frightening for them; we just have to manage it as best we can. We want him to accomplish some things before he dies.

Well you just have to understand that he is very set in his ways and that he likes things done his way. This is not a common thing in patients his age but it is for him. For example he has a colostomy bag and he does his clip up a certain way so if you go to do his colostomy care and you do up the clip maybe the way that you've been taught which is different than how he has been taught, he'll get very upset and tell you that that is wrong, it is not going to work. It will work, it is just a different way, both ways are ok. I just happened to be one nurse that did it up his way. As long as you know he is just more set in his ways than most, that he is young and that he cannot handle anything that deviates from how he has been taught. It's just that if you don't know what ways he is set in, the way he

goes about telling you about it, he tries to make you feel incompetent but at the same time you know that he is only 19, scared, his future isn't great, so that probably adds to his stress. But it is little things, like you'll be moving away from his bed and reaching out to put the table closer to him and he will say, "put my table beside me, don't forget my table." It is a little thing but you want to say, "but I was going to do that", so that is hard...um doesn't sound like much but time after time and never a please or thank you and if someone is really sick you don't expect that but an occasional acknowledgment that you are doing something good kind of helps rather than negative comments all the time.

It is also hard because Mom's here a lot and she is quite anxious and he is hard on her too. We have heard him snap at her. It is very hard on her though. The odour or the colostomy is very hard on the Dad; he cannot acknowledge the colostomy. One day near the beginning before we were able to get him stabilized he was cheyne-stoking and had a very drowsy level of consciousness. He was really getting hard to assess. Mom was so upset that this was it, that he was dying, so we turned down the morphine drip and tried some other things. We called the physicians and suggested some things and they worked and brought him around.

He is doing better right now; there was a big family conference that didn't include him at all and they decided to put him on more chemo right away. We nurses feel he should go home for a while because we worked so hard to get him better so he could do this. He needs some time at home to bring him back to himself and while he is as healthy as he can be right now. This has been such a shock to him. He had two rounds of chemo and his cancer is still growing. Right now he is over at another hospital getting a gastric-tube and broviac central line in and he just had more chemo on Friday.

A lot of us have a lot of mixed feelings about this because his prognosis is poor. He's got a foley catheter. He's got a subclavian line. He had an NG tube. He's on oxygen occasionally. He had the morphine drip. I mean he has tubes coming and going everywhere. You know he is just starting to feel not too bad since the last chemo and so his quality of life this next round of chemo, he's not going to have any because of the nature of the chemo. We really felt he needed to go home, be in the family circle again and then come back. Or because his

prognosis is so very poor, we think that deciding to have chemo right away is dangerous for him. The danger is he could die from the chemo and not the disease right now whereas if they waited he could go home and see to his life a bit. But at the same time if he were my child I might too want everything done possible and who knows, maybe this chemo will buy him time. It's just that we know his prognosis is poor, he did not tolerate any of his treatments well so far, he needs constant care, he needs time in his own room at home to come to himself and then go onward with treatment or not.

But all these are ethical considerations, like they had this big family conference to discuss it all and everyone was there except the patient and we nurses protested that but the family stood firm...

(long period of silence)

Yeah, so it is really hard. And all of us have expressed the feeling that pretty well none of us want to be here on the floor working if he was to die...because of the family dynamics and because he has not had time at home. We are not looking forward to that, so it is really hard, Psychology is really involved with him and we hope they can help. He is very manipulative too, like "give me a drink, hold it to my lips, don't spill it Stupid." He can do this himself. You don't want to be mean but you need to encourage the use of some muscles, so you make him do it and he gets upset...so it is hard

It is really sad. He was going to university in Ontario, an honours engineering student, so you know he is really smart. He went in for suspected appendicitis and they opened him up and found the tumor and took most of it and his appendix and sewed him up. Two weeks later he ended up here in Emergency with a bowel obstruction from further tumor growth even before he could see the Oncologist here.

You know what he said to me one night about 0300 after I had done his treatments and gotten him settled again. Earlier he had been screaming at the evening nurses, the dietitian, the psychologist, especially the psychologist. He said to me, "I really wish you guys could have known me before I got sick because I thought I was a pretty neat guy." And then he and I cried together; we had such grief over his circumstances, his behaviours. And then I sincerely told him that that neat guy was still right here with me.

Here these nurses do not describe step by step nursing actions. Rather they talk about nursing a particular person in a particular situation. They have a way of telling the story that focuses on the person without the specific nursing interventions, nursing acts. You can probe for this. "Tell me what you did first?" And they look at you as if to say, "Why? What I do is dependent on the situation; more important is who this young person is, what he is suffering from, getting him through it and planning for the future however brief it might be."

It is not that nurses don't value their nursing actions. It is just that they are so complex that it is difficult for them to speak them scene by scene. Nursing has to be participated in for it to make any sense. What is unique for them is not the techniques of the bedbath they give this young man. Rather it is his personal circumstances.

#### **Nursing Take Four: Congestions**

I was in the inner city at a single men's hostel with my student and her preceptor. The residents of this hostel are street people. It's hard to describe how dire the living conditions of an inner city are if one has not actually been there. What one sees is end stages of everything; end stages of lives, bodies, buildings. All is full of tragedy and neglect. This particular hostel is extremely run down, itself an endstage, a blight on the street. Yet it offers a bit of respite from the street for a while. The residents are as debilitated as the building.

Joe, an Inuit artist from a Northern community, and I talk for a long time. His art hangs in the art galleries across Canada and other places in the world. Sometime long ago, Joe was flown out to Edmonton for medical care and when he got better, never went back.

We speak of drawing. Tremors from Joe's addictions now show in his hands. He shows me the tremors and tries to hold a pencil. He draws a shaky line on my paper and I see the beginning image of a seal hunter, ice floes, open water. We speak of life and meanings, of seeing through his hands, of making the first line of a drawing, planning spaces on the paper so others can see too; the arctic spaces so full yet so empty. I tell him that sometimes nurses tell things through their hands too and that I have had this experience. "Does your soul go into it?" he asks. "Sometimes", I reply. "Too much of my soul goes into those drawings," he tells me. "Sometimes too much." After a moment of silence he decides to sing a song for me as if the poignancy of the moment is too hard to bear. We address and fix some of his health concerns, mostly his badly infected feet. The talking ceases quickly when the volunteer who handles the residents' money arrives. Joe needs his money to make his daily purchases.

To this day, I think of Joe. The nurse practitioner told me of others with genius, concert violinists, published composers and poets who live on the streets. "Sometimes they have evenings here and you should hear the musicianship, the creativity in the writings" she said. "But here you need to just be with them where they are, while at the same time always a gentle pushing towards health or whatever bit of health you can connect with. Not an easy task. I work on harm reduction, to prevent them from further harm in their choice of lifestyle", she said. She interacts closely with Joe. They know each other well. There is genuine expressed human relation here, relation with one who would be called a degenerate of society.

In the next room, I help my student draw blood from another resident at this hostel. It is for a test for the blood level of Dilantin (anticonvulsant drug). The nurse practitioner is now in the next door with someone else. We can see her through the glass window separating the two tiny closet like rooms stuffed with first aid kits, medical and nursing supplies, files, papers, bottles and cans to be recycled, and other unidentifiable stuff.

The student, the resident and I have a conversation as we carry out this procedure. We speak of what this resident did before he entered this hostel. He was a trucker, a “heavy hauler.” I notice that these residents are always candid if they detect sincerity in people. During this act of drawing blood with the student shaky at times but solid; following the course of the vein, patting the arm to bring the vein into view, applying the tourniquet, inserting the needle, attaching assorted test tubes, waiting for them to fill, gently agitating and labeling the tubes, we talk and we listen, a give and take, back and forth conversation. He assists us in clenching his fist, positioning his arm, encouraging the student, “don’t be scared, I won’t even feel it, just do it...”

As our procedure and conversation continue, he talks about the nurse practitioner in the next room.

“You know I have been off the booze now for 4 and 1/2 weeks just for her.” He shrugs his body in the direction of the next room.

“Just for her, the nurse”, he emphasizes. He gestures toward the room again.

“She told me I had to stay off the booze so she could get a blood sample which would give her a good reading of how many pills I need to take.”

And a little later in the procedure:

“That nurse is the only one who really cares when I hit my head during my fits, the only one. I don’t even care for myself.” He looks at the student. “You’re going to be just like her too. I can see that right now.”

He adds thoughtfully looking at me, “Oh we have lots of kinds of workers that pass through here, let me tell you. You get to know them, they have their own agendas, usually nothing to do with us or our situations. But that one, the nurse, she cares about me...”

### **Nursing Take Five: Secretions**

My father died during my master’s study and my mother dies during my doctoral study. In the course of my father’s death, I learned much about a close one’s human body consumed with pain, with dis-ease and dis-comfort and subsequently comfort-as-lived as a concept misunderstood in nursing practice. Comfort was the concept I studied for the masters degree. In this doctoral study I look at the qualities of the nursing relation as revealed in practice; the nurse’s way of relating from which her nursing practices arise.

I remember Rod. He told me he worked in ICU because he liked to “fix” things. Before becoming a nurse he was a pipe fitter on a pipeline crew. “I could fix anything, get anything going. I’m still doing the same thing here”, he laughs. Funny how one anecdote connects to the other. The resident above on whom we did the blood draw spoke of his veins as pipes to the student. “Just think of them as pipes, pipes connect to other pipes. Go right into the pipe but miss the bindings, the connections”, he said. “Valves”, I supply.



Rod's uncle who raised him, developed Alzheimer's disease and Rod was unhappy with his institutional care. Subsequently he upgraded his high school, became a registered nurse, nursed in a hospital and cared for his uncle until he died. Rod then took an ICU course and at this point had worked in this area about 6 years.

He stood beside me as I stood alongside my Mom during the time in ICU. In the beginning as I automatically reached my hand out in response to the alarms, to silence them, to "fix" things, Rod quite gently, but firmly, caught my hand and guided it back to my mother's person. "Leave this stuff to me. I'll deal with the alarms for now. You deal with your Mom and how she is doing in herself. I promise you I'll tell you when something is amiss", he said.

During this time Rod spoke to me in ways that only a nurse to nurse can. Yet later he oriented my sister and brothers who are not in health professions in quite a different way to my Mom's situation. And five weeks later on another unit, he was there when it was time to let her go.

How hard it is to be a daughter and a nurse! I remember feeling annoyed that "they" were doing the things I wanted to do for my Mom. "Couldn't they leave and let me get on with it?" I thought. "I know her better than they do." And later when I sensed they were closer to my mother, closer to her body and herself and her dire illness at that moment than I was, I cried.

I wanted it all. I wanted my relation to my Mom as daughter, but I also wanted the nursing relation. I know that relation. I know how to live the nursing relation. I didn't know how to live my mother's dying.

Yet as much as I wanted to nurse my mother, in truth, I was not always in the here and now of it. I was in my memories and my fears. And the nurses knew this. I felt my desire so keenly for my mother to heal. My body longed for her body to function properly, to stay with me. My chest, my breathing, my stomach contractions would become as laboured, as painful as hers as if I could somehow ease her pains, pull her through them, breathe for her.

I relinquished the nursing aspects of my mother's care. With the help of nurses like Rod, Bonnie, Karen, Cheryl, Debra, I slid back into being with my Mom as a daughter. Not that the nurse in me ever left. But it went back a long way. I learned to enjoy feeding her jello at meals, making the moment as if we were at

the kitchen table in our family home. I helped to turn and position her. I became aware of the changing expressions in her as she battled life and death. I learned to respect her rhythms of breathing, of pain, of expressed and unexpressed feelings, of her regret and her concern for us. And I knew that what she wanted was more life.

When I left one evening to shower at the hotel (my mother had been airlifted from her home to another city) in preparation for a long night ahead, my mother in her extremis, indicated she needed to say something urgently. It was a whispered admonishment, "Watch the ride home in the taxi, it is dark you know." And I thought, even in dying, mothering never ends.

One early morning, just as the sun came up, I looked out the 6th floor window and saw the wheat field waving in an age old pattern in the path of the morning wind, each wave and sometimes each blade of wheat itself shimmering and flashing in the early morning light. They are like ocean waves, each one its own rhythm, duration, its particular path; some waves long, beautiful in formation, lasting, some short, fading quickly. I counted them, timed them, thought of musical intervals, timings and notations for them. I had a syncopated rhythm in my mind, an orchestra really; my mother's ragged breathing that reverberated through my body to my very soul, the periodic cadenza of a long ripple of wheat, the beeping monitors beating out regular time, the short waves of wheat a sporadic modulation, the long waves sustained minor haunting notes.

My mother and father grew up through the depression years in Saskatchewan, the 1930's, when wheat did not grow and wave, where daily food was not always present; a potato, a sheaf of wheat a luxury. They often spoke of how hungry they were. The rhythms of waving wheat symbolized for me my mother's own life rhythms here so clearly on display; these struggles with living, with dying, with adversity. As much as her current misery affrighted me and made dying seem kind, I did not want her to die.

The rhythms continued, representing somehow cycles in life, a time of plenty, a time of famine, a good breath in...no breath...a sigh the next. This living/dying was but one more rhythm of her life, as yet an interrupted, indecisive one. Yes she lives. Now she dies. There I see a faint rise of her chest. Now I see the amber and angel broach I pinned on her gown last night flutter barely with the

rise. The pulse in her neck I trace. It's gone. I wait. It returns, dub dub dub, shows itself. I release my breath.

One of the nurses came in as part of her early morning rounds and stood beside me at the window. She said, "I often watch the waving wheatfields. It's sort of a part of this hospital's scene." And she spoke on. It's hard to capture what this nurse did for me in these few moments, but she helped me let go. How? I don't know. Mostly she stood beside me, my mother's laboured asynchronous breathing filling the room, the various monitors marking off time in seconds, the wheat fields unremittingly waving below us, the nurse's presence and hand stroking my back, and her gentle words; her quiet presence filling all the in-betweens and the unseens, the regrets, the promises. It would not be long before she dies.

At some point before this, the doctor had told us that our mother would die within 24 to 48 hours. I looked at her and thought, "No, she is not a dying woman, a critically ill one, but not dying." She kept on living. Yet four weeks later when the nurse called me at our hotel and said, "There is a change in your Mom, nothing apparent yet, no significant change in level of consciousness or vitals or output from when you left to shower. But something has changed. I just have the sense she is shutting down, pulling away", I knew to listen. Not because I pitted the nurse against the physician. Not at all. But because I knew her perception of dying came from nursing's relational care, a different knowledge system.

I don't, and didn't at the time, deny doctors their expertise as some are wont to do. On the contrary. I felt fortunate and privileged to have had such comprehensive medical care given to my mother by the surgeon, by her physicians. This medical expertise used all its knowledge from the time of diagnosis, spotting the bleeder, replacing blood loss several times, dealing with a pulmonary embolus, balancing electrolytes and fluids, pinpointing the bleeder in the bowel, doing surgery to correct, directing post surgical medical care. I felt the doctors working well with my Mom, with myself, my sister, my brothers. My mother needed these medical practices. But she lived and thrived and died within the practices of nursing; nursing relation, a fusing of bodies, minds, and spirits.

After she dies, I worry about many things. The worry somehow holds back the lived grief as if guilt were a better self punishing thing. But I worry. Mostly I worry about the medical and nursing world of which I am part, but not part here. Did I do all I could to influence her care world? Was I just another phenomenon in this medical and nursing world immersed in its own pursuits, someone else for them to deal with, work around? Did I actually posit, constitute the world for her too? Did I advocate enough for her? Should I have insisted on TPN (total parenteral nutrition) to enable the nutritional healing of the delicate tissues? Should I have asserted my knowledge and skill more? Should I have pushed for further surgery? Did my Mom want me to do more or to comply with another's expertise as was her wont in life? At times I did withhold my comments, my requests, or I came at them another way because I sensed I could easily break the fragile string between the institutional community and myself; the forged and odd somehow superficial yet significant relationship we had. We were after all dealing with death and depthness. My fear and probably lived truth is that I was just a phenomenon in their world, some other consciousness they had to conquer in the care of my mother and that my positing anything more than I did at the time, would have resulted in them turning away from her care in an engaged way. Yet I wonder still, could I have affected her living, her dying more in her last weeks on this earth?

Because of her death, I no longer have access to her. More terrible is that I lose the world that was her. The scope of my world narrows immensely. What was that old rice pudding recipe anyway, those cinnamon buns? Who is there now to remember my baby time, my growing up time? In time I learn to keep her within my horizon. But right then, I floundered with the questions, the meaning of what it is to be daughter and nurse.

### **Nursing Take Six: Ventilations**

The bath is perhaps the oldest act of nursing. One can see the nurse carrying out bathing behaviours, surface gestures such as soaping, rinsing, stroking, drying, turning, positioning. Yet too if one is attentive, one can appreciate that there is more going on. Gestures penetrate beneath the skin and inward *felt life* comes to the fore in this nursing act. Unseen, yet still present under the surface skin, are the feel and reverberations of the strokes as they penetrate one's personal body and self; the closeness, the feeling of having an ally, someone there just for you in this moment. The strokes mimic and assist the flow of blood returning to the heart to be reoxygenated and recirculated, the flow of lymphatic fluid throughout the body. Nurses know

anatomy, how muscles and bones connect to each other; physiology, how blood flows through the body. Their bathing gestures incorporate this knowledge, knowing just how to bathe what, how to move what, how to position bodies. Try to move the dead weight of a body or just one limb. One needs specialized knowledge to be able to use one's own body to shift another's.

Outward nursing gestures penetrate muscles, bones and blood flow. Nurses knowledgeably move the washing cloth over the joint and muscle connections, the different textures and contours of the body. The intimacy of this nursing act for the person, the blend of knowledge and tact inherent in the gestures, the essentials of water, cleanliness, and relation as aspects of normalcy and lived life are expressed here. At the end of the bath, the nurse knows more about this person than she did when she started. She knows now what is needed to nurse this person.

This attention to the lived detail of the bath in nursing practice is not found in the official discourse of nursing. Rather the value seems to be placed more on the hygienic abilities of the nurse or the theoretical cognitive understandings of bathing. But in the zeal to "capture" what are efficient hygiene procedures or to "contain" nursing acts in the theorizing, the essence of nursing falls away. The sense of gathering information about the person, the inherent assessments in every realm of personhood that occur during the bath, these are not presented in the purpose of the bath as a hygiene need or a deficit in self care. Despite the fact that nurses in practice continue to value the bath as a wholistic nursing act, theory fails to find a form of representation for these acts. But nurses in practice know something. They know that the act of bathing itself has enormous value to nursing prudence, to nursing practice. Many nurses know that the ability to think critically, to make sound nursing judgments about an individual finds its genesis in direct nursing practices like bathing.

Reducing the bath to procedures of hygiene not only trivializes the act of bathing as described here, but allows others inside and outside nursing to demean it. If the bath is only about getting clean, could we not simply hose people down. Or could we not give this function to a worker who would cost less than a nurse? Reducing a practice to mere procedures may pervert the nursing act and the experience of the bath. Inherent then in the question of how nursing is revealed in its practices must be another: *How faithful are the presuppositions of the existing discourse of nursing to the lived nature of the practices of nursing?*

In order to capture the elusive meanings of nursing we need to find nursing in its world of practice; nursing that is not reduced to concepts and procedures. Rather, we need to apprehend nursing as it happens. It has taken me a long time to gather courage to think beyond established nursing theory and wonder about what is essential to nursing.

In my Master's work on the nature of comfort to hospitalized patients (Cameron, 1988, 1993) I investigated the patient's experience of illness and hospitalization in an endeavor to understand it better. I wrote of the fragmentation of self, the person who "just the day before was involved in running a complex business suddenly becomes a series of malfunctioning body parts in an alien environment" (1993, p. 10). I spoke of a very basic level of human comfort missing in these patients and therefore for lack of a better term at the time, I investigated *comfort* as a way to describe this area of patient experience. The major finding of the study was that patients worked hard during hospitalization to achieve comfort through a series of strategies; watchful vigilance called monitoring; purposeful human exchanges through networking; and throughout the process, patients endured hardships, formulated meaning, and integrated a perhaps changed self into their lived world. The process reported was called *integrative balancing* (monitoring, networking, enduring) as the patients balanced all of the above, the hazards, the resources, everything that came into contact with them. Balancing the complexities of the hospital environment became central to each person's coping.

While the study did give insight into the arena of patient experience, I knew I had fallen short of my personal goal. I wanted to understand the lifeworld of the patient pulled into this environment by the ultimate interruption of the human lifeworld, illness, tragedy, death, lifestyle and health concerns. I wanted to show the immediacy of it, the very here and now-ness of it, the very personal uniqueness of it; all of these with the view to situating and valuing the patient experience as it intersects with nursing. And in some ways the study did these things. But the actual categorizing of the patients' lived experiences meant in truth, that I lost some of their directly lived experience. Later I was able to show how the category of enduring intersected with established nursing practice; the nurse asking a person, "how are you?" (Cameron, 1992). I envisioned a patient's enduring and a nurse's how are you as a blend; enduring encompassing a waiting time, a hardening time, a time when something essential emerges in the person; the "how are you" an appeal to the person, a calling forth of new dimensions of being. In the mix of the two the "who" of the person became the "how" are you going to be (who and how are etymologically related). In these situations of health and illness are opportunities for things to come forth that can only come forth here.

How to get at this rather ineffable thought without becoming too mystical or too inane? Pursuing studies in the tradition of interpretive inquiry enabled me to make some sense of the comfort study and its meaning to nursing. Hermeneutic phenomenology as explicated by van Manen (1990) allows me not only the opportunity to describe what is before my eyes, but also helps to keep a respectful openness to what is given rather than jumping to abstraction, to categories. One must believe that there is always more in whatever meets the eye in the enacting of the phenomena. Hermeneutic phenomenology provides a promise to show in a thoughtful way what constitutes the nature of nursing. Yet we must never assume that we can describe completely nursing and its lived meanings. Van Manen (1990) states that pedagogy is "in an ultimate or definitive sense unfathomable" (p. 149) and this very unfathomable nature of pedagogy evokes continued reflection and thoughtfulness. Kestenbaum (1982) writes that "a phenomenological sense clearly is fundamental to most care-giving and helping functions typically associated with nursing, and for this reason it is not surprising that nurses traditionally have been concerned with how the sick experience their world" (p. 21).

In the main, the relation of nursing is not neither a lofty thing nor a mundane list of skills or intricate cognitive reasonings. Primarily it is a practice. Moreover, this practice is deeply rooted in the actual realities of lived life. Here understanding not explanation holds sway. Thus nursing practice is the place to search for meaning not in cognitive theorizings, not in borrowed theory and concepts, but in the place where it happens. How did that nurse just act that way? Well not necessarily because she knows Roy's (1984) theory of adaptation but rather because the complexities and nuances of the situation calls forth an active knowledge that has prepared her for this situations. The knowledge that the nurse looks so simple yet in reference to the bath above, is so complex. It is shown in her body's gestures and actions, in the felt palpable sense that emanates from every action and non-action. If nursing as a discipline expresses itself and finds itself in its practices then *how can one present nursing in its fullness in a way that does not withdraw it from its world of practice, understandings, and conducts?*

*Presenting* nursing then becomes the guiding endeavor and overall concern of this research study. The contents of the study come from situating myself within the practices of nursing. The questions of nursing originates from this place of practice, the practicing nurse and those within her mandate are the central concerns of the study. The findings attempt to stay close to nursing practice and those whose lives intersect with nurses in that arena. In one of the participant's words, I seek a "full-blooded" way to present nursing.

What follows then is a methodological experimentation with presentations of nursing practice: bits of theoretical literature, slices of texts from writers of fiction, examinations of certain usages of language, chronologies of specific happenings in the day of a nurse, a patient, and descriptions and interpretations of pieces of data. Each of these are encased in the tenets of the hermeneutical phenomenological tradition (van Manen, 1990). The aim of the dissertation is to let things *appear* as they appear and to be attentive to *how* they appear. In other words, things come into presence, into our consciousness in certain ways, times and places. How things appear is a basic interest of the phenomenological tradition of human science research; the phenomenological task being the “descriptive investigation of the phenomena, both objective and subjective, in their fullest breadth and depth” (Spiegelberg, 1965, p. 2). One must be particularly careful to note the appearance of things “not only in the sense of *what* appears, whether particulars or general essences, but also of the *way* in which things appear” (Spiegelberg, 1960, p. 685). There is also an effort to draw the body of the practices of nursing into the epistemological system of nursing.

### **The Research Questions: Conspiring (breathing together)**

What is it like to stand in the midst of nursing practice and ask questions there? This study “*Understanding Nursing and its Practices*” will follow the path of van Manen’s (1990) treatise of hermeneutic phenomenology, Bergum’s (1989) sense of intersubjective inquiry and enlivening phenomenological tenets in the field, and of Burch’s (1986) notion of questioning within a continental philosophical tradition. In addition a case for direct description of nursing as a valid way to investigate this phenomena will be made below. A guiding premise will be the following statement from van Manen (1990).

So phenomenology does not offer us the possibility of effective theory with which we can now explain and/or control the world, but rather it offers us the possibility of plausible insights that bring us in more direct contact with the world. (p. 9)

Bergum’s (1989) respect for her participants’ stories in her study, not as a vehicle to fit their understandings into a researcher’s preformulated theory, but rather as “a sharing of a common concern and experience” (p.49), will also guide.

The phenomenological method attempts to push off method for method sake, to push off sureness and become unsure, to resist conceptual analysis with the view to explain. As a result, this method becomes an attitude, a way of looking... (p. 48)

Burch (1986) states, “We do not so much posit a question, as we are encompassed by it; we do not so much have a question, as we *are in it*” (p.7). The question of nursing is a question in which I am involved essentially (Burch). Practicing nurses solve problems almost every moment of nursing. But they live the question: what is it to nurse in this particular situation. It is in the enacting of the relation of nursing expressed through the practices of nursing for that particular person, family that remains the question of nursing posed above.

Problem solving is intrinsically abstractive, calculative and exacting. In contrast, one thinks upon questions, seeking by means of this not a definitive answer, but an ever more radical and comprehensive context of understanding. Questioning is intrinsically disclosive, integrative, and invocative...While problems seek correct information, questions “concern the elucidations of meaning” (p. 7).

By and large the answer to a genuine problem concerns what we do, that is, how we can better deploy the various “objective” realms that our theoretical,

scientific, and practical activities posit...The response to a question, however, concerns who we are as human beings: In all questions, it is we ourselves, our having and doing, thinking and being together, that is the principal matter at issue. (p.7)

Formal research questions for the study *Understanding Nursing and its Practices* are:

What are distinguishing qualities of the nursing relation as revealed in the practice of nursing?

To what extent does the theoretical discourse of nursing approximate, inform, and present the practices of nursing?

And because this study took place in an institution with cancer patients, a related question is:

Are there significant distinguishing characteristics of the practice of nursing that are important and unique to nursing people with cancer? (more easily seen when nursing people with life-threatening disease such as cancer)

Hannah Arendt's (1994) notions of understanding are foundational to this work.

Understanding is unending and therefore cannot produce final results. It is the specifically human way of being alive; for every single person needs to be reconciled to a world into which he was born a stranger and in which, to the extent of his distinct uniqueness, he always remains stranger. Understanding begins with birth and ends with death. (Arendt, 1994, p. 308).



## CHAPTER 2: (RE)PRESENTING NURSING

*"The subject matter appears truly significant only when it is properly portrayed for us"*  
(Gadamer, H.G., 1989).

How difficult it is to show the complexity and reality of a practice! While nursing practice, as with any human practice, embodies certain observable and sometimes habitual actions, much inheres in these actions that is not immediately discernible. How then does one *present* a practice? Practice is most often a pre-reflective act and pre-reflective language is needed to describe it: what inheres in it emerges in the practice of it.

Consider again the bath in nursing practice. An embodied nurse meets an embodied person. A bath contains certain outward gestures on the part of the nurse, gestures that can be replicated, gestures that carry with them therapy, health giving actions. Yet too the bath as a human practice has an innerness, a notion of felt life experienced by the patient as immediately present. And it has an inwardness too on the part of the nurse as she gathers information through her hands washing, eyes seeing, nose smelling, ears listening, and a third ear listening to what is not said, that body sound not heard, to absences. Here the nurse processes and forms judgments based on findings during the bath.

How can one speak to these aspects of a practice, the experience of having a bath, of giving a bath? The deskillers or skillologists may say, "A bath is a bath is a bath; there is nothing more. Start at the head and work down, head, torso, arms, legs, back, genitalia. Soap, rinse, dry." "True", a nurse would say, "I do that. But I do it in a certain way with a certain judgment and a certain demeanor with certain ineffable expertise." And this nurse will be able to describe or *present* how she bathes a particular person at a specific time and place. She will know not only what she learns about the person's health situation but also how she relates to the person, how and if the person responds to the shared interaction.. Here her *description stays close to the experience*. There is a difference between this and having a bathing procedure, (step one, step two) to follow. Following a pre-formed template turns an act into a procedure and removes one from the notion of a bath. Rarely is one able to remember a procedural bath enough to tell a story about the particular situation unless it was horrific. And some are.

People are very vocal about a bath. "It saved my life, it felt so good. I had been sick at home and had not washed for several days." "I was scared to move until the nurse during the bath showed me how to move my joints without damaging my incision." Or the opposite: "The bath water was too cold", "The nurse didn't rinse off the soap", "My back was not washed and I've been lying on it since my surgery." "They handled me so roughly moving from stretcher to tub and at the time I couldn't speak to stop them; I felt violated." People can describe with vigor the experience of having, or not having, a proper bath with dignity.

The bath is denoted in nursing education under *fundamentals* of nursing practice. The bath is considered a fundamental of nursing which makes it both baseline knowledge and skill for a nurse and essential to nursing practice. Yet the bath also finds its place in nursing curricula under complex nursing interventions where certain kinds of baths are done i.e. towelbaths in intensive care units (ICU). The technology in the bath can range from simple water and cloths to highly mechanized baths with spraying jets, to automated stretcher and chair lift baths, to many and complex technologies attached to the patient. Here students are taught not only how to bathe patients who are confined to bed, but also those in extremis. Towel baths—where the individual is covered with a pre-treated lubricated and soaked body towel—the nurse massages the person through the towel, then the skin is air-dried, are intricate and meant to be used on those who have much machinery attached to them. Here the person is never uncovered. It is quick, prevents exposure, conditions and stimulates the skin as it removes bacteria and debris from the skin.

Activities such as bathing in *Nursing Fundamentals* incorporate and integrate a wide range of previously learned baseline knowledge. To bathe one must know the structure and function of the body; anatomy, range of motion of joints, musculature, physiology, flow of body fluids, blood, lymph, how to move and position bodies, specific pathologies with resultant effects on bodies and persons, microbiology, psycho-social literature, safety and respect for individuals and nursing, and more. The integration of the content and understanding of same, demonstrated in the actions of the student enacting of the bath, is perhaps the beginning of the student developing their unique nursing person expressing nursing.

Currently not only do we have external deskillers rearranging the dynamics of the bath around an economic and political agenda but too, nursing has as its theory base certain ways of depicting the bath in nursing practice. Hands on activities (concrete nursing interventions) like the bath, often cause theorists problems as opposed to abstract conceptions of aspects of nursing. Select nursing theories view the bath in particular ways. For example, Orem (1985) has a series of *universal self-care requisites* which are human actions that maintain structure and function and bring about human development and maturation. They are air, food, water, elimination and excrements, a balance between rest and activity and between solitude and social interaction, prevention of hazards, and normalcy in these sense of “that which is essentially human...and in accord with the genetic and constitutional characteristics and the talents of individuals” (p. 42). Orem considers the bath a hygiene deficit and places it under the “provision of care associated with eliminative processes and excrements” (p. 43). One then calculates which self-care requisites the person cannot meet and then proceeds to acting for or doing for or teaching modalities. Immediately our view of the individual is one of being a deficient, rather undesirable human being if one is deemed dirty and an elimination deficit and a hazard to healthy living.

There are other ways theorists represent concrete nursing activities. The bath can be represented as a hygiene need (Henderson, 1966), a self care deficit (Orem, 1985), an organism interacting with its environment (Rogers, 1980), a moment for human becoming (Parse, 1981), an interaction or lack of (Peplau, 1952; Travelbee, 1971), an outcome (Johnson, 1980), a problem of adaptation (Roy, 1984). Would Harry like to be known as an individual with hygiene deficits? Harry probably thinks there is more to himself than his hygiene deficits. When needs and deficits and energy systems describe the experience of being bathed, a particular way of viewing this nursing act is generated. And it is most often not true to the directly lived experience of bathing. When a student then bathes Harry based on learning about the bath as a personal hygiene deficit, Harry and Harry’s body (split now in two) become sort of icky. Will the student nurse and the patient Harry now experience each other as deficit fixer and deficit fixee? Or what if surprisingly a serendipitous event occurs, and each become more as a result of the bath? Could this be one of the origins of the much talked about theory-practice gap? That the theory somehow skews the experience, the bath skews the theory? Or is it simple mis-representation; that the selected focus (representation) misses the mark of what is true in practice as lived?

What are ways to show what the notion of the bath means to nursing practice, as a *fundamental* of nursing, as an essential to understanding the modus operandi of nursing? Here we spurn for a moment the ways nurse theorists and deskillers represent the bath and look for ways a nurse could use to show the value of the bath to persons, to nursing as a discipline? How does one make or unmake the bath as a nursing activity? We can either argue it or we can show it.

### **Arguments for the Bath as an Essential Nursing Intervention in Nursing Practice**

What sort of research and theory would show the bath as integral to nursing practice and also, assist a nurse in the giving of a bath? In an ideal world, a blend of nursing practice activities and

research investigating the same would benefit nurses and those who are patients for a time. *Are we doing the best we can with this intervention* would be the question-at-hand, recognizing a blend of practice tradition, empirical evidence, experiential records, part/whole relations, a part of nursing relating to the whole of nursing (particulars to universals), interdisciplinary considerations, showing the phenomena as it shows itself in life, pertinent actors included in the process and nothing contrived or outside the nature of nursing imposed upon it.

Research efforts should be made to study how nurses develop the practical skills involved in measures of hygiene, comfort and medical treatment. Although this is difficult, the research should emerge from the clinical setting, where nursing actions develop influenced by context and interpersonal relations. (Bjork, 1995, p. 11).

Sometimes people think that the catch phrase in nursing academia, “evidence based” or research based practice encompasses all of the former stated elements. But no, this is not always true. There is a difference from what we seek here. Research based practice in nursing literature often refers to research issuing from aspects of a specific theory of nursing or that of implementing the nursing theory framework on a nursing unit. These entail implementing conceptual areas in the practice arena rather than research on a specific nursing action. Research utilization specialists could argue the former statements, but in fact research enabling and informing specific nursing interventions is sparse. Rather the specialists expect that nurses through implementing specific nursing theories in practice will be the *practitioner exceptionale* because the specific nursing action is not as important as following the constructs in the theory. Nursing theories based on what *ought-to-be* practice rather than practice *as-is* (Barnum, 1990) fail to take into consideration the complexities and the situatedness of practice. They neglect to first find out what exists in nursing practice at a fundamental level. In their hubris, they have devalued aspects of practice that are filled with meaning and have rational and practice reasons for doing something a certain way. But the rationale for this way of acting only comes clear as one immerses oneself in the practice and *sees* all the parameters affecting this one situation. Barnum states that the majority of nursing theories are based on the ought-to-be nursing practice and as such, they are mental constructs only.

The *source* of nursing for many theorists is not the real world of nursing practice; instead, it is a fantasized ideal world of nursing practice as it *would* be if it were done in the best fashion. In this respect, the nurse theorist is unlike the scientist who first seeks to discover the extant state of his subject matter. (Barnum, 1998, p. 6)

But here in Part 2A, we speak of research and literature that enables nurses to practice a certain nursing activity better, safer, smarter and to show how the activity is integral to the *raison-d'être* of nursing. In investigating a particular nursing intervention we too gain insight, (seen as a complicating factor to researchers but a boon to practicing nurses) into the *modus operandi* of nursing; the essential core of nursing. This sort of academic inquiry shows what nursing is; why a nursing activity is done, what critical skills and judgment are involved in the activity, benefits to the patient, and more. Here both domains of research and practice are in dialogue with each other. Barnum (1990), using the language of theory, states that *intervention based research* has a narrow scope in that it addresses only a specific clinical application but she is clear that it is just this sort of research that has *utility* in practice. However as much as one can argue for the importance of the bath to nursing practice, so too can one argue against aspects of it.

Practice is a series of nursing activities integrated into an ever divergent whole. A nurse consistently works hard at bringing the diverse pieces together in just the right sort of context for

this person, for this family. The bath has just the right sort of milieu to assist the nurse to bring the pieces together. The beauty of the bath is in its elegance, its simplicity, its lack of artificiality: an activity seen on the outside as so very simple or so very complex, yet all of it meaningful to lived human life, lived nursing life. It has been integral to nursing as a discipline since its inception; it is an independent action of a nurse, not subject to medical direction or based on one of the other more highly regarded (by both nurses and administrators) nursing actions now called “transfer medical functions”, or based on a conceptual area of practice only i.e. caring. It has it all, theory, research, practice wisdom, lived life; it shows the nature of nursing in all its inherent parts and too, serves as a window to see defining qualities of nursing.

***Argument: You need physiological knowledge to bathe, bathing and physiological status***

To bathe or not to bathe, that is the question. Assessment of physiological status is very important in nursing practice. Nursing activities and the timeliness, the appropriateness of them, must not be taken for granted. Much knowledge and skill is embedded in the bath even though the bath’s appearance may seem simple. For example, the measurement of the oxygen saturation in the blood is an important physiologic measure in determining the overall physiological status of an individual. The nurse connects this finding with others, knowing in her knowledge base how this particular measurement interfaces with other organ functions, respiratory rates, haemodynamic functions, structural anatomical functions, comfort. Here a dialogue between research and practice is necessary for nurses to function in practice safely.

Bodily activities require oxygen to carry out normal metabolic processes and when one is ill, nurses must be attentive to how much they ask a person to do in terms of bodily exertion. The body must be able to sustain a certain level of oxygen in the blood to carry on the processes of metabolism and healing. The body tries to shunt its oxygen to the tissues that are in need of healing.

In the *bedbath*, there is an anterior bath, the person lying on their back, the anterior of the body is washed, arms and legs are raised and flexed to do a passive range of motion and also to wash all sides. The genital area is done at this time as well. The person then turns or is turned onto his/her side, the back is washed and rubbed, the rectal area is washed, and the bed is made on that side. The person turns or is turned over to the other side rolling over a lump of bed clothes which are then pulled through and tucked in on the other side of the bed. In the *shower*, the person stands to wash and bends or flexes their body to reach the lower extremities. In the *tub bath*, the person either crawls into the tub themselves or they are lifted on a hoist lift, either on a chair or a stretcher and lowered into an appropriate tub. There are also *chair showers* where the person sits on the chair and showers, and there are also *sink baths* where the person sits at the sink and bathes.

White, Winslow, Clark and Tyler (1990) demonstrate that nursing care of critically ill individuals increases their oxygen demands and advocate using continuous monitoring of mixed venous oxygen saturation as a tool to assess the patient’s supply/demand balance of oxygen during bathing and turning, suctioning, and other nursing care measures. To explain further:

In a healthy person a direct relationship usually exists between oxygen consumption ( $VO_2$ ) and cardiac output. Because heart rate is a major determinant of cardiac output, a direct relationship also exists between heart rate and oxygen consumption. As  $VO_2$  increases, heart rate increases to meet the increased demand for oxygen. Thus, bathing or turning a patient can increase heart rate due to sympathetic stimulation and the increase in oxygen demand. During oxygen demand increases, the body’s compensatory mechanisms maintain an oxygen supply/demand balance by increasing cardiac output, oxygen

extraction from peripheral blood, or pulmonary ventilation...Increases in oxygen demand associated with a bedbath result from increased muscle movement, pain, and excitation of the sympathetic nervous system. (Atkins, Hapshe, & Riegel, 1994, p. 108)

Many conditions can threaten the oxygen delivery of critically ill patients to the extent that even resting demand is not satisfied. A decrease in cardiac output or an uncompensated decrease in haemoglobin reduces delivery of oxygen to the tissues (White et al, 1990).

Numerous conditions and activities increase the oxygen demands of critically ill patients. O<sub>2</sub> consumption increases 10% for each 1 degree C increase in temperature and as much as 100% with shivering, head injury, or burns. Patients with a combination of conditions, for example, fever, infection, and increased work of breathing, commonly have an oxygen demand two times resting O<sub>2</sub> demand, resulting in an oxygen consumption of over 500ml/min. Routine nursing care also increases the patient's oxygen consumption, from 10% during a dressing change to as much as 36% during weighing of a bedfast patient with a sling type bed scale. (White et al, 1990, p. 550)

Because of the above, the measure of the oxygen saturation level has become an important piece of assessment data for nurses who assist individuals or provide individuals with hygiene care along with the medical regime prescribed by the attending physicians.

Verderber and Gallagher (1994) show that turning patients from side to side during the bath and back care significantly increases the oxygen requirement of the body. In addition, patients who are hypothermic, hyperthermic, shivering, or in pain require much more oxygen at a cellular level. "In patients assessed as having marginal oxygen reserve, such activity could produce episodes of tissue hypoxia or "neahypoxia", the latter being a condition in which irreversible changes in cellular function occur in response to oxygen deficiency" (p. 374). The findings of this study indicate that for both healthy men and women the need for oxygen consumption rises to 20% (White et al, 1990 state 23%) above the baseline oxygen consumption level for the individual with unassisted turning from side to side and the back bath. The anterior bath required little extra need for oxygen unless the individual was "hypothermic, hyperthermic, shivering or in pain" (p. 380). The authors point out that the activities of doing the bathing procedure in bed, the turning for back care, and bedmaking, turning from side to side, are often done all at once without giving patients an opportunity to rest, to decrease the oxygen requirements for a time.

All compromised patients are at risk for physiologic changes during hygiene care and cardiac patients especially so. The concern of nurses and physicians is to how much activity can be tolerated by the individual, and how much rest is needed to encourage the cardiac cells to heal. Johnston, Watt, and Fletcher (1981), Winslow, Lane, and Gaffney (1985), Robichaud-Ekstrand (1991) have all looked at oxygen consumption in cardiac myocardial infarction patients during bathing. Johnston et al (1981) found that showering demanded more adjustments in the haemodynamic response resulting in ECG changes possibly because "considerations relative to showering are that more body flexion occurs in bathing lower extremities and that standing involves more use of large muscle mass" (p. 670). Cardiac auscultatory sounds changed, the heart sounds became softer, third heart sounds (S3's) were found in three patients and occasional premature beats were heard in two patients. Patients developed more episodes of "electrocardiographic S-T displacement after showering than after tub and bed bathing and more of these changes occurred in patients with inferior infarctions" (p. 670). S-T displacements are serious because this is the time when the heart is supposed to be resting and recovering in preparation for systole.

Atkins et al (1994) studied the effects of a bedbath on coronary artery bypass patients. They looked at bathing patients in the first 24 hour period after the surgery, early bathing at 3.6 hours and late bathing at 18.5 hours and noted the mixed venous oxygen saturation and heart rate measures. These researchers did not find that the addition of a 10-minute rest period between the bath and turning phases gave any benefit to the physiological status of the person.

Rising (1993) investigated the relationship between selected nursing activities, turning, suctioning and bathing and variations in the intracranial pressure (ICP). Patients with brain injury, cranial tumors, meningitis, basically any cranial or systemic condition, need monitoring of ICP during the acute phases of illness. It was found that during the bathing procedures 2 patients out of 5 "elicited an ICP greater than 20 mm Hg." (p. 307). Other observed baths elicited minimal increases and in 5 instances decreases in the ICP occurred and the author here cites the therapeutic value of the bath as responsible for lowering ICP. Turning associated with bathing and positioning elicited increased values of ICP in all patients. There is a caution given not to instigate nursing activities if the ICP is above 20 mm Hg.

Parsons, Smith Peard, & Page (1995) measured the effects of hygiene interventions on the cerebrovascular status of people with closed head injuries. They monitored the mean ICP (MICP), heart rate (HR), mean arterial blood pressure (MABP), and the cerebral perfusion pressure (CPP), the CPP calculated by subtracting the MICP from the MABP. They show that nurses must know when to stroke and when not to during the bedbath.

Body hygiene interventions led to increases in all dependent variables...While the peripheral stimulation of moving body parts may increase blood flow to contralateral somatosensory cortices... pain associated with stroking injured or bruised parts of the body can elicit an immediate release of catecholamines and subsequent increases in HR, MABP, and CPP. Additionally, rubbing large muscle groups during bathing "massages" blood vessels traversing these areas, thereby elevating HR and MABP by increasing the return of blood volume from the periphery. The bath itself also may contribute to further physiologic changes, which occur when water chills the body, increases peripheral vasoconstriction, and momentarily increases MABP. Elevations in MICP, however, may be due to the single factor of head turning, causing compression of jugular veins, and obstruction of some venous outflow from the brain. (p. 179)

Similarly Muraki, Kujime, Kohbu, Kaneko, Taketomi, Ueba (1993) studied the respiratory and cardiac responses of tub bathing on elderly people with cerebral palsy. Their finding were that in five-minute bathing periods at two water temperatures, 37 and 42 degrees C, that the maximal energy expenditure was equivalent to "light exertion such as half-an-hour sitting in a chair" (p. 54).

Nakamura, Takahashi, Shimai, & Tanaka (1996) studied whether or not healthy individuals bathing in tepid water, 30 degrees C, would facilitate recovery from fatigue following riding a stationary bicycle. Three bath situations were studied following the exercise, one at 30 degrees C, one at 38 degrees C, and one with no water in the bath tub. It was found that 30 degrees C bathing resulted in the largest percentage recovery from fatigue based on more rapid removal of lactate from the muscles, and quicker reduction/return to normal of the body core temperature. It is suggested that the 30 degree water:

might increase blood flow in the intra-abdominal organs such as the liver and kidney caused directly by parasympathetic splanchnic vasodilatation and indirectly by peripheral vasoconstriction...The faster return to normal can be reasonably explained by the increasing intra-abdominal blood flow, which must

facilitate removing intra-abdominal excessive heat. Consequently, lactate metabolism may have been augmented due to increased blood flow into intra-abdominal organs. (p. 264)

Peters (1996) studied the physiological and observed stress cues of premature neonates during the bath. She studied the oxygen deliver, the heart rate and oxygen saturation levels and behavioral responses while neonates were bathed. She found that either the heart rate rose above or below normal limits and the oxygen saturation level fell below normal during the bath. In addition the physical behaviour of the neonates demonstrated high motoric stress cues. Premature neonates did not like to bathe.

Barsevick & Llewellyn (1982) used a statistical study using the State-Trait Anxiety Inventory (STAI) to determine whether conventional methods of bathing or the towel bath would generate less anxiety. There were 105 patients, half in the conventional group, the other half in the towel bath group. They found that both groups experienced significant anxiety reduction, both baths had calming effects that lasted for at least one hour. When the two types of baths were compared against one another, the towel bath was slightly more effective and the researchers believe this is due to the relaxing physiological effects of "heat and massage inherent in the towel bath" (p. 26). As part of the design of the study to control for "the influence of therapeutic interpersonal exchanges between nurse and patient during the bath, research assistants were instructed to converse of a neutral, superficial level when possible" (p. 27). Skewes (1994) and Carruth, Ricks and Pullen (1995) also the towel bath to be effective physiologically and cost effective.

While many health science professions study specific organ systems, nurses on the other hand must understand and integrate the whole of the effects of specific body systems with the whole of the person. This is a complex synthesis of information which must include interacting social systems as well. A delicate balance among often equally competing systems, the social, the physiological, the technological, the spiritual, the kindness and gentleness must be built (created?) by each individual nurse in each situation. [It is not difficult to see, knowing the above about one specific nursing act, how theorists (below in Chapter Three) in an attempt to capture the complexities of nursing went off the mark, so to speak, as they tried to encompass all of this by incorporating theories outside nursing.]

#### ***Counter Argument: It is only a meaningless routine***

Nursing practice is entrenched in repetitive procedures and routine tasks. This is why many researchers have turned their back on practice as an arena to inform a professional discipline. The bath fits this category. Walsh and Ford (1989) call the bath a meaningless nursing ritual. They state that the bath and hygienic care have become devoid of meaning because "individualized care is subordinated to institutionalization (p. 120). Adams (1984) states that the general bath was the central act that the entire ward was based on; "all other nursing care was seen as a mere supplement to the daily rites of ablution" (p. 31). Adams believes that the bath is part of a tradition of institutional life. It is a routine task, a cleaning job rather like washing the floors. Indeed those who advocate the American trend of multitasking recommend that hygienic care be part of the janitor's mandate.

Chapman (1983) and Spiller (1992) concur and search for what might be other meanings for nursing in doing hygiene care; what they both see as meaningless repetitive tasks. Chapman (1983) believes that bathing as a ritualistic practice in nursing is a defence against anxiety and stress within the job; these ritualistic practices reduce anxiety by their very task oriented, black and white nature. Spiller (1992) states that conforming to patient washing rituals "helps nurses feel they are doing something to help their patients, even though they may feel impotent to deal with deeper problems" (p. 434).

Conversely, Wolf sees the notion of and enacting of *ritual* as integral to nursing as lived. Wolf (1988) defines nurses' work as consisting of therapeutic rituals and occupational rituals: the bath is identified as a therapeutic ritual and change-of-shift report is identified as a occupational ritual. While Walsh and Ford suggest that ritual action in nursing "implies carrying out a task without thinking it through in a problem-solving, logical way" (p. ix), Wolf's notion of ritual in nursing practice, gathered from an extensive ethnography of two nursing units, does not represent meaningless repetitious tasks to be done, but rather that rituals embody the sense of rite and ceremony in nursing activities.

What is it that Ford and Walsh reject so much about bathing? It is not so much they reject the bath as much as they reject task oriented care. They speak of the "dawn scramble" (p. 112) as nurses wake patients up at the crack of dawn to do their assessments, treatments, and their baths. They see tub baths as portals for cross-infections, they see bedbaths as coercive, they see daily bed linen changes as unnecessary, they see "bath record books" kept on wards as task management and not individualized care, they see nursing process as jargon and not an improvement in changing the nature of routinized care. They state that individuals and the elderly do not need frequent baths and that soaps left on the skin cause itching.

Credence must be given to Ford and Walsh in that they show aspects of practice that are not based on human healing at all but rather on adherence to routines that fit better within the institutional framework. Chapman (1983) and Spiller (1992) search for reasons other than getting someone clean for some insight as to why anyone would bathe another (other than it is dictated by the routine). But Wolf (1993) goes in and watches. She looks at the act itself. Important reasons for bathing patients as ritual were for cleanliness of the skin and after excretion, as an initiation process, a sort of purification following admission to a unit, to make someone who smells bad more nurse-able.

Failing to keep patients clean or omitting a bath violated a nursing norm. The bath was an opportunity to cleanse patients, inspect their skin, and evaluate their status. Nurses taught, listened to, or talked with patients at the time they bathed them. On an implicit level, bathing purified patients and helped nurses heal them by washing away disease and some of its traces. The around-the-clock bathing that nurses performed for their patients ordered the easily disordered activities of the nursing unit studied. (Wolf, 1993, p. 144)

Wolf too speaks to bathing after death as an important nursing ritual. Post mortem baths are a part of nursing's culture and mandate. "post-mortem care is part of nursing's long tradition with the laying-on-of-hands. Even after patients die, nurses care for them, touching them with gentleness. (Wolf, 1989, p. 139).

Elizabeth Winslow cited above (Winslow et al, 1985, White et al, 1990), and speaking out in the Critical Care Nurse Supplement (*What Heals?*, 1995) comes at the bath in yet a different way. She has made her life work researching nursing interventions as to their efficacy for thoughtful nursing practice. She follows a tradition Florence Nightingale began when she reduced the casualties mortality rate in the Crimean War from 40% to 2% just through observations, statistical analysis, cleanliness, dietary improvement, (*What Heals?* 1995, p. 7). She refutes the "routineness" of nursing interventions through advocating intervention research (Barnum above, 1990). Winslow cites several "routines" that have been either proved or disproved. For example, for many health care situations daily weights are essential to monitoring one's physiological status. Daily weights are another "dawn scramble", where patients are hauled out of bed for weighing, sometimes even before dawn. It has now been shown that "evening weights were just as useful in conveying water retention data and true weight as were AM readings, and were far



less intrusive to the patient” (What Heals? 1995, p. 13). [While Winslow does not say this, it is of note that the “routines” that have the least efficacy are the ones that are enacted because of better fit with institutional workings or professional workings i.e. the dawn blood draw so results can be on the chart for the physician’s rounds, evening blood draws just as acceptable to physiological status in most cases.]

Hardy (1996) too applies research to specific long-held notions in nursing practice. She reacts against claims that bathing dries the skin of the elderly. She has shown through research that skin dryness is improved in older persons who bathed frequently as compared to those who did not. Often patients who need particular teaching concerning their illness or situation or anticipatory guidance for things that may occur in the future, or just plain understanding and encouragement, are taught during the bath time. Or if a nurse is concerned about a subtle change in the person, often she will be very attentive to what is different during the bath as she assesses all body systems. This is different than filling out an assessment check list. This is “hands-on”, very present, assessment. Mitchell (1984) writing about the *nursing process* technology laments the time when nurses went to stand beside their patients to see how they were, rather than remaining at the desk with a long and complicated check list written to the specifications of the particular nursing process invoked. Smells from the breath, the skin, signs of pallor, blueness, can only be seen standing beside someone, says Mitchell somewhat facetiously. But he makes his point.

Ford and Walsh and others in their zeal to target routinized methods of giving nursing care too easily give up a valuable nursing activity. Indeed there are those amongst the nursing profession who even now devalue the bath, not for its essence but rather for its penchant to be relegated as a task and given to others. Wolf (1993) states that discarding the “bathing ritual by giving it to nonprofessional personnel is unthinkable, the bath is more than a standardized and repetitive series of activities...the bath can be viewed as a healing rite with greater healing power” (p. 145). To reduce the bath as a nursing intervention to a task or a “routine” to be done is to remove the nature of nursing from the activity. Clarke (1986) asserts that “one could argue that an action for which the only explanation is that it is routine is no longer a responsible action since no reflection has gone into the choice of the action nor has any reflection gone into the choice of explanation suited to the other parties involved in the nursing action” (p. 9). Why did the bath become a task, a routinized procedure on these nursing units Ford and Walsh speak about rather than individualized assessments and care? Or did it truly become a task? Was there still an element of a “healing rite” in it regardless of the nature of its delivery, its appearance in the world? In Webster, Thompson, Bowman, & Sutton’s study of 1988, 91% of nurses felt the bath to be extremely important to nursing patients and 86% of patients thought so too.

***Counterargument: It is dirty work; the bath and contagion***

Bathing is only dirty work with no redeeming qualities. Nurses, more than any other health care personnel, care directly for bodily fluids of patients and with contagion of all sorts. Wolf (1988) points out that nurses in her study classified body parts during the bath in terms of clean and dirty.

Giving the bath required that nurses handle infected materials, excreta, such as urine, perspiration, and stool, and secretions, such as mucus, blood, and wound drainage. The nurses responded to their contacts with profane materials with humor, tolerance, complaint, and magical thinking; with the protective medical aseptic practices of bathing, handwashing and wearing gloves; and with the pathogen-specific precautions of isolation procedures. (p. 182).

While nurses were free to refuse a specific patient care assignment due to contagion concerns on the units Wolf (1988) researched, the philosophy of the unit was that “all patients deserved care that respected the dignity of the human being” (p. 183).

Lawler (1991) refers to body products and to excreta as dirty work. She names 21 bodily excretions; “ear wax, desquamated cells between the toes, nose pickings, hair, faeces, semen, human milk, dandruff, face sweat, saliva, blood, vomit, menstrual discharge, blackheads, tears, pus, phlegm, nail clippings, pubic hair, body sweat and urine” (p. 83). Both Lawler and Wolf (1988) provide a social and anthropological history of dirty work, of work considered to be profane, of dirty work equating with women’s work in history. “While women were supposedly suited to this work, and while the work itself was recognized as dirty, there was a concomitant emphasis on the need not only for personal cleanliness on the part of the nurse, but also for her to remain morally pure” (Lawler, p. 46); hence nursing’s association with religion and purity.

Colliere (1986) has another “take” on the body in nursing and its religious relevance. Catholic nursing orders gradually replaced the “wise women”, healers of the village during the medieval period. Colliere refers to nuns as “consecrated virgins” (p. 99). These consecrated virgins having little bodily experiences of their own were taught to value spiritual care above all and leave the bodily contact to subordinates. Through these consecrated women, Colliere insists that an important change occurred in the concept of care.

Nuns as care-givers introduced a total separation between all the knowledge gained by matrons and midwives based on everything which stimulated life faculties...and replaced touching by talking and verbal advice. Exhortation and counseling took the place of the previous direct body practices such as baths, massages. From this time verbal communication became a main tool for care until it was to be replaced by technological methods in modern hospitals. (p. 99-100)

Colliere ends this discourse with a “kicker.” “Consecrated women did not have to learn to build up judgment; this was prohibited, but had to learn behaviour dictated by rules” (p. 100).

Lawler (1991) states that there is little literature beyond dirty work that has to do with the body in either the social sciences or nursing. Dealing with the body is a problem for nursing. Fagin and Diers (1984) state that when one mentions one is a nurse, colourful descriptions of the other’s experiences with hospitalization, surgery, etceteras occur and of course the usual question, “how can you bear handling bedpans (vomit, blood)?” (p. 16), comes up. These authors state that “nursing evokes disturbing and discomforting images that many educated, middle-class, upwardly mobile Americans find difficult to handle in a social situation” (Fagin & Diers, p. 16). On the other hand Suzanne Gordon (1997), journalist and advocate of the nursing profession, speaks to the intimacy of the relation, that it is too personal to discuss at any time. She states that nurses’ work goes unrecognized and unstated for a reason. Nurses are a reminder of illness, of vulnerability, of pain and loss of control. Adults find this difficult to discuss. Gordon believes that nurses are “secret sharers”, and explains that “even though they are lifelines during illness, when control is restored, the residue of our anxiety and mortality clings to them like dust, and we flee the memory” (p. 88).

Lawler (1991) chastises the nursing profession for ignoring the body through various avenues. She talks about nursing developing a theory of ‘holistic practice’ as a way to individualize care with holism not “necessarily grounded in empirical work or practice” (p. 216). She believes the trend to holism became:

...A very 'clean' image of nursing to promote. The body care and dirty aspects of nurses' work disappear, to be replaced by neologisms and euphemisms. Body care is subsumed into a range of nurse-identified needs of the patient. This period in nursing can be seen as an attempt to both overcome 'the problem of the body' in an occupation of dirty workers who deal with the messy details of physical being, and to scientise and sanitize nursing knowledge and practice. (p. 216).

Dunlop (1994) too talks about the "cleaner caring" that some nurse theorists e.g. Watson (1985) espouse and discusses that in shedding physical care, nursing becomes difficult to distinguish from what it does that is different from other professions who also care.

In caring for sick people...there is a temptation to concentrate on either the troubled body or the troubled psyche in order to simplify nursing work, yet what the nursing community agrees is good nursing is neither purely physical nor purely psychosocial. The nurse must thus find her way between the twin temptations of physicality and disembodiment. ( p. 33)

In a pinch, though, and sometimes through choice nursing remains embroiled in physical care, which involves contact with the mess and dirt of bodily life, even while it is aspiring to the "cleaner" caring that deals with people's minds and emotions. ( Dunlop, p. 32)

Reutter (1993, 1994, 1995) researches a specific pathology and pathogen. She discusses nurses' responses to the risk of contagion in working with People with AIDS (PWA). "Initially, most nurses used an 'overcautious' approach that even went beyond the recommended guidelines. Many attributed this to their inadequate knowledge or their concern about medical uncertainty regarding HIV" (1994, p. 56). As time went on and nurses gained more experience working with these patients, they "became less afraid to hug, bathe, or otherwise be in contact with patients, nevertheless, most continued to focus on 'theoretical' risk" (p. 57). Nurse assessed the risk involved with various procedures according to existing guidelines and did not embellish risk any longer. Reutter (1993) found that nurses worked hard at achieving a sense of control over uncertainty. They cover the notion of risk with finding meaning in the nursing act.

A sense of meaning was found to be related to three major factors: accepting the patient as a person who needs and deserves care, finding work enjoyable and worthwhile, and professional commitment to care for all patients. Attaining a sense of meaning led to a reappraisal of the risk situation as worthy of investment and provided the motivation to care for patients in spite of risk. (p. 1377)

***Counter argument: It's a "carwash"; bathing and the dependent elderly***

The status of bathing as *hosing down an object* can clearly be seen with the institutionalized elderly. Wagnild and Manning (1985) investigated personal care complaints in a geriatric long-term care facility where complaints about bathing topped the list. They found that nursing aides and care assistants bathed residents. They did not make any effort to maintain client dignity in bathing procedures. Two or more residents were bathed at the same time in the same shower room; undressed, bathed or showered, towed dry, redressed and returned to their rooms. Genders were washed together as well. Clients felt they were not shown respect during the procedure or given any other choices concerning bathing. They had to conform to the routine and feared repercussions if they did not. Meaningful interaction between the caretakers and residents, stimulation of the person's perceptual abilities did not occur. Adams (1984) suggests that the

“general bath” of the elderly is mostly unnecessary for cleanliness. Rather it serves as a rite that represents a change of lifestyle, that of submitting to the will of the institution.

Armstrong-Esther, Browne, and McAfee (1994) point out that the elderly are still sitting clean and quiet with little evidence of substantial interaction occurring during hygienic care, the time of most direct contact with a caretaker in the person’s day. Even less interaction occurs following direct care such as bathing. Iwasiw and Olson (1995) state that outward appearances do not tell the complete story about the quality of care in long term institutions. They found that a large percentage of nonprofessional caretakers focused the entire interaction during morning care on themselves and their involvements in life. After describing the hygienic activity to the person, the caretaker then proceeded to structure the conversation around their own needs where “their priorities took precedence over matters of significance to patients.” At times caregivers disclosed personal troubling situations to the resident. There was at no time a meaningful probe into how the resident was doing that day and/or on the inner life of the resident.

Kovach and Meyer-Arnold (1996) found that cognitively impaired older adults become very agitated during the bath or shower. Bathing or showering procedure generated moderate to severe agitation in the demented elderly. Participants who became agitated were easier to calm if they were in the tub bath. Kovach and Meyer-Arnold state that untrained caretakers who do the hygienic care are in a “primitive state” in terms of understanding and having the abilities to cope with the agitation. McShane (1996) too shows that bathing is an important and complex activity in the elderly and the demented population yet administrators continue to relegate the bath to caretakers with little or no training. The instruction of these lesser trained staff “de-emphasizes psychosocial care and does not often include specific training for expertise in responding to very challenging disruptive behaviours and psychosocial needs of dementia residents” (p. 40). Miller (1994) state that disruptive responses to bathing by elderly residents come as a result of not individualizing the hygiene to the individual, not allowing for privacy, not keeping them warm before and after bathing or showering, and going ahead and putting the person in a bath chair and quickly rushing them into the tubroom without first explaining and cueing them that they are about to have a bath. Rader, Lavell, Hoeffler, and McKenzie (1996) delineate a carefully thought out bathing approach based on function, form, and frequency. It is thoughtful of course, but when reading it one thinks, if one were respected as a person, these sort of approaches would not be necessary.

Lindell and Olsson (1989) found that caregivers who were not nurses had a general lack of knowledge of physiological changes in elderly women and this resulted in faulty cleansing practices especially in the genital areas. Institutionalized elderly women had genital problems; dryness, soreness, burning while voiding, itching, genital discharges, yeast infections. The study showed that caregivers did not have knowledge of the normal changes with aging, the normal physiologically altered mucous membranes in elderly women, and so were not giving appropriate care.

***Counter argument: Bathing has been culturally engineered in lived human life***

In America, culture and commerce and not a desire for cleanliness formed the basis of the advent of the bath as a normative behaviour in people (Bushman & Bushman, 1988). Bathing came about as popular culture, a sort of daring, risqué thing to do. Bathing was first seen as an invigorating stimulant, a tonic if you will, to the system. Cold water baths and showers were seen to give one a new lease on life, a renewing sort of moment. It was thought that cold water and bathing shunted the blood back to the heart and that was the origin of the good feeling following bathing. Sending blood back to the pumping heart was seen as sending it to the source of life. People were instructed to rub their skin vigorously with a towel following the bath to bring the

blood back to the surface of their body: *vivifying* was the word commonly used following a bath. Existing Bath houses offered warm water baths, and ocean baths and mineral springs baths were already in place in the culture, but the most popular baths in the bath house in cities were the salt water and cold water ones (Bushman & Bushman, 1988).

In medieval times, baths were offered travelers as a part of hospitality. As early as the eleventh century, the bath was recommended to prevent plague. It was a common practice for female servants to bathe husbands and travellers. Often meals were served in the bathtub. The established church at the time forbade all such activities and prescribed three days of bread and water if the individuals were caught (Fox & Driver, 1993).

Cleaning the body might include removing lice, scraping the skin, and flagellating oneself with branches to stimulate circulation. The body was then rubbed with ashes and soap before being washed. Washing the body, whether one's own or those of others, seems to have been mainly women's work throughout the Middle Ages. (Month of July, 1993)

While religion and purity originating with ancient Hebrew and Roman writings linked good morals to cleanliness and John Wesley stated that "cleanliness was next to Godliness", what Wesley meant was quick rinses and quick immersions, not scrubbing and cleansing (Bushman & Bushman). Earlier religious practices also discouraged the bath. Cope (1957) discusses the current thinking about the bath around about the twelfth century.

...The use of baths for any other than a medical purpose was sternly forbidden by the Benedictine rule. Baths were for the use of the sick-not for the young or strong...This was due partly to the ill fame of the public baths which in mediaeval times were sometimes mere brothels, and partly to the idea that it was more difficult to keep the vow of chastity if the body was exposed. At Westminster, baths were allowed twice a year, at Christmas and Easter. For a short time the monks put in two extra, one on St. John Baptist's day (midsummer) and another at Michaelmas. When this came to the notice of the higher authorities, the luxury of the extra two baths was suppressed. (p. 32)

There was too a time in history when baths were seen to be medicinal for madness, for skin conditions, for fevers. A 1923 edition of *Lippincott's Nursing Manuals: State Board Questions and Answers for Nurses* (Foote, 1923) states that bathing and baths are essential to health and healing. Bedbaths are carefully delineated as to the procedure, and admonishments and ways to keep the patient well covered during the bath are clearly articulated. Cleansing baths, hot pack baths, cold pack baths, fever sponges, infant baths, tepid baths and mustard baths are described and the indications for, and the benefits of each, are also carefully noted.

Foucault (1965) writes about medicinal baths in medieval and modern times. He states that the polyvalence nature of water can permeate the body, absorb and expel all manner of disease and madness. Water itself is the healer, "an irresistible flow washing away all the impurities that form madness; by its own curative power, it reduces the individual to his simplest possible expression, to his merest and purest form of existence, thus affording him a second birth" (p. 172). Cold and hot baths have different therapeutic effects; from overcoming an attack of the humors, and the destructive activity of the body and the mind.

Cold baths attack the blood that is at the periphery of the body and "drive it more vigorously toward the heart." But the heart being the seat of natural heat, there the blood is heated, especially because 'the heart, which struggles alone against the other parts, makes new efforts to drive out the blood and to overcome the

resistance of the capillaries...the hot bath draws the blood to the periphery, as well as the humors, perspiration, and all liquids, useful or harmful. Thus the vital centers are relieved; the heart now must function slowly; and the organism is thereby cooled. (p. 169-170)

The notion of the bath for cleanliness came to the fore when skin as a bodily system came to be understood. "The change from cold bathing to invigorate the blood system to warm bathing in tubs to remove dirt came about because of the spreading understanding of the skin's function in the removal of wastes" (Bushman & Bushman, p. 1222). It was also thought that if a person put on dirty clothes after bathing, the skin's pores would suck in the wastes back in.

At the same time, cleanliness grew in social circles and soon became a mark of moral superiority and dirtiness a sign of degradation. "Cleanliness indicated control, spiritual refinement, breeding; the unclean were vulgar, coarse, animalistic" ((Bushman & Bushman, p. 1228). Vinikas (1989) reports that the growth of the soap industry had nothing to do with health at all, but everything to do with advertising that soap and cleanliness enhanced beauty. The soap industry became a powerful magnate and the industry was incensed when technologies such as electricity replaced kerosene lamps as kerosene lamps of course were very dirty, soiling hands, tables, windows, and floors. The backlash of the industry was to target educational institutions and women's domain of household cleaning and of course, loveliness. "Three basic appeals were employed in the advertising experiment: loveliness, cleaning, and the bath" (p. 623). Information concerning balneology, the treating of disease by baths and mineral springs was carefully disseminated. Women were told that their house could not ever be clean, only cleaner. The school student learned about cleanliness.

Knowing chapter and verse of the Cleanliness catechism-fearing unclean toilets, respecting the unseen bacterial enemies around him, meticulous about his appearance and environment-he also appreciated the part which habits performed 'in acquiring a satisfactory job after leaving school.' (Vinikas, 1989, p. 619).

The culture of cleanliness was upon us.

Wilkie (1986) states that the need for bathing grew too as the technology for bathing advanced with all sorts of bathtubs, water closets, plumbing, and personal bathrooms in homes. "While tubs may have helped people to be productive, orderly members of society, private bathing also indulged the industrializing individual's narcissistic impulses. Whether for health or regeneration, the focus of a bath was on caring for oneself...secluded submersion" (p. 659).

Memories of early bathing experiences are recorded in the York Oral History Project (1987).

We'd a long tub—a wooden tub—and of course, we used to put the kettle on, and we got enough hot water that way and then just have it in the bath. With so many of us we always had some clothes, and we used to put the clothes-horse around us and that was full of clothes and you couldn't see one another, it was very nice...yes, we always were taught to respect privacy and to be careful and thoughtful to one another.

Well, Friday night...was both bath night and physic night. We had our weekly dose of whatever...was the favourite in your house: ours was the syrup of figs or, I think castor oil laced with orange juice—every one of them was horrible. But you had to have it, if you didn't you had your nose nipped until you did. They we had a bath; girls on Friday and boys on Saturday...there was a few of us, but it was nothing unusual to bath a few friends who happened to be there. My aunt would throw a handful of soda for the last bath to sweeten stuff up, and

you were lucky next morning if you didn't wake up with no skin on your back.  
(p. 53, 54)

Estabrooks (1987) searches references to touching in early nursing literature and finds them in records of bathing. As infectious diseases were rampant in the early 1900's, the then popular modes of treatment were different types of baths called "hydrotherapy"; all of which were under the domain of nursing.

I learned to give the full bath, the half bath, the sponge bath, the spray bath, the sitz bath, the Turkish bath, the Russian bath, the sheet bath, the salt bath, the mustard bath, the hot vapor bath, the cold douche, the hot pack, the wet pack, the cold pack—these with various modifications—and the carbonated bath; until I began to think as one of the attending physicians jocularly remarked one day, in a 'hydrotherapeutic circle.' (Crawford writing in 1910, cited in Estabrooks, p. 36)

Hektor and Touhy (1997) state that looking at the history of the bath in nursing as it was skillfully and artfully practiced, and attention to the aesthetics of bathing, will help nurses to rediscover the comforting and therapeutic nature of the bath. They also state that we should build on the art of bathing as much as on the science of bathing.

***Counter argument: It is a caretaker's janitorial duty, the bath, multiskilling, and politics***

Nurses are not needed to do the bath; they need to be doing much more important work. The bath is one of those nursing activities that is in many instances relegated to an unskilled worker and performed as a task despite the fact that bathing, for example a spinal cord injured patient, is a complex skill. When nurses are asked about the bed bath, they speak of the importance of this time with the patient in terms of getting to know the patient, performing physical and personal assessments, knowing after the bath how to plan the patient's care, and making judgments in terms of timing and coordinating allied disciplines, and so on. It is, in many instances, the largest amount of direct contact time with an individual.

Suzanne Gordon (1995) writes about a 72 year old man in good health who underwent surgery for lung cancer and everything went well. Afterward he was discharged from the ICU to a surgical floor that had seen drastic cuts in the numbers of registered nurses and the replacement of same with unskilled workers called assistive personnel. This gentleman died because he developed a pneumonia that went undetected and untreated for 3 days during which time he was discharged. Stunned at the outcome, a family member laments:

At the end, he was surrounded by all this incredible high-tech medical equipment. But the tragic thing was that all he needed was the most rudimentary piece of medical equipment—a stethoscope- and a nurse who had the time and experience to check on him, listen to his chest and hear the unmistakable wheezing of pneumonia. If he had gotten that kind of routine attention, he would probably be alive today" (p. 201).

We could add that even 5 minutes of direct bathing activity with this man, bathing with its inherent assessments, would have told the nurse's critical judgment that all was not well. In fact, she only needed to turn him to notice, an ear close to the chest would do it. Gordon (1997) in a recent publication based on studies showing fewer mortality rates with registered nurses caring for patients, strongly recommends that potential patients quiz their doctor not only regarding their proposed medical intervention and treatment but also about the nurse to patient ratio, whether there will be qualified nurses present.

What are the results of replacing nurses with unskilled workers, with devaluing nursing activities such as the bath to a "getting clean" situation only? Generalizing tasks/skills to job specifications which up to the present were considered specialized nursing interventions, leaves the bath within the context of clean and dirty and bereft of any sort of meaningful activity. Individuals need bathing for cleansing of course but the event of bathing in nursing is interwoven so intensely with the fabric of nursing's efficacy that "cleaning" is rarely all the bath is about. At the same time, institutional demands lie heavy on the nurse's agenda and it is becoming more frequent that hygienic care is delegated to a less prepared individual as other "more skilled" activities are deemed necessary for a nurse to do. But nurses know that to give up all involvement in hygienic care, a time of direct personal care, even that of only providing a basin and towels to a person, is to restrict their effectiveness in the care of this individual. One sacrifices the possibility for connection and for intersubjective meaning which is more difficult to achieve with other nursing activities i.e. administration of medications. Every nurse knows too that she does not have to bath every patient she meets; but this would be a critical judgment made by the nurse and not dictated by institutional policy.

In some areas of health care restructuring, especially where the American-originated trend of multitasking (Blayney, Wilson, Barnberg, & Vaughn, 1989) is in place, the bed bath, hygiene and excretion care are now the duties of the cleaning staff, the janitor. Definitions of multitasking or cross-training abound but an agreed upon one comes from the National Multiskilled Health Practitioner Clearinghouse.

Persons cross-trained to provide more than one function, often in more than one discipline. These combined functions can be found in a broad spectrum of health-related jobs ranging in complexity from the nonprofessional to the professional level, including both clinical and management functions. The additional functions (skills) added to the original health care worker's job may be of a higher, lower, or parallel level. (Pietranton & Lynch, p. 38)

O'Donnell (1996) gives a physician's view to cross-training. Cross-training originated with footwear; one shoe made for a variety of sport. "The concept implies mediocrity. Cross-training is for dabblers" (p. 38). If you want to be a long distance runner, you buy a running shoe. "I want the best-trained nurses taking care of my family and my patients. I don't want fill-ins. I don't want substitutes-and America shouldn't either" (p. 38).

Schindul-Rothschild studied nurses' working conditions and patient care in Massachusetts' hospitals in 1989 and 1994. The trend to employ unskilled workers to do nursing activities and the decrease in registered nurses as staff began in the early 1990's. Nurses were also polled as to instances where they felt unsafe care resulted in these downsizing activities and reported 15 deaths because of inadequate and inappropriate staffing (Gordon, 1995; Schindul-Rothschild, 1995).

Prescott (1993) cites 13 studies done in North America that relate nursing care and nursing staffing levels to the mortality rates associated with the staffing mix. Prescott states that "the majority report that a higher percentage of RN's to total nursing personnel is associated with severity-adjusted lower than expected hospital mortality rates" (p. 194). Low skill mix is a predictor of unsafe patient care and higher mortality rates (Schindul-Rothschild, 1995). Schindul-Rothschild (1994) shows that when there is an increase from 60 to 70% of registered nurses to ancillary personnel, the quality of patient care improves and the productivity with it. Hartz, Drakeauer, Kuhn, Young, Jacobsen, Gay, Muenz, Katzoff, Bailey, and Rimm (1989) show clearly that hospitals with a high proportion of registered nurses have lower mortality rates and fewer complications. Knaus, Draper, Wagner and Zimmerman (1986) show that effective



communication patterns between physicians and nurses in Intensive Care Units has a direct effect on mortality rates. Carr-Hill, Dixon, Griffiths, Higgins, McCaughan, Rice, and Wright (1995) show that as the higher skill mix of registered nurses improved the quality of nursing care, so did the overall costs involved in employing qualified staff improve. The patient outcomes were so positive and the lack of complications so glaring, that the increase in costs paid for themselves.

Despite the fact that sound research has shown that there is a significant relationship between the number of registered nurses and decreased mortality and morbidity rates on nursing units, administrators seem to have an unwritten rationale of cost cutting measures; the arguments of reduced mortality rates with a higher skill mix do not influence traditional decision making practices and ways of decreasing costs. Their rationale is still to look at the most numerous personnel within an agency (nursing), decide that their salaries escalate health care costs, move to close hospital beds because that eliminates nurses, and to hire assistive personnel to take up the nursing slack (Holzemer, 1996). Yet Prescott (1993) shows that salary costs are not what drive up health care costs. Rather it is new technologies and the necessary support personnel, the performance of expensive tests and procedures that are costly.

It is not the emergence and contribution of professionals that has created problems in healthcare. In addition to the unrestrained proliferation of technology and medical services, the growth of hierarchical and bureaucratic structures of work in healthcare have contributed significantly to both cost and complexity. (Porter-O'Grady, 1994, p. 12)

Cost savings come from limiting these rather than decreasing salaries of personnel. In fact, Prescott also cites studies that show that a high proportion of registered nurses decreases the length of hospital stay and the incidence of complications. Costs are reduced. Hiring assistive personnel does not help nurses have more time with their patients. In fact they have less time overall as fewer nurses still have to do what is deemed "registered nurse activities i.e. medications" for more patients when the nurse:patient ratio is decreased significantly (Huber, Blegen & McCloskey, 1994; Holzemer, 1996). In addition, the policy for early discharge has resulted in nurses having less time to evaluate their patient's status. A physician adds his voice to this now very common dilemma.

...Nurses constantly re-evaluate patients and recognize the most subtle changes in vital signs, mental status and sophisticated monitors that may herald a catastrophic event...Physicians now, more than ever, rely on nursing assessments and recommendations when making diagnostic and therapeutic decisions. There are certainly deserving targets for cuts—physician spending, pharmaceuticals, hospital middle management and insurance. But don't cut nursing care. (Dr. John Merrit O'Donnell, chairman of Surgical Intensive Care at Lahey Clinic in Boston cited in Gordon, 1995, p. 201).

Holzemer (1996) insists that what is most significant about the trend to assistive personnel and decreased registered nurses is that little data are available on the quality and outcome of nursing care with this type of mix; there is no established baseline data for patient outcome research, nursing outcomes, or provider outcomes with which to compare changes. Nursing has in the past been responsible for outcomes with sound nursing care measures. Now as their access to patients is limited by using assistive personnel, sound nursing care does not ensue. Barter, McLaughlin and Thomas (1994) found in sampling 102 hospitals that use assistive personnel that these workers receive less than 20 hours of instruction and less than 40 hours of clinical instruction.

Brooten and Naylor (1995) warn that researchers must be careful as to what types of patient outcomes should and can be measured accurately other than mortality and morbidity rates.

Hegyvary (1992) states that studying the actions of a single provider group, eg. nursing, runs several risks from ignoring the context to the complex interplay of sociocultural, economic, political, and organizational factors that also effect outcomes.

The current search for “nurse-sensitive patient outcomes” should be tempered with the reality that nurses do not care for patients in isolation and patients do not exist in isolation. While some outcomes may be more influenced in a given context or environment by nursing practice, in other settings, these same nurse sensitive outcomes may be influenced more by other disciplines or by family situations. (p. 99)

Beck (1995) states that mechanisms/surveys to measure patient satisfaction with care must also include a way to determine whether or not patients actually receive adequate care, information, and coordination of services. Beck states that patients are not the same as consumers of other products and services. Patients are vulnerable, know they are vulnerable, know they may need additional care, and consequently do not report as accurately as they should. Kinnear, Scammon, & Beck (1995) compile a review of published instruments and methods used to measure patient satisfaction and include those who attach a specific way to evaluate nursing care other than patient self-report. Again they recount the same difficulty; how to get at patient satisfaction and evaluation of outcomes while taking into account all the factors that influence such health care situations.

The fact that there is not an established code of ethics for deskilled or multiskilled workers, assistive personnel is a concern (Cameron, 1995). Caplan (1996) states that the “only way to regulate the health care market is to stand ethical values up against it” (p. 95). Does this practice of deskilled, multiskilled, crosstrained workers modify standards of care? It would seem so in terms of the above literature. With the new categories of caregivers and job redesign, employers change their perception of the work that is essential to be done and not essential to be done. Erlen and Mellors (1995) state that these new categories of care workers have altered the “nurse’s primary and direct care role” (p. 45) and that the standards of care have changed with the policies and practices based on the “usual or typical patient and not on the individual” (p. 43).

This opens up a Pandora’s Box for nursing practice. Is it possible to believe that an unskilled or deskilled worker called a myriad of names in the literature such as the multiskilled or cross-trained worker, the assistive personnel, the patient care attendant, the nurse extender, caregiver#4, and others, can take over with just a few days’ training what it has taken nursing as a practice and professional discipline years to build up? Badger, Cameron and Evers (1989) discuss the difficulties facing nursing auxillaries who are not trained to give a bath to people at home with complex health problems. They state that each individual needs a careful assessment as to the type of bath that can be managed and nurses are the ones that can do this. They raise the issue that many administrators, physicians, and those organizing home care “translate the needs of diverse individuals into the common requirement for a “bath”, as opposed to an occupational therapist for (advising on) walking or living aids (equipment), or a physiotherapist for advice on improving mobility?” (p. 17).

One of the most disturbing things about health care restructuring is the decreased centrality of nursing in the planning and redesigning scheme of patient care (Porter-O’Grady, 1984, 1992, 1994). Porter-O’Grady states that hospital and community care should be structured around the relationship between the nurse and patient and all other services should emanate from this ( 1984, 1992).

Nursing, because it is living and working at the heart of the problem, often gets caught in the cross fire between shrinking external support and increasing

internal demand for its services, while faced with a decelerating base of resources necessary to do the job. However, if the executive does not know how to ask the questions related to getting the service provided in a different framework that may lead to a different set of relationships between the variables, the nursing organization gets mired further down in its own morose, waiting for the next shoe to drop or ax to fall. In this set of circumstances, control over the work of the nursing profession gets subverted by those in the system who have no idea of what it is and how it gets done. (Porter-O'Grady, 1990, p. 121).

Nursing is typified and manifest by its relation to the patient rather than by its tasks and skills. What is appropriate for the patient comes through the nurse's very direct contact with them. The "task" itself is not the purpose of the work for the patient; it emanates as necessary or not from the relation, from the judgment and assessment of the nurse. It is difficult for administrators to see this and even more difficult for nurse to describe this. Nursing is defined by and through its relation to others.

To become excellent in the practice of nursing, for example, one must achieve certain standards of skilled practical knowledge, moral agency, discretionary judgment, and patient advocacy...These caring practices can be learned only within the rich tradition of nursing practice, which reflects how the human skill of caring has evolved over time in many concrete situations. (Balasco & Cathcart, 1992, p. 69).

### ***Nursing as bathing***

The intent of arguing the bath in the first part of the chapter is to show theoretical and research arguments and popular culture that relate to one specific activity of nursing practice. Here the literature shows that there is much more to bathing as a nursing activity than meets the eye; that there are conflicting views of the bath *within nursing* practice i.e. is it a nursing intervention or just a routine task, the lens the nurse theorist puts on the bath orders its status in the specific scheme of nursing events; that *outside nursing* those in the health reform movement see it as a menial activity; that recipients of bathing care benefit by the thoughtful and skilled enacting of this nursing activity; that assessment of personal health status is enhanced with hygiene care when the nurse spends direct time with the individual; that nurses doing nursing activities results in decreased morbidity and mortality rates; that unskilled workers cannot replace all the elements, the tacit knowledge and the expertise involved in one specific nursing activity; that while there is a need to move toward efficient cost effective care, patient needs have not changed and patients must still have access to a continuum of nursing care.

It is time to take an accounting of how nursing is represented to ourselves and to others and why our central place in advocating for, appropriate and competent patient care continues to be eroded. If we do not address how to present our profession and its meaningfulness and importance to others, sooner or later we will see new versions of these mistakes and those entrusted to our care suffering and dying needlessly.

Do arguments address and discuss fully this one specific nursing act to our satisfaction? Do they show nursing and its effectiveness? Do they persuade us? Would they be convincing to those in power concerning the nature and value of nursing? As above with the multiskilling argument, it seems administrators and health care policy makers choose to see the argument they *need* regardless of other sound statistical and oft replicated research that proves contrary to their thinking? Meaning and tacit understandings that inhere in this one particular act of nursing cannot be defined well enough or shown well enough by theory and research; theory convinces theorists,

research, especially statistical research, can be disregarded or elected at the whim of one's intentions. Where does that leave nursing? Well in Part 2B, we present it...

### The Bath

The review of theory and of research above speak to aspects of the bath as a nursing intervention and its arguments in literature. Here we attempt to show it. What does it mean to show how the bath belongs to nursing? We look for how the bath reveals itself in life as we live it. What is the bath in nursing practice. Here it is.

#### *The English Patient*

Consider the bath in the *English Patient* by Michael Ondaatje (1992). This story is situated in the aftermath of the Allied invasion of Italy where the Allied forces push the Nazi army northward. The medical and nursing personnel follow close behind the Allied forces to treat and tend to the wounded on the combat lines. Seriously injured soldiers and civilians and a few nurses are evacuated from temporary field medical stations to Italian hospitals recently liberated from the Nazi Regime and others follow the push North. A young Canadian nurse chooses to stay behind in a nearby Italian villa with a severely burned patient who cannot withstand the move to the hospital, some distance from the field station.

Every four days she washes his black body, beginning at the destroyed feet. She wets a washcloth and holding it above his ankles squeezes the water onto him, looking up as he murmurs, seeing his smile. Above the shins the burns are worst. Beyond purple. Bone.

She has nursed him for months and she knows the body well, the penis sleeping like a sea horse, the thin tight hips. Hipbones of Christ, she thinks. He is her despairing saint. He lies flat on his back, no pillow, looking up at the foliage painted onto the ceiling, its canopy of branches, and above that, blue sky.

She pours calamine in stripes across his chest where he is less burned, where she can touch him. She loves the hollow below the lowest rib, its cliff of skin. Reaching his shoulders she blows cool air onto his neck, and he mutters.

What? she asks, coming out of her concentration.

He turns his dark face with its grey eyes towards her. She puts her hand into her pocket. She unskins the plum with her teeth, withdraws the stone and passes the flesh of the fruit into his mouth.

He whispers again, dragging the listening heart of the young nurse beside him to wherever his mind is, into that well of memory he kept plunging into during those months before he died. (Ondaatje, 1992, p. 3,4)

Michael Ondaatje's writing is so compelling. Here in this writing he brings a small piece of experienced life to the fore; brings it into being, so to speak. For our purposes, he *presents* it for us and to us. *And Hannah, the nurse, not only presents the act of bathing for us, but through the act, elements of nursing itself.*

Here the nurse is *present*, committed, absorbed. This is not a routine task to be done, but an act of absolution almost; an act complex and full of judgment and skill. It is this nurse's enacting a fundamental nursing act in a certain way that pulls at us. *There are no mechanistic actions here; it is a work of art, a work of skill, a work of judgment.* She gives the English patient his dignity, his living.

Hannah deals with extreme embodiment. Bodily care, normal maintenance and those bodies in extremis are ever present entities in nursing practice. The story does not mention the smells, the odours that would emanate from the English patient's body, or the sight of burns, the black eschar, the hard crust that harbors necrotic tissue, the psychological horror of seeing the overt disfigurement. Somehow these aspects of the English patient's body and bath are just taken for granted as part of the ordinary war time scene.

Rather Ondaatje concentrates on the nurse's actions and on the English patient's body; her absorption in what she is doing, her attention to the body as is, how she knows that there is at least one part of his body that resembles normality; "the hollow beneath the lowest rib, its cliff of normal skin." *There is an immediacy to this act of nursing.* The English patient's body has become as familiar as her own. Her hand constantly changes from one of bathing touch to one of soothing touch even in one stroke.

When he mutters, she understands, he is hungry. When it is a chilly night and the English patient is shivering, she lies beside him to share her body heat with him. Hannah, the nurse, stands alone here. She does not have technology, supplies, resources to employ in her care. She has only herself, her nursing skill, a bit of cloth, a bit of morphine. *Yet she weaves a pattern of care that is elemental and profound.* A harmony forms, a mutuality, despite the disfigured body.

What is it that motivates this young nurse? This is a war that has pushed the boundaries of humanness and overturned all there is to know about being human. To be human will never be the same after this war. Incomprehensible actions have been done to human beings in concentration camps. Never again will the term "murderer" have the same connotation again; there is no known form in the history of the world yet to absolve humankind of the nature of these atrocious acts (Arendt, 1994b). Yet here is a tiny island of human caring; a skilled, devoted nurse with a listening heart, a patient with desperate needs, and what happens between them. *There is something unforgettable and irreplaceable in this certain bath.*

This bath has a poetic quality that seems almost *surreal*, one unique wartime situation among many in the book. Yet for our purposes here, it is a shared moment of nurse and patient. This nurse endeavors to keep her patient safe and comfortable amidst the aftermath of the war, amidst unseen and unheralded land mines exploding around the building at any time, amidst the lack of food and supplies and human support. She nurses him. *[In any bath milieu the sheer intimacy of the engendering of it often conjures up a surreal experience.]*

When this part of the book was read on CBC Radio, there was the sound of water in the background. You could hear the nurse agitating the water, wringing out the cloth in the basin. Also in the book and portrayed in the movie, after a few hours of sleeping Hannah tiptoes into the English patient's room. She does what countless numbers of nurses have done before her and will do again; the timeless act of entering a patient's room. You enter the room and you notice, you listen for what is different; their voice, their breathing, the smell, the sense of presence. Hannah walks slowly up to the English patient and puts her nose right up to his to see if he is breathing. The English Patient opens his eyes and whispers, "I'm here, I'm always here. This little bit of breath I have, it never leaves me."

In watching the movie, if one is a nurse, or one has been nursed, one recognizes these particular gestures, these actions used by the nurse-actor. In fact, the nurse-actor does the gestures as well as, and better than, some nurses. She shows us nursing in a performance. And performing is what we do in nursing. In a performance, a violinist at once plays and interprets a piece. The "interpretation is understanding in action; it is the immediacy of translation" (Steiner, 1989, p. 8). Here Hannah's performance and interpretation as nurse-actor, displays *understanding in action as ever present and evocative within the nursing act.*

The bath in human experience and the bath in nursing practice is sometimes much less about getting clean than it is about something else. For some the bath is a symbol of grace, of benediction, of cleansing in a bodily and spiritual sense. It is an absolution of sorts. There is a sense of this in the *English Patient*, that the nurse's care and relation assists the English patient to work forward through his memories, his hauntings, his life written on his body.

And now to come to our own time and place in history and nursing practice to see that the bath has not changed all that much. "No," I say to the student who has just bunched up the washcloth, neglected to wring the cloth well, and proceeds to pat the cloth at the arm here and there, water from the cloth running down on to the bed. "Try this" I say, "You must firmly grasp the cloth and you must stroke upward in the direction of venous return." And I say, "we can't turn him just yet on his side, he needs rest for a moment, notice his oxygen saturation level has dropped." And the student says, "Gosh there is just so much to this, to notice all at once."

To stroke is a particular nursing gesture. To stroke the flesh in this way is to be in-touch; in-touch with being and life itself as the blood in the blue veins just visible beneath the skin course their way toward the heart, in-touch with the who of this person I stroke, and too, in-touch with the fledging *sui generis* of this person; that which hovers and waits to be actualized because now this individual pushed to the edge of her world must muster herself to contain, to integrate this event, this way of being in the world now.

Elizabeth Gordon writing in 1923 has this to say about touch during bathing.

Let the patient regard the process with pleasure, and not with dread...Endeavor to be an artist in sponging. Know why you sponge...Let your touch be gentle, firm and soothing. (p. 595)

### ***Tom and Agnes's Bath***

It is clear in Tom's bath that a neuroscience nurse's work of several days previous has come to fruition. Tom is a farmer, a husband, and a father of two school aged children. Four weeks ago, Tom was hit by a bale of hay and his spinal cord was severed in his thoracic area. He is on complete bedrest, total parental nutrition, catheterizations every six hours, and skin care every two hours. Agnes is Tom's nurse today, and she gives the following account (Cameron & Mitchell, 1994).

One morning I started my usual morning routine of closing the curtains in around Tom's bed, taking off his TED stockings and placing the bedpan under Tom's buttocks. Outside the curtains I fill the plastic blue basin with warm water, and arrange the bedside table with Tom's deodorant, washcloths, towels, soap, powder and lotion. I like to take time to have things arranged so that I am comfortable in order to give a comfortable and relaxing bath. Quite often I will turn the radio to an easy rock radio station to set the mood. I like to use two wash cloths, one to soap a patient's skin and the other to rinse with water. I need two towels, one to keep the exposed area of the body warm and the other to dry after washing the exposed area. I place the bedpan under Tom's buttocks, I can smell that Tom has had some kind of bowel movement and I ask him if he is done. He says he is not sure and I have to check. Meanwhile, I'm very

conscious of my facial expressions, not to show Tom how the smell of the bowel movement has filled the stuffy room. As I initiate a discussion about the latest hockey game, I logroll Tom to his side to take out the bedpan and wipe his buttocks. I roll Tom back and take the bedpan to the toilet for the contents to be flushed and the bedpan cleansed. Tom makes a comment about how bad the room smells.

I return to start the bath and somehow I sense this morning that Tom is ready to start his own bath with my help. I offer Tom the wash cloth to wash his own face and hands. He is willing and reaches for the wash cloth. He seems to enjoy doing it. So I continue to give him the cloth. I offer him a soapy wash cloth to do his chest and I stand in attendance.

Tom slowly and methodically begins to stroke his chest with the soapy wash cloth up and down, and up and down. I realize that Tom is finding the imaginary line of sensation and no sensation in his body. I stand in silence by his bed ready to exchange the soapy wash cloth for the rinse wash cloth. He moves the wash cloth up and down and up and down. A few minutes pass but it seems like an hour while I wait for Tom to discover just one of many meanings of his thoracic injury during his bath. Tom has been told about his paralysis by his physician followed with teaching from his nurses, his physiotherapists from the first day he was conscious. Yet in this bath, he discovers it.

Tom logrolls over to his side with my help so that I can wash his back. I am very conscious of every stroke I make on his back with the facecloth, with the towel, knowing that today Tom is very attentive to what he can feel and what he cannot. I change the water and I leave. Tom has the wash cloths in easy reach for Tom to wash his own genitals and perhaps check too for sensation. I return in a few minutes to powder his inanimate legs and put his TED stockings back on. Our conversation returns to the hockey game. I change the linen with Tom helping as much as he can. Soon Tom's refreshed body lies between clean sheets and the smell of the soap and clean linen refreshes the smell in the room. The atmosphere in the room has lightened immensely.

The next couple of days are so busy on our unit with new admissions that I cannot spend much time with Tom and his morning care. He helped himself a lot and didn't seem to need much of my attention except for his legs and stockings.

I quickly did what had to be done and left because now I have a new “Tom” to nurse. But it didn’t matter to Tom. Somehow Tom had moved on. He likes my jokes and hockey talk more than my bath now.

Several months later Tom returns to my unit from the Rehabilitation Hospital to say hello to me. He is going home soon. I hardly recognize him in a wheelchair, dressed and wearing a baseball cap. He looks so different. His body has changed shape. He has aged around his eyes. Yet too I sense his contentment. He tells me about his new hand-controlled tractor/harvester he gets to go home to. I say, “Not to mention maybe your wife and kids.” And we laugh together.

Agnes, for all her nursing and technological skill at bathing neurologically impaired patients, spinal cord injury patients, does not know prior to this situation that today Tom will be attentive to his body and to himself. This is one bath in many. But here Agnes comes face to face with Tom in his need to know; to know not in expert and exact medical terms, or in another’s certain opportune time-line, or in treatment options and future capabilities, but to know what it means to live this body, the moment by moment lived-ness of his body alone. Somehow today, it feels safe to do this. It is Agnes’s attentiveness to Tom that picks up Tom’s readiness to now know in an embodied way what his injury means to himself, to his uniqueness, his way of being in the world. How does she let him “know?” She gives him the cloth. Tom strokes himself to life.

Agnes’s thoughtfulness in the midst of the situation, “action full of thought and thought full of action” (van Manen, 1990, p. 128), enables her to make a critical decision during the bath; to know when *to do* for Tom and when *to stand back* and wait. Another nurse harried by all the things she has to do, not having time to know Tom the patient (as is the now too commonplace nursing situation), may have missed this moment. Agnes though, waits.

Agnes’s nursing persona knows that she must continually protect Tom and make constant movement toward decreasing Tom’s vulnerability; to move him to coping. Indeed it is her response to this felt need that enables this action of discovery. She urges him toward it. Something about this bath’s atmosphere encourages him, encourages him to seek this bodily knowledge, to determine his present assets and vulnerabilities. He develops a livable relation to his body and to his world.

What else operates here in the performance-art of the bath? What more would a nurse see? A nurse would see that Agnes pays particular attention to the environment, the space for the bath. She makes it safe. She carefully draws the curtains and sets up a space that is both non-threatening and comfortable; a space of normalcy. It is in fact a transcendent space; a space where nurses call others to come forth.

Iris Marion Young (1990) writes about how females tend to experience space as rooted and finite. Males when they step forward to catch a ball, reach out into the available space whereas women may prefer to stay within the immediate space and wait for the ball to come to them. Nurses are experts at using space in both ways, in rootedness to set up healing spaces manageable for vulnerable individuals, in finiteness to make it safe, yet too in reaching out to continually broaden a patient’s enterprise.

Abram (1996) speaks to the notion of space and the notion of time. When we allow the “past and the future to dissolve, imaginatively, into the immediacy of the present moment, then the “present” itself expands to become an enveloping field of *presence*” (p. 204). It is this



“remarkable fit between the temporal concept (the “present”) and spatial percept (the enveloping presence)” (p. 204) that Agnes and Tom live here.

In this open present, I am unable to isolate space from time, or vice versa. I am immersed in the world. (p. 204)

### ***Lymond and Ada's Bath***

Lymond is an academic, an historian who has moved to a quiet town, the town of his youth, and to the house of his youth, in order to write a biography of his grandmother. Lymond has a severe crippling form of arthritis. Ada, a nurse afflicted with a milder form of arthritis, comes to bathe Lymond every evening.

Whatever you think, come on, Ada. I (Lymond) need that bath and that bed and that bedtime bourbon. Whatever you think, I have learned to think nothing. I run by routine, I accept from hired women services that I would never have accepted from my wife before I became a grotesque. When you block the doorway with your bulk, and shuffle in on your bunioned arthritic feet making comfortable noises, my soul rushes out of me with gratitude.

Already we have a comfortable rut, we go through habitual motions whose every stage is reassuring. While she starts the bath water I wheel my chair into the bedroom, just beside the bathroom door. We don't bother with the crutches. She helps her grotesque doll to stand up, and it clings to her while her gnarled hands, the end joints twisted almost at right angles, fumble with zippers and buttons. She has never complained of her arthritis to me-thinks it amounts to nothing beside mine. Grunting with effort she lifts me-she would say "hefts" me-while she flops a testing hand in the water. Then she returns and hefts her maimed doll bodily into the air until the last clothing falls from its foot, and lowers it with grunts and sighs into the tub.

The water is so hot that it makes the cicatriced stump prickle and smart, but it must be that hot if it is to ease the aches away enough to permit sleep. Painfully she wallows down on her knees and without diffidence soaps and rinses me all over. Her crooked fingers drag across the skin stiff as twigs. Her doll sits stiffly, pointed straight ahead at the fixtures that emerge from the wall. When she is finished she bends far over and guides its arms around her neck. Then she rears upward, and up it comes, naked and pink, her hairy baby, its stump bright red. Its dripping wets the front of her dress, its rigid head glares over her shoulder.

Holding it, clucking and murmuring as she works, she towels it down as far as the knees, and then she takes it around the waist and tilts it upon her great bosom

and rotates until its leg, bent to miss the tub's rim, can straighten down on the mat. Pressing it against her as intimate as husband, she towels the rest of it and eases it into the chair and wheels it to the bed. Another lift-the buttocks sink in softness. It sits there shivering in its damp towel until she comes with urine bottle and tube. When I have attached them she checks the hookup with a casual tug.

Now the pajamas, delicious to the chilling skin, and the ease backward until the body that has been upright too long is received by mattress and pillows. She sets the telephone close, she tucks up the covers. Finally she waddles over to the cabinet by the desk and gets the bottle and two glasses, and we have a comfortable nightcap together like cronies. (Stegner, 1971, p. 29, *The Angle of Repose*)

For certain, Lymond is very aware of his body as object and describes it as an object as Ada manipulates and cares for it. And as Lymond relinquishes his bodily care to Ada, he also reveals Ada's knowledge and skill in bathing a crippled and painful body.

When illness and disability strike, suffering individuals become watchful and vigilant, and closely monitor their bodily workings (Cameron, 1988, 1993). They can be found focusing on the particular body part that malfunctions. They learn the medical language to describe the body part and they learn from medical and nursing assessments and examinations just what signs and symptoms to watch for in that body part. Gadow (1980) describes this as a shift from the lived body to a focus on the object body, the body objectively known by science. Lawler (1991) sees nurses' work as *somology*; one of integrating the object and lived body through nursing measures after the shift has occurred.

But according to Lymond, he is not too concerned about whether his body is the object or the lived one; his object body is lived regardless. And he acknowledges too, that the nurse has an object and a lived body that gives him succor; an object body which "hefts and lifts", a lived body which directs and shares life. The bath enables the living somehow. It could be that Lymond takes pleasure in standing outside himself in this bath. He shows us that turning oneself into an object one observes, or a clinical object another prods, enables a necessary dimension of coping; a sort of "I am not one with this body that has gone so painfully awry."

Lymond requests this caring for himself, specific kinds of caring for his body, kinds of intimate caring that he had not experienced even in his relation with his wife. He likes Ada's coaching, her clucking sounds of encouragement. In nursing, we call this coaching, "just one more step", "almost there" can be heard walking by any nursing unit. Lymond needs it. He becomes even more aware of himself as an entity as Ada holds him closer than a lover, nestled in against her breast as she moves him efficiently yet in a manner that minimizes the pain the most. He calls for this attention. He has suffered today.

What would Ada say? She might say that bathing others includes water, correct water temperature, soap, towels, washcloths, bed linen, wheelchairs, commode chairs, bath stretchers, neck collars, ankle supports, and various other personalized equipment. Bathing also includes unpleasant body odours, lifting the dead weight of paralyzed limbs, untangling equipment such as

catheters, IV tubing, connectors, dressings, heavy pieces of traction, and repositioning and realigning bodies. Nurses get wet and dirty while patients get clean (Cameron & Mitchell, 1994).

But again, she might say that she knows she has given Lymond comfort again; helped him shift back into his lived body? Perhaps. And yet it also seems that in this story Lymond says something else: "I in myself am not an ill individual, I am who I am: still very much interacting with my world as it wraps itself about me. I just experience it in a different way. I live my body in its pain and ecstasy."

Lymond also might say to nurses that "Ada, the nurse, enables my wholeness because she addresses my person as I was, as I am, my *sui generis*." It is merely a shift of focus for a time. When it is permanent, then the grace of living with a body that now works in different ways does come to us. Nurses help Lymond to daily embrace his body. Nurses address this coming forth of the individual, in fact, we call it forth and nourish it.

Lymond at the end of the story, describes the ecstasy of the warm pajamas, the comfortable bed clothes, the bourbon shared together, the moment at the end of the bath where he moves out of feeling his body as a mass of pain to feeling as a person again. He may describe himself as an object for the sake of the reader, so somehow the reader can understand just how difficult it is to maneuver in a compromised body. But Lymond does not give up. With the daily doses of Ada, he continues to write and completes his biography of his grandparents, early settlers in Idaho State.

Embodiment, what is it? One day we live and move and have our being in a body of which we are only vaguely aware, and the next day, we live in a body we are unable to move and position at will? Lymond describes for us what it is like to live when the awareness of the body dominates existence.

Is it not an extraordinary thing that the lack of something, although we do not know precisely what it is that is lacking, can reveal the miraculous existence of health? It is only now, in its absence, that I notice what was previously there, or, more precisely, not what was previously there but that it was there. (Gadamer, p. 75).

### *A Contentious Bath*

We received a man today who totally repulsed me. He was supposedly brought in for seizures, he has epilepsy. But the nurses say he comes in every month to get back on schedule with his medications and to get cleaned out and cleaned up. He has nowhere to live and apparently only sees a bath each time he's at the hospital. He is from a nearby reserve and there is no running water there. He is a longtime alcoholic and is not compliant with his meds.

When he came in by ambulance, I could smell him all the way down the hall, this sounds like an exaggeration but it is not. It was a foul disgusting smell. There was one person in the room with him trying to get him undressed and get him to the tub. He was being admitted to her empty bed. No one else came to help her. All of a sudden everyone was real "busy." So I thought I should lend a hand because I could hear her losing her temper with him. He's not an easy person to

deal with being drunk and having just had a seizure. He was still quite disoriented and didn't know what we were doing.

I gowned and gloved up and went in. The smell nearly made me gag. Dorothy told me to watch out because he was loaded with lice. And he was. His hair which was hanging past his shoulders was just thick with them and I could see them all over his skin. It wasn't just the smaller younger lice, the nits I had seen quite often in the children's hair in the public schools in Edmonton. He had the nits but also the large adult lice and they were all over him.

Of course, immediately I could feel every hair crawling on my head. We wheeled him to the tub to wash and give him a NIX (Anti-lice) treatment. He had arrived at the hospital with an IV and he wouldn't leave his pole alone or keep his hand with the needle in it still. It was just Dorothy and I in there trying to control him and bath him at the same time. No one else even peeked in to see if we needed help. Finally it was the 2 paramedics who brought him in who came and helped us. Dorothy was almost out of control. She was so angry and disgusted with this guy and that no one came to help.

We gave him two NIX treatments and still the lice were crawling everywhere. Even after the bath (with bleach in the water) he just reeked. I cannot for the life of me understand how someone could let themselves get like this. I understand he lives on the streets but there's a difference between being homeless and letting yourself get to this level with no concern for yourself at all. To me it just shows how little regard he has for his life and his well being. And I realize he's an alcoholic but he only gets so much money for that so he surely would have clear moments to see how far he has let himself go.

Throughout the bath he remained agitated and unpleasant in mood. Because he is a longtime alcoholic, I don't think he understood at the time that we were in fact trying to help him. I think that at that moment all he could see was that his body and his personal space were being invaded for something he maybe didn't feel was necessary or value. And I felt that way too. But Dorothy said no one would come near him unless we cleaned him up, and she didn't want the other people to be exposed to lice. When I went home that night, Dorothy made me take some NIX and use it for a couple of nights in a row to be certain I didn't have any lice and to wash my uniform in bleach.

For the duration of his stay at the hospital he had baths and a haircut, had his medication stabilized again. But his mood remained less than pleasant and he was totally uncommunicative. When he did speak it was slurred and he became agitated if he had to repeat himself. He mainly spoke Cree anyway. But I had picked up quite a few words of Cree by this time and I understood quite a lot. Because I figured this experience to be so negative for him, I will always remember his reaction towards me when it was by chance that I saw him weeks later at the Health Centre on the reserve. I had flown in with the doctor for clinic on that reserve. I looked up from what I was doing and saw him staring at me. He immediately broke into a big smile and his eyes were shining. He came over to me and patted my shoulder and started talking to me in Cree. He remembered me from the hospital. After he saw the doctor, he shook my hand. I was told that he doesn't do that to whites very often, but he must have remembered that bath and the times we spoke afterward. That bath somehow connected me to him even though at the time I didn't want to be connected with this dirty drunken man. (Personal communication, story told to me by Nicole Rosendale, student in Northern and Rural Nursing, written with permission)

Should the nurses have bathed him or let him be? Wolf (1989) would say that this bath made this person nurseable and approachable by other disciplines. But Adrian Jones (1995) too speaks in a student voice about a situation where he knew in theory that he must individualize care but in practice it was more important to "get the work done." He coerced a patient into having a "wash."

The activity of washing is important, although the daily routine cannot be legitimately defended. The coercion employed did not appear to be acting on the principle of beneficence, but solely on my personal agenda to be fulfilled. Although my personal nursing agenda may have been written by the socialization process, a degree of self-awareness is warranted to ensure unacceptable practices are not permitted. However, this requires nurse education to create both a teaching and clinical environment to be receptive to such activity. The process of supervision would appear essential to facilitate this activity. (p. 287)

### ***An Invasive Multiskilled Bath***

Two weeks after my brain tumor surgery two young men came into my room. They did not introduce themselves with their names or positions and that bothered me right away. Maybe they were embarrassed. But they just started taking off my clothes, my pajamas, my underwear. I was scared, real scared. They had to roll me on a stretcher to the stretcher bath tub. There they pulled the gown off that they had loosely put over me after they had undressed me.

I couldn't speak yet after the surgery, well just a few sounds. My one side was still paralyzed. I couldn't walk. I couldn't move on my own at all yet. I didn't have control over my body. I had to be lifted. They did stuff to my body that I wasn't used to because they took care of my body in a very different way than I would have.

So here I was unable to move, talk, stark naked, exposing my body to two young guys my age. Now I know young guys like viewing that kind of stuff. And these two had such a cocky attitude. I could tell the two young guys were checking me out. They were probably saying, "look at her boobs." How could they not? They are human young men. I was not deluded. I knew my body was not attractive at all. I was nowhere sexually attractive. But I also knew that attractiveness is not the motivation for sexual assault.

I wish now I would have said no to the bath. But I was not myself and couldn't think quickly enough and also I was afraid of what they would do if I didn't cooperate. Now I wish I would have caused a commotion with grunts and squeals.

In the tub they both washed my body; one on either side with a cloth. It felt like someone taking a piece of sand paper and pushing and rubbing it hard in short jerks all over my body; even the tender spots. They did not talk at all; not one word. They put a cloth into my good hand at the end and gave me a non-verbal command with their eyes and slight nod that said to me, "you deal with that part."

When I was in the tub, I wasn't afraid of being assaulted. I felt safe there thinking that the tub was a physical barrier if they should try to assault me. But before lowering me into the water and when they worked the machinery to get me out of the water, I was shaking I was so scared. They didn't put a towel or blanket on me at all and so I lay naked on the stretcher bath shaking and waiting for them to work the machinery. It's hard to say how I felt; a sort of mix between being a sort of a piece of nothing, like a floor they scrubbed yet at the same time, a potential object for sex.

They roughly toweled me down and put on my own clean nightgown and panties. The nightgown was put on inside out and the crotch of the panties were inside out and backwards. They took me back to my bed and lifted me into it. I lay

there shaking for the rest of that day and the following night because I thought they would come again the next day to bathe me. They didn't. I never saw them again. Maybe they came from another ward to help. I don't know. But I do know I felt assaulted. It was their seeing and handling of my body that really disturbed me. I felt violated. It was like my body was given over to them for nothing. It wasn't worth anything and neither was I.

Lakeman (1996) states that there is little written about the ethics of basic nursing actions such as bathing. He goes on: "This is surprising as selecting, initiating or giving physical care is often a large part of hospital nurses' role, particularly in psychogeriatric areas" and "bathing may easily be interpreted by a cognitively impaired or mentally ill person as an overt physical or sexual assault" (p. 14).

It is not surprising that some people may respond to this perceived assault with aggression or internalized feelings of powerlessness, helplessness, hopelessness and lack of control. Given the potential for harm inherent in forcing a person to bath, when if ever is it morally justified? (p. 14)

In the end, Lakeman states that the nurse and patient have many options for cleanliness and there is always room for compromise and mutually selected paths to go down.

### *A Haunting Memory Bath*

One of my most awful memories of bathing is that of caring for a severely brain injured young girl of about 17 years old. It had been the result of her getting hit in a crosswalk by a speeding car driven by a drunk driver. She had regained consciousness but it would of course take a long time for us to see how much brain activity she would recover. The CAT scan was not encouraging.

She had been bathed in bed when she was stable enough for the procedure and by now, and especially this morning, was very dirty with excretion and she had gotten her period so her lower body and bed was covered in menstrual blood. She had regained consciousness now for about a week and was much better so we decided to take her to the tubroom to get her really cleaned up. We put her in the chair shower and then two of us started to bathe her. She became upset so we worked faster, encouraging her now and then to take the washcloth. And then she literally went berserk. I will never ever forget this. She was so upset at us washing her with the cloth. When we tried to wash the blood off her legs she started kicking us. She screamed, kicked, scratched, hit out at us. We stopped of course and managed her aggression, got her back to bed; her bed completely changed, mattress turned over as she had been in it a long while, supports changed, and she was clean, shampooed, menstrual blood cleaned and contained.

But we never should have done it. We realized, but not soon enough, that this young girl had developed a hypersensitivity to water as part of her brain injury. Later we told her parents about their daughter's altered brain function and explained it as a sort of water phobia.

About a year later I saw this patient and her mother at a rehab class I was teaching. The daughter had not improved very much at all, but seemed more manageable. Her mother told me she needed 24 hour care still. I asked her mother how they kept her clean this past year. She answered, "We didn't."

### **Baths from literature**

Literature presents for us possibilities in human life. Here we offer some excerpts from literature that show lived experiences of bathing and what the bath signifies for others "in the minds of authors, in the lives of their fictional characters, and in the experiences of the readers" (van Manen & Levering, 1995, p. 36).

#### ***Bathing to impart knowledge to become***

Anita Rau Badami (1996) writes in *Tamarind Mem* descriptions of generations of women in an East Indian family. The stories are about women and children engaged in daily life; men mostly absent at work. Central to the rhythm of women living and moving together in a certain space and time is the age old act of cleaning oneself and one's children. This is a memory of the child when she was still in a high chair; a child's voice.

Hindi melodies from Mukesh movies streamed out of the bathroom along with the sound of rushing water as Ma washed her cascading black hair. She hummed in the bedroom, patted puffs of talcum powder under her arms, across her back, where sweat sprang and wet her Rubia blouse. She sang as she wrapped a rustling cotton sari around herself and then came out to dry her hair on the verandah, where the sun roared out of a blue, blue sky. I remember how she smiled at me upside down, through a flying sheet of hair, and I stared in awe at my luminous mother. (p. 47)

Baths in this group of women are ritual affairs. "My mother is the only other person who has seen my body unclothed. Every Sunday, I wait for Amma in the smoky warmth of the bathing room, an old petticoat tied below my armpits. In one corner, where the slime needs to be scraped away daily, a huge copper pot simmers over the cement oven" (p. 196). This mother begins by giving her daughter advice about husbands.

"It is wrong to address him as 'you,'" she would remark, her mouth pursed with disapproval. "Be respectful, say 'thou.' Don't give him the impression that we haven't done our duty as parents and brought you up properly."



All her advice is given to me during the long Sunday baths when she rubs and slaps warm mustard oil into my skin. Those are her private sessions with each child, when she has the time to pass on wisdom handed to her by her elders, or to scold misdeeds. With me she always-always starts with, "How many times have I told you and still you don't listen..." Her hard hands knead the muscles of my back, and I sit in a daze of steam from the copper pot, the acrid stink of oil, and the muscles in my body slowly unwind. (Badami, 1996, p. 187)

When this daughter becomes the mother of the child in the high chair, she too bathes each of her children separately and talks to them. Things happen during these baths.

"You didn't get these strands of grass from my side of the family for sure," she said one Sunday, vigorously rubbing castor oil into my scalp. A friend had advised Ma that castor oil was better than coconut oil. And what was left over from applying to the hair could be drunk to cleanse out the bowels. "Dual-purpose oil, Mrs. Moorthy," she told my mother. "Inside and outside it will clean and shine."

I imagined my intestines glistening like polished silver after a dose of the thick, evil-smelling oil and told Ma that I would never, ever talk to her again if she made me drink it. (p. 74).

This same child grows and matures and the tone of her baths becomes different.

Now that I had turned twelve, I noticed that Ma spoke to me differently, almost like a friend. Even the dreaded oil-bath day was no longer a wet battle ground but a time when Ma talked to me, told me of her own childhood, gave me advice. Ayah was not allowed into the bathroom to pour water over my head any more. Now only Ma could see my body, decide that it was time I wore a brassiere. I wanted her to buy me a red one from the vendor outside our colony gates. The man claimed that it would give me a figure like that of the film actress Rekha. Then maybe Frankie Wood the club caretaker would look at me.

"Only harlots wear those things," Ma said as she pushed my head downwards, her fingers stroking oil into the base of my skull, so warm so warm. "Be careful how you dress, be careful who you speak to. You are twelve years old and you don't know what all can happen." (p. 125)

Both Mem's here show a nurturing care for the *sui generis* of these little individuals, their children; These acts are integral to their notion of protecting their children, preparing them for life, noting their specialness yet imparting cultural norms.

### ***Bathing as shared inwardness; women's community building***

Valerie Staats (1994) describes her experiences in a *hammam* in Morocco, a public bath place for women and children where ritual weekly bathing takes place. Ritual bathing for men takes place in this society too but in different locals or at different times in the same *hammam*. Here she describes the smells of bathing, the smell of soap, the smell of henna that women put in their hair and then wash out in the bath, the smell of oranges which women and children suck to combat thirst while bathing, the smell of cloves rubbed into the hair, the smell of the water draining upon the floor area. This is an intense communication place where everything is discussed.

Protocol begins in the dressing room, where bathers take off all but their undergarments...Inside the *hammam*, a bather chooses a room among the two or three connecting rooms of varying degrees of heat...she tries not to take someone else's floor space, and must try not to splash others with the water as she bathes. The wise bather finds a spot that is upstream, not down, of all the dirty water that swirls its way clear space on the floor...before sitting down, the bather must perform a ceremonial washing of the floor area, which means splashing water from the buckets and swishing it away with her foot...toward the drains.

The *hammam* bather applies *sabon bildi* (soap) to every centimeter of her skin. She relaxes for a few moments to accustom herself to the heat and allow her skin to start perspiring. Then, she slowly scrubs with the *kees* (course black mitt and scrubbing stone), going over each part of her skin several times. This step is vital to the bath. The *sabon bildi* melts into her skin and makes scrubbing with the rough *kees* easier.

Women scrub and rub each other, unselfconsciously, in what is certainly a pleasurable experience. It is proper form to ask someone nearby to scrub one's back, and she will usually do so with care. One may offer to do this for someone sitting close by. Or, one can pay a woman who works there for a complete scrub and rubdown, which sometimes includes an intense massage.

A common sight at the *hammam* is a woman lying relaxed on the floor while another kneels over her, lifting her arm or turning her over, scrubbing away the old skin. One smiles and perspires as she works hard; her partner smiles, eyes closed, as she gives herself up completely to the other's ministrations. This intimate, uninhibited way of relating to each other is part of the satisfaction of the *hammam* for Moroccan women. They may perform this act of love for their friends, children, their own mothers, or sometimes, an older woman will take

charge of a younger one, perhaps the rare foreigner at the bath and give her the rubdown of her life.

The bath continues, women refilling water buckets as need dictates...For the final rinse, the bather stands up and douses herself with all the water left in the buckets. Back in the dressing room, she sits or stretches out on benches for as long as it takes to settle the red flush on her face and become reaccustomed to the temperature of the real world. Older or pregnant women often lie down and nap.

(p. 4,5)

Here in a society that is under male domination, this is a woman's space, a narrow woman's space in a very structured world (Staats). Here women care for each other, their children. Here they exchange information, who is the best doctor, how to feed babies, who is having trouble at home, what treatment either alternative or western medicine works best, and so on. Here is an intimate form of relating to each other, a communal form of caring for one another's body as well as their own.

Waiting for the soap to permeate the skin, scrubbing with a stone to remove dead skin cells, scrubbing the backs and bodies of others, washing one's hair that has been treated with henna to condition, scrubbing actions "going over each part several times" (p. 4), relating stories of lived life, admonishing some and giving advice to others, all actions intertwine and become an intricate dance of being, almost a celebration of being, so to speak. There is a transitional space before the bath where one removes one's clothes, pays someone to care for them, prepares to enter the hamman. And then again after the bath there is a transitional space where one reaccustoms oneself to prepare to enter the "temperature of the real world" (p. 5).

This traditional bath for women in Morocco takes two to three hours, a group experience of talk, laughter and the occasional dispute over territory or splashed water, which is forgotten after five minutes. When someone leaves the hammam, she says *b'sahahtik l'hammam*, a traditional blessing that means "to the health of you and your bath." It is as certain as are the Muslim traditions that shape Moroccan society that she will hear *Allah atik saha*, the second half of the formula, "God give you health." (p. 5)

Skin is the natural barrier that protects our bodies from invasion of foreign, harmful material from the outside world. Yet skin is also the entry point of good nutrients as well. Skin rejects, skin absorbs. And here in some special way associated with the ritual, the cleansing, the shedding, allows not only for careful attention to the body, but too for an *inwardness* to develop in the midst of community that builds harmony within and without, an opening of selves to an other reality rather than *othering* others. A natural generosity flows.

These ritual baths in certain cultures are not so common to North American bathing practices. North Americans prefer privacy when bathing. While in ritual bathing practices the person is usually able to bathe himself, in infirmity and illness the person cannot. And so there is an essential difference to these particular cultural baths and to bathing in nursing. Yet these descriptions offer us insight into the many lived dimensions of bathing as a human activity.

### *Bathing as purity, confirmation of status*

Susan Grossman (1992) writes of the *Mikveh*, “a pool especially designed for the purpose of ritual ablution which contains a prescribed minimum amount of naturally gathered (rather than piped-in) water” (p. 7). Traditionally in Rabbinic law in the Laws of Family Purity, a *mikveh* is required after a woman’s menses to purify her before she resumes sexual relations (prohibited during menses) (Grossman, 1992, Chernick, 1988). The *mikveh* is also required “in the rite of conversion for both men and women” (Chernick, p. 61).

The male bath is called the *mikvaot*. Men who follow the Hasidic tradition go to the mikvaot “on a regular basis, before Sabbath and/or holidays, as a way of enjoying the experience of being spiritually renewed” (Grossman, p. 16). Other men do not observe the mikvaot or observe it in conjunction with the woman’s *mikveh*. “The requirement for abstention during and after the woman’s menses and the joyful coming together after *mikveh* fall equally upon the man and the woman. Some couples may choose to go to *mikveh* together as a sign of the renewal of their relationship or the man may want to go alone on the day preceding the evening when the woman goes” (p. 15,16).

Grossman (1992) points out that “Judaism is a guide for holy living, for turning the world as it is into the world as it can be. This dedication to holiness has fueled Jewish commitment to social justice and its utopian vision (p. 13).

As a feminist, I was first attracted to observing *mikveh* as a way to sanctify the cycle of my body, to celebrate the body when it works the way it should. (We celebrate other aspects of our bodily functions each morning in the preliminary prayer service.) *Mikveh* provides a way to sanctify God’s gift to women, the ability to imitate God on a sublime and holy level, the ability to create life. (Though we are still distinguished from God, as limited human beings, because we require the help of our human and Divine partners to create life.). (p. 13)

In addition Grossman (1992) writes that the *mikveh* also is an important historical link with women in the history of the Jewish tradition.

We must also consider if there is a place for women outside of a relationship with men. Immersion after completion of one’s menses links each woman with a community of women, past, present and future. It was a treasured female observance to which our foremothers clung, even in the icy waters of Russia’s winter rivers. It is a time for a woman to look over her body carefully, to be in touch with its ebbs and flows, to appreciate its potential to create life and thereby to share in the creative powers God granted us when God created us in God’s image. This sense of wonder and appreciation is a gift to all women, whether or not they are in a relationship with a man. ( p. 16)

Ritual bathing with significance to purity, to holiness, to celebration of new life forming, to a connection with a historical past remains an important part of a religious tradition.

### ***Bathing as dehumanizing, an evil ritual, a perversion***

One cannot do a literature search in any CD-ROM format, be it history, sociological, literature, psychological, legal, etc., without coming up with the ritual cruel showers the Jews were forced to endure at the entrance to concentration camps. Elie Wiesel (1972) describes many such entrances to camps where the people were stripped, shaved, and showered with powerful disinfectants before they were marched naked to barracks. Wiesel was moved from Birkenau to Auschwitz and there were other smaller camps along the way.

A barrel of petrol at the entrance. Disinfection. Everyone was soaked in it. The hot shower. At high speed. As we came out from the water, we were driven outside. More running. Another barracks, the store. Very long tables. Mountains of prison clothes. On we ran. As we passed, trousers, tunic, shirt, and socks were thrown to us. Within a few seconds, we had ceased to be men. (p. 45)

Auschwitz. First impression: this was better than Birkenau. There were two-storied buildings of concrete instead of wooden barracks. There were little gardens here and there. We were led to one of these prison blocks. Seated on the ground by the entrance, we began another session of waiting. Every now and then, someone was made to go in. These were the showers, a compulsory formality at the entrance to all these camps. Even if you were simply passing from one to the other several times a day, you still had to go through the baths every time. After coming out from the hot water, we stayed shivering in the night air. Our clothes had been left behind in the other block, and we had been promised other outfits. (p. 51)

### ***Bathing a dangerous luxury***

In *The Bath* by Janet Frame (1983) the story is told of an elderly woman who attempts to have a tub bath. Tomorrow she goes to visit her husband's grave and for this visit, she needs to bath. It is her ritual. The story evolves around the difficulty of bathing now at her great age; of turning on the tub taps with arthritic powerless hands, of setting up the chair and towel and nightdress for ease of getting out of the tub, of the pain and weakness in an aging body. All of this is described and all is permeated with a strong sense of sadness, that she must soon give up bathing as a personal joy and get in some help. It reminds me of my mother. One of the things she most missed in her nursing home was being able to bathe whenever she wanted, to bathe by herself, and to bathe in her accustomed manner in the tub.

She undressed and pausing first to get her breath and clinging tightly to the slippery yellow-stained rim that now seemed more like the edge of a cliff with a deep drop below into the sea, slowly and painfully she climbed into the bath.

I'll put on my nightie the instant I get out, she thought. The instant she got out indeed! She knew it would be more than a matter of instants yet she tried to

think of it calmly, without dread, telling herself that when the time came she would be very careful, taking the process step by step, surprising her bad back and shoulder and her powerless wrists into performing feats they might usually rebel against, but the key to controlling them would be the surprise, the slow stealing up on them...

Sitting upright, not daring to lean back or lie down, she soaped herself, washing away the dirt of the past fortnight, seeing with satisfaction how it drifted about on the water as a sign she was clean again. Then when her washing was completed she found herself looking for excuses not to try yet to climb out. Those old woman's finger nails, cracked and dry, where germs could lodge, would need to be scrubbed again; the skin of her heels, too, growing so hard that her feet might have been turning to stone; behind her ears where a thread of dirt lay in the rim; after all, she did not often have the luxury of a bath, did she? How warm it was! She drowsed a moment. If only she could fall asleep then wake to find herself in her nightdress in bed for the night! Slowly she rewashed her body, and when she could no longer deceive herself into thinking she was not clean she reluctantly replaced the soap, brush and flannel in the groove at the side of the bath, feeling as she loosened her grip on them that all strength and support were ebbing from her. Quickly she seized the nail-brush again, but its magic had been used and was gone; it would not adopt the role she tried to urge upon it. The flannel too, and the soap, were frail flotsam to cling to in the hope of being borne to safety.

She was alone now. For a few moments she sat swilling the water against her skin, perhaps as a means of buoying up her courage. Then resolutely she pulled out the plug, sat feeling the tide swirl and scrape at her skin and flesh, trying to draw her down, down into the earth; then the bathwater was gone in a soapy gurgle and she was naked and shivering and had not yet made the attempt to get out of the bath.

How slippery the surface had become!...She leaned forward, feeling the pain in her back and shoulder. She grasped the rim of the bath but her fingers slithered from it almost at once. She would not panic, she told herself; she would try gradually, carefully, to get out. Again she leaned forward; again her grip loosened as if iron hands had deliberately uncurled her stiffened blue fingers from their trembling hold.

The story goes on as the old woman tries alternatively to get out of the slippery tub and to rest in between, each time hoping she will have the strength to get out the next time. She gets angry and bangs her fists in frustration against the side of the tub. Eventually she succeeds in getting out after almost an hour of trying. She sits in an empty bathtub, the water long since gone down the drain, and tries to get out.

She wondered how long ago it was since she had been able to look up at the sky without reeling with dizziness. Now she did not dare look up. There was enough to attend to down and around—the cracks and hollows in the footpath, the patches of frost and ice and the potholes in the roads; the approaching cars and motorcycles; and now, after all the outside menaces, the inner menace of her own body. She had to be the guardian now over her arms and legs, force them to do as she wanted when how easily and dutifully they had walked, moved and grasped, in the old days! They were the enemy now. It had been her body that showed treachery when she tried to get out of the bath. If she ever wanted to bath again—how strange it seemed!—she would have to ask another human being to help her to guard and control her own body. Was this so fearful? She wondered. Even if it were not, it seemed so. (pp. I-24, 25, 26, 27)

How zealously we value and guard our private moments of personal care, those moments when we sit replete with who we are and care for our bodily selves, experience aloneness and revive ourselves, or experience the other and an intimate! How difficult it is to give up these moments of loveliness to the senses! How labourious body care becomes! How I should not like to give up my bath!

***Bathing as celebration, as sensuous, as shared***

A family travels in Ceylon, a search for one's roots, an exposure to relatives alive and long dead, a description of relations both present in the ones who travel and the ones who are met are presented in *Running in the family* by Michael Ondaatje (1982). Here they have driven with a tracker for 10 hours towards the Wilpattu Jungle in very hot weather on "bad roads of red clay and sand" (p. 140) and reach a rest house.

We empty the jeep of all the food we have brought and begin to change out of sweat-soaked clothes...A delicate rain begins pattering on the tin roof then suddenly veers into a thunder shower which whitens the landscape. To the left of the house is a large pond, almost a lake, where water lilies float closed at this hour, now being pounded bouncing under the rain. The girls are out there in their dresses getting wet and suddenly the rest of us decide this is the only chance for a bath that we will have here and walk out into the storm. Nine of us holding up our arms for all the rain we can reach.

We are slightly drunk with this place—the beautiful house, the animals which are appearing now, and this tough cold rain turning the hard-baked earth into red mud. All of us are in our solitude. Not really concerned about the others, just reveling in a private pleasure. It is like communal sleep. The storm falters then starts up again, wilder than ever. The bungalow's cook and the tracker watch from the doorways of the house not quite believing what is happening to this strange mixture of people—Sinhalese, Canadian, and one quiet French girl—who now soaping themselves with a bar of soap and throwing it around like a foaming elixir so everyone is suddenly white, as if in a petticoat, and now trying even harder to catch the rain everywhere, bending over to let it land on our backs and shoulders. Some move under the warmer rain of the trees, some sit as if it was Sunday afternoon on a bench by the pond of water lilies and crocodiles, and the others wade ankle-deep in swirling mud by the jeep.

Then a new burst of energy. A val oora—a large filthy black wild boar has appeared majestically out of the trees with tusks that turn his quiet face into hair-lipped deformity. He watches, making us aware of each other half-soaped, happy and ridiculous, dresses heavy with rain, sarongs above the knees. All of us—the lilies, the trees with their wind drunk hair, this magnificent val oora who is now the centre of the storm—celebrating the elimination of heat...Wild black pig in a white rainstorm, concerned about this invasion, this metamorphosis of soap, this dented Volkswagen, this jeep. He can take his pick, any one of us. If I am to die soon I would choose to die now under his wet alphabet of tusk, while I am cool and clean and in good company. (p. 141 )

Holding up one's arms, embracing the rain, a bodily gesture of praise in some circles, of response in others, here, one of thankfulness for the cooling rains. A dance of sorts, a private sensuous experience in a foreign land, yet with its foreignness comes a simple celebration of the senses and of being one with the visible and invisible world...a cooling and cleansing one's body.

### ***Bathing as Sexuality***

Poems evoke direct images; they flood instantly into our awareness.

*Nude* by Duncan Forbes

The door is open and yes she is naked,

The blonde at the basin cleaning her teeth.

I and her toothbrush are over-excited;

I could catch her quivering rump and eat it



Now as she steps through the steam to the bath.  
Her skin wears a two-piece of next to no suntan.  
And striped in brown and orange (just like mine)  
A flannel, saving energy for later,  
Floats in the warm promiscuous water.  
Soap and flannel are lucky men.  
Sweat on the mirror. Soap in its slime.  
Waters have issued, the plughole has moaned  
and the bath is empty except for the scum,  
The dead hairs, puddle and dirty rim.  
She was on two counts not a real blonde. (Forbes, 1990, p. 185).

***Bathing as baptism***

The first bath of an infant in some cultures is significant. The original title of this poem is “His-erh”, the Chinese ceremony of giving the infant its first bath on the third day after a child’s birth. It is a blessing of such.

*Bathing the Infant* by Unknown Author, Translated by Chiang Yee

Most people expect their sons to be clever,  
My whole life was ruined by cleverness.  
I only wish my son to be dull and stupid  
And without suffering or hardship to reach the highest rank. (Wu-chi Liu & Yucheng Lo, 1975, p. 348).

***Bathing as the coming of sexual awareness***

*The Bath* by Ira Sadoff

Mother might have drowned me,  
had she caught me watching her.  
I watched her scrub her skin so hard  
it seemed to blush. I saw desire there,  
before a mother wants to be a mother.  
The keyhole-ring of light that skims the flesh-  
drew me to the pleasure. I understood  
that water scalds, dripping from the wrist.  
Everything else, like a lamp  
turned on and off, was thought: pure, impure, pure.  
Years later, I can’t repair the shock of hair  
crackling to the static of her brush,

or grant her mermaid's wishes. I can't  
re-trace her hands: the first amphibians  
waiting to emerge. In the beginning  
we know too much of everyone  
until we fail them, until we see them  
as they can't be seen. When Actaeon  
came upon Diana's naked body  
and the dogs made cloth of this flesh,  
he knew he'd truly burn. His voice  
was not his own, his face not his face.  
How could one touch heal all of us?  
Since I can't go back  
to what I wanted, since the flesh refuses its own flesh, I can't suggest  
what might have pleased them,  
those long-haired creatures whose touch  
soothed and satisfied. What pleases them,  
these mothers, sisters, lovers,  
whose oars row out to the island  
I keep lonely? What pleased her  
she never said. That night I saw her dream  
so sheer, so self-contained, that mist surrounded it.  
I never knew its subject matter.  
The flesh has its cannibals, its boiling pots.  
We prepare the body badly for its future.  
Every household is full of crimes.  
A moon shines in every window, wanting  
Each night I hold a different woman in my arms. (Sadoff, 1991, p. 331).

***Bathing as absolution, as letting go, as mercy***

In *The Snows of Kilimanjaro* Ernest Hemingway (1927) tells the story of a man who has been injured hunting in Africa. Accompanying him is his female partner. It seems as if there is an infection, gangrene most likely, in the wound. They are waiting for a plane to come to pick them up and they have become quarrelsome with each other, the man antagonizing, the woman pacifying. They have a problematic relation. The man reviews his life and finds it wanting. He finds the woman shallow, his own motives and intentions weak. His past is vivid.

"I'm going to die tonight," he said. "I don't need my strength up."

"Don't be melodramatic, Harry, please," she said.

“Why don’t you use your nose: I’m rotted half way up my thigh now...”

“Do you feel anything strange?” he asked her.

“No. Just a little sleepy.”

“I do,” he said.

He had just felt death come by again.

“You know the only thing I’ve never lost is curiosity,” he said to her.

“You’ve never lost anything. You’re the most complete man I’ve ever know.”

“Christ,” he said. “How little a woman knows. What is that? Your intuition?”

Because, just then, death had come and rested its head on the foot of the cot and he could smell its breath...it had moved up on him now, but it had no shape any more. It simply occupied space.

“Tell it to go away.”

It did not go away but moved a little closer.

“You’ve got a hell of a breath,” he told it. “You stinking bastard.”

It moved up closer to him still and now he could not speak to it, and when it saw he could not speak it came a little closer, and now he tried to send it away without speaking, but it moved in on him so its weight was all upon his chest, and while it crouched there and he could not move, or speak, he heard the woman say, “Bwana is asleep now. Take the cot up very gently and carry it into the tent.”

He could not speak to tell her to make it go away and it crouched now, heavier, so he could not breathe. And then, while they lifted the cot, suddenly it was all right and the weight went from his chest.

He dreams of the plane coming to pick him up. They can only take him in the plane. He watches as they rise up over the plains and the mountains on their way to Arusha where there will be medicine.

And then instead of going on to Arusha they turned left ...and looking down he saw a pink sifting cloud, moving over the ground, and in the air, like the first snow in a blizzard, that comes from nowhere...They began to climb and they were going to the East it seemed, and then it darkened and they were in a storm, the rain so thick it seemed like flying through a waterfall, and then they were out and Compie turned his head and grinned and pointed and there, ahead, all he could see, as wide as all the world, great, high, and unbelievably white in the sun,

was the square top of Kilimanjaro. And then he knew that there was where he was going. (p. 18-27).

Going through the rain cloud, rain so thick it seems like a waterfall, brings absolution to this man for all the things he has reviewed in his life as wanting. Suddenly he sees it is over and how he has lived is how he has lived and his shortcomings and regrets are sluiced off him with a powerful rain cloud. Bathing can be about absolution, a cleansing of past experiences one regrets, a sort of bodily confession, the water pouring over the body, different water droplets each time, each one a sort of renewal, a promise of forgiveness.

In the writings of Shakespeare, bathing, water, often occur as elements of mercy, of absolution, of gentle rains dropping from heaven.

The quality of mercy is not strained;  
It dropeth as the gentlest rain from heaven.  
Upon the place beneath. It is twice blest;  
It blesseth him that gives and him that takes.  
'Tis mightiest in the mightiest; it becomes  
The throned monarch better than his crown.  
His scepter shows the force of temporal power,  
The attribute to awe and majesty,  
wherein doth sit the dread and fear of kings;  
But mercy is above this scept'red sway;  
It is enthroned in the hearts of kings;  
It is an attribute to God himself,  
And earthly power doth then show likest God's  
When mercy seasons justice.

(IV I lines 182-4, Speech of Portia, Merchant of Venice, Wm Shakespeare), (William Shakespeare: The Complete Works, Viking, Penguin, 1969, p.236)

### ***Bathing for sending beyond, for timelessness***

Nurses bathe into life and beyond. When a patient dies, nurses bathe the body in preparation and anticipation of the family's visit to their own, and in preparation for the journey down to the morgue, the pathologist's domain. Perhaps to some this is distasteful, this bathing of the absence. And to some death means failure, failure to cure, a failure of care. Yet nurses see this kind of bathing as a continuation of their relational care. In relation the sense is not failure, the sense is loss. It is part of the sending beyond that nurses deal with on a daily basis. Valerie tries to explain this:

You know when I do the final bedbath, I know this is the final act of caring that I can do for this person and the family. To me it is just an honour to be able to do that. I don't think I'm trying to be this wonderful perfect nurse but for the people who have gotten to know me as much as I know them, it is like a gift to be able

to give to them. I just take this extra special care along with removing and disconnecting the lines and monitors from the body and stuff. I make sure that their teeth are in, their hair is combed, that I fold their hands and position the body in a certain way. I too try to remove some of the ravages of suffering from the person. Of course I can't and know I shouldn't hide them all, but I can diminish them somewhat; because it is such a terrible time when you have lost someone.

But if you take that extra bit of care, going back again to the respect and the dignity for the person, you know they are not there any more. Yet still they are in a way. Oh their breathing and voice isn't there and that seems different. But I look at it like this, they are there. It is more of a spiritual presence. It is so hard to speak of this.

There is a timeless quality to the bath in nursing practice. Tom's bath with Agnes would be familiar to Florence Nightingale during the Crimean War, to Hannah in World War II, to Ada bathing Lymond at home, to nurses working with complex technology today. Nurses are able to somehow nullify experience and pain of extreme embodiment, alive and dead, by their intense relatedness, their attentiveness to the person. They cover it with nursing. Is this not a unique relation nurses have with persons? Nursing is such a unique blend of life essentials. It is a tact of the heart (Steiner, p. 155).

The symbolic meaning of the post-mortem ritual rests in the nurses' need to remove the manifestations of suffering, to purify the patient's body and the hospital room of the soil and profanity of death, and to gradually relinquish their tenure of responsibility for the patient, given up only as the escort personnel transports the dead patient to the morgue. Explicitly, post-mortem care helps nurses make their dead patients presentable for family viewing. Post-mortem care is part of nursing's long tradition with the laying-on-of-hands. Even after patients die, nurses care for them, touching them with gentleness. (Wolf, 1988, p. 139)

It is through the nurse's body that the nursing acts come to form, are expressed; the act comes into being in the gestures. Yet what needs to be done, brought into the world, is already there as a possible. It is in Tom himself waiting to be acknowledged and born. [Or as Dufrenne (1987) phrases the a priori, not only is the "subject open to the object or transcends itself toward the object, but also that something of the object is present in the subject prior to all experience, and that, in turn, something of the subject pertains to the structure of the object prior to any project of the subject" (p. 9).]

Here we do not analyze the structure of the bath; rather we relive its making, its structuration (Dufrenne). As the object of the painting is first seen through the painter's eye and has come to be through the body of the painter (Merleau-Ponty), so too does the bath come into being in this way, through the body of the nurse. The nursing space evokes and makes possible the nurse's gesture. The nurse keeps working things through (labouring) to give time for the particular face of the bath in this situation. Once it is there it is a possible forever in the nursing world; the nurse

knows now how to address this person, this situation needing nursing. Even as the situation changes, she labours through it to bring yet another possible into the world.

Nursing lives in the realm of possibilities. A possible is born, becomes real. Sometimes there is a medium between the hand and the person and the bath coming to form and sometimes there is only an intent to bathe that dies aborning. The mediums are extensions of the nurse's body, they enable the actions. The nurse's hand in the bath strokes with a cloth, with a towel, with the bare hand, with a glove covering the hand, through a bath blanket. All are in direct contact with the person. The tools of nursing do not stand for nursing; rather they assist to bring nursing into life. Stroking, the "inexhaustible gesture" (Dufrenne), with hand or tool actualizes the nursing act. Sterile forceps, gloves, masks, catheters, suction apparatus, dressings, IV's, medications are tools, extensions of the nurse's body engaged in nursing. These tools are a part of the relation of nursing as long as they are not perverted into technologies not attached to a nurse; with anyone wielding the tools.

### *Summary of intent to show*

There is a particular set of photos that set one to thinking about the bath. Vladimir Zhirinovsky is featured on the front cover of The New York Times Magazine and billed as a populist and powerful Russian extremist (Specter, 1994). In this cover page photo he stands sideways, wet mussed hair and naked to the hips where there is a *fade out* of the photo. He is caught in action, soaping his chest, soap bubbles covering his chest. It is not so much a risqué sort of photo as much as a surprising one. Inside the magazine, there is another photo of him fully dressed in a bullet proof vest that covers his entire chest and abdominal area. It has huge straps holding it in place, over the shoulder and around the torso. It is the contrast between the vulnerable body engaged in its ablutions and the heavily guarded body that tugs at reflection. Are we at our most vulnerable in the bath? Or are we most vulnerable when we cover the body so? Still we engage in questions about being human and our lifeworld.

Here I come to the end of the bath as argued and represented in literature and as presented in the characters of fiction and in real life accounts ending with yet more questions. I self-accuse myself, and too sometimes find myself charged, with *over-anesthetizing* the bath. Yet always each time I get too far involved in the *aesthetics* of the bath there is a mindfulness that stops this from happening. And I think this is a characteristic of nursing; we are never allowed to over indulge in just one aspect of what it is to be human or to enact nursing in only one particular way. In describing the particulars in the bath, or in branching out to the universals in the bath, I keep coming back to the body, to the person, to the microbes, to the social-psychology; the de-limiting yet far-reaching characteristics of the particular person in a particular time and place. Acts of nursing call you back from wherever you are into the concreteness of lived life. As much as I like the dreaminess, the sensuousness of the bath, and sometimes the depth of meaning in the bath, nursing does not allow you to stay there too long. Rather instantly you are pulled back to a constantly changing world of smells, sights, sounds, elements coming to be and those passing away...the nursing world.

The intent of this chapter is to speak to the difficulties of showing a practice and to suggest that there are ways to do so that are in keeping with the lived life of the participants. We argue it, we present it, we never assume we know everything there is to understand it, we still approach it with openness. The bath here for us has become a window through which to see the nursing relation enacted; to look at what inheres in nursing while being in the midst of a nursing act.

In the next chapter we look at the discourse of nursing and discuss nursing as it is conceptualized in theoretical and mechanical terms. We question whether these forms are windows to the

presentation of nursing as lived and practiced, or whether they are formulations, representations of nursing that show nursing in ways not true to the lived nature of it.

### CHAPTER 3: FORMS OF (RE)PRESENTATION IN NURSING LITERATURE

*The life-world is thus peripherally present in any thought or activity we undertake. Yet whenever we attempt to explain this world conceptually, we seem to forget our active participation within it. Striving to represent the world, we inevitably forfeit its direct presence. (Abram, 1996, p. 40)*

#### The Tension between Presentation and Representation

One of my students, about to start work as a graduate nurse asked, “how do I keep the nursing theories alive in my mind now that I’ll be in nursing practice full time; practice is so different?” At the time I was embroiled in the controversy of the “multiskilled” worker. I protested the trend of relegating nursing skills to lesser prepared workers in order to save the healthcare system money. In an effort to show why this is not an ethical way of acting, I spoke and wrote about what is inherent in nursing acts and why it is important that these nursing acts be connected to the critical judgment base of a registered nurse.

Why do I mention these two events together? Because both situations led to an awareness of the lack of coherence between our theoretical and our practical knowledge of nursing and the need for an integrated discourse that is ready-to-hand. To what does the student allude? She alludes to a shift of venue and focus; from that of the theorizing of nursing, a safety net for her in some ways, to the practicing of nursing, a living breathing, metamorphosing reality for her to meet and contend with daily. No longer will she be able to make the practice fit into the disembodied theory designations in pages of assignments. She must now live the practice. And she intuitively knows that this will require of her a change of being, of embodying nursing.

To what do I allude? I allude to the fact that as I tried to find literature and research to back up my bold statements, I found there was little in our theorizing of nursing to convince administrators of the importance of the practices of nursing as a primary health care profession within the health sciences framework. Those involved in the administrative arena of nursing practice worked against me too in that when asked what nurses do, they listed tasks without including the accompanying discourse and rationale for the nursing act.

And so this seemingly innocent question, couched in the anxieties of a new graduate, will take us to the heart of the concern here. To be asked this question by an award-winning student on the eve of her graduation 100 years after Florence Nightingale and 47 years after Virginia Henderson and Hildegard Peplau first presented their nursing theories, is to be called to examine what our theories depict. The hourglass calls for an accounting. In deference to this graduating student then the question that will guide the following discussion is “*to what extent do the varying representations of nursing that inhere in the discourse of nursing still resonate with the practices of nursing?*”

According to Skeat (1958), the word *present* comes from the latin word *prae*, which means before, in front, being in sight, in view; and *sens*, which means “being which is cognate with *sant* (being) or *esse* (to be)” (p. 473). To present nursing would be to show it as it stands before us, to break open the “being” of nursing so to speak. To present nursing is to be *in touch with* and *immediately involved* with it. One will sense an “*élan vital*” (Bergson cited in Bachelard, 1964, p. xii), a vital impulse, a flowing of life as lived.<sup>1</sup>

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<sup>1</sup> According to Bergson, the *élan vital* is the dynamic origin of human life



On the other hand, *represent* comes from the word *representer* which in old French means *to exhibit the image of*; to act the part of; to bring before one *again* (Skeat). Klein (1971) shows the difference between present and represent as: *present* is to *be directly before* the phenomenon, whereas *represent* is to *place something before* the phenomenon (p. 586). To represent nursing then is to *place* something in front of nursing at a distance from the aliveness of it; to not be directly involved in it, to be at a bodily and cognitive distance from it.

What would constitute a presentation of nursing? That which is attentive and mindful of directly lived and experienced phenomena, is a presenting. Marcel (1950a) writes that experience cannot be objectified without losing its experiential quality. The notion of experience “is not so much an absorbing into oneself of something *as much* as a straining of oneself towards something, as when for instance, during the night, we attempt to get a distinct perception of some far-off noise” (p. 47). Much of our nursing awareness comes from just this straining towards understanding the particular lived moment.

What would constitute a representation? That which pulls away from nursing as lived, that which does not show the complexities of practice, the contingencies of practice, is a representation. Always at the heart of representation is a reductive and discriminating element; a representation selects the knowledge it will depict.

In addition, there are certain technologies that have been imposed on nursing. And there are economic and efficiency documentation systems imposed on the practice of nursing by administration systems. These too will be looked at in terms of those where the “what-is” of nursing as directly experienced and evidenced in practice holds true in concert with the representations.

My intent is not to polarize artificially the theoretical writings of nursing as either presentation or representation. But rather my intent is to discover which representations of nursing (theories and mechanistic models) still resonate with the practices of nursing. And so there will be representations that retain aspects of the lived-ness of nursing. Some representations, some theory development will remain closer to the experiential, to the presentation of it. In truth, all presentations contain some representation, and vice versa. Herein lies our dilemma.

For example, knowledge of the field of grief, writings and theories of grief inform us as nurses. We understand stages of grief, of mourning, of bereavement. But none of the elements contained in these theories of grief can address the question of what grief is for the individual, the family in the moment. This can only be lived. We can only be respectful of it. Theories of grief tend to lack concreteness, presence, they lack the *being* of the phenomenon of grief.

### ***Indices of presentation and representation***

Where will these distinctions take us in looking at what is nursing and who decides what nursing is, and in looking at how the theoretical and research development in nursing resonates with the entirety of nursing i.e. the practices of nursing? Problematizing the notion of experiential directedness in nursing literature will involve looking for the following indices of presentation and representation:

- theories and research in nursing hold to the realities of nursing as lived.
- theories and research that *present* nursing need to retain a certain livedness, a vital impulse to the daily aspects of the enterprise of nursing. They need to address the dynamic, constantly changing nature of nursing.
- theories and research that move away from the directly lived experience of individuals to a more plenary focus will be discussed in terms of the extent of *representation* within the

depiction of nursing and too, as to what is discernible in the representation that presents nursing.

- technologies that impose mechanistic tools on the practices of nursing without attention to the mode and being of nursing also remove us from the core of nursing and lead to presentation and representation in a different way.
- if the notion of nurses being accountable for their care in an ethical way is paramount to this review and in addition, if mechanistic tools have emanated from the theory, has the theorist in any way attached an ethical evaluation for this?

If the match between the empirical and the experiential details of nursing are too distant, the representation will be called the *envelope* of the theory or research or practice technology. "They present the object by its outside, or its envelope" (Merleau-Ponty, 1964, p. 172).

In order to stave off the criticisms of those who favour theory and research development over the practice of nursing, admittedly it is the nature of theory to be abstractive. Representations of nursing via theory do try to emulate what nursing is. Yet it is time to ask how representation is related to presentation in the notion of theory and research in nursing. But because theory and research hold a privileged place within our discipline it is time to see if that place is a deserved one. One must be cautious and sensitive when developing theory for a practice discipline. Theory has a penchant to hold illusion before our eyes or perhaps if that is too strong a statement, weak theory can fix ideas in our minds to the detriment of the enactment of the profession. Above all theory and research must resonate with the lifeworld. Van Manen (1990) asks "what is the significance of theorizing and research and scholarly thought if they absolutely fail to connect with the bodily practices of everyday life?" (p. 148). Our overall purpose is not to refute theory but rather to find ways to present nursing that stay close to the lived experience of it.

### Theory as Envelope

*They present the object by its outside, or its envelope. (Merleau-Ponty, 1964, p. 172).*

What is at issue here is not theorizing as a scholarly endeavor but rather theory as a representation, as causal, as standing-in for nursing. An envelope without content or letter tucked inside it is like a theory without experience embedded within it. It is as an envelope that has lost contact with the world; there is no diffusion from one to the other. And it leads our student to the dissonance she states so well above.

Gadamer (1981) laments that today theory has become synonymous with science and its applied methods. How should we approach theory in the midst of our moratorium world in the profession of the primary? First we would acknowledge freely that the *constructed* nature of theory equates it more with the constructed *mechanistic* ways of operationalizing nursing, i.e. turning nursing acts into tasks and templates, rather than equating to wisdom and nursing acts as *tactful practices* such as in the descriptions of bathing above. We would be in good company here. Gadamer states that "modern theory is a tool of construction by means of which we gather experiences together in a unified way and make it possible to dominate them" (1989, p. 454). Constructed theory is "aimed at dominating what exists and so must in itself be called practical" (p. 454).

We are said to "construct" a theory. This already implies that one theory succeeds another, and from the outset each commands only conditional validity, namely insofar as further experience does not make us change our mind. (1989, p. 454)

Barnum (1998) likens theory to a road map. "The map does not display the full terrain (buildings, moving vehicles, grazing livestock; instead, it picks out the parts that are important for its purpose" (p. 1). The aim of one map may be to guide travelers with roads while another may show only the physical terrain. But "no map reflects all that is contained within a phenomenon" (p. 1). The metaphor of the map perhaps shows theory as causal in its appropriate light; that theory making approached in this way is a commodity, a tool to be used for a certain representation but not scholarship nor attributed as the sage author of all that comes to be within the discipline of nursing.

Those who de-skill or multi-skill, depending on your perspective and entry to practice level, are too involved in constructing (or deconstructing), the practices of nursing by replacing them with tasks and entities foreign to the practices of nurses. They remove the nature of nursing from the tasks. They *un-make* nursing practices. They turn nursing practices into mechanistic operations with predetermined ends judged for their *use* not their *intrinsic worth* (Arendt, 1961). Arendt calls this fabrication.

Fabrication...determines and organizes everything that plays a part in the process-the material, the tools, the activity itself, and even the persons participating in it; they all become mere means toward the end and they are justified as such. Fabricators cannot help regarding all things as a means to their ends or, as the case may be, judging all things by their specific utility. (p. 215,216).

Contrast those who construct and those who fabricate with the notion of *theoria*. "Ancient *theoria* is not a means in the same sense, but the end itself, the highest manner of being human" (Gadamer, 1989, p. 454), and ancient *theoria* "means sharing in the total order itself" (p. 454). Here we search to understand nursing as lived as a *profession of the primary*; nursing directly given, directly received. It is a place of immediacies (Steiner, 1989). A place where we seek the highest manner of being human in our profession's closeness to what it is to be mortal in health and illness; where the elemental in life holds sway; where nursing is practiced in the most direct way possible. Nursing is a place of diversity. "It is the marvelous complexity of the human condition that makes nursing such an exciting enterprise" (Levine, 1995, p. 13).

### ***Early Theorists***

Early theorists in nursing tend to present nursing with fidelity. They present nursing as it appears in front of them in their time. As-is does not mean deficient. Rather their conceptualizations of nursing are indeed workable in practice because they are embedded there first. They have watched nursing come to form and they have described and enhanced its coming to form. In fact, their theory-making describes *what-is* in the sense of the *eidos*, "Plato's term for all that which is really real, not its truth or being, strictly speaking, but the very thing itself" (Burch, 1991, p. 225) rather than the "as-is" reality in Barnum's terms (1990, 1998) or the "ought-to-be" nursing in later theorists (Barnum). They speak out against unthoughtful "routines" present in practice. In reading early theorist's writings, Florence Nightingale (1859/1969), Virginia Henderson (1966), one senses the concern nurses have for their patients, their regulating the necessary environment to promote proper healing: the patients' welfare hangs heavily in their minds as the embodiment of it hangs ever present in their hands. They are "hands-on" theorists. One feels the practice in their writing.

Florence Nightingale, the founder of modern nursing, is credited with explicating the first conceptual model or theory of nursing (Meleis, 1991; Fawcett, 1989). She states that what nursing has to do is to "put the patient in the best condition for nature to work upon him" (*Notes on Nursing*, 1859/1969, p.133). Right she was as hospital conditions for patients at the time were

abysmal. Nightingale focuses on the patient and what will contribute to health and overcome illness. She concerns herself with establishing a safe environment for ill people, exposing first and then improving these areas with cleanliness, diet, and hygienic practices. She writes about the *conducts* of nurses in bringing about a safe environment. In addition to the explication of nursing, Nightingale set up an education and training process for nurses based on two streams, one, care of the sick, and another, promotion of health (Ellis, 1992). "Nightingale Schools" became established in North America; the Mack School of Nursing at St. Catherine's in Ontario, Canada, the Bellevue Training School in New York, the Connecticut Training School in New Haven and the Boston Training School (Dolan, 1978).

Florence Nightingale, who, through the wisdom she gained from her work in the Crimean war, linked health with environmental factors, linked care with systematic data collection, and linked hygiene with well-being. Her efforts resulted in a clear conceptual schema of the client and the goals and the interventions in nursing. (Meleis, 1991, p. 182)

Within the theoretical writings of nursing there is a term to denote nursing practice as it goes about its daily endeavors. Meleis (1991, 1997) refers to it as *extant* nursing practice and states that Florence Nightingale's articulation of the domain of nursing developed from extant or manifest nursing practice. In other words, Nightingale described nursing practice as it stood before her: her observations, her experiences, her interpretations, her dictates. Nightingale's conceptualization of nursing is based on both observing and enacting it. She does not purport that she knows exactly what elements make up nursing. Rather she begins with the statement that the "very elements of what constitutes good nursing are as little understood for the well as for the sick" (p. 9).

In her text Nightingale (1859/1969) admonishes nurses to perform certain duties (conducts) in certain ways against the traditions of the time. For example, she abhors the practice of not letting fresh air into the sick room. In her view, it is a mistaken understanding that to do so increases the ill person's exposure to chill and worsens the illness. She exhorts nurses to aim for cleanliness of the bedding, the floor, all that comes in contact with the patient despite the fact that she does not believe in the then current "germ theory." She improves the dietary practices for patients, cleans up the kitchens, believes a good diet "comforts" the patient; comfort in Nightingale's day meant to *strengthen* the patient (Cameron, 1988). She states that a person suffers not from the "symptoms of the disease at all, but of something quite different-of the want of fresh air, or of light, or of warmth, or of quiet, or of cleanliness, or of punctuality and care in the administration of diet, of each or of all these" (p. 8).

Nightingale is certain that "the art of nursing, as now practised, seems to be expressly constituted to unmake what God had made disease to be, viz., a reparative process" (p. 9). Nursing is a reparative process. How does one *unmake* disease? Certainly not with medicines alone, Nightingale insists but with *conducts of nurses*. She states that if all we did was to give the medicines and nothing more, this would not *unmake* the disease. She believes that giving air, warmth, cleanliness, good nursing care assist the healing process.

In these (cholera, fever) and many other similar diseases the exact value of particular remedies and modes of treatment is by no means ascertained, while there is universal experience as to the extreme importance of careful nursing in determining the issue of the disease. (p. 9)

There is much to be said and noticed about Nightingale's treatise for nursing today. She was patient-centred, person-centred, nurse-centred. She cared about the universe of nursing which was patient and nurse, family and nurse, other disciplines and nurse. Nursing actions emanate

from what is best for the patient at the particular time. Nightingale was fortunate in a way. She had experienced the *absence* of nursing care, the absence of any assistance at all to patients. Wounded and ill soldiers lay three to five to a bed in the Crimean War, many of them with draining wounds dripping on the others. The filth of the situation included the filth of the kitchen and the absence of any thinking at all as to how one might be cared for better, shouted to her to pay attention.

Nightingale challenged the political, social, and economic climate of the day. She used the knowledge of the day i.e. careful keeping of statistics. Yet she did not allow this knowledge to impinge upon what she knew was integral to the conducts of nursing, the patients and the nurse together. She set about proving that cleanliness improved the statistics of people getting better and carrying on their everyday life. She kept track of the incidences of diseases and complications of such. She spoke out against the common notion of the day that the care of the sick was a good occupation for those disappointed in love, or those poor women who cannot do anything else in life. Nightingale was adamant that there are enough challenges in nursing to keep a person busy studying and improving the delivery of nursing for a lifetime.

The everyday management of a large ward, let alone of a hospital - the knowing what are the laws of life and death for men, and what the laws of health for wards - (and wards are healthy or unhealthy, mainly according to the knowledge or ignorance of the nurse) - are not these matters of sufficient importance and difficulty to require learning by experience and careful inquiry, just as much as any other art? They do not come by inspiration to the lady disappointed in love, nor to the poor workhouse drudge hard up for a livelihood. And terrible is the injury which has followed to the sick from such wild notions! (p. 134).

There is so very much we still do not know about individuals, why some with the same disease live, why some die, why some treatments work and some don't; in short, we don't know what combination of factors will aid one and not another. But Nightingale still exhorts us to carry out and trust the practices of nursing. They work. She says to question dictates from other disciplines such as medicine if they do not seem to be in the best interest of the patient. And she challenges us to run a nursing ward that has the interests of the patient at heart and not the disciplines or the institution (1859/1969).

Meleis (1991) states that extant nursing practice, as a source of theoretical knowledge and theory development, was de-emphasized and ignored by theorists. Meleis makes an insightful statement: "one cannot help but wonder, if nurses had continued to consider extant nursing practice as the major source of ideas, whether or not the theoretical development of the discipline would have taken a different path" (p. 156).

What can we learn from Nightingale? We learn that it is in the acting of nursing, *through the actual conducts of nursing*, that nursing comes to unconcealment, comes to being, that a nurse nurses. We recognize nursing in its conducts, its gestures.

Today we still speak of Nightingale. The contents of an editorial in New Scientist (1998) disturb. They discuss a report by the House of Lords Select Committee on Science and Technology concerning antibiotic resistance and its alarming growth.

Hospitals in Britain and elsewhere need to relearn old hygiene skills and reduce dependence on antibiotics. Conditions described in the report would make Florence Nightingale turn in her grave. Cost-cutting in Britain means that hospitals are not properly cleaned, beds are too close together and "hot bedding" - where patients move around the hospital as beds become free - spreads

infections everywhere. Isolation wards have vanished to save money and basic standards, such as washing hands between patients, have slipped. (New Scientist, 1998, p. 3)

Following Nightingale, development of theoretical nursing did not move forward until the 1950's and this time the theory development took place in the United States. Hildegard Peplau (1952) and Virginia Henderson (1966), Henderson developing her theory beginning in 1955, are pioneers of theoretical writing in nursing. Peplau introduced to nursing the notion of the nurse-patient interpersonal relationship and this was, is and always will be, central to the mandate of nursing. Her vision of setting the relation between the nurse and those she nurses as the primary act of nursing is exemplary. She went on to design a theory of intrapsychic needs that provided a basis for psychiatric nursing. Henderson delineated 14 activities that the patient may need assistance with and they range from breathing normally to social situations to learning and participating in their health and seeking out appropriate health giving activities. She asserts that "the patient has more to contribute to the nurse's education than anyone *else if she can learn to let him show her what help he needs*" (Henderson, p. 44).

Orlando (1961) and Weidenbach (1964) followed with their conceptualizations of nursing process: Orlando describes deliberate nurse patient interactions in situations where the patient is distressed within the nursing process framework. Weidenbach's (1964) validation of nursing process speaks about patients with unmet needs and how to enact the nursing process through the strength of the nurse's interaction. Orlando shifted the focus from the patient and the nurse to the *interaction* between the two. Weidenbach in fact was one of the first theorists to write about the notion of caring in nursing; she terms it *concern*. "It is the nurse's way of giving a treatment, for example, that enables a patient to benefit from it, not just the fact that a treatment is given him; and it is her way of expressing her concern-not just the fact that she is present or speaks-that enables him to reveal his fears" (Weidenbach cited in Barnum, 1998, p. 71).

Henderson (1966) wrote a definition of nursing that was adopted by the International Council of Nursing and the World Health Organization as the direction and purpose of health and nursing. She believes that the nurse "who operates under a definition that specifies an area of independent practice, or an area of expertness, *must* assume responsibility for identifying problems, for continually validating her function, for improving the methods she uses, and for measuring the effect of nursing care" (p. 38). She developed a way to order the practices of nursing in response to a call from various health care disciplines and governing bodies to state the functions of nursing and to legislate them. In pictorial form Henderson shows how the multidisciplinary team would function in various health care situations, i.e. a newborn baby that fails to thrive, a rational adult following cataract surgery, and more (1966, pp. 18-20). This conception of interdisciplinary teamwork and nursing's contribution to same shows that Henderson was far in advance of her time. Rather than fighting the medical system and medical model, Henderson works within it claiming for nursing a domain of our own. Her focus on patient activities deviated from Nightingale who focused more on the nurse's conducts while caring for patients (Ellis, 1992). While parts of Nightingale's book may be filled with techniques and admonishments to the nurses, it was the patient's welfare she had in mind. One could say that while Nightingale had the nurse as the figure and the patient as the ground, Henderson and Peplau had the patient as the figure, the nurse as the ground.

Henderson (1966) exhorts nurses to focus on the person, to be responsible for those under their care, and to use research as a way to improve the delivery of nursing care to the person.

I see nursing as primarily complementing the patient by supplying what he needs in knowledge, will, or strength to perform his daily activities and to carry out the treatment prescribed for him by the physician. (p. 21)

### *(Re)presentation in Early Theorists*

Nightingale, Peplau, Henderson, Orlando, and Weidenbach probably did not consider themselves theorists at the time of developing their discourse. Rather they tried against the political climates of the day, to legitimize, to formalize nursing as a profession. According to available literature, these nurse theorists were very much involved in the actual practices of nursing. They desired greatly to move nursing practice out of a series of “routines” and “task oriented care” which at the time dictated many of the actions of nurses. They wanted nursing to be thoughtful and directed. They believed that if they could educate nurses to be more aware of the dimensions of what it is like to be human, to be ill and faced with health threatening diseases, nurses would be more effective, more in control of their practice, and more involved in improving their care through experience and engaging in research (Henderson, 1966).

Early theorists address concrete nursing situations. They speak to the *what-is* of nursing practice and incorporate their theorizing within what is actual in the practice and they propose to bring about attention to human practices. Even their choice of Maslow’s hierarchy of needs as a background influence for them, speaks well for these theorists. In this existential theory of needs, the notion of life as lived still resonates throughout the hierarchy. Nurses such as these know that the hierarchy is flexible and open which is necessary in working with people. Dying patients lose their interest in the physiological needs and focus on their relationships with their loved ones, with coming to terms with meanings in their life.

While Nightingale, Peplau and Henderson seem unsophisticated to contemporary theorists and scholars, and Orlando and Weidenbach incomplete, it is useful to note that in articulating aspects of patency and the relation between the nurse and the nursed, these particular nurse theorists provide clear direction to nurses in practice to be attentive to these areas of lived experience. Peplau and Henderson knew nursing practice; Peplau in articulating the nurse/patient interrelationship saw it in action before her eyes. Henderson knew that people who are ill have certain needs. Orlando articulated the interaction between the patient and the nurse as being central to deciding on appropriate interventions. Here the theorizing stays close to patients and nurses and yet provides insights to the nurse in terms of enacting nursing without falling on routinized practices. They honour the experiential aspects of nursing practices for both nurse and patient. They stand sovereign. When one hurts, one hurts. While they exhort nurses not to remain in or fall into routinized practices, they also maintain the integrity of nursing by articulating the practice wisdom embedded in the age old practices of nursing. Practice wisdom refers to nursing actions already present in practice but not yet categorized, not yet abstracted out of the place they arise. They present nursing for us.

To summarize: the envelope of early theorists:

- holds to the realities of the lifeworld of nursing (writings assist nurses to focus more clearly on their mandate).
- increases the efficacy of nursing interventions (all things under the nurse’s independent functions).
- does not interrupt the flow of nursing or impose something foreign on it (in fact it pulls what is strong about nursing out of a myriad of routinized procedures and highlights the relation of nursing).

- is still commensurate with the nursing reality (the representation reflects nursing working mainly within the medical model of care in terms of physiological needs, yet the theorists also speak to the lived nursing and human dimension of life and interdisciplinary interactions).
- impose few mechanistic tools on practice (assessment tools of needs and beginnings of nursing process, yet the nursing process still reflects the context of specific lived life and not disengaged scientific method).
- lets us “see” nursing as situated in the nursing world (the world not too disembodied or too decontextualized).

### *Middle Theorists*

King’s (1971) theory of goal attainment, Travelbee’s (1971) therapeutic use of self, and Paterson and Zderad’s (1978) humanistic nursing pull from tenets based in interactionism, psychological theories, systems theory, and existentialist philosophy. Middle theorists in nursing’s history perhaps had a *raw deal* in that they were developing their theories during a time when there was a tremendous push for positivist paradigms in the social science communities and a great emphasis on explanatory and predictive theory. Based on what we can understand from their writings, they believed they needed to explain the phenomenon of nursing to others and be able to prove why nursing as a discipline was worthy. They believed they could not show what was inherent in nursing from the practice of it and still have it valued by others outside the discipline. Perhaps this was so. But these particular theorists were very instrumental in setting up theories and research programs which set the stage for *mechanistic tools* to be then applied to practice i.e. nursing process, nursing diagnostic labels, patient classification systems, quality of care checklists. And the very odd thing about these mechanistic tools is that they come about after some quite lovely articulations of nursing.

King (1971) believed that nurses had already spent time on the “how” of nursing and it was time to address the “why” of nursing. She states that nursing theory had been based on “practical techniques” (Fawcett, 1989, p. 100) and desired to explain the “why” of nursing actions. King develops her theory addressing four universal ideas, “social systems, health, perception, and interpersonal relations” (Fawcett, 1989, p. 102) and linked these through the use of systems theory (King, 1971). The focus of nursing is human beings interacting with their environment and patients interacting with nurses to develop and attain mutually agreed upon goals (King, 1971). King’s theory is often classified as an interaction theory. The nurse and patient “act, interact, and finally transact, that is, agree on a goal or goals” (Barnum, 1998, p. 74). Barnum looking for clarity, asks King to be more specific about what makes her particular theory a nursing interaction and not an interaction of any other discipline.

While the interaction theory seems to be a dance of roles between the nurse and patient, Barnum states that King needs to make more explicit the context and the utility of her theory in practice. A tool called goal-oriented nursing record (GONR) was developed based on this theory and the tool figured prominently in the chart in terms of the mutually agreed-upon goals. The tool also showed the limitations of the theory in that it excluded many within nursing’s mandate, those unable to make mutually acceptable goals i.e. comatose, very young, demented (Meleis, 1991).

Travelbee (1971) wrote about the therapeutic use of self, focusing on the interpersonal aspects of nursing and how the nurse and person establish a relationship. She writes about building rapport and how this facilitates the relation between the nurse and nursed. The goal of relationship building is to help the person find meaning in the midst of suffering and pain. Suffering and pain are the elements the nurse seeks to eliminate through the relation. The nurse gets to know the



patient, establishes needs, becomes involved, and works to alleviate suffering. The oft-quoted and valued phase in nursing, “therapeutic use of self” comes from Travelbee.

Paterson and Zderad (1978) have written a treatise called “humanistic nursing” based on the tenets of existentialism. They describe what it is to nurse and be nursed as the *presence* of both patient and nurse set up a situation for human *becoming* through a *shared dialogue*: “nursing itself is a particular form of dialogue”(p. 22). The emphasis of nursing is on the awareness and the experience of the individual in coming to authenticity; suffering brings out authenticity and the nurse must facilitate this. “Man’s undeterminedness makes him all-at-once frustrating to study, impossible to distinctly categorize, and excitingly mysterious and the most worthy focus of nursing research” (p. 52). “Although King designated the nurse as a central concept in nursing theory, she did not go as far as Paterson and Zderad in focusing on the significance of the consideration of the continuous growth of the nurse in every interaction” (Meleis, 1997, p. 334).

Nurses experience with other human beings peak life events; creation, birth, winning, nothingness, losing, separation, death...through intouchness with self, authentic awareness and reflection on such experiences the human nurse comes to know. Humanistic nursing practice theory asks that the nurse describe what she comes to know: (1) the nurse’s unique perspective and responses, (2) the other’s knowable responses, and (3) the reciprocal call and response, the between, as they occur in the nursing situation. (Patterson and Zderad, p. 6,7).

### ***(Re)presentation in Middle Theorists***

Why did the precepts of Paterson and Zderad never “catch on” in nursing theoretical circles at the time, 1978, whereas elements of this theory keep getting “borrowed and tucked into other theories” (Barnum, 1998, p.210). Barnum states that these existential theories have now become “new age” theories in later theorists, Rogers, Parse, Newman. In reading this work, of Patterson and Zderad, one who knows the lifeworld is moved by their descriptions, their vocabulary signifying nursing. Did these precepts not figure prominently because nursing as a discipline was not ready to accept the notion of nursing practice as unpredictable and as a blend of art and science because our research thrust at the time was one of positivistic endeavor? To pull a theme through from theory development in nursing, we seem ashamed of our particular knowledge base which is very tied to context specific situations. Here these theorists, Paterson and Zderad honour nursing as coming to form in practice.

At the same time, there is almost a “backlash” against the sort of theorizing based in more open systems other than the positivist paradigm. Odd that the openness of these theories led to machinations of practice. While King, Travelbee, and Paterson and Zderad propose a focus on interpersonal communication, mechanistic ways of operationalizing nursing come to the fore; almost in the name of progress back to the routinized practices early theorists spoke against. Here they mechanize the operation of nursing with a view to better enact it. Or could we say so those rooted in the positivist paradigm could better “study” it? To implement the scientific method one must have a clear definitions of the concepts they address in the process of applying the scientific method. Here such mechanics as *nurse-patient relationship* includes prescriptive ways to act and communicate with patients and families i.e. communication feedback loops, re-iterating, re-phrasing statements; *nursing process*, a remake of the scientific method, as a way to diagnose others and assist them to attain goals and objectives determined by nurses; *nursing diagnostic* labels make their appearance as ways to classify patient problems and nursing work; *meta-paradigm* concepts are agreed upon for theory making and testing. These will be discussed below under the envelope of nursing practice.

It is an enigma that while middle theorists espouse interaction and the importance of the same, in fact by explicating the interaction in specific ways, they offer others an opportunity to mechanize it. It is as if, as soon as an aspect of the lifeworld of nursing is theorized, others take it to develop mechanistic tools. It is clear that mechanistic tools are essential to theory-making in this view. The focus moves off nursing as an entity to how to accomplish relationship, how to implement techniques of relationship, how to use communication styles to effectively entice the patient and make the patient perhaps divulge things they wish to keep private. The patient is displaced for mechanisms. There is much focus on the nurse and the experiential aspects of *herself-nursing*. What began as a presenting of nursing, enhancing understanding of the interactions of nursing in the central core of the relation of nursing, became a representation in various mechanical forms.

In other words, middle theories replace the *doing* of nursing with the *whereby* nurses do it. The *whereby* then stands for nursing rather than nursing coming to form in different ways itself. In an odd way, we move back to routines of nursing which is exactly what the theorists wanted to move out of. These theorists wanted the *why* not the *how* of nursing, and their answer to the why led to mechanistic enactings of nursing. In an attempt to push the theoretical side of the discourse further, nursing becomes more abstract and distant, and represented by these various forms of interaction. The form, the representation, then becomes our captor.

To summarize: the envelope of middle theorists

- holds to the reality of the interaction between the patient and the nurse as lived in description only. (How this is lived out in practice is to reduce nurse/patient interactions to mechanistic operations.)
- technicizes nursing. (Communication between nurse and patient is one of communication techniques where the nurse uses certain linguistic mechanisms to draw out, find out more about the patient; techniques used as a means to accomplish relationship i.e. to find out information from the person through techniques like feedback loops, showing empathy, restating the obvious. The patient is displaced for mechanisms. Once the information is processed and the person “figured out”, no occasion to note the vital impulse changing to something else. All denotes a lack of respect for persons.)
- purports to use existential tenets but often these tenets are just superimposed on already existing operations. (For example, the element of choice figures prominently in existential writings. Are nurses all that comfortable with some destructive decisions patients and families make and will they let them make them? Existential tenets call into question our personal value systems and whether or not we just “play” with these tenets but not enact them.)
- acknowledges a focus on relationship as core. (But its demise to mechanistic tools to replace authentic relation while purporting existentialist tenets disturbs. It seems a pseudo-philosophical language.)
- tries to describe what it is to be with someone in the very elemental human experiences of suffering, of being ill. (This part is admirable and respectful of the person. The mechanistic tools however destroy it.)
- interrupts the flow of relation for tools and only the interpreted reality the tools allows them to see. (They manipulate the interiority, the self divulging nature of the person/patient for their ends of so-called more appropriate care.)
- obscures the true interiority of the person and nurse, and presents a persona instead. (“They just want something to chart” states one patient.)

### *Late Theorists*

The goal of nursing care with late theorists is to bring back “balance, stability, and preservation of energy or enhancing harmony between the individual and the environment” (Meleis, p. 261). Johnson’s (1980) behavioural system theory, Neuman’s (1982) systems theory, Orem’s (1985) self care deficit theory, Levine’s (1967, 1989) theory of conservation principles, Leininger’s (1981) caring in culture, Newman’s (1986) theory of health as expanding consciousness, Rogers’ (1980) science of unitary beings, Roy’s (1984) adaptation model, Parse’s (1981) man-living-health theory and Watson’s (1985) carative factors theory are based on systems theories, on adaptation, developmental, anthropological, energy transference, and sociological theories. These late theorists try to give a full account of anything that would touch or impinge on the person’s personal sphere of living. Barnum (1998) calls some of these theorists “new age” theorists because they focus on the spiritual using transpersonal psychology and the interacting energy systems of a holistic model. These theorists’ conceptualizations are based on nursing as an *ought-to-be* mental construct (Barnum). Their belief is that they can bring about their theorized reality to produce predictable practice.

Johnson (1980) focuses on the individual as a *behavioural system* with *subsystems* to carry out unique tasks and functions needed to maintain the person and the person’s relationship to the environment. The subsystems are attachment, dependency, ingestive, eliminative, sexual, aggressive, and achievement. The goal of nursing is to aid individuals to “restore, maintain, or attain behavioral system balance and stability at the highest possible level for the individual” (Johnson, 1980, p. 214). Because nursing behaviours are based on an analysis of this subsystem, their actions are accurate and planned and make a significant difference to individuals. Once the nurse understands the patient behaviour, she can manipulate the variables to bring about the desired outcome. Using this model and its categories of subsystems of patient behaviour as a basis, a patient classification system evolved enabling administrators to predetermine levels of staffing (Auger & Dee cited in Meleis, 1997). In addition, a research tool was developed, the Deridarian behavioral system model which categorized patient responses to cancer using the subsystems listed above as a guide (Meleis, 1997). Two mechanistic tools emanate here that in the name of scientific management replace nursing judgment as lived as events come to be and pass away. More on this later in the envelope of practice, but for now, I’m not certain how happy I would be at someone assessing my “subsystems”; an error could be fatal to me or at the very least attract annoying attention. The subsystems represent various aspects of the person but cannot present the nature of nursing practices in living out nursing.

Rogers (1980) *science of unitary human beings* credits Nightingale with her own concern for the person and the environment. Human beings and their environment are regarded as unitary and interacting energy fields. They are irreversible wholes “that cannot be understood when they are reduced to their particulars” (Fawcett, 1989, p. 266). Energy field patterns change continuously and three principles of haemodynamics describe the energy field; *resonancy*, the change from high to low frequency wave patterns, *helicy*, the continuous change of energy fields, and *integrality* (formerly complementarity), the mutual human and environment relationship (Rogers). Nursing actions are appropriate because there is individualized assessment and individualized nursing care because each person is a unitary human being (Rogers, 1980). This theory is classified as a dialectic in that the whole is more than the sum of its parts, “the parts, taken together, do not exhaust the whole; the whole organizes the parts” (Barnum, 1990, p. 132), and the part is explained as to its relation to the whole. The utility of this theory for practice is dependent on the nurse understanding the language and the interrelationships of energy systems, and the focus is on the patient as a unitary individual, not on what would be uniquely nursing.

Rogers's theory has generated additional theorizing in terms of energy fields and in terms of interacting systems (Parse, Newman). Newman (1986) using Rogers's energy fields concepts, constructed a theory of expanding health consciousness using the concepts of movement, space, time, and consciousness. Each share the conviction that the person's being is enhanced through overcoming the health insult (Barnum, 1998).

Neuman (1982) through a *systems* model tries to order the immense amount of information one needs to know and collect in order to nurse a person with multiple health conditions. She reflects the thinking that people are "holistic systems whether sick or well and the environmental influences on health" (Fawcett, 1989, p. 194). A focus on systems in nursing shows discreet parts and their interrelationships to the whole (Barnum, 1998). Neuman's client system is depicted by five concentric rings of resistance around a central core, the central core being the client. The central core represents the survival factors for a human being and the five concentric rings represent resistance areas; physiological, psychological, sociocultural, developmental, and spiritual. The outer ring is a flexible line of defense and the next ring is a normal line of defense, followed by the five areas of resistance and then the central core. The further apart the flexible line and the normal line of defense are, the greater protection against stressors; the closer together, the less protection is available (Neuman, 1982). Neuman in interrelating over 35 variables in her systems theory shows the complexity of her model. It is this very elaborateness of systems and how each relates to each other that nurses find hard to manage in practice.

Orem (1985) states that her *theory of self-care* is a helping model with the patient as a self care agent and the nurse as nurse agency. She has a formal system in place categorizing assessment of patients in terms of eight universal self-care requisites and she has categories of the nurse-agent ranging from acting for and doing for the patient to encouraging complete self care and a teaching role. The universal self-care requisites translate to assessment in practice as air, food, water, elimination, activity and rest, solitude and social interaction, prevention of hazards, and normalcy. These requisites maintain optimal human functioning. A lack in one of the requisites generates a self-care deficit and generates a therapeutic self-care demand which then needs self care to address the deficit. If the patient cannot meet the therapeutic self-care demand then the nurse as an agency must meet it. Experienced nurses often say of this model, "we do all this anyway; this is just putting other language on what we do without the model." The operative concepts and the language used in this model are often confusing and the person is relegated to a group of deficits. Yet a closer look finds that the meanings involved are already there in practice just not seen as a deficit system, rather as a human dealing with illness. So does this model present or represent nursing? It equates to nursing as lived closer than the energy fields theories. Its application of odd language not necessary to nursing care limits it as a presentation. As a representation, self care probably does show one of nursing's mandate; to put the person in the best condition for nature to work on him (Nightingale above).

Levine's (1967, 1989) theory of the *four conservation principles* with conservation meaning "keeping together" emphasizes that "to keep together...means to maintain a proper balance between active nursing intervention coupled with patient participation on the one hand and the safe limits of the patient's ability to participate on the other" (Levine quoted in Fawcett, 1989, p. 144). The four conservation principles are conservation of energy, structure integrity, personal integrity and social integrity (1967). They do not integrate with or interact with each other but are four separate entities for the nurse to solve. Conservation results when there is concrete solving of the four separate principles.

Parse (1981) was influenced by and builds on Rogers' theory. She formulates a man-living-health which uses Rogers' "principles and concepts about man with major tenets and concepts from existential-phenomenological thought" (Parse cited in Fawcett, p. 279). Parse builds her

theory on Rogers' conceptions of resonancy, helicy, and integrality, and the openness and organization of the energy field. Here humans "live at multidimensional realms of the universe all-at-once as they prereflectively and reflectively choose from options incarnating imaged value priorities" (Parse, 1995, p. 8). Parse calls her theory a human science theory, a theory of human becoming.

The principles of the human becoming theory specify the view of the human-universe process as a rippling, risking flow weaving together the changing fabric of the now moment, incarnating the side waters of remembering and anticipating, while forging the present yet to be. Human becoming, then, is a cocreated process of evolving. (Parse, 1995, p. 8).

She writes about coconstituting the environment and about interchanging energy. Barnum (1998) states that Parse has crossed over from existentialism to new age. With Parse's interpretations, man transcends multidimensionality with possibles and health is unitary man's negentropic unfolding (Parse, 1981).

Roy (1984) credits Johnson, Rogers, and Orem with influencing her theory of adaptation. Roy states that as humanistic nurses we put the onus on the individual and his/her coping mechanisms and people adapt to continuous change in a holistic way. The holistic adaptive system has two major internal control processes, the regulator and the cognator subsystems (1984). These are innate or acquired coping mechanisms used by the adaptive system of the individual to respond to changing internal and external environmental stimuli (Fawcett, 1989, p. 312). Regulator and cognator activity is shown through coping behavior in four adaptive modes; the physiological, self-concept, role function, and interdependence mode. The goal is to move the patient's focus off what is and free his attention for other stimuli (Barnum, 1998). Nurses who turn away from stimulus-response representations of individual behaviour will not like this particular theory.

Watson (1985) focuses on caring as the central tenet of her theory. She describes ten *carative* factors and the focus moves from caring between the person and the nurse, to transpersonal systems with the potential to transcend time and space (Watson, 1988). Here the notion of caring is mostly focused on the nurse caring and the spiritual and subjective aspects of both patient and nurse are paramount (Barnum, 1998). Barnum questions whether in Watson's later work, one could substitute spiritual for caring as the central tenet. Leininger (1981) is also concerned with caring in nursing but she focuses on caring for the person as the nurse being attentive to the culture and cultural norms that surround the person. Leininger moves the focus of nursing toward the cultural and from the hospital institution to the wider enterprise of the nurse.

### ***(Re)presentation in Late Theorists***

While speaking to the complexities of existence, to the person's projects in the world and beyond, rather than showing a depth of being, the late theorists show a "depth of depthlessness" (Smith, 1995, p. 18) that is forgetful of the "deep questions of its sustenance" (p. 18). Pedagogy is "reduced to a pointing to a parade of facts and information available through the multiple technologies of the age with little attention to the way the facts carry a story of culture" (p. 18,19). Sometimes all a person with a broken leg wants is to have his fracture reduced and set. And a blind person just wants the plastic taken off her sandwich and her tea at one o'clock on her tray.

Paying heed to the nature of every possible conception or variable that may affect the person (and making up more based on the mental construct as source of reality) often utilizing complicated language and borrowed theory, the focus moves from the situated experience of the person to the

constructs of the theory and those that point beyond the theory. The relation of nursing as enlivened in the practices of nursing is not facilitated.

Theorists seduced by the myriad of factors that may bring about a myriad of outcomes *on the outside* makes what-is nursing practices look small and insignificant indeed. Yet when all that can ever come to be in nursing practice is encapsulated into usable, albeit reduced, abstracted bits of outcomes, one longs for situated, context specific nursing realities. All people who suffer, suffer in a context of their own. One facetious practicing nurse participant said, "They are trying to turn Mrs. Jones and her gall bladder in bed 4 into someone with interacting systems and energy fields and mystical becoming. Couldn't we just meet in the middle somewhere?" Aldridge (1994) concurs with this practicing nurse and states that nurse theorists "who are working so hard to transform patients from 'the hepatitis in the corner bed' into unique and complex individuals with an array of capacities, needs and rights, should turn to epistemologies which marginalize the social" (p. 7). The focus on caring when it shifts from context to content or process...becomes, not the *attitude* with which the nurse delivers her taking care of, but *the care itself*" (Barnum, 1990, p. 76).

To summarize: the envelope of late theorists

- are constructed around ought-to-be practice. (and are not commensurate or reflective of the reality of the lifeworld of nursing.)
- speak to and represent the complexities of human lived life. (but the more they move to do this, the more abstract they become.)
- do not reflect the lived world of nursing. (What they do is acknowledge every possible nuance that may be present in life and so they represent in the worst possible way...mental constructs claiming to encompass everything in a nurse's enterprise.)
- purports to know all that occurs in the life of a patient. (This is not part of lived nursing. While the notion of privacy and of interiority of people in nursing is respected by nurses, when something of importance comes up or when something needs to be brought up, it is.)
- lend themselves to mechanistic tools imposed on practice. (There is also on the other hand, a vagueness and an abstractness that nurses don't know what to do with when they are engaged in an actual situation of nursing in our actual reality. How are they supposed to and expected to, apply the theory based on mental constructs on situated reality as lived? And too these theories are like a theology, a study of mysteries, where challenge is taken as apostasy. Sometimes mystical things, things out of the ordinary, do happen as they do in all human practices. But the notion of "represented reality" does not enable these to come anymore often than before.)
- regard the experiential and situated nursing reality as too pedestrian. (Theorists try to get people to live not within their own thinking and being, but within the theorists' constructions, representations of life.)
- may satisfy the demands of science and contain materials and content essential to scientizing but are not the thing itself.
- is seductive; multi-coloured and odious.

## **(Re)presentational Modalities of Theory**

### ***Paradigm theory***

Nursing paradigm theory takes an all encompassing notion such as holism, caring, advocacy and tries to encapsulate the whole of nursing within it. Paradigm theory takes sensitive words like caring and abstracts the meaning of it to encompass the theorist's conjecturing i.e. Watson's (1985) notion of transpersonal caring. We begin here with a summary of the meta-paradigm concepts which are prescribed to be the building blocks of theory development in nursing. In showing some literature concerning these meta-concepts the intent is to show how they themselves are paradigmatic modalities of nursing; macroconcepts that in fact, also attempt to masquerade as standing-for the essence of nursing.

*Person, health, environment and nursing* were named central concepts of the discipline of nursing in the early 1980s (Fawcett, 1989; Meleis, 1991). These elements are called *metaparadigm* concepts and appear in the theoretical writings of nursing. Each developing nursing theory addresses these concepts in specific ways and then adds concepts central to the tenets of the particular theory. The way these metaparadigm concepts are addressed within the theory form a basis for metatheorists such as Meleis (1991) and Fawcett (1989) to critique the theory. For example, in hindsight, Meleis (1991) as metatheorist credits Nightingale with developing *environment* and *health* as foundational concepts.

Research on the metaparadigm concepts of person, nursing, environment and health is almost nonexistent. Macroconcepts such as these metaparadigm concepts are too large and too abstract to be useful in nursing. Barnum (1990) calls the meta-paradigm concepts "contentless containers" (p. 14) that must be filled by the theorist. The conceptual areas espoused as the main focus of the particular theory i.e. energy fields, systems, caring, are the figures that are researched, the concepts of person, nurse, health, environment place second to these or are "fed back" in the light of the figure.

While these macroconcepts may facilitate theorizing, they in fact do not facilitate understanding nursing and its practices. Here the practices of nurses evolve in daily life, daily action. Here "the concrete subjects of flesh and blood must always be recognizable (Miedema, 1987, p. 227). To be effective in the actual practices of nurses, the theorizing of these macroconcepts must "always play a subordinate part" (p. 227). In truth meta-theoretical concepts abandon patients and their situations for theoretical posturings and a disembodied setting.

Recent nursing literature provides some critique of the metaparadigm concepts and how their conceptualizations reflect a paucity of thinking and a narrowing of the true actions of nurses that occur in practice. Mandelbaum (1991) criticizes the concept of a person and states that it could never include a cultural and a personal description as these are unique to individuals. Only the biological and psychological descriptions of persons are amenable to some delineation. Ellis (1982) and Kleffell (1991) state that our limited vision of what the environment includes within nursing's metaparadigm framework restricts us from including aspects that would enable us to advance nursing's mandate of health. "This image of environment as immediate surrounding or circumstances of an individual or family has kept nurses from addressing the larger social, political, economic, and global structures that affect health" (Kleffell, p. 6). MacPherson (1987) speaks to health as a concept and cites Chopoorian.

In discussing the need to reconceptualize the concept of environment in nursing theory, Chopoorian implied that nurses generally do not see promotion of health care policies for changing, adjusting, or altering environments as part of their

role. Instead, it is the client or family who is expected to adjust, assimilate, or accommodate while nurses support them in this process. (p. 10)

It is just this obvious absentia from the political climate that drives feminists crazy when they look at the nursing profession (Mulligan, 1992). Grumet (1988) warns that disciplines identified as women's spheres can be trapped into the "support of feelings" (p. 90) only, and not move to action. "By identifying the perception of emotion with a form of solace rather than with action and communication, we replicate the patterns constituted by patriarchal relations in history and society and its divisions of public and private experience" (p. 90, 91). Mulligan (1992) states that nursing as a profession pursues academic discourse while remaining embroiled in bureaucratic organizations and as a result abdicate their mandate to speak effectively for people needing health care. While nurse academics' careers are furthered, nursing as a discipline is not.

The metaparadigm concepts of person, environment, health and nursing do not hold true in countries other than North America according to Huntington and Gilmour (1996). Mandelbaum (1991) states that only the North American culture is addressed in nursing theories. Timpson (1996) states that the prolific nursing theories originating in North America are "rarely evaluated empirically in the practice setting, and cannot, therefore, be adopted uncritically as either theoretically tenable, culturally applicable or easily adaptable to the particular system extant within United Kingdom health care practice" (p. 1031).

Mayan Indian communities of Guatemala would not be able to understand the concept of a person and attention to the health of one individual only. Rather they think in the collective (personal communication with Wendy Neander, nursing professor in Guatemala). If their community is healthy, they are healthy. Environment to them incorporates political and economic forces that restricts them from growing food on their land rather than cash crops such as coffee, sugar, or removes them from their land so others can plant the crops. Environment to them means clean water and health care, and such like things. Mandelbaum states that the thought of a single unifying theory of nursing called for by some nursing leaders (Sarter, 1987) would not be thinkable in an international framework.

Nursing has many similarities around the world. Whether it is a family member or good friend nursing someone who is ill, whether it is a trained or educated nurse in that country, nursing exists as a fundamental human experience. The question is, can nursing ever be delineated and delimited in the pursuits of theory and research, or should it be situated in nursing endeavors? Do we want to preserve this very basic human to human experiential, nursing relational experience?

### ***Borrowed theory***

Much of nursing's theoretical base is based on borrowed theory. As a result the gap between the theory of nursing and the practice of nursing widens even more. Borrowed theory is theory nurse theorists extract from another discipline and use to form literal nursing theory (Fawcett, 1989). Often theorists do not first establish the credibility of the borrowed theory for nursing practice. Because logical congruence with the practices of nursing does not ensue with the implementation of these theories, nurses in clinical areas find it difficult to utilize them in their practice. In addition, nurses in practice are suspicious, and rightly so, of these borrowed theories based on content very alien to them in both their formal education and their personal practice experience.

There is a bit of a difference here between outside theory informing the discipline and actually basing a nursing theory on an outside theory. Early theorists carefully contemplated and scrutinized what stood before them in nursing practice. What they could not capture in their articulation, they left open. Maslow's hierarchy of needs influences and provides insights to these theorists. They know that something was there before the theory and that nursing will continue to



exist after the theorizing is finished. They worked to make nurses more thoughtful and more accountable for their care. They strengthened nursing as a discipline with their writings, with their theories.

In addition nurses practice nursing from an eclectic theoretical basis. Nurses use theory from many disciplines while enacting nursing, particularly science and social science. Bacteriology delineates the properties of certain organisms and nurses use this theory while carrying out sterile technique, washing their hands, using gloves in certain ways and at certain times. In fact nurses use the science of bacteriology every moment of their practice and are thankful for the knowledge. Nursing takes tenets based in scientific theory (bacteriology, biology, chemistry), functional theory (physiology, pathophysiology, anatomy), psycho-social-anthropological theory, (coping, group behaviours, culture), spiritual theory (meaning making), political and management theory (institutional hierarchies, economics), international theory (primary health care) to name but a few. All these and more come together in the practices of nursing, that of relating to individuals who experience a change in their emotional and embodied selves. Tenets based in these disciplines inform nursing practice. This is not of which we speak when we state "borrowed theory."

Allmark (1995), Conant (1992), Cull-Wilby and Pepin (1987), Lowery and Jacobsen (1987), and Johnson (1992) warn nurse theorists not to appropriate borrowed theory in nursing's theorising. Cull-Wilby and Pepin (1987) caution that in the past nursing has assumed that "'imported is best' and that now nurses have begun to look inside and value nursing activities" (p. 519). Conant is critical of the practice in nursing research of borrowing research instruments and theoretical concepts from other disciplines and applying them to nursing without first determining their value for the nursing situation.

The value of knowledge from other disciplines for nursing practice cannot be taken for granted...Too often those in nursing have sought to obtain knowledge from other disciplines, without seeing the contribution that nursing could make to the general knowledge of human behaviour. (Conant, 1992, p. 466).

Other authors, (Meleis, 1991; Levine, 1996; Johnson, 1980) say that once these borrowed theories have been appropriated for nursing they are shared theories and the worry that they come from another discipline disperses. Allmark (1995) though does not believe that the theories become shared and unique. "The common assertion that nursing brings a unique perspective to the findings of such theory is ludicrous, rather like saying that driving buses brings a unique perspective to the theory of internal combustion" (p. 22). Prymachuk (1996) concurs with Allmark about borrowed theory.

Of the practice-based disciplines that have sought out theoretical justifications for their actions, most (and nursing has to be included here) have merely borrowed theories from other (usually more powerful), scientific disciplines, using those theories to define their practices. (p. 680)

Theories and their "rhetorical elitism...effectively reduce the pivotal role of theory within what should arguably be a fundamentally dialectic process seeking to refine and advance the pursuit of nursing practice via the critical analysis of intelligible narratives" (Timpson, 1996, p. 1031). "If we remain wedded to the illusory security created by immersion in the discourses of disciplines other than our own, the practice of nurses will remain partial in realization and articulation" (Huntington & Gilmour,, 1996, p. 365)

### *Part theory*

Sometimes in the midst of a situation, a nurse will think of a fragment of a nursing theory that at once will be helpful in the moment. But the fragment doesn't bring nursing to birth. Susan James (1994) compiles a comprehensive review paper titled, "*Reclaiming that which inheres in Nursing.*" She asks if it is theory that inheres in nursing and asks whether nursing theory is an appropriate way to dialogue and enact nursing. One of her key points is that nurses working out of a theory base alone (and remember this is what ought-to-be theorists want) "may be forced to choose between the general over the concrete" (p. 13) in nursing practice situations. In other words, the nurse would sacrifice the particular nuances of the particular situation for the universal precepts in the written theory. Yet Walker (1992) admonishes nurses to do so; "the nurse who resolves the conflict by choosing the particular may be seen as obstructing theory development" (p. 32). While James does not state this, one can see that she shows clearly how the application of theory to practice brings out an acting out of a technical rationality mode (seen below in envelope of practice), a mode in which authentic practice cannot exist (Taylor, 1991b; Schon, 1987). Huntington and Gilmour (1996) concur.

Using a grand theory in practice can prevent the nurse from working with the patient in a creative way, incorporating all the complexities of the situation. It could be argued that practising with these predetermined conceptualizations leads to interactions between nurses and people being shaped by elements of the theory rather than responding to the individual and context-specific moment. Also, the effort and emphasis on creating master narratives, in what has proved to be a futile attempt to order and define nursing practice, shut down the possibility of alternative discourses that may have explored the multiple subjectivities of nurses. (p. 366).

James further contends that theory making prevents the generation of knowledge for practice. "The use of theory as an external expert in how to act in practice interferes with the primacy of relations in developing knowledge" (p. 24). And her last lament, "it is curious that the very place that nursing theory is intended to inform is the place that interferes with its development" (James, 1994, p. 14, 15). Miedema (1987) concurs and states:

But where theory ignores the relatively autonomous status and nature of practice, it does so to its own detriment. After all, practice is no *tabula rasa* nor just a theoretically constructed straight-on practice (orthopraxis)...(p. 221)

Langer (1967) writes that the visual arts can become model-bound. "Instead of merely providing artistic ideas, a model may dictate to the artist; its practical functions, which served to organize the conceptualization of it as a form, may claim his attention to the detriment of his abstractive vision" (p. 250); the place where creativity frees itself.

Nurse authors are now speaking out about theory development in nursing. Bjork (1995) states that theory development has been "derived in relative isolation from any systemic observation and analysis of what nurses actually do" (p. 10) and that "in order to set nursing apart from medicine, theory in nursing has highlighted expressive, caring and psychosocial elements versus the instrumental, curative and biological elements more prominent in medicine" (p. 10).

Bjork (1995), Aldridge (1994), and Dunlop (1994) state that one cannot leave the body and technical skills behind in the evolving theoretical discourse. Bjork shows that over 40 years of research show that patients continuously state the competencies in the skills and decisions as to their health status are the most important elements of nursing to patients whereas nurses still rank as their number one attribute for nursing's mandate as the skill of listening and caring. Aldridge

states that she would “counsel against devaluing of the technical in favour of the subjective/mystical (and of course feminine) in professional ideology...keep the technical skills in the foreground and build relationships upon them” (p. 727). In our search for the abstract in order to order the concrete in nursing (ought-to-be nursing practice), we no longer embody nursing. Without including the context of situations, we lose relation, relation is built on living concrete individuals. We lose the intention of nurse in her world to nurse the patient as needed. The intention is to nurse, but pre-ordered and fabricated tasks in nursing withdraw life as lived from the nurses’ intention. Nursing can’t come to form.

### *Meta-theory*

There is presently a trend toward meta-theory, meta-analyses of nursing theory as theorists in nursing endeavor to explain where we have been, where we are going, and just what we have been doing in our profession. Meta-theorists work with a double handicap in terms of (re)presentation. Metatheorists create conceptualizations of conceptualizations. The challenge they must live up to is this: not only must they use representative organizing elements that order the theories, but too they must also represent the practices that the theories represent in the first place. Or in ought-to-be theories of nursing, meta-theorists represent the representation of the theory. Can meta-theory ever be sensitive to experiential dimensions of nursing, the life-world of nursing?

An immutable fact of the life-world of nursing is that all manner of things come to be and pass away continuously. It is in the experiential, in the situatedness of human cares and sufferings that nursing comes to form. Burch (1989) asserts that “our everyday dealings always have a prior context of meaning which recedes from focus in favour of our involvements with the immediate objects of experience, cognition, and action” (p. 198). And while the formulated conceptualizations of (re)presentations may foreshadow nurses and student cognitive behaviours, in fact, these do not stand up in the moment. Why? Because a phenomenon such as nursing “presupposes a meaning already implicit in lived experience and yet is true to that meaning only by constituting it anew and thus transforming it” (Burch, 1989, p. 198). The phenomenon changes even as it happens. So we have meta-theory promising insight and yet again are left with another empty envelope.

Meleis (1991) classifies early theorists and Orem (1985) with her self-care deficit theory, *Needs*, theorists, middle theorists working on interaction nursing process models are *Interaction* theorists, and late theorists named above are *Outcome* theorists. Meleis is clear in her distinctions. For example, the difference between Outcome Theorists who revisit Nightingale’s person and environment, and health concepts and the original Needs Theorists is this: while outcome theorists speak of “harmony with the environment, stability, conservation of energy, and homeostasis as potential outcomes” (Meleis, p. 263), needs theorists discuss these elements at a high level of abstraction and subsequently limit the “utility of (these) theories in outcome measures” (p. 263). Above we saw the level of abstraction working the other way; as the complexity of the theory increased, so too did the abstraction. Riehl and Roy (1980) classify nursing theories according to developmental, systems, or interaction typologies. Fawcett (1989,) on the other hand, declines to categorize them and *describes* the major theories instead and mentions the minor theories that fit categories, i.e. substitution theories. She is careful also to admit that these categories of theories serve us well in showing the different ways to look at the nurse-patient situation.

It is important to note here that the classifications of needs, interaction, outcome theories plus other constructs developed by the theorists and meta-theorists, later become technologies imposed on practice. We will return to this below in practice modalities.

Parse (1987) subsumes nursing theories under two categories, the totality paradigm and the simultaneity paradigm. The *totality* paradigm describes a person as “a sum of bio-psycho-social-spiritual-cultural parts who copes or adapts to environmental stressors” (Mitchell, 1988, p. 26). In this paradigm “nursing focuses on helping people cope or adapt with illness or limitations. Nursing manipulates the environment to reduce stressors, and teaches people how to be healthy” (p. 26). This paradigm would include all the nursing theories listed above in the theory envelope with the exception of Rogers (1980) science of unitary beings, Parse’s (1981) theory of human becoming, and Newman’s (1986) health as expanding consciousness, Parse and Newman basing their theories on Rogers.

The *simultaneity* paradigm describes a person as “an open being, more than and different from the sum of parts, who changes and is changed with the environment” (Mitchell, 1988, p. 26). Here the nurse “focuses upon quality of life from the person’s point of view” and “nurses offer the person true presence and guide the person to uncover meaning and move toward hopes and dreams” (p. 26). Barnum (1998) would call this “New Age” theory and includes Rogers, Newman and Parse in this group.

Later Fawcett (1993) undertakes to look at the philosophic claims (world views) behind the models and classifies theories into two arenas; the *mechanism-organicism* dichotomy and the nature of *change versus persistence*. Newman’s (1992) classifications are particulate-deterministic, interactive-integrative, and unitary-transformative. *Particulate-deterministic* reflects objective, observable phenomena. *Interactive-integrative* reflects “both objective and subjective phenomena” (Fawcett, 1993, p. 57) and although it is contextual, its “emphasis is on objectivity, control, and predictability” (p. 57). *Unitary-transformative* reflects human beings as “unitary and evolving as self-organizing fields” (p. 57). Its emphasis is on “personal knowledge and pattern recognition” (p. 57).

Fawcett (1993) tries to determine what philosophic basis these four sets of worldviews and organizing paradigms base themselves; totality and simultaneity; mechanism-organism; change versus persistence; and Newman’s particulate-deterministic, interactive-integrative, and unitary-transformative. She suggests that a “single parsimonious set of three world views would encompass them all and she names them reaction, reciprocal interaction, and simultaneous action” (p. 57). These classifications include *reaction* being that humans are bio-psycho-social-spiritual beings who react “to external environmental stimuli in a linear, causal manner” (p.58), *reciprocal interaction* being human beings are holistic and “parts are view only in the context of the whole” (p. 58), and *simultaneous action* being unitary human beings are identified by pattern and are in “mutual rhythmical interchange with their environments” (p. 58).

### (Re)presentational Modalities of Research

It is difficult to discuss theory and research as separate envelopes because the correlates between them in nursing are both somewhat obscure and yet definitely entwined; entwined because they are integral to our written discourse, obscure because they often do not show a connection to lived practice. Research development in nursing plays a large part in the way theory development takes place in nursing. Here our focus is on how well research and theory development stay close to the lifeworld of nursing.

#### ***Research hierarchies***

Dickoff, James, and Weidenbach (1968a) are consistently quoted as the ones who initially proposed a structure for theory and research development in nursing and called for a practice theory of nursing, a theory that is at once explanatory and predictive. Dickoff et al were asked to

give structure to theory development in nursing by the Dean of Nursing at Yale University School of Nursing (Weidenbach cited in Nicoll, 1992). These authors purport 4 levels of theory development within a hierarchical structure of research. The reason given for the hierarchical structure is that a practice profession needs a “practice theory.” A practice theory must be predictive of outcomes.

The levels in this structure are; factor-isolating theories or naming (level one theory), factor-relating theories and situation-depicting theories (level 2 theory), situation-relating theories (level 3 theory, level 2 and 3 based on relation between things), and situation-producing theories, prescriptive theories (level 4 theory, predictive). Content concerning nursing is not embedded in Dickoff et al hierarchical structure. Researchers and nurses are expected to fill the content. They too are rather like the contentlessness of the meta-paradigm concepts. Dickoff, James, and Weidenbach (1968b) state that “theory at any level requires invention” (p. 598).

The goal for nursing in this view is to achieve the fourth level of predictive theory for practice. Empirical research is necessary to reach the predictive level. Literature concerning the components of a practice theory proposed by Dickoff et al (1968a,b) abounds. Jacox (1974) believes that the scope of a practice theory in this paradigm must develop and include specific prescriptive theories for specific client problems. Beckstrand (1978) states that there is no need for a practice theory because nursing practice only applies a set of rules based in science, ethics and logic. Collins and Fielder (1981) believe that a practice theory concentrating on predicted outcomes ignores nursing’s moral practice base. None of these issues are resolved in the nursing literature but they attest to nurse authors either working with or questioning this structure of nursing theory development and the viability of a practice theory.

Practice theory, as formulated in this context, still produces issues today (Kim, 1993, 1994). Kim (1994) provides a framework for conceptualizing a practice theory pertaining to the nurse rather than the patient or client. Kim (1994) states that practice theories have had too much emphasis on the client outcomes and not the nurse-patient relationship including the nurse’s clinical and ethical knowledge. Benner (1994) writes a response to Kim’s (1994) and states that in this particular writing, Kim still privileges theory as the way to direct and inform practice and does not acknowledge practice as a similar source of nursing knowledge.

A paradigm is set up that is to plague nurse researchers for 3 decades. Coming out of the proposed Dickoff et al (1968a) structure are theories that are descriptive (factor-isolating, naming of variables), explanatory (factor-relating, situation relating), or predictive (situation-producing) (Fawcett, 1989). Because the structure includes descriptive theory development as acceptable only to identify factors and variables that can then be measured with appropriate research methodologies, herein lies much of the early and continuing conflicts with qualitative nursing research. Along with the privileging of nursing theory over nursing practice comes the privileging of measurement research over descriptive research.

Nurses have been critical of the push for quantitative data that pulls nursing in one direction to the exclusion of the other and because nurses, grounded in everyday realities of life, are very much aware of what is excluded in many scientific studies as the *excluded* by their very *variableness* is not open to testing. Authors have called for a rethinking of this mode for some time (Munhall & Oiler, 1986). Prymachuk (1996) states that research that is bi-directional, that is originating in practice as well as theory, is the way to go. He states that nursing has been entrenched in unidirectional research based on a technical rationality paradigm or similarly unidirectional in reflective inquiry. Researchers write of the validity of qualitative research and its appropriateness for a practice discipline. They believe that qualitative research is a choice fitting the question and area of investigation. Moccia (1988) speaks to the debate about quantitative

research versus qualitative research and/or a combination of the two, triangulation. She admits that the quantitative paradigm is the predominant one, but she points out that the choice of paradigms is “an ethical, moral, ideological, and political activity, and not only an epistemological one” (p. 4). The choice of methodology is a matter of one’s choice of world view, either a closed view of the world or an open one (Moccia).

But as we shall see below, even this calls for rethinking. Qualitative research is acceptable to be used for factor searching and variable delineation that leads to formulating hypotheses which can be subjected to measurement testing to find the relationships between the variables and a predictive theory can be produced. And perhaps there is some theory development in this genre that does assist the lifeworld of nursing though it is difficult to identify it. While many will still defend this model and that we must build for explanation and prediction (Polit & Hungler, 1985) others know that the very basic lived facts of nursing cannot be explicated or contained in this model (Drew, 1986). In the science paradigm, nursing practice questions translated to hypotheses and research testing often generate findings that lack utility in practice. Nursing practice questions originating in practice, studied qualitatively first to generate hypotheses, and then quantitatively second, also lose the fullness, the richness of the phenomena because the phenomena must be reduced too much to contain much of the “natural quiver” (van Manen) of the original. And to make matters worse, we now have an emerging body of knowledge called research utilization where authors find that nurses fall short in applying research findings to practice (Gennaro, 1994). Rather than seeking for root causes for this identified trend in practice, rather authors blame the practicing nurses. As stated above, even when the research question comes from practice rather than generated by a nursing theory, the methodologies used and the research tools implemented to measure are not easily adapted to practice situations. Questionable data collection techniques and findings produce questionable results. As stated before, the nurse in practice then, experiences ambiguity and dissonance within the theoretical part of her discipline and her particular area of nursing practice. Too, nurses are not willing to jeopardize their patients.

What is most certainly true and often underestimated is the knowledge and skill of the individual nurse. Every practicing nurse theorizes a bit, researches a bit, and practices a lot. The point taken in this dissertation is that because nurse theorists and researchers underestimate and little understand the importance of lived nursing practice as a way to build knowledge, several practice situations were either misconstrued or devalued (Beekman, 1983). In human lived experience and in lived nursing practice, it is often the nature of tiny things that show the essence of what nursing is all about. So one could question what it is we research; the air in nursing practice, the disembodied structure on someone’s desk or true lived human experience?

What started nursing on this path of measurement research is not clear. We could speculate that the prevailing science paradigm of positivism influenced theorists; that the lure of professionalization and a statistically proven theoretical base impassioned nursing leaders; that a way to separate the nursing profession from the medical profession in the guise of measurable outcomes in nursing’s independent functions propelled nursing managers; that educated women desirous of advancing their careers within academic routes drove nurse academics; that the need for theory on which to base nursing educational programs in university environments inspired nursing educators. Perhaps there is a little truth in all the statements.

Two things are certain however. What is most clear from our late 1990’s lens is that this form of theory development and research excluded an understanding of a discipline that is a practice. It is frightening now to look now at Dickoff et al’s (1968a,b) perception of a “practice theory”; that nothing inheres in practice except that which is research based and predictive and the more we

manipulate our variables the more we control others' health behaviours, other' healing modes. How could we have thought this for a minute let alone 3 decades!

While theory and research development in nursing pulled nurse theorists away from the practices of nursing, it is clear, (but seems a contradiction), that nurse theorists were sincere. They sought to show to the world of science that nurses were an important link in health care delivery. While their theorizing removed them from nursing as practiced and toward the knowledge systems of other disciplines to delineate nursing's characteristics, nursing's karma, it cannot be disputed that they felt they were formulating nursing with the best ideas ever and that they would have the authorship of the practice. It has taken us to the time of health care reform for theorists and researchers to show some humility. Little of the theories of nursing and the research of nursing as a mental construct, of notions of predictable practice theory, were of any benefit to assist nurses who were asked to delineate why they are an important health care discipline other than to facilitate other's work. Specific intervention based research delineated in the chapter on the bath, serves to do this. This sort of mentally based research does not.

Odd. Nursing practice is the one area of the triumvirate of theory, research, and practice, that belongs solely to nursing as a discipline; we generated our own practice in the midst of both institutional dictates and a powerful medical profession, here our practice with all its goodness and scabs shows who were are without relying on outside or fabricated data to delineate it. Yet it is also the one area that is the least predictable. Things get messy in practice. Independent and dependent variables change at will and frustrate researchers in the prevailing positivist paradigm of research. It is rather like the figure/ground connotations, what is the figure, what is the ground? In nursing practice the figure/ground constantly shifts. It is like looking at those pictures where one concentrates on the spaces and sees one image, on the figures and sees another. This is part of the inherent nature of nursing practice. One moment I look at the deteriorating bodily functions, a shutting down of bodily systems, and the next moment I look at the depth of the spirit of engagement of the person and family to come through this crisis.

### *Research concepts*

According to the view of Dickoff et al (1968a, b), the function of qualitative research is one of isolating factors or variables germane to the phenomenon of study. Factor-isolating and factor-relating aspects of theory development belong to qualitative research and constitute first level theory (Meleis, 1991). Identifying these variables or factors inherent in the phenomena of study is the important beginning step. Predictive theory must be able to accurately define and show the interrelationships among these factors. I myself thought this once; that the way to build theory was to constitute the concept, identify and build relationships between the variables.

Nursing research aims at isolating and describing concepts and their conceptual links with each other, analyzing and making explicit the content of the concepts, and moving along up the ladder so to speak to hypothesis generating and hypothesis testing. This makes conceptual analysis an important step indeed in theory construction. Delineated concepts can be the source for the development of a construct, defined and synthesized concepts. For example, restlessness and insomnia as concepts have a common attribute of increased vigilance, increased vigilance being the construct "which underscores a new entity, a nursing perspective" (Meleis, 1991, p. 162).

There are various ways to analyze a concept and several nurse authors discuss the appropriate ways to delineate a concept (Walker, 1971; Walker & Avant, 1988; Fawcett, 1989; Meleis, 1991; Rodgers, 1991a). Meleis (1991) gives a comprehensive description of concept analysis.

The process of concept analysis may include semantic analysis, which is analysis of linguistic meanings of the label given the concept; analysis of logical

derivation, which is the logical progression of identifying, supporting, and labeling a concept; and context analysis of the concept, which includes the conditions under which the concept is manifested. Any inferences about concept should be analyzed for their sources, whether they are logically or empirically derived. (p. 224)

With respect to the specific nursing theories listed above, research, in terms of level 1, 2, 3, and 4 (Dickoff et al, 1968a), can occur at any stage in the development of the theory. Research testing of theories includes any of these steps and specific questions and contexts emanate from the propositional statements of the theory (Fawcett, 1989). And research too can occur using a specific methodology developed for the theory either in its development state or in its operational stage eg, Parse (1995), Melnechenko (1995). Rodgers (1991b) points out that the current trend in nursing research to "identify concepts and phenomena unique to nursing is still evident" (p. 178). The difference is that some nurses now eschew some of the dogma attached with theory development as presented above and focus solely on developing particular aspects of nursing

Concepts are the building blocks of theory development. These are analyzed and defined. Definitional propositions of concepts are required as a basis for theory, relational propositions link two or more concepts and form the theory (Fawcett, 1989). Specifying and classifying concepts is a first level theory. "Labeling without description of what is labeled and without propositions for testing is not a theory" (Meleis, p. 161).

Conceptual analysis as one aspect of theory development, and concepts as building blocks to theory development are consistent themes in nursing's discourse. Fawcett (1989) defines a concept as a word "describing mental images of phenomena" (p. 2). Meleis (1991) delineates two types of concepts used in theory. *Primitive* concepts are those that originate and are introduced as new within the theory. These must be defined, have observable properties and boundaries. *Derived* concepts, "are concepts from outside the theory that have taken on a different meaning within the theory" (p. 220).

Peplau (1992), early nurse theorist, demonstrates this systematic development of a theory. She discusses the notion of the concepts involved in her nurse-patient interpersonal relations theoretical framework. She is clear on her assumption that "what goes on between people can be noticed, studied, explained, understood, and if detrimental changed" (p. 15). Concepts are "a definition of a small, circumscribed set of behaviours, pertaining to a particular phenomenon such as conflict" (p. 16). She shows how delineating the concept of conflict resolution and patterns of same within the theory lead to effective action in dealing with problems that arise, for example, anxiety.

Nurse theorists can make too much of a concept, develop delineations that do not fit. Too much constituting of the concept and what inheres in it diminishes the experiential living. There are various examples of conceptual development that may be questioned. Henson (1997) analyses the concept of mutuality. She uses Walker and Avant's (1988) method of concept analysis and describes mutuality within Walker and Avant's denotations, antecedents to, consequences of, and empirical referents of mutuality. Mutuality is studied as part of an interaction style for "both providers and clients that encourages accountability" (Henson, 1997, p. 77) and partnership in the relationship.

It is not the notion of lack of rigor that one reacts to here. Rather an extensive literature search and analysis has occurred in accordance with Walker and Avant's methods. A model case is presented. The model case does not reflect the complexity of everyday nursing practice. In fact, it is just a small and quite ordinary communication and organizational change. Perhaps the author felt a simplistic case might allow her to reflect the properties of mutuality more. But in



fact the model case diminishes the reality of nursing and does not show its dynamic ever-changing face. Being in the lived moment of nursing is just not that simple, that linear.

Because the knowledge identified here does not address the complexities in practice and in fact serves only to diminish the lived moments of relation to a simplistic interchange, this conceptual analysis will not assist a practicing nurse. Rather Henson could have identified all of the properties she did and more in a conversation with a nurse at coffee time where nurses often engage in everyday theorizing, discussions. To be connected with practice is to know what kinds of situations need illumination and understanding in terms of mutuality i.e. patients are usually very vulnerable individuals, the relationship concerning mutuality is not on an equal footing and patients know this in institutions and outside in the community. Nurses are watchful and care for this lived-vulnerability (Gadow, 1980, 1989).

One could also ask the questions, "If I were doing a concept analysis of respect, conversational interchange, or listening, what would be different in this analysis?" What nurses in practice need is sound situated knowledge, not diminished entities (for the purposes of applying rigor in the analysis or to have fun with a research methodology). In truth, mutuality in lived nursing practice ranges from wonderfulness to sheer horror of intertwined agendas as nurses manage varying contexts of care. In contrast Peplau's (1992) writing as to how to understand anxiety and conflict within situations of nursing practice gives direction to the discipline; she writes of situated cases. Kolcaba's (1991) findings of comfort based on actual lived moments in nursing, do assist the practicing nurse to broaden her understanding of comfort in all contexts.

The material content of the concept must be determined separately for every historical-social situation. The economic, social, and political aspects of a context have to be taken into account and only on that basis can there be an adequate filling-in. And it is within the bounds of possibilities to do this. (Miedema, 1987, p. 223)

Practicing nurses can delineate what they do in practice. Authors who do conceptual analyses such as these must not pretend that this is new knowledge unknown to practicing nurses. Or on the other hand, if the author is aware that nurses do know these things and describes a known concept for categorization, then nurses in practice must be acknowledged as knowing and already enacting the concepts. Those then reading nursing literature would not be *mised* as to what a practicing nurse does *not* know. The problem with categorization is its too simplistic nature. Nursing looks weak as a discipline if this stands for its discourse. Imagine some disciplines looking at nursing process in its prescriptiveness for nursing on paper. Would they not wonder why an experienced practitioner needs such regimented dogma?

To reduce nursing to a concept or a set of concepts is as reductive as using empirical methods of theory development. To use this to represent nursing portrays again a part reality, a part theory of the complexity of nursing as lived and experienced. They do not reflect practice realities. Often concepts in nursing are analyzed and defined with more attention given to another discipline's theory rather than nursing and that too makes them difficult to transfer to practice. Basically the scope of human experience shows itself in nursing practice. Nursing intersects with those who struggle with situations of health and illness, life and death, disease and curative measures, adopting healthier lifestyles, changing patterns of behaviour.

Rafael (1996) sets the record straight in terms of conflicting nursing literature about the concepts of *advocating for*, as opposed to *empowering of*, patients and families. She too disputes simplistic findings. She states that conflicting literature generates conflicting actions in practice. Concepts, delineated in a reductionistic manner, limit us in our practices of nursing. Rafael rather returns to Gadow's (1980) identification of the effects of two reductionist concepts in health care

to show how these two concepts live out in life and limit authentic interactions in advocating and empowering patients. These are:

...The belief that health care providers should limit their involvement with their clients to a professional rather than a personal relationship and the separation of clients as objects from their lived experience. One fragments the client, the other the nurse. (Rafael, 1995, p. 25)

It is timely for nurse theorists to reassess the thinking behind and the means by which concepts are identified as building blocks of theory. As understood by theory-makers and researchers in nursing, the concept "refers to analytically defined constructions of the discursive intellect" (Rosen, 1980, p. 53). To the contrary, the point of view taken here is that concepts must be embedded, must be part of the ground of nursing practices. Grumet (1988) states that the "bonding of thought and relation is consummated in our word 'concept.' It is derived from the Latin phrase *concipere semina*, which meant to take to oneself, to take together, or to gather the male seed" (p. 8). Nurses know their actions are closely bound to relation and thinking through this relation. Their thinking and relatedness and actions consistently applied to context specific situations is first formed in binding themselves to the other. Both the challenge and beauty of nursing is that it intersects with individuals in any way they choose to live their personal events, no matter how hard we try to fill the containers of the concepts with pre-filled notions of how they will or should behave. We cannot trap nursing. We can only respect and value its practice.

How to come to terms with this? Perhaps it is by *looking at the original* (Rosen, p. 159), or as close to the original as possible. To do anything else puts us "on the road to the replacement of initial intuitions with analyzed concepts" (p. 159). Rosen (1980) simply states that there is "no concept of the 'concept' as such" (p. 42). In nursing we can, as described in Hensen's work above, determine how to cognitively apply the intellectually constituted concept in various ways once we bring it to language. Here "a concept is then a grasping of some definite, and hence countable, object" (p. 46). But the inherent warning has to be, we must not think that this replaces a piece of uniquely lived life or is apt for every person's projects in their lived world. Because then the "ostensibly pure reception by noetic vision of the essential form has been replaced by the cognitive construction of the concept of the object that is thought...the object is the project of the thinking subject" (p. 44). For Rosen then, what we do is grasp the constructed concept and therefore our involvement is activity. Activities "performed with or upon concepts" (p. 51) and not with lived-life. The tension of (re)presentation lives on actively with research concepts in nursing.

### ***Research metaphors***

Nursing is often represented in the literature with the use of metaphorical language. Watson (1987) uses metaphors from literature to describe nurses' "caring consciousness" (p. 11). To Watson, metaphors are a way of expressing "something complex, contextual, and often unknown about caring in an instantaneous, almost unconscious flash of light" (p.11).

Metaphors were chosen through the creative process of attempting to find new language (literary rather than scientific) to express the covert, intangible, tacit, expressive dimensions of caring in nursing. No one pervasive theme other than tacit "soft" aspects of caring, which are often invisible and unrecognized, was selected. (p. 11)

"Holding up the arc" from D.H. Lawrence's *The Rainbow* connotes the timelessness of caring, the "*Poem for the Left and Right Hand*" by Marilyn Krysl (1989) connotes the blending of the eros and logos, the masculine and feminine aspects of caring, *Women's Ways of Knowing* from

Belenky, Clinchy, Goldberger and Tarule (1986) shows breaking the “roar of silence”, the idea of oversoul from Emerson’s *Selected Essays* displays clinging to wholeness, *Gift from the Sea* by Anne Morrow Lindberg (1955) uses different sea shells to represent aspects of caring. These metaphors assist Watson both to understand nursing and to give direction to nursing’s pursuits.

This essay reads well and it is interesting to see these metaphors used as a way of lending understanding to the caring component in nursing. Yet even more appealing is Watson’s (1987) explanations in her own words about nursing, speaking about it directly. “Nursing and women are creating a new consciousness of their place in the system and in the universe, and a new awareness of the interrelatedness of all life. Nursing in this sense is on an evolutionary edge of human consciousness” (p. 15). Watson, using her own descriptive language, does very well describing her notion of caring in nursing without the metaphors.

Langer (1967) states that “in a genuine metaphor, an *image* of the literal meaning is our symbol for the figurative meaning, the thing that has no name of its own” (p. 139). Nursing does have a name of its own. It is nursing. Langer (1967) continues and warns that “if a metaphor is used very often, we learn to accept the word in its metaphorical context as though it had a literal meaning there” (p. 140). Such a word becomes a “faded metaphor” (p. 140). Caring as a metaphor in nursing is a faded metaphor, so faded that Watson above must search literature to find more metaphors to resuscitate it. Or caring as standing for the focus and essence of nursing has too worn itself out. What is nursing stands before us, in its own name and its own practice.

Yet on the other hand, an analysis of metaphors used by patients to describe their experiences, people as recipients of nursing care, has been useful to Jenny and Logan (1996). They examine the meaning of metaphors that critically ill patients use to speak about their ventilator weaning experience, a situated nursing study in an ICU, an intervention research study. These patients use metaphors in an “ascending order of frequency: physical discomfort, nurse caring, altered self, and patient work” (p. 350). Patients describe how they are *physically* with direct language, less frequently using metaphor to do so, eg. the dry mouth, the local irritation of the tracheal tube, the suctioning experience. Nursing acts, integrating an altered self into a new world of meanings, and working hard are mainly described with metaphors. “I just ran out of steam”, “I thought I would be a vegetable”, “That is real hard time...you hear of guys that go to jail, they’re doing hard time” (Jenny & Logan, p. 350).

It is interesting to note the difference in metaphor use here. The physical discomfort is in the here and now, lived directly moment by moment and is spoken of directly. Other categories such as acts of nursing, people working hard to get better, forging a path through the illness and treatment are less expressible in outright language. Patients find these experiences less accessible to standardized explanations. Czechmeister (1994) states that whereas metaphors may stigmatize illnesses such as cancer and have negative consequences, they also through their expressive function, help people who are ill to express the meaning of their experience. As a result of this metaphorical analysis, Jenny and Logan (1996) make some strong statements that ring true to a nurse’s ear. They believe that patient work needs to be recognized more and “deserves a place in theories of caring” (p. 352).

Fagin and Diers (1984) also use metaphor in an explicative way. They write that the public image of nurses and nursing is disturbing. It evokes discomfiting images and so these authors undertake to examine this social perception by looking at “the metaphors that underlie the concept of ‘nurse’ - metaphors that influence not only language but also thought and action” (p. 16). The metaphors they expose are nursing as motherhood, class struggle, equality, conscience, intimacy, and sex. Each of these has a negative connotation within society at large. Fagin and Diers say that we should use “nurses” and “nursing” to represent ourselves to society and not

metaphors. They suggest we remember our nursing leaders and cite Lavinia Dock and Lilian Wald (see below) as nursing leaders in health care and health promotion and the rights of persons. Nurses should think of themselves as “Florence Nightingale, tough, canny, powerful, autonomous and heroic” (p. 17).

Lawler (1991) writes critically about holism as a metaphor to stand for nursing. Holistic care distracts readers from the essence of nursing. She states that holistic care has been used to “clean up” (p. 216) the image of nursing, to professionalize nursing, and to separate it from medical practice. Czechmeister (1994) too questions nursing’s preoccupation with holism. “In the quest for the ‘whole person’, insight from the real, phenomenal world of neither patients nor clinical nurses has been sought” (Czechmeister, 1994, p. 1228).

Rawnsley (1990) cites Ricoeur’s analysis of metaphor as a part of speech. “Metaphor is postulated to be an innovative linguistic device of discourse that has the potential to redescribe reality” (Rawnsley, p. 43). This appeals to Rawnsley as she wonders if there is “congruence between the lived experience of nursing practice and the intellectual pursuit of caring as nursing’s professional crest” (p. 42). She introduces “instrumental friendship” as a metaphor that can resolve the tension between practice and theory. In her view, because neither nurses or patients choose each other in most places where nursing takes place, instrumental friendship, the nurse with her knowledge of caring and the patient with their need, together overcome the theory/practice gap. For her, instrumental friendship as metaphor explains why a nurse can care for a stranger and vice versa. Does this give us a purchase on nursing as it happens in practice? Perhaps, but it also gives us the sense of something contrived, something not quite there. Practicing nurses would not take kindly to the term instrumental friendship.

Rawnsley (1990) in her example of caring as nursing’s professional crest gives us a sense of mutating metaphors in nursing. The notion of caring as an ideal for nursing, as the essence of nursing has shifted meanings over time. In addition the notion of caring as an ideal and metaphor for nursing has not moved the practice of nursing out of traditional metaphors describing its essence i.e. nursing as military, religious, paternalistic under the thumb of physicians, maternal (Munhall, 1988). In fact, the practice of nursing has become even less caring and more technicized using caring as a central feature. What is most significant is that few if any of the constructions of caring approximate the original meaning of what it is to care. Heidegger (1962) describes care as worry, burden and uses the German word *sorge* to explain its meaning (p. 237). Worry and concern are central features of people experiencing health crises. But in nursing, most often caring is seen as the activity of the nurse for the patient not as the patient carrying a burden, a concern, a care.

To stay with caring for a bit is useful here to see how this particular mutated and carefully researched metaphor plays itself out in nursing literature. What is most important to note is that caring which once was a way to illustrate a point, a characteristic of nursing now obstructs understanding of nursing. It has become too embellished without approximating the lived world in nursing practice. What was once a way, a vehicle to understand better, now obstructs “the progress of pure thought” (Marcel, 1950a, p. 63).

Leininger (1978, 1981) developed a conceptual model to classify specific caring constructs derived from different cultures. In the 1981 work, Leininger identifies comfort, concern, compassion, stress alleviation, support and trust as a major caring constructs. Leininger states that depending on the culture, different aspects of these constructs will be expressed and emphasized. Leininger (1984) makes what we could call the ‘quintessential statement’ that tantalizes nurse theorists from this point on. She states that care is the “essence and the central,

unifying and dominant domain to characterize nursing” (p. 3). Newman, Sime, and Corcoran-Perry (1991) state also that caring is the central focus of nursing.

It is important to note here that Leininger emphasizes culture and transcultural nursing as an important part of the expression of caring. She recognizes the lifeworld. Later writings of caring fail to mention culture as a situated and integral component of caring; this grounding in situated knowledge fades.. Anderson (1987) admonishes nurses to be culturally sensitive in all our nursing interactions with patients and families and discusses a nurse-patient negotiation model that advocates culturally sensitive health care.

Watson (1985) and Leininger (1978, 1981) above would agree that caring is the moral ideal of nursing. Some of Watson’s ideas are certainly attacked in the caring debate. Barker, Reynolds and Ward (1995), Barnum (1998) facetiously refer to this notion of caring as a sort of ‘theology’ and ‘spirituality’ respectively and that if the right sort of ‘magic’ of care can be applied, people can overcome anything in the disease/illness continuum. “If ‘caring’ can realise the capacity to choose between health and illness, regardless of external circumstances, disease or bodily or human condition, ‘caring’ might be strong ‘magic’ indeed” (Barker et al, p. 387). They also state that Watson’s carative factors are not central to nursing at all, and many of them are drafted from psychotherapy theory and research literature.

Caring is seen in a cultural format (Carper, 1979; Leininger, 1984, 1988; Anderson, 1987), as philosophical (Ray, 1981; Griffin, 1983; Gaut, 1984), as moral and ethical ideal (Watson, 1985, Gadow, 1980), in helping activities (McFarlane, 1976), as interactions (Gendron, 1988; Forrest, 1989), as caring behaviours scales, quantitatively measured, Larson’s (1984) Care-Q instrument, Wolf’s (1994) Caring Behaviour Inventory (CBI), as phenomenological (Reiman, 1986; Drew, 1986; Forrest, 1989), activist primary caring (Hagedorn, 1995), as defense against stress, to enable coping (Benner & Wrubel, 1989), as holistic (Gaut, 1993), as a practical science (Johnson, 1991; Bottorff, 1991), and more. This is not an exhaustive list of caring literature in nursing. But it shows how theorists substitute metaphor for metaphor in hopes of explaining nursing and its pursuits.

Larson (1984) found that in the CARE-Q instrument, nurses evaluated listening to patients the most important nursing behaviour whereas patients ranked nurses monitoring them, competency in skills, and following through on things the highest (the patients’ ranking found before in more than 80% of nursing studies, Bjork, 1995). Nurses in Wolf’s Caring Behaviour Inventory (CBI) instrument which scales nurses perceptions only, also evaluated attentive listening as the highest ranked nursing behaviour. Conin and Harrison (1988) concur with the patients in Larson’s study. These patients too ranked nurses’ knowing what they are doing and being technically competent as most important. Patients are very clear on their perceptions. Why don’t we listen to them, I mean, really listen?

Dunlop (1986, 1994) critiques the caring inquiry in nursing and cautions us to remember practice. In theory one can shed practice and have a “disembodied caring” (1994, p. 32). But those who remain in practice cannot shed the body. Dunlop gives us a warning.

In a pinch, though, and sometimes through choice, nursing remains embroiled in physical care, which involves contact with the mess and dirt of bodily life, even while it is aspiring to the “cleaner” caring that deals with people’s minds and emotions. But to the extent that it is able to shed physical care, nursing becomes increasingly hard to distinguish from other occupations in which people make their living and justify their involvement by recourse to caring in its emergent sense. (1994, p. 32, 33)

Reverby (1987a, 1987b) provides an additional perspective on caring. Looking historically at nursing, she asserts that nurses were "ordered to care in a society that refuses to value caring" (1987b, p. 1). She writes that caring was imposed as a duty on women and then as a paid labour force. Reverby (1987a) states there is dissonance in nursing about caring as a conceptual ideal and caring as experienced in practice. The feminist discourse concurs with Reverby. Puka (1990) states that caring is "not a general course of moral development, primarily, but a set of coping strategies for dealing with sexist oppression" (p. 59). Sherwin (1992) states:

Within dominance relations, those who are assigned the subordinate positions, that is , those with less power, have special reason to be sensitive to the emotional pulse of others, to see things in relational terms, and to be pleasing and compliant. Thus the nurturing and caring at which women excel are, among other things, the survival skills of an oppressed group that lives in close contact with its oppressors. (p. 16).

Rafael (1996) calls for empowered caring which is not associated with timidity and subservience but with awareness of social and political forces. Rafael states that caring can only be enacted in certain ways determined not by nurses but by the social and political structures governing nursing. Wolfer (1993) while admonishing us not to forget or leave out the body, the mind, and the spirit as modes of inquiry and realities of nursing rather unsurprisingly leaves out the economic and political situation.

Swanson (1986, 1990, 1993) is a nurse author and researcher who interprets caring acts in a situated clinical episode. Because of that situatedness, her descriptions and stages of caring in nursing acts ring true. In 1986, she identifies five process involved with caring; knowing, being with, doing for, enabling, and maintaining belief. In 1990 in a NICU unit, she adds attaching, managing responsibilities and avoiding bad outcomes. I would say that all of her findings are the gestalt of nursing, a blend of many pieces of knowledge and practice found in this situated study; nursing not caring. This following statement is not arrogant and does not make statements it cannot support in practice.

Making the claim that nursing is informed caring for the well-being of others does not mean that only nurses are caring, and that all nursing practice situations may be characterized as caring. It also does not suggest that nursing is the only profession whose practice involves informed caring. What it does claim is that the therapeutic practices of nurses are grounded in knowledge of nursing, related sciences, and the humanities, as well as personal insight and experiential understanding and that the goal of nurse caring is to enhance the well-being of its recipients. It is the blend of knowledge/information and the goal of practice that distinguishes nursing from others whose practices includes caring. (1993, p. 354)

The operational practices, the original ground (van Manen, 1990) of nursing elude representation by metaphor. Barker et al (1995) believe the focus on caring has been narcissistic and harmful to nursing. They concur with Dunlop. "There is little reason to doubt that caring is profoundly shaped by the social structures of the institutions of care" (Dunlop, 1994, p. 40). If you care, you will forfeit coffee breaks and work overtime to get your work done; this ideology of caring has not served practicing nurses well.

...It is a common experience to encounter plumbers, electricians and double-glazing technicians who proclaim the "caring" nature of their service. It may be a sad, yet incontrovertible, fact that the term "caring" has been abused beyond recovery. As a result, an additional challenge faces nurses; to discover, or coin, an expression which represents an adequate "fit" for the complex activity of

nursing; one which does not overlap, unnecessarily, with other areas of human endeavor. (p. 396).

Van Manen (1990) reminds us that the metaphor is not “simply the bottomless ground, the empty core, the final destination of language” (p. 49). He writes that rather metaphor can take us to the *original ground* of our phenomenon. Langer (1967) writes that “metaphor is our most striking evidence of *abstractive seeing*, of the power of human minds to use presentational symbols” (p. 141).

At first blush it may appear as a paradox that metaphor, which enriches poetry and prophecy with concrete imagery, should be an instrument of abstraction. Yet that is its true nature; it makes us conceive things in abstraction; the bloodless abstract language we usually associate with abstract ideas only names them after they have long been conceived, and have grown familiar. (Langer, 1957, p. 104,5)

### **(Re)presentational Modalities of Practice**

Nursing practice has not come through unscathed in light of the above history of (re)presentation. There are representations of practice and mechanistic tools that too, fall short of the richness of nursing. And as stated above, many of these representations and tools emanate from theorizing, from research findings. What is different though is that because practice is close to lived daily life, the absurdity of the constructed mechanisms are perhaps easier to see. In theory and research one has invented language to stand behind the dictates, and the sheer linear-ness of theory protects it: in practice though while specialized language systems abide, one is able to see through to the density of the situations and the juxtaposition of the abstract with the concrete. It can be laughable or dreadfully disquieting.

Theorists and practicing nurses have an uneasy alliance. Yet too much focus on the relative merits or distractions of both leads to not facing true battles in terms of patient care, i.e. political systems, lack of resources for care, deskilling workers. “While there may be problems with the relationship between theorists and practitioners, exclusive concentration on internal differences diverts attention from profound external constraints upon the operationalization of effective nursing care” (Porter & Ryan, 1996, p. 420).

Campbell (1988a,b) studies the effects of documentary processes on nursing practice from a managerial perspective and states that nursing increasingly becomes “a theoretically oriented and document-based practice” (1988a, p. 30). She quotes Dorothy Smith who argues that ideology is a practice, “a method of transforming experienced reality into abstractions and, as such, is open to empirical investigation” (p. 33). Not only now do we have our theoretical writings converting us to abstractions to stand for nursing, but now too from the other end, so to speak, we have the managerial pressures to make nursing predictable for cost containment. As nursing practice in the main is housed in institutions, it is a profession that cannot freely enact its own judgments; here “the work relies on an internalized knowledge base but is organized by objective managerial processes” (Campbell, 1988a, p. 32). Add to the managerial processes the constructed mechanisms coming from theory and research, and one finds a whole lot of restrictive dogma to shift through to come to the patient, the family; nursing’s transformation to a text-based system is almost complete. “The most sophisticated documentary accountability devices are subject to the same weakness in reliability between the document and the underlying reality they purport to represent” (Campbell, 1988a, p. 38)

The story of practice is a sad one, perhaps the saddest of all in this account. In days of late, nursing practice exists to apply research findings or particular mechanistic tools or management

processes. Or practice exists for one to explore a particular concept, where it arises in practice, and then is distorted with academic abstractions. All of foregoing have the goal of generating predictable care and predictable outcomes where the fullness of the practices of nursing are not able to be addressed. Gadamer (1981) laments this turn of events in the wider world arena of science. "What novel and singular turning by modern science has led to the transformation of practice into the anonymous and all but unaccounted for (on the part of science at least) application of science?" (p. 69). He warns against this devaluing of both theory and practice. And he presents his fear.

If abstract relations between initial and terminal limiting conditions become graspable and calculable in such a way that the positing of new initial conditions has a predictable outcome, then the hour of technology has arrived by way of science as understood in this way. (p. 70).

To follow the evolution of nursing as a discipline moving towards professionalization, below we can see how mechanistic tools have diminished the practices of nursing. Throughout the course of this study, nurses often stated that nursing has changed; that it is now a rule-based, formulaic discipline and to deviate and truly *nurse*, is to go against the system.

Practice itself is an entity. It is the world as lived by particular individuals at a particular time and place; it is constituted and brought into being by these. Theorizing and researching and mechanistic tools take up a big space in nursing and the space keeps getting bigger. True practice, where the nurse nurses from her own knowledge and experiential base and not from pre-formed plans, takes up very little space in comparison. In fact, if nurses could nurse through their own professional judgments, nursing would be cost effective as well as taking up little space. But for now, nursing shrinks into little pockets of nursing here and there, pockets stolen from the constructed entities. The real event of nursing hides itself, protects itself.

### ***Process practice***

As the metaparadigm concepts are the sine qua non of nursing theory, nursing process is the *modus operandi* of nursing practice. With this process, nursing now becomes scientific. Nursing process serves to both integrate and operationalize theoretical and practical nursing. The components of the nursing process follow closely the scientific method: assessment, problem identification and problem statements (later named, nursing diagnosis), developing short and long term goals to address the problems, choosing nursing and other interventions to overcome the problems, developing a nursing care plan, and then evaluating and revising the care plan. Specific nursing theories each with their specific foci, contribute a specific skew of the assessment process.

Nursing students have been taught the nursing process in this way since approximately the 1960's. Indeed I was taught the nursing process and writings of Virginia Henderson. We were taught how to make problem statements and formulate care plans according to the 14 activities of Henderson's theory. And in this beginning time, because the nursing process was based on nursing theory that was grounded in practice, in truth, the nursing process enabled individualized care and nursing activities well. Since this time as seen above in the nursing theory development, the nursing process has evolved into an elaborate system of physical and health assessments, an unwieldy nursing diagnostic system of labels for client problems, (the patient has become the consumer of care, therefore called *client* in much of nursing's literature). Then following the implementation of this system, either identical nursing interventions are implemented that would have been implemented anyway without these elegant systems of assessment and diagnosis or more frequently, distortions of understanding the patient result in distorted interventions imposed on him.



Practicing nurses think and implement together. It is often such a quick process of taking in and forming judgments that one moves from seeing (assessing) to doing (critical judgment, acting) in a split second. Such is the nature of nursing practices; they can be instant in time or long suffering until one accumulates enough sensory and objective data to act. Prymachuk (1996) has a problem with these mechanized views of the nursing process, its documentation systems and linear ways of thinking. While the nursing process assists novice learners, Prymachuk asks why experienced practitioners in nursing still must use and document it. Other disciplines' practitioners who have also integrated theory like this are autonomous.

As a simple set of rules for systematizing nursing care, it provides a particularly useful guide for the novice nurse. However, the nursing process soon becomes internalized in most nurses (most reasonably experienced nurses intuitively carry out the nursing process), so why does the nursing profession insist on documentation under discrete titles like 'assessment', 'plan' and 'evaluation' and why does every nursing action have to be rigidly recorded? (p. 683).

Students of yesterday, like myself, and students of today, often complain that this process distracts them from what is going on with the patient. Assessments today almost take the place of the nursing interventions as the assessments are complicated and long and must be charted immediately in most hospital environments. Nurses now become more and more concerned with accuracy of their findings and documenting the findings which in some institutions legally must be done every one or two hours. The need-ful body of the patient in nursing practice is displaced for the demanding body of the charting and administrative system. The intervention becomes the documenting NOT the nursing of the patient. Multitudinous stories abound of patients who lie in wait for their nurse to return following their assessment of them, and to do a specific nursing intervention, i.e. the nurse who assesses the wound drainage, now must immediately chart it, and the patient waits for her to come back to change sodden, wet, infectious, wound draining green discharge, dressing material. But in the nurse's mind (under this documentation system), she has nursed, done her assessment and now charts it.

Diekelmann (1993) identifies what is inherently difficult about representing nursing to students in terms of mechanistic nursing process, nursing diagnostic labels. She describes how one student had carefully done her preparatory work concerning her patient the night before her clinical day. This is standard practice in clinical teaching and clinical learning environments. The student arrives on the unit the next day with her nursing care plan, the nursing process delineated, the nursing diagnoses made, the plan of how she will act this day all worked out; she nurses paper, she does not really know how the patient is doing or what *burden of care* the person experiences (van Manen). When the student arrives, she finds the person she is to nurse dying. She writes.

...During the night my patient took a turn for the worse and when I went in there, her daughter was sobbing and clinging to my patient. Then all that stuff about emotional needs and diagnoses is useless. I just wanted to know what to do, stay or leave...(p. 248)

So much of nursing practice is knowing what to do in the moment. Each moment in practice we stand in a moral, ethical relation to the patient, to the family. The student with the crying patient and her family writes that she knows about theories of grief and bereavement. But no aspect of this content showed her how to act tactfully in this situation. Nursing in practice is about the aliveness, the livedness of humans relating to humans.

Diekelmann (1993) states nurse educators cannot assume that applying content implies thinking. She states that "one danger of behaviour pedagogy is that it emphasizes learning content and the acontextual application of content; *thinking* is de-emphasized and/or defined as merely applying

content to specific situations' (p. 247). What mattered in this situation was not the ability to assess and identify nursing diagnoses and pre-planned nursing action, "rather it was the student's ability, as a novice, to know and respond; to be able to think contextually and stay in the situation" (p. 248).

The graduating student's question "how to make sense of the theoretical side of nursing with the practice of nursing" lives still. Lawler (1991) found too that experienced nurses complain of these mechanistic things of nursing's knowledge disparagingly.

(They)...have remained skeptical about such things as the nursing process and nursing diagnoses - instruments believed to foster holistic and scientific practice. They regard them as imposed models that do not reflect the real world of practice as they perceive it, experience it and practice it. Such imposed models are also reductive and they fragment an otherwise integrated and composite (somological) view which typifies the practice of experienced and expert nurses. (p. 216).

It is interesting in light of the above to recall a recent conversation with an experienced public health nurse leaving the field by retiring early. She explains that the documentation systems have truthfully "finished her." Whereas she used to be able to make quick notations about her home visits, things to follow up on, things to act on, now she must fill in 3 page reports under nursing process and intervention headings even if her findings are within normal guidelines. She laments, "a public health nurse has long since interiorized all of this and can act very well on brief notations and other nurses understand them too. But now I fill out these pages because I am mandated to by management and now I'm 3 home visits behind. I don't get to see my people anymore."

Now it is as Mitchell (1984) states above, one could spend their time filling out the forms rather than going to stand beside the patient, the person in their home. This nurse estimates that the time needed for these forms replaces several more important home visits, being in actual contact with the people. Mitchell (1984) exhorts nurses to leave the forms at the desk and go and stand beside the patient to find out if she shows pallor of the skin.

Nursing practice then, being deficient in the eyes of theorist and researcher alike and so they endeavor to invent a scheme to make it work theoretically, deficient in the eyes of health care restructuring management committees as nursing cannot make its importance understood by same, is abandoned and in turn, the patient and the practicing nurse abandoned too (Baer et al, 1996).

### ***Diagnostic practice***

Above in the discussion of nursing process, we stated that the nursing diagnosis takes the place of the statement of problems in an older version of the nursing process. One assesses and then one either states the problems or applies a nursing diagnostic label. Nursing diagnoses describe a person's response to a health problem. The official definition of a nursing diagnosis according the North American Nursing Diagnosis Association (NANDA), the association that has developed these categories, is that of "a clinical judgment about individual, family, or common responses to actual or potential health problems or to life processes" (Sparks & Taylor, 1991, p. 10). For example a nursing diagnosis could read, "potential (or actual) for self-care deficit" in bathing and hygiene due to a musculoskeletal impairment, or due to a perceptual or cognitive impairment. Levine (1995), early theorist, states that the language of nursing diagnosis, the use of the words *actual* and *potential* are vague and imprecise terms, and that words such as choosing, valuing, exchanging, defy specificity.

The word "diagnosis" works well for medicine, where the primary intent is to state what is wrong in pathological terms. Diagnosis does not work well for nursing practice. The diagnostic labels are dependent upon the patient being able or willing to articulate his/her needs, and/or the nurse being able or willing to notice and interpret these signs and symptoms in her own pre-developed framework. Next comes the difficult problem of fitting these findings into one of the copious categories of care. It is difficult to capture nursing care in categories. Some hospitals, primarily in the United States, have now computerized these labels, so that once a person is admitted and the history taken, the information is fed into the computer and an appropriate plan of care spits out the other end. While the term technical rationality does not appear in nursing's literature as a critique of these mechanistic versions of applying nursing care, the whole process manifests it.

Levine (1995) explains the evolution of the diagnostic labeling process. She describes how nurse clinicians gathered to discuss various aspects and areas of nursing practice with the goal of explicating commonalities of nursing care.

And then the theorists arrived. What had, until then, been an exchange between practicing nurse clinicians became the focus of an ill-fitting, superimposed theoretical structure. It is an example of how theory could have improved practice by allowing the evolution of a taxonomy from the workplace rather than the impatient imposition of an imperfect one. (p. 12).

Meleis (1991) makes strong statements about nursing diagnostic labels. She speaks to the work of almost two decades of nurse theorists and nurse clinicians and includes a warning.

The taxonomy that evolved out of these two decades of work resulted in a list of diagnoses that are esoteric in language and nonrepresentative of the complexity of human beings. They are nontheoretical or do not emanate from a coherent theoretical perspective, nor is there evidence that they have contributed to clarifying the nursing mission or to improving communication among nurses and with the rest of the health care team. (p. 161).

Allan and Hall (1988) dispute that diagnostic labeling in nursing is valuable at all in any way.

This process has an overdeterministic effect on symptomatology; it constrains efforts at prevention; it forces practitioners to label everything, even when no valid labels exist within the organizing framework; and it leads to treatment of disease as an end in itself, not as a means to a better life, to happiness, or to self-defined goals. The diagnostic labeling of the medical model robs people of their control over their lives and of what they feel about their bodies. (p.25)

Mitchell (1988) shows examples of a nursing care plan based on the use of nursing diagnostic labels versus a care plan based on Parse's (1981) theory of human becoming. She protests against the use of preprogrammed nursing diagnostic labels and shows how they cannot stand for individualized nursing practice. Later, in 1991, Mitchell calls into question the ethics of labeling individuals with nursing diagnostic labels from the point of view of the nurse and not the patient. She believes that the nursing diagnosis system violates the ethical principle of nonmaleficence.

When the debate over nursing diagnostic labels is placed within the totality and the simultaneity paradigm classifications of nursing theories, one gets the sense that the theorists involved in the simultaneity paradigm were involved in making a backlash against computerized care. But it is a backlash at the theoretical level only. In reality in practice, nurses go about participating in their nursing care and their charting based on their internalized knowledge system. The nursing diagnostic labels where in use, remain an entity attached only to the computer or the paper of the chart. Tick charting has become the body of nursing.

### *Outcome practice*

Although there are some who would argue that the focus on preformulated patient outcomes today as cost containment (eg. patient care maps) does not equate to the late theorists consumed with outcomes of nursing, one could conjecture that there is correlation. Theorists must be responsible for the language they use, for their published work, and what elements in their theory “catch on.” There is currently a focus on predetermining client outcomes in nursing practice imposed both by those who advocate predictable and explainable practice theory and also by the administrative systems of the institution. The impetus for this is the need to control costs of health care. The thinking goes like this; if one can predict and plan in advance by means of a *patient care map* or a *critical pathway* map, the nursing care this person needs, and how this person will progress daily, and discharge achieved on a certain day, then a significant reduction of care costs can occur. Nursing units and nursing specialties struggle now with the task of developing these care maps for very specific conditions. Again, while these are in some way helpful to the novice nurse in describing the management of a particular condition, expert nurses oppose them as they believe they restrict their practice and individual professional judgment system. One nurse tells a long and complicated story of advocating for a person who had had extensive day surgery and was unable to go home due to copious bleeding. Regardless of this, the physician believing that this would dissipate discharged the person. The nurse, having taken the person’s history and having been with him for 10 hours at this point, was certain in her professional judgment that more was going on with this patient. But because the caremap based on pre-formed outcomes stated that the person was able to be discharged, the nurse had difficulty having her professional knowledge base heard. The person must be discharged and not take up a hospital bed. Finally because the person lived 5 hours north of the city, the hospital administration decided to put the person up in a hotel for the night. The nurse continued her advocacy. Once the nurse convinced the physician, and he did agree with her assessment eventually, both could not persuade the administration that a hotel room would not be safe for this particular person in this condition. The situation was finally resolved with the person lying on a stretcher in the hallway of emergency for the night. About three o’clock in the morning, the individual hemorrhaged severely necessitating emergency measures and more surgery ensued.

Professional nursing associations also embrace research on client outcomes. In a way, this too is a backlash against the trend to turn nursing interventions into tasks deliverable by anyone. The associations believe that solid evidence will add to nursing’s knowledge base of care for individuals, and in addition, show others (such as administrators) that nursing care by nurses is needed. It is an admirable endeavor. But again, the associations like the theorists, abandon the experiential situations by nurses and patients and instead search for theoretical guideposts to back up their assertions. They cannot be blamed too much however as it seems that this is the type of knowledge that administrators and health care restructuring committees seek. Yet as with all theoretical knowledge and research findings, people can choose which finding they will embrace, so even catering to and abiding by these dictates for this type of knowledge is not effective. In Edmonton, we had an example of this as the decision to close one trauma unit (the city has two, one north and one south with a river and bridges separating the two) as a cost reduction maneuver was based on one piece of research that was later found to be fallible in its research design. There were also 15 other pieces of sound research found by Dr. Lynn Redfern (1997) that showed that two trauma units were needed in situations similar to the Edmonton one (Keynote Address, Margaret Scott Wright Research Day, March, 1997).

Mark (1995) warns against equating patient outcomes with effectiveness and quality of nursing care. She quotes Donabedian as saying, “Although outcomes might indicate good or bad care in

the aggregate, they do not give an insight into the nature and location of the deficiencies or strengths to which the outcome might be attributed" (p. 42).

Campbell (1988a) gets to the heart of the matter in saying that documentation systems (of which patient outcomes are one,) is "the production of appearances" (p. 34) where nursing does not deliver personalized care, rather nursing delivers *appearances*. And so, we return to what early theorists fought against, a more sophisticated form of "routines" and "tasks" externally ordered by management systems.

Mitchell (1994) is part of a discussion on care maps on *Nurse Net* (nursenet@utoronto.bitnet). She states that if critical care pathways are necessary to guard against people falling through the cracks of care, then a ALL disciplines need to be involved, the care map is a multi-professional issue.

...it seems that nursing assumes control for policing the practices of all other disciplines, as opposed to having a unique practice and contribution to make to the patient/family and thus to the health care team...nurses will not survive if all it manages is the *white space*, the space between all other health care professionals. We need to clarify our contribution to the person and explicate how we influence the patient's quality of life. (October 16, 1994)

### ***Documentation practice***

Campbell (1988a) cited above states that the required documentation systems for nursing care is "a new form of subordination, in which nurses' judgment about patient care is transformed for use in management decision-making in which neither the interests of nurses nor patients is paramount" (p. 31). In fact, Campbell warns against the trend to make nursing practice a *text* rather than a *relation*. She studies how documentation systems, i.e. patient classification systems based on needs.

The capacity of the nursing management system to make patients' needs for care fit constrained budgets is a feature of its documentary character. The documents stabilize or objectify patients' need for care, something which in real or experiential terms is not possible. The documenting of the quality takes precedence over the giving of actual high quality care. (p. 38)

In the classification of patients' needs as a tool to decide how much nursing care is needed enabling management to bring in the appropriate number of nurses to meet to documented systems calculation, the concept "needs" is cut loose from its determination by the mediating work of nurses and "in its documented form, it becomes adjustable to management's cost-constrained "realities" precisely because it is an abstraction" (p.39). What is most disturbing is the fact that the nurses contribute to this system of degrading nursing judgment.

The construction of an objective statement of needs to replace nurses' individual professional judgment requires that nurses participate, on a daily basis, in the documentary process of estimating and standardizing their patients' needs for care. (p. 36)

And more in terms of deskilling nurses:

When nurses are given only enough resources to meet the objectively defined needs, those are the only needs that can be met. To meet any other needs that nurses might recognize, nurses would have to act unofficially, that is, on unbudgeted time. Control exercised over the timing of nursing interactions works to narrow nurse-patient relationships to the "prescribed" tasks...The ruling

process relies both on using nurses' knowledge and, at the same time, sideplacing the authority of nurses' knowledge.

Carrying out the management of "quality of care" for instance, means that nurses so engaged must transfer their interest from practical nursing issues, as they previously understood them, to tasks relating to documenting and evaluating "quality." (p.47). And so here too an abstract, ideological system of nursing equating to the theoretical and research development above is generated.

Wolf (1989) states that nurses' actions such as when nurses "recognize individual qualities and needs, provide a reassuring presence, give information, assist with pain control, spend time, promote individual autonomy and demonstrates surveillance activities" (p. 463) are not "associated with improved patient outcomes in our research literature" (p. 463). Rather the research outcomes are preformulated as categories such as shorter hospital stay.

### *Skills practice*

Along with the technologizing of nursing practice comes the ability to replace nursing technologies with those other than nurses already discussed in chapter two. But it is important to include it here as well in the envelope of practice. Current health care terminology describes a strategy called multitasking. The multitasked worker is a person who, in theory, can perform tasks in more than one discipline (Hedrick, 1987; Blayney, 1986; Crissman & Jelsma, 1990). It is proposed by policy makers that nursing work (tasks) could be generic to a variety of health care workers. Generalizing skills to job specifications which up to the present were considered specialized skills, raises issues of competence and accountability in life critical situations.

Critics have warned that to relegate nursing to technical tasks, and then transfer the tasks to less prepared and less costly individuals is to deprive patients of competent health care (Prescott, 1993). It also restricts the nursing to mirror certain prescribed behaviours rather than to reflect the nurse's assessment of individual health care needs, and consequent choice of appropriate care. To reduce nursing to a set of tasks is to splinter, to dehumanize nursing care.

It seems that hospital organizations believe that they can understand work activities better if they can break them down into their components and measure them. But nursing care activities cannot be seen by breaking them down into component parts. In fact the result is to de-skill workers, not multitask them. To reduce nursing to tasks is to remove the nature of nursing from the activity.

So when we use a list of tasks/activities to capture the delivery of nursing care, it implies a unit of analysis that does not capture either the content or the context of the care provided. The activity cannot capture the knowledge embodied within the activities nor can it reflect the multiple other activities that may or may not be a part of that activity. Furthermore, the tasks/activities cannot capture the relevance of the activity which is contextbound and that affect "how" the activity is performed. (Rodger, 1991, p. 26)

Gulino (1982) states that "procedures and rituals tend to dull the nurse's perceptions of those she serves; institutionalized customs have become barriers to authentic communication" (p. 354). Clarke (1986) makes a strong statement about nursing practice as a series of tasks.

One could argue that an action for which the only explanation a nurse can give is that it is routine is no longer a responsible action, since neither has any reflection gone into the choice of that action nor has any reflection gone into the choice of explanation suited to the other parties involved in the nursing action. (p. 9)

Nurses have been unable to clearly articulate what they do. Nurses tend to undervalue and devalue what they do, so they don't list the decision making skills, the leadership skills, the relational skills they constantly use when asked to describe their work. Nurses know that it is through their unique relational and nursing practice skills that they determine what is best for a particular patient, yet it is difficult to speak about the importance of this aspect of their work in a way that administrators can understand.

Pyles and Stern (1983) describe the nursing Gestalt as "a matrix operation whereby nurses link together basic knowledge, past experiences, identifying cues presented by patients, and sensory clues including what nurses call 'gut feelings'" (p. 52). Gadow (1989) illustrates the knowing that comes from nursing practices especially well when she speaks about ethical decisions that nurses must make for silent patients, decisions to withdraw life support from the person.

Because advocacy involves learning to enter patients' worlds through embodiment, it requires infinitely personal devotion to the most mundane intimacies of physical care. This is not to propose that after bathing an unconscious patient, a nurse will know whether the person wants to refuse further treatment. It is to propose, however, that after many days of physical involvement, the nurse will slowly sense where the boundary lies between harm and benefit in the patient's world. (p. 540)

When trying to capture nursing, we must leave room for openness of meaning to allow for complexity to show itself. To remove nature of nursing from activity is serious ethical issue. The effects of multiskilling are just starting to come through in terms of increased morbidity and mortality rates (Prescott, 1993). What is this thing called nursing that we can't seem to show: we theorize about it, we borrow theory to explain it, we mystify it in language and concepts, we try to control it in management techniques, we make it task oriented or use ICU and videos to legitimize how technical we are and how knowledgeable we are, we understand other discipline's mandates, we humourize it, and it still defies us. The phenomenon changes even as it happens.

An understanding of practical nursing actions as 'psychomotor skills' does not take into account the 'invisible' aspects relevant to the practice of skilled nursing actions in natural settings. The nurse's intentions and self-belief, the organizational and social values pervading the clinical setting and the reactions of the patient are examples of 'invisible' factors mostly overlooked in this research. (Bjork, p. 10).

Skill has uniqueness. It is a response to a "unique situation...what you need in order to do your art and craft, getting things done with things" (Bjork, p. 10). Nurses look for the particular in the situation, nurses look for it, deskillingers do not. If you can't articulate the situation or answer questions about it, then you can't ask advice, seek wisdom and counsel (Flyvbjerg, 1991). In situations, you are always trying to bring about something; in nursing situations we try to bring about nurseness.

Instrumental rationality is thus defined as just trying to bring about ends as opposed to trying to decide what ends to bring about...(there is not) any rational way, in general, to detachedly find out what the right ends to bring about are, but only wisdom. (Flyvbjerg, p.106, Hubert Dreyfus speaking)

In practice we need to be attentive to the making of nursing rather than the capturing of it into certain modes such as nursing diagnostic labels, categories of patient classification systems. There can be a perversion of nursing when one fails to work things through. A patient knows

when a nurse has nursed and some patients wait for certain nurses to come along to ask for a specific thing because they know that nurse can make it come to be.

### ***Medical practice***

Much of our theory development in nursing had as an impetus to separate nursing as a discipline from medicine following the medical model of care, to show what was different, to cleave and cut in two these closely associated professions. One cannot dispute the effects of the medical model on health care planning (Allan & Hall, 1988); that medicine holds much power in our society, a profession of control that masks its agenda in the guise of caring (Foucault, 1965); that doctors (in the past and some to this day) treat nurses disparagingly in practice; that games are played between doctors and nurses where nurses advise and subtly manipulate doctors into making care and treatment decisions for the benefit of the patient but this fact cannot be acknowledged by doctors (Stein, 1967); that the salary scales are so enormously different for very similar practices (Smoyak, 1987); that some nursing associations believe that if we in nursing get to deliver more transfer medical functions (thereby leaving behind what is essentially nursing) we will become a more acknowledged and powerful profession. The power difference between medicine and nursing recently manifested itself. When the administrative committee to restructure health care decided to take registered nurses out of the operating room despite sound quantitative research studies to the contrary, voices were raised across the province of Alberta: nurses, nursing unions, our professional association. These bodies protested and presented sound, available research showing this act would be to the patient's detriment. The committee and the government of Alberta only rescinded this decision after medicine joined the protesters and spoke out for registered nurses.

Stein (1967) is a physician who describes the "doctor/nurse game." Here the physician "must seem in complete authority and the nurse must give direction deviously, indirectly, so that it appears to have been the physician's idea all along" (Heide, 1973, p. 826). Stein (1967) calls for both doctors and nurses to take steps to dispel the game which he calls institutional neurosis, inhibitory to open dialogue, and stifling to the growth of the intellect.

In truth, while there has been a proliferation of theories of nursing, nursing practice remains entrenched in the medical model of care. Norris (1982) explains the dependence of nursing on the medical model.

Nursing knowledge, because of nurses' close alliance with medicine, has been traditionally oriented to symptoms. Symptoms represent processes whose end products are failure of bodily systems unless there is medical intervention. It follows that much of the nursing assessment has arisen out of a process of identifying a problem and tracing it back into the medical model where it is considered from the point of view of failure of the human organism. Much of nursing intervention has emerged from attempts to assist in or complement medical intervention and to provide measures that reduce the discomfort caused by the pathology or medical treatment of it. (p. 157)

Yet if we step back and come at this from the point of view of practice, both professions are practices, the presenting question would not be to get out from under medical dictates as much as how to coordinate care to the benefit of the person, the family. Barker, Reynolds, and Ward (1995) ask what I think is an important question in this debate. "What makes a difference to the course of the patient's health needs or problems?" (p. 389). They state that "all who claim to offer 'health care' need to determine what (exactly) makes a difference; rather than demonstrate how one profession or another, possesses an hypothetical essential component of health care" (p. 389). Good communication between physicians and nurses is a variable that is predictive of a



good patient outcome. Poor doctor-nurse communication results in higher mortality rates (Prescott, 1993).

While it was not until the 1940's according to Smoyak (1987) that nurses began to challenge the established medical order of "nurses as subservient handmaidens, useful creatures as long as they kept to their proper place and did not challenge authority" (p. 35), it was the advent of technology that encouraged doctors to relinquish some of their control to nurses. Prior to this, there were not a lot of technologies, no antibiotics, no operating suites, etc and so nurses and doctors were more collegial. "They (doctors) could do little more than nurse their patients" (p. 35). Smoyak cites Garfield in stating that "around 75% of all health practitioners in 1900 were either doctors or nurses, and they were almost equal in number and in level of skill" (p. 35). Susan Smith (1995) states that during the world wide influenza epidemic of 1918, the people who survived did so because of the nursing care, not the medical care (personal communication).

Mitchell (1984), a physician, and Rowden (1984), a nurse, have a discussion about the nursing process. Mitchell, situated in Britain, believes that nursing process is an adopted transatlantic jargon and he deplors it in nursing practice. He questions its efficacy and cites that the jargon, the unnecessary complexity, the time requirement for assessment and documentation take nurses away from the patients. He suggests nurses escape the long check list of symptoms and such and just go and look at the patient.

Anything that takes nurses away from patients is to be deplored...The spectacle of a row of nurses beavering away at complex and irrelevant checklists fills me with gloom; the documents should be the servant of nursing care and not its master. (p. 32)

Rowden defends the nursing process stating that it moves nurses away from task allocated care.

The development of an overall view of the patient has always been the basis of sound medical practice. In reality, however, the average amount of time that doctors and other health care workers can give to each patient is limited. Nurses do have time to give to people faced with illness, disability or the prospect of death and are the only health workers in close and continuous contact with patients. This is what makes nursing unique. (p. 33)

It is a concern that doctors and nurses have drawn away from each other in practice. In reality, nursing and medicine are closely associated disciplines. It has not made the work of the nurse in practice easier, nor has it benefited the patient. In nursing education we as nurse educators must prepare the student to be acculturated in three paradigms, nursing theory, nursing gestalt as enacted in practice but poorly articulated, and nursing as operative within the medical model of care. Roberts (1983) quoting Kramer's research on reality shock pulls these thoughts together.

In discussing the difficulty of baccalaureate graduates working in hospital settings...it therefore becomes evident that there is an increasing disparity between the growing nursing culture and the medical culture, so much so that a person educated in one must be reacculturated to function in the other. (p. 28)

Mitchell (1984) laments the separation of medical and nursing practices and believes a fundamental error "is to presuppose that problems of daily living activities can be separated from diagnosis and treatment" (p. 29) and formulated in check lists.

In truth, the conflicts between doctors and nurses evolve mostly because of administrative rules and regulations within the institution. And in addition, what is becoming a common theme here, a lack of resources in practice also escalates these conflicts. Doering ((1992) believes that the

uneasy alliance of medicine and nursing has limited nursing's knowledge development. I would concur and state that in an attempt to move away from the medical model of care, nurse theorists as seen above, also moved away from practice as lived, and so threw out the positive interactions with physicians as well.

It is a fact of nursing practice that nurses enable others to do their work. But inherent in the enabling is the fact that the nurse also coordinates what she assesses to be necessary for a person's regime of care. Jacques (1993) sat on nursing units and observed nurses aiding other professions to do their work. He observed what he called 'connecting activities' of the nurse.

Such activities occurred 87 times per day, an average of once every 6 minutes! In post-observation interviews, the nurses - who had been very articulate about other aspects of their work - had little to say about this role. It was not something they spoke of when asked to describe their work. However, despite the fact that this role was taken for granted both by those who perform it and those who benefit from it, all workers on that unit, physician, social worker, technician, therapist, or maintenance worker, were routinely aided in the performance of their work by a network of nursing communication that: scans the environment, selects the information appropriate for the various workers, delivers this information to the recipients, who can concentrate on their specialized work, confident that such knowledge will just appear when needed.

Nursing and medicine need to humbly come together again. It is time to stop differentiating, splitting hairs over what is essential to each practice. In this time of restructuring health care, in unsafe patient practices, in working with a lack of resources, nurses and doctors are slowly engaging in dialogue to the benefit of both.

### ***Professional practice***

This analysis cannot come to a close without acknowledging a group of nurse activists and authors who endeavored to improve the practice of nursing through activism. The identifying features of these individuals is that they stayed *close to practice* and that they endeavored *to better the situations* of their patients and families (Cameron, 1991).

It is worthwhile here to look at a part of nursing's history in the late 19th and early 20th century for a moment. Poslusny (1989) asserts that "nurses were the first group of professional women to organize and form professional associations, to publish a professional journal and to establish a federation of health care professionals at the international level" (p. 64). The public health movement, of which "district nursing" was a central part, fought against poverty and disease. These nurses worked with extremely disadvantaged people from the working poor and the immigrant population. Working with the poor, with women and children in extreme poverty, led them into the political domain. Lavinia Lloyd Dock, Lilian Wald and Jane Adams all championed for not only women's rights but also for political reforms that would free people from oppression and disease. These women realized that in order for poverty and poor health to be addressed, they must be social activists. Emancipation must occur for all marginalized people (Roberts, 1956; Poslusny, 1989). These women became suffragettes.

Lavinia Dock states that it was while working with these disadvantaged people that "I really began to think" (Roberts, 1956, p. 177), and that she conceptualized a "world public health movement which would emphasize prevention" (Roberts, p. 177). She challenged the nursing professional association, the Superintendents of Nursing (early forerunner of the American Association of Nurses) in 1903. She stated at that time:

This society...has not done what it might do; has not made itself a moral force; is not a public conscience; takes no position on large public questions; is not feared by those of low standards;...Yet this society, as one body, would often be astonished at the actual extent and weight of its influence if its whole latent and at present unsuspected power were actually to be systematically exerted in an intelligent and energetic manner. (Dock quoted in Poslusny, 1989, p. 66).

The American Association of Nurses (ANA) “declined to endorse women's suffrage until 1915, although the struggle for the vote for women had been going on for 40 years before that” (Bunting & Campbell 1990, p. 19). The ANA chose the quest for professionalism instead and believed that as a professional organization, they wished to remain neutral. “Faced with a choice between feminist ideals and nurturing of the threatened infant nursing profession, many nursing leaders rejected feminism and chose professionalism” (Bunting & Campbell, p. 19). Dock replied to this with “my abounding discouragement that our ANA actually voted opposition to the equality amendment on which women of all nations are pinning their hopes” (Roberts, 1956, p. 178). Articulation of nursing practice to a “dominant male profession (medicine) and the stigma associated with female work and femininity (home and family)” (Campbell, 1988b, p. 57) are the two elements that professional associations wished to end. It was thought that making the profession discourse based, articulating concepts with judgments, linking in a formal way thoughts and actions, would make an independent practitioner of nursing. But just like the student at the beginning of the chapter, “nurses “must now be able and willing to reinterpret their experience to make it fit conceptual forms which are ‘accountable’” (p. 59).

It is a sad irony that Lavinia Dock and other public health nurses, who recognized that woman's rights went hand in hand with equal rights for social class and race, who were ahead of their time by advocating disease prevention, and who were extremely successful in turning the tide of ill health and disease within these communities with nursing care measures, were not supported by their professional association. The irony or paradox is the failure of the professional association to recognize that these nurses's specific body of knowledge development would have assisted their goal of professionalization.

By isolating a body of knowledge in the area of health promotion and disease prevention...public health nurses at the turn of the century more closely approached professional status than have any other nurses. However, as medicine expanded the boundaries of its expertise to encompass all health-related areas, public health nurses sacrificed their claim to specialized expertise and forfeited the relative autonomy they exercised over their practice. (Hughes, 1990, p. 29)

Meleis (1991) too suggests that Nightingale's followers:

failed to continue to differentiate the focus and goals of nursing and medicine and failed to further Nightingale's theorization of nursing. Somehow the medical domain of practice, better developed and more powerful, replaced what was starting to become a nursing domain of practice (health: hygiene, environment, and care). (p. 156)

We now experience a repeating theme in nursing's history. As nursing leaders distanced themselves from the practices of nursing and from the recipients of nursing care, in short, the *practices* of the profession, early leaders also abandoned effectual knowledge development for a practice discipline. Hughes (1990) also believes that the nursing associations failed to recognize a significant point. Because nursing at that time was equated with domesticity, societal values would make it even more difficult to establish nursing as a profession. Hughes (1990) explains:

If women were given responsibility for the moral and aesthetic environment of the home, then nurses were given no less responsibility for the moral and aesthetic environment of the hospital. If the needs and comfort of husbands and children were women's primary responsibility, then the needs and comforts of physicians and patients were nurses' primary responsibility. If women possessed innate qualifications for their domestic role, then nurses clearly possessed innate qualifications for their occupational role. The paternalistic arguments that stymied the development of nursing as a profession...drew their strength from the ideology of domesticity. (p. 28-29).

Ashley (1975) notes that "second class citizenship brought second-class professionalism as well" (p. 1466) and nurses by not advocating more the health and care needs of their patients continued to parallel the medical profession as handmaidens to their purposes. During the time of Lavinia Dock's efforts, there was the prologue to and then the events of World War I. Beeber (1990) has something to say about nurses in hospital practice at the time. While they were restricted at home in what they could do, they were not restricted on the battlefield. Beeber writes of nurses' accounts of horrific body wounds and severe mental disorientation from primitive war machinery, of the effects of mustard gas and other forms of inhaled lethal substances as a grim reality. Recruitment in the United States had focused on Nightingale in the Crimea going amongst her cots with her lamp.

It is interesting to note that nurses who served in the World War I experienced an immediate and demanding call to independent practice without the presence of doctors or hospital bureaucracies. Accounts from the diaries of nurses state that "confronted with overwhelming suffering and awesome responsibility, nurses abandoned their customary obedience to authority and assumed independence in judgment" (Beeber, 1990, p. 39).

One of these nurses, L. Herrick, RN, quoted in an interview that "the experience made me different from nurses, and from other women I knew...so different that when I returned, for a long time I felt lost - I didn't fit in anymore" (Beeber, 1990, p. 37). She emphasized "how the experience had changed her, and how difficult it was for her to resume her nursing practice when she returned because the nurse was restricted from making even the simplest decision" (p. 37).

Our early nursing leaders engaging in the drive to professionalization inadvertently began to present nursing in terms of tasks. They followed requests from hospital management to list in the form of tasks what it is that nursing does. The Goldmark Report in 1923 then advocated moving nursing to the university system, but also called for the creation of a new grade of subsidiary nurse.

In an effort to differentiate professional nurses from these sub-nurses, nursing leaders unwittingly contributed to the stratification of nurses. In applying principles of scientific management they cooperated with hospitals to break down nursing tasks and assign them to the most inexpensive worker available...What nursing leaders thought would enhance their professional status ultimately enhanced hospital control. (Leroy, 1986, p. 30)

In the 1970's and in the early 1990's, nurse managers again sought to break nursing down into a series of tasks for the hospital management teams. This literature appears in the writings of nurse feminists following the three waves of feminist activity, the first being the campaigning for women's rights (Roberts, 1956), the second being the radical reforms of feminists of the 1960's (Cleland, 1971; Roberts & Group, 1973). Some believe we are in a third wave of feminism in the 1990's. Cleland (1971) blasts nursing administrators for perpetuating potentially unsafe nursing

practice areas by acquiescing to hospital policy makers rather than defending and advocating good nursing practice. "These leaders have risked the lives of patients rather than take forceful, public stands to insist on the closing of improperly staffed areas" (p. 1545).

Choosing inaction in the political arena is the same as choosing action according to MacPherson (1987). MacPherson charges that health care policy formation and subsequently nursing's theory development following in its wake supports "the dominant American values of individualism, competition, and inequality" (p. 5). Nursing as a profession in her view has not served nursing or the people well, two of nursing's metaparadigm concepts. She states that we must move toward the "more humane values of collectivism, cooperation, and equality" (p. 5). MacPherson is critical of nurses and Nursing Associations in the United States for not speaking out against health care policy changes such as discharging patients too early from hospital.

In 1989, MacPherson continues this critique and calls for nurses to make health care policy a central concern of the nursing profession, to separate health care policy from politics and economics, and for increased social activism. She rages against the number of individuals who are without health care in the United States and writes of poverty as a determinate of poor health. MacPherson believes that nursing will not be taken seriously as a discipline until it engages in the "hard" work of working toward political action for health. "It is therefore important to recognize the degree to which the formation of economic structures impinges upon the possibilities of nursing actions" (Porter & Ryan, 1996, p. 419).

Campbell (1988a) states that one of the rewards of being a professional is that of "the continued capacity to exercise professional knowledge in the workplace" and that nurses's judgments, because of documentation systems, are made to appear consistent with management interests. Moreover, nurses begin to or are led to believe that compliance is the same as professional accountability.

Nurses'...loss of discretion over their use of time, routinization and standardization of clinical decision-making, and bypassing of professional judgment about quality represent important erosion of traditional professionalism. It is in such practices that de-skilling occurs, and de-skilling of some nurses seems inevitable. (p. 48).

Authors such as Liaschenko (1995) call us to authenticity and ethical nursing practice amidst the competing tensions of the day. "If nurses are to act for patients in a way that preserves the integrity of the patients' lives, the nurses must pause at exactly those times that most call forth a routinized response. (p. 10). Parker (1990) cites Millette's dissertation findings that "nurses who refuse to give up a caring orientation were more likely to leave the profession than nurses with a justice orientation (based on a principled ethic)" (p. 36). In addition, nurses who were consistently unable to enact their discipline in a "manner congruent with their conscience...become moral schizophrenics" (Millette cited in Parker, p. 37).

### *The theory-practice gap*

In 1987, Canadian Nurse Association (CNA), called for nursing practice to utilize a conceptual model as a basis for practice and the effective use of the nursing process. In 1991, the Alberta Association of Registered Nursing (AARN) also recommended the use of a conceptual model to guide nursing assessments and nursing diagnoses resulting in the development of a nursing care plan. The implementation of these nursing models or nursing theories in nursing practice has been fraught with difficulties. Theorists who have constructed the nursing theories often do not have enough knowledge of practice to assist practitioners to operationalize their theory and rely on the practitioners to determine how to incorporate them into their practice. Research on nursing

theories also has not shown itself to be prescriptive as to how to adapt the findings to specific nursing units. Practicing nurses find it difficult to understand the theories and the sometimes obscure language used in the theories and research findings. And so in an attempt to abide by the dictates of the professional associations, some nursing education and practice venues simply instituted the language and labels of the theory in a charting protocol. For example, the preset charting titles would include "adaptation" concepts if they were incorporating Roy's adaptation model. Or nursing educators decide where to subsume certain content within the categories suggested by the nursing theory. I remember how much discussion we as a faculty had over which category to include diagnostic tests such as blood tests within the Orem model of self care. We ended up putting them under the self-care requisite of "air."

Nursing practice as the place to apply theory has long suffered through the various styles of implementing the nursing theories with existing nursing practices. It results in what some call the theory-practice gap (Clarke, 1986). To review, as theorists became more sophisticated in theorizing and in research development, they drew further away from the nurse and the person and family in nursing practice. While theorists thought they were accomplishing more with the drive to have a practice theory with predictive outcomes and as they utilized cognitive systems to cover all aspects of being human and nursing, as we saw above, they were in fact representing nursing practice with theory as the discipline. The *represented* becomes the norm of the discipline but the actual reality of practice is still with us. Theory and research production were formulated without a view of nursing practice as an entity and many theoretical findings did not fit practice very well because practice as an entity was not well understood.

As a result and not surprisingly, nursing has abundant literature that bemoans the theory-practice gap. Cook (1991) deplores that fact that nurses do not implement theory in their practice, that many tasks in practice are at the level of routine functions with no thought going into them. Scott (1994) and Kenny (1993) believe that existing theory does not address practice, that nursing models do not have utility in nursing practice. Allmark (1995) states that nurse theorists have not understood the classical view of theory. They falsely claim that nursing theory is also science and that practice can be represented by theory.

The preponderance of difficult language, an integral part of nursing theories proves daunting for practicing nurses. Levine (1995) summarizes this difficulty with language and also adds to statements above that theorizing in nursing has a penchant for distancing itself from nursing practice; sad insights for a practice profession.

...Too often the language of theory introduces another set of terms that have little relevance in the workplace. Added to the already considerable burden of imprecision in the language of nursing, the introduction of new words that are unfamiliar and not easily related to nursing activities legislates against the use of theory by the practicing nurses. Theoretical language cannot be simply superimposed on a clinical environment. (Levine, p. 12)

Kenny (1993) states that nursing models have never been "truly employed in the delivery of client care" (p. 133). He cites as a reason for this that these models are based on assumptions with which the nurse and patient do not concur and that many of the inherent aspects of the model are poorly understood by nursing's practitioners. Allmark (1995) agrees and states that nurses in practice often don't have the knowledge of the theory on which the theorists have based their models and this also adds to their suspicion of the utility of models in practice. Kenny states a common occurrence, that even if a model is implemented in practice it is difficult to sustain it. Kenny goes further and states that theories or models or whatever they are called, should take their direction from nursing practice. He quotes McFarlane who writes that "nursing is a

practice-based discipline and if innovative ideas do not spring from practice then there will inevitably be an unreality about them and a lack of utility" (p. 134). Mayberry (1991) states that staff nurses become frustrated and distressed when nursing administrators introduce conceptual models into nursing practice. Nurses have difficulties with the language level, with understanding theoretical underpinnings of the model, with working within the new organizational structure dictated by the model.

Rafferty, Allcock, and Lathlean (1996) state that the irony of the theory/practice gap is that "it may itself be the victim of nursing's academic success" (p. 687). Cooke states that this gap is "the result of post-industrial class structure, in that while this structure is enabling for academics it is constraining for practitioners" (cited in Porter & Ryan, p. 416). Porter and Ryan (1996) found that there is not sufficient resources available to bridge the theory-practice gap.

The autonomy that academics enjoy has led them to underestimate the constraints upon practical nursing activities and this has coloured their pronouncements. For nursing theory to be adequate, it must take cognizance of the uncomfortable realities that lie beyond the narrow confines of pristine models. Theorists' predominantly uncritical approaches have had the effect (albeit unintentionally) of helping to maintain social structures which generate constraints upon the operationalization of their own theories. (Porter & Ryan, 1996, p. 419)

MacDonald and Miller-Grolla (1995) developed in consultation with nurse theorists, Madeleine Leininger and others, a culture specific nurse caring practice model for hospitals. This model was implemented in a nursing practice area and is ongoing. While the authors state that caring practices are the fountainhead of this theory, the acceptance and utility of the model in practice is unstated. Best, Maslak, Thurston and Wild (1994) implemented a self care framework along with Gordon's (1987, 1991) functional health patterns and nursing diagnostic taxonomy in selected nursing practice areas. These authors believe that "clinical decision making is the heart of professional nursing, providing life to the nursing process by connecting assessment, diagnosis, intervention and evaluation" (p. 17). The implementation of this framework was done in phases with ongoing teaching and discussion of pertinent aspects of the model. The authors do not state whether or not there was an improvement in patient care, in nurse satisfaction, or issues of compliance. They do, however, conclude that enormous effect is required to operationalize conceptual theories and that a step by step process in implementation requires energy, resources, and support from all levels of administration within the institution.

Gillette (1996) has written that perioperative nurses in the operating room show caring in their practices no matter how task centred their functions are. Gillette (1996) shows how the writings of theorists Nightingale, Henderson, and Montgomery can be applied to existing practices in the operating room. McNamara (1995) studied how caring practices according to Watson (1985) were practiced in the operating room. It is interesting to speculate that theory on caring as a focus of operating room nurses might be a response to criticism from others that operating room nurses don't care. Perhaps it is an outcome of making "caring" the essence of nursing.

Nurse educators struggle daily with knowledge of theory, with the realities of practice, and how to represent these to their students (Graham, 1995). Some believe that a way of bridging the theory-practice gap is one of encouraging reflective practice, reflective praxis based on Schon's (1987) reflective practitioner tenets (Johns, 1996a, 1996b; Hopton 1996; Waterworth, 1995; Burrows, 1995; Graham, 1995). Sarvimaki (1994) states that reflective practice will clarify the role of practical and theoretical knowledge in nursing. Davies (1995) found the most important result of encouraging reflective practice in nursing to bridge the theory-practice gap was that of "the emergence of the client as the central focus" (p. 174). Rolfe (1993), Rafferty, Allcock, and

Lathlean (1996) state that students should be told these debates about theory, research, and practice upfront and encouraged to discuss them. And they warn that there is a danger with reflective practice that it will “encourage introspection at the expense of more outward-looking and political analyses of nursing problems” (p. 689). And they say to reframe thinking, the gap can be “considered a metaphor for the failure of nurse education to fulfill the expectations held by different interest groups” (p. 689)

Conceptualizing the theory/practice gap as simply the failure of transmission, assumes that we know *which* theory should inform *which* practice, and underestimates the enormous complexity of the implementation process. Accepting the theory/practice gap as traditionally conceived assumes that we know where the boundaries between the two begin and end. (p. 689)

Is there also much more to this debate, something that underlies it all? Rafferty et al (1996) state that the tension in nursing education to present theory, research, and practice obscures the necessity for taking into account the “political factors which prevent nurses from advancing and elaborating nursing practice” (p. 686). They believe students need to be aware of political structures and how these affect nursing practice. Porter and Ryan (1996) believe that the theory practice gap perpetuates itself because nurses in practice do not enjoy the resources needed to implement nursing theory in practice. Best et al (1994) and MacDonald and Miller-Grolla (1995) attest to the need of sufficient resources to implement and sustain a model in practice.

Nurses in academia have benefited from their own theorizing and that of others, while those in practice have not had such luxuries (Rafferty et al, 1996). Those in practice remain entrenched in and tossed about at the will of agencies and institutions whose mandate is toward cost reduction not care. One is reminded here of those who write that the feminist movement has benefited middle class white women, not women in poverty, women of colour, or women with handicaps (Collins, 1990). Perhaps we as a profession that is 97% women have done the same. We have empowered some and disempowered others. Have we developed an underclass in nursing, the underclass being those nurses in active practice? Again we see irony but more now, peril. Nursing is a practice. We abandon the practice at our peril. Abandoning practice leaves practice open then for wolves to impinge upon it with mechanistic tools.

What is true, and mentioned above and experienced in the participants in this study, is that if anything affects nursing practice profoundly, and we speak of both nurses and patients/families, it is one of lack of resources and political and economic changes forcing tools on the practice. Political structures influence how nurses practice nursing. Yet the majority of nurses will “break their backs before they compromise care” (Schindul-Rothschild, (1995).

William Mahan (1994) contributes to a discussion list on Nurse Net.

When you are working on the floor (practice) and each year a new nursing model comes out, which your supervisors embrace then demand that you learn that new model, it causes a great deal of animosity toward the “elders”...what I call for is that before someone races to print their latest and greatest, we truly need a *peer review process* and yes, this would include 2 and 4 year graduates in nursing...(October 20, 1994)

Carper (1978) is credited with calling nursing back from intense theorizing to a focus on the nurse acting in practice. She describes four ways of knowing in nursing, now a classic writing in nursing literature. Empirical knowing is factual, descriptive, and generalizable. Esthetic knowing is the art of nursing and involves the “active transformation of the patient’s behaviour into a perception of what is significant in it - that is, what need is being expressed by the



behaviour” (p. 17). Personal knowledge “is concerned with the knowing, encountering and actualizing of the concrete, individual self” (p. 18). Ethical knowing is the “knowledge of morality (that) goes beyond simply knowing the norms or ethical codes of the discipline. It includes all voluntary actions that are deliberate and subject to the judgment of right and wrong - including judgments of moral value in relation to motives, intentions and traits of character” (p. 20).

Boykin and Schoenhofer (1991) believe that the use of story to describe nursing situations links knowledge and practice in a way that cannot be done with theorizing. They refer to Carper’s four patterns of knowing as pathways to understand and transmit nursing knowledge through the concept of the nursing situation. They speak of alternating rhythms in stories that allow students of nursing to move among empirical bases of knowledge to development, to nursing systems, to research for the situation.

In fact, it is surprising that stories, nursing situations, are recognized by a nurse theorist as significant not until the early 1980’s. Benner (1984) was the first nurse theorist to use stories extracted from actual nursing practice situations. She calls these clinical exemplars as they each capture an essential part of nursing. She encourages nurses to collect clinical exemplars. Harvey and Tveit (1994) take the notion of exemplars a bit further and demonstrate how the use of exemplars can help to identify skill acquisition in nursing.

One must be careful with stories. Narratives most often need interpretation to identify salient points. And sometimes nurse theorists after retrieving a story will apply an alien framework on top of it. For example, while Benner (1984) described skill development in nursing practice using the Dreyfus model of skill acquisition, she did not describe in depth the nuances of nursing interventions in the nursing arena. While the Dreyfus model shows how the person mentally and intuitively “attacks a task on different levels, how the practical aspects, the ‘hands-on’ skills of nursing, are in fact developed is not considered” (Bjork, p. 11).

Telling stories allows an individual to present or represent some part of their lived life. The story can never be the same as the happening and the more one tells a story, the more easily it becomes a sort of *spiel*. “Moreover, these representations do not simply represent, but rather (re)construct lives in every act of telling from at the very least, the outcome of any one telling is necessarily a re-telling” (Sandelowski, 1991, p. 163). Stories must be monitored.

Parker (1990) states that the “values essential to the moral foundation of nursing cannot be extracted from any abstract or decontextualized moral theory” (p. 34). Baer et al (1996) state that management systems have not been successful in unraveling the tapestry of nursing, unable to grasp the complex interweaving of skills, knowledge, patient assessment and judgment. Baker and Diekelmann (1994) state that we as nurses begin our care for individuals in listening to the storied nature of their lived experience. People “live narratively and that it is the storied nature of our existence that sets up the possibility for one of us to dwell within the lived experience of another” (p. 67).

### **Conclusion: Beyond the theory-research-practice (re)presentational dilemma**

In this chapter I have aimed to document how the knowledge base of nursing expresses an ongoing tension between representational and presentational forms. The more the knowledge base tips towards re-presentational forms the more it tends to lose contact with what is present in lived practice. I have suggested that the representational forms, in which nursing knowledge is cast, resemble envelopes - theory, research, and models of practice are the envelopes that contain the literate traditions that make up nursing wisdom. The problem is that some envelopes are

nearly empty and others contain little of the lived meaning that still relates to the experiential reality of the recipients of the envelopes. There is no osmosis between them; diffusion neither.

While the existing knowledge forms of nursing offer various mixes of the ingredients of representation and presentation, it seems that all fall short in various degrees of the kinds of knowledge that can speak to our embodied understanding. The challenge of this study is to attempt to find linguistic means of direct description that retain as much as possible the vibrancy of the actual experience of nursing. The hope is that more presentational forms of nursing knowledge will contribute more directly to our embodied knowledge since it aims to inform practice not only technically but also expressively, not only gnostically but also pathically (van Manen, 1995). In this way, I hope to contribute to a better balance between the intellectualized forms of knowledge that serve primarily the more technical (cognitive) aspects of nursing and the felt (non-cognitive) forms of knowledge that may lie more at the very heart of nursing as a human caring-healing practice.

In the next chapter, I discuss direct description of nursing as a way of presenting and interpreting nursing as lived, and how hermeneutic phenomenological inquiry lends itself to this particular mode of inquiry in researching a practice profession.

## CHAPTER 4: DIRECT DESCRIPTION AS A METHODOLOGICAL WAY TO UNDERSTAND NURSING AND ITS PRACTICES

*The humanistic sciences, in contrast, indeed all the sciences concerned with life, must necessarily be inexact just in order to remain rigorous. (Heidegger, 1977b, p. 120).*

Taking our clue from the gist of the bath in Chapter two where nursing can be argued and/or presented, keeping in mind the themes in the discourse of nursing in Chapter three, and of course the research question, it is clear to see that nurses experience a tension between being merely bodies, tasks, documentations (representation), and being part of a profession that enacts lived expressions of human caring-healing practices (presentation). Researchers of nursing practice too live this same tension referred to in the opening paragraph of the chapter. So the only thing to do is what many nurses do: nurse from one's own critical professional gestalt of nursing when in direct contact with patients and families, and negotiate in earnest a way through the fabricated and mandated mechanisms of nursing away from the patient/family. The lived-truth, lived-tension of nursing is that patients, families are ever before us. They are there before we even assume responsibility for them (Levinas, 1985). Such is the lifeworld of nursing.

As I listen to those who disparage nursing practice I always become greatly uncomfortable as I do when a fundamental morality is in question. We discredit our practitioners at our peril. When I am with nurses in practice I am taken-a-back as an educator as to how very complex and synthesized nurses' actions are. And yet the nurses are blissfully unaware of this demonstrated intricacy, the dialectical manner inherent in their acts.

So the question of nursing for me in this chapter is to describe how to bring nursing-as-lived to life in a text format. My own experiences of living the nursing question figure prominently here and throughout the dissertation. This history of myself is integral to understanding the array of things, the matrix if you will, on which the study is built. A nurse always operationalizes nursing from the person of herself, the relationality of oneself to others. Direct descriptive research calls for the same. To begin, I will track the path of the study. Second I will show some similarities between hermeneutic phenomenology and nursing living its tensions. Third I will describe research in the lifeworld of nursing, and conclude with salient points that apply to the notion of direct description of nursing practices. "As soon as we have the thing before our eyes, and in our hearts an ear for the word, thinking prospers" (Heidegger, 1971a, p. 5).

### Researching Nursing as Expressed in its Practices: The Path of the Study

My doctoral work began with reading and writing and engaging in academic discourse. While nursing, the teaching and practice of it, was central to my program, learning and understanding the development of other human centred disciplines and research traditions was a priority. I sought a tradition of inquiry that would not distort, add to, or fabricate nursing as practiced. I found that tradition in hermeneutic phenomenology in the nature of van Manen's (1990) interpretation of it. Van Manen encourages writing and indeed writing and re-writing are central to the tenets of hermeneutic phenomenology. Writing is the path to presenting the phenomena in question and to interpretively understand the generated text. I began writing about nursing experiences directly culled from practice. In the beginning it seemed these pieces were trivial and inane, and regardless of how often in these early stages they were re-written, still turned out the same. I began to understand how administrators can disparage nursing acts when they are written. Presenting them as lived needs presentation and interpretation. Listing them as steps shows nothing.

It was then I realized that it is a special way of writing, a special way of presenting something enacted before your eyes. With persistence and more careful observing and participating, the

writing began to take on more meaning; the language became more apt, more focused. The lived descriptions did not seem so inconsequential now. I gained courage in showing things in the situation that remain hidden in nursing.

Near the beginning of the study I observed two physicians taking a bone marrow sample from an individual's hip, a painful and fearful procedure. One I saw done with such expertise that I thought, "this is excellence to make a procedure like this so livable." The second was not so and lived suffering ensued. Why is it important to mention this here as we study nursing not medicine? Not certain. It is something to do with the lived nature of invasive procedures. I could have described the second procedure step by step to an administrator's delight to copy and put in a procedure manual and designate a cheaper worker to do it. But the step by step one did not do the job. It did not even extract enough bone marrow for laboratory examination. It had no inherent expertise. To write up the first one was difficult because I had to capture the nuances of it, the expertise of it along with the procedural-ness of it; what made it livable. Learning to write in this way takes time. (I'm happy to say the repeat second one was done by the first physician.)

This sort of writing parallels in some ways the age-old practice of a nurse charting, writing her nursing notes, that moment in the day where the nurse sits and records her nursing of a patient. It is a re-collection of that person and that person's needs, a re-collection of how the nurse met these needs, what she learned from the interaction, why she will need to change something, where she will communicate this to others to ensure continuous care. When I imagined myself doing this, writing with insight came to life. As mentioned in Chapter Three, tick charting and charting by exception have replaced most of our narrative charting in nursing, replacing it with contrived categories of care, not all categories essential to the person's lived nursing. Gadamer (1992) writes that "writing is my secondary form of self-presentation" (p. 65). The writing of the nurse's records shows as much about her as it does the patient; what she leaves out, what she includes. Nursing as practiced is forever bound to interpretive thinking as one decides what is best for an individual. Moreover it is bound to mutuality in the moment where what is most essential to healing, to life, to death is drawn out of both nurse and patient, family. It is drawn out in relation.

Human phenomena are not primarily substantial, but relational. The phenomena doesn't end at the skin but in the world, as far as the meanings being bestowed by a person can stretch according to interests, goals, modalities and possibilities. (Giorgi, 1992, p. 215, 216)

During this time of reading and writing, I found myself lured by other discourses and their ability to explain, to be insightful, to seem so coherent in their posturings. The temptation to incorporate or add layers of their discourse to nursing as practiced was immense. Yet I resisted the temptation to do so. Just as a nurse who keeps starting over again to see what piece she has missed with this person's nursing, I kept coming back to the nursing situation itself; back to the beginning and the question of nursing. The philosophical discourse, its probing into the nature of being, the nature of knowledge and its integral relation to questioning, to thinking, became essential to the study along with lived accounts of nursing situations.

As the dissertation proposal came to form and was defended, the ethics proposal presented some initial hesitancy on the part of the agency where ethical clearance was requested. There were two things operative here: the first was the question as to how knowledge could be generated from a study that was not a clinical trial or a quantitative or structured qualitative method and that the presence of myself as researcher would skew the findings; the second was the concern that the study had potential to show that registered nurses were needed to enact certain nursing procedures. This brought the political to life.

Our vulnerability as members of the nursing profession was apparent here. Those in authority did not want research to demonstrate the effectiveness and the needfulness of nurses doing nursing acts. This became data for the study. While the above two objections to the study were not ever totally resolved, further discussion, slight modifications of the research plan, and the presence of patients on the ethics committee who wanted the study for its potential to show the essentialness of nursing to cancer care, meant that the study was allowed to go ahead. When my study was presented to the Head Nurse of the nursing units, she immediately said yes to it because I would be directly with nurses as nurses nursed. Nothing would be contrived or added and she liked that.

The study on-site began with my going to the regularly scheduled staff ward meetings to explain the study. The first day on the unit, I was assigned to a nurse who had earlier agreed to take part of in the study, had read and signed the consent. I shadowed her. I buddied with her. I accompanied her as she went about her day and at a later time scheduled an audio-taped interview. While the audio-taped interviews were deemed to be important to the validity of the study, in truth, more truthful conversations happened in hallways, at coffee time, arriving and leaving the unit. It was the same with the patients and families. I was with many patients and families and recorded all of it in care-ful observational and participational notes. Where the health of the person permitted, I audio-taped our interviews, sometimes with the flat microphone lying on the pillow of the person's bed. But again, more sincere interactions often happened while observing nursing, while participating in nursing, while discussing nursing right after it happened with patients, families, nurses, and others in the multidisciplinary team. It was during these times of directness with individuals that I could really see how these individuals dealt with the realities of their lives, of their situations. The study was lived very much in the moment.

As the study progressed and intersected with whatever was going on in the unit, often a group of nurses would discuss nursing around the coffee table, the report table, at spontaneous moments throughout the day as something happened and I would question it. Or when something-as-lived on the unit was being discussed and resolved by the nurses. The nurses were familiar with the research question and would bring forward certain things for discussion. The same happened with patients as they sat in groups waiting for treatments, as they participated in support groups for patients, as they endured their treatments, as they were often very very ill. Sometimes they would just come up with something they wanted to tell me. During the study I would diligently try to never interrupt or be intrusive or put them on the spot. Never did the needs of the study take precedence over the needs of patients and nurses. I admit to being frustrated sometimes with how long it took to get to the audio-taped interview format as a requirement of the science and reliability of the study. But I knew too that this was also data for the study. Nurses and patients wanted to show me, wanted me to see without having to bring to words what was going on with them. It is not easy for nurses and patients to have extra people around and yet their very graciousness with the study lives with me still. While this felt intrusiveness inside myself seemed like I was "putting myself upon them", in the actual reality, the nurses and patients just got on with things. The difference the nurses told me, was that I was with them in their pursuits; not them with me in my researcher pursuits.

When nurses meet they tell each other the events of the day. During my shared time with nurses in this study, they described and conjectured, retrieved knowledge systems, sought new knowledge, remembered experiences and just about always, solved the patient or family problem at hand. In fact, they "theorized" in the moment, at coffee, at the nurses' desk, leaving and returning to work. The theorizing ran the gamut of knowledge, Dickoff et al (1968a,b) and their hierarchical knowledge system would be proud of them. One nurse told a story of recognizing low calcium levels in patients because of an experience with one patient. Within the story she linked symptomatology with pathophysiology with nursing phenomena and then all of that to

certain early behavioural characteristics in the nursing moment. A sort of epistemology of practice evolves: an interweaving of strands that are simultaneously theoretical and practical but put together in a *nursing* way; a nursing re-cognition system.

I always made an effort to get out of the way in very private emotional moments. Yet other times, I did not. For this alone, the study gained respect. If I would take time to analyze when I stayed and when I left, it would be cumbersome and wordy. But suffice to say, I had an sense of rightness within myself. It was very much an intuitive judgment call; "intuition...implies that subject and object are present to each other on the same level" (Kockelmans 1976, p. 30). To state it briefly here but recorded in detail in my researcher's journal, I would summarize the intuitive knowing as recognizing the difference between intimacy and privacy in the moment. In intimate nursing moments, bodily, emotionally, spiritually, intellectually, I stayed and was part of it. In private moments where the person or the nurse sought seclusion or a particular interaction with someone, I left. I could read the situation. Intimacy is a shared human experience. Privacy is one of "being oneself among others, in one's own room, at one's window, with one's own property, one's own purse, and one's own faults" (van Manen & Levering, 1996, p. 117).

Well into the study, I was often called by a nurse to come with her, for me to take part in something. The same happened for patients undergoing various things or just to have a chat about something. I tried to consciously not misconstrue things for science sake, such as "Ah the nurse does or does not use research data for practice"; for embellishment sake, "Ah the nurse advocates"; for recognition, "Ah this will show knowledge and power relations"; for justification, "Ah that's just the doctor/nurse game" while the temptation to do so was often so palpable it hurt. But to make myself totally without a discourse base was not truthful either. And so I wrote. I would write the ambiguities, write what I saw and thought and then decided if I described the experience or applied something else to it. I always seemed short of understanding something; as if it just eluded my grasp and to this day, feel the same. The closer to the thing I got, the further it seemed away. But in this way, I lived the life of the nurse and patient somehow juxtaposed in my body, in my heart.

Recording all of the above became one of the most difficult parts of the study. Spending from 8 to 12 hours a day on the unit sapped my energy immensely. This was also data. It is different from being a nurse and yet not so different. It seemed when I tried to see with many parts of myself I would miss whole dimensions of activities, of meaning. And so again I wrote in order to see, in order to see as one. On the unit I would keep my recording journal in the report room but often could not get back to it to write. So I would write on scraps of paper in my pocket and on my "nursing sheet" which became an odd entity; a cross between a nurse's working sheet and a researcher's recording sheet. Yet the queries and notations were not much different. I also wrote on spare medication record sheets, on paper towels in bathrooms, on my own body. For a time I used a small dictaphone that I kept in my pocket and would go into the tubroom or somewhere like and speak into it. This proved not to be as useful as the act of writing. Speaking the moment was not as truthful and apt to the experience as writing it. Writing moved me instantly to reflection even as part of the observation. Sort of like nursing: even as you record the blood pressure you mentally process if this is a good blood pressure for him, what past measures have been, is this finding significant to the rest of his illness trajectory? Later at home I would record all that happened that day and try to integrate the various pieces of writings, etc, into one. The originals were kept in my journal. I would also record all discussions concerning the question of nursing, all coffee break times in which we spoke the study, all ways in which nurses asked me questions about the study. In short, I wrote and wrote and wrote.

Late in the study I still recorded and wrote and drew pictures and kept pieces of writing and art given to me by patients. The audio-taping continued throughout the study and the periods varied

in time as nurses did not have time for long interviews unless scheduled on a day-off and as the patients were not well enough to continue speaking for very long. And because fatigue is such a large part of cancer and cancer therapy as lived, some moments of audio-taping were indeed short, ten to fifteen minutes. Initial interviews with nurses and able patients lasted one hour to an hour and a half. Interviews were carried out on the unit, in patient's rooms, in the dayroom, in a private soundproof room for patients on the unit, in a private office on the unit, in a researcher's private office area on another floor; wherever we could find a private and sometimes, not so private place. Interviewing on the unit, even when in a private and soundproof place on the unit always elicited better results than going to a different place away from the unit. Recording in the setting kept us focused, kept us close to the action in the setting, the lived realities of the setting.

Nurse participants were not always amenable to the taping because they worried about what I would ask, what they should say. Yet because I had already observed their nursing, I was able to begin with addressing specific situations, "I want to talk to you about nursing John." I would always use the word nursing or nursing practice and not caring or other pseudo-nursing word. Seeing through observation, then seeing through taped discussion proved not only fruitful but methodologically sound in terms of bias, in terms of misconstruing or misunderstanding something. Later I understood why this was so. It was because of the lived tension of the study, shepherding a way through representation and presentation. A formal audio-taped interview can be lived as a representation where the interviewee will conceal sometimes what is most significant to them because they see it as trivial, as too personal to be of consequence. And if my questions or statements came from presuppositions not in any way part of the phenomena, that too set up a represented reality. So while we lived the audio-taping together and while at times the conversation was very informative and interpretive, better hermeneutic conversations occurred directly. Questions that are inept too disturb people who suffer, who live with active disease. They distort reality too.

I knew already that nurses who practice, are often unable to say what it is they do or did or will do. Nursing happens very much in the doing of it and therefore to ask them too much about it made them think they must provide theory and explanations for their actions. Instead I wanted descriptions and the interpretations of things happened in the conversation. Patients were just very kind and very gracious. They always wanted to add insight to nursing a person with cancer. Patients fall automatically into description. Often patients with cancer are veterans of the health care system and very knowledgeable. I was always so very impressed with how much personal research many of them do concerning the nature of their particular disease manifestation. It was important though to keep before my eyes the fact that patients feel very vulnerable in the health care system and may feel coerced to participate in the study. In their vulnerability I could see that the thought of risking poor treatment later from the hospital was in their mind. I was always careful to acknowledge this fear and to explain that the research had nothing to do with the running of the agency or the nursing or medical care they receive. Many had been in clinical trial studies and had experienced some backlash when they did not conform to all the mandates of the study. As soon as this worry was dispelled, all else followed very naturally. Nursing as lived and interpretive inquiry, here practiced as hermeneutic phenomenology abide well together. Their pursuits are similar.

What came clearly to my consciousness at this time is that often researchers ask questions of practitioners that those engaged in practice would never ask. And so the practitioner becomes confused with the researcher's intent in asking alien things. Errors abound with the researched not knowing answers; the researcher not knowing her questions are inappropriate ones. Rather than the researcher divining that her questions are not apt, the practitioner looks at fault or diminished in stature. The practitioner looks "for answers to a spectator's questions that practice

never asks because it has no need to ask them" (Bourdieu, 1990, p. 82, 83). The researcher then jumps to conclusions "instead of wondering if the essence of practice is not precisely that it excludes such questions" (p. 83).

As time went on I became somewhat more selective of experiences I delved into but not much. The notion of openness to whatever comes is still paramount in the field of direct description. The litany of going back to the beginning again and again is very necessary. But as the study deepened, so did I, so did the participants. I became more enabled to present the gist of the study. Our mutual understanding of the question of nursing, the qualities of nursing revealed in practice, widened. It did not become more focused on particular things at any time, a difference from the grounded theory methodology of my master's work where I eventually slotted findings in categorical envelopes. There was always an element of openness, like, "what do you think about this today given this happening?" It was like a waterfall that keeps a fairly constant shape when one looks at it from afar. Yet the molecules of water constantly move and change (Langer, 1957). Never once was an enacting of nursing anew (a molecule) left out, in favour of a particular form of the thing.

To stay with the question concerning qualities of nursing in practice in its broadness, its all-encompassing nature became at times unwieldy. And perhaps this will be a justified critique of the study. I found that each time I was tempted to apply a finite thing to nursing expressed or a theory or concept from somewhere else even a nursing one, I lost the "natural quiver" (van Manen, 1990, p. 54) of the phenomenon. It did not quiver or even wobble then. It stood still. And as mentioned above, I went back to the beginning again, to another nursing situation and tried to see anew. Going back to the beginning became a persistent strategy. It again worked well for both hermeneutic inquiry and nursing. In doing so I found I lost yet another presupposition or at least identified it. I saw a connection I had missed. Going back to the beginning was always fruitful. "Phenomenology typically begins not as in the empirical sciences with empirical 'data' that, all empiricist pretensions aside, typically belong as such to no one's immediate, actual experience, but with understandings that are current, commonplace, and familiar - and yet not so" (Burch, 1991, p. 220).

Hermeneutic conversations concerning the nature of lived human experiences was essential during the data collection time and central throughout the developing study. I was part of a small hermeneutic circle of doctoral students where we regularly discussed lived experience, the beauty and wonder of it, the horror and fleetingness of it. On-going discussions with my supervisor, Dr. Max van Manen were essential to learning respectfulness for the phenomena as lived, for understanding how lived life comes to text, for synthesizing the research tradition of hermeneutic phenomenology. At all times van Manen's respect for my discipline and his uncanny ability to point me in serendipitous directions remains phenomenal to me. Dr. Vangie Bergum lent her expertise in researching intimate relations and interpreting the same respectfully. She too, while in the stage of ethical approval and on-going ethical approval, was a strong embodied advocate then and now for my type of research. Dr. Robert Burch taught formal understandings of philosophy yet in a way that I could see their relevance to lived life. Dr. Olive Yonge supported my development during the differing phases of the study.

I mention the support for the study here not in terms of acknowledgments, which of course are also due, but to bring forth a salient point. One of the difficulties of this form of research is to stay diligent, to remain steadfast, to keep working things through. This diligence is so very necessary in direct description. When one gets so very close to human lived life at its origins, the sheer naked reality of it pushes you away. We seek some defense mechanism to counteract it, to hide it. And I confess to taking breaks from the study because of this. But the breaks were not just about this and not either about shutting oneself off from the phenomena. Rather respite from



the study was essential to getting the self out of the way and by that I mean, as yet another aspect of oneself would come to one's awareness, one would have to examine it, understand it and move on.

These conversations with others would dispel my presuppositions (which were many having personally been steeped in nursing theory for teaching purposes, for academic purposes) and too, because I as an acting human had built up many assumptions, many preconceived notions about life, living. For example, I always thought that dying is inevitable and part of human existence and those with mortal disease will die at some point. What I didn't understand until it happened to me personally with my mother, and as a researcher/nurse/patient in this study, is that to live another's dying is quite a different thing indeed than the cognizance of it. Mortal disease or no, assurances of dying or no, that significant person wrenches your soul from you; your very on-going being becomes a question. While this may at this point in my life sound naïve for me to be saying, it is not naïve to live it. It is as well, to not have language to express it. C.S. Lewis (1976) said that he never knew bereavement felt like anxiety, like the whole world coming to an end, and he wishes the visitors would talk to each other and not to him. But he does not want them to go and leave him alone.

Bringing the study to a form that fits into a dissertation style is the challenge that confronts me still. Bringing the focus of (re)presentation to the discipline is an act that requires both commitment and openness to criticism. Bringing to language expressions of nursing for which there is no language, sits and tantalizes me. The richness of the lived instance of nursing thwarts efforts to explicate it thoroughly and completely. But that is OK somehow; that all human phenomena are much more complex and situated than we can ever explicate and we must just be respectful of it. For me though, this will be the enduring question of nursing; how to show nursing, to bring nursing to text in its fullness, in its contingent and lived nature. As Montgomery-Whicher (1997) states that while we can never really show the fullness of lived experience, we must "dare to say something." And Gadamer (1992) acknowledges that "one can never say fully what one wants to say. A statement always falls short of what one wants to say" (p. 69).

#### *Attentive to context: The researched lifeworld*

Beekman (1983) writes that an inquiry is best started by "*participating* in the daily life and the interests of our informants. This is the place where *dialogue* can start. And if we are not accepted there, on that common ground, what right do we have to go on?" (p. 38). Rather than expect the lifeworld to conform to my research expectations, I enter the lifeworld as simply as possible, knowing a priori I disturb events in the lifeworld on one hand, and on the other, I enable them to be, to come forth. "The best way to enter a person's lifeworld is to participate in it" (van Manen, 1990, p. 69), but "as soon as this is said we should be cautious of a too simplistic interpretation of close observation as a variation of participant observation" (p. 69). Sometimes we might wish for a video camera, but if we as nurses cannot describe the action in the setting, why should we think a camera can?

Van Manen gives another clue to *close observation* in the research setting and it is about relation.

Close observation involves an attitude of assuming a relation that is as close as possible while retaining a hermeneutic alertness to situations that allows us to constantly step back and reflect on the meaning of those situations...The method of close observation requires that one be a participant and an observer at the same time, that one maintain a certain orientation of reflectivity while guarding against the more manipulative and artificial attitude that a reflective attitude tends to insert in a social situation and relation. (p. 69)

Bergum (1989) states that research is a “drama, an interactive involvement of both the ‘researcher’ and the ‘researched’” (p. 43), and most importantly, *both* or *all* are affected by the “lived tension between the inner passion and the outer activities as experienced” (p. 43). In my particular setting for this study, a special care nursing unit in a cancer institution, all who were in this unit and all who were on the neighboring nursing unit, experienced this research process. In my bodily interacting I carried the question with me and still do to some extent. All knew about me and my question. Eventually there were few corners I had not looked into; the morgue, the lab, radiation, chemo, pharmacy, outpatients, daycare, tumor specific groups of people, diets, tea rooms, waiting rooms, chaplains, support groups, bereavement groups, and more. Each area had its own dimension of engagement. The litmus paper test was the patient, the family, the nurse; any of these involved in any of the former, opened the door for me. In the end I even had the elevator repairman telling me how different people access the elevator and it seems to depend on their sadness, their stress, their outlook on life, how much time they have been told they have left, as to how they do so.

Carrying the research question on your body in its very honesty (“I really don’t know what I’m hoping to find”) and openness, opens doors and pathways that don’t open easily. People seem to sense the passion within, that I needed to know, that I needed to see and understand their lived experience. This in some way forced a commitment from some and let others “off the hook.” They could withdraw freely once they knew my intent rather than to superficially participate. A recording from my *researcher’s diary* follows.

The nurses and others tell me my study is different and that I want to know about nursing in a different way than other researchers they have experienced. At the moment nurses seem to go about their nursing care seemingly unaware that I am here but I know they never once forget me. Nurses are aware of everything that moves, lives and breathes in their vicinity, and also all that does not. It seems an uncanny sensibility they have somehow.

My first nurse participant said in an audio-taping session, “You want to know what it is we do, you don’t want to put labels on us or get us to fill out this checklist and surveys and such. Your project is for us and for our patients because we see you care for the nursing the way we do. We feel this.”

Another recording from my *field observation notes* near the beginning of the study.

I am with Michelle. She is a former student of mine and we have a relaxed and easy going relationship. We enter a patient’s room together, an older male very ill yet known for his jokes and laughter. “Hi,” says Michelle, “Meet Brenda, unfortunately she is doing a dumb research study but before that she used to be my instructor. So be nice to her, we have to show her about nursing and what we do.”

“Gosh,” says Jimmy laughs, “We’d better be careful today, no smooching in the bathroom and pilfering food off other people’s trays.” [Jimmy engages quickly with us in the shared humour in the room. We speak of what was on the food

trays this morning. He shows a normalcy even though I know that Jimmy has not been able to eat much for a long time, or move on his own for that matter.]

Later I watch Michelle do a complicated wound irrigation, with special packing and dressing to one of Jimmy's many wounds. Odd. I remember teaching her how to do this both in lab and clinical areas and now ten years later, she shows me how to do it with some new wound management materials. She is very very good.

I relate the above here as a way of showing a part of the lifeworld of practicing nurses. Nurses in practice discern research that is beneficial to their patients and that which is to their minds, questionable. Nurses then choose to engage or not in the research. And if they engage, you better be ready because they bring to your attention all sorts of things, all sorts of dimensions that don't fit neatly into pre-formed research methods and emerging research findings. And nurses do not let you get away without seeing. It is the same with patients in this study who were well enough to continue dialogue about the question after close observation. They keep talking to you, problematizing situations and events. They hold you ransom so to speak. They do not give their lived life easily. Nurses know intuitively the appropriateness of research method. What Gadamer (1992) asserts is true here; "hermeneutics is the art of employing methods where they belong, not where they don't belong" (p. 70).

#### *Attentive to drama and passion in the lifeworld*

Bergum's (1989) notion of *research drama* and *passion* is true as the study gains a momentum of its own and becomes "a dialectic between the inner commitment (the interest, the passion), and outer activities (stating the question, establishing the approach, operationalizing the tasks, writing and rewriting)" (p. 43). This statement is true of the research participants too because they too manage you the researcher and too show the passion, the drama as they engage in addressing uncertainties inside them.

Questioning indicates the existence of an unsettled issue, a difficult matter, an uncertainty, a matter for discussion. It also invites a reply, a dialogue, a searching out of opposites and similarities. It opens possibilities and leads, in some sense, to uncertainty, for it throws what may have been thought secure into disequilibrium or imbalance. (Bergum, p. 45).

Jardine (1997) writes about a nursing graduate student (not unlike myself), this one was experienced in Stroke and Stroke Management Nursing and he describes what happens to her as she undertakes her first research interview in the field with a "stroke patient." Following all the guidelines of the research protocol the student quickly finds that her patient is upset with her physical limitations of not being able to speak for the interview and being very emotionally upset about this limitation as a part of her stroke condition. The student moved to active nursing interventions and then later felt a failure for "messing up" the research field. The student said that what she was doing in carrying out the research protocols "felt so wrong" (p. 163). Jardine makes the point that the student indeed was not "messing up" but rather was very involved in the phenomena that the student hoped to understand. The patient's observed problem with speechlessness in a moment of emotion is a very profound comment on what it is like to live with a stroke.

Dealing with this phenomenon well, understanding it deeply and generously and speaking its truth, might also be a problem of character, of wisdom, of patience, of becoming someone who can hear and tell the truth of the tales that their own lives tell, unafraid, willing to not blunt the intractability of living one's life with troubles such as strokes and the mumbling drools of loved ones...(p. 165)

Involving practitioners in interpretive research is to engage in conversation with them. "Doing research in a conversational mode changes the relationship between persons who have been hitherto labeled as 'researcher' and 'practitioner.' While it is unlikely to totally abolish the distinctions between them, conversational research does offer the possibility of developing a community of cooperative investigation" (Hammersley & Atkinson, 1983, p. 83).

***Attentive to the expression of our practice: Going to the nearness of the nearest***

When it comes right down to it, what do we have to show about nursing as it breaks into life but the practices of nurses? To be fundamentally involved with human life in times of illness care or in times of preventative, promotion of health activities is to be *fundamentally* entwined with being. Fundamentally entwined with being means being face to face with mortality. Face to face with mortality is to know that nursing is not a set of detached ideas but rather present in the flesh of contingency (Steiner, 1987). The flesh of contingency teaches us that nursing acts are not lofty things, complex and enigmatic, but simple elegance, situated and unique.

What is difficult for us to realize is that the great deeds and works of which mortals are capable, and which become the topic of historical narrative, are not seen as parts of either an encompassing whole or a process; on the contrary, the stress is always on single instances and single gestures. (Arendt, 1961, p. 43)

Actually situating ourselves in the lifeworld where the daily lived drama of nursing takes place, calls us to accountability in a profound way. Directly observed people, time, space, events cannot be misconstrued easily. It is too easy, Beekman (1983) states, to misuse our participants' "understanding of events to fit our own beliefs about what is important" (p. 38). And Bourdieu (1977) assures us that "to restore to practice its practical truth, we must therefore reintroduce time into the theoretical representation of a practice which, being temporally structured, is intrinsically defined by its *tempo*"(p. 8).

***Attentive to the ethical imperative: Hermeneutic ethics***

A profession such as nursing, humans acting for each other who experience vulnerability in various forms, requires moral and ethical insight. This ethical insight is essential to hold the vulnerable one's best interests at heart and most especially to prevent the suffering involved when illness and disability strike one most often unawares. In addition, when one's discourse has removed itself from the enacting of its profession to the extent that there are few intersecting avenues and little congruency among the discourse and the lived practice, it becomes imperative to be extremely attentive to those we are mandated to protect.

Ophir (1989-90) states that hermeneutic ethics are necessary where suffering results from hegemonic discourse where certain categories and representations determine right action. And too for the profession of nursing where other dominant bodies, political and administrative, have control over or have the ability to restrict the acting of nurses for the person's best interest, an ethics of interpretation is necessary. Hermeneutic ethics engages in interpretive work and seeks depth in understanding. Hermeneutic ethics too has the ability to retrieve things out of plurality, out of distorted forms and representations (Ophir). Hermeneutic ethics relates to all forms of discourse, theoretical and popular, journalistic and artistic, that outside the phenomenon in question and that inside the personal selves involved.

"Hermeneutic ethics must therefore relate first and foremost to those types of discourse which do capture what the hegemonic moral discourse usually misses" (Ophir, 1990, p. 113).

For if suffering is preventable and one knows, even vaguely, how, it is immoral to stand by; and if thinking and discourse are capable of making suffering appear

and be conceived of as preventable and unbearable when not prevented, the philosopher has an urgent task. (p. 117)

In terms of the researcher and the researched, while engaging in direct observation, one too must be constantly engaged in interpretive work and self-work. Each moment that presents itself presents choices, possibilities for action, for non-action, for understanding self.

Can research ever be anything more than a subtle form of writing the self? Or not so subtle. Perhaps it is time to reveal the writer of the research as much as the data. The writer is the data; the data is the writer. The writer who initiates the research, creates the space, becomes implicated. The research bespeaks her; she bespeaks the research. (Luce-Kapler, 1997, p. 187).

### ***Onward***

Nurses live in a sensuous world, the world of bodies, smells, sights, sounds, touch, taste. As I walked and lived in this world, as I inhaled it with an in-breath so too I added to it with my out-breath. Both breaths were the world of nursing with no one thing taking precedence. It just all was(is). To borrow and paraphrase a side heading from Dostoyevsky (1958), this treatise on methodology could more aptly be called, *Confessions of an Ardent Researcher in Anecdotes*.

Many of these events listed above will show themselves in various parts of the following chapters. In some instances I include a part of my researcher journal word for word and state it as so. In others, I state what I do at the time of the recording. The way of the study is very much tied to the methodology of the study.

## CHAPTER 5: NURSING MOMENTS: RUNNING ALONGSIDE A NURSE

*Humans are tuned for relationship. The eyes, the skin, the tongue, ears, and nostrils-all are gates where our body receives the nourishment of otherness...the beings with whom we are engaged, with whom we struggle and suffer and celebrate. (Abram, 1996, p. ix).*

### *Entering*

I enter my research institution weaving a path between 2 ambulances parked on the pad directly outside the immense front doors; one ambulance attendant waits for his patient to come, the other helps an individual on a stretcher into the back of the van. One feels already on this ambulance pad the hub of the place, a sort of humming along. Much of the humming I don't understand, have no words to put to the music so to speak, but I feel the enormity, the impact of entering an agency solely concerned with cancer.

To go through the front doors is to enter a new world of meanings even though I am a veteran nurse. Much catches my eye. As I move, differing things come to my view: the reception area, the person at the information desk, the security people who watch me enter and glide by the newly renovated lobby and tea shoppe, the brightly coloured chairs and couches on the side inhabited right now by two very tired looking, slumped over individuals. They watch me walk by. I feel their exhausted eyes on me. I move past the public elevators, down the hallway and around the corner, past the coffee shop area, xray and lab, to find a different set of elevators. Despite the predawn time, (I have left a sleeping world at home), people already seem busy, some in uniforms and some without. Individuals lie on stretchers and either look at the ceiling above in a distracted way or attempt to angle their head downward in an engaged way, their eyes looking toward their feet in order to see what is around them, to see the path in front of them to wherever they are going. They are being transported to various sites. Some have family members following them. Little groups of concern like this move as one entity through the corridors.

Janitors push the mop. They put the finishing touches on washed floors in hopes of beating the morning rush of traffic. The intercom calls, paging someone urgently; the swish swash of the mop stops for a moment as I tiptoe by, the janitor meets my eyes and smiles. Do all these people know this is my first day? This janitor continues to greet me every morning shift I work for the duration of my time here. The same genuine smile from the coffee shop attendant welcomes me as she fills her coffee machines. Mmm, that smells good. I arrive at the right elevator and call it. The day begins early in this place.

As I step on the elevator to go up to my floor, someone yells to hold the door. I hold it open for a portable xray unit and a technician to come in. "I think it feels like snow out there," she says to me as she maneuvers the unit over the bump and onto the elevator. After going up one floor, she and the unit execute a perfect exit as I hold the door for them. They *are* a unit actually. They move as one. Her body/unit, (hard to tell which is which here), moves and steers itself out of the elevator; her human arm projecting and guiding the hanging protruding arm of the xray machine. Both lead the way out and lead the turnings. On the next floor, a lab technician enters the elevator as I leave, her glass tubes rattle as she steps into the elevator. There is a notion of blood and pin pricks about her. I smell the alcohol and preservative solution odours about her. (Can I or do I imagine this?) Strange how we are all defined by our stance, our movements, our added attachments to our bodies. How do we wear our commitments? What are my attachments I wonder? Just hands I think; hands poised in readiness, hands that gesture, hands that accomplish treatments, cause pain, relieve pain, soothe, illustrate connections, diminish aloneness, muster meaning in a light touch, apply pressure in a heavy touch. The fact that I carry no tools other than stethoscope, pen and paper secreted away in my pockets and my lunch is probably

significant; the enterprise of nursing is not so narrowly defined as to have a tool to stand for it, like a test tube, a machine.

Before entering the special care unit where I am assigned, one must wash one's hands. There is a cubicle with a sink to the side of the entrance to the unit. The entrance looms as two large closed metal doors. One thinks of fortress doors. There is a huge and prominent red sign with white letters saying that anyone who enters these doors must wash their hands first. Fresh flowers, fresh fruit are not allowed.

I move into the cubicle, set down my bag of lunch and wash my hands. As I do I think of this as a ritual act, preparing myself to enter. Or perhaps a symbolic act, one of setting aside the former and entering this one specific place; this place engrossed in its own pursuits and full of its own intentions and narratives. Here the possibility of something anew comes to presence, something not yet, only a promise at this time. Yet while I have these perhaps lofty thoughts, I too know on this level of awareness that I need to minimize the possibility of the spread of organisms, even some innocuous ones that could be deadly to those with a compromised immune system. "I'm making too much of this" I say to myself and move away from the sink.

I push the automatic button on the wall to open the doors and instantly a mechanical sound grates upon my ears as the fortress doors swing open. I enter. It is very very quiet. The lights are still turned down for the night and it is quite dim. I pass by patient rooms. Each room has large windows and doors beside the windows that are also clear glass. I see through the window door that faces out to the hallway that there is an anteroom behind the entrance door. It has a sink and then another inner door that is also a window. Here one enters the person's room or for me at this moment, one peers into the patient's room, a voyeur of sorts. My truth of my being here is revealed already with all these clear glass windows around. I am a voyeur. I am as one peeping through the keyhole (Sartre, 1957).

Each window has a name plate on the door and an assortment of various pieces of information, precautions for care noted on signs taped to the window i.e. *Mask and glove in this room. Nothing by Mouth.* The nursing station is in the middle of a U shaped hallway. I walk up one side of the U, come to the station which is a curved counter and desk space and contains a computer, fax machine, telephones, intercom, slots for different forms, a shelf for patient charts, an assortment of chairs, and a open door leading to the medication room behind the station. I keep on going, bear left and enter a room off to the side that has a kitchen table with chairs, a small sofa, a sink, nurses in white uniforms sitting at the table, and the glorious smell and presence of a coffee pot.

### ***Morning Report***

Here the nurses give report at 0700, 1500, 1900, and 2300. Some nurses work 8 hour shifts and some are on 12 hour rotations. The nurses are sitting, huddled, at the table writing up their paper, their personal nursing sheet on which they will record certain things for each patient as the day goes on. How important it is to have this sheet in your pocket when you nurse! Each nurse has her own style of nursing sheet. Here I see the three nurses folding a 8 by 11 size recycled paper in half lengthwise, writing each patient's name on it with blanks for information that will come in report and for information that they will gather themselves. They prepare to nurse.

The nurses greet me and offer me coffee. (I had been in previously to explain the study in this same room and I recognize two of these morning nurses from the meeting.) I move to sit on the sofa as I realize there are only two chairs left, one for the head nurse and one for the night nurse. (One must be careful about sitting arrangements at nursing reports. I remember taking my students to a hospital unit once where report was held in the patient lounge. One student

accidentally sat in the head nurse's traditional chair for report and it was not an auspicious beginning for us on that unit.)

The head nurse and the night nurse come in, discussing a particular case. The head nurse asks me to pull up a chair to the table but I am comfortable where I am and say that I am fine. She introduces me to those who don't know me, tells them that I am looking at nursing practice and report begins.

And here I sit within the hub of nursing practice. From this flow all "yet to be" nursing actions, all "past but not over" nursing actions, and hints of "what to do, 'whuttodo!'" nursing actions. I listen as the night nurse reads the patients' lab values and other objective data. "Gosh," I think to myself, experiencing alarm, "This information is just too private, too individual to be part of research! Is this form of doing situated research truly ethical? How can I protect them when it is time to share the research? Should I really be here? Is there another way to get at my question, to get at practice as lived? If it were me as patient or me as nurse, would I want an outside researcher to know my inner body workings, my lab values, my particular nursing way of approaching that gentleman who has diarrhea and psychotic interludes which might be holding him to ground him? Why in my zeal to get at nursing as lived did I not think of these things sooner? I did, I told myself, it was there in the ethics proposal. But it is too intimate too individual, I can't protect their identity enough. How do we then *do* lived research I wonder?"

These thoughts accompany my racing heartbeat, my shallow breathing as the enormity of what I have undertaken takes hold in my being. I have underestimated the privacy, the intimacy, the morality, all of this, even though I thought I had not. Even the formal research ethics body was only concerned about this not being a clinical trial, not this access to personal data and respondent privacy that I will have. This is why we think in constructed concepts in our discourse of nursing I think. We are fearful of exposing others, we withdraw from intimacy. Our code of ethics does not allow this. And I experience extreme dissonance with the moral/ethical aspects of my role here and prepare to walk out as soon as report is over. This is the first of many such moments of my sojourn here. And I decide in this moment of panic that much of what I will see and hear will be subjected to my own discretionary judgment as to what will be revealed and what will not. Somehow this brings with it enough psychological comfort to be able to return to the live scene before me.

I start to listen again as the night nurse adds her own judgments and comments to her assessments of the person to her read report of the objective data about how the person is doing: "Watch this one." "He's improving, doing really well now." "This one needs his blood right away." "He slept for the first time." "The family was very upset last night." "Gosh this one is hard to nurse!"

Report moves on with a combination of language forms listed above. Here and there a nurse asks for more information. I am lost with the lab values and make a note to ask in what order they read the tests as the numbers are just given. I make a note to refresh my memory of normal ranges. I talk to myself, "The first one the WBC, I think so because of the numbers, then the haemoglobin, and then the platelets?" Somehow it is very important that I understand this. I feel this keenly. This will be important to understand the practice. Serum electrolytes are read on many of the patients too, these numbers are easier to understand, but these numbers also portray just how ill and immunocompromised some of these people are. I get a picture of acutely ill people. And I lose some of my dissonance as I become drawn in to narratives of individuals' nursing needs.

The nurses listen attentively, a palpable listening which reminds me of the story of the child saying, "I can't hear you listening." I think, "I hear you listening, all of you." The teacher in me sees all sorts of different kinds of listening; focused body language, recording information



presented, making pertinent notes to selves, eyes darting to one who has an answer. All are engaged in this drama that unfolds before my eyes; information vitally important to the care for these individuals today.

I experience another surge of feeling. “Oh this is good, so good to be back” I think to myself. I enjoy sorting out the puzzle of values and tests in my mind, what I would do with that one if she were my patient today. I relish in the night nurse’s language where one word sums up a whole lot of things, a one word picture. I revel in her abbreviations some I know and some I don’t, and I regret treatment decisions made as she says, “He shouldn’t be dying right now, the disease is not killing him, the chemo is, he needs to be looked at right away today.” I rue the disease of cancer with a vengeance in my mind. I think of the lyrics to “*If I had a rocket launcher, I’d make somebody pay*” by Bruce Cockburn.

What a gamut of feelings I experience within seconds. My vulnerability speaks loudly here.

Nurses have their own special language for practice. In the preceding chapter I write about language that nurse theorists have invented or borrowed to apply to nursing dimensions, and nurse categorists who have written categories of nursing needs and interventions. I think to myself “Why didn’t they listen to a few reports? They would find all the language they need to describe nursing practices.”

But more immediate here is the reminder that I am in a unique sort of world. One that could be construed as an alien world as I don’t understand much of it, the specific names of cancer treatments and chemotherapy protocols, bone marrow transplant issues; a sort of type of unique time/space continuum as referred to on *Star Trek*. I hear and search my mind and memory and come up with some major blanks. But there is too a comfort here; it is a nursing world and I know this world even if I don’t know the specific culture here yet.

There is concentration here, exceptional mind work as one nurse tells and the other hears and synthesizes, each mark their sheets with pertinent information; precautions that come to mind, a connection they make that needs to be investigated. This intense concentration is almost akin to a group meditation moment, an intense prayer service, a lecture that speaks deeply to the audience, a focused group mentality. Nurses’ communication, that which sustains not only the patient and the nurse, but also several other disciplines and the institution itself, weaves its way around my mind and body and into my being. Later I will find just how much I have taken in.

In days to come where I spend time with and later interview people on audio-tape, several people refer to this network of communication. They know it exists and they appreciate it. They even like it.

These nurses talk to each other and tell each other things so you don’t have to feel you are inventing the wheel each time a new nurse comes on. And they tell the doctors things too and stand up to them and suggests things to them. Yes and sometimes they tell you things you would rather not hear but need to in this disease. But it is always told with hope and that we can do this and this...

### ***Sarah and her patients***

The first nurse I pair with is Sarah. Following report, Sarah welcomes me. She has already read the consent form for my study that has been carefully prepared, revised, and approved by the Interdisciplinary Ethics Committee’s rules and regulations for access to human subjects (their language). She is comfortable to be a part of the study. Before we leave this room, Sarah goes

over her patients with me, their diagnoses and their relative status, nursing care that will need to be done, some coordinating/referral work, and she says she also has an empty room so there is the likelihood of a new admission. "Our beds don't stay empty for long and you can count on it being someone who is quite ill." Therefore she wants to organize her day so that she is ready at any time for this possible, quite probable admission.

We go out from this cocoon of discussed care, this place of comfort where all is as it is at this moment; care caught up for a moment, nothing new on the charts so to speak, a sort of stasis. There is too a sense of a lingering regret as we leave this place of enveloping convergence. It is difficult to explain but is something like this; that the stability that is here for us in this one moment in time now dissolves in a compository of human and institutional needs. The phenomena discussed have moved on in time, mutated if you will. What is new and coming on, awaits us.

Sarah introduces me to her patients as a nurse researcher who wants to know, "Does nursing make a difference?" I am impressed that she has so quickly grasped what my study is about and in truth I have wondered about how we will present who I am to patients and families. And here Sarah just does it with grace and smoothness. On tape at a later date, I ask her about this. She laughs as I ask her how she had come up with that description.

Well you sort of had it on the form, that's what clicked in for me and that's why I was so interested in it. And for the patients, well patients here are very ill and they are not into hearing long explanations so I sort of went from 30 words down to 5. I didn't want them to think that you were a first year nursing student or someone who is learning the ropes and that was why you were with me. No - you are much beyond that, and this is a different working relationship, a different relationship to them than mine for example and I wanted them to understand that. They have many disciplines seeing them all the time and I feel I must keep them in the picture.

And of course, I didn't want them not to tell us things, problems they were having just because they might think you wouldn't want to hear about them or wouldn't know how to deal with them, so I wanted them to know you were a nurse.

Well what can I say. Early it is clear that she nurses me, makes a way for me, helps me through the awkwardness of a new place, of negotiating a role; all those things research texts refer to when they speak of "gaining entry." And perhaps this is necessary. This morning at report there were two nurses who had been my students and who warmly welcomed me. While it is gratifying and delightful to see them again as colleagues, I also 'read' that one of them is uncomfortable. I know too that I make some of the other nurses uncomfortable because they know I am "faculty" with whatever notion that conjures up. The task in front of me is very much to diminish all these things so that I can begin to describe what is here. Yet these things too are here. And indeed as my time progressed I met many nurses who were my former students and worked with many nurses who had the "faculty" query, or were working on a postbasic BScN. But by then the word had gone out to the nurses that I knew how to nurse and that made me somehow "OK." It was to be my saving grace.

## ***Rick***

Sarah and I enter Rick's room. It is still early, about 0730. At the beginning of each shift each nurse visits and assesses her patients, provides necessary care at that moment, plans treatment and intervention times with them. Sarah knows Rick because he has had a bone marrow transplant about six months ago but she meets him again for the first time this morning. They chat together about this. Rick is excited because he is going to meet his bone marrow donor today in Outpatients. (Recipients are not told their donor's name until 6 months have passed). Rick is gracious to me and said he will help all he can, and also told me I should go to Calgary to the transplant unit there. "That's where I learned an incredible amount about transplants, the disease and treatments I learned about here. People need to know about this stuff, how we experience it," he said. He too quickly "catches" the nature of my study.

Rick just really wants to sleep this morning. But he discusses his care with Sarah with alertness. They determine when to do his treatments. Sarah tells him what his vital signs are, what his oxygen saturations are as she does them. And she tells him the results of his blood counts taken the previous day. While Sarah takes his vital signs, temperature, pulse, respirations, oxygen saturations, she also turns his pillows over as she replaces the blood pressure cuff, pulls the draw sheet of the bed tighter on that side, places the fresh water jug she has brought in with her closer to him, pours him a glass, offers it to him and reminds him to drink, reattaches the call bell to his bed, and asks him if he is warm enough, takes a blanket from the chair to cover him.

Rick talks about his cyst on his kidney and that he needs to have it removed. Sarah checks his IV amounts, looks at the medication bags, re-programs the pump, makes some notes on her cumulative, carefully drawn at report, paper, and prepares to leave the room. She turns the lights back down, makes certain the curtain is across the window that looks out onto the hall so people cannot look in. It also helps to darken the room for him. She checks the bathroom for supplies, towels, soap, picks up some used towels, dishes and begins her exit. "Ok Rick, see you in an hour and a half unless you call." As we move out of the room, Sarah tells me they are querying graft-vs-host<sup>2</sup> disease with Rick and that they are very worried about him.

While we were in the room, Sarah relayed everything to Rick, all aspects of his assessments, his care, his blood tests, his medications. They planned together when to have the pentamidine inhalations, the treatment to protect against PCP, the pneumonitis of a depressed immune system. Rick was at the centre of the planning. Rick does not sleep well at night and his best sleeping time is in the morning. Sarah pointed out to him some things he needed to know with the planning of his day such as this drug must be given before this one because of interactions. She asked if he knew how to breath during the treatment, if he had been taught, and so on. Rick processed it all, Sarah engulfed it all. The day was planned. It would be not inaccurate to say that no one here was the director of care, it was a dialogue, a shared event.

Later I talked to Rick about his involvement in his care.

Yeah well you know I've been in this game for a while now, the cancer game, and these nurses respect that I know stuff, heck they taught it to me. You see they all know me, or they have at least met me and they know my story from report and from others. Sometimes some nurses take more control than others

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<sup>2</sup> A tissue rejection situation where the recipient rejects the bone marrow of the donor.

but that is minor and doesn't really matter, I just go with the flow. But you know if there is a question of what to do with me, all you have to do is ask the nurses. You know a good nurse nothing much gets by her.

But you know I've also manipulated the system to my advantage. I meet the nurses halfway. I tell them exactly how I am or if I'm worried about something. The nurses have gotten to know me and my likes and dislikes very well, and I bent some of the rules for sure like being able to sleep in like this, but it all helps you to get through this kind of dreadful time. There's nothing like a good nurse standing beside you. The other day the doctor was beaking off about something. He was mis-informed. I was too tired to fight back much but the head nurse, she just told him what was going on here and he listened.

As I stand at the end of Rick's bed and watch all the above transpire, I am confronted with Rick's face. His face shows his past and wears his present moment. "It is what cannot become a content, which your thought would embrace; it is uncontainable, it leads you beyond" (Levinas, 1985, p. 86).

Obviously a handsome man Rick is, yet the ravages of graph-vs-host disease are clearly seen on his face. It is covered in a red and purple raised rash. In looking at this corrugated face engaged in conversation with Sarah, I enter Rick's world. I cannot but help it. His face and his fatigue tell his story. And I know I will never ever with all the best research techniques and ethical parameters available, know what he has truly lived through in this very present fight for his life. I can only show what I can show, understand whatever I can synthesize out of his world into my own.

Yet despite the fact that he may be rejecting his bone marrow transplant even as we speak, Rick chooses still to see his donor later today to thank him. As time passes, I get to know Rick and I interview him. We build an inter-world together. I learn about Rick's world where he is transported from a successful carpentry business to surgery for an inguinal hernia to a sudden diagnosis of leukemia to the world of "the cancer game." I share my world as researcher, as questioner, as intrusive at times in the lives of patients and nurses on this unit.

### *Leigh*

Sarah and I move on into Leigh's room. She is up, showered early and waits for her morning assessment and chat with her nurse. Leigh is anxious to get her chemotherapy drugs hung. She is bright and cheery and very much wanting to "get on with the stuff" because she wants to do some things today. "A couple of my friends are coming by. Do you know what you should tell people to buy people who are in hospital? Not flowers and chocolates, but 2 ply toilet paper and a good box of Kleenex tissues. No one ever thinks of these things but this is what people really need," she says. Here I not so much enter Leigh's world as Leigh instantly embraces me and pulls me in. Before I am in the room three minutes, she has me "sized up." She knows just about every thing there is to know about why I am here this particular morning not the least of which is that this study has been approved by the research ethics committee.

Leigh greets me. I realize that Leigh talks all the time. She tells me how much respect she has for nurses, that she talks a lot and is willing at any time to have a conversation. Sarah goes ahead with her assessments. Leigh has a central line, a line leading directly to the upper chamber of her

right heart. It is through this line that Leigh's chemotherapy is given. Today Sarah needs to do a blood draw on these lines, to culture them to see that no organisms are growing as Leigh, like Rick, also has a low immune system. Sarah has brought a blood draw tray in with her, a tray with cleansing solutions, needles, test tubes with different colour stoppers for different tests, and a large piece of foam to stick the needles in after using them. Sarah begins with taking Leigh's vital signs, asks her about certain symptoms and situations that were given in report and they discuss them. I watch Sarah carefully cleanse the ports (openings) of the central line and then proceed to draw up a vial of blood from each port. There are three. She labels them and puts them back in the test tube container in the tray in a certain order. Sarah and Leigh talk all through this procedure which requires careful technique. Indeed it is a procedure for which nurses need special certification in order to do. Yet both patient and nurse are unruffled and the procedure goes smoothly.

I think to myself, "This is a line straight into her vessels and then into the superior vena cava and then the atria itself." How *ordinary* Sarah makes this seem, how at *ease* Leigh is, how the procedure, the talk, the bodies cooperate, lean together, how Sarah's hand movements are strong and secure and purposeful, how Leigh's head and neck are positioned so that all her vessels, muscles show their anatomy, their place in the human body, how Leigh's upper chest is exposed and yet she exudes comfort and peace with this procedure. Sarah handles sharp needles, strong solutions, blood with confidence, the felt specific tension on these tubes is significant, yet her hands move assuredly through each step. Sarah covers this serious and skilled procedure with commonplaceness.

Medieval writers of medicine looked upon this access to bodily innerness as taboo. Bodily cavities were seen as a microcosm of the universe that God had closed up (Turner, 1991). To look inside was to access a universe, a mystery, one which humans should not gaze upon. Yet here it seems as if they are having tea, that this is an unremarkable thing.

"What about this?" I ask Leigh later, "Does any of this disturb you? What about Sarah's procedure with the *central* line and the seriousness of it? And her practice of putting you *central* in the planning of the day, that is exceptional, and how did you learn so much about all the blood counts, the treatments? Your knowledge astounds me." Leigh responds, "Yes well I guess you could say I am the *central* one here."

And we laugh. Leigh catches me. I ask too many questions all at once. Why did I do that? I am too intense here. But Leigh turns me instantly around with humour. She deals with many varieties of health care people. After what she has been through, she can teach a fervid researcher how to behave. "Along with Sarah preparing my way, now I have the patients managing me too," I mutter to myself.

"Did you know anything about blood work, blood pressure, all of these vital signs and vital readings of organs before your illness, or about these central lines, lines to your heart?" I ask.

"No," she replies. "The nurses just kept telling me things. At first you don't take in anything, you are too shocked. But slowly you pick it up and the nurses don't let you get away with not learning about it. Of course being a math teacher I pick up numbers quickly, but I would have picked it up anyway. The nurses are gentle but they keep repeating until we show some understanding."

"In fact," she goes on, "They told me what my counts mean, what neutrophils are, what platelets are, this sort of thing and so that's how I got to know it...they make sure that anything that has to do with you is not confidential, secret, something they write down with a book and keep kind of hidden away, that is only for them. You know the attitude, like 'We are superior beings and we are the only ones who can understand it.'

No, here the nurses make sure you know exactly what your temperature is as soon as they take it. You know you have to watch a temperature with this disease when your immune system is depleted so you get the idea of how important this is. You could die within hours if you become septic. They make sure you know what your blood pressure is as soon as they take it, the same with the blood counts as soon as they come to the ward and they make certain that you understand what they mean."

"And this is great because in the process of this illness I have been in places where they think that the patient doesn't understand so they won't even bother talking to you about it or they just don't take the time. I remember my brother with heart disease, he was really annoyed because no one would tell him what was going on, what was really wrong. The doctors would whisper away at the end of the bed."

"But Leigh," I say, "What about these lines to your heart, can you tell me about them?" "No, well yes, I had lots of questions let me tell you," she answers, "I just know the nurses explained to me what the doctor was going to do, to thread these lines in, that these are large tubes going into a large vessel and that this was the best way for me to take the chemo and for them to monitor the effects of the chemo, and they made it seem so ordinary, I just accepted it."

And she adds, "I am fighting a big disease here Brenda, I need all the help I can get. The nurses take my fear away or rather, they take it a long way back."

Back to this morning in progress, Sarah takes time to explain some of the potential side effects of the chemotherapy protocols that she will have today and how she will manage them. I also ask Leigh about that.

Well you know they always make sure that you know that there will be side effects, possible side effects but they never tell you the horror stories of the worst ones. They just do the average side effects, you know like, "this might happen

and this is quite often what might happen but that would be kind of unusual to happen.

With the extreme side effects I have asked if that has ever happened to a person and they have replied, 'Yes it has, but you know we can deal with these effects. There is a pill for this or a salve for that so there is never any problem.' You know there isn't much that they haven't seen in terms of reactions, side effects to any of these drugs. They believe the more you know the better you are able to notice things quicker and also handle what comes and I have to say in my experience that that is true.

I find myself thinking about this chemo, these solutions that are toxic to the cancerous growths yet they are also toxic to us as human beings, to all our normal cells. I think of taking this truly "other" substance into our bodily systems, absorbing its toxicity in order to destroy cells gone awry, sending bad after bad, or is it good after bad, hard to say.

### *Cel*

We leave Leigh promising to come back in 15 minutes to hang her chemotherapy. The third person we go to see is Cel. Cel has just come through a severe medical crisis where the medical team and family discussed withdrawing life support. I heard about Cel from the nurses in report. Before I started the study I attended a ward meeting where I explained that I was looking at the practices of nursing as lived and experienced directly. At report this first morning after discussing Cel, one of the nurses who was at that ward meeting said to me, "See this is nursing."

Cel has multiple myeloma, a disease of plasma cells that usually strikes individuals between 40 and 60 years. The malignant plasma cells infiltrate the bone marrow and from that point on there is back and bone pain and often trouble with the urinary system in terms of renal insufficiency. At this point Cel is on dialysis twice a week, his spine is very involved, and his movements very painful. He also has spinal cord compression as a complication of metastatic disease.

When the multidisciplinary team discussed Cel on Friday they felt he was dying as he was unresponsive and almost comatose. They recommended to withdraw life support. The nurses and his wife felt that it was more likely a drug reaction due to his compromised renal condition where he cannot detoxify drugs and as a result they were not being cleared well enough from his system. He has lived with dialysis for several years. The physician in charge of patients on that unit was convinced with this argument and she decided to withdraw the drugs and wait and see. Cel woke up on Sunday night and said he was hungry.

So when Sarah sees him this morning, he is in very good spirits indeed and so is his wife. Sarah says, "You both must have been surprised." His wife answers, "Yes we were all surprised to see him come back like this, but I just knew after all we'd been through that his life wasn't over yet."

Sarah does his assessments all the time speaking with him and his wife and including myself in the conversation. They plan his care, the three of them together, his wife pointing out that he has dialysis later in the day. Cel wants his colostomy "fixed" before this time. He says he is quite itchy with the sheets in the night and Sarah checks his body for a rash. He is really hungry today and Sarah and he toss back and forth what food he could eat and tolerate. They discuss when to have his pain medication and decide that he should have it just before they put him on the

mobilizer (stretcher) to go to dialysis. Sarah says that she will notify the lab that he is going off the ward for a while.

Cel's wife says she would like to manage his bath today as today really is a special day with Cel waking up like that last night, not to mention it will soon be their wedding anniversary. The talk then centres around why so many people their age have their wedding anniversary in October and November. "It was because of the crops, of harvest, and because Cel was a hunter. He even hunted the day of our wedding and was an hour late for the wedding because of getting stuck in snow and mud, and I still married him," his wife recalls. All of us laugh and talk about weddings, anniversaries as Sarah goes about her assessments and making Cel comfortable. Cel adds funny cryptic comments.

Sarah comes out of the room and hears an alarm ringing. She enters the next room, not her assigned patient that day, says hello and checks the IV line. She stops the flow, removes air from the line, and starts the pump again. This patient is a judge from the another province who is on this unit because she has undertaken a high dose chemo regime to combat her recurring and aggressive breast cancer. She is sleeping but a friend is sitting with her. She has been there all night and is waiting for the patient's husband to come in and relieve her. Sarah asks her if she would like some coffee. The patient wakes at the sound of voices and smiles at her friend and tells Sarah that she just feels better and rests better with someone to watch for her. Sarah says she understands. I notice how very beautiful this woman is; her bald head symmetrical with prominent bone structures. But mostly, I realize I did not know how lovely women look without hair!

Inside the patient rooms, Sarah is calm and goes through her assessments with grace and an unruffled sense about her. Now outside the rooms I see her pick up speed. She wants to get Leigh's drugs prepared to hang immediately, she has other drugs due, she wants to find some sort of cream or be ready to suggest a medication to the team for Cel's itching skin, and she wants to do this first as she knows that Cel will be bathing soon.

Before she starts any of this however, she phones diet kitchen and orders additional food for Cel. Next Sarah discusses the itching with Anne the head nurse. Anne first asks for more assessment, what is the skin like, dry, moist? Is there a rash, describe it, is it all over his body? She says they cannot use anything with zinc in it because Cel has radiation treatments. Calamine has zinc in it. She suggests something she thinks might work and will get an order for it on rounds. She also asks when his pain medication is due. Sarah decides to move the time of the pain medication up and reminds herself to talk to Cel about this. Anne also makes Sarah aware of some lab findings for Rick as she has just been going through the charts to check for continuity of treatment and records new findings.

### *Anne*

Anne has both a wealth of personal and professional knowledge. She tells me they have primary nursing here where the nurse is in control of her patients' care. She is approachable, provides skilled care at times, talks to all the patients and their families everyday, coordinates nursing care and the allied health care disciplines. The patients all know her and she *knows* them. When you speak with her you have the sense that she is "right there", very very present. It's hard to describe what she exudes. It is something like gentle expertise with the certainty that comes with mastery. Families just want to talk to her. They know she knows. Anne keeps everything running smoothly. I bow to her proficiency and at a later date one of the physicians refer to Anne as the "glue" that keeps the unit together. I think of the properties of glue and agree, stick-to-it-ness, holding fast, mending, joining, fixing, making whole. I think about expertise such as Anne's and how she puts so many multivariate pieces of information together instantly and



knows. This level of nursing personnel has been dismissed in many nursing units. I remember a phone call I had the week before at the faculty.

It was an “urgent” phone call on my voice mail, a lawyer who said that he was consulting me as an expert medical/surgical nursing person. He had a client who experienced a work accident which resulted in trauma to his shoulder and femur. The femur was fixed surgically, the shoulder was reduced in the emergency room, and an xray was ordered to see if the shoulder was back in place. The person was discharged 2 weeks later, and 2 weeks after that was seen again by the physician, and the shoulder was found to still be dislocated. It had not been reduced and now it was fixed with the result that the young man in his early twenties had permanently lost the use of the joint, “a wrecked arm for life,” the lawyer said.

The lawyer’s investigation found that the xray report stating that the shoulder was dislocated was on the chart at the time of discharge and so the physicians, an orthopaedic specialist and a general practitioner, admitted to 80% of the blame. The lawyer, of course, was trying to find someone else to blame and cover for the 20% remaining in the payout to the client. The question the lawyer asked was, “Is this a nursing responsibility to bring the xray report or any reports to the attention of the physicians?” “Was it indeed on the chart at time of discharge?” I ask. The answer was that if normal hospital procedure was followed, it should have been on the chart 48 hours after the visit in emergency, but this could not be proved. The lawyer also told me that his brother was a physician in another province and there the head nurses check these things out.

In fact, it is the discharging doctor’s responsibility to check all the reports he/she has ordered. And it is also the radiologists responsibility to see that abnormal results get communicated to the physician. In actuality, the question that should have been asked was, “What was the precedent on this unit? Was there a head nurse on the unit? Did nurses usually check these things for physicians?”

As I probed a bit more before answering the lawyer’s question, I found he just really wanted to target nursing. He also was vague and would not answer my question as to who charted on this patient, was it a registered nurse or was it another level of hospital personnel brought in to reduce costs. “Did the head nurse or a registered nurse sign the discharge slip?” I asked. “No,” he conceded.

Yet here on this special care unit of acutely ill people in my research institution, the head nurse is still a valued part of the staff. I was reminded of this as I watch Anne work this first day and I remember that Gadamer (1981) discusses the notion of experts in his essay, “The Limitations of the Expert.” He points out to us that just because there is an expert around does not mean that we abdicate our own thinking, our own intellectualization. He states “the more an institutionalized form of competence is constructed, which proffers the expert, the specialist, as an escape from our own not knowing, the more one covers up the limitations of such information and the necessity of making one’s own decisions” (Gadamer, 1981, p. 188). I think about this as I see Anne teach, hang back, prompt, demonstrate and so on. She doles out her expertise carefully so as not to jeopardize the thinking of her staff. I am also reminded of pre-prepared patient care maps which are the paper experts in areas where registered nurses are not plentiful or where another level of staff now preside. Here I see Anne at times jump in with hands on expertise, with discussions of the most appropriate care, with coordinating of care, and many other things. But I also see her too standing back at times, using quite sophisticated teaching/learning principles, developing her staff, her physicians, her oncologists. She is smooth and ingenious. And she is embodied, thank goodness.

### *Sarah nursing*

Back to the happenings on the unit, I watch Sarah prepare her drugs. She has medications to give every hour. These are complex medications, all have side effects and harmful interactions with other drugs, with many things to watch for in patients such as allergic reactions, bladder and stomach bleeding, cardiac symptoms to state a few. The IV lines are complicated and are carefully planned as some drugs cannot be administered through the same line.

While Sarah prepares her medications, she is interrupted by a phone call from Rick's wife wanting to know how he is today, a phone call from the lab wanting to know if she did the blood draw on Leigh's central line this morning, a phone call from the Diet Kitchen asking something more about Cel, and another nurse who asks her to help turn a patient. As she finishes pouring her meds, she phones pharmacy to alert them that she will need more of a certain drug by 1600 that day and to see them through the night doses too.

Sarah then moves through the ward first stopping at Leigh's room to start the chemo running (really a very complex affair yet done with skill and precision), administers medications to Cel and to Rick, inspects and adjusts IV rates, provides nursing care for some specialized dressings with special solutions and techniques, answers patient call bells and requests, sets up Rick for his inhalation therapy. Cel has become nauseated and Sarah does not want to poke him with a needle each time he needs medication for this, and also his skin has the rash described above that is still as severe as it was early in the morning. She decides to set up an intradermal infusion set, prepares it in the medication room and then goes back to his room and tells him it will be one poke and then it will stay put on his upper chest. "Here we can give you more medication immediately without poking you each time," she tells him.

Leigh's chemo is a bag of clear blue solution, reminiscent of the sky's colour on a clear day. I have seen clear (most common), white (lipid in TPN), pale yellow (protein in TPN), blood red (blood transfusions), greenish (some platelets) all of these commonplace in IV therapy, but I have never seen this colour of IV solution. It makes the chemo again seem alien. Leigh comments, "Yes it took me a while to get used to the blue in the lines and going into my skin too, odd isn't it?" Another chemo solution that Sarah hangs needs to be covered with a bag because light destroys its composition. These substances are truly "nursed."

Finally it is coffee break time. I'm ready for this. Sarah gives a verbal report on her patients to another nurse, goes to the fridge for her lunch, picks up her coffee cup, makes certain I also have a coffee cup and money, and moves down the hall toward the doors I have entered that morning. We are almost in reach of the door when the glass door to a patient's room on the side opens and a patient stands there and says, "I rang my bell 5 minutes ago, I need a nurse I'm having the symptoms she told me to watch for. She just started this blood 10 minutes ago."

Mr. Lee is having a blood transfusion and on first glance one can see he has the beginning symptoms of a blood reaction. Sarah quickly puts down her lunch and cup on a nearby stretcher and assists Mr. Lee back into the room, adjusts his IV drip rate, helps him sit on the bed, covers him up, and grabs the thermometer. Sarah asks me to find Mr. Lee's nurse. I go to find her as she will need to call the doctor for medications to be given right away, tell her what is happening, she returns with me, sees Sarah giving the care. By now the patient is shivering, his whole body shaking. She tells Mr. Lee she will get something to help and leaves. I run to the linen cart to get more blankets to cover him. His nurse returns quickly with some medications that she adds to the IV and soon Mr. Lee becomes calmer.

He starts talking to Sarah. I learn very quickly he is a computer engineer. "You know you need to try to get the computer reprogrammed to ring automatically because if that receiver is not

properly placed on that hook, it doesn't allow incoming calls to ring" he tells her. Sarah assures him that she will look into it right away. Sarah leaves him in Karen's care and goes to the desk to find that the receiver is not properly placed on the hook. She corrects this and goes back to his room to let him know it is now on the hook. She tests it for him and someone at the desk does answer. And so once again we start on our way for coffee; the report given, the handwashing, Sarah's lunch and coffee cup have gone the way of the stretcher. She shrugs her shoulders and we walk down the hall toward the doors. I'm hoping we make it through them this time.

### *Coffee break*

I have several things I want to ask Sarah. But I also know that coffee time is one of connecting with her co-workers, getting caught up on personal lives as shift work often leaves large intervals between when you do and do not see your colleagues. We get our coffee and sit with staff from the in-patient units. Sarah introduces me and there is outrageous humour back and forth about researchers, how they never seem to know what to do about studying nursing so they videotape it, not to mention the faculty who send out their students to their units and then never come to see them. I can see that both my roles are not seen in good light here.

I laugh at their stories and decide to add some humour of my own; give it back to them really. But then being nurses, soon there is a serious moment where they want to know what my study is about and how it is going to benefit nursing especially nursing practice. We start discussing what it is that nursing does, what nursing is.

I enjoy myself. It is good to be with nurses again. I feel an emotion akin to report time except that here I know all the nuances. The speaking ways, abbreviations and lab values are not an issue here. I recently heard a woman speaking on the radio about her husband's illness and care who said that the nurse is her favourite health professional and I think about how much I agree. Truthfully if I could choose my company I would choose nurses anytime. They just seem to cut to the quick of things, they have marvelous humour, they 'read' you before you have read yourself, and they know what is essential and important to people, to living, dying. I promise them that when I am finished I will come and tell them about it so they can judge if it is a useless study or not. They reply that they will hold me to this.

We cut our break short as Sarah wants to pick up an article in the library. At the moment, she is involved in a decubitus ulcer (bed sore) research study, a study suggested by the nurses themselves. It will test a bed sore scale, called the Braden scale, to see if an additional daily skin assessment will prevent the incidence and formation of decubitus ulcers. She has requested an interlibrary loan and the librarian left a message for her that it is in. We pick up the article, she has a brief chat with the librarian and we return to the ward. (A year later Sarah presents this study at the Faculty of Nursing's Margaret Scott Wright Research Day. I listen to her presentation. She first identifies herself as a "bedside nurse.")

I have not had time to ask Sarah my questions. In fact, it is a week and a half later before we arrange a time for a taped interview. Nurses live hectic lives. Shift work does not make planning events easy. This is a clip from my taped interview with Sarah. I ask her about being so explicit with the patients. She answers:

Well you know it answers one of your questions on your typed sheet, "what are the essential qualities of the nurse relation and how are they revealed in practice?" Well I find that I try very hard to be honest and have integrity and to be up front and to be clear. You have to look after the patient not only 2 or 3

days in a row but a month later. A lot of our breast patients are often here for a month or two, and then they return. They are very quick these women.

These people when diagnosed with breast cancer go through the system diagnosed usually from a GP to a surgeon, they often have had a lumpectomy done. They've been referred here for their chemo and it didn't work or else they have had radiation and it worked, and now they are in remission, and now they are out of remission. By the time these people come to us they are more professional and more knowledgeable about the healthcare system than you and I and how to deal with it, I would challenge anyone on that, so when they come in I try to deal with them as if getting a consultation with them.

If you are not upfront with them, honest and candid, they'll get you on it down the road and I guess too I always think personally, in my personal life how you treat people is how they treat you. I don't mean to sound like 'oh gosh that is very admirable' but that is how I operate. And if I meet a person who frankly doesn't want to know everything yet or if they have been recently diagnosed say with leukemia and they can't take everything in yet...you can see that the concentration is not there. I know that at the moment they don't want a blazoned upfront type of nurse thank you very much, but it is up to me to assess all of this when I first make contact and I do. It is part of my education and experience.

Twenty years ago most patients would just take the directive, 'You need this test, come on this day.' Nowadays a patient will say 'Well I have a job, I can't make it that day' and you accommodate the patient. It's definitely relationship and negotiation, not just a one way communication belt with the health care individual, whether doctor or nurse.

When I come on in the morning, it is probably the longest time I have in that room apart from the bedbath and so you just plan the day with them. And lately I also let them know that I am a nurse, a registered nurse, and I know how to do this and I am here to do this for them. I do this because now the new staff coming in are not registered nurses...

At the same time of the interview Sarah also tells me that she brought Mr. Lee's observation of the call bell system to the Nurse in Charge of the inpatient units and that the system had been modified to ring even if the receiver is not placed on the hook. "It took me a week to do something about it and by then this patient had been discharged, but it is now fixed."

### *New admission*

On our return to the ward, Russell has arrived. Russell is a gentleman in his 60's who had severe abdominal pain and so his son took him to a medicentre. Here the doctor examined him and told the son that Russell probably had the flu and to return if it had not cleared up in 72 hours. Oddly a young nurse who approached me at coffee this morning with questions about our post RN baccalaureate course also comes to talk to Sarah about this patient. She works casual hours at this medicentre and is also doing the oncology certificate course at this institution. She tells us about being with this patient while he was being examined in the clinic. "I took the son aside afterwards and told him to take his father to emergency. You could see this man had a huge swollen abdomen. I thought he had a lot of fluid in his abdomen and suspected an enlarged liver because of the size of the abdomen. I tried to say this to the doctor, but he was not listening. I think the doctor was trying to rule out flu first but I could tell this man was severely ill. I'm not surprised he is here today."

While exact diagnoses and treatments are not yet available for this man, he is very ill indeed. It was last night he went to emergency after the clinic visit and there he lay on a stretcher in the hall all night. The next day he was seen by a haematologist/oncologist and referred immediately to this institution for assessment and treatment.

Sarah goes in and greets Russell, tells him she is going to do some assessments and begins to take his vital signs and such. He is sweating profusely, has soaked his bed in the 15 minutes he has lain there, his gums are bleeding and so he needs to spit blood every few minutes. His bed is wet with blood and with sweat. He also smells badly of bodily odour, genital odour. Sarah completes her assessments quickly, asks him a few questions, not many as his bleeding gums don't let him answer very well, tells him she is going to check his orders and that she will be back in 5 minutes. He is very quiet, obviously in great discomfort.

Outside the room Sarah tells me that she will not do much explaining today with Russell or any explaining other than what she is doing at the time. "There is a time to teach and impart information to them and another time to just care for them. If the family comes in I will take them aside and speak with them, but for now we just need to get Russell settled and on a treatment and care plan." Later when I ask her about this she tells me about her most recent experience teaching a newly diagnosed leukemic patient. "They were both in shock, both of them, and the wife was holding the baby of 6 months who was crying, wailing really. There were certain things I had to tell him in that moment, but the rest I left and came back to days later."

Sarah goes to the desk and speaks with Anne the head nurse. They discuss possible scenarios of illness for this man. At this point there are no orders except for hydration, pain, bloodwork and xray tests. Sarah goes back and decides to bathe Russell right away as xray will call for him soon. She also tells me that she needs to get his skin cleaned from the sweat and get him more comfortable. "He probably has been sweating like this all night in emergency, so we will just clean him up a bit, and then we can also see just how profusely he is sweating."

Sarah gets a basin of hot water and begins to bathe him. I stand on the other side of the bed and indicate that I will assist as he needs to be bathed quickly, his physiologic status too unstable at the moment to linger. She offers me a facecloth and rinsing cloth and towel and we work together. Russell seems fine with this, really too miserable to care. Sarah tells him she is just wiping some of the sweat off his skin to make him more comfortable and then she will also change his wet sheets. After she bathes his head and neck and provides him with some mouthwash, she puts a basin and towel right under his chin with tissues in one of his hands. "Ah, that's better," he responds.

I notice that Sarah watches me as I watch her. All nurses have their own styles of bathing and their own ways of positioning patients depending on their condition. Yet basically it is the same procedure, the same gestures. She decides I am competent, I think, and then we work quickly and well together, parallel actions. Russell's abdomen is huge, very swollen, and Sarah takes a moment to auscultate for bowel sounds, and to ask him if he feels pain there. Sarah notices that he has a yeast infection on his testicles and Russell says it has been there for some time. Sarah registers that this could be the result of a failed immune system. She takes her time in this area making certain that it is dry after washing. She changes water about 3 or 4 times during this bath, fortunately there is a sink within easy reach in these rooms. We put a clean gown on him.

Together we assist him to turn over and as it on my side, I scrub and rub his back while she holds him steady. Then I strip the sheets and begin to make the bed on that side. Sarah tells him he must roll over a bump of bedclothes and we assist him to turn towards me. All the time we keep the basin under his chin and empty it often during this entire procedure. Sarah pulls the bedding through and makes the bed on the other side. Russell is then positioned on his side with pillows, the basin under his chin, clean tissues in his hand, and a top light sheet loosely covers him. His call bell is at his side. Sarah checks the IV site and rate again and then begins to clean the room of dirty linen, tissues. She washes the basins, tidies the bathroom and the room, exits, brings in more clean linen, towels, gowns and organizes these within the room for easy access. Before leaving the room, Sarah speaks to him and asks him if he is comfortable, hungry, thirsty, and such. He shakes his head and closes his eyes. He is asleep before we leave the room.

I think about Sarah always setting up the space for nursing to occur or cleaning up and arranging the space in each person's room before she leaves. Things of nursing must be ready-at-hand instantly. Disorder or lack of supplies reduces nursing space; order expands nursing space.

Xray calls for Russell about an hour after this. He seems a bit more rested now. Because he cannot move himself well, a patient mobilizer is used. This is a stretcher with a panel that automatically slides under the patient's bottom sheets and then retracts and moves the patient over to the stretcher. Even though the stretcher does the majority of the work, it is easy to see that Russell is quite depleted with this movement.

Russell returns in about another hour later. I help him into bed with the help of the porter and the mobilizer. Sarah is assisting Rick with some care next door and I have been following the multidisciplinary team rounds. I ask Russell how he is as his colour is very poor, he is again drenched in sweat, his gown has blood on it from his mouth, and his breathing is very rapid and shallow. "Poor," he answers, "They kept me waiting in the hallway again, the IV was beeping, and I had to spit up constantly and the basin was full. I was scared, they were nice to me though but they just didn't know what to do with me." Sarah comes in now and tells him that sometimes when the IV beeps he should just straighten his arm because sometimes it is just the position of his arm.

Together Sarah and I again wash him briefly, his face and upper chest and neck, give him a clean gown, remove the wet bedding, position the basin under his neck again and leave.

The remainder of the day is spent giving direct care to Rick, Leigh, Russell, and Cel, checking orders, calling for orders, carrying them out, coordinating disciplines and treatment protocols, attending a brief meeting about a research program for bedsore detection, discussions with other nurses in the med room and at the desk about certain patients and their care problems, engaging in some humour here and there with the staff and patients, putting extra food from trays in the refrigerator for patients to eat later, arranging the most mundane of things and the most serious of things.

There is a flow here of nursing actions within the patients' rooms and outside in the halls, the treatment and equipment rooms, the nursing station, the medication room. The flow just keeps on, constant motion here, a continuity of rhythm. I have yet to see Sarah sit except for our coffee break. All these actions are for the patient's welfare, the patient's plan of care. When the doctor comes to see Russell, Sarah says, "We need to get the family on board quickly."

*Mrs Klar*

Somehow I find myself in Mrs Klar's room. I have answered a call bell for her. She explains to me that she is desperately trying not to have Total Parenteral Nutrition (TPN) per IV. "These IV's you know, they are a constant reminder of your conditions, their drip, drip drip...really it drives me nuts some days, I just don't want more of it." Mrs Klar requests some specific additions to her meals that she thinks she can eat and tolerate in an effort to ward off a TPN with this series of chemotherapy. We speak for a while about this and for some reason I know the particular type of cracker she wants and tell her I will relay this message to the Dietitian. Mrs Klar explains to me that she is trying to lie still and meditate and keep quiet after she eats so she will not throw up. But this is very hard for her as she has not done this before in her life.

Suddenly a flock of birds fly by her window making little bird sounds. She moves her eyes and attention to the window.

These birds you know, they fly by here and perch on the roof of that building over there. I watch them a lot. You know I am a business woman, I run the business and my husband and son work for me. So I am always in an analytic mind frame and I have approached this treatment in the same way. But it doesn't work the same I find. Just as I get things planned, something unforeseen happens. It is hard to plan for all the variables. I find myself thinking of how nice it would be to be free like a bird and fly like that above your troubles. Or I start hoping that there is more beyond this life. And I wonder about the stuff you read about spontaneous healing and remissions in cancer. I feel myself reaching out toward something but I don't know what...but toward something that is not so concrete, so pre-planned, so statistical. I have been given the statistic for my life already and I didn't like it. Really this is so odd for me. But I feel this strongly.

I do not comment on Mrs Klar's musings. It does not seem appropriate somehow. I read fatigue in her face. But I am very engaged and involved in her conversation and she senses this. There are some things I would like to say in response to her and indeed later on in the study, I do. But for now it is enough to listen. She stimulates my thoughts.

When I entered the room and introduced myself, she too, checked my name tag, a requirement of the agency, which reads, Nurse Researcher. She looks at it again and says, "What are you studying?" And I briefly tell her about the study. She replies,

Before I came in here I read these letters to the paper about how we should not spend our health care money keeping people alive and you know because of my

profession, I'm all for balancing the budget and I remember agreeing with these letters. But you know I was kept alive by these nurses when I first came in and I didn't expect this at all, this level of care. When I came in I had severe vomiting and cardiac problems. The nurses were so good, so compassionate. I sent my husband and son home because they could not cope with me like this. When I did this, Karen looked at me and said, "we are here for you, we will take care of you." I saw a nurse today, Karen, I only had her on nights when I was so ill and throwing up, and I couldn't talk much to her I was so bad. But I see her today and I know her as well as if we had talked for days. She knew I was feeling so very ill and she just took care of me. It is hard not to be able to respond, to be socially correct for me, but here I was throwing up in a totally new place. To see Karen today, I know her and she knows me.

I do a few things for her in the room and leave. Her eyes are already closed.

#### *Arlene*

Sarah answers the phone at the desk while she is in the medication room and it is the Blood Bank informing the unit that a patient's stem cells are ready to come to the unit. We have been told at report that there will be a stem cell transplant today on the unit. Sarah goes to find the nurse to inform her and tells her that she can assist.

This particular treatment protocol (and there are many chemotherapy protocols), consists of the administration of high dose chemotherapy drugs over several days. Then on a particular day in the course of this treatment the patient receives an infusion of his or her own stem cells. Patients like this have had chemotherapy before and now either have a reoccurrence of the cancer or the previous treatment protocols have not been successful in stopping the cancer growth.

Individuals go to the Blood Bank and there they undergo an aspiration of their bone marrow. From this their stem cells<sup>3</sup> are "harvested", frozen and stored until this particular day of the protocol. Chemotherapy kills normal cells along with cancer cells. High dose chemotherapy intensifies these effects. A stem cell transplant, stem cells really, stimulate the blood cell growth and stimulate the immune system (both having been "wiped out" by the chemo).

The procedure involves a member of the Blood Bank who brings the frozen bags of stem cells from the Blood Bank, then proceeds to thaw them in the sink of the treatment room. The nurse administers them in the room. This consists of attaching the bag to the IV system already in place, staying beside the patient to assess how she does, and to move quickly if there are any untoward reactions. There are usually several bags of cells, about 4 to 8. Sarah couriers the bags between the Blood Bank staff and the patient's room and stands at the patient's door in readiness to carry out orders from the attending nurse.

Because there is a danger of an anaphylactic shock reaction to the transfusion (yesterday someone's tongue swelled so large the person could not breathe), Arlene's nurse goes over the

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<sup>3</sup> Stem cells are part of the blood forming organs.



protocol again with Arlene. Trish tells her she will get an oyster taste in her mouth and her room will smell like that for a few days. Also she will have blood in her urine so not to panic when she sees it. Following the treatment her face will look flushed in the mirror and she will need to urinate a lot. She is to tell the nurse as soon as she feels something happening in her body. Arlene says, "I didn't hear all that from my doctor." Trish tells her how to live, cope with this procedure. Trish tells her she will be beside her all the time. I think to myself that much of nursing care is "getting one through something."

Trish gives the signal through the glass window to the Blood Bank worker that she is ready for the first bag. He takes it out of a ice packed container, thaws it in warm water, Sarah takes it to Trish who hooks it up to the IV system, stands back and monitors it. I become a runner now between Sarah who now stands at the door of the patient's room and the Blood Bank worker. When the stem cell infusion is at a certain point, I go and tell the fellow to thaw out another one. It takes about 2 minutes to thaw in hot water. There are 5 bags and this goes on for some time. Trish stands next to Arlene. They talk about her children aged 2 and 4.

All goes well. Arlene has begun to suck on a lemon to take away the awful taste in her mouth. Sarah tells me we must not leave until the infusion is finished. Arlene begins to have excruciating cramps in her abdomen. She curls up, brings her knees to her chest. Her shoulder starts to hurt as well. Trish asks Sarah to prepare an antispasmodic drug and analgesic drug, and a hot pack. Sarah does so, enters the patient's room to administer these drugs and treatments which help and goes back to stand at the door. Later I asked Arlene about this particular procedure.

It was really scary you know because both the nurse and the doctor had told me about all the potential side effects and problems with the administration. Apparently it is what the cells are diluted in that gives people the problems. I'm an xray technician so I've seen some awful things in my time and I was imagining all of these. I was told I could die right there from an allergic shock reaction, die in seconds.

But Trish my nurse was so calm and then Sarah was at the door and you were there too helping with the IV and getting me that basin when I started throwing up. These nurses are so exceptional, this treatment is so horrific, you could not wish it on your worst enemy, yet it is all I've got - my children are only 2 and 5, they deserve to have a mother (she silently weeps for a moment)...But these nurses cover all this awfulness with common sense. You feel, after they explain and see you through something, that you can manage even though when the doctor first tells you about it, you can't somehow take it all in. The nurses make it livable later.

I hear Arlene talking to her doctor later this day. She tells him the transplant went fine, no problems. I remember seeing her in such excruciating pain and wonder why she does not tell him about it. I also think to myself how lucky the allied workers are. Nurses carry out all these things, make things work for everyone who visits the floor along with taking care of the patients. In fact, I think that I need a nurse in my life to help me get coordinated, adjusted, coping, seeing me through.

### *Moving the day to a close*

The day moves to a close now. (Sarah has had a brief lunch break this day but she has used it to meet with 2 other nurses who will assist her with her bedsore study.) Sarah says to me, "Now you will see me rushing." (I think to myself, 'Is this not what you have done all day?') "In 10 years of nursing experience I have not yet figured out how not to rush like this sometimes. We have several things to clean up now before report." She lists them and then proceeds to do them, turning patients, straightening and changing the beds if needed, giving out pain and nausea medications, helping another nurse position a patient, emptying excretion and drainage bags, determining intake and output amounts and if they are balanced or not, adjusting the IV rate, signing off drugs, trying to chart her findings from her special nursing paper on flow sheets, most of them numerical values. At the end of this busy mad dash, she sits down again with her charts. "Now I'm collecting my thoughts about each patient as to how they have done today. If I have missed anything, and if something comes clear to me as I write the chart and as I see how others have charted on them, I will do it or suggest it to the next shift in report and say it was not done on my shift."

### *Cel*

The interhospital transport team arrives on the unit to transport Cel to another institution for his dialysis treatment. Here I get a glimpse into the closeness of these relationships. Sarah, Cel's wife Ellen, and I move the patient mobilizer into position, Sarah and Ellen at the head, and myself at the foot. The mobilizer platform moves automatically under Cell and the sheets on the bed and then moves back with Cell in position on the stretcher. Once Cel is on the stretcher he lifts his arms up and backwards to reach Ellen to give her a good-bye kiss. He grasps her head, opens his eyes and realizes it is Sarah not Ellen. We all laugh.

I thought it was Ellen," Cel says, "It's difficult to tell today because you both ate garlic last night and smell like garlic. The only one in this room who doesn't smell like garlic is Brenda.

Sarah says, "It was my ribs last night, I brushed my teeth and tongue like crazy this morning." The porter comes and Cel and Ellen leave. Later I write about smells, smells in nursing. Cel, whose alertness fades in and out with his disease, relies on smells to tell him a good deal about who is who and what is what.

Cel becomes one of my favourite people on this unit. It's difficult to say why. We laugh and tease each other. In the beginning Cel, like many seasoned patients, assessed me so quickly and so accurately it took my breath away. He knew I had clinical expertise and clinical judgment. Yet he also knew that I was not there to use that expertise. I could see him looking at me and sometimes challenging me when his care was being discussed by others on the unit.

On one occasion I was the only person around when he got into trouble with his colostomy bag. I moved quickly to rescue the situation, cleansed and irrigated the colostomy, attached a fresh bag in a new secure way, quickly got the bed in order as I knew Cel was very ill and has little stamina. He said, "You should quit watching and get nursing. We could use you around here." I reply, "Well I'm hoping to learn something about nursing and something about taking care of patients so I can write it in my dissertation."

Cel answers, "You know enough, you should be doing it or teaching it. Forget that writing, just do it. The more I lie here, the sicker I get, I know I can't last too much longer...but the more I lie here, the more I appreciate people who just can see what needs doing and do it and not talk about it or ask me to how to do it. I get so tired of talking to medical personnel." Cel closes his eyes

wearily. I clean up the area and then move to the sink to wash my hands before I leave the room. Cel seems to be sleeping, deep breathing sounds fill the room.

As I turn off the sink, dry my hands and turn to leave, Cel opens an eye and says, "Come back when they bring that mobilizer in. I like the way you get it moving under me, some of the porters don't know how to do that..." I salute him, wink at him, he laughs, I exit the room.

### ***Rick***

Rick has returned to the floor after meeting his donor for his bone marrow transplant and comes toward us. He says, "You know it was quite emotional, I'm just so thankful to him, and I asked him if he was allergic to cats and he said yes. You know, I sneeze and sneeze around our cats now and I never did before in all my life and my doctor told me that maybe my donor had allergies. Isn't that just something?"

### ***Afternoon Report***

Following this Sarah moves into afternoon report. I listen to her give report on her patients. She again gives all the objective data but it is interspersed with her nursing judgments and comments about the status of the person. "Watch Russell, there is something not right there, he is going down fast. It may be DIC. I think he will take a lot of time tonight. The family has still not come up to see him. I've asked him about it but he doesn't reply much at all about them."

As I listen again to report I am again impressed with the network of communication that sustains this place, this place of nursing, these patients who are so ill. I ask Sarah about this.

In all my 10 years of experience I have not grown inured to someone with cancer.

I always, I shouldn't say the word "always," but pretty much all the time, approach my care as "what if it is me, or what if it is me lying there, what would I be thinking about?" Hey you know that you might get these medications and these treatments all the time and you hope that you will get someone with skill to do them - but sometimes for some people frankly they are feeling so sick that just giving the person a facecloth, they'll thank you until the cows come home. It's always been a fine line, so whatever I offer a patient, I always try to come through or if I can't do it right then, I'll say "I'll be back in 10 minutes" and I get back there then. I make my day more chaotic as a result but that is part of being consistent and having respect for the person.

Sarah leaves. She is off to do her running and then a cello lesson. I thank her and we arrange to meet again tomorrow at report.

### ***Postscript: The multidisciplinary team***

In the above description of my first day with Sarah I have not discussed the multidisciplinary team rounds that occur every day during the week. These rounds are an integral part of this unit. Nurses both love them and hate them.

About 1030 a group of individuals come to the nursing station. They are the multidisciplinary team, the house doctor, the head oncologist and one visiting oncologist, a nutritionist, the head nurse, and a pharmacist are represented. On other days I note that there are nurses who work with

specific oncologists and monitor their patients. I have noticed the pastor of the hospital on certain days depending on the patients on the unit, and I have seen a psychologist now and then from the psychology department at the hospital to discuss a specific person.

The rounds begin at one end of the U - shaped unit. The group stand around a chart trolley and as each person is discussed, his/her chart is opened on top of the trolley. The focus point outside the patient's room is the chart; inside the room it is the patient. Outside the closed door of the patient room, that particular patient's nurse describes the person's status and the members of the team ask her questions about the patient, about certain responses to treatments.

Sarah and I join the team rounds just as they finish discussing Shirley. The entire team goes into Shirley's room. They speak to her and ask her how she is doing. She responds and discusses her treatment as if she is another professional on the team. I know she is articulate as a high school principal and as an individual, but I am amazed at the level of interaction, not a whiff of condescension at all. I think to myself, "Gosh most 'rounds' are physician centred to meet medical needs, but I would say at least today, in this particular situation that this patient is the hub of interaction."

Shirley states she is beginning to experience nausea, a result of her treatment. Her nurse asks, "Could we have the gravol ordered orally as well as IV?" One doctor says disparagingly, "If she is nauseated she can't take it orally." Her nurse replies carefully in a laughing joking manner, "Yes I know it seems ridiculous but in my experience gravol is sometimes more effective given orally with this particular chemo protocol, and if she is mildly nauseated she will be able to keep it down." The other oncologist turns to the patient, "What do you think?" She replies that she would rather take it orally as long as she can.

Now outside the principal's room, there is an order written for oral gravol and a discussion happens about the effectiveness of some antiemetics. There is a discussion about the antiemetic maxeran and the head oncologist, in charge of the aggressive breast cancer protocol (high dose chemo and stem cell transplant regime) tells the team that it has been clearly shown as long as 4 years ago that maxeran combined with vinblastine (chemo), causes psychosis in some patients. Sarah tells this doctor that they have had several patients in psychotic episodes and yet no one has mentioned this interaction before. The other physicians are equally surprised along with the pharmacist. The head nurse said that she would write it in the communication book for staff so it would not be prescribed again with this particular chemo drug.

It is now Sarah's turn and I listen to her relate our morning so far. She summarizes many things I would have taken longer to describe, makes jokes with the team, asks the nutritionist if the TPN mixture is meeting Rick's requirements as he has been a bit listless today. The head nurse adds some lab findings and some queries about his status and suggests a couple of things. Then we enter Rick's room. They speak with him and ask him how he is doing. Rick responds and while he is not a formally educated man as was the previous person, he also speaks very well for himself and is quick to refute and challenge decisions he does not like. Rick is amazed at some lab results and the nutritionist answers, "It was the reduction in lipid, you see nutrition works!" They discuss some of the medications Rick is on and the pharmacist says that Rick's symptoms are not side effects of these drugs.

Later on in another person's room the nutritionist speaks to another patient about diet and says to her, "As you are going home, I think we should load you up for a few days on food and fluids first, to be able to cope with the stress of the plane, the trip, and the homecoming." Then she says, "That is what I think, but I want you to say what you think, do you think you could manage that amount of food and fluid for the next few days?"

I notice again that the team asks the individuals to take an active part with the decisions of their treatment, and I notice this day too that when the physicians are out of line, the rest of the team compensates for them. There are also times when the oncologists and physicians discuss treatments with each other outside the door of the patients' rooms. These discussions can become quite heated and quite adversarial. I notice nurses leaving at these times, to the med room to pour another med, to check on an IV site, to see if someone has pain, to call diet kitchen, all activities that are brief and can be quickly left when the discussion stops and the team is ready to move on. Later when I interview nurses, they discuss how difficult it is to stand there through this when all they really want to do is discuss the condition of their patients and get some orders changed, and yet these medical people get into great lengthy "diatribes" about their opinions of certain things. Patients who were well enough told me that while they could not hear the discussions, they could often see their faces, their gesticulating, and that when they come into the room on these days they are stiffer with them in terms of interactions.

### *Endings*

The day has now ended for me and for Sarah, but not for the patients who remain there battling their illness, their treatments, nor for the nurses who carry on with their unique modes of care. I change out of my uniform and think about the flow of nursing care, how there just seems to be a flow, a fluidity of actions, some intense dealing with life threatening things, some essential yet mundane, a rising now and ebb then, and so on.

As I leave I am reminded how fortunate I am to be able to leave and go home to my family, call a few co-workers, have students to teach, that I can make plans and not only that, I can expect them to occur. I am reminded of my friend Frances from Utrecht who recently lost her son, a 27 year old working in computers and business. He died suddenly, in his sleep one night, the result of an unknown cardiac rhythm, probably a genetic heart block.

The very worst part for me was seeing Franz's clothes carefully laid out for the day. Franz had the habit of lying out his clothes for the next day on the table; his suit, his shirt, his socks, his wallet, his watch...what was so awful was to see those clothes and things waiting for him to put them on and knowing he wouldn't, couldn't...that he had plans and then nothing.

The lobby, coffee shoppe, tea house are much more hectic now as I walk by. I feel a sense that this place breathes as one soul as I walk through these spaces again. The faces seem familiar yet I realize that it is their expressions that are similar, compassionate faces with laugh and worry lines and a way of looking to see if you are OK, worried preoccupied and tentative faces. I think that in just a short time these faces have taken on much meaning for me.

A different janitor cleans up the front entry now, the hospital store is open, staffed with volunteers, families sit together in the seating area, security again watch my retreating movements. After my first day I know that this disease and treatment process is much more desperate and much more hopeful than I ever thought or imagined.

I am just at the information desk, almost to the outdoors, then the walk to my car. I hear my name called and I turn around and see a nursing instructor from another institution. She greets me warmly, introduces me to her husband and daughter, and asks me what I am doing. I tell her about my study. It is vague to describe at this point but she graciously listens. I am brief. She tells me that she is now a patient here and so will be seeing me again. But I already know this. I

have seen her face, her colour, her worry lines, her overall demeanor. I notice the gentleness her husband exudes, the attentiveness of her daughter, and I am certain she wears a wig.

I walk outside toward my car and think again how good the air smells; how lucky I am that my body, though tired after this day, works for me, how fortunate I am to have a work to do, how it feels and smells like snow. My heart contracts, palpitates really. I think of the people on the unit and what stretches out in front of them...

## CHAPTER 6: NURSING LIFE: A NURSING UNIT

*"How is the world given to us? At first, not in representation, from a distance, but in the experience of presence. Here the subject is still one with the object, our flesh is still symbiosis with the flesh of things: such is originary perceiving" (Dufrenne, 1987, p. 124).*

*"Rather than bringing one's self to the nursing situation, it is through the nursing situation that one's self exists" (Carolyn Oiler Boyd, 1988, p. 78).*

### *Jim*

Jim, a newly diagnosed man with an aggressive leukemia needs his chemo started as soon as possible. His cells are proliferating madly. He waits for his nurse to start his chemotherapy. Jim paces. He circles around the unfamiliar hallways of the U-shaped nursing unit, his body movements stiff and guarded.

Yesterday Jim finished up an engineering consulting project, helped his wife in the market garden, took the kids to soccer, and answered a late night phone call from his doctor. "Jim this is not an ordinary cold and flu. I've been trying to reach you, your blood work is back. I don't want to alarm you, but your blood work strongly shows that you may have a possible leukemia. Be at the Cross tomorrow at 9 AM for an appointment with an oncologist and he will do a thorough workup." Today, two days later, Jim awaits his treatment.

Jim's drugs have just come from the pharmacy department to the nursing unit. His nurse is in the medication room behind the nursing station. She sets up the complicated IV lines for the initiation of chemotherapy. An aura of concentration surrounds her as she plans the administration.

"Let's see, 2 lines for the chemo, and just in case Jim should experience some side effects, I need some med lines. This particular chemo protocol causes gastrointestinal side effects of nausea, vomiting, diarrhea, mouth and mucous membrane breakdown and pain, perhaps joint inflammation. And it needs to go at this rate per minute in order to give the required dosage in 24 hours, it needs to run 6 times in 24 hours. I need to alert pharmacy that we'll need more on the floor for the 0400 dose just in case they think we won't need it until 0800. If I plan it with these times, he can be free to shower and then visit later. And now to label these lines so it is clear which line is for which medication and on what date the lines need to be changed and then get an IV pump, thread the lines, program the pump. I hope he's still walking while he can." She cranes her neck toward the hallways to see.

She leaves the medication room pushing an IV pole with bags of fluid swinging to and fro, dangling long lengths of IV tubing attached to them and wound around the middle of the pole. She stops at the equipment room and grabs an IV pump. She pushes it with the other hand. Under one arm she carries the electronic thermometer and under the other, the oxygen saturation machine. She smiles at the watchful Jim. He instantly sees "his nurse", ceases pacing, and waits

for her. They walk together to Jim's room. This very morning Jim's nurse has told me that he is in shock and cannot take in any teaching yet.

### ***Rozalia***

Rozalia is dying. She needs almost constant attention as she every now and then jumps up and tries to get out of bed. It is as if she asks, "Am I still here or am I dead?" She propels herself halfway up and then her strength wanes. She grasps the bedside railing. Her upper body flops like a rag doll over the bed rail. There is an alarm on her bed and every time she surges up, the bed alarm rings loudly all over the unit. There is a sense of ambiguity in her room.

### ***Helen***

Helen, in the room across from the nursing station, starts to throw up. It is a violent throwing up, right down to the depths of her intestines. The nurse in Rozalia's room hears her and runs to assist her. Helen's treatment has not pushed her leukemia into remission this time. Helen, a lovely Polish woman has been told that her condition is grave.

In a fluid movement, the nurse enters the room, grabs a towel from the sink as she passes it, quickly wets a facecloth as she moves in what seems to be one unstoping motion to Helen's side. Helen throws up into a basin. The nurse stands beside her, talks to her, hands her some Kleenex to wipe her mouth, washes her face and mouth with the facecloth, stands there. Her hand rests on Helen's shoulder. She asks if the nausea and cramping are severe. Helen nods her head weakly. The nurse empties the basin, returns to the bedside with a clean wet facecloth and a clean basin.

Helen, for the moment ceases to heave. She wraps the facecloth over her face and sits huddled over the basin, her body speaking its suffering. The nurse's concern and Helen's distress fill the room. After a few moments the nurse leaves Helen and hastily comes to the nursing station. She grabs Helen's chart as she moves into the medication room and starts to prepare an antiemetic/antinausea medication for Helen.

### ***Multidisciplinary Team: The Hallway***

A team of health care professionals, about 5 individuals, oncologists, physician, pharmacist, dietitian, have gathered to do patient rounds. They wait for Anne, the head nurse, and each nurse in turn as is the protocol, to join them and tell them the status of their patients. One team member knowing the workload that awaits him elsewhere, has become impatient at the delay. He asks the ward clerk for Anne and Glenda tells him the ward has "gone crazy." He replies that rounds are at 1030 every day. Anne, knowing rounds are imminent and hearing some of this dialogue, emerges from the room where she has been using her advanced nursing skills to assess a clogged central line, a line that goes directly into the cardiac chambers and used for chemotherapy. She moves to the desk, approaches the team member and says with grace and confidence, "We just need a few minutes here. While you wait, would you look at Jim's blood work and muga scan and also Gwen's. The thoracic surgeon still hasn't come to see Gwen."

Helen's nurse comes out of the med room with an injection for Helen and speaks to the physician about the vomiting episode and asks for an additional antiemetic. He agrees and the nurse hands him the chart so he can write the order. Anne quickly disappears back into the patient's room to the central line.

Gwen's husband Ray, comes out of her room and tells Helen's nurse who is now moving quickly back to Helen's room with medication that he is going to get some coffee. But he wants to ask the team about Gwen's chest filled with fluid and her difficulty breathing. He wants to know when it will be drained. Ray has been waiting with his wife for this procedure for 48 hours now.



The nurse tells him that it will be a while before the rounds get to Gwen's room and not to worry, she will bring it up. Ray greets one of the oncologists warmly as he passes by. They speak about sailing. Gwen's hope is to go sailing just one more time.

Leigh too coming out of her room sees the "team" gathered around the desk and in the hallway. Leigh awaits a decision as to whether she is a good candidate for a bone marrow transplant or not. The hallway is a latent space, a potential space, a safe space. No treatments occur here. It is an interaction space. No one is excluded here.

A nurse, a lab technician, and an oncologist have been working in a patient's room. They have just finished doing a bone marrow biopsy on Mr. White. The doctor and the lab technician have just come out of the patient's room. Leigh, while looking at the gathered team, turns to walk down the hall and sees her doctor coming out of Mr. White's room and walking toward her. She takes advantage of the moment to ask her oncologist a question. "Oh I have got you! Doctor, I've been thinking, remember that I am an identical twin, I could use her bone marrow."

At this same moment Cel walks by with his wife, using a walker. Dr B says, "Gosh you look good." Cel replies, "Well they said I could go home if I could walk so that is what I am doing, walking." Then Dr B turns to Leigh. Leigh repeats herself, "So what do you think, how about a transplant?" Dr B who has been smiling broadly watching Cel walk slowly down the hall turns to her and says, "You know a sibling is better than an identical twin because the body needs some rejection to make the transplant work. However I think you are doing well right now and probably don't need a transplant. We'll talk about this." He moves to the desk and pulls out Mr. White's chart to document the bone marrow biopsy.

Chris, the orderly and LPN, pushes Mr. Graham in a wheelchair around this little group, through the gathered team, and past the nursing station toward his room. He wears a blue hospital gown with a towel around his shoulders. His legs and feet are glaringly bare and cover the wheelchair's leg and footrests. He has nasal prongs for oxygen and a portable cylinder balanced on the back of the wheelchair. They have just returned from the tub room, the tub with a lift for debilitated patients and with automated jets, a sort of Jacuzzi. Elsewhere I call it a "carwash bath." Mr. Graham beams in more ways than one. A happiness, a contentment surrounds him. His skin has a reddish glow that radiates. He has appreciated this Jacuzzi bath.

Mark, the mail and specimen courier, arrives at the desk to pick up envelopes and specimen tubes. Glenda, the word clerk, greets him and asks him to pick up more order forms on his way back. He agrees and moves down the corridor, past Mr. Graham, past the health care team and out the door.

### ***The Nursing Station***

The phone rings and it is a cancer nurse from Regina whom one of the nurses has been trying to contact for a day and a half. Glenda, speaks to the nurse on the phone who tells her what the phone call is about. She puts the phone down and just seems to know exactly where to find this nurse. How does she know where she is so instantly? I have been watching all that happens here and I don't know where she is. This nurse needs to give the Regina nurse an assessment of the Rachel's status; set up a blood work and checkup appointments; plans care for Rachel as it will be a weekend when she arrives. Rachel has finished her high dose chemotherapy treatment and has been anxious to have these arrangements in place before she leaves for home. I have interrupted Rachel, her husband, and a Catholic Sister standing together and praying this morning as I entered the room to check her IV pump as the alarm was ringing. Rachel is nervous about leaving this institution where she tells me she gets the care she needs.

The other phone rings and it is the Ultrasound department. Glenda is doing her best to get a patient scheduled for ultrasound moved up to an earlier time because of his deteriorating condition. She speaks with tact and a hint of humour and a sort of promise of reciprocity. When she hangs up, she has successfully booked the patient earlier. As she hangs up the phone, she winks at the nurse just coming into the station and says, "You can take her to Ultrasound right now." "Thanks Glenda", the nurse answers. "I couldn't get them to move it up when I phoned, you're a gem." Glenda then asks the health care team if they need anything as they peruse the charts, retrieves what they ask for, makes a joke about the fax machine having ghosts. The team laughs.

### ***Mary***

The emergency call bell rings and two nurses emerge running, one from Helen's room and one from Rozalia's room. They run into Mary's room. Mary bleeds from her mouth. The blood flows in a steady bright red watery stream down her chin, onto her chest staining her nightdress with ever-growing wet blobs of red. "I know you told me not to brush but you know," she sputters, a shower of blood coming from her mouth, "It was the stew for supper last night, I just had to clean my teeth. I used a tooth pick I asked my husband to bring." "It's all right," croons the nurse, "Don't try to speak right now and we'll get this fixed up."

Mary has no platelets for blood coagulation. This is a serious situation. A quiet controlled flurry of nursing activity ensues. Her bed is rolled up, ice is put in a facecloth in her mouth, she is positioned forward onto the overbed table, the blood now flowing into a basin. Soothing talk continuously flows from the mouth of the nurse. Anne comes running in, assesses the scene, goes to the desk, calls down to the blood bank to see if Mary's platelets scheduled for that day are there, sends another nurse running down the hall to the blood bank. A registered nurse must pick up blood.

A patient's room bell rings through to the central intercom system at the nursing station. It is Rick's room. He has just returned this morning from another hospital where he has had kidney surgery. He is very relieved to be back. He has many serious conditions to battle against. Not only is he a post surgical patient, he also now has confirmed graft vs host disease following his bone marrow transplant. There is a query that he now has hepatitis B along with everything else. Glenda answers the bell with the intercom phone and tells Rick his nurse is helping in another room and will be there as soon as possible. She goes to Mary's room to tell her. Rozalia's bed alarm rings yet again. The flurry in Mary's room moves to Rozalia's. Anne remains with Mary.

### ***Rozalia***

Entering Rozalia's room, two nurses move quickly to the bed, one on either side. Rozalia is draped across the side rail, her upper body twisted at 90 degrees from the rest of her body. Her head hangs down over the side of the railing giving a grotesque sort of shape to her body, almost like a contortionist. How does she get into these positions? The nurse speaks to her soothingly, gently lifts her upper body away from the side rail and holds Rozalia against her. The nurse on the other side of the bed puts down that side rail, smooths the sheets, and lifts one knee up to the bed. She moves in close to take hold of Rozalia's upper body. Together the nurses turn Rozalia straight, adjust her position to proper body alignment. The one nurse holds her as the other then puts down her side rail, puts up a knee to the bed. Then they together lift Rozalia up to the top of the bed, all the while telling her what they are doing. They say they will lift on the count of three and do so.

Rozalia is now in proper alignment. They position her limbs with pillows. Rozalia settles having never fully awakened. She slips back into a deeper state of sleep.

### ***Mary***

The two nurses move back to Mary's room. Here Mary's nurse now administers the blood platelets to Mary, platelets to aid blood clotting. She stands beside the IV pole and hangs new bags of platelets every 1 to 3 minutes. Each bag has about 30 to 50 mls in it. Mary, while still in critical condition becomes a little more stable. The flow of blood recedes. She is in remorse for cleaning her teeth and causing this. "You just never know", she says, "Things you used to do so naturally and unthinking you can't do anymore."

I have spent some time with Mary and her husband. They have just celebrated a big anniversary. The nurses in Outpatients have had a party for them. When they arrived last week for Mary to receive blood products and to have blood work as an outpatient, there were balloons in the room and there was cake. They so much appreciated this party as Mary was not well enough to mark the occasion in traditional ways. I remember still their happiness as they described the event.

### ***Mary, Jim, Helen, Rozalia, Angie, George***

One nurse remains with Mary, the other nurses move out. One goes toward Jim's room to see how the chemo is running. Jim's chemo is running well. She checks his vital signs, reassures him that all is well. Another nurse enters Helen's room where she quickly checks on her. Helen sleeps, the medication has helped. She checks her IV, covers her with a blanket, and moves off down the ward to see Rick, to answer his call. Another nurse goes to where the health care team stand around a rack of charts in the hallway.

Things start to calm on the unit. A sort of quieter, but no less intense momentum, re-establishes itself. Those dire needs of individuals have only been temporarily stayed. Much work must be done now to manage these needs with protocols, interventions, discussion, thinking.

Anne moves to join the health care team and the team moves to stand outside the first patient's room. Before discussing this patient's care and treatment plan, changes, modifications, and untoward events that have occurred, the oncologist clears his throat and tells Anne and the others that he has heard that Angie has died last night. Angie is a patient with breast cancer who had had several bouts of surgery, chemotherapy, radiation, and some alternative therapies. There is a palpable hush, no one moving, no one clearing throats, just stillness.

I look at my watch. Only 10 minutes have passed since I started keeping track of the events on the ward. And I forgot to mention that in the midst of all this activity, George comes to the desk. He says that for the 3rd morning in a row he hasn't received peanut butter with his breakfast and he is angry.

Rozalia's bed alarm rings again. I tell them I will stay with Rozalia for a while at least until the ward rounds are finished and whatever new treatment protocols are carried out. And so I enter just one of these rooms, just one of these patient's lives, in a specific time and in the company of specific others.

### ***The call***

I first met Rozalia a few days ago. I answered her call bell. She wanted me to bring her a tape recorder. She did not want to talk, she just wanted music. I gave her a tape machine and left with the feeling that this individual wanted solitude and personal time. I complied.

Four days later I again answer her call bell having not seen her at all in the interim. Yet I know something about her. I had heard about her in morning report. As I listened to the description of Rozalia's night, of her IV meds and pain status, of her latest blood work and other diagnostic findings, of her unfortunate experience at another hospital where she was sent for diagnostic

assessments of a possible abdominal obstruction, of the night nurse's concern that Rozalia is one to "watch", of the nurse's continued admonishments to monitor Rozalia carefully, "She seems caught in a downward spiral", "She might be going sour" as we sometimes say, I realize I have already a picture of her in my mind.

Morning report begins a continuous 24 hour flow of patient information and communication among nurses. Nurses who have worked either an 8 or a 12 hour night shift go through the patients one by one. They discuss their condition, including their physiological data such as diagnosis, blood work reports, treatments and medications in progress, fluid levels in terms of oral and intravenous intake and output in terms of any sort of excretion, pain levels and interventions, communication from other disciplines such as medicine, pharmacy, foods and nutrition, and so on. They also discuss how the person "is doing", including the person's reactions to the diagnosis, disease progression, and treatment protocol, voiced concerns by the person and/or the family, and end with each nurse's interpretation of the total condition of the person, how things are really going. It is here the nurse giving report will often say, "Watch him, something is not right there."

Yet report never fully prepares you for the impact of actually seeing and meeting the person encoded in the objective/subjective data at report. And it is difficult to get a clear picture of everything that has occurred with Rozalia, i.e. when she first started her high dose chemotherapy regime, when the radiation treatments started, how this possible obstruction came about. I do know that Rozalia developed gruesome pain in her abdomen following radiation treatments, and the physicians and oncologists could not explain what was the cause. She was sent to another hospital for a consultation and further diagnostic testing where she spent two days and two nights on a stretcher in a hallway. She was then sent back to this hospital for further treatment. Rozalia's primary cancer site was in her breast and now she has mets (metastases) to her liver. Before she was sent to the other hospital, she apparently also had some radiation therapy too in hopes of shrinking the cancer in the liver. Rozalia's young family, husband, daughter, son, live in a northern city and are not with her.

What strikes me as I enter Rozalia's anteroom this time is not that Rozalia wishes solitude now but rather that she is an individual alone, unaccompanied. These observations are made all the more poignant by the fact that Rozalia is in a room within a room. I must go through a room to reach her. There is an ante-chamber, a room to wash, mask, and perhaps glove, and this room then leads to another door which enters into her room proper, an inner sanctum so to speak. Both the door to the entry phase and the door to the room itself are encased in windows where one can see into the room and right to the person if the curtains around the bed are not drawn. I stand and gaze through the window.

The ante-chamber seems a transition room. It is a room where one leaves or sets aside the greater institutional workings for a while, workings that push and pull the nurse in many different directions, scatter and fragment one's most careful planning, yet too workings so necessary to interface with in order to coordinate any regime of patient care. Really here one sets aside one world for another and whatever awaits within the room.

Because Rozalia has a very low white blood count, "neutropenic" in medical terms, she is at high risk for contracting an infection. I don a mask and I wash my hands at the sink. As I shed the transient bacteria on my hands and arms I shed too for this moment my other commitments and focus on her. As I scrub my hands, wrists, and forearms, I turn my head from facing the sink to look through the glass window at Rozalia to see if her distress is visible. She calls. I start to assess from a distance.

I see Rozalia lying hunched down in the bed clothes. She is a little person. She looks small in the hospital bed. My eyes are instantly drawn to the middle of her body. An incongruous protrusion of her abdomen dominates the look of her, irreconcilable with her littleness. In truth her abdomen is one of a pregnancy in its eighth month. Is she pregnant with life or death? I wonder. My eyes move to her pale face, still, masklike, remarkable really in its lack of expression, no welcoming turn of the head towards the windows as she hears the washing. Her eyes are held tightly closed.

"She is in pain", I mutter to myself. I look purposely at the IV pump, florescent red numbers displayed on the dials, nothing blinking, nothing ringing, all bags have fluids in them, red medication labels on two of them. My eyes move around the room. It is a sparse room, very little personal belongings in sight. The tape recorder from last week sits idly on the window sill, the cord wrapped around it still. There is a commode chair by her bedside. She waits.

What I don't know rushes to meet me. Patients like Rozalia sometimes change their status very quickly. What has happened since report time? She seems not to have trouble breathing, her colour is pale but not dark or bluish. Has she just finished some painful treatment? I know she is exhausted from her transfer and treatment at the other hospital, but this look is more than exhaustion. How low is she? How are her vital signs, what is her oxygen saturation? Is she febrile now? What is under the covers inside that protruding lump? What does it contain, what does it compress? Is she nauseated, does she have diarrhea, no stool, is she incontinent along with the pain, why is the commode chair so near; I think of these things that I can't see or know at this point, but I associate with this grotesque form.

What I do see is a fixed and immutable human form ensconced in a pile of bed clothes wrapped around her body in disarray as if she has been tossing about. Her face shows no expression. What does she conceal as I think of the mask I have donned and think of her face as masklike? I see a huge abdomen protruding under the bed covers, a little Being holding herself still, almost like a prelude to a corpse. Odd how that thought comes to me.

I do know she is a person who calls. A call must be answered by a nurse, call and response is our discourse, our mode of being, our ethical commitment, but more than that, a call invokes both of us into being. How will this call and the actions and possibilities that ensue from it bring us to more being? Because in a second I'm going to have to "call it" as in baseball game; say it like it is, make a decision, interpret it for others.

I know too that her nurse has gone down to pick up blood products for another patient. And I see her nurse has placed some equipment on the counter beside the sink to take into the room the next time someone enters. I pick the equipment and supplies up, and enter her room.

As I get closer I recognize the sweat on her face and other little things that I know are pain manifestations, the textbook sympathetic nervous system physical symptoms of pain. But mostly I see the person of Rozalia standing in the midst of pain, suffering and alone. I see and feel her desperateness.

I move to Rozalia's bed, put the supplies on a table and lean close to her head. "Hello Rozalia, I'm Brenda, can I help you? Roxanne has gone down to the lab for a moment." Rozalia tries to speak and croaks. I reach for the water glass, support her head, and give her a sip. She clears her throat with a facial grimace and whispers to me, "The pain is terrible." She speaks in a thick accent, Polish I later find out. She indicates that she cannot talk because of her throat.

I have already checked in a sweeping head and eye gesture what is running in the IV. I have seen that the medication IV line, the bag where nurses add the pain medication, is empty but I also now see that she has had the medication only an hour ago. "This medication has not held her", I

think to myself, “She needs breakthrough pain medication, thank God this hospital understands pain management.”

I want to do many things, pull her up and straighten out her body alignment, have a look, a listen to her abdomen, are there bowel sounds there? Then I would decide how best to position her, get some dry sheets and pillow cases on her bed as I see sweat on her face. I want to talk and reassure her as I care for her, cluck over her here and there. All these nursing gestures I want to do immediately. But I don’t.

I ask, “Is it a new pain right now or is it the same pain as before?” She nods. It is the same pain just much worse. Good, as other thoughts in my head about possible causes of the pain cease. Rozalia lives a pain filled world, pain from the disease of cancer and metastases but pain too from the treatments to eradicate, to control the cancer growth. Pain, how can one really measure it anyway? It is what she says it is.

I know that I cannot do any of the above nursing care measures for her because she is in too much pain. She needs the medication first, other nursing later. I am struck with a memory of Tony, my haemophiliac participant, telling me that there is a level of pain that is purely biological. He calls it “the animal level”, where nothing can distract him from it, not books, not newspapers, not TV, not thinking, dreaming, fantasizing; the pure anguish of this level of pain cannot be diverted.

### *The response*

“I’ll get you something right away, hold on for another few minutes”, I say to her. I ring out the facecloth that is on her bedside table in a basin of water, and I wipe the sweat from her face and neck. She moves her face from side to side to help me, stretches out her neck for a wash. I am reminded of my cat stretching her chin up to be scratched. I wash and then dry the areas. She is thankful. I reach for the glass of water and give her a sip of water for her throat. She is grateful, closes her eyes, and slightly nods her head in thanks.

She has not moved her body at all, it remains as a stiff entity. She does not raise her arms, hands to help. She lies unaltered really from my original gaze. I touch her nearest arm briefly and say, “I’m going now to get the pain medication”, and I leave the room.

As I leave, I think about continuous care. I cannot resist doing a couple of small things to make her more comfortable for the few minutes before the medication comes, even though I know I cannot do or assist her with the “big things” of repositioning, etc at this level of pain. I could do those small things in a moment because I know they will help, are pretty non-invasive and will give some immediate relief for a couple of minutes. But I know that I really COULD do them because her nurse has set up the space around Rozalia in a way unique to her care. I could just move in, wipe her face, the basin of water, facecloth and towel were right there, the glass of water with ice chips was there, the IV clearly marked with what medication has most recently been running, etc. And I could have also done the bigger things as the needed equipment and supplies, foreseen by her nurse, were waiting to be taken into her room. They stand in readiness for use, eg. the oxygen saturation machine, the lotion, the linen, the fresh ice chips.

Rozalia’s nurse is back on the unit when I exit and I tell her about Rozalia. “Gosh her pain is really increasing, I wonder what is going on,” she mumbles as she thanks me and goes to the medication room.

Later this day, I again enter her room to give her more music tapes that the recreation therapist has brought to the unit in response to a request by Rozalia’s nurse. As the therapist can’t enter the room, I again go through the entry phase and preparation routine in the anteroom. Rozalia blesses me with a sweet look, indicates that she knows exactly who I am, whispers she is much

better now thanks to getting the pain medication. I set the tape recorder on her overbed table and put in the tape. Rozalia asks me to move her table closer to her. She still lies on her back but now in proper alignment, her protrusion still present but now covered up by the clean sheets, and she both greets and thanks me for the tapes. She still appears exhausted and very ill with a somewhat surreal quality that continues to hang about her. I hover and wait to see if there is more she would like, if she wants to engage in a conversation. She does not and I leave.

### *The interim*

Two days later I am with Laura. Laura is Rozalia's nurse today. Rozalia has become quite ill in the intervening days, has massive diarrhea and is very weak. She needs to use the commode chair frequently as she is too weak to walk to the bathroom. Rozalia prefers to get up to the commode chair rather than use the bedpan and the frequency of times of getting up and down exhaust her. Laura and I assist her to get up. I know that Laura senses my need to help rather than stand and observe, to be involved with Rozalia, and she somehow understands it. There is no doubt that the most heavy nursing measures are easier with two nurses yet this is not what motivates Laura today. My need motivates her. I, as researcher-nurse, continue to be nursed in this setting as I am given permission to nurse. Here myself as nurse nursing, yet nursed, myself as researcher researching, yet researched. Odd. It is akin to the treatment modalities I was trying to equate: cellular destruction (effects of both disease and treatment) with the necessity of regenerating the immune system make me think of the person's self; re-making the self to cope with this onslaught of disease, treatment, care, recovery, return to lived world.

Several times this day Rozalia gets up and after a while Rozalia in her extreme weakness, forgets and starts speaking in Polish. Laura becomes concerned about this especially as Rozalia has always been fully aware of her situation and her surroundings. She seems now to come in and out of confusion. Laura sees this moment as a turning point. I know she worries about cerebral ischemia, the first symptom often being a change in mentation although she does not say anything. She negotiates a move to another room close to the nurses station, again with large windows that enable nurses to watch Rozalia from the desk. She discusses and requests some additional blood work from the physician.

Each time Rozalia finishes on the commode chair, she insists on carefully wiping herself with tissue. Then she stands up beside the bed for a minute and proceeds to lie her torso across the bed. She bends from the waist and places her head, her chest and her abdomen on the bed. Her head turns to the side, her eyes close. She lies there. Laura and I look at each other and wait.

Rozalia seems to be in a state of suspended animation here, her huge abdomen compressed on the mattress. It serves to remind me that even as I see the size of this abdomen as incongruous, I suspect and know that Rozalia it is a part of herself, something she must manage. As I watch her torso lying on the bed with her feet on the floor, I think, "Oh gosh, just what does she compress, is this ok, will this pressure cause a blood vessel to rupture? But what I see is that she is comfortable. Perhaps putting pressure on it, lying on it, relieves the press of it against her spine for a while.

Laura and I wait. We wait for Rozalia to signal that she is ready to move. Somehow she knows that we will wait. We wait for her to not only gather her strength for the move into bed, but also for whatever is happening here for Rozalia, the comfort of the position? Still I think, "What an odd stance! How individual we are in our self comforting."

Laura and I bathe Rozalia in bed. She lies still, seemingly relishing every stroke we make. Now and then she moans, appreciative little utterances as we stroke, wash, rinse, powder, massage, apply lotion. Laura and I become quiet and work in tandem; one on each side of the bed with

opposite yet identical motions. It somehow seems like a liturgy over her body complete with Rozalia making responses, responses of comfort, responses of pain. I catch myself thinking these thoughts and wonder where they come from.

I watch Laura make skilled assessments in conjunction with bathing various parts of Rozalia's body. I see her watching her respirations, feeling the temperature of the extremities, checking for pulse points, listening for bowel sounds in the abdomen, palpating the abdomen very gently, all the while speaking softly to Rozalia. My own eyes follow hers as she quietly goes through these assessments. I check the right foot and ankle for pulses. Sometimes I jump ahead as I see where she is going with these silent checks and try to catch what she thinks. We put a bed alarm on her bed as Laura worries about her cognitive state and decides she is getting too weak to continue to get out of bed as often.

The day wears on and Rozalia becomes more and more restless. Rozalia now speaks and mumbles in Polish only. Her blood platelets fall to less than 10 and she is given transfusions of platelets and blood products to prevent spontaneous hemorrhages. (A platelet count of less than 10 signifies that they cannot find any platelets to count. Any little tear in her body, inside or outside, can result in a major hemorrhage. Little tears happen all the time within the workings of the body but blood platelets rush to the scene and start the clotting process).

The doctors, oncologists, assistant oncologists, ward physician, gather outside her door. Rozalia has been on a high dose chemo protocol. The physicians discuss the fact that they now believe her to have veno-occlusive disease of the liver. Or it could be disseminated intravascular coagulation (DIC)<sup>4</sup>, a condition where there is an alteration in the clotting mechanism of the body where both clotting and hemorrhage occur the same time. These situations sometimes occur with metastatic cancers. The physicians deliberate; their expertise shared out amongst themselves.

As the discussion continues, the physicians begin to debate quite heatedly with each other about how to manage Rozalia's treatment, whether or not to try special treatments. They do not discuss prognosis. The pharmacist, nutritionist, nurses, look on. These discussions sometimes frustrate the nurses as each doctor seems to have his own stance on how they should precede. Anne, the Head Nurse, tolerates this well and can be seen mediating and suggesting treatment that is in keeping with the person's condition. Or she can be heard to veto some suggestions with specific questions as to the expected results. Yet she is so gentle and quiet, her management of these diverse individuals amazes me. She should be in the United Nations.

I notice some other nurses walk away when these discussions start because they become annoyed with what they see as discussion and what they see as argument superfluous to the person's condition. "They sometimes forget that there is a person here, they don't discuss pertinent things and if so, they only do so for a minute, and carry on another argument", one nurse tells me. Another says, "Well I know they are working through how to best treat the condition, but

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<sup>4</sup> Normally blood clotting is restricted to a local area; "however, if the stimulus to clot is great, the mechanisms that control the spread of clotting (blood flow and clotting inhibitors, especially antithrombin 111) are overcome and widespread clotting occurs" (Lemone & Burke, 1996, p. 1280). "Endothelial cell injury or the release of tissue factors may cause widespread activation of either the intrinsic or extrinsic clotting pathways or both. As a result, numerous microthrombi form throughout the vasculature, causing ischemic tissue damage. Simultaneously, the rapid consumption of clotting factors by the coagulation pathways and fibrinolytic mechanisms triggers widespread bleeding" (Lemone & Burke, 1996, p. 1282).



sometimes it is hard to stand there because a lot of it is different opinions on how to treat. But we need these physicians because they need to direct the medical care.”

If the physicians discuss treatment for their patient’s current problems and care, I notice the nurses stay. If there is a power struggle or battle of wits in terms of new research, past successful treatments or talk in generalities going on among the physicians, the nurses walk away, continue their work, and return every so often to see if there is any progress back to the care and treatment matters at hand. I am amazed that the nurses seem somehow able to “time it”, to be there when the final pertinent treatment decisions are made, which unfailingly and uncannily result in the doctors ordering what the nurses or Anne suggest in the first place before the arguments. I think to myself that someone should do an ethnography of these rounds, there is so much in them in terms of interdisciplinary workings. I also wonder if they notice when the nurses wander away, if it has an effect on them coming to consensus and I suspect sometimes it does. I too have a sense that this is how these physicians vent; how they express their emotions over failed care.

I am however, filled with respect for these nurses. Their ability to connect deeply with their patient’s suffering enables them to just “know” what is right for the person at this particular moment. To me it is a knowing by engagement with the person, officially, it is called *clinical phronesis* (Schultz & Carnevale, 1996).

But back to the medical rounds. These comments are not to diminish medical care. Anne, the head nurse, tells me that these seriously ill patients must be discussed carefully and thoughtfully, because there is usually more than one way to treat the condition, some recent research or experience of the individual doctor. I wonder though to myself why they don’t include the patients in these arguments. Whatever they have to say cannot distress them anymore than what most patients visualize themselves in the absence of information.

This time however Laura stays with the discussion (quite loud arguments really) and insists that whatever they decide they must call the family as she feels Rozalia is changing quickly. One doctor does call Rozalia’s husband, but does not emphasize the seriousness of Rozalia’s condition. He tells the husband that Rozalia is not as stable as she has been but that they will try some more treatments. Laura is very unhappy about this because she believes Rozalia is visibly deteriorating before our eyes and should have her husband with her. Afterward Rozalia’s husband phones and Laura tells him that Rozalia is doing very poorly and that she is worried. Rozalia speaks to him in Polish but as she is so weak the conversation ends quickly and we don’t know what she has said.

Odd, it seems these physicians can only see this woman right now as a body who has failed to respond and eluded their treatments. It also seems that the person cannot be judged “dying” even in the face of total systems failure, until the physicians can accept them as dying. Even then it doesn’t seem as much a loss of an individual as a failure of their treatments. This sounds harsh, and it is probably not entirely accurate. It is in the nature of medicine to try to treat whatever they can in hopes of a cure, a turnabout. Yet there is some operative element here that that leads me to think this. The physicians seem really at odds with one another; Rozalia deteriorates moment by moment. I, as most nurses, greatly respect medical knowledge. Decisions like this are not easy to make. I think, in truth, that these fine doctors believe they can still reverse Rozalia’s state by this calculative type of reasoning. And I hope they can too. It is just that the signs of progressive deterioration are too present right now and Laura feels this keenly. She is wanting to get the family together, to do certain other things for Rozalia because she believes that this could be it. For me, I think about medicine’s *modus operandi*; that it is quite different from nursing. It is not primarily relational. It is diagnostic. If it were relational, I think they would feel a sense of loss of Rozalia. Rather here they feel a sense of failure.

It is at this point I volunteer to stay with Rozalia because her bed alarm has started to ring again on the unit. I have too had enough of the physician's arguments. If I go, Laura can be part of these 'discussions.' It too will be a while before the emergencies and situations described above, have settled down.

Rozalia is too restless to leave alone. She lies in her characteristic "still" manner. Then at unpredictable times, she jerks herself awake, instantly sits up and tries to get out of the bed.

In the midst of these jerks, I talk to Rozalia. I say, "Rozalia, Hi, all is fine, we are still here, it is OK Rozalia, it's Ok", and stroke her arms to soothe her, to let her know in a bodily way that someone is with her. She settles down immediately. I do small things; reposition her with a pillow under her legs or put her on her side with pillows supporting her. But her body is quite non-malleable, inflexible, and side lying is not something she finds comfortable for too long. Yet I know I must continue to change her position. If she has DIC then she should not be lying in the same position for very long, too much pressure on blood vessels.

She is enormously grateful for these ministrations and for these small chats, the soothing sounds I make. I also try, in the different positionings, to hold her body close to mine as I move myself into position to position her body. It is easier to move someone by positioning oneself close to the other (body mechanics), yet this special closeness is also deliberate as it seems to soothe her. I notice she stays quieter longer if I do this. I give her sips of water as thirst becomes a serious problem in end stage disease. Did I really say this? I don't think the physicians yet consider this end stage disease. Later I give Rozalia mouthcare as she begins to breathe through her mouth, and will not accept sips of water anymore. I drop water droplets on her tongue, she still swallows.

As time moves on additional technology is added to the room, to her body. At this point it remains in the background as her personal self, her personal body care at this point supersedes the monitoring of the machines. One monitors her vital signs giving frequent readouts, the IV drips on a pump, yet now and then I disconnect the pump to run blood platelets quickly to decrease the hemorrhage possibility. The physicians worry because the haemostasis associated with DIC alternatively clots and hemorrhages. Laura comes in and out of the room, adds different types of medications to the IV, asks me questions about her relative status as she carries out the new protocols decided upon by the physicians. They endeavor still to find something to reverse this process.

But despite these efforts, Rozalia's body shows signs of continuing deterioration. Her abdomen increases in size as we watch, petechiae appear all over her abdomen, chest and back, we can see these little vessels breaking and forming bruises as we watch. Difficult to describe this scenario; to be with this body as it deteriorates before our eyes and to care for it and yet too to be so very aware that this body is Rozalia and Rozalia lives still. This body affects us deeply. Even bodies such as this, deteriorating ones, are lived. How best can we help Rozalia live it, leave it?

Where Rozalia is in the spectrum of life and death, we are uncertain. The physicians believe they can reverse this process. Laura believes that she dies before us. Rozalia has retreated to interiority. She is in herself. Yet she still craves these small ministrations.

Rozalia pulls us into the mysteries of life and death. We feebly try to explain these mysteries. We cannot. Rather we understand that she lingers here perhaps? Those signs that signify life, that signify death are both apparent here. Something hovers though. Something waits to be actualized. Waiting takes the place of curing; waiting to see what treatments may work, waiting to see if the body will shut down even further, waiting to see how Rozalia responds, watching for signs from her, from her body.

Funny I think, I hover too here. I remember someone once describing a family member at a death bedside as a “buzzard”. Am I a buzzard here, the voyeur I so worried about at the first report on this unit? Or am I a companion on Rozalia’s way to death. Perhaps from the medical point of view, I am a buzzard, a watch dog. From a nursing point of view, I am a companion on Rozalia’s journey. My mandate is clear: assist her to live this deteriorating body. Rozalia lives every moment of this body’s life, the pain, the relief, the comfort of medication, the acceptance of platelets, the chilliness of the blood transfusions, whole blood to counteract the destructive processes of DIC, the ability to hear the crooning, soothing of Laura and me and others, the resurgence of the will to live as she jerks herself upward every so often. If there is one thing I know it is that Rozalia wants to live. Her unuttered cry echoes in this room.

Laura constantly moves about in and out of the room. She manages and charts and reports Rozalia’s responses to treatments, her non-responses to them, her unexpected responses to them. She describes and interprets these to the doctor who comes and goes throughout this time. I see Laura managing too the doctor’s gradual coming to know and coming to accept what seems to be a shut down of all systems, multisystem failure as we call it. In addition, Laura still cares for her other patients out on the ward; drugs need to be hung, care needs to be given; other patients immersed in their own unique situations experience Laura as herself, their nurse, calm, unhurried, confident.

Nurses do not have the option of choosing distancing behaviours in these dire cases. We leave the room, but we take her with us in every action outside the room. To live this is distressing to say the least. Anne and the other nurses help Laura with some of her care as they are able. In fact, the support of the whole nursing staff is here, people ask if they can do things, offer to run to the blood bank for blood, say they will hang a medication for them. When they hear the bed alarm ringing, they come in and help myself or Laura turn her, re-settle her.

Late in this shift, there seems to be another turning point as Rozalia begins to pull at all her tubes, especially at her central lines, her oxygen tubing, anything she can get her hands on. Her level of consciousness fades. Meanwhile the physicians continue to discuss the different treatments as she fails to respond to some, responds to others. They order more blood work, additional medications, blood products, etc. At this point Laura is in constant contact with them, informing them of Rozalia’s condition almost moment by moment.

I leave this shift after 11 hours of care with Rozalia. It is hard to go because there is a bond of concern here that is difficult to leave and turn over to the next nurse. But Rozalia needs fresh nursing care. Yet bizarrely it seems that this is where my life is. I don’t want to go. It is hard to leave this world and engage in another. Even though I know as I pass through successive worlds, the Other will eventually become my essential world, my personal dwelling place. But right now all of it seems very Other. Others are not in the throes of life and death. Rozalia is. Out there, others seem like poor actors missing the essential themes in life, where there seems to be little concern for living well, for the fragility of life, for the thankfulness to be disease free, to not have a disease entity encroaching on their life.

Here essential elements of life cleave and crackle, the margin between life and death clouds. That mystical line seems palpable. Reality, true reality, not something contrived, is within this room right now. I think of Rozalia’s husband, her two young children. Rozalia does not want to die I know clearly. She wants to live for her children. I am reminded of those who embrace the futility of life yet have health in their bodies. What would these people say to this heroic quiet personal private struggle? I think of Simone de Beauvoir as she sits with her mother as she dies too of cancer in the abdomen and her thoughts; whether you think of it as heavenly or as earthly, if you love life immortality is no consolation for death.

All throughout this day Laura has asked me if I need a break from the room. She knows it is difficult to be with patients like this for very long. And too, she still nurses me knowing how she too feels in these situations. But she also has this uncanny insight (where does it come from? I have not spoken with her before today), that I need to be in this situation right now. It presents something that other nursing situations have not. I need to understand something more about life, about death, about nursing. Yet she wants to protect, to make certain I can handle it.

I am aware of all these things, all these thoughts. I know I have reached my limit. If one nurses well, one learns to know one's limits, the effect of one's behaviour on others. An acute self awareness is present in nurses who nurse well. The signs are all there. It is time to go.

I grumble. I'm annoyed that Rozalia's husband who lives in Fort McMurray is not here, that the doctor did not make it explicit to the husband. I find myself irked that this high dose chemo did not work. And I know I know too little about the medical status of her situation. I know too much about her personal status. Yikes!!! It is my former student Christine who takes over her care this evening. I am happy about that. I leave.

Later at home this same evening, I find myself overreacting emotionally to something very insignificant. I think back and remember Laura telling me, "You have to be aware of when you need to take a break, All the nurses here know this and you only need to ask." I find myself acknowledging that this situation with Rozalia affects me more than I know. And that while I am very self aware I have ignored my insights because here I am the researcher along with being the nurse and fellow human being in this particular situation. One said "leave", the other said "stay." I have not paid attention.

#### *The next day*

At report the next morning, Christine gives us a long account concerning Rozalia. When she is finished, she gets up and returns to the nursing station. As the day shift nurses make their special work paper, consult the kardex for information, plan their day, talk about the expected inservice today and how to organize relief, Christine keeps coming into the report room to tell Laura more nursing communication about Rozalia's IV lines, about the blood results, about Rozalia's status. Laura says to me quietly, "Christine is having a hard time leaving this morning."

During report, Christine tells us that Rozalia has continued to deteriorate, that she has pulled out her urinary catheter and now has a perineal bleeding. This is important as her platelets are very low, and this could be a potential hemorrhage that could not be easily controlled. Christine states she is now unable to get a pulse in her arms and feet.

As Laura and I enter the room, Christine takes a long time to leave. She is in the room working the automatic BP machine monitor as it is impossible to get one otherwise and gives us some hints about what is working best with the monitors. She tells Laura more anecdotes about the night and adds much technical and pathological knowledge. Laura listens carefully. Christine talks of how she could not get out of the room there was so much to do. Yet she still had 5 other patients to look after. I watch her finally walk to the stairs visibly drooping her shoulders and upper body. I see her fatigue. Because she is one of my former students and an excellent practitioner and I think that she may have some of the feelings I had last night, I run and catch up to her just before she reaches the stairs. "Well done Christine, Laura will take care of her. If Rozalia could, she would thank you too. I know you are one of the best intensive care nurses on the floor." She acknowledges her old instructor and says she knows this, it is just hard to go. We stand and talk for a few minutes. She has nursed Rozalia several times on this unit and knows her medical history and her personal history. Her conversation impresses me deeply and I am very proud of her. Christine thanks me and turns to go. "I will not see her again," she says.

This morning Laura too is concerned about Rozalia's breathing, (communication from Christine at report). It is very much laboured and sporadic. Her core body temperature is falling, it is difficult to arouse her, she loses consciousness fast. Laura asks her if she would like her husband to come and Rozalia nods her head and then lapses back into semi-unconsciousness. Laura calls the physician.

The physician comes immediately to the ward even though it is only 0745. He enters the room and goes to Rozalia, bends down, touches her arm, and says with great emotion to her, "Oh you poor unfortunate woman." He shows much concern and much emotion. He examines her, decides to order more platelets because of the perineal bleeding and leaves saying he will be back. Laura says to him, "Please phone the husband and tell him to come immediately." He says he will.

Laura follows Richard out. At some point he has become to me, Richard not Doctor. She wants to make certain that he calls. She says she will call if he doesn't. Laura comes back into the room and says that she had to insist that he call her husband when they got to the desk. He wanted to wait a bit longer. "He called him and said that anyone who wants to see her should come right away. Then he immediately went to the med room and drank some diovol," says Laura.

There is a phone call in the room and Laura answers it. It is the husband. He says that he has just spoken with the doctor. He did not know she was so bad. He is on his way. Laura asks him if the children are coming and he says yes. He asks to talk to Rozalia. The phone is put on her ear but she does not wake. It is a 6 hour drive from her home so Laura calculates the time he will arrive. She ends the conversation by saying to him, "Make certain that you drive carefully and safely, we'll be waiting here for you when you arrive."

She hangs up the phone. She bends down close to Rozalia, almost nose to nose. She takes Rozalia face between her two hands and says quite loudly, "Listen Rozalia, your husband and children are on their way to see you. You hang on now Rozalia because they will want you to be awake when they come." Rozalia seems to slightly nod her head within Laura's hands.

The day progresses with different treatments being prescribed, blood products given, monitoring equipment nursed and recorded. Rozalia is turned and positioned and cleansed and kept warm. I spend the day with her wondering most of the time just what I should be doing. It is true that Rozalia has become mostly corporeal, her body more thing-like but I rebel against such thinking. She is still Rozalia. The white expanse of the sheets covering the rise of her abdominal protrusion, the littleness of the rest of her seems like a shroud, a body-bag somehow, a pre-shroud perhaps. Sometimes she sleeps very deeply and seems far away. Other times she is restless; now not able to pull herself up with grasping the siderails. In fact, she cannot propel her body much at all anymore. "The body by itself, the body at rest is merely an obscure mass, and we perceive it as a precise and identifiable being when it moves towards a thing, and in so far as it is intentionally projected outwards" (Merleau-Ponty, 1962, p. 322).

I want to talk to her and I do so and it seems to comfort her. Then at another time talking and noises within the room disturbs her. I stop talking, turn down alarms and techo-noise as much as I can when I see it increases her restlessness and pulling on tubes. She is surprisingly strong for a little person in this physical state. Today the betweenness, the line between life and death is clearer. I stand in it. I think of my Cree students who talk about there not being such a distinct line for them between the earth and the spirit world. It seems I can almost see the spirit world yet I know this is fanciful and stand up to attach the next medication to her IV.

Should I try this or that? Basically I provide nursing to her, the monitoring of bodily signs, treatments, activity in the room. But one feels one should be able to do more. At times I ask just

what am I doing here anyway? Yes I am nursing her with concrete measurable actions, yes I am with her in a deep way, yes I feel myself almost in a constant dialogue with her and with the universe, asking what would be the best way to “be with” her right now. A response always comes back the same, “Just be with her, don’t leave her alone, stand beside her.”

I think to myself that she is a wise woman with the wisdom that comes from a European background, a place rooted in much suffering across the decades of the 20<sup>th</sup> century. And I know that the nurses here, Laura, Christine, myself, others who have cared for her over the times of her hospitalizations, suffer too. To see suffering such as this brings us face to face with our own vulnerabilities, our mortality (I, too, will die), our own capacity to suffer and the likelihood that we too will suffer in this life.

She still is so alone, a little woman alone. She is surrounded by such a sense of aloneness it is hard to describe. It seems she prefers it this way. Worldless. That’s it, she is worldless, I think and “worldlessness is always a form of barbarism” (Arendt, 1955, p. 13). The world of her family has yet to appear. Her world is here with us as we posit our actions, our bodily movements directed toward purposeful objects and determined actions. We as nurses are dissolved in this space. We are as integral to the space as she is.

When I, in my mind say to Rozalia, “What can I best do for you?” I imagine I hear her to say, “Stay with me as much as possible and watch for me please. I’m better with someone with me, when I wake and hear someone’s voice, I just think, yes I am still here especially when I hear someone’s voice. When I am alone I wonder where I am.”

Somehow I hear this clearly and I think to myself, “Gosh I mustn’t do that, give her a voice. What will the feminist researchers say?” Yet acceptable forms of communication fade quickly here. And I think there is some irony, some sense of rightness here. I think, “Yes I who don’t know her well stay with her. I wonder if she has always known that it would be I who would stay with her. She always had an eye for me, a recognition maybe similar to the insight of Laura’s; that I needed to be here. It makes sense somehow, congruent with her aura of aloneness. It is hard to penetrate, yet she seems comfortable with me, me, a relative stranger. I calm her as others can’t. It seems to me that from the first call, the call bell, somehow she has wanted this.” I become fanciful here yet I have talked to people who have told me that it is hard for patients to leave their favourite nurses, and they have told me that it is hard for nurses who have known them to see them deteriorate like this. I also think of my own human personal characteristics and my own nursing behaviours intersecting here and ponder a while the blend. Which ones are me, my inner core? Which are nursing?

Richard returns and tells Laura that he wants to try something that may shunt the blood away from the liver. It is an experimental treatment but has been proven to work. He is in the process of phoning around the province to see if this particular tissue protein is available. I see an academic paper in his lab coat pocket that has a title “*Tissue protein and veno-occlusive disease*” or something like that. I think to myself “Oh you poor unfortunate man” to echo what he has said to Rozalia. He believes he has failed to control this disease process. Or do I judge too harshly. Is it that he must exhaust all avenues, this is his mandate as a physician, a director of her treatment? Yet as I view Rozalia and her body continuing to shut down, a living corpse really to be truthful at this point, I wonder how he as a physician can hope that all present cellular damage can be reversed. But again I acknowledge I do not know the medical domain as I know the nursing one. Yet I am also humble in the face of Richard so engaged in his own way, trying so hard to treat this woman.

Laura shakes her head when he leaves. “You know if they decide to go ahead with that experimental treatment and it makes her worse, I will be very angry and I will talk to Richard

about this. Right now I have to keep Rozalia with us until her family comes. Her family must be able to see her, and my hope is that she can respond to them. That is why I am giving her the best nursing care I can, protecting her from too many onslaughts of treatments, so that her family can see her alive when they arrive. I also know that I will be doing some of the hurting for the husband when he sees her like this.” Some say that nurses have a calling, a vocation. Others would scoff at this notion. But here I see Laura being called. Her calling calls.

I continue with Laura to nurse Rozalia along; Laura doing the IV medications and blood products now, myself comforting and caring for Rozalia’s physical needs, both of us speaking to her now and then. Laura and I in our relatedness, work silently together, moving, lifting, cleaning, positioning Rozalia. We create a world together. We work together in unison again with nursing gestures. I noticed this my first day on this unit. Another nurse can come in the room and instantly engage in the flow of nursing care; their bodies work in harmony.

I no longer feel the terrible sense of Rozalia’s worldlessness. I know that she is in a special nursing world, a world of expressiveness, where each of us reveal our particular blend of our ownness and our nursing selves in our unique way. It is a revealing like a painting, our acts transformed into consecratory gestures.

Rozalia’s body is truly shutting down. Her temperature is now 34 degrees C and her extremities are very cold. Even though I know she is not cold, I still want to put blankets on her because I think she will be more comfortable. But she is not. She feels the weight of them and does not want them and pushes them off. I move the pillows around, straighten the sheet. She likes this and becomes quiet. Early the first day Laura established with the doctor that she was a full code, that she will be given full treatment should she stop breathing or should her heart stop. A code will be called if she arrests. It is hard to note when this plan of action changes. Because today she is not a full code. Today she dies. The transition from all active treatment to passive care has been hard to notice; it just seems to have crept into the room.

Realities keep shifting here. Now they have decided not to give the tissue protein as it would cost \$2000 or more for it, it would have to be flown here, and the results are not certain. I suspect that in consultation with other physicians especially the one that heads this protocol, it was discouraged. Rozalia’s state is too far advanced. Rozalia’s body shifts too; as it becomes more a thing it is as if it too prepares itself for a sort of transformation or transportation. Perhaps when we are ill and even now as mortally ill, as our bodies express themselves more fully, become more adamant, perhaps this prepares us for the transformation of life.

But where is Rozalia? Where has she shifted to? I imagine she has shifted to an interior realm, “into the invisibility of thinking and feeling” (Arendt, 1955, p. 19). Has she done this, an *inner emigration* (p. 19) in the face of an unendurable reality? Is this now the space for herself to be, a “flight from the world into concealment”? (p. 22). Is this why I feel she is so alone? She has left us? Maybe I feel so alone? She is not obligated to this world anymore (Arendt). I should not pull her back. With thoughts such as these I leave again with great difficulty at the end of the day.

Laura stays, she waits for the family. So much waiting occurs in life and death. Laura is clear that she wants to be there to orient them, to be with them as they enter their mother’s room, to gently show them how to be with their mother in the state Rozalia is now in. The last thing we do together is to look for Rozalia’s lost slipper, we worry that we have sent it down the laundry chute with the many bed changes we have done today. We moved two slippers to this room, slippers she needed in life. Today we can only find one, slippers no longer needed. We straighten the room, put Rozalia’s belongings, so very few belongings, a housecoat, one slipper, some personal

items, in the closet in an orderly fashion. I leave Laura still worrying about the slipper. We have been through all the laundry bags that are now on the floor.

### *Next morning*

The next morning, Karen in report says that Rozalia dies at 6 AM. Her husband has stayed with her through the night. Laura is not here today, she is on days off. Christine is on days off. Karen says that she has not done up Rozalia's body because the husband went to pick up the children where they were staying so they could say goodbye to their mother. They are now on the ward in Rozalia's room together.

They arrived last evening and Laura embraced them and took them into see Rozalia. They stayed with their mother and then the children went to a Polish friend in the city to sleep and Rozalia's husband stayed the night. Rozalia knew them when they came, spoke some Polish words. I think to myself, "You did that Laura. You told her to stay."

When we emerge from report, I see the husband and children come out of the room. The husband is as young looking as Rozalia would have been if she would have had hair, health, no destruction from the cancer, the treatment. The children are about 10 and 16, pale and wan. Each carry something of their mothers' belongings in their hands, the 16 year old her light suitcase, the 10 year old a few plastic bags. To see these children leaving their dead mother, carrying her few possessions in their hands distresses me terribly. It seems to me that they are too young to have to experience this. And I think of several of the women I have met here with breast cancer, most of them with young children. Somehow I know these European children understand that their mother is no longer in the body they just left. There is more of herself in the bags they carry, these things she last wore, these belongings she last touched, the music tapes she loved.

I'm angry. I silently rage against the malevolence of cancer. Why did she go for that last high dose chemo that causes these terrible complications? She could have lived out her life at home with these children in a conscious state? But I know why. It offered a chance. What mother being offered this would say no? She did it for these two little ones, these two children embody what was her hope; that the treatments, the experimental protocols offered potential cure, a longer life perhaps. She had to try it for their sake. And I think of the young woman who told me she sobbed at her physician's office. He had just diagnosed a recurrence of her cancer. He said to her, "You've already had five years you know." Five years is not enough for young wives, young mothers!

The husband stops to speak with Helen, a patient very close to Rozalia and her family. They met in hospital and became friends. Helen is also Polish. He goes into her room. This will be hard for her because she has not been able to achieve a remission from her bone marrow cancer regardless of how much they have tried with different treatments. I imagine that in Rozalia's death, her own mortality stretches out before her. I know mine does.

The children walk down the hallway, out of the ward to the sitting area just outside the fortress doors. "Oh someone must be with them!" I think to myself. There is a new staff of nurses on the ward today. Judy, who has Rozalia today has been on extended days off and does not know Rozalia at all. "Laura where are you?" I silently cry. But I know Laura has done her part, her work with this family.

I wait for Judy to move out toward them. I think that she will know what to say to them. She has stood watching the children walk down the hall with me. She does not. It is then I know it is I who must speak to them. The father is still in Helen's room. I follow the children out to the lobby. I sit down with them. They look at me sadly, guarded looks on their faces. I simply tell them I helped to take care of their mother, that I liked taking care of her a lot. I tell them Rozalia



spoke often to me about them and how much she loves them and how proud she is of them. And after a few moments, would they like to ask me anything? They sit quietly, one of them weeping silently, and the other one says, "Thank you for caring for her." This is not what I want to hear. Maybe I needed to hear it. But it fits with all I know about this private family. There is so much I want to say to them, but they too seem to be surrounded with a wall of silence and aloneness just like Rozalia's. It seems so impenetrable. I stay with them in silence, move closer to the weeping one. I end by telling them some stories of things their mother said to Laura and me, about their mother's tremendous courage and dignity during these past days. They seem less ashen, less shocked now. The little one asks if it hurt his Mom to die. I say, "No, it only hurt her to leave you because she loves you very much. And she told us she knew your Dad would take good care of you." He likes this answer and settles back into himself, more at peace now. It all seems so inadequate. What do I know of what it is like to lose your mother at 10 years old? I want to say more to the 16 year old, but what I want to say I don't want to say in front of the little boy. And so we sit again in silence.

After a little while I see their father coming down the hallway. He is very young, I think how young he looks. Rozalia was only 35. He weeps as he walks. I see Judy go to speak to him and I am tremendously grateful. They stand there and speak for a few minutes. Judy leans toward him, puts her hand on his arm. She leaves him for a moment and goes to the desk. She comes back with something in her hand and gives it to him.

They are staying here for 4 days, they have signed for an autopsy. In death, someone will know what that abdomen, pregnant with death, holds. I watch them leave and go to the elevator. This is very very difficult. There must be more to do for them, how I wish at that moment I could restore their mother to them. As my heart contracts and I feel its erratic beat, I too know they most need sleep, to be with each other and their Polish friends. I want to tell them that grief sometimes feels like anxiety, like panic and they are to understand this when it happens. But of course, it is not timely now to say so. This seems so unfinished somehow. It is a moment of immeasurable sadness.

### *The body*

Judy comes over to me and says, "This is really hard when you don't know the patient or the family and you are just faced with the body. It was hard to know what to say to them especially as this family seems to want to keep you away. I sensed that strongly. By the way, as I am assigned that room today, would you help me do up the body?"

We go into the room. Rozalia looks much like she did yesterday, lying on her back, her body mottled with blue and black bruises, her abdomen and labia extremely swollen, her eyes closed. But I know that Rozalia is not there even though the body looks the same as it did late yesterday. This is a body only, her absence. I feel it even more keenly than ever as I remember myself caring for this body when it housed Rozalia. And I grieve the absence of Rozalia in the body, a Rozalia who could take care of, be part of her children, her husband's life; her projects engaged with them through her body. This left-behind body shows its suffering; its moments of torment are written on it.

Yet this body is Rozalia's and as Judy and I begin to prepare it, wash and wrap it, it is done with great care and gentleness and great respect. I don't want to clutter this with any sort of religious stuff, but I want to make very clear that there is no Rozalia as a tangible presence in this room. It is a thing; a thing consisting of decaying cells and organ systems. Yet seeing it as a thing too calls to my mind the suffering of Rozalia and herself in herself; her body expressing a unity of essence and existence. And I realize this is my closure, my saying goodbye to Rozalia.

Again I think of shifting realities, shifting relations. For a time it was a relation with Rozalia as an individual and her awful predicament and deep suffering. As Rozalia drew more within herself in her suffering, her own interiority, the relation somehow became more of a bodily one with periods of reaching out to her personal self. Then added to her bodily space is ever more and more technology; her body extends further making it more a presence. Now I interact with her body and its added technology, technology helping in some ways, worrisome in others. Nursing the technology takes some focus off her, but not much. Reality shifts again, and now I remove technology from her body and we are just bodies together again. As the body continues to shut down, I find myself relating to Rozalia spiritually (dare I use the word), but a sense of reaching out to her spirit pervades. Re-membering her in herself takes place in the waiting to see what the body will do, what she will do. Now here again I am with the body, but there is no sense of Rozalia.

This body is stiff. As her body temperature regulatory mechanisms shut down yesterday, as her extremities became cold, so too did rigor set in. Judy says to me, "I swear some bodies get stiffer faster than others." I tell her about yesterday, in a way clueing her into what had happened here. Even as I do it I remind myself that she as an experienced nurse on this ward has been through this before many times. Yet I also know that she needs to know the little details about Rozalia and her dying in order to "do up" the body well. I tell her to wear gloves as this body had some serious bacterial infections that we were combating yesterday. She listens graciously to me even though I suspect she knows.

We need to cross her arms and tie them, we need to tie her legs together and we need to put the toe tag on. We cannot get her arms to bend, we cannot get her legs together. We do our best, try to get them as close together as we can and wrap her in a sheet. But when we turn her over, blood pours out of her nose soaking the sheet.

It is as if the body makes a statement, "I'm here. I am an entity even if I am an absence." And I think that yes, our bodies cause us stress and strain in life. And cause us joy. But in the end this is all there is as proof of lived bodily life; the body. The body commands its own respect. "I worked once, I housed a great soul." We try again with another sheet, pin it on her, and put her in the plastic body bag.

Again as we turn her, blood pours out. This body is difficult to "do up." Judy looks at me in an exasperated way and says in a voice of woe, "You know today is my birthday and it is very hard to start the day this way."

And we begin again. This body will not be denied its due. As Rilke states in *Washing the Corpse*, "And one without a name lay clean and naked there, and gave commands" (1989, p. 63).

Chris, the orderly, has been called because he holds the keys to the morgue. He comes with a special stretcher with a coffin like top that fits over the body. Chris says to Judy, "You haven't seen the new morgue yet, come, and Brenda, come too? I showed you all the new tubs and whirl pool baths, now I might as well show you the new automated lift in the morgue. I show you all the bodies here. It's all about bodies!" He laughs, I laugh and Judy laughs and we go down the hall.

Chris and the other nurses have shut all the doors of the patient rooms. It brought back rather a strong memory of a patient in Wales telling me that when the staff shut the doors a body is being taken to the morgue. And I want to tell Chris not to worry about the doors, the patients know anyway, but I don't because I know this is Chris's way of showing respect and care for them.

We go down a special elevator. Chris unlocks the door and we enter a cold, clean sterile feeling place with steel refrigerator panels against the far wall. There is a rectangular body size lift with

hanging hooks dangling from the ceiling, something like a crane. This room has a toilet visible for all to see and an office beside it with windows that are very small. There is a smell that permeates the room, a formaldehyde sort of smell that brings strong back memories of other times and places.

Chris locates the controls. Together we lift the coffin top off Rozalia's body, and we see the body bag. Chris attaches the hooks suspended from the ceiling to the edges of the moveable platform on this special stretcher. He activates the controls and the platform with the body moves up and over to another stretcher that has automatically come out of one of the refrigerator panels. The body and platform move as one and end up perfectly placed on the new stretcher. He detaches the suspended hooks, pushes the second stretcher with the body on it into the refrigerator and closes the door. Foucault (1973) observes it is the body in death, the corpse, and not the body in life, that opened the door for medical perception and understanding, the seeing that is necessary to understand the functionings of the body. Life hides the body workings. Death reveals it. "Death...opens up to the light of day the black coffer of the body" (p. 166).

But for now I am reminded of the funeral liturgy, "In the midst of life we are in death." I think to myself, no, "in the midst of death we are in life."

Goodbye Rozalia, rest in peace. We stand quietly together for a second.

### *Aftermath*

As we go up in the elevator, Judy says to me "Didn't that remind you of a meat tray that she was placed on?" Chris adds that this new morgue is great. He is 63 and has handled a lot of bodies. Judy says, "I remember lifting them, the bag and all, and heaving them into the refrigerator, it was very hard thing to do both physically and emotionally, especially if it was the middle of the night and no one to help you. Not to mention how creepy it is to be in the morgue by yourself."

When we reach the unit, Norma hands Judy the clipboard to document patient acuity status, and tells Judy that it has to be done right now. I watch as Judy quickly go through her patients, checking off their status with ticks, bed patient, up patient, stable, unstable, time needed for care, seriousness of their care, and so on. We get to Rozalia and she says to me, "Well how should I evaluate her? She is my patient, she is in my room, and she took my time." It seems incongruent somehow to evaluate Rozalia's care status now she is dead, but Norma and Judy and I make off-color jokes about documentation systems and laughter ensues.

There has been a phone call for me. Laura on her day off, has called the unit to find out about the family and how they were. She has also left a message for me, "She found the missing slipper." Glenda, the unit clerk, says, "That is what she said, she said you would know what she meant." Glenda shrugs her shoulders and walks away. I know what Laura meant and I am thankful she calls. The slipper symbolizes Rozalia's projects in the world, her carrying out her activities, her ends. She once had life and lived life with two slippers. Also dying with one slipper shows the slipperiness of life...

Later I stand at the desk having a brief moment of respite after this early morning task but really I am watching carefully an interaction between the Head Nurse and Rozalia's physician. It seems so clear to me, doctors leave death to the nurses.

Cindy, the new chemo nurse, who I don't know very well comes to stand beside me. She had helped me lift and position Rozalia a few times yesterday. She says to me, "You know we could have never managed Rozalia without your help, there was so much going on in the unit. We don't usually let others in like that when someone is in that state, but you just seemed to know

what to do, and Rozalia was all the better for it, thanks a lot.” I say, “You’re welcome, it was a privilege”, and I tell her I feel quite sad about it all.

Cindy replies:

“You know, I can never leave here and tell anyone just what it is like to work a day like yesterday with Rozalia and some of the other patients who were so ill, and those who weren’t but needed specific timed treatments. I can’t tell them what it is to work as a nurse. They cannot understand what it is we do, and so sometimes I end up calling another nurse at 1030 at night to talk because I know I will not sleep if I don’t.”

“She will understand when I say I put a patient in the tub with the hooyer lift and as soon as he was in, he had an enormous bowel movement in the tub. Only a nurse can know just what this will mean in terms of cleaning the person and the tub up, in terms of getting him out of the tub to clean it up, back into the tub to clean him up again, how unsightly and disgusting it is to clean that up, just what you have to do to then maintain his dignity and self worth as he watches you do all this cleaning. And these sort of things always happen when there is so much else going on like Rozalia...but only a nurse would understand the difference this will make to your day.”

“You know, I gave Rozalia the chemo and there is something about knowing that this high dose chemo really killed her and I feel responsible for this. I mean there is some discussion that the radiation also caused the DIC but you just never know when working with chemo.”

“I don’t always feel this way, someone I gave chemo to in outpatients was in yesterday, a well individual. She and her husband literally wept when they thanked me. But this one I cannot help but think this way. There was something about Rozalia that I can’t put my finger on.”

I said, “She seemed so all alone.”

“I know,” continued Cindy. “You know, I found a one-way bus ticket in her belongings when I was cleaning up. She took the bus down here for this treatment, came to the hospital in a taxi. When we transferred her to the other hospital she went there by herself and lay alone for 2 days and 2 nights on a stretcher. She was very alone, something about her just called out to you. Maybe it was because she was so little, I don’t know, I just know that we all feel very disconcerted about her.”

Cindy and I together talking is just what I need. There seems to be a process of reclaiming ourselves after such intensive nursing and perhaps that says more about the space of nursing, only backwards this time; Rozalia's space, the space of the entry room, the nursing station, the med room, the hallways, the elevator, the morgue, the elevator humour, the documentation humour, the nursing station. Moving in and moving out of intimate space as if one cannot sustain that amount of intimacy that long. The nurse exchanges worlds, creates worlds, sheds worlds.

The day progresses but I can't seem to connect well with many people. The ward remains very very busy, the patients are very ill. The nurses have heard that a young girl, one who has spent a lot of time on this unit over the past two years has died peacefully at home. Another elderly long time patient whom I had not met, also died yesterday.

It is a sad ambiance that permeates the ward today. Norma tells me that the elderly man was her all time favourite patient and his funeral is on Friday and she will be there. I ask her about another patient Elizabeth whom I have helped to care for because somehow I need to know right now. Norma tells me that she is doing very well, that they did have the trip to Mexico, and that she is holding her own. This helps somehow. The last time I saw her she was sent home not expected to live much longer.

This somehow balances things for me. I remember Elizabeth saying to me, "I just want more life, I want to write another editorial tomorrow." And it was clear that she and her husband had not had enough life together with their professional careers in different cities. She has been given "more Life." I find myself in a silent thanksgiving. This world is not lost to us yet.

Because it is a loss of a world. We have lost access to the world of Rozalia. Now her absence lies on the meat cutting tray. What is loss in these terms to nurses? It is the loss of our nursing selves engaged with Rozalia. Only in Rozalia's world can a particular possibility for ourselves and Rozalia expressing ourselves together, ourselves engaged in certain projects, come to be. Only here, a particular way of coming to presence, resides. And now it goes.

Later one of the nurses tells me that Arlene wants to talk to me. She is now in isolation as she is neutropenic. She has started her second high dose chemo treatment. I had observed and interviewed her during her first go around with the high dose protocol. I go to see her. As I enter her nurse is leaving and says Arlene is nauseated and wants to rest, but Arlene says, "If it is Brenda I want to see her." So I go in and see she needs to talk about Rozalia as she is from the same city as Rozalia, also has breast cancer, has young children, and is under the same regime.

She too mentions as Cindy did about the fact that she was so alone. "My husband and I saw her husband in the corridor on another admission, and went over to talk to him. He was standing in the corridor because the doctor was examining Rozalia. Now really why would he not of been in there with the doctor and Rozalia, this is what my husband and I thought."

We enter into a long conversation. At first we talk about Rozalia at length, and she says to me, It is most helpful to me to know that you were with her Brenda, that you stayed with her. I reply that I was just with her nurse, there were other nurses too. She says, "No I heard about what you did from my nurse. I know that you would be with her in a way that is really important to us, a personal way, and I am very thankful to know you were there." I don't pursue this as Arlene is teary.

We move into talking about Arlene's second high dose chemo plan.

You know, I have to do this chemo for my kids...but you never know, look at Rozalia...my kids are only 2 and 5 and I can't help but be afraid for them. My

Mom died when I was 9 and it was so hard to grow up without a Mom and now this might happen to them...This lesion on my liver is 2cms, imagine Brenda it is thousands of cells. I don't know, but I had to do this experimental chemo for my kids, that it can help somehow. However if it makes me sick, then I should have spent the time with my family.

But you know what another patient told me, 'Don't listen to them when they tell you there is no hope, don't listen to them, go for the best possible outcome in your mind and don't let them discourage you.' So I am going for Gold, I am hoping for the best possible result.

I remember something Arlene said in her first interview with me. "Arlene, remember what you told me in that first interview. That you have to live every day. I'll always remember exactly what you said. You said to me, 'The doctors don't seem to understand that I still have to live every day even if I am dying.' Keep going for the gold Arlene, the very best that can happen, go for it..."

About 7 months later I receive a card and a letter with a family snap shot in the mail from Arlene. Arlene has hair! She writes to me, "Though it was terrible to go through those protocols and such, it was somehow worth it to have met so many wonderful and professional people." And I think of a memo I wrote about these breast cancer individuals being clothed in a mantle of grace; their loveliness shines still in my mind.

I leave Arlene to sleep and I help Judy admit a new woman from the Outpatient Department. She is in for the same protocol as Rozalia had and Arlene currently undertakes. The story is the same; young women, young children, young wives, recurring breast cancer. And in my fatigue, I think to myself, "Where do they all keep coming from?!"

## CHAPTER 7: NURSING THEMES: LIVED EXPRESSIONS OF NURSING

*We should really take hold of this being present to the world at is coming, but we can only describe it after the fact (Dufrenne, p. 22).*

In demarking domains of meaning that belong to the life of nursing and to patient life as lived, certain thematic understandings can be articulated. These themes I will at times articulate in italicized form within the narrative expressions that follow. Alternatively I will include more in the nature of the interpretive judgments of the nurse, of the patient, in a reprise section at the end of each domain of meaning. Additionally some domains of meaning will contain transcript material and thematic essays as to render intelligible the domain and others will not. In these presentative ways I endeavor to stay close to directness in presentation and to guard as much as possible against abstracting the constituents of the lived expressions through too distant a thematized style. Here too I ardently wish to convey a respect for the mysterious, the unclassifiable, the indescribable in whatever manner of expressed human lived life presents itself below, where “perception and thought have an intrinsic significance and cannot be explained in terms of the external association of fortuitously agglomerated contents”(Merleau-Ponty, 1962, p. 147).

Nursing as expressed in living form (Langer, 1957) can be deeply involved with someone over a period of time such as Rozalia. But too, nursing can be the very briefest of moments. Here we just “jump in” to lived nursing life. We jump from thing to thing not unlike typical nursing moments: discontinuous and sometimes bizarre, fulfilling, poignant, messy, unfocused, deep, mysterious, simple and easy, repetitive while working things through. The styles of presenting and the actors within it and the voices expressed too will change with the differing situations of nursing. This chapter through and in its messiness, shows much of lived nursing experience and much of my lived experience in direct participation and description as a researcher.

### Human Bodily Lived-Life Calls

Walking down the hall, her hands full of towels and gowns, dragging a gastric suction pump behind her, Denise walks toward her assigned patients’ rooms. A small sound of distress comes to her ears. She, in automatic response, turns toward it. She looks through the doorway. A very young man lies on his bed clutching his abdomen. Blood infuses. A couple sit beside him.

*A call summons nurses to immediacy. It is an appeal to come forth into the very now.*

Denise focuses more closely on the young man about 17 she thinks as he is on an adult ward. His breathing, his colour. Her eyes shift to the bag of blood. “It is platelets,” she says. This decides the next action. With a last seeking look stretching toward her own patients down the hall and with simultaneous movements, she piles her towels and such on top of the suction apparatus and shoves it against the wall. She enters.

*A nurse is called forth into a particular situation. While the call originates outside herself, it too calls her out of herself. Being calls to being.*

Doorways are not entered lightly. Denise knows that once through connotes commitment. Engagement. She enters a world. Things have been posited in this world. What constitutes the personal world here, she knows not yet. She recognizes though, bodily and pressing human need. She hears the call. She responds.

*Nursing is attuned to the call of the body. Even from a distance, nursing not only assesses what presents itself, what is already ‘there’ in the world, i.e. presenting human gestures, causative*

*factors and such. But too, nursing hears a call within a call. Possibilities hover and await one's response, one's acting.*

This proves to be the beginning of the young man's particular brutal reaction to blood platelets. Denise moves toward the bed. She rolls the top of the bed up a bit. She reaches for the oxygen and puts it on the young man. The back of her hand lingers on his forehead, his face as she checks quickly for fever. She takes his pulse quickly, his respirations, his blood pressure, his temperature, all the emergent things. Blood pressure is up to 210 systolic on 125 diastolic. She checks the labels on the blood. She searches the room, sees and reaches for the oximetry monitor sitting on the window shelf to take his oxygen saturations. Her body, his body hold a "nexus of living meanings" (Merleau-Ponty, 1962, p. 151). "Where is his nurse?" she thinks.

*A nurse perceives with her hands, with her bodily senses, through the closeness of her healthful body to his complaintful one. The thermometer, the stethoscope, the wall monitor, the oxygen saturation machine, she perceives with these things. These become extensions of her body, of her coming to know. They show both the patient's and the nurse's life vitality measurements in a blend of subjective and objective knowing.*

"What is wrong?" his mother asks. Denise knows she is his mother; mothers wear mothering on their bodies. "It is a blood reaction," she replies. "We will need to give him some things to help him." "I'm going now to get these things and to tell others about this. If he gets worse than this before I return, pull this emergency bell. He is still doing well breathing and he will be fine but we need to attach some anti-reaction drugs." She turns back to the young man, tells him she will be right back, and leaves.

*Nursing not only engages in lived worlds of others. She assists them to world. The call of the body brings forth a nursing world. Nursing fills the space with skilled bodily presence, shelter, security, safety, trust. Nursing erupts into the world just as the bodily reaction has made its presence known.*

Out the door Denise goes. Once beyond the doorway, she runs to the nursing station, grabs his chart on the way by, calls for the nurse at the desk to come with her, turns into the medication room, starts opening drawers while simultaneously reading the orders on the chart and reaches into the drawers for medication. These actions are extant, needful, continuous and have an exigent aura to them. Both nurses bend over the chart. Denise asks the nurse to call for more orders and asks who the patient's nurse is, who has hung the platelets. The patient's nurse cannot be found. The nurse at the desk quickly pages a physician over the hospital intercom system and says to Denise as she flies back down the hallway, "call the emergency bell if these don't do it!" Denise flings back, "Just get me those orders, the ones on the chart won't handle this one. Have him phone me in the room if he wants to know more. Hurry!" Denise propels herself back to the room, her arms full of needed things.

*A nurse "gives over" her own lived body to the immediacy of another's lived body. It engulfs her.*

Almost at the doorway, Denise slows herself down and takes a breath. She walks calmly through the doorway again, no hesitation this time. Over to the bed, Denise speaks quietly and calmly to the young man. She now knows his name and calls him by name and checks his armband. "Luke," she says, "We need to add some medications to your IV and I'm going to put these hot packs around you and cover you up with a lot of blankets. Then I'm going to check your blood pressure and such. Just stay with me and we'll get you through this." The fear on Luke's pale face pervades the room like an ice storm. His eyes fill his face. His whole body shakes. Surges of jerky movements run down his body. He has rigors, serious ones. Bodies have minds and



make-ups of their own. This body doesn't recognize these foreign substances as its own. It rejects them.

*The life of the body, the disease entity, the treatment choices confront the nurse. In illness and horrific corporeal expressions, bodies are not forgettable. They are so very corporeal, flesh on the outside, blood cursing on inside, organs assert their precedence. They will not be passed over.*

Denise checks her watch, adds a medication to the IV and writes it down. She breaks open the hot packs and positions them around Luke's jumping body under the covers. Three more blankets are added to his top sheets. In one more instant, his blood pressure is being taken again. Sometimes it seems his body jerks as high as the bedside rails. Denise adds more blankets, opens more hot packs, more medication. The minute she stands still, Luke reaches out and clutches one of her arms. Now Denise's body linked to Luke's body tremble. They shake together. Denise looks at his face again and says, "I'm not going anywhere until this is over. I'm staying right here."

*Nursing in its responsive answer to the call makes a transition from gestation to presence. The nurse fills the world with things that now belong to it, things that make sense in this world; needful technologies, needful actions, the feeling of rightness, closeness, safety, hope. An embodied being with another embodied being.*

To this point she has not addressed the parents sitting stiffly and dreadfully silent in the chairs on the other side of Luke's bed other than a silent acknowledgment of their presence. She has not asked them to leave and they have not. Neither have they stood up or moved to comfort the boy. They are paralyzed with fright. This body jumping in uncharacteristic, unfamiliar bodily ways before their eyes is of their own flesh, their own soul.

*Nursing knows when a person is ill, the family is ill. Their posited familiar world changes each millisecond. They are swept along with it.*

She speaks to them now. "I have given him some benadryl which should counteract the worst of the reaction. I expect it to work in two to three minutes. We will see some changes in him. And I will keep adding things until they work." She goes on further, "He will start to calm very soon. We have to keep him very warm. In two minutes he will calm." "Now I'm going to take his pressure again. These reactions are scary I know, but we can get people through them."

*Nursing breeches feelings of fear, separation and anxiety with concreteness, with specificity, with aliveness, with relation. Nurses reach across the fearful space and fill it with appropriate and situational something-ness. Here it is facts, information. Another time the fearful space will be bridged by laughter and humour initiated by the nurse. In relation one recognizes the other, anticipates, interprets, nurtures the other.*

Luke hears nothing. He is terrified. He holds Denise's arm even while she manipulates the blood pressure cuff. To add another medication, Denise gently takes his hand off her arm, adds the next medication, records it, turns around and takes hold of his hand. Luke rather links his arm around hers. He is not letting her go. They stand entwined. Denise and Luke hang and shimmy together. She turns to the parents, "In two minutes, this will work."

*Nurses lend their hale bodies to others. One hale body supports an involuntarily vibrating hostile one. It is a clonic hug of the body. Motor and sensory fibres of one fire the other.*

The phone rings. Denise answers it and quietly states some medical findings over the phone to the resident who is in the Operating Room and cannot come. He orders something else, Denise asks for something else and he concurs. Then she says in an ordering voice, "I'll give these and

write them for you but you better get up here right after the OR to sign for them. If you hear from me again in the next five or ten minutes, come right away.” She hangs up. Not only is the medical domain’s knowledge essential here in case things progress toward death, but too, medicine holds the prescriptive practice abilities that Denise needs to see this through to resolution.

*Nurses anticipate and actualize Other’s expertise. It too is a symbiotic relation. Nurses prepare for all eventualities.*

She turns to the parents. “The doctor will be up after the OR but he has given me some more medications to use to help here. I’m going to give one of them right now and in three more minutes Luke should be OK and I won’t leave until he sleeps.”

Luke’s body gradually calms and he becomes sleepy due to the medications. He loosens his hold on Denise’s arm but will not yet let it go. The parents sit back in their chairs, more relaxed now. Luke needs her arm. Each needs her competence, her reassurance. Luke’s bodily condition needs her skilled nursing interventions. They have been nursed. Denise in taking the reaction into herself has neutralized it for them. There has been both death and birth hovering here.

*Nursing becomes sacrament to others. Action and thought blended together in appropriateness, thoughtfulness, concreteness in the moment. A nurse’s ministrations and gestures contain purpose-filled actions, situated understandings, and evoke primordial meanings.*

Denise takes some blankets off Luke now, turns down the oxygen, removes some hot packs but not all, straightens Luke’s pillows, turns to the bedside table which holds remnants of medication vials and associated things, sorts and cleans it. She folds up the blankets and puts them away. She takes Luke’s vital signs once more and prepares to leave. She has much to carry out of the room. Luke sleeps.

*Lived-bodily-manifestations are messy. Nurses both make the mess to sustain and heal the body and clean it later. Ravages of bodily expressions both mandate and create untidiness. Nursing deals with bodily wreckages and its adjuncts. When it is over, nursing wipes the face of it clean; hides the expressed memory of it.*

Before Denise leaves, she turns to the parents and puts her hand on the Mom’s shoulder. “He will be fine now. We will watch him. I will find his nurse for you.” Mom cannot speak but puts her hand on Denise’s and squeezes it hard and whispers “thanks, thanks.” Denise leaves. She does not enter this doorway again.

### **Encumbrances of the Body Clutch Nursing**

When Lynn enters John’s room this morning, she finds him suffering from severe abdominal pain. John has been waiting for her. He is not one to ring his call bell. The pain started in the night sometime and John thought it was just simple cramping, a little wind, a natural bodily happening. It has gotten steadily worse. The pain now consumes him.

Lived pain pulls the “corporeal out of self-concealment” (Leder, 1990, p. 76). John is very much with himself (Buytendijk, 1950), experiencing himself acting upon himself. The very presence of this pain brings the visceralness of John’s body to his awareness, his consciousness. He knows his pain. It is ‘there.’ “Our intuition of pain is not just a feeling, but also the grasping of an actual essence” (Rosen, 1980, p. 80).

*Pain projects us into the very “now.” It is immediate and all-consuming. Nursing intersects with others when the integral relation with one’s body is disturbed. It is encumbered. Patients know nurses can help them through this, live this.*

Lynn asks John questions. He can hardly reply. She checks John's abdomen. It is full, board-like and very swollen. Lynn goes through her nursing assessment, asking John about symptoms, about the pain. She places her stethoscope on his abdomen. Even with this light touch, John flinches. He guards his stomach. Lynn listens. She begins to palpate. As she moves her palpating hand, dipping very lightly into the flesh of the swollen mound, she watches his face intensely. A blood pressure, pulse, respirations and she is finished. She is very attentive to him, tells him that something is going on here and she will call the physician to come and have a look and leaves calmly. Outside the room, Lynn becomes a whirlwind, pages the physician on call, checks the chart for changes and most recent complete lab data set, collects equipment. The presence of this type of pain is a call to action, immediate action.

*Visceral pain is ambiguous. Not like pain in the finger at all. It has a spacial ambiguity. While pain brings the body to our awareness, the origin of the pain hides itself. The lived body conceals.*

During Lynn's assessment, John's wife arrives. She is distressed to see John in so much pain. "I've never seen him like this. He never has pain like this," she says. She stands on the other side of the bed. John lies stiff. He is afraid to move. Each movement brings on worse pain. John and his wife make eye contact and worlds of information and meaning exchange.

*Lived pain affects lived relations. It refashions them and pulls them too into the immediate, the "very now." Those in intimate bodily relation are pulled into this contingency too. A change in one effects a change in the other.*

The resident physician arrives on the unit. Lynn gives him information concerning John outside the door, brings him up to date on his latest lab tests, and they enter the room. Lynn assists the physician with his assessment. A similar assessment takes place as Lynn's. But here the resident physician presses deeply into the abdomen and asks John to tell him when it is very painful. Lynn then suggests to him some additional things she needs to nurse, to assist the diagnosis. Things that need to be ordered; ultra sound, specimens, medications.

Lynn needs to assist the physician as much as he needs to assist her. The hand of the nurse and the physician palpate the mysteries held beneath the surface body. Both hands are gnostic touch (van Manen, 1995). They seek answers and information. They try to see what cannot be seen. The physician and the nurse are corporeal hermeneuts (Leder, 1990). They seek interpretation of the accumulated facts.

Inside the room, Lynn is absolutely there, standing beside John at every moment. Outside the room, she not only directs and requests care and information from various members of the multidisciplinary team, but also she cares for her other patients; hangs a medication here, checks an IV there, does a wound dressing, makes certain they are all right at this point in the early morning and that those who eat are ready for breakfast. She tells them she will be back. She quickly goes to the medication room to prepare meds for various times during the morning and then she locks the prepared drugs away in a drawer.

*Pain robs people of the future. A change in the patient's world changes the nurse's world. But other endeavors in the nurse's world still move forward in linear time. While the person in pain lives in the very present, the now, the nurse must still take part in actualizing the future for others; her medication preparation for others, her searching for pain relief and causality while living the "now exacerbation" with the body in extremis.*

Lynn and John's attending oncologist speak together. He has come to the ward early to do a procedure, to retrieve bone marrow from another patient but he also comes because Lynn has alerted him. At the nursing station, together they discuss what is happening, what could happen.

Lynn worries about cardiovascular collapse, heart valvular problems as this is in John's history and John is already in a weakened state. The physician worries about the interactions of the drugs that have been ordered earlier by the resident physician in John's weakened body. Both of them stand together in concern and concentration. Inside the room, they move as one organism, the nurse anticipating and facilitating the doctor's movements, the doctor addressing her queries, John's wife asking questions, the physician answering, the nurse bringing something else to the physician's attention and so on.

*It is a litany of searching, of seeking cause and healing. All are deeply involved with one another and with the disease; physician, nurse, interpersonal personal family knowing. Flesh joins to flesh. Visibility comes to nurses and others via the flesh.*

Chiasmatic relations with the world according to Merleau-Ponty (1968) show that the lived body both perceives and is perceived. The very flesh of our perceiving body reaches out for the very flesh of perceived bodies. All who are with John have gazed at, have touched his body in some way, either with gnostic touch (diagnostic) or pathic (soothing) touch (van Manen, 1995). There is an intertwining here of all. We know ourselves in a new way when others see us. "For the first time, the seeing that I am is for me really visible; for the first time I appear to myself completely turned inside out under my own eyes" (Merleau-Ponty, 1962, p. 143).

There is no standing still time here. Lynn and the lab technician collect more body specimens to bring the workings in the body into view. Lynn hangs pain medication, calls up yet another team member for an opinion on John. The pain has not abated. In fact, it is worse. It has a very palpable presence within the room. It consumes all.

Lynn moves in and out of this room with brief stoppages at her other patients' rooms. She expects something to show itself soon. And it does. When the massive diarrhea starts, it is apparent she has been expecting it. She has prepared the space with blue waterproof pads and towels and cloths and soap and cream, and deodorant. And she has orchestrated and organized her other patients, her other duties in readiness for this now very intense care.

*Nurses prepare for actualities of all kinds, always probing ahead, anticipating, actualizing some and not others. Acts of nursing are intentional and directed.*

Wave after wave of running liquid stool pours out of John. Lynn cleans it up and in seconds he lies in another pool of stool. This is cleared and again another tide fills the bed. The stool overflows the blue waterproof pads and runs down to the end of the bed. John is mortified with this lack of control. He desperately wants to get up to the bathroom but he is too weak, he has too much pain to move. He holds himself still and guarded. He hopes this may curtail these involuntary acts of his body.

This gentle shy man in his late fifties, was diagnosed with acute leukemia one day when he was working at his electrician business, wiring his physician's office. This physician had a look at him and suggested a blood test because he was so pale. He has been through a protocol of chemotherapy to arrest the disease.

Lynn reassuring voice drones on and on this whole time. "Just lift up and we'll get this out from under you", "I know this is hard for you not be in the bathroom and having us wash your bottom, but we can't leave you lying in it or your skin will break down, and you are too weak to go to the bathroom as you know." And a few minutes later, "It is very good for you to expel this, this is the way to get rid of the organism that is causing this." The organism later is identified as clostridium, a virulent bacteria responsible for many lived human ills as forms of it cause such things as botulism, gas gangrene, cellulitis, wound infections, tetanus.

*Nurses coach. They make these episodes of bodily and lived crisis live-able. In augmenting their relation to the expelling one, they make the body recede. They work to succor, to heal, to make the body forget-able again.*

The loose runny stool continues. John's wife has been present during this time. After about an hour, she has to leave. She comes up to Lynn at the bedside and tells her that she thinks she might faint with the smell. She says, "I know I am running out on him but I have to leave, I just have to..." Lynn turns from John and says to her, "This will last about another hour or so I think. I'll come and get you if you like." John's wife nods, tells John she will be in the waiting room. She leaves. Lynn remains in place. Her movements, nursing gestures are now almost synchronous with the fluid flow from John's body. Each flow requires the same managing, cleansing gloved hands, blue soaker pads, cloths, towels. She sort of rocks back and forth with in time with the visible visceral peristalsis on John's abdomen; their bodies seem as one. She moves briefly now and then between bed and bathroom. This flow of fluid lasts for a long long time. It is an overflow.

*True acts of nursing restrict mechanization. Each act is unique and irreplaceable. Nursing comes forth as uniquely presented; essential to this experience happening in its very immediacy, in this 'now.' This act of nursing is not exhausted until the reason for its being ends. Each act contains the whole of nursing.*

As John's body expels this organism, as the medications take hold, as John becomes severely exhausted and weakened, he sleeps fitfully. The pain has gone a long way back now. His viscera sleeps again. His body, now in exhaustion rather than pain wracked, inserts itself still into awarenesses. The lived-drama of it falls back-a-ways. "Whether it is a question of another's body or my own, I have no means of knowing the human body other than that of living it, which means taking up on my own account the drama which is being played out in it, and losing myself in it" (Merleau-Ponty, 1962, p. 198.)

*Pain pulls individuals out of their natural context of life. When a specific act of nursing ends, the relation of nursing goes onward. Nursing in its expressed nature enables individuals to relate this experience to the whole of their existence, to their lived life. People feel a lived closeness to nurses who see them through these times and put them back in-life. The closeness is closer than their most intimate other. Nursing enables their on-going life with intimate others and a thankfulness wells up in them. For nursing the thankfulness is that they have brought someone through. They have covered the unlivableness of it with relation and skill; they assist the person to recover themselves, to reinsert themselves back into their lived world again. They make it and their bodies live-able again.*

John's body and viscera recede from his awareness as he gradually sinks into a more restful and secure sleep. But John and his viscera do not recede from Lynn's. She watches. Perhaps John would say, "my body everywhere bears the imprint of Otherness" (Leder, 1990, p. 66).

### **Lived Smells, Foul Substances are Pungent and Consequential to Nursing**

It is one thing to say nursing is a series of full moments. It is another to look closely at what these moments contain. What is this ability nurses have to be in the moment like this, to be able to both live and diminish the horror of dealing with body fluids, the notion of contagion, the embarrassment of John's having someone else clean up his stool? And not only that, to make it seem really quite an ordinary thing to help John get through it. In truth there was a terrible stench in the room and the terrible presence of very foul liquid. Some aspects of the body in extremis really are horrific.

Lynn and I discuss this on audio-tape. I look for more insight into John's nursing; her ability to cover this incident with care, to help John live his expelling body, to bring him back as it were, to himself in a more deeply understood relation to his body and what it was doing.

It was hard to handle John's embarrassment and discomfort and to let him know that it is OK. Because while you are in there cleaning it up, it is not pleasant, like it really isn't pleasant, it is not a task that most of us like...it is the least favourite task of nursing I think, and yet it is one of his physical needs at the time. And he still has these emotional needs because of his anxiety and his embarrassment and everything and so it is really hard sometimes to go in and not show your dislike, how you are really feeling inside, because it is not pleasant.

And when that call light goes on again or you go in there to check, you think "Oh please God, not one more time, I can't handle one more stool." Because when you do go in, you have to be you. You have to be there for him despite the fact that you don't want to be in there cleaning that stuff up again. But you do go and you do, do it. You just put that part aside. Its not the important part, you may not want to be in there cleaning that stuff up but it's just a little part of nursing, just a little part that you don't like, its not the major part. The major part is to be in there with John, with the patient, getting him through it.

You know I love nursing more today than I did 20 years ago and I can honestly say that and it's not because I get to go in and clean up that stuff, and I know that for sure!! I would be really weird if that is what I liked about nursing. But it is the patient and partly because they are so vulnerable right then they need you to be honest and to be yourself when you are there with them. This kind of episode incapacitates them. They need you to be with them. They just need you to be right there in that particular yucky moment for all of us. You know Brenda, I didn't think you come with me again after that incident! But I sure appreciated your help. (We laugh together.)

I look still for insight, Lily, John's wife, offers this to me later.

You know I feel bad to the depths of my soul (weeps) that I left him just then. He's my husband for God's sake. Oh I know you and Lynn were with him and I knew he was getting good care. It's just that you expect both the best and the worst of this disease and you never seem to know which is which. But you sort of wonder how death will come, what will it be, what will it look like? So I thought, "Is this it or not? Is it now?"

But the smell, oh that was so awful. Lynn told me a while ago when John was starting his chemotherapy that I was welcome to be in the room as much as I wanted or to leave if that was my choice when she was giving care. I appreciated that. I've had nurses elsewhere put you out of the room no matter what. But I just couldn't stay there. I just couldn't. I was so afraid this was it, that he was dying until Lynn came and sat with me and explained what was happening.

This is a soul and body destroying disease for both of us. I so feel destroyed because I couldn't be there for him like that or even just stay beside him, after all he's the one going through it not me.

Does it not seem odd indeed that nurses can care for others who are not their own? Our own baby's stool is not repugnant to us. We cover nasty odours and material compositions with love, their body a part of ours, an extension of ours perhaps. We can even pick up our own dog's stool without too much of a problem, yet another dog's leavings are disgusting to us. But how about caring for a stranger, cleaning up his stool?

Smells are strongly tied to the sensuality of the world. Smells put us immediately in touch with things in the world. As we smell the trees, the flowers, somehow they become part of us. In nursing, it is as if fumes such as the above transmix with our own body fluids. You simply inhale it and become it, the exacerbating symptom, the illness. The flesh of the world becomes your own flesh; you perceive and are perceived (Merleau-Ponty, 1962). Literally to be in touch with the world is to be in smell with the world; you *take-in* the world. Senses are not easy to deceive. They plant us in the moment; in the present. They are so very there.

What does that mean for nursing? Smells that emanate from patients orchestrate direct actions by nurses. In fact, we sniff out things we are not quite certain about. Smells give nurses clues not only concerning their physiological and emotional status, but also as to how to act; ways to be with the person, ways to take care of the person, ways that get to the core of the person's being and how they feel at that moment. Smells have a *living significance* to nurses. One can instantly smell the acetone breath of a diabetic in a room and move to appropriate action. Nurses are the perceiving subject and as such smells present to nurses sense data that direct her in the "re-creation or re-constitution of the world at every moment" (Merleau-Ponty, 1962, p. 207).

Smells trigger memories, smells are recorded within the brain. I find myself chuckling and thinking facetiously, "I wonder if this would stand up as a nursing model or nursing diagnostic label, or pre-planned patient care map. I can see it now. "If you get a whiff of this, then do this." And yet this is not so alien an idea. If we don't have human smells then what? Suskind (1986) writes about an abandoned baby who has no smell. In fact this baby grows up to be a murderer; a murderer who murders to capture someone else's smell. The town Friar becomes involved with this baby when the local wet nurse refuses to feed the baby anymore. The Friar ridicules her and tells her she is the most primitive of peoples and says that only fools see with their nose and not their eyes. She stands her ground and tries to describe how a baby smells.

They don't smell the same all over...their feet, for instance, they smell like a smooth, warm stone- or no, more like curds...or like butter, like fresh butter, that's it exactly. They smell like fresh butter. And their bodies smell like...like a griddle cake that's been soaked in milk. And their heads, up on top, at the back of the head, where the hair makes a cowlick, there, see where I mean, Father,

there where you've got nothing left...right there, is where they smell best of all. It smells like caramel, it smells so sweet so wonderful, Father, you have no idea! Once you've smelled them there, you love them whether they're your own or somebody else's. And that's how little children have to smell... (p. 12).

The Friar continues to ridicule the wet nurse and she goes, leaving the baby behind. He looks at the innocent baby and silently hopes for reason to come soon and banish ignorance like that of this wet nurse. The baby wakes and instantly his nostrils flare wide smelling the Friar, taking in his scent as if the nostrils were a man-eating plant. The Friar is frightened; he feels his essence gone up the baby's nose. He tries to smell the baby. He cannot. The baby has no smell but now has his. And he is bereft. To be without scent is an act of violence. To be without scent is not corporeal.

I think about a nurse's own smells, my body smells, after thinking about this baby cum smell-murderer. I refer to some writing after recording, after carefully describing an observation note. I have written this note to myself on a scrap paper one day on the unit. So much life passes so quickly by on a nursing unit, it is hard to find ways to record it.

It is interesting to smell one's breath behind a mask. One thinks of the breath of life, that the breath in eastern religions is sacred, seen as the soul of a person made visible. In Christianity, Jesus breathes on his disciples and they receive the Holy Spirit. My colleague has a way of asking how someone is, "How does his breath smell?" Cel (Chapter Four) made me very conscious of the closeness of the nursing relation when he discerned who was who by the smell of garlic on the breath of those bending over giving him care.

In the morning I smell my coffee breath mixed with toothpaste behind my mask, early afternoon I smell my acetone breath as the need for food presses, late afternoon I smell my own dry mouth breath as I have not had time to have an adequate fluid intake during this day. All these are reminders that I am embodied. Odd to think of this now. I think it is the closeness of the relation of nursing that initiates this thinking. When I reflect on bodily awarenesses, I experience my body nursing again and for a slight moment I am aware of its movements as it fits quite well into this nursing space; walking quickly down the hall to answer an emergency light, to wish for more hands to deal with all the IV tubing and solutions as I move to change lines. Just as the nurse brings her nursing to this space so does the space contain nursing. I am aware that I can reach as high as is needed for IV stuff as I watch the short nurses try to reach the top of the IV pole or reach a medication on the top of the cupboard, but I am also aware of not being able to scrunch down easily to straighten a messy bed, to empty urine bags, to assist a patient to move up.



Other sorts of smell memories come to mind. I remember Gwen having a coughing fit triggered by a nutritionist who was wearing perfume, and Lynn then telling the nutritionist that people on chemotherapy drugs cannot tolerate perfume smells. Karen told me when we went in to see Mr. Frank, that she smelled something not right with his body and indeed it was a prelude to a physiological crisis and his demise. Later she told me that she always uses her nose in patient care. There is the smell of unwashed bodies, the smell of a chemo-full body, the smell of blood, the smell of sepsis, the smell of death. These smells immediately connect or disconnect us to the patient. With all of John's diarrhea from a virulent organism Lynn did not at any time display repugnance.

Mr. Frank, old and weak, liked the smell of my shampoo, my hair, as he leaned on my torso as I stabilized him in his systemic weakness while his nurse washed his back. It was some tea tree oil shampoo that friends Ian and Rose had given me; something nutritious for my hair and for the environment, and I guess for Mr. Frank. Mr. Frank told me that his sense of smell since he has been on chemo has been different. "To myself I smell like a big chemical factory and I can't seem to smell much else. That's darn nice hair smell you have." His nurse and I make eye contact and giggle and he joins us. It takes me a while to "live down" this hair smell comment with her.

More memories. I remember smelling my babies all the time, putting my nose close to their head and hair, their skin, their tummies when like all mothers to blow on them and to hear their chuckle or see their smile. To keep them smelling clean and nice was important and challenging. Then I remember smelling some babies in community health who were not cared for and how dreadful they smelled and how I still cared for them anyway. And I remember one day working in emergency when a baby who had not been fed for a while was brought in. When I received her, she was sucking and chewing on a soiled piece of disposable diaper. Getting intravenous infusions started on her was a challenge but as soon as it was done, I bathed her quickly, cleaned out her mouth, fed her a little bit from a bottle to get her sucking. She went to sleep. Funny these memories I haven't thought of in a long while are with me in this nursing space today. There is so much about nursing that is hard to make explicit and I worry if

it should it be made explicit? How could I tell anyone that Mr. Frank today had a very nice experience smelling my hair today and it was an important one for him? Who would understand this?

Smells pull us closer to patients and at the same time, push us away, and as such are a good allegory for nursing practice. Nursing always works with and against something. We deal with bodily fluids from strangers, yet we are enabled to do it because of the whatness in nursing practices? A nurse provides nursing against all the idiosyncrasies of bodily life, institutional life, multidisciplinary life; each with their alternating perverseness and resourcefulness. A nurse seeks the relational qualities that will cover these distancing phenomena with care.

Sense and sense data are essential to the perceiving nurse. It is a form of cognition. "The terminae of all of these-nose, eyes, ears, mouth, some of the most sensitive areas of skin-are located at the surface of the body, the mediating boundary between inner and outer" (Buck-Morss, 1992, p. 6). These senses, the entire corporeal sensorium of the individual, their immediate access to the inner body encounter the world "prelinguistically, hence not only to logic but to meaning as well" (p. 6). One could say, prelinguistically the nurse dwells. The nurse dwells in directness, direct access to inner bodily workings, both hers and others. These trigger instant interpretive judgments.

At some point in my field observation recordings, I notice I begin to write of "nurseness." I decide to look up "ness" used as a suffix onto the root nursing. Nursing etymologically has its origins in the latin word, *nutrire*, to nourish, to nurture (Skeat, 1958). I find in an etymology of "ness", that it is a promontory, a headland, a ground, and a strong association with the nose (Skeat). Smells ground us in lived bodily life, smells are part of the bedrock of the patient/nurse interaction. Smells direct our care and our interventions. And just like the fleetingness sometime of a nursing moment, so too are smells. They can come and go instantly. They leave no traces in history (Suskind, 1986). Smells present truth directly.

To access sense data nurses have to be close to patients. Closeness puts nurses in an aesthetic relation (Gadow, 1982) to the bodies of others where the body expresses itself as both object and subject and in the complex balance between, both inform and "reciprocally affect and develop one another" (p. 97). To distance ourselves from patients vis-à-vis our position as registered nurse, educator, manager, academic, and others, moves us to an anaesthetic relation to them. Aesthetic and anaesthetic come from the same root (Buck-Morss, 1992). One whose face, whose smells are not before us can anaesthetize us to their import.

### **Nursing is Contiguous with Tangibles, Intangibles in Lived Life**

#### ***Mr. Stanley***

Mr. Stanley sits upright in his bed. He has a fever. He sweats, breathes quickly, his skin is flushed. Beside his bed is his commode chair. Kathleen moves toward him. She begins talking to him as she takes his temperature. She sticks the probe in his ear, it beeps, she takes it out and looks at it. "Gosh you have a fever this morning. How do you feel?"

Mr. Stanley looks at her and replies, "Oh I'm hot all right but mostly it's this diarrhea. I have to keep getting up for it."

"Are you coughing very much?" Kathleen asks. "Yes I guess so." He pants. It is hard for him to speak. Kathleen goes on to take the rest of his vital signs, his oxygen saturations, listens to his chest, straightens his pillows and bed clothes out around him. "I'm going to give you a quick sponge bath right away. I hope it will make you feel better. But first I'm going to call your

doctor and see if he can come up. We need to get this fever looked at and under control.” She speaks slowly and matter of factly.

Mr. Stanley is a handsome man of 50 with red red hair. It matches the flush of his skin. He is immunosuppressed and experiences opportunistic diseases that a normal immune system would easily fight off. He has PCP, the pneumonia of a compromised immune system, diarrhea, very low blood counts, a long history of hospitalizations, cardiac problems, and more. He is a successful CEO.

A few minutes later Kathleen is back and begins to bathe Mr. Stanley starting with his face. At first he assists in a quiet and dignified way. But then he stops. Kathleen continues to stroke his chest, his arms, with the washcloth, the water, the towel. Tears form in his eyes. One starts dribbling down his cheek. Kathleen notices and says, “Oh you are going to wash it again, are you?” Mr. Stanley smiles, catching the sparkle of laughter in Colleen’s eyes. “My little girl died when she was only 4 years old. She climbed up on the stove and turned the burner on. My wife was in the house, in the other room. She couldn’t prevent it. But my little girl burned up and died.”

*Bodily disturbances disturb memories. Accelerations in bodily processes naturally accelerate remembrances. Stored bodily memories. Nursing dwells innately with these primordial recollections. Conjoint bodily life makes it so.*

Mr. Stanley sobs. Kathleen stops bathing for a few moments and covers his chest with the blanket. She stands beside him, her hand on his arm. His sobbing increases. He is in agony, remembering, reliving this tragedy. This is a visible world of two, but an invisible world of much more; individuals, sorrows, regrets, guilt, reproaches, triggered this morning by what? Kathleen too has recently lost a young niece in a car collision. The two stand as one in this shared moment of grief.

*Nurses are intimates. Patient see them as lived confessors. Intimacy with another’s body opens us to candidness, to sharing of being in whatever dimension the person chooses. One might say, unconcealing the body unconceals inwardness in nursing situations.*

Mr. Stanley begins to cough and sputter with his sobs. Emotion like this jeopardizes his decreasing lung function even further. Kathleen makes soothing sounds with her voice, strokes his arm and shoulder with her hand, places she has just washed, makes motions to begin bathing again. Kathleen says, “I know, I know, my sister has just lost a 4 year old child. It is very very difficult.”

*Nurses touch tangible things such as bodies, but the bodies encapsulate entire worlds for individuals. In touching the body, the nurse touches and is cognizant that she touches these as yet intangible worlds; that she has access to them should the person, should the nurse choose to do so.*

Mr. Stanley becomes breathless. Colleen’s voice now takes on a different tonal quality. “Stop now, it’s ok, ok. It happened a long time ago. We must stop now.” Kathleen continues to speak. Her voice has changed from a soothing tone to one with firmness in it. He starts to calm down.

Kathleen knows that getting this memory out and putting it in a perspective Mr. Stanley can live and die with is akin to his breathing here. As he remembers he becomes more tachypneic which manifests itself along with his hyperpyrexia. As he expels sharp quick breaths, he expels deep-felt memories. He vents. Kathleen lets this happen to a point but that is all. To let him continue would cause him to experience significant respiratory distress; intercostal retractions painful to

the metastatic disease in his ribcage and too, he may move to respiratory acidosis, a serious patho-physiological state. She stops. She calms. She encourages slower breaths.

Kathleen continues and quickly finishes Mr. Stanley's bath. They speak of remembered pasts together, how the past will not stay past. She changes his bed, and tidies the room, attaches some gamma globulin to his IV in hopes of stimulating his impaired immune system. His doctor enters.

Next day, Mr. Stanley is improved. The change in medication for the PCP has helped him a lot. Today Mr. Stanley soaks in the bath tub in his room. It has been difficult getting up and organized, but this bath he sincerely wished. "I don't know what came over me yesterday. I was all wrapped up in that memory. It wouldn't let me go," he explains. "But I needed some way to get it out, and it came out that way. I was thinking about it all night and I hadn't thought of it in years. You know that nurse lost a four year old niece. She really understood everything I said and you know, most people other than nurses don't. I mean I would never bring it up but if I did, you can read in their eyes, 'get on with it guy!' But I told my wife last night that somehow I feel better about our daughter dying now, if you can say, feel better about something like that. At least I can say I feel peaceful about it. Somehow Kathleen changed all that for me. I felt safe to cry and let it come up while she was washing me. Well actually, it just came. I had little control over it. Funny the things that come to mind when you know this might be your last bit of life."

Reprise: This lived-through past concerns Mr. Stanley deeply. "Memory reopens time to us" according to Merleau-Ponty (1962, p. 85). In health, Mr. Stanley is able to have a "flight into a self contained realm" (p. 86) where he could structure the event in his own way. In illness, he cannot. Staring directly at his own mortality, the face of his own death, evokes this horrific, memory; death by fire. Is his coming death to be anything like a death by fire? It is as if his body-itself sheds excess baggage in order to deal with life processes, life-giving processes, breath.

Kathleen has made a safe place for him to bring this forward. It is a space where only he and she will ever know about; this "former present which cannot recede into the past" (p. 85). Mr. Stanley entrusts his very self and very body to her as ever. But now, his secret self-thoughts are confessed to her. The discussion turns quickly toward his inability to deal with many things; why his wife was not watching more closely, why there had to be a death of such a little one generated by and of his own flesh. Things that could not be spoken of before are spoken of now. Kathleen in her openness allows this, accepts this as necessary for him. She trusts his body to expel this excess, ever watchful for the signs when it asks too much of his current physiological status. Then she closes it. In effect, she moves him on to embracing life again through calming deepened breathing. As he gives utterance and excretion to his memory, he recollects himself; she ministers absolution. As we descend into personal relationships we ascend into transcendence according to Marcel (1950a). Mr. Stanley and Kathleen have been able to transcend a horrific experience.

Breath connects us with our very being. To breathe freely is to embrace life. Breath is elemental. Our lungs are flexible tissues that expand, contract, make the rhythm of life for us. We breathe life in, death out. We balance our electrolytes, our cardiovascular, our neuromuscular systems through breath. Breathing unites our interior organic life with our exterior world. Without it, we have no life. "Air...is the most outrageous absence known to this body" (Abram, 1996, p. 225).

Kathleen makes a primordial space for breath; a space that provides air for body processes, air for utterance. It is a communicative space (Levin, 1987). Voice and breath are integrally connected. "Breathing beings will suffocate unless they have space to breathe; a space, as it were, of

possibility" (p. 132). "So, to pray is to breathe, and possibility is for the self what oxygen is for breathing" (Kiekegaard cited in Levin, p. 133).

### *Elizabeth*

Elizabeth has waited too long to have her leukemia actively treated. She has few normal blood cells left. She and her husband are professional people with careers in different cities. Their lives have been busy, hectic. Elizabeth consistently refuses the chemotherapy regimes available to her. She does not want the sickness. When she was young, Elizabeth had an episode with Hodgkin's disease. She vividly remembers the suffering involved with the treatments. While Elizabeth has decided no treatment, now it becomes difficult to live this choice.

But now Elizabeth has few choices open to her. Her platelets are *less than 10* which means that she could hemorrhage at any time. On the weekend her mother gently bathed her neck and even this caused several hemorrhages into the skin. These little hemorrhages spotting and mottling her neck have frightened them. It is too late to give her any chemotherapy because her bone marrow has been too destroyed. There has been disagreement and now some enmity between Elizabeth and her husband. He wanted her to have treatment all along.

Kathleen, Elizabeth's nurse, worries that she is seemingly unaware of the gravity of her position. Now Elizabeth, and her very worried, upset husband who has taken a leave from his work, want to have treatment and even possibly a bone marrow transplant. "Somehow I have to get them to understand that they are past treatment options, that they must enjoy this time right now, right this minute, because there may not be much more," explains Kathleen as she walks down the hall.

Inside the room the husband sleeps beside his wife. It is an intimate scene to walk into, a couple's bedroom. The two are curled tightly around each other. Yet Kathleen does this with grace and a bit of humour. A book falls to the floor as the husband stretches. Kathleen picks it up. It is *The Robber Bride* by Margaret Atwood. Kathleen uses this book to bridge the awkwardness of the moment.

"We really got into that last night", the husband says. "We were waiting to see when the others would recognize the evil one as evil. But we fell asleep before we could find out. It is a really interesting story of women friendships." The discussion for a few minutes centres around this story. Kathleen tells them that the doctor is coming in to see them soon and she wants to wake them up. "Good," the husband replies, "I can't sleep much in here. I keep listening to her breathe and every time she stops I have to rouse myself and look at her. Sometimes she just breathes quietly and then I have to put my hand on her chest to see if it rises."

A few minutes later the doctor comes in. Apparently this doctor has tried to speak with Elizabeth before but her husband was not with her and she "did not want to take the news alone." The doctor speaks now. "You know, Elizabeth, that you do not have any platelets, that basically your bone marrow has been destroyed. Even when we transfuse you with platelets, your counts do not come up. We are in a very serious situation here. You could hemorrhage at any time. Platelets travel the bloodstream all the time and fix up little tears in our body of which we are unaware. When there are no platelets, you are at risk for a bleed at any moment. We can give you more platelets but after a while, you build up so many antibodies to them and so they are destroyed almost as fast as we put them in. It is difficult."

The husband becomes very agitated and begins to yell. He wants them to use better quality blood. He wants a bone marrow transplant. He wants a second opinion. He wants chemotherapy. He wants treatment for his wife. The doctor recommends another oncologist to contact. She explains again why Elizabeth's condition is too advanced now for successful treatments.

The doctor leaves. Kathleen sits beside Elizabeth, her hand holding Elizabeth's. "How can they stand there and tell me I have very little time? It is too hard to believe. I am only 42. I want to go and write an editorial next week. I want to go back to my job, I want more life!" The husband paces up and down the tiny room. He now begins to yell again at Kathleen, at Elizabeth. Elizabeth becomes firm. She says to him, "You are being very testy and rude. Please bring the car around to the front door. I want to go out for a drive." He leaves. Elizabeth apologizes and Kathleen shushes her, "Don't Elizabeth, he loves you very much, he loves you. Go now for a drive. Buy a coffee and just be together."

Kathleen helps Elizabeth get dressed. Just before she leaves the unit, Elizabeth says to Kathleen, "Do you believe in miracles? Do you know any special prayers?" Kathleen answers, "Yes I do. Here is one right now."

Reprise: Just as the nurse manages her care, so too do patients. The paradox always is, the sickest one watching, managing and coping with the behaviour of intimate others.

But what of the husband, the significant other? What does he face? He sees the loss of her and not only her, what he is when he is with her. He risks losing the unique and "unrepeatable properties" of their shared life; properties only realized in relation to her and their irreplaceable history together (Nussbaum, 1990). Why would he not fight against this? Later when I spoke with him he said, "When she was first diagnosed with cancer, I wouldn't let it come into the house, and I didn't discuss how serious the doctor told me it was because I didn't want cancer in our house."

"More life" is what Elizabeth asks for. More life when her blood cells have given her notice that there is no more life in this particular physiological state. Even life-giving additions of blood are destroyed as quickly as they are infused. Access to her world of marriage, of being still a child to her mother, of the immediacy and drama involved in participating in news and editorial generation presents limited involvements now.

I hear her question: how can I access my worlds without the physiological apparatus to live them? Merleau-Ponty (1962) points out that changed persons still access their familiar world because one is still attached and committed to one's projects in that world. But as one attempts to go about one's projects, one experiences limitations..."the world cannot fail simultaneously to reveal it to him" (p. 82). For this alone, there is no notion that can cover the cruelty, the inhumanness, the awful significance of this for the person. And so Kathleen concentrates on their couple-ness, their reading together, the world within the world of the book, for these moments of life together. It is such a fine line really; acknowledging their grief yet wanting them to know the full significance of it, encouraging "more life" in limited ways now. Kathleen is very worried Elizabeth could hemorrhage and her life be over a second from now. She knows a drive, a coffee, will bring them together as a couple again and pull out their unique couple-ness.

Should Kathleen have concentrated more on the hopefulness of life in spite of the medical diagnosis? Perhaps. Perhaps not. This inheres in the question of nursing too; to choose the better in each relational moment over the weaker. The moments are essentially ethical-moral ones; a particular context of meanings, an interpretive response. Kathleen speaks:

With each patient I try to make a difference and I try to see what would make a difference in their life this particular moment, physically, emotionally, spiritually...sometimes that involves a lot of really active technical nursing skills and assessments and physiological monitoring but here for Elizabeth, for her

right now it is primarily emotional and spiritual. I don't have any fast answers but I find as a nurse, you're a bit of everybody. We are so diverse and sometimes you want to whisk them off to the psychology department and we do use that resource. But often we play a big role in facilitating them to express their feelings because they deal with us on a regular basis, they open their heart to you. We also see the entire picture. Even after we refer them to counseling, that department is up here asking us things about how they are doing. Dealing with them bodily too is such an intimacy, a closeness, and body work generates intimacy. There are many secrets I hold for others that I will never breathe out. Did you notice how involved they got when I got them talking about their Christmas traditions, baking and such? We never know the truth of medical diagnoses; we've seen lots of people turn the diagnoses around. But this couple has been in a great lot of denial and I've not yet seen someone turn their situation around who didn't first accept the medical expertise given them. So that is my hope for them, to come to terms with it in their own way, and to be together and I will still hope and work for *more life* for them together.

### Nurses guard against Patient Indignities

#### *Miss Collins-Hill*

Miss Collins-Hill is an elderly stately woman, an employment supervisor who "puts the right people in the right job." She wants to know what nursing research means and what I am doing on this unit. She tells me she already knows I am a nurse. "I've watched you" she says. Then she tells (orders?) me to sit down because she has some things to say to me.

Well what I want to tell you what is important about nursing is this. And I want these things written in your document and not how many times I called a nurse or got up to the bathroom or threw up. Make certain you get this straight now.

It makes me feel better when the nurses are part of that team of doctors and others, because you know if I forget to ask something, the nurse always remembers to ask it for me. I haven't met one here yet that does not remember what I need. Also if I don't understand something, I often don't ask the doctor. I'll wait until after and ask my nurse to explain it to me. And I depend on this because doctors give the illusion that they are always in a hurry and also at my age, I don't like to look the fool.

When I was admitted, I was very ill and there was a resident physician on who didn't know anything...I call him Peter Sellers. He was so ridiculous, he didn't

know what he was doing and they put him in charge over the nurse! I tell you this is hard on an employment supervisor to see this sort of thing happening. He just treated me like I was a piece of meat.

But then after he left my nurse, a little one, Karen, came in and she checked where my pain was, looked and felt my abdomen, took my temperature and told me I likely had a bladder infection. She went out and talked to the resident, and came back in and catheterized me and said when she saw it, "Yes you have a bladder infection, we will get you on some medication right away." Now I know lots of people and doctors would say, "Well what would she know?" But I tell you she knew about me after she examined me and talked to me, she knew what she was doing, and then when she made a decision. She was very quick on the uptake, very quick indeed, and it was exactly so. It was a bladder infection, and then the next day, my oncologist came in and changed all the resident's orders anyway. You know I don't know why nurses put up with this, it is hard for someone of my background and experience to see this.

And you know Anne, the head nurse, she argues with the head oncologist on these rounds when she thinks something is not right. Yes it really makes a difference if there is a smart nurse around. Nurses water down a lot of blabber, and other times nurses repeat things you would rather not hear, because sometimes you only hear what you want to hear when you have this disease.

Here Miss Collins-Hill pauses for a moment, I wonder if she is finished, I look for the signs of fatigue. But she continues.

I think nurses are born to be a nurse because no one suffers fools gladly. No, they must have an inbuilt tolerance that most people don't have, you have to have the right sort of person for this job.

Yes and something that is very very important is that nurses don't forget about all modesty. This is very important to me; they keep the privacy for you, they are very considerate. You know with this pin in my leg, it is difficult to get into the bath and I need help. But they give me that help and then they leave they shut the door and the curtains. You know there is a personal side to each nurse too and I like it when they start calling me Beth instead of Miss Collins-Hill.

But you know I have been in hospitals with this bone cancer where there are no nurses and so you have these aides or whatever they are called and they don't understand privacy. They walk in when you are on the toilet, they don't knock or



anything. They don't cover you up when you are bathed. They don't have the same level of professionalism, they are so casual. Nurses don't talk about the patient's case in front of the patient, and some times these aides can't even speak English!! Honest to God sometimes I think I am in a Peter Sellers movie.

No you need a nurse. A nurse understands that just because they help us with intimate things, our intimate personal care, that that doesn't give them access to all our privacy. No, they preserve the privacy when they can. They make notes and talk to each other in the morning; their communication is very good; they help each other out all the time; and seem to really care about us. It surprises me how personal these nurses are, nothing is too much trouble for them, just nothing...

Reprise: What Miss Collins-Hill speaks about are very ordinary expectations of any human being; privacy and respect. For individuals in situations like this, Miss Collins-Hill wants the fact that she is a human being and a part of society remembered. Ordinary things like, oh, a person should be able to expect attention to medical problems, a person should expect to be treated with dignity and respect, a person should be able to have safe treatment, and the freedom and permission to keep their hope alive. Yet these ordinary things of life are the things that are most mentioned when patients speak about nursing. Nurses guard basic human comforts. Ruth too adds her voice to this and is very clear that even though a nurse and a doctor are granted access to a person's body, they must not assume then that the patient deserves no privacy. Doors to bathrooms must still be knocked upon.

But there is more. Miss Collins-Hill identifies what happens when contact with a not-I brings you face to face with the self of yourself (Franck, 1989). You see another through the eyes of yourself. Here this employment supervisor wonders quite rightly about routines and functions of different personnel. But more importantly to her, she sees herself as the other sees her and it is not an admirable thing to see herself; herself with this malady. It diminishes her and she feels like a diseased entity not herself experiencing dis-ease. She is something other to herself and she doesn't like it. Yet here the nurse looks through the layers of flesh to the person of the malady. And she pulls the person's self back to the forefront of this relation.

### **In Dialogue Nursing Exists: Nursing Seeks to Actualize Lived Insight, So too do Patients**

#### ***Mr. Phillips***

A conversation at nurses' report one morning. It is 0700.

Night Nurse: Mr. Phillips had a psychotic episode tonight, he hasn't had this before has he, at least I couldn't see it written in the chart.

Head Nurse: No he hasn't, what happened?

Night Nurse: Well I heard this singing and banging at about 3 AM. It was coming from Mr. Phillips's room so I went in to see him. He was really agitated, talking about the sky falling down and he was singing to keep the sky up. He

wouldn't stay in bed and he was pulling at his IV site. He said the IV pump was his bass and he couldn't find his bow to play it.

I calmed him down. At this point I didn't challenge him. I mean that the pump was his bass. I checked his vital signs. His blood pressure was up, temperature normal. I asked him about pain but he wouldn't answer. He didn't seem in pain, just confused. I settled him, told him I'd be back in 5 minutes and went to check the chart.

I checked out his fluid status, his medications and possible interactions, his blood work. He has not been getting anything for pain. His temperature has been normal. Electrolytes are ok. Bacteriology reports were negative. There was no documentation that he had ever been like this before. Apparently Dr. B has his old charts so I couldn't check them. I got an order for Haldol but when it started working he fought even more.

It was very hard to see him like this. Basically I just had to stay with him most of the night. I left only to do the things that were essential for the others. He could not be left alone for long. I thought of calling his wife but wasn't certain if that was a good idea in his state. His blood work is back this morning and the values are the same as yesterday, not much of a change here at all.

His wife was visiting when I started my round but she left about 8 PM. I called the resident but he was reluctant to order anything in case it was a drug reaction, so basically we just sat in the room all night, sat on his bed, staying with him, trying now and then to reorient him.

He was really odd. He is sleeping right now, he fell asleep about 1/2 hour ago and he is really out. I think he exhausted himself. But even as he sleeps he fights, he is having huge myoclonic jerks. Gosh that guy is strong, he has worn me out keeping his arms away from his IV site, his pump, trying to keep him safe. He was not combative or anything, just determined. I didn't need security. I could most of the time talk him out of things, or keep him talking about something bizarre that he had brought up, or singing with him. He was gentle about this outburst, but it is really disconcerting. Well we made it through anyway, I hope when he wakes up he is in himself again.

Staff Nurse 1: I have been off a few days but does his wife still visit him in her silk suits and read the Globe? Not that there is anything wrong with that, but I

don't think she has engaged much yet in this reoccurrence. He might be reacting to that, I think he's been really alone through this.

Staff Nurse 2: Well she asked for some clean sheets and towels for him yesterday before I left at 7 PM so I showed her where to get all of that and to feel free to help herself and to call us for help if they needed it. When we were in there making the bed she left the room. He was very quiet.

Staff Nurse 1: Has he talked at all to any of us? He seems to hold himself in and just to talk to the physician. It's hard to get a reading on how much he knows. I tried to explain his treatments to him but he acted as if he already knew. Later I realized he didn't know and I began to tell him about it. I think he just talks to his physician which is good, but there are a lot of hours in the day and he needs to talk to someone in there, his wife or us. He seems to be withholding himself from our talking.

Staff Nurse 3: Someone phoned yesterday from his work and asked if they could come and see him. I went in and asked him and he said no he did not want to see anyone, so maybe he has isolated himself. I think his coming out of remission is very very hard on him this time and I think he is very worried. Could we get some more extensive blood work on him today, maybe he is really reacting to something?

Head Nurse: It could be the human gamma globulin (IGG). Some people do get a episode like this, when did he last have it?

Night Nurse: Two days ago and he is due for more today.

Head Nurse: I think we will hold it until we can discuss this with the doctor. I'll go in and talk to him this morning too. I think we just need to keep him talking. I'm sorry to see him like this, he is such a dignified man. He told me he just published a new book.

Night Nurse: All I can say is watch him closely. He is somewhere, I'm not certain where but it is important for him to be there right now. He is just plain scared. He works something out I think and this episode gives him permission to do so.

Nurses do not always know what is going on with patients. Patients are often submerged in realities that may appear bizarre and strange to the nurse. Looking for causes, seeking information, envisioning certain outcomes, is a reality of patient life. It is an "ongoing interpretive quest" (Leder, 1990, p. 78). "The treater's gaze provides an extension of our

own...we come to see our body in a series of technological and conceptually extended ways that otherwise would be unavailable" (p. 78).

Patients keep a vigil; they watch and monitor everything within their view (Cameron, 1988, 1993). Sometimes in looking for causes and gaining information patients can comfort themselves. When things seem ambiguous, there is a certain hopefulness in the uncertainty. But too closely looking and too closely monitoring exhausts patients and also can bring a certain sense of lived unreality to the person's mind. Or perhaps it is better to describe it as lived multiple unrealities; all those things one can imagine to be happening or will happen, unlived future realities. And sometimes the unreality is much preferable to the reality. For when one experiences reoccurrence of disease, life possibilities come to mind that frighten.

The Head Nurse describes this: "He sees what is before him. It's difficult. This may be his last fight with this disease. In fact the doctor may have told him this. But whatever, it doesn't matter. What matters is that we just have to keep watching and listening, keep ourselves ready for when he wants to talk and not impose ourselves on him. This happens to some of our patients, these psychotic episodes. It is sheer terror of what is reaching out in front of him. He expects a lot of himself, he is sleep deprived, he has not been talking to the nurses very much. We can get him through this as long as we can keep in touch with him and keep him from harming himself."

Before this episode, I, in the researcher hat, too had noted in my observations that Mr. Phillips holds himself apart from nurses. I even thought at one point that this situation could be a negative hermeneutic. I reasoned that he must know that while doctors hold the diagnostic and treatment knowledge, nurses help him live it. So why was he not?

Yet after my conversation with the head nurse, I knew how shallow this thinking was. We who have not personally looked serious illness and death in the face cannot presume what another goes through. Here at report in the morning, the episode seemed a call; a call to acknowledge the depths of this man's suffering, his knowledge that perhaps soon he will lose life. Researchers of lived experience who do on-site participation must fight against too simplistic answers. They must rather keep asking questions and learn to live with ambiguity too just as patients and nurses do. It is true too that when an answer comes, it generates five new questions of lived experience.

In the end as much as one can be certain as to what causes psychotic episodes like this during illness, it was thought that indeed a part of the reaction was due to the IGG infusion. These nurses in report pursue an understanding of his behaviour and try to modify causes. But until they know, and they may never know what caused this episode, they perch on the bed like the night nurse, keep him from harm, stay open to what is given to them. They call to him. "The call is from afar unto afar. It reaches him who wants to be brought back" (Heidegger, 1962, p. 316).

There is much more to say about Mr. Phillips. As I write this I feel privileged for what he taught me. Some part of me became defensive and I wanted him, as the scholar he was, to acknowledge nursing's expertise, to admit that nursing expertise is as important as medical knowledge. It is shocking to admit such self-centredness in the wake of this man's lived pain. But involvement in lived-experience research shows much about oneself, not all of it pretty. The self-awareness granted me through my contact with Mr. Phillips was momentous.

In hindsight, even at this point Mr. Phillips was dying. This was a dark night of the soul, a dark heart of being (Conrad). Perhaps he wanted to know if someone would be with-him in the most bizarre behaviours. Perhaps this night he knew and accepted the contingency of his life, perhaps the path to dying. Perhaps here he gathered strength and assurance of support from this close human nursing companionship for saying goodbye to life, to his loved ones. Who knows? The nurses kept talking to each other, to him, to his family. They kept close.

Reprise: Nursing is a dialogue. In nursing often the dialogue is with the body. Nursing's unique contribution to dialogue is the call and response of the Other, the vulnerable Other (Gadow, 1980). The patient calls, the nurse responds. The nurse calls, the patient responds. The nurse calls the physician and allied team members. They respond. Through dialogue we increase our understanding of things. "We humanize what is going on in the world and in ourselves only by speaking of it, and in the course of speaking of it we learn to be human" (Arendt, 1955, p. 25)

Lived dialogue and lived understandings are often incomplete. Nurses rarely have a full picture of what is going on before they respond. But they respond anyway. Mr. Phillips' life task at this time was to understand something that cannot be comprehended based on facts and causalities and familiar things in the world. It is the world of the not-yet. Yet to cut oneself off from others restricts oneself from actualizing possibilities i.e. ways to cope with this. Co-mutualities cannot form. Lived life and lived nursing fulfill themselves only in expressing it.

Dialogue involves a going back and forth, a giving and a taking. Gadamer observes that "to conduct a conversation means to allow oneself to be conducted by the subject matter to which the partners in the dialogue are oriented" (p. 367). Through the dialogue something emerges that transcends the initial understanding of the participants. "What is said is continually transformed into the uttermost possibilities of its rightness and truth, and overcomes all opposition that tries to limit its validity" (p. 367, 8). Dialogue forces us to move beyond our presuppositions, our prejudices when we are in the company of others who thoughtfully comment or challenge our interpretations of things. Thinking begets care when we are granted insight. Gadamer (1989) writes of insight.

Insight is more than the knowledge of this or that situation. It always involves an escape from something that had deceived us and held us captive. Thus insight always involves an element of self-knowledge and constitutes a necessary side of what we called experience in the proper sense. Insight is something we come to. It too is ultimately part of the vocation of man - i.e., to be discerning and insightful. (p. 356)

### **Nursing lives with the Family who live the Illness Too: Whose body is it?**

#### ***Eye contact***

I stand as a fly-on-the-wall observer. This means that I will not engage in nursing activity or any activity in this room. I know this is a total life-as-lived-impossibility, but these are in the early days of being in the setting and I find my way. There is in me a challenge to those who misunderstand human science research and worry about the researcher changing the research setting; that this must be avoided at all costs.

But here I am in a room with Mr. Brown and his nurse and his wife. Mr. Brown's wife and his nurse are having a conversation. His wife insists his stool was green after her husband has told the nurse that it was brown. His wife goes on talking about the green stool and its details. It is important to know as the colour and form of the stool does give information about him that is important to his particular regime of chemotherapy and radiation.

My eyes meet the person in the bed. Remember even though I take up a fairly large space in this room, I try not to *be*. It would make some researchers and ethics committees proud to see my efforts at non-participation. And I wonder where would a video camera's eye be focused here? Although I am in the midst of what happens here, because I occupy a certain spot within this room I see what goes on from a specific viewpoint. And so too does Mr. Brown. But here our eyes search for each other's. We are the only ones not talking here.

We do not know each other but we have a silent communication going with our eyes. His exasperated and tired eyes say to me, "You and I are the only ones who see the foolishness of this scene. My wife and my nurse think they know my bowels better than I do." I believe myself to communicate to him, "You see how ridiculous it is that I stand here as one at a peephole." Because as I see him see me, I see myself and the ludicrousness of it shows itself as well as he sees the ludicrousness of his predicament.

I decide to lighten up his perception, his irritation; well, my perception of his irritation at his perceived foolishness of the scene and move out of voyeurism, narcissism. I act. I seek relation. I send the notion of humour with the incongruity of the situation with my eyes and face after first determining that the nurse and the wife are looking elsewhere. He catches the humour and his eyes crinkle up in humour. Our communication is broken when the nurse turns to engage him in the conversation.

Later I see him on a stretcher going somewhere, his wife walking beside him. We smile greatly at each other. We don't speak. We are content with our visual relation. We have been part of each other's landscape. It is as though we have shared and share still a stolen moment in time, a secret. Our vision becomes gesture for each other (Merleau-Ponty, 1964).

### ***The toll of prescribed treatment regimes***

Lori Russell (1992) in her story One Last Time writes of traveling to a place that has had great significance to this couple in their lives together. They have stopped for coffee and have just resumed their journey. There is an upset about the pain medication, morphine, which is profoundly needed by patients for pain control who have metastatic disease, who are near the end stages of the disease. They have forgotten it in the restaurant.

"Damn! Well, it's not here."

"You forgot the morphine?" His eyes widened. "Doris, how could you?"

"I forgot because I'm taking care of everything. Everything Mac. Every pill, every meal, the driving, you, everything. Can't you help with just one little thing like the morphine?" I clenched the wheel and stared straight ahead.

"No. I'm sorry, but I can't."

His words hit me like a slap. I turned toward him stunned. Tears flooded his eyes.

"Damn it, Doris, I can't remember anything anymore. Half the time I don't know whether it is day or night. I just wake up, take the next pill, and go back to sleep. I hate it" He pressed his lips together as if trying to stop the flow of words.

"I know you can't help it," I said, beginning to cry. "It's just so much to deal with...to see you this way." I slumped against Mac's shoulder. How many tears have I held in during the chemotherapy sessions--the loss of hair, the vomiting, the suppositories, the pain. I hated the way we endlessly track every bodily function and then waited - for the next side effect, the treatment to stop, and the inevitable. Was this all there was?"

"I don't want you to go. You just can't die," I said sniffing. "I'm sorry, I've tried to be strong, be the good wife, but it's not fair. It's just not fair." My sobs erupted again, rushing out and echoing off the car windows.

"I'm here with you now, Doris," Mac said softly. His body starts to shake. (p. 101)

### ***Confusion and disorientation***

"Did I hit that nurse?" Cel asks Ellen. "I don't want to hit her."

"You didn't hit her, you didn't, shhh, shhh," responds Ellen.

"I wanted to. It hurts. I'm so itchy. Make certain I don't hit her."

"I will. I will watch. Sleep now," Ellen murmurs.

"I'm not taking anymore of that morphine. Tomorrow I want to be able to talk to Sally when she gets here. Don't let me hit anyone Ellen!

### ***Who cares for Who?***

"How about we give you the blood tonight then? We'll start it around midnight."

"No, No, my mom is staying the night with me. She is coming at 11PM."

"Ok how about as soon as visitors leave at 9PM?"

"No, my aunt comes tonight from the North."

"Let's get it in right now. Taylor, your platelets are too low and you need this IGG right now too. How about another room?"

"No. How about I wait until my Mom goes tomorrow morning?"

"Too risky. How long have you been hiding this now?"

"About a month. But they will get upset and maybe disown me and I need them now."

"Is there anyone who believes in blood transfusions who can stay with you tonight and you can book your Mom for tomorrow night?"

"My boyfriend, that is all. He's been keeping it a secret too."

"See if you can change then. You need this two hours ago when we got the results back, except your Dad was here."

### ***Nose hair***

Mr. L'Anza is combative. He hits out at anyone who comes near the bed. His nurse determined that he is most combative when he needs to urinate and so a urinary catheter is now in place and he seems more comfortable. He is dying and has not been fully conscious for about two weeks now. He does not speak English and even when he was conscious he did not participate in his care. He rolls around his bed a lot and gets into unbelievable positions and postures. The nurses and physicians have him on a regime of pain control which has helped but really he needs constant care.

Nothing seems to soothe him except the presence of his wife, a very beautiful and elegant elderly Italian woman who spends most of the day with him. This morning she arrives and says that she is expecting some other visitors from the Italian community and she is quite happy to see that he is freshly bathed and his bed clothes are tidy.

Mrs. L'Anza wants her husband shaved. She has brought his electric razor. She hands it to me, and I begin to shave him. But I see by her movements that she wants to shave him herself, so I stand back and hand her the shaver and instead, hold his face in various positions and stretch the

skin now and then for her. She is meticulous. She is very careful to get every hair. I am about to stop her when she turns off the razor and says, "In my bag, I have a straight shaver to get the hairs on his neck." She goes to her purse to bring it out. I stand there in a dilemma. She should not use this razor as any cut in this man with absolutely no WBC's and few platelets would be an instant cause for hemorrhage, sepsis, etc. Yet I argue with myself that he is dying anyway, has a dementia that does not allow her to communicate with him, and this seems to be very important to her. So I decide to assist her. I explain how careful she must be, and she nods grateful that I will let her do it and assist her.

I hold his neck steady. She is careful and goes about it slowly but determinedly and gets just about any hair in sight. She finishes and thanks me and says, "This is good, it has been so very hard on me to watch him deteriorate like this. He was so proud, so handsome. Everyone would look at him. Now we will cut his nose hair. See I have brought some very small scissors too." She retrieves them from her purse.

(I think in horror to myself. "Cut nose hair, not on your life, not on this man, not today, not ever. What's a little nose hair compared to a hemorrhage. This is too dangerous for me, a nasal hemorrhage would not be a pleasant way for this man to die, and it would instant death. I have recently seen one of these deaths from hemorrhage, another death from exsanguination, no, this is not judicious, no!") "

And we speak. And then we speak some more. And as we go back and forth my horizon of understanding deepens, moves. And I acquiesce. Her intensity and longing to do this for her husband hold me.

I position the light, myself, and then carefully hold his head, I hold the nose and help open the nares. She starts to clip. I tell her and show her how close to the mucosa she can go. Mrs. L'Anza looks tolerantly at me.

She has done this before. She is an expert. I stop her for a minute and go and get a wet cloth to wash his nose which is now covered with nose hair and visibility is not good. "Don't worry, I can still see, I am almost done," she tells me. But I do so anyway. We are lucky Mr. L'Anza is so quite right now. The bath and bed have tired him.

While I get the cloth, she continues to speak. "Oh thank you, I wanted to get that out of there for some time now. Now just one or two more hairs..." And she keeps clipping! Each clip causes a spasm in me.

Finally she senses that I have had all I can tolerate (not hard to pick up at all, at all). I have noticed however before that she is quick to know what one is thinking. I have seen it in her interactions with the doctors, with the nurses.

She helps me reposition him. Together we lift. I look at him and sort of sigh. "He is my baby," says she.

"You've cut his nose hair for a long while now," I say. "Yes," she replies, "for a long while."

Reprise: Mr. L'Anza dies early the next morning. She is with him. Later she tells me that his close friends and dignitaries from the Italian community did come to see him. And she tells me she knew he was going to die and that is why she asked his friends over. "I didn't think the funeral home would let me do this the way I like to do it, the nose hair you know. Only a nurse would understand. I shall never forget it."



### ***Hair***

David walks through the double doors of the unit with his wife Sarah. Julie walks toward the door on her way to coffee. Instantly both David and Julie see each other and smile. A lot is said in this quiet smiling as they walk toward each other. Julie doesn't speak. She just raises her hand and runs her fingers through David's hair. It is a gestaltic gesture. He grins, she laughs, his wife's face beams with happiness. Nothing has yet been said.

Julie says, "Wow, hair, I haven't seen you with hair for a long time."

Reprise: I think of the incongruous yet very fitting nature of this. Julie, a very gorgeous redhead, David, a good looking man, and his wife, blond lovely Sarah, stand together smiling. They are all joined as one flesh. This is remission. The chemotherapy worked. Sensuality floods this moment. There is a sense of the erotic and felt passion here; erotic in the sense of bodily feeling, bodily attractions; each reaching out to the other, bodies who know each other, bodies that can't stand too far away from each other. It does not feel odd or sordid. It has a wonderful feeling of rightness about it. At coffee Julie tells me about this man and his struggles with leukemia. "I nursed him back from death so many times. His wife and I cried together so often and look at him now. He's been in remission for almost six months now."

### **Abdications of the Nursing Mandate cause Patients to Suffer the Absence: The Distance**

#### ***Rick***

While I was at this hospital for my kidney surgery, I met a young kid who came in as an emergency and was put in the bed beside me. He had been in a construction work accident where somehow he was caught and dragged between two vehicles. He had broken his leg in 2 places and also his hip. He came in at midnight.

I was awake at midnight because I had just had my surgery that day and at 8PM or so, a nurse tried to hang 3 meds on me that were not even for me. I asked her what they were and she told me and I told her that I didn't get those meds. She told me that I did and that these were my meds and I had just had surgery and often drugs change after surgery. I told her she could not hang these meds because they were not mine. She went away and came back and told me I was right and that she had made an error. So at midnight, I was waiting for my next set of drugs and I knew I had to stay awake to watch what they were. Also I was in pain and was hoping for some pain medication. I had asked for some earlier but it never came. I even turned on the code bell to see if that would get a reaction and it didn't. Later I found out this nurse was passing medications for 2 full wards and she was mostly on the other ward.

Well anyway at midnight here I am hoping for accurate drugs and a pain killer, remember I had the tumor removed from my kidney this day. I have a big

dressing and can only lie on one side or slightly on my back, there are at least two drains that I can see coming out of the dressing. No one has checked my dressing at this time, midnight, and I came back from the operating room about 4 or 5 PM I think. I was quite drowsy then. But now I was wide awake and watching. I wasn't taking any chances for the midnight meds.

But this young kid, apparently they told him that they would xray his leg at 8AM the next day but it took two days for him to get an xray. Well that is just bullshit. He just lay there in such pain. You know bone pain is the worst. I can't tell you how much pain he was in and he never got anything for pain. You know that kind of bullshit just frustrates you. He had a twisted leg, he was only a kid of 21, he had no pain killers. On the second day he was in, now I mean not the next morning but the morning after that, two people came into change the bed. I don't think one of them was a nurse. They only knew how to make a bed one way. They didn't know how to move him to keep his leg straight and how to roll the covers underneath someone in bed so they can roll over them. Not one of them knew anything about broken bones. He had these pillows taped between his legs and they were messing around with that too. It was awful...awful.

These not-nurses twisted him this way and that. They couldn't figure out what to do with the bed clothes after they made the one side of the bed and they were yanking on this kid's legs and pushing his hip. Did I say he broke his hip or cracked it or something too? This kid was in such pain. Anyway, finally one of them went to get someone else so now there were three people standing around his bed trying to decide how to make the bed with him in it and not touch him. So they started all over again.

I tell you I was watching him, this kid was in such severe pain I cried for him. Finally he yelled, "Get the f--- out of here!!!" He was so upset. Upset hell he was in pain. I know about pain and I could see it. The sweat was pouring down his face. He was just about crying. I think maybe he was too. Anyway they just stood there paralyzed after he yelled and they turned and left him. So here he was in the bed twisted around and the old covers and new covers messed up around him. He sobbed.

I was just beside myself. He should have yelled sooner but what did he know. He had never been in a hospital and hadn't seen a doctor since he was a little kid.

I should have yelled at them and I was mad at myself that I did not. I guess I just kept waiting for them to do something right. But I knew they weren't nurses. Nurses can be busy and not have time to do things but when they do it, they do it right. Nurses know many ways to make beds and turn patients. They've done it for me through all my bone marrow transplants and such. I felt so much for this kid. His first time in the hospital and I'm telling you this kid will die before he ever returns to hospital again.

I suffered through this hospitalization. It was hard to see the nurses. They had such stressed out, tired looking faces. I felt so bad for them too; but I felt worse for myself and the boy. Since when can one RN give meds for more than 28 patients on two different wards. We not talking little ailments here. We're talking accidents and emergencies and kidney surgery. Two days after this happened to this kid, I saw a man charge up to the nursing station, rip out his IV and throw the IV pole at the desk. I don't know what was his story but I knew he was in crazy pain. Pain killers are given from three to four hours apart. It takes at least four hours to get one to you. That particular shift I didn't get any of my medications but I knew I was being transferred out the next morning. I don't know where the one nurse was that day, probably had three wards to give medications to.

When I got home, that hospital phoned me to ask me to contribute some money to the hospital because I had just been a patient there. I yelled at the phone, "Give you money, you almost killed me." I know it wasn't her herself that gives this kind of nursing care but I just couldn't help yelling out; like it was the final indignity, the final straw. You know I really believe my complication of hepatitis B came from that place and so does my doctor. He reported it to them. Their not-nurses don't understand how to keep needles and dressings sterile. And they sure don't have time to wash their hands.

Patients recover faster here. The morale is high here; just everybody is connected. You just don't find that kind of bullshit here. It's not a nursing institute there. The nurse here is not just hanging a bag of medication or analyzing your colour and oxygen balance, she's looking at you as a person too and seeing how you are doing with everything that is going on.

Maybe there is just more blood inside these nurses over here!

### *Laura*

I was called into work from 1900 to 2300 on two post cardiac wards. I had floated here before and knew the ward and the conditions of the patients quite well. I was to give medications and manage the TPN's and float between the two floors which I did. But many of the patients were being directly cared for by either RNA's or nursing aides. What this means is that there is unevenness in the care and the assessments. Some RNA's have experience and can assess not too bad, but some don't and the aides just can't do it.

So here I was passing medications and came across a gentleman who was desaturating. I could see it in his colour, his fatigue, even his respirations were shallow and quick. Just one look and I knew he was going to get in trouble if we didn't move on this. So I put the oxygen on him and rolled him up and went and found the staff member responsible for him and told her what else to do with him. I also found the other RN on that unit and told her that he was desaturating and should be looked at by the resident. She said she would take care of it. I then got called to yet a third unit to relieve the nurse there so she could go to supper. She hadn't had a break yet.

About 2 hours later I was on the other ward dealing with a wound that had suddenly burst open and I heard an arrest called for that ward. And I just knew it was him. I ran there and went directly to his room and it was him. Apparently the RN had called the resident up but the resident first had to look at someone in chest pain and the RN and the resident got involved in this same person's tracheotomy and such and they just didn't get to him. Also the staff member taking care of him took the oxygen off him because he complained that the prongs hurt his nose.

He died. And I knew we were responsible. He only needed monitoring, oxygen, a medical assessment for further orders. That's all. Simple things we used to do all the time. Now it seems we only do them for the ones in emergencies or those who have family to keep asking for things to be done. Families need to watch over their people 24 hours now.

### *James*

At a rally to protest health care cuts I, Brenda, met James. We stood beside each other while waiting for some response from the legislature. He was about 18 or 19 years old, very tall and extremely thin, emaciated really. My nursing eye assessed him from a distance, so to speak, and I

was instantly concerned about his ability to be at this gathering and whether or not he could stand up for very long. My husband and I decide to move behind the crowd to sit on the concrete edge of the fountain there. We knew our wait for the message or appearance, epiphany perhaps, of the Minister of Health could be lengthy.

Our moving, watched by James, results in his coming to sit beside us at the fountain edge. I strike up a conversation. James has Crohn's Disease.<sup>5</sup> He had just been through a severe exacerbation where he was hospitalized for six weeks, fed through TPN, was too weak to get out of bed, and mostly lay in one position the entire time. James is tall and extremely thin. He has splints on his wrists and forearms and it is because of these that we first start talking.

"I have to wear these because I didn't move my arms and legs very much while I was sick and now I have some contractures here and I have to take therapy too. It is a worry because I may never get feeling back in one or at least it will take a long time."

"You were extremely ill, it sounds like," I comment.

"Yes I was and it was hard to just lie there day after day. I couldn't get out of bed at all. When I tried to get to the bathroom I fell and tipped over all these things I was attached to, IV's and TPN's and medications. I couldn't get up after that either so I lay there for a very long time with blood running out of my arm and fluids running out all over me and the floor and bedcovers dangling on the floor. But that's why I'm here today, taking time to come today. I've been home about 3 days. Most people don't understand about the health care cuts because they have never been sick. I can't tell you how awful it was to be in the hospital. I couldn't even piss. They gave me this bottle but no one ever emptied it. It was always full. I was on all these fluids and IV's. I had to go all the time."

I sit listening intently, feeling his distress, feeling my distress.

"You know the worst were these people who weren't nurses and tried to do nursing things and didn't know how to do them. I can't tell you how many times I had to ask them to stop doing what they were doing because even I knew it wasn't right; things like disconnecting my IV at various places to put my gown on or something, and not being careful with the tubing end, keeping it clean, and then hooking it up again to the wrong thing. It was awful. You lie there and watch these things so you know which gets hooked up to which. When I would see a nurse it would be for a pill or something. Some of them looked worse than I did and I was only looking at the young ones and they looked terrible. They would do these checks on me now and then but they couldn't give me any care. The guy in the next bed told me that they had to have something to chart but I don't know about that."

"I don't know what to do about my experiences because if you complain they may treat you worse. And I will probably end up in there again. But at least I can come here and ask for registered nurses for our health care. I heard on the news that they want to remove nurses from the operating room. If they replace them with some of the people I had, I feel sorry for anyone getting operated on. I've been told that if I would have had my arms moved by someone else during the time I was so weak and almost unconscious, like exercised for me I mean, I would not have this perhaps permanent damage to them, to my muscles."

Reprise: To be nursing and to be unable to give appropriate care moves nurses to something more than despair; it is a splitting off from themselves. It is like you false advertise. There is

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<sup>5</sup> A chronic inflammatory bowel disease, unknown etiology, results in serious nutritional difficulties.

nothing there. But worse, the ethical space, the space where you enact your commitments to others, diminishes, disappears. Your identity totters between nursing and not-nursing. The sense of yourself nursing becomes misplaced. Taylor (1991) states:

Your identity defines the background against which you know where you stand on such matters. To have that called into question, or fall into uncertainty, is not to know how to react, and this is to cease to know who you are in this ultimately relevant sense. (p. 305,6).

### **Nursing Abides with the Gamut of Patient Multifarious Experience: “A Nurse lives it with You”**

#### ***To tell or not to tell***

You know my doctor told my sister about my leukemia before he told me. And I knew there must be something wrong because all of a sudden everyone started acting differently toward me. They did more blood tests and wouldn't tell me what they were about. I had gone in to have a hernia repair. But my pre-operative blood work came back funny. Then they called in a haematologist and he would not make eye contact with me. And so the third time I saw him, I literally stood in front of him, grabbed his collar, and forced him to make eye contact with me. By then my sister had investigated all avenues of treatment for leukemia. She even called the University of Nebraska which had an experimental treatment. My Mom right after offered me a trip to Europe. I didn't want to go to Europe, I wanted to be home, with them. Your home becomes so important to you...it is wonderful to be at home.

#### ***Arlene***

“Let me know as soon as he goes in the next room, then I can get ready. I'm going to pull the curtain slightly around the bed so he can't see me until he gets to the end of the bed.”

Arlene plots a scene. As soon as the physician goes in the room next to Arlene, her nurse gives her door a knock. After a few minutes, he exits the one room and enters Arlene's, washes his hands and forearms, masks, enters.

Arlene sits on her bed. She has a arrow on her head, a gismo that looks like there is an arrow shot through your head. The doctor looks at her and laughs. It is a big laugh. Arlene laughs too. It is a new beginning.

#### ***Why Arlene?***

This man almost ended me. I wonder if doctors realize how much effort patients put into being patients. I have had to battle against this one doctor only taking away my hope. Most recently he told me I would not need another chemotherapy regime. Why? Because I would be dead before it got started. You

see I had a misreading of an x-ray, which had shown that there was metastases to one of the bones in my arm. The second xray showed no metastases.

My husband didn't understand when the doctor said, "You won't need that chemotherapy anyway, don't concern yourself about it." Later my husband said, "Well he meant you won't need it (the chemotherapy) because of the second xray. I said, "No he meant that I am going to die so I won't need it."

This physician kept doing and saying demoralizing things to me, indicating I was fighting a losing battle. This man never ever smiles or jokes or lightens up. There was once I wanted to approach him and talk to him about the importance of hope for us, hope is hope, and it is very important. But I didn't do it. I didn't want to do anything nasty to him as I can't afford to alienate him. But I realized that I had to live with this man, I don't take anything much as his time.

He needs to understand that I have to live my life every day until I die irregardless of how long it is. Now we talk in comfort, in mutual exchanges. He has come a long way.

### *Don*

The other day, my doctor introduced me to another oncologist the other day as his Porsche Patient. You see, I was supposed to die 4 years ago. He told me so himself. Each time I come in for my checkups, he sits down and we have a good visit. We talk about how hard it is to be in this line of work, telling people how much time they have left. I keep telling him that that is the doctor's time, not mine, not people-time. They might know about the disease but we know about ourselves. When I was diagnosed I was told I had eight to twelve months to live and 70% chance of not having any treatment work at all. And here I am. I've packed a lot of living into these four years.

His colleague asked him what he meant by Porsche patient. And he said, "Better than a Cadillac, he is my miracle."

I gave him a cartoon that shows a huge crane swallowing a frog; the frog's legs are the only thing outside of the mouth. And it says, "Don't ever lose hope." He looked at it for a long time when I gave it too him and said nothing. Then he put photocopies of it up everywhere, in his office and in the examining room, in the waiting room. I think he put them up to remind himself of this as much as us.

With cancer, you have to stay positive and you have to have the inner drive to sustain it. If you don't, it will beat you. When those doctors tell you that you only have so much time left, if you let it into your brain then you live only that long. I've seen it with patients here. That's the doctor's time; it's not yours.

*Angie*

To have chemo or not, to have radiation or not, I couldn't decide. Because I was in shock when I was diagnosed, I decided to go with the chemo which meant stopping breast feeding and such, and when it spread to my spine I decided to have radiation, but you know I also decided to have alternative treatment and so went to a medical treatment clinic in Poland. I asked the chemo nurse about the effectiveness of chemo. It seemed to me from my reading that the chemo and radiation were killing my good cells and knocking out my immune system that I needed to fight the cancer.

You take the good with the bad I know, but the bad so far outweighed the good. I began to talk to all the professional people I knew in the cancer circle, nurses and doctors. The chemo made me so sick. When you are that sick, the diarrhea, the throwing up, the loss of hair, you can't even give any time to anyone else when you are feeling so bad physically. You become self-enveloped. You can't think of other people or your kids or enjoy them. I can't do that, and so I chose alternative treatment in Poland.

I just can't sit there and have someone tell me how long I have to live, because it is not up to any human being you know, I believe my life is in God's hands, that he had a certain number of days for me to live, and I'm going to live everyone of those days but I can choose how I live them. I have four children, I can't just wait to die, so I decided that it is probably a better thing to learn how to live each day than to learn how to die.

*Helen*

I had such dreams. I did want to fall in love again. I used to dream of love and travel and excitements. Then I just wanted to be able to enjoy special holidays at home with my family. And now I just try to make it through the day, the minutes of the day really when the pain is so bad.

Those nurses out there, they know me so well. And they know what I know; that this is my last time here. I delayed coming because I knew it would be my last



time. It is hard on the nurses. I change each time I come in. This \*#% illness changes all the time, it just keeps traveling no matter what you do and each time the illness changes, I change. So is this the real me, or is this the real one; I keep changing with this traveling. Then the nurses have to come in and see that and it is hard on them. I read it on their faces this time I'm in. And I'm scared that I may be a real asshole when I die and be mean to them. I mean I don't want to take my hurt out on them. They got me through to here.

### *Gwen*

Gwen: Last week a doctor came in and told me I will have to understand that if I have a cardiac arrest, I won't be resuscitated. How can they do that? Yes I have metastatic disease and yes my lungs are bad, yes I understand I will die but I want to be resuscitated should I die tonight.

Lynn: There was no reason to do that. We would call a code no matter what here. It is our policy. We are not certain what was going on here.

Ray: You know, my wife has enough to cope with without this. It is a though they keep saying to us, have you figured out yet that Gwen dies? Well yes we know but we are just trying to live our lives and live through this. Sometimes I think they would be happier if we both just lay down on the bed and die now. But we still have our dog to care for, I still have my job, our life rhythms go on until she dies. And we have to have some hope for the next minute, the next hour. They keep trying to take that away from us because they are afraid we have not understood and they won't have fulfilled their medical mandate to tell us. But we know. Tell them we know. We still have to live somehow. They make it difficult. How do we get through to them that we know what is going on here. But should I keep saying it in front of my wife when they are there, "Yes we know Gwen is dying, yes we know she dies, yes we understand!" But you know it is them we take care of doing that and not Gwen foremost and me second. I wish I could teach them this.

Dr. Black: We are legally responsible here. We must be certain they understand so they can make their arrangements. This was unfortunately done and that is too bad. But there it is. It has to be done.

### *A week later*

Gwen and Ray: And here we were talking to the doctor about our boat and I say to him, "I want to go sailing one more time and we are thinking of going South next week." And he said, "South next week, you won't even be alive next week." We were speechless. We couldn't respond, we couldn't. We called Dr. Black up and he came and told us to forget this comment and to go on doing and planning what we were. And his parting comment was, "You have trusted me this far, now trust me some more."

Lynn: This is so unfortunate. You know, we nurses can turn around most comments made to people. For example if the doctor does not tell them enough about the side effects of treatment or whatever, we do. We make certain that they know that the chemo will be a bit more complicated than that. But when it is a negative comment like this, we can't turn it around, we just can't no matter how hard we try. People believe doctors have answers and sometimes they do for sure, but not always.

Reprise: When a particular world is projected for you, here a time limited one, it is almost impossible to turn this around and constitute your own world. Why? Because you believe you can

only conform to what has been determined for you and so you in turn, constitute it in exactly the empirical way given to you. What happens is the person has to work dreadfully hard then to self-determine her world in her own way because she must constantly work against this powerfully planted future.

### *Eric*

Eric, a veteran patient, recounts the moment the doctor tells him he has cancer. Eric is a pharmacist. He understands all the "medical jargon" as he calls it. But he will never, ever forget this moment.

The doctor looked at me and told me I had cancer in my neck, in my salivary glands, in my lymph glands, in a lot of the tissue and he told me how much time I have left. I can still remember the date, it was the 13 of October at 11 AM.

After he told me he went on talking about curing and treatment and such. And then suddenly he looked at me, he put his face opposite, straight next to mine. He caught me by the shoulders and he shook me and said, "You're not listening to me!" And I said, "With the news you just gave me, you've made my mind go blank!"

So then he started talking to me slowly about options and things and of course being a human brain the grey matter took over and I suddenly realized "Well, it's got to be faced - I'm not done yet." So by the time my wife knew, I was a little better. She was bawling her eyes out. But it's an experience - the only one I'd wish to have this experience is Hitler.

Reprise: Time left to live, life left to time. How can we leave life to time, to let life live its time? What is it to be told that there is only a little time left and to use the time accordingly? It is this: It is impossible for lived-life to acknowledge death in this empirical way because dying cannot be actualized until it comes (other than suicide).

Heidegger (1962) writes about the face of one's forecoming death. Empirical certainty is in "no way decisive as to the certainty of death" (p. 301), and is tied up with "tasks, rules, and standards, the urgency and the extent...of solicitous being-in-the-world" (p. 312). Heidegger (1962) calls this the publicness of death. But people do not approach death in certainty because of theoretico-thematical considerations of it (p. 305). Rather, they look away from the possibility of it. To look death straight in the eye would be to actualize it, bring it about, wait for one's demise.

When it is myself in question, my death, and I understand it to be my death, I still have to look away from it. If I look only to my death, I will terminate all my active involvements in my world. Should Arlene stop mothering two small children who are part of her world? Should Gwen and Ray stop living their world together, terminate their dog in anticipation of death? It is just these sorts of things that those of us involved in the medical profession ask when they worry that we have not yet "understood our impending death."

Because we must still act in our world, we have to evade death and tranquilize ourselves and others in order to snatch our demise back (Heidegger, 1962). Gwen and Ray know about the doctor's time for death. But they have wrenched it away from those death-sayers and now say,

“We know we die, we are prepared. Now we will continue to live and please let us!” They now anticipate the death in their own self actualized way.

Physicians, because this is part of their medical domain, and nurses also to a certain extent, worry when a person does not show signs of understanding his impending death. Physicians above repeat it plainly to Gwen when it seems to them she inappropriately plans another trip. But the planning of sailing trips is integral to their life together. They imagine the sensuousness of the wind on their face, the freeing feeling of moving with the wind. Arlene wants to be with her children as much as she can and she plans to bake for the Christmas concert at the Kindergarten. For these and others cited above, the possibility of no-longer-being-able-to-be-there (Heidegger, 1962, p. 294) dis-integrates life and they cannot afford to do that to their loved ones. As Lynn says, “In all my experience as an oncology nurse, as much as the cancer eats away at their bodies, their inner and outer self becomes more beautiful. That is why there is the saying, ‘cancer only takes the good ones.’”

These individuals live with another understanding that Marcel (1950a) helps us to see in terms of serious illness and death. When first diagnosed it takes time for the illness to become a presence to me, a presence I learn to live with; something akin to learning to live with a new roommate. In terms of our theme here of representation, I can too objectify the disease and not see it truly as a part of me for a time. But when I become somewhat incapacitated “the illness becomes a presence in so far as those who care for me, and play the part of a Thou to me in my need, become intermediaries between me and it” (p. 210). The disease is now present to me directly through others. When “my illness has utterly prostrated me, in a state of complete collapse or acute pain, my illness, paradoxically, ceases, as a separate presence, to exist for me; I no longer keep up with it that strange acquaintanceship which can be a struggle, or a dangerous flirtation, or the oddest blend of both” (p. 210). The illness and I are now one.

### *Managing isolation, Managing care*

I had five rounds of chemo plus total body radiation before my transplant. Doesn't that sound frightening, total body radiation. The sound of the machine is like this, nzzzz, nzzzz; it's rhythmic and very scary especially when you see the technicians run out of the room so quickly. After each chemo I was in isolation for 33 days. Imagine being in isolation for 33 days! But after the third course of chemo I went into remission. Then after six months I relapsed and it was then my blood was harvested and they looked for a donor. But the next round of chemo put me into remission again.

Imagine being alone for 33 days, only my wife to visit and the nurses. And you are so sick with the chemo, you have to be very careful with your care, you must keep your mouth clean and your bottom clean. I continually washed. Once when I was really ill, I became delusional. Funny I knew it was happening at some level but I couldn't help it. It was terrible terrible. I was vomiting and such too but the delusions were the worst; thinking my wife was going to put the

pillow over my head and such. I'll never forget it. I understand mental illness now and have much more compassion than I ever had before.

When I felt better I made the nurses little broaches made out of wood, squares and circles and stuff. I chose each figure to go with the specific nurse. I made 30 of them. But these nurses, we created our own little relationship, each one. One thing constant in all of them was that they would try to get me not to see the sickness all the time and make me see other things. Being in isolation they would come and visit me and sit on the bed and talk to me. We got to know each other on a personal basis, I mean, I would tell them some things about my personal life and they would tell me theirs. I don't mean like how many kids do you have, but real private stuff. You know life is entwined with problems. Yup, we solved a lot of problems those nurses and I; isolation makes you share.

*You nursed them...*

Yeah maybe...but too they would sit and tell me jokes and make me laugh and laughing was good. They watched over me and you know when I got out of isolation or when I was sick other times, if I hadn't been for a walk and had been lying in bed all day, they would come to me and say "get your butt down that hall right now" and they could do it because we knew each other so well. I have my top ten list and I know which nurses should be cloned. One of my favourite didn't come to see me right away with the last relapse. But when she came, she and I just cried together. And she said she didn't want to come in because she was afraid she would do this. It's hard on nurses to see us relapse. I made her a little mouse broach because she is always quietly watching, sniffing out things for her patient.

*Angie*

Now the cancer has reached my lungs. Each time it spreads you feel like you have been kicked in the face. You go about in a daze and then you start to fight again. I spent a half day in Emergency waiting to have my lungs drained of fluid. You can't breathe you know. It's like you can't get your lungs full enough sometimes...and you ask them to turn up the oxygen and they tell you it is at the highest and you despair even more and wonder, "where can I go from here?"

But here in emergency I met an internist who did more xrays and told me that he was not going to drain them because we would risk collapsing the lungs. He also

said the fluid was not as bad as the oncologists had initially thought before they sent me to see him. He said to me, "I'd really like to wait until it is worth the risk." I haven't had good medical care and that's why I went the alternative route. Each time I asked the doctors about their opinions of treatment options and such, they would quote me studies and things but would never commit themselves to what might be best for me. But this internist took the time to assess me further and the courage to tell me that it was not time to take the fluid off my lungs just yet. He told me he thought I was very courageous to give up the chemo treatments and I told him I did not want to take it until I was dead and be sick and not be able to hold my babies. I told him the side effects were not worth it and he said I was very right. He respected my choices for a quality of life and said if he could in any way assist me further to let him know. He showed me a great deal of empathy. He said he would be happy and honoured and pleased to help me fight my battle with breathing. He said, "We run the risk of infecting the pleura, the lining of the lungs, which will then cause even more problems with fluid buildup."

This internist had a heart. He was patient with us. He helped us make an informed decision. He checked me out and then said, "Don't risk it right now." You know I took three hours of his time, and it came to nothing for him and we shook hands and left.

Reprise: This physician in his actions becomes gift for Angie. Angie did not meet many who treated her compassionately during her time dealing with cancer and cancer treatments. There were no nurses that stood out for her, that helped her cope or get through things. There were no physicians that helped; they only quoted statistics to her and offered treatment and gave her choices. But here in a place where she did not expect it, a physician really cared for her not as a statistic, not as a referral for a certain procedure, but for herself and her personal situation. He treated her with dignity not as a statistic. "His own essence is a gift...not a datum" (Marcel, 1950b, p. 173). Probably what he did most was to validate and support her and her decisions. And he saw something in her; not denial of disease and death but wide awakeness in the face of overwhelming deterioration. He saw her authenticity, her self-actualized self. She saw his authenticity, his willingness to take time with her case. Both saw in each other what only Marcel (1950a) seems able to say well, "this superior reality in the depths of myself, which is more me than I am myself" (p. 65).

### *Saying Goodbye*

#### *Voice One:*

This is the sickest I can remember, I relapsed after 6 months, some nurses couldn't come in and see me, they felt so sorry to see me back here. They needed

to be a support to me yet they did not rush to see me, just my nurse that was actually doing my direct care. But after a while they all came back, they know the cancer game, I know the cancer game as well as any nurse, it can strike again.

*Voice Two:*

I have no plans. All of a sudden all my Christmas traditions mean nothing to me anymore, none of this means a thing to me because I can't be there. You know like Christmas is a common gold thing for me, and Easter is a common gold thing for me and my traditions. Somehow all that joy I have inside me somehow is just disappearing. And I sort of turn it off, you just shut everything off, your brain, so you don't have to think about it.

*Voice Three:*

It is hard to know that your life is over and still be living it. It is hard to lie here and know what was is past, what is before me is death. How hurtful it is to still be living when one's life is over. What is it to live, to breathe, to be, when there is no life. What is it to have no life. It sits heavy on me. I can't be a part of the life I know; death comes soon. Well it is when there is a way you can live your day. I didn't come into the hospital until I couldn't stand it anymore because this is to be my last time here.

Reprise: The notion of false hope can send the multidisciplinary team into existential panic. Should take away hope, should we hope at all for this person in light of the cellular status of their disease? Nurses live their hope through intersubjectivity; through being with their patients, their families. They are not only with their patients, they are with the disease, with the treatments. Any "relationship expressed by the preposition *with* that is eminently intersubjective" (Marcel, 1950a, p. 177).

How does intersubjectivity give hope? It gives the notion that someone lives the illness with them in a way that sees them and not the illness. In concentrating on pulling strength and courage from individuals, the notion of hope is "an active reaction against a state of captivity" (1950b, p. 160). To suggest to someone through word and/or gesture that there is no hope is to reduce their life to a "certain representation...a psychic contraction" (p. 161). But hope is not a contraction, it is an expansion (Marcel). Hope gives "an *open time* as opposed to a *closed time* in the contracted soul" (p. 162). And more is offered here; no matter if a life is weak or the chances are slim, the multidisciplinary team must ensure that life no matter what "retain a certain character of sacredness" (p. 163). An attitude of sacredness (sacred, sacral, spine, spine connects us to the earth, to the ground according to Skeat, 1958) binds one to the other in an aurora of hope.

### ***Blood***

Leder (1990) states that we are not only known by our flesh. Our flesh signifies our outside, our surface body and not our insides. Leder calls the flesh our visible and our blood our viscosity. Blood is corpuscles, flowing fluids, life sustaining oxygen containing cells. But what is it like to

be known by your blood work, your inside outside, so to speak? Rick says, "Don't get too excited about it." Ena says, "It's just another treatment."

*Brenda:*

Hi Rick, do you have anything to say about blood and your experience with it?

*Rick:*

You know as soon as you said that on the phone the other day, the first thing that came to my mind was one day when I had to go to the Red Cross for a harvest of stem cells. I told them my name was Rick Beauchamp. The fellow became very excited and he came around the desk and offered his hand to shake. I took his hand and shook it and then he said he was glad to meet me in person. He told me that he had been preparing my blood products for some time now. Then he convinced me to come with him and he took me around and introduced me to the other technicians. They all said, 'We're very glad to meet you, we've prepared a lot of blood for you and we know you are doing well. You look well!'"

They have, there is no question about that and I'm very thankful for them and for my donors, especially now as I have to have single donor ones. You know when your blood is low you are low, there is no question about that at all. And I've needed blood a lot of times and been so grateful that it is available to me. But its just another part of the treatment. Don't get too hung up on it.

More important to me is that I'm finally getting some of my strength back and it feels so good. I cried at home when I couldn't lift a less than 10 pound bag of garbage, to take out the garbage. People are dying all over the place and I'm crying because I can't even twist the cap off a jar for my wife anymore. I used to be in construction, a carpenter and I lifted huge wall board and things and now I can't even take out the garbage. You know it was then when I thought, 'This is just too much. It asks too much of me, takes too much of my life away.' Odd, I wanted to take the garbage out for my wife, I mean I really wanted to do this yucky task. Sick isn't it and I cried because I couldn't. But the doctors say that sometimes it takes 3 or 4 years to get your strength back.

What's my answer? I have no answers. But I believe that living with this is 95% positive attitude, it is the whole thing with cancer, positive attitude and sense of humour and someone from your family watching and checking things up for you. And when you are in the hospital, it is the nursing that counts for you, nothing much gets by a good nurse.

I already told you about my sniffles with this transplant and that it could be that my donor had allergies. My doctor told me that whatever my donor had in his blood is now in mine and if he had allergies I will too. And back to blood, I started out Rh- and am now Rh+ and I don't know about my blood type now just what it is, it is different. So in some ways I am a whole new man, different flesh and blood. This puny man doesn't do garbage.

### *Ena*

Blood isn't anything. It is just another treatment product. What is more important is the patient and why she gets it. But I have to say that patients can get excited about blood. They treat it differently than antibiotics or chemo per IV. And they talk about it in pints. I mean I know about pints as a measurement but in my lifetime I have never been exposed to pints. It is on American TV I think.

Patients do see receiving blood as more serious. I've gone in and asked patients "How do you feel today?" and they answer, "I don't know, I didn't get my blood counts yet." That is their response. And I say to them, "I didn't ask how was your blood doing, I asked how are you doing?" And this usually gets a laugh out of them.

It is as if they define themselves in terms of what their numbers are, and they are very up when those counts go up and very down when they go down. Sometimes I tell them, "That is just the sensitivity of the titre, this is not an increment or a drop, it is just the machine" and I try to tell them, "This is our limitation or rather, a limitation of the test so not to put so much store in them. If they are breathing better today, and able to do more things, not feeling as weak, they can feel sure their haemoglobin is up. But they still want the objective test. Doctors too. You know doctors used to use more assessment with patients, now they order more tests. I sometimes say, "Do you know what the patient will go through with this test and she is quite weak?" But they want a test to back up their diagnosis. For example, there is a smell to ketones in a patient, you note it as soon as you enter the room. Doctors used to just order based on that. Now they want proven certainty.

### *Diagnostic tests*

What is it to live with these screening and diagnostic tests? Certainly we need them to plan treatment, as adjunct to chosen treatments. But the above describes how some people live these



tests. Van Zurren (1993, 1994) cautions us about Health Care Technology. Tests induce more and more uncertainty, and even when you get a negative result, you still worry because of the screening the screening has caused you to lose faith in your body. No longer do they judge how they are by their subjective feelings of living their body, rather they give this up to objective tests. And when the test is over even if it proves something or is to no avail, people say, "well it was the best thing to do" even though it has caused them serious consequences in their personal lives. "On the one hand medical science and its applications, meant to overcome human suffering from diseases and malfunctions, have grown so very rapidly, whereas on the other hand so much human suffering in this area still exists or is created" (p. 2).

It may sound strange, but as I see it, the core problem of many screening, diagnostic, and therapeutic devices is simply that they exist and are available. Once a person is informed about the mere existence of these devices (which may happen by looking at the television or by reading magazines and which in most cases is the duty of the attending medical practitioner), his naiveté has gone and the world looks different. There is an extra possibility now, apart from the status quo of trust and of not trying to know whether one is afflicted or not, apart from simply having to endure the natural course of things...Being confronted with this extra possibility implies that one is forced to make a decision on whether or not to make use of it, where earlier, without knowing of the existence of the (technology) or new technology, no decision had to be made at all. This very fact creates unfreedom where, before, freedom prevailed...For this reason, the availability of a new technology is not a neutral affair, as biomedical scientists implicitly claim. And not making use of it is even worse than that. It has the much more ponderous status of an active rejection. (Van Zuuren, 1993, p. 8)

### *To be life-bearing in the face of illness/death*

Radley (1994) states that "the chronically ill must bear their illness in ways that do not imply either that this burden is too heavy for them, or that bearing it makes them markedly different from the healthy. On the other hand, should they...act as if they are 'really normal', then sanctions will be applied to remind them of their 'true status'" (p. 158). Judith Lynam (1990) states:

While many of the stresses experienced by young adults with cancer originate with the illness, there are also relationship stresses to which the cancer patients must respond. Many of the participants assumed a burden of caring for persons in their social world as well as finding they needed to educate those around them about their illness so that they could resume or maintain relationships they perceived had been supportive prior to their illnesses. (p. 191).

Yet Nuland (1995) states that "the dying themselves bear a responsibility not to be entrapped by a misguided attempt to spare those whose lives are intertwined with theirs" (p.243). Nuland suggests people be honest and stay involved until the end with significant others; not to protect them because in the long run, it does them more harm.

### *Dying: Wilfrid, Student Nurse*

A woman diagnosed with the final stage of pancreatic cancer was dying. Her husband came to her bedside every day and night. She was only able to say several words, or to nod her head. These were the last modes of communication remaining in her. At times, her husband held her hand and whispered close to

her ear. The love and care her husband showed is still vivid in my mind. I believe it is one of the most devastating and tormenting events when someone watches his loved one wasting away and dying without being able to help in the dying process. The painful experience I imagine must be extremely hard to take. I felt incompetent at that particular moment. It was not mainly because of my inability to save this dying person or to alleviate her agony of suffering, but due to the fact that I could not share the sorrow that her husband was experiencing. Her eyes were closed at all times, however, her husband looked at her with a glimpse of hope and peace. The expression of love of the husband on his beloved wife was so dramatic. Unfortunately, one morning she passed away two hours after her husband, their son and daughter left the unit.

A sense of ambivalence emanated within myself as I was preparing her body which was then wrapped by a shroud. The question of whether she was really dead came back and forth in my mind since her body was still warm even though she was pronounced dead three hours earlier. At that moment, I instantly felt that I totally lost contact, both physically and spiritually, with the person lying in front of me. The reason was that she was no longer alive. She had turned into a corpse, not feeling or breathing like a normal human being possesses. It was the first time that I strongly felt being completely disassociated from another individual. That sense of separation was horrific and formidable (personal communication, Wilfrid Chiu).

Reprise: To be present to the transformation from the living body to the dead body is horrific and formidable and remains so throughout one's career as a nurse. One never becomes immured to death unless one is immured to self. To be present to another's lived grief too is disturbing, laborious, and very solitary. It is as if you yourself take a journey along with the dying one because no matter how you try, the dying one dies in a personal way, the family grieves in a personal way. One cannot help but be drawn into this personal way of living dead and dying. It is as Leigh says earlier, "No one can be in the same place you are." It is as Heidegger (1962) writes: "A psychology of 'dying' gives information about the 'living' of the person who is 'dying' rather than about dying itself" (p. 250).

Our natural human abhorrence of the dead body, the body void of breathing processes is profoundly significant to nurses to Wilfrid. We as nurses listen for breathing; its rate, rhythm, depth, smell tells us much about the physiological, psychological status of an individual. Wilfrid, as student, reacts to this event with horror, with a response from his very soul. His revulsion and response are authentic and very very human. What is it for him as student to note in the above account that the dead body did not have feeling or breathing: "She had turned into a corpse, not feeling or breathing like a normal human being possesses." It is for Wilfrid to experience the horror of the non-relational (Heidegger, 1962). In nursing education our primary *modus operandi* for clinical experiences is to consistently tie the contextual with the conceptual. But how does the

concept here, the theorizing of death, in any way touch this very elemental showing of what it is to be deeply human and embodied.

The writer of Ecclesiastes has a pragmatic approach to death albeit a truthful one, and captures the horror that Wilfrid cannot name totally.

For anyone who is linked with all that live still has some hope, a live dog being better than a dead lion. The living know at least that they will die, the dead know nothing: no more reward for them, their memory has passed out of mind. Their loves, their hates, their jealousies, these all have perished, nor will they ever again take part in whatever is done under the sun. (Ecclesiastes 9:4-6)]

Heidegger (1962) states that death is a person's *ownmost* possibility. Impending death is "no-longer-being-able-to-be-there" (p. 294). The person is no longer able to fulfill herself. Dying is "essentially mine in such a way that no one can be my representative" (p. 297). For Wilfrid he must face this; dying is one's uttermost aloneness. And he must let her go.

Gadamer (1981) shows us something about the enigma of death. He states that we as humans abide with the dead and this makes us fundamentally different from the rest of the animal kingdom. In the following rather long quote, he points us to salient point about death that often does not reach our knowing selves.

This is why the burial of the dead is perhaps the fundamental phenomenon of becoming human. Burial does not refer to a rapid hiding of the dead, a swift clearing away of the shocking impression made by one suddenly stuck fast in a leaden and lasting sleep. On the contrary, by a remarkable expenditure of human labor and sacrifice there is sought an abiding with the dead, indeed a holding fast of the dead among the living. We stand amazed before the wealth of mourning gifts that continually flows up toward us from the graves of every ancient culture. Gifts of mourning are a way of cherishing human existence. They do not let death have the last word. We have to regard this in its most elementary significance. It is not a religious affair or a transposition of religion into secular customs, mores, and so on. Rather is it a matter of the fundamental constitution of human being from which derives the specific sense of human practice; we are dealing here with a conduct of life that has spiraled out of the order of nature. As compelling as the vital instincts that we can observe are, say, among birds, how astonishing is their shunning of dead members of the species or their total indifference toward them. This contrast points up how humanity has begun to be turned against the natural vital instincts of survival. (p.75)

In organ retrieval, dead bodies are treated as live ones. They are given anesthetic, organs are removed and stored appropriately. It is almost a ritualistic act like consecrating bread and wine. Organs removed, received, handled with care each in a particular solution in a particular container, all stored in the hopes of making another whole again. The dead body in organ retrieval is shown respect at all time. It is treated as if it is in life. Somehow for students, for humans, the difference here is that these actions maintain the relational through hope, through thanksgiving for the consent to retrieve, for the sacrifice. One knows that these organs will be the possibility for life in another.

How to help Wilfrid here? It would be in some way to directly present death in terms of nurse's lived accounts of what it is like to be with a person who is dying. It would be to diminish as much as is possible the representative nature of death and dying and the categories and stages of it. We must better present the lifeworld to Wilfrid. Did Wilfrid recover? Yes and he is of a

certainly one of the very best nurses now working on a surgical ward. The notion of recovering is essential to nursing. We uncover to see better and choose our actions, we cover to protect, to make things livable, manageable, we recover bodies in shrouds for the next step of corpse-life, we recover, reclaim ourselves and others who live on bereft in some way. How do we recover best? We recover by turning the non-relational back into relational or in some way being able to sustain the relational now manifest as the nurse's essential moral-ethical dilemma in the face of a corpse. What does that mean for the person of the corpse? It means just this: that the nurse makes relation for them in the threat and presence of the non-relational even when the person can't. Nurses still relate and negotiate with the family, with the physicians, with the morgue and pathologist, to autopsy or not; the nurse carries on relation for them.

Death in everyday life is concealed, the possibility of death covered up. In fact, where death and dying is concerned, we reside in untruth (Heidegger, 1962). Nurses cannot do this and nurse. Nurses are stripped of the ability to cover up so to speak. Lived truth in nursing is to see all uncovered, to live each person's coping, enduring (Cameron, 1993).

***Succor: Lydia speaks***

The most important thing is patient and family comfort, your relationship is not only with the person but also the family. There is a lot of emotional upheaval during illness and crisis and with the bedbath, you open up a door to be able to communicate with them and then hopefully help them with a few situations. I often have times when the person is comatose and sometimes the family just sits there while I do it and I talk to them. And we have conversations about the person and involve the person even though there is no or little response.

I find that this is the time the family ask me about when their loved one is going to die. And I answer them by going over physiology with them, like I talk to them about the person's purple legs meaning their circulation has shut down. So when I bedbath I explain things to them. And because the person is cold, they want to cover the person with a lot of blankets and I tell them not to because it makes the person uncomfortable. So basically I teach them about dying and if is always better for the family than to leave them without knowledge.

***Death: Moira speaks***

I work on a cardiac unit so we have quite a few deaths...Sometimes the bedbaths after death of people we have known well, sometimes they are so emotional that 2 of us do it together. And we could be crying as we relive the last few days. We say to each other, "Well you know he was such a pleasant man or woman who always laughed even on her death bed and the family is so nice." It's like the bedbath is there for the patient and for us as a sort of closure to us, a way of dealing with our grief and going through this point and on to the next. It is

necessary for us, but it is also necessary to get the person ready and presentable for the family.

If I can make their last few days comfortable and meaningful, whether they are aware of it or not, is important. Sometimes I do it just for their family. That really means something to them. The family still need to see that their loved one is treated with respect, that they are still a person and for me to give that bedbath demonstrates that. I still respect them as a person. I might not have ever known what they were like but I see them and for me it is just another way of relating. It makes me feel good, you know it is just humanity, what comes around goes around sort of thing. And I hope someone treats me with that much respect and sort of tender loving care. There is so much crap out there, that the patients have to experience that if you can make that one little difference in someone's life...

I often have people come back and say "Oh you're the one who gave me the bedbath," or I've had family hug me and say, "You really treated my father with respect, we really appreciate it." They may not know my name but they remember my bath or my back rub.

Reprise: Of such is the nature of nursing. The person cannot remember the name of the nurse or sometimes even the person of the nurse who did the deed, the nursing act; but nursing itself is remembered. What remains and endures in the person's being are the qualities of nursing. In the movement between nurse and patient, nursing and its qualities take precedence over the individual subjectivities of the people involved. It has no substrate (Gadamer, 1989). No matter how many times this particular act of nursing has been performed in nursing's history, here with in this moment it is practiced anew.

*Hardened Off: Ena speaks*

Some people think that here we are a little "hardened off" because if you take everything home with you it affects your family life and you do not survive. I've learned to leave a lot at the door when I leave and pick it up again at the door when I enter. I try to concentrate on the positives, how I did my best with the time I had, how I made a difference for that family. When my grandmother died three years ago, I don't cry that easily, but when she passed away I cried for three days straight. But I know I cried for about 50 people that I had grown to know and love here. I really went to pieces. It was like a tap was finally open for me and I was able to vent a lot of emotions. We get to know patients so intimately here.

Reprise: Barthes (1978) writes of having an Other-ache where there should be a union of the one suffering and the Other not suffering. Here the loved one in her suffering and in the progression

of her suffering draws away from, abandons the partner. "His suffering annuls me insofar as it constitutes him outside of myself" (p. 57). The lived answer to this is to then also draw away from the suffering one, to remain a little detached, to keep a certain distance. "So I shall suffer with the other, but without pressure, without losing myself"(p. 58).

If a lover decides to pull away from his loved one in the interest of self survival during suffering what is it that a nurse does? The very embodied nature of nursing where at every moment of our interaction with the suffering one there is a strong possibility of bodily interaction, so too is there an intimate relation with lived-suffering. It is an Other-ache that cannot be put aside because one has to immediately do something about it. Beauvoir (1969) writes of her great relief to leave the room when the nurse comes in to deal with the ugly draining dressing on her mother's abdomen. Later "during the dressing of the wound I turned my face to the wall thanking my good fortune I had a cold that was blocking my nose" (p. 63). For a nurse to turn her face to the wall would be to turn from nursing. For a nurse to leave her patient in this state would be to compromise her code of ethics. And when it is all over, the nurse can express herself and cry with the family if she chooses. But more often the nurse must deal foremost with the family, the medical community, the body, the morgue. Family members appreciate nursing and what nursing does for their loved ones and at times can be resentful of the lived closeness of the nurse and her stamina, her will to be there. This feeling though soon passes as nursing expresses itself in the moment with all involved.

### **Summary: Lived Expressions of Nursing**

Somehow this writing, this text, has become like a nursing unit to me. I am in it. I re-live it as I write. I nurse it.

But has the text shown nursing yet? Each time I try to add the purely cognitive element, to extend the notions inherent in the expression, to pull out here and there something significant, I intuitively feel that I disturb the lived moment of nursing and all the qualities thereof. I remind myself yet again that interpretive inquiry is to show the many possible ways we may experience and meaningfully express and understand the nursing world and the relations which comprise it. It is not a making or producing of nursing. It is a showing.

But my desire remains; to show how we are when we nurse; to show nursing as a "mode of replying to a situation and transforming it as a projected new world" (Buytendijk, 1950, p. 130). In the text, we continue to endeavor to show the qualities of nursing given to us directly as they occur. Or given to us as something that shows itself in itself (Buytendijk). There has been a conscious effort to show things directly, to show that nursing as a phenomenon happens in response to being in a situation that calls forth response. Most importantly, we have tried to show that nursing is NOT a constituted object among other objects in the world (pre-set tasks) or even a pre-constituted object (nursing theories, documentation systems) in a given world. Nursing work expresses nursing as it expresses the nurse: "the expression is indistinguishable from the thing expressed, their meaning, accessible only through direct contact" (Merleau-Ponty, 1962, p. 151).

Lived expressions of nursing too reach out to the one calling without a pre-formed response. Initially nursing is incomplete; understanding and interpretive judgments are always "on the way." This way we do not fall into "restricting ourselves to those objects in which a certainty of understanding is guaranteed by their very nature, but by venturing out into the uncertain, trying to grasp what is meant and intended... even if it has not been brought to full expression" (Bollnow, 1979, p. 25).

Expression thus has the profound result of creatively producing something new from the depths of life, in a manner unconscious even to the creator himself...its

meaning is difficult to grasp because in expression there is no understanding already present to be improved upon. (p. 25, 26)

Lived expressions of nursing show that nursing is often in a state of gestation and as such it is warranted to be so. It shows nursing as truly professionally based on interpretive judgment. But this as our greatest essence concerning nursing proves too to be our greatest handicap; we find it difficult to both verbalize and conceptualize it. One could say that nurses and nursing is encumbered by the not-yet. There is a contingency, a sort of nursing-in-waiting-to-happen that is very very much part of the lifeworld of the practices of nursing. But the notion of expression “offers us a matrix; what appears to us is an aurora” (Dufrenne, 1987, p. 143).

In a mirrored reflection of nursing, people who live with cancer also express themselves through this disease. In truth, cancer has as many lived expressions of it as do the number of individuals who have it. “Diseases have a character of their own, but they also partake of our character” (Sacks, 1990, p. 229). The illness is understandable only in reference to ourselves, to the who that we are, to the who that interfaces with treatments, nurses, possibilities.

I catch myself here again trying to explain too much. And so rather like nursing on a nursing unit, in this reprise, the question of nursing here is “who needs nursing, who or what have I missed?” I worry that the pure voice of the nurse, of the patient lose itself in the presentation of the text. Yet in nursing the pure voice comes through relation. In Appendix One I include an instance of the voice of the nurse, the voice of the patient in relation with me in audio-taped format. Directly following here though, we present the qualities of nursing.

## CHAPTER 8: THE QUALITIES OF NURSING THAT INHERE IN ACTS OF NURSING

*"One analyses with one's ability to jeopardize oneself" (Nussbaum, 1990).*

*"You must write in such a way that your own text becomes answerable of your response" (van Manen)*

Nursing, like other professions, is too complex to capture in writing. But it is possible to bring out or suggest qualities that make possible different nursing scenes. Below I will list certain qualities that can be illustrated only in relating them to specific happenings of nursing that appear in the preceding chapters. Before doing this however, it is necessary to make a few statements concerning the nature of qualities.

First, to write about qualities of nursing and how they are revealed in the preceding descriptions is not to find yet another way of representing nursing and thus to divorce it from its life origins. Rather the qualities show thinking and acting as lived activities of nursing. They are inherent in and actualized in acting. "Your abode is your act itself," says Merleau-Ponty (1962, p. 456).

Second, these qualities are not intended to stand for nursing as a discipline and indeed not all of the qualities inherent in the preceding descriptions will be listed. They are not meant to be simulacra of nursing. To do so would be to look from the wrong side of nursing, the represented side. Rather qualities are integral to the living contexts of the worlds nurses and patients inhabit. The expressions of nursing in which the qualities inhere can be seen as ways of comporting oneself within a nursing situation; a place of nursing where form is content and content is form (Steiner, 1989).

Third, while it may seem that in this chapter particular qualities are isolated from nursing situations, we must acknowledge that in lived life qualities of nursing as revealed in practice are related and linked to each other. To focus on one quality to the exclusion of others is to do what we accuse those who purport that for example, "caring" can stand as a single metaphor for nursing (Chapter 3), whereas in reality, there are many qualities that inhere in nursing. Yet here and there in particular nursing moments, certain qualities may be seen more clearly.

Fourth, speaking to the qualities of nursing is not the same as referring to the step by step mechanizations of technical skills listed in a procedure manual of nursing. Qualities of nursing are different from the executing of skills. Skills are about generalities; how to perform a selected skill on anyone at any time and any place, i.e. "regardless of the fact that this person cannot lie on his side for this dressing change, because it is listed to lay all people on their side for this particular dressing, I will do so." Qualities, on the other hand, are about the particular, the specific, i.e. "because he cannot lie on his side I choose to do this dressing another way keeping the principles of the dressing procedure intact but changing the details of it to fit this gentleman's needs."

The technologies of nursing, here referred to as skills, that make up a nurse's enterprise are enacted through the nurse's quality. Here we turn from a realm where a myriad of possibilities present themselves to a particular moment in time: what a nurse chooses to actualize in this particular moment, with these particular individuals, in this particular place and context. Our rationality, our skillology, are integrated within our relationality. Skills on their own, abstracted and dissociated from the experience of the specific instance, are not nursing. Here we speak of a practice.

Fifth, we acknowledge that the institution is responsible for the external goods of a discipline (MacIntyre, 1984). Yet the external goods are dependent on the qualities of the practice, internal goods, held within and without its walls. Without individuals embodying, expressing these qualities, without institutions safe-guarding these practices, the integrity of the profession and the



institution is jeopardized. This is important to state because the qualities we list do embody a certain rightness of action, action for the good within the concreteness of the nursing moment.

Sixth and finally, qualities can be likened to virtues (Pellegrino & Thomasma, 1993). Virtues such as fortitude, temperance, justice, wisdom (Plato) are necessary to act well, as the basis of a knowledge of the good for humans (Pellegrino & Thomasma). But these virtues are too general for us, too encompassing. Here we seek more situated, concrete lived life realities. Our professional code of ethics is important to our moral belief and as a moral basis for nursing, but here too, these expressions of morality are too unsituated for us in our direct descriptions. Here we speak of qualities in the particular moment.

### **Time and Gwen and Qualities**

I think of fluid trapped between the visceral and parietal pleura (linings) of the lungs causing Gwen breathlessness, to feel as if an elephant sits on her chest, to experience air hunger. A thoracic surgeon skillfully inserts a long needle connected to a tube that penetrates the chest wall; a painful and tricky insertion. Sometimes the fluid contained between the pleural linings drains freely according to the laws of gravity. Other times it is a slow process. It depends on its qualities, i.e. thick or thin; or whether the site of the needle is the site of the accumulated fluid. So too the entire procedure depends on its qualities. It can be a long one or a fairly short one, a painful one or a manageable one, a treacherous one or a safe one. That it is a continuous one is for certain. It is, was, and will be 15 minutes from now. The quality of hope here is a tangible one: that as the seconds tick by, Gwen breathes more easily.

Nursing makes this continuous act possible, livable. There is a certain knowledge of how to position Gwen to facilitate the draining, how to best assist the person to refrain from movement, how to discourage and bring about non-coughing as coughing could damage the pleura, the lung. The nurse stands beside the bed, her body juxtaposed to Gwen's, IV and medications lie within easy reach, resuscitation equipment poised in readiness. The nurse watches for and guards against signs of shock that ever looms on the horizon as the needle enters the pleural space. If the needle punctures the visceral pleura, the lung collapses and systemic shock ensues. While the physician attends to his needle, his insertion points on the body, his accuracy, his drainage system, the nurse attends to Gwen. She attends with patience, with voiced distractions, with confidence to enable Gwen to relax the musculature of her chest, with judgment as to the amount of morphine to continue adding to the IV drip without suppressing respirations, with direct massage to her chest near the insertion site. The pain for Gwen is unbearable.

The relational way of being of nursing Gwen enables the nurse to pull on personal attributes, personal circumstances that are part of Gwen's expressed way of being in life. Gwen finds her unique way through things (her active imagination, her lived image and experience of sailing, her freeing of others to be, her loving animals, her strong and intimate relation with her husband and family). The nurse calls forth these coping abilities. The nurse demonstrates involved constancy in standing beside the patient; the physician, involved diagnostic, anatomical, respite-seeking desire; the patient, a giving over of herself to others.

To discern qualities in this situation, do I present or represent this? In our problematization of same in Chapter Three, I aim to present it because I do not apply something alien or peripheral to nursing to stand for what it is the nurse does. This situation happens directly before our eyes in this text, before my eye in lived life. The qualities inherent in the situation are ones that are embedded and grounded in immediate lived life and time. Through relation with the nurse Gwen attaches herself to the nurse's expertise and not her own situating factors seen here as pockets of fluid in various sites in the lungs, the thoracentesis procedure, the collapsibility of the lungs, low

oxygenation of the tissues, the end stage metastatic disease and its characteristics. This attachment describes what Leigh earlier stated about nurses living it with you. Gwen attaching herself to the nurse binds herself to hopefulness, to competence, to looking forward with the perspective of the nurse. You might say it is a moment of total being (Merleau-Ponty, 1962) as Gwen releases the past, lives the present, and seeks a future that cycles around the nurse, the physician, this disease, the relief.

To problematize both presentation and representation a bit differently, we could say both are present to us at once and both are not contrived in otherness. They are the 'very there'; experienced agony and respite entwined together to bring forward a future, indeed make a future possible. Gwen, from our first "Take One" (page one), lives through this chest puncture and drainage and breathes freely once again. Why are presentation and representation together at once and how does that preclude us from "standing something before" the true acts of nursing and yet also enable us to pull out qualities?

Until the nurse and patient and surgeon begin this experience, the experience sits as a possible, as a thinkable thing with situating factors; in fact, a visualized, representative thing but a not-yet. Once the scenario begins, the act pulls the thinkable thing into the present. It is 'there', actualized by this particular grouping of people in a particular way. The surgeon, the patient, the nurse will all actualize qualities incumbent to their ways of being in a particular moment. It is like climbing a mountain. A certain person may perceive a mountain in one way, another, an other. But what the climbing will be like, what attributes the climber will confer upon the mountain, what way up through the rock face will be actualized can only be achieved in the climbing of it by a human presence (Merleau-Ponty, 1962). The qualities become manifest in the doing.

In terms of time and qualities, as the elasticity of the lungs hold in balance all that signifies peril within this situation, so too do the lived qualities of Gwen, the nurse, the physician. The nurse's gestures and understanding of the situating factors pull the future into the present. Her situated knowledge of the past make her actualize the present in a certain way and move the present along to a breathing-freely one. Above we mention gestation and involved constancy. These could be qualities of this situation where very life holds itself in a state of gestation, bringing something forth, sensing the way it might best come forth, moving along with it. What is the difference between this and what we complain about the mechanisms in Chapter Three? Here we don't represent something not-yet with certain attributes and categories. We assess the situating factors. We live it in actual lived time.

This description is an effort to show that from nursing's co-existence with others spring qualities identifiable in situations and lived moments. Qualities of nursing revealed in the foregoing practices of nursing encompass expressions that have to do with the personal, the intersubjective, and the intrapersonal. The personal concerns those qualities that originate in the perceiving individual; the intersubjective, those qualities that are constituted and expressed within relation; the intrapersonal, the self-understanding, the self-growth that occurs within oneself as a result of circumstances, of relation.

Because nursing is a performative and interactive profession, it is difficult at times to distinguish the genesis of each among the presenting qualities, i.e. is this the nurse, is this the patient, or both? or situating factors or something else? We acknowledge that nursing is a relation, that we believe that qualities come forth in relation and not already there as if we are a property-like substance. There can be no exact re-occurrence of nursing acts. Nursing is enacted as an irreplaceable moment. Therefore we speak below of events that occur and characteristics that can be seen in the particular situations described in the text. Our understanding of the situation and

the qualities there-in is our self-making, our self-growth (Burch, 1995). To lay down qualities is to lay down being (Merleau-Ponty, 1962).

### **The Qualities**

To be and act as nurse requires that one possesses:

#### ***A). The ability to address the personal (see Chapter 5, page 130).***

In the morning, Sarah (in Chapter Five) greets her patients. Her assessments include objective measures such as vital signs and others. But they are situated measures; Rick's blood pressure and what it has been over the last few days, Rick's excitement over meeting his donor this day. They are primarily about Rick and how Rick is. These are not done only for charting and documentation purposes only. These are done to assist Rick through his day in his particular way within his own particular situating parameters.

Patients learn quickly that they are a medical identity to the multidisciplinary team. Here they answer "how are you" questions with what they have learned the questioner wants or expect to hear. (see Ena and blood, page 220 and "nurses water down a lot of blabber", page 196.). This is not so with the Sarah's "how are you?" In fact "how are you" is the nurse's question.

Sarah's "how are you" addresses Rick; a particular person in a particular time-space-contextual relation. For Rick, the question addresses "Rick" in his uniqueness, not anyone else. It is not an arbitrary meeting. Sarah asks: "how do you find yourself in this situation?" More specifically she appeals to inner felt life: "Rick, how do you find yourself in yourself?" or "how are you in yourself?"

#### ***B). A sense of genuineness in response (see Chapter 6, Rozalia calls, see page 159)***

To call someone is to show our relational being; our being constituted in relation. The nurses in Chapter Six experience the call of Rozalia as an appeal; "an ethical appeal for dignity" (Desmond, 1990, p. 187). Calling is a form of discourse (Heidegger, 1962). Babies call, mothers answer. Mothers anticipate calls. Mothers call their children out of themselves. Rozalia and her nurses in Chapter Six experience the nature of the call. Pain-filled suffering bodies call. The nurse who has a sense of genuineness most times understands the call in an instant. Little more discourse is needed.

There is a sense of an unfolding of the self toward the one who calls. A patient in nursing can be thought of as one who calls. Inherent in the unfolding within the personal self of the nurse is a showing of what is seminally contained within the self (Bollnow, 1972). In other words, that which is genuine. The call of the person claims the nurse who is genuine. The unfolding of the self opens the nurse to the actuality of the patient, the genuineness of the patient. Laura (see page 162) takes the call within herself; Denise (see page 179) hears the call of the body. How Laura and Denise perceive and understand the varying situating factors inherent in the situation is the beginning of their response, their expression of nursing.

There is more to a call though. To call is to summon one's "ownmost potentiality-for-being" (Heidegger, 1962, p. 365). Here the being of oneself calls out to its own being. While Rozalia and Luke call forth response and action from the Laura and Denise, in acting, they too nurse their own being.

Nurses who have a sense of genuineness are aware that they meet and touch a particular part of a person's life. It is not the whole of the person's life nor do they strive to know it. Yet this particularistic touch in a moment in a person's lifeworld has lasting and infinite implications to

this person's being. As Betty states: "I shall never forget them, what they did for me. Never has anyone done this for me. Not even my husband of 25 years."

**C). *The ability to interpret sensibles (see smells page 185).***

The discussion on the smells in nursing describes how nurses are able to have a sense of a direct referent. Little further cognition is needed. According to Summers (1996) following Plato, sensation "rather than simply reporting the world analyzes it into the modes of the several senses in the very act of apprehending it" (p. 4). And further, not only does this apprehending through the senses assist with determining one's actions in the world, it also "refashions the world" (p. 4); understanding and knowledge pursue.

A sensible thing leads nurses to direct analysis, i.e. to negotiate the world, to determine one's actions, and to generate understanding and knowledge. A sensible thing is always about something, i.e. the smell of something, and nurses with this ability to interpret sensibles not only perceive what-is, but also know not to distort the sensible into an object-like thing. "Such is the role of our body: the senses are not so much apparatuses intended to collect an image of the world as they are the means by which the subject is sensitive to the object, that is, in attunement with it as two musical instruments are in attunement with one another" (Dufrenne, 1987, p. 8).

To think this further, a nurse such as Lynn (see page 182) perceives specific realities. Lynn responds to the lived pain that assaults her senses when she enters John's room. Dufrenne (1987) believes that aesthetic perception, as opposed to direct cognitive perception often clouded with concepts and representations of things, shows the truth of a thing immediately given in sensuousness. There is an interpretive response, given as soon as the reality is apprehended. Lynn answers. She acts from a moral and authentic nursing stance. Her understanding is at once "simultaneously analytical and critical" (p. 8) as she goes about facilitating diagnosis, preparing for what she suspects will happen. In this mix of sensate information, affective interpretations, and cognitions, that which is most basic to being, to living is understood. Lynn understands the feel of John living within his situation of deep visceral pain, of the embarrassment of bodily fluids. The essential character of the particular circumstance, the direct referent, Lynn senses and trusts. When the massive diarrhea starts, Lynn has expected it.

Lynn through her ability to interpret sensibles and act upon them in a nursing manner, is expansive of others. While those around her, in this case John's wife, his most significant person, responds to this episode with revulsion and fear of death ("is this it, the death?"), Lynn does not. Rather her approach is to not limit John in any way. She tells him that his body expels a harmful bacteria; that it does what it should. While side effects of treatments and other things particular to the person's biology and diagnosis are discussed and experienced, nurses such as Lynn refuse to let these limit another and predict how they will do. A nurse does not consciously limit another. (Leigh and side effects page 136).

**D). *An integral understanding of body-knowledge (see pages 1 to 3).***

When Gwen is breathless Lynn knows how to position herself next to Gwen, how to direct her restless, panicked limbs, how to place her hand on her chest and the amount of pressure needed for Gwen to feel just where the nurse directs her to breathe. In bathing, positioning others for long treatments, dressings, Agnes knows how Tom's body can best tolerate these (see page 42).

Nursing as expressed in the preceding chapters shows itself as at once wholly corporeal and present. Agnes's body is the very genesis of the presence of nursing for Tom. Agnes's body both announces and offers nursing. She wears it on herself. Lynn and Agnes show it in their actions, their gestures. Leigh (see page 136) asserts that nurses live-it-with-you; *it* being

whatever it is that assaults your health, your integral self. Living it with you is to be both bodily-present and bodily-participating in whatever it takes to live with *it*.

Frank (1995) writes about the monadic body and the dyadic body. The person living the monadic body lives a solitary existence; medicine encourages a monadic body with its diagnostics, its treatments, its organ language, its symptoms and signs. On the other hand, dyadic bodies are aware that they exist for each other and offer “a ethical choice...to be a body for other bodies” (p. 37). Nurses who have an integral understanding of body-knowledge endeavor to understand what it is in particular to live in this suffering body, i.e. Tom’s body, Leigh’s body, and how to alleviate it. Agnes, Hannah (see page 40) know a lot about skin as the protective covering of the body but too about a touching-touched reflexivity (Merleau-Ponty, 1962). For them the notion of dyadic bodies would not be at all strange. Nurses spend much time bridging the monadic (gnostic body known to science) with the dyadic body (pathic body that expresses itself).

Whether it is a question of another’s body or my own, I have no means of knowing the human body other than that of living it, which means taking up on my own account the drama which is being played out in it, and losing myself in it. I am my body. (Merleau-Ponty, 1962, p. 198)

***E). Recognizable nursing gestures, nursing touches, knowledge to be with (see page 205, 145).***

Nursing gestures are syncretic. How is it that I can be across the bed from a nurse and a patient I have never met before and still know how to bathe, to turn, to make beds, to position for procedures, and to do this with another nurse very naturally. I see what she sees. I actualize what she actualizes. I live her expressed nursing as she lives mine. We move into the flow of nursing, our nursing gestures complimenting the care, coordinated, continuous, rhythmic bathing Russell in Chapter Four (see page 145).

Nurses like Kathleen (see page 193) do not use gestures that do not fit into the particular personal world they enter. Kathleen knows she enters a couple’s lived bedroom. She inserts herself into this world through her hands, her arms, her movements first by picking up the Atwood book that has fallen to the floor. It opens up the personal world of this couple to her, its understandings, integral meanings. “The hand becomes another sense organ” (Lingis, 1995, p. 150). The hand itself in its reaching, groping, handling instruments, tools in doing so designs, fashions, brings certain things to presence (Heidegger, 1977a). The hand as sense organ gains a notion of what is practicable, necessary here as it gropes its way in the world (Lingis, 1995). This notion of hand, of gesture, is embedded again in the directly experienced nature of the nursing way. Kathleen does not speak her theories or her documentation systems or her own particular pursuits in the world even though she alludes to them in her conversation later. Rather she enters the moment, the space and is there to what is there. The nurses observed in report the first morning( see page 131) do the same. Regardless of what they have just left, or where they have come from, here they are directly present to each other and to the patients who embody the report.

While these oncology nurses are experts in technological care, they diminish the integrality of this knowing for the person so the person can manage the invasiveness of medical technology. I have seen many times the oncology nurse covering up things so to not disturb the specific individual because of specific circumstances. These bodily gestures of the nurse are understood immediately by the patient, by other nurses. Gestures are seen only in action; nurse acting, gesture-presentative. While Kathleen stands beside Gwen during the thoracentesis (see page 229), she massages her chest gently, she adds medication, she assists the physician, she indicates to the husband that all is in control. In fact, the message in her gestures surges forward when Gwen and her husband’s knowledge and rational thought processes fail. Merleau-Ponty (1962) clarifies: the sense of the gesture is understood not analyzed (Merleau-Ponty). Gadamer (1986)

states that “what a gesture expresses is ‘there’ in the gesture itself” (p. 79). Patients watch and determine through this watching who is and who is not a nurse (see Miss Collins-Hill, page 195).

Nursing gestures such as Colleen’s is the vehicle whereby word and deed become one. According to Merleau-Ponty (1962), the meaning in the gesture “is intermingled with the structure of the world outlined by the gesture” (p. 186). I wonder often at how very upset, how very enraged patients and families become when a nurse turns her back on those in need of nursing. And today, some of these individuals are not registered nurses yet to the patient they are nurses. The empty gesture enrages. Individuals in this inquiry see that not only is the nurse the one hired to give nursing care, but too she is to be the nurturing one, the one who through engaged personal interventions, aids one. An empty gesture is an act that dies before coming to birth (see Rick, Laura, and James, page 205). Here in Rick’s and James’s experiences, the empty gesture bespeaks against the word and the presence of the nurse, i.e. she is to nurse but she doesn’t act like one. Word and deed are not one. Rick and James may say that the nurse has “mere gestures.” The effect of this on a vulnerable person is devastating, all-consuming, and exhausting. Energy for healing is compromised (Drew, 1986).

***F). An ability toward extemporizational-immediacy (see Denise and Luke page 179)***

Denise responds immediately to Luke. Meeting another is a most basic form of immediacy. It begs response. The notion of presence is not only what is before our eyes and selves in actual space-time moments but also in the sense of what stands out about it, what concerns us directly, what is present-at-hand “as opposed to the past and future which are ‘out of reach’” (Summers, 1996, p. 6). To be aware of immediacy one must be aware of contingency, the idea that something quite impossible and awful could happen at any moment.

In the moment nurses who have this ability such as Denise must quickly improvise and treat. Suddenly Denise changes from a person/nurse pushing a piece of technology and carrying clean towels and clothes down the hall to a skilled, competent, in the moment person/nurse. Qualities are evoked in such situations, i.e. covering up the horror of a symptom, of a treatment, of a technology, of a bodily expression. Nurses who are present to this, make themselves available to this, know what the sense of rightness is that will make this horror livable, in order to bring out the coping behaviour of the person. It is in the true sense of the word a coping: an arching overhead of a particular thing that will enable Luke to get through this, that will give Luke’s parents hope and safety. There is a spontaneity about nurses such as Denise. One has an increased sensitivity to people, to situations. Nurses who speak of what they like about nursing often speak of just this heightened sensitivity, a “rush”, a sense of “living on the edge”; a place of primordial experience, of origin, of others.

***G). Knowledge of bed-geography (see page 163).***

When Rozalia propels her body upwards on the bed to hang over the side rails nurses know how to guide her back to a comfortable position. As technology is added to her body and her bed, nurses design the best way possible to work with these extensions to her body. The bed, overbed table, bedside table are significant geography to nursing space, being able to nurse as one wishes. Nurses know how to engage their bodies with those bodies in the bed. Nurses position bodies in beds. You might say they have bed-sense.

Wilfrid (see page 221) finds the absence of the spirit, the breath of the person who has just died frightful. He has nursed her in her bed for some days now. He has talked to the family, noticed how they placed themselves around the bed. And now she dies and she does not occupy the bed anymore, her corpse does. To not have a living person in the bed, yet to still nurse her, makes him think of the bed in quite a different way, a repository for her body’s cells and organs. Yet he

still nurses the one without the breath now and he watches how the family surrounds the bed in grief, touching each other, touching the bed, touching her.

Kathleen understands a couple sharing a bed and encourages couples, parents, to get up on the bed and touch each other, to use the bed as a part of their everyday life now, to place their bodies on it in a way that is “at home.”

***H). A sense of rightness and accountability enacted in tactful practice (see page 170)***

Laura works hard to bring physicians to a decision, a decision that will not be detrimental to Rozalia or her family. One could say that nurses like Laura who have a sense of rightness in human practices designate all which occurs within the direct presence of the patient. It is as if she draws a circle around Rozalia and says, “what passes by here is my responsibility.” Whatever happens within the circle around the patient, the nurse accounts for and works with the consequences incurred.

After delivering Rozalia’s corpse to the morgue, Judy admits a new patient with breast cancer (see page 178). Judy makes her welcome on this nursing unit, gives her a sense of what will happen in the next while, and works to make the person feel at home at least for a time. The key here is that nurse’s actions such as Judy’s and Laura’s in the lifeworld often resonate with a sense of rightness that is felt keenly by the patient.

Sockett (1987) gives us a purchase on what it is to be engaged in a practice. First of all he gives credence to the fact that an onlooker can never understand all the nuances that occur in practice of which the teacher in Sockett’s case, nurse in our instance, is constantly aware, i.e. this person losing consciousness slowly, this one a possible hemorrhage, this one cognitively impaired and so on. And so the practitioner continually makes judgments that balance out ideal and possible practice within the situated context of the moment. He calls this contextual knowledge. Second, the practitioner constantly chooses *what is best* based on the context, the moment, rather than what is ideal. Sockett calls this practical judgment.

At the root...therefore, are not items of knowledge as discrete measurable techniques, but judgment, which is itself a form of knowledge. Tempered by growing practical understanding, that judgment emerges as wisdom. (p. 210)

Sockett points to a third element with a warning; to ignore the crucial place of context and practical judgment is to risk ending up with knowledge given out as vacuous (applied to all circumstances no matter what), redundant (because the knowledge is determined by researchers who operate in limited contexts if at all, and limited (it discounts the detail in lived contextual judgment. See Succor, Death, p. 206).

Sockett’s discourse resonates for nursing in light of the previous chapters. He cautions that we end up with knowledge-as-technique. But perhaps Sockett’s greatest warning is this: when we impose the above tools on practices we compromise the practitioner’s moral virtues in enacting her profession. When we investigate practices there must be a language and a method other than scientific ones for scientific findings call for a morality that approximates its discourse. Nurses know they cannot directly apply what is listed in documentation systems to their practice as most often, it would violate their code of ethics (see page 99).

***I). Discretionary-judgment (see page 205, page 179).***

Ruth says, “I knew she didn’t know about my central lines just by the way she looked at them. So I asked her and she told me she had only worked with them in a lab. She had done it once in a lab. Heaven help us if all we have is nurses who learns things in labs only. I proceeded to tell

her how to do it because I knew she was the only nurse there was on duty. Otherwise I wouldn't have let her do it."

How do we trust a nurse who doesn't see us as we think we are? How do we trust a nurse who sees us as not any different from the one in the next bed? How do we trust a nurse who makes mistakes, neglects our care? How do we trust a nurse who is incompetent in skills? In short, patients don't. Patients make discretionary judgments too.

Nurses with discretionary-judgment must determine who is the sickest, who needs care at the moment. Denise chooses to delay her own patients care to take care of an emergent situation. She who have several things to do at once makes a judgment as to who gets nursed first. Denise learns later that this particular family has reported the nursing and medical staff to the administration. They change their mind after their encounter with Denise and ask that people who nurse Luke have the expertise of Denise.

*J). A sense of openness to the unexpected, to contingencies (see page 145).*

When Russell is admitted as an emergency admission, Sarah takes him on. Because he is too ill to speak much for himself, Sarah takes her cues and knowledge of how to act in the situation through how he bodily, non-verbally presents himself. Immediately she gets him settled, cleanses him knowing he has been in emergency all night, provides rest for him, positions him in the bed and adds his technologies, i.e. basin to spit blood into, in a way just right for him, generates medical orders for him, carries out the medical orders. For Russell, for the first time in several days, he is being looked after. He relinquishes himself to her ministrations. Before this Russell is an unknown. Upon admission, he is now hers.

*K). A sense of joining flesh to flesh ( see page 182).*

What affects my patient today affects me. This is not a body fluid in the sense of type, substance, consistency, etc. This is John's body fluid and we relate to John and John's flesh and body fluid specifically and personally. Because nursing John through this episode of diarrhea is part of John and John's need at the time, it becomes for the nurse the way this body of John's reacts at this time. Therefore it is part of her pursuit. For this period of time, it belongs to her.

*L). A sensitivity to the motion of life-lived (see Mr. Stanley page 190).*

Kathleen and Mr. Stanley are caught up in a vivid life memory that just so happens to also be part of Kathleen's recent lived experience, i.e. the loss of a child. Kathleen copes not only with the memory but with keeping Mr. Stanley safe within his health and illness parameters. She knows she must let him re-member, re-frame this experience within his psyche, his lived breath, his breath that pains and burdens him at this moment. But she knows too she must move him on.

Nurses tend to have a sensitivity to the motion of life-lived. Nursing acts like Kathleen's are a series of changes, adjustments akin to organismic changes within the body. Here with Mr. Stanley, the flow of breath, the movement of elastic lungs. Lived-life moves. Even thinking is movement in Kathleen's case as she determines how much she can let him express himself without moving into metabolic emergencies. The movement is in the thinking, the mental running through of possibilities, ruling out entities. Once a thought and action is actualized, it ends. Another takes its place.

An ethical encounter with another is "a nurturant relation," says Bergum (1992, p. 82). This nurturant relation moves and changes with the rhythm of the other. Kathleen attaches herself to Mr. Stanley and his breathing, memorialising rhythms. Kathleen, in her nurturant relation to Mr. Stanley moves lived-life because to be in relation is to move; something is affected, something changes, something begins and is grounded where the relation is anchored (Haase, 1996). A



nurturant relation (Bergum) moves but remains connected to the essential bedrock of the person. You might say as Kathleen mediates among so these diverse yet situated lived tensions of Mr. Stanley, i.e. suppressed blaming of his wife, as she sustains the individual, she moves the relation along.

Nursing acts such as Kathleen's have a beginning and an end. They have a periodicity (Langer, 1957) about them. Discreet periods are the essence of rhythm. One, here Mr. Stanley and Kathleen, ends up in another place through a nursing act.

*M). People-knowledge (page 147 and 213).*

Mrs. Klar states that she must protect her husband and son from the awfulness of the chemotherapy treatment and how it will affect her. They leave and Karen, her nurse remains for her and tells her that the nurses will watch for her and take care of her. Karen knows that this is a stately independent woman and that to be vomiting in front of someone is very dire and difficult to her sense of herself. Yet Mrs. Klar states that she knows Karen like a soul mate even though they had no significant conversation as she was admitted in extremis. But Karen knew what to say when her family left and how to assist her with dignity, how to give her whatever privacy she could, how to protect her from the eyes of others at these times of bodily eruptions. Nurses with people-knowledge tend to know whether to go or whether to stay, whether to do the bath now or later, whether this wound dressing would be better after the patient's rest period, whether the interaction unfolding in the room is deleterious or serendipitous. Karen knows how Mrs. Klar's actions or non-actions relate right now to her singular feelings, to her specific intentions toward others. Nurses tend to recognize and acknowledge another for who she is. Karen affirms Mrs. Klar in her being. She is respectful of her interiority. She gives it precedence. While she recognizes need and vulnerability here, she does not trample on it.

Gwen too was devastated when the doctor tells her she will not be resuscitated should she arrest. Gwen and her husband then work hard at overcoming this devastation, re-working it, transforming it to something palatable. And they do. Gwen, through active imagination and whatever available action left to her, changes her world and changes herself. To see herself sailing, the freeing nature of it, overcomes her physical limitations. Those who live with physical limitations often state when seeing a runner, a ballerina, that they are with them in their activity: they experience it directly through them. This is one of Gwen's strategies. Yet it is of note that this particular encounter serves to strengthen her resolve to live her dying in her own way.

Nurses such as Karen and Kathleen are open to and cognizant of a plurality of knowledge, their own and others; of understandings of how to actualize, how to access, how to synthesize people-knowledge. It is not epistemology. Rather it is common-sense knowledge, tacit knowledge, blends of theoretical knowledge and sense-data. (see Lynn as she accesses the knowledge base of physicians, page 182). Nurses with people-knowledge tend to understand that the history of the person is very significant to the person's present moment (see "who cares for who", page 203). Without an increase in self understanding and an understanding of one's situation with close relatives, there can be no investiture in history or movement because nothing changes. Indeed this young girl suffers tremendously because she knows she goes against her parents wishes for blood transfusion, that which keeps her alive. Yet she is unwilling to inform them, confront them in their chosen reality with her realization of her health choices.

*N). An ability to live with ambiguity (see Mr. Phillips, page 185).*

Mr. Phillips who experiences a psychotic episode, evokes a question for the nurses at report this morning. Even in the midst of a precisely ordered technological world, i.e. forms and documentation systems, nursing lives in ambiguous situations. While things appear orderly and

in their place, the nurse who sat on Mr. Phillips bed half the night to keep him calm sees through to him and the parameters of his situation even when understanding is not-yet. You might say this night nurse, Michelle, forms a dialogue with what presents itself; here as yet ambiguity. Here she finds herself in union with another and because of the lived nature of illness (that ultimate unpremeditated experience of human life), the authenticity of Mr. Phillip's suffering pulls her out of lethargy and suffuses itself into the deepest core of her being. It is so very difficult to be present to a psychotic episode such as this.

Adherence to the concept and theory can deceive us sometimes as to the very nature of what a patient presents. But the very concreteness of the lived experience of another such as Mr. Phillips, the presence of the lived body or mind in suffering, can now and then pull us into the directness of the spirit of the thing that presents. When the particular, the specific person stands before us, nurses who have the ability to stay close in a time of ambiguity, such as Michelle here, respond. In the larger framework, nursing is never only about these two who are involved in lived-nursing. Nurses like the ones discussing Mr. Phillips in report, may start with certain assumptions but they mostly get disrupted as soon as they enter the doorway to the room. Something arrives, addresses nurses, disrupts assumptions, presents ambiguities, yet together nurses move to build anew whatever is called for in that situation. In nursing the whole is not often given, only the instance, the particular presenting thing. Yet in taking care of the particular, we take care of the whole.

***O). Tendency to personal review, to reflective pondering (see page 176 and page 216)***

Cindy reviews the fact that she has administered the chemotherapy that has caused Rozalia such difficulty. She discusses the difficulty in accepting a death such as Rozalia's which in her view is caused by specific treatments. And in turn Cindy tells us that few people who are not nurses could understand the lived reality of her experiences, her self-recriminations and how this plays out in her life. Nurses have a tendency to ponder, to personal review, and sometimes self-accuse. At the end of my first day on a nursing unit, I run into another nursing instructor who experiences cancer and its treatment. Her diagnosis has been recent and the ravages of it are written on her body, in her demeanor. It is a reminder to me that I exist because my body works for me now in this moment.

Interaction with a nurse and the nurse in consultation with the interdisciplinary team, offers the very possibility of my personal coming to terms with my health, my disease, how to live it, how to move on into life with it. Angie finds that she cannot anymore tolerate western medicine's approach with chemotherapy and radiation. She moves out to find alternative treatments. Some of these aid and some don't. But for her, this type of therapy has meaning and the meaning it gives her moves herself in herself outside now of contingent life. She is ready for what comes now. Angie was clear about her choices, about her life, her death; possibly the clearest person I spoke with during the course of the study. Yet for her the thoracic surgeon became grace (bread) for her because he did not question her conduct of herself with this disease. Rather he enables her to live longer in the way she wishes. He, protects her from yet more insult and invasive procedures. He was her angel.

***P). The ability to live within closeness and distance (see Lily, page 212)***

Lily, John's wife, who is so very close to John, cannot stay in the same room where John experiences severe pain and horrific diarrhea. To see John suffering like this is for herself to suffer. Lynn, the nurse, in a paradoxical way, links herself to the ailment, to the identification and alleviation of it. Through nursing the ailment, she connects herself to John. For her, it is a way of distancing herself from John's lived agony so she can nurse him until it is resolved. It doesn't mean she thinks less of, or relates less to John. In fact she relates to him more deeply.

*Q). A notion of the performative in lived life (see Laura page 163)*

Here I think of an analogy to nursing to show how the integration of skill and judgment and finesse nurses such as Laura, Kathleen, Sarah, Karen display lives itself out. It is a heart-filled moving event to see a nurse actualizing nursing, actualizing life. Merleau-Ponty (1962) writes of a musician who is to perform on an unknown organ. Simultaneously as I read his description, I see myself settling in to play an unfamiliar organ at a wedding, a funeral. I adjust the seat, check out the manuals, run my heel and toe over the foot pedals, listen for where the sound reverberates in the building, adjust myself to easily pull on the stops to change tones quickly, add one here, play a combination there, a reed here, a string there, see if there are any sticking keys, odd tones I will have to work around, and so on. And then I begin to play no longer thinking of any of the above. I weave the music around the drama, the liturgy taking place before me.

Between the musical essence of the piece as it is shown in the score and the notes which actually sound round the organ, so direct a relation is established that the organist's body and his instrument are merely the medium of this relationship. Henceforth the music exists by itself and through it all the rest exists. There is here no place for any memory of the position of the stops. (p. 145)

There is of course foundational knowledge to nursing and of course, embodied knowledge that inheres in the acting of nursing. But the expression of it is unique to the particular nurse, the particular person, the particular nursing event required. When the organist begins to play the organ, the people involved in the ceremony in question, may not know that the organist has pulled out a different stop adding a different tone on the music. Some will know for certain I have changed the tone, some will have the sense that something changed or feels different, some will naturally just move into the new musical expression with little direct knowledge of the shift. Such it is with nursing. Patients and individuals, families and aggregates within this study were not always conscious of how the tone, the modality of nursing changed now and then for them, but they know that something has happened because somehow for them, the performative act has enabled them in some way; it has spoken to their need. Miss Collins-Hill (see page 195) knows that her nurse Karen has orchestrated her diagnosis, her comfort, her treatment in spite of a perceived lack of medical support in this moment. She sees the difference between authentic performance with herself in mind, and being "a piece of meat" for someone else.

But of course, nursing expressed through Karen is much more and other than a performance. There are definitely mechanics, techniques, procedures, complex technologies in nursing's expressed discourse. But the person of the nurse, the presence of the patient, the historical tradition of nursing, the universality of nursing embracing a multitudinous number of possibles move these procedures and those performing them to critical judgment and critical moments of expressed nursing. Nursing transcends itself in the expressing of it. It says in a mystic way; we are doing what we say we will do and we are what the word and the gesture are. It is performative in that at some point suddenly the gesture itself is nursing itself, wholly there, wholly present. As the what-is of nursing builds, forms, expresses itself, fades, moves to memory, there is a notion of the dismissal; that one goes onward fed and nourished, empowered to live and express oneself in one's own world again.

The nursing gesture presents itself to me as a question, "bringing certain perceptible bits of the world to my notice, and inviting my concurrence in them" (Merleau-Ponty, 1962, p. 185). The act, the gesture, are irreducible to something else. Nursing renews itself in the doing of it. It is as if a nurse craves a patient because it is self creating work for nurse for patient. Lynn states that she loves nursing as much today as she did twenty years ago and it is not because of cleaning up diarrhea episodes. It is because she gets to participate, to make a difference to those who suffer,

who must learn to live with debilitating and long term illness. Nursing is pure self-presentation at the same time as it presents nursing. "They present themselves, for at the same time they point beyond themselves" (Gadamer, 1989, p. 108).

### Summation

This list of qualities is not comprehensive or all-inclusive of what has gone before this point in the dissertation. Rather it is to show that qualities slumber until they are evoked. And nurses who work in cancer care will perhaps have different qualities at different times than emergency nurses or operating room nurses. A nurse who works in labour and delivery will have some qualities similar to an emergency nurse, i.e. the closeness to life and death, the effort needed to support lived life. Qualities come to the fore with engagement in specific instances, specific circumstances.

To present nursing and its qualities then is what? It is to engage oneself with the phenomenon at hand and to *stand in the midst of it*. "To let be - that is, to let beings be as the beings which they are - means to engage oneself with the open region and its openness into which every being comes to stand, bringing that openness, as it were, along with itself" (Heidegger, 1977c, p. 127). To be mindfully present, that is, not standing something before the happening taking place in front of us, asks much of individuals. It asks us to be open, to stand in readiness for what comes, to choose, to be willing to engage in responsiveness, to accept responsibility for our actions past, present, and future. "The ethical self...It is born of the fundamental recognition of relatedness; that which connects me naturally to the other, reconnects me through the other to myself" (Noddings, 1984, p. 49).

In representation, the thing itself becomes other. It does not refer to the original; in fact it replaces it with something else. Because of this, nursing in its nursing theories discourse becomes other. In Chapter Three we speak of research hierarchies and how nursing theories lose the presence of nursing as lived. There is a hierarchical notion to representation (Summers, 1996). Here the representation not only has a dis-relation to what it represents, it points to what is considered a higher order of meaning (Summers, 1996). One thinks then of nursing as for example, energy fields (Rogers Theory, 1980). Nursing now becomes abstract.

In giving to the world a discourse that is in dis-relation to the lifeworld of nursing, we have opened up a way to turn nursing into standing reserve (Heidegger, 1977a). In representation, the subject matter is chosen as to what the author wishes to express, how it is to be represented; its synthesis, its schemata is also chosen. As such it becomes more distant from the collective subjectivities of the individuals who practice nursing (Summers, 1996). And we end up with empty envelopes without essential relation to the "appearing world" (Haase, 1996, p. 246).

How then do we call ourselves to stand in the midst of nursing as it presents itself? We continue to ask pertinent questions. We ask: How do we know the world is what we represent in its discourse? How do we know that if we represent the world in one way, is it represented in the same way for everyone? Are the concepts, metaphors and theories we use to represent the world truer than the sensations with which we capture directly lived life? How do we call ourselves back from the predominantly Western way of representation?

One way is to recognize that the work of nurses and patients and members of the multidisciplinary team always begins and ends in the lifeworld. "The world is not simply projected from the mind, it is made, and even the simplest artifacts involve techniques of gathering and working as well as the teaching and transmission of these techniques" (Summers, 1996, p. 15). To express our nursing as lived and experienced within particular spatial-temporal situations requires attention and sensitivity to determinations of nursing. We must live this

tension in a practice profession. Representation is primarily concerned with communicating something to others regardless of its true or false images. But presentation is living it, expressing it. We need to embrace expressions of lived human corporeality in situated time and space, including all the nuances within such; all that is contiguous to our acting in the lifeworld.

Human science inquiry always remains an attempt. To capture lived life in its directness, always falling short of its goal. Just as we see something, something else slips by. It was my lived dilemma described in Chapter Four; to be cognizant that in an moment, one sees, feels, hears things directly and peripherally slipping by one even though one is attentive. And while for an instant some aspect in the lifeworld is visible, transparent to us, and through it we seem to see directly into life itself, to bring this to language places us head to head with the tensions inherent in the ambiguities of (re)presentation. As human science researchers, there is a constant tension between life as lived and our attempts to (re)present it.

## CHAPTER 9: THE END AND ONWARD

*"All departures, all beginnings out of the peace of nothingness, are fearful"*  
(Steiner, 1989)

*But is he who opens a door and he who closes it the same being?* (Bachelard, 1964, p. 224)

*"This is not a fairy story, or a confession, or a tract of redemption, resolution or sublimation, and I am happy to concede that what I think I understand is overcome with dispute as I soon put it into words. Words are like that. Pregnant, sly, slippery, undiminishing in their rereadings as they make their ritual voyage into memory"* (Gurnah, 1996, p. 216)

This work has been an effort to explore and describe aspects of nursing as revealed in its practices. In particular, it has been an attempt to show aspects of the experiences of those who treat and are treated with cancer. The cancer context brings out the richness of nursing as a discipline, the richness of the human spirit affected with cancer and those who work to eradicate it, to help those live with it. Through narrative and direct description the attempt has been made to show directly what goes on in nursing as a practice and thus to honour its practitioners.

### Theses Statements

Direct descriptive knowledge is not material one can easily develop in terms of conclusions and generalizations. Rather on the basis of this study, I pose the following theses statements and assertions:

- That theoretical writings have not kept pace with and have not presented nursing in its fullness.
- That the central significance of nursing is its relation to the patient, family, community, aggregate. This relation must be central to all administrative organizing of nursing as an enacted profession.
- That nursing is a discipline that blends varying forms of knowledge in a unique way: scientific knowledge, relational knowledge, personal knowledge. This blend of nursing knowledge is best seen expressed in nursing practice as more direct forms of knowledge are integrated within it.
- That nursing as a discipline is in need of a "work of retrieval" (Taylor, 1991, p. 23), a moratorium on all forms of discourse and research that seek representation as its primary modus operandi and distance nursing from its practice origins.
- That there is a need to re-language our discourse to apprehend life as we live it not as we theorize it.
- That we recognize that the striving for directness in nursing can never be fully realized because lived life cannot be apprehended in all its totality and complexity; that even as we seem to apprehend something directly, other things slip by. While images may evoke the actual in the lifeworld, in truth, we always live the tension of (re)presenting it.
- That political systems take whatever is not self-evident and not pre-determined and make it something that fits their mandate. Nursing as a discipline must become explicit of its pursuits and involvements.

- That attention needs to be given to the daily hour by hour practical situations nurses encounter in concrete nursing situations; that these should be thoughtfully brought to text, to be used not as exemplars necessarily, but rather as situations of nursing that show its complexities and do not leave aspects of nursing out in order to make it simpler to fit theory.
- That we need to identify and preserve those dimensions that are pertinent and integral to the tradition of nursing and that a critical analysis should be made of the lived elements in nursing practice that are not relevant, that are distorting to the discipline, where ideology and procedural techniques hold sway.
- That research into the direct effect of documentation systems and other systems imposed on nursing practice by the institution should be studied in relation to the ability of the nurse to enact her practices.
- That the economic, social, political, and ideologic factors that affect nursing practice should be considered in depth and the question asked why the discourse of nursing has been so blind to these entities that so very heavily influence the ability of the nurse to engage in exemplary nursing practice.
- That nurses must be given the mandate in institutions to self-govern.
- That what is considered nursing expertise and essential to an area of practice should be determined by nurses following their professional mandate and code of ethics.
- That an interpretive ethical body, hermeneutic ethics, is necessary as both a watch dog to ensure that nurses are able to act freely in the patient's best interests and also as an advisory group where nothing with direct and indirect influence on moral/ethical practice is disregarded. Attentiveness to hermeneutic ethics will lessen the possibility of missing something important (to human being's lived experience) because it is not contained within the hegemonic moral discourse.
- That nursing education should be more comprehensive of the various forms of knowledge that are present in nursing practice.
- That technical knowledge and competence is based on a scientific mode of knowing (gnostic) and essential to the practice of safe nursing care but nursing is also about the pathic, the relational and it is this form of knowledge that brings the expression of nursing to form.
- That we search for avenues in practice to teach and show the pathic as foundational to nursing as lived.
- That more direct forms of nursing knowledge related to the pathic are difficult to teach and we must use a variety of forms that show how representation and presentation live out in practice and the tensions between same.
- That the difficulty in presenting the relational, the pathic is not to go overboard on the spiritual. To do so is to say that we still seek our answers in something outside ourselves like the Buddha (Kopp, 1972) whereas the question of nursing is what we must live in concrete terms. Rather we must show the sensitivity that is there without going overboard into spiritual tones to explain.
- That we must take up a ceaseless critique of the theoretical and practical engagements in nursing; a constant questioning of congruence between and among same.
- That direct textual research, direct description as an epistemological aim is a valid way of inquiry for nursing.

## **To End**

The question of nursing posed for us in Chapter One served to interrupt us in our conceptualizing of nursing and its discourses. It serves as a call still. The course of this interruption brought us directly into the presence of the lifeworld of nursing. To be directly in the lifeworld of nursing is to listen to everyday personal struggles of people living with cancer and its treatment modalities, with the lived nature of illness that extracts us from our track of life and propels us toward another rather contingent one: to know the torments, the lived understandings of those who suffer. It is too to see as firsthand as possible a nurse and her attentive tending to the personal details of lived life, to nursing work as it intersects with the multidisciplinary team. It is to be in the presence of the “really real” (Frank, 1995 citing William James).

To hear and read these lived moments is often to know experiences of embodiment that we would most like to ignore. Yet to have read them is also to have listened to these moments, to be a witness to them. It is in listening that we most show our morality, our sense of an ethics of relation, our inter-mutuality of need and call and expressions of same. We become knowledgeable of a pedagogy of suffering (Frank, 1995). To call this a pedagogy is to know that those who suffer and those who alleviate suffering have something to learn from each other (Frank, 1995). We as nurses and patients and readers of the dissertation are not present to one another to palliate only. Rather we form a community of attentive tending to living one’s pursuits within the “really real.” To choose not to relegate lived experiences to categories, theories, diagnostic labels, and previously decided upon documentation systems, is to show our ethical commitment to lived life as an active, immediate process. Ethical sense inspires being according to Levinas, “the ethical is an inspiration, a pneuma, of being” (Brody, 1995, p. 195). Breath allows us to enact our pursuits, to understand being. We are as we breathe together, conspire together.



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## **Appendix One: The Voice of the Nurse, The Voice of the Patient**

### **Nursing: The Voice of Nurse**

Brenda: Do you think that an interview can offer any insight at all into a nurse's world?

Moira: Insight yes, of course. But the doing of nursing, no. I'd rather show you directly on the unit because a lot of what we do we don't know we are going to do until it happens. It surprises even us nurses sometimes!

Brenda: Can we talk specifically for a few moments about the bath? Has the bath has become very devalued in nursing practice?

Moira: Not among nurses, it hasn't, registered nurses I mean. It's not the nurses who devalue it. It's the ones that try to divide up nursing and give it to a cheaper employee. But no, the bath is very important, even the shower. If I can get someone up to the shower, I'll so it because we can get them cleaner in a shower. But even then you don't just leave them on their own. You stay with them until they can manage it all on their own.

But you are on to something here. Certainly right now in the way the bedbath is done in most places, it shows the erosion of nursing and how nursing has had to change its face lately because of lack of qualified staff, lack of resources. Our patient design team has determined who does what pretty much in terms of categorizing the skills and dividing them up among workers. They even include the time allocations for each skill you have to do, without really understanding the difference some of these changes make to the patient and to the disciplines. I was doing a dressing last night that according to the design team, I had to do in three minutes. Well when I got the dressing materials off, I saw that the wound had opened a bit and then that took more time because it was draining, etc, and the patient was upset because he had been complaining for two days that it felt funny after he coughed once and no one was available to look at it and he needed to talk about that. So twenty minutes later I am almost done, but that was seventeen minutes more than I was to spend on it. At coffee we laugh at these things but we are called on the carpet for it later. And if I use more time on something, I often have to take it out of my break time.

But back to the bedbath, yeah when I think about it, it shows just about everything good and everything bad in nursing. With the budget cuts we have to prioritize and sort of juggle things along you know. Sometimes we have to do our bedbaths at 5 AM because days and evenings are so busy and not enough staff to work. So in effect, we interrupt the person's rest to bath them.

Patients are vulnerable and they don't get...well people do not necessarily treat them with respect and during the bath they don't cover up certain aspects of their body. They sort of whip off all the clothes, wash them here and there and dress them up. There is no preparation or follow through to help them have dignity...I have seen people take the gown off and wash them that way and it is more for the expediency of the nurse. They lie there shivering. And because our laundry is now done off-site, often you can't even offer them clean cloths and towels. I mean a bath is just water, soap and towels and gowns in terms of resources used, not like someone on monitors and several IV lines and such. But often don't have what we need to nurse. We make do.

Moira: You know even offering back rubs now has sort of gone by the by. Back rubs are kind of associated with bedbaths. We don't have time to do them now. But I still do them sometimes; like I always do it on someone who has had an angiogram. They have to lie flat for so long so I usually turn them on their side to get them off their back, just that little thing they will always remember. You know it takes 5 minutes to give a good back rub. Anyway a back rub is sort of history now in nursing because we just don't have the time. Most nurses now would rather or actually have to, because of other pressing things, give the person the tylenol for their headache

than rub their back when rubbing their back and repositioning is not going to take that much longer and might even be better for them in the long run.

Brenda: So would you say that some of the qualities of nursing have gone too as with the changes to the bedbath. Is nursing really a changed profession?

Moir: Well yes and no. Because you still nurse as you know you should nurse when you can. But when you have even one really sick person on the unit and there is only you as the registered nurse, well you have to then give the pain killers to some of the others rather than nursing them which would be better for them. So no, I still nurse when I can but the structures are not there to support us anymore. In fact, they work against us even more. And the bath is a good case in point. All people need this care and in nursing it is a point of connection, a relationship builder and of course, much else in terms of assessment but that goes without saying. I know the more time I spend with someone, the more I know what is going on with them, the more I call it when they are getting into trouble; I prevent them from getting into trouble and the docs on our unit really listen to us in this way. The bath was the best vehicle for doing this...not that we bath everyone in sight, but usually those who really need nursing also need hygiene care. But even in mental health nursing, the more you are with them, the quicker you know how to help them heal or how to protect them from harm.

I was thinking of this the other day because a 42 year old man had a huge cardiac arrest and he was in a vegetative state, it is quite unfortunate. And the medical diagnosis for prognosis was not good at all. But the nurses now say he knows his wife is there and the other day they took out his endotracheal tube and gave him O2 by nasal prongs. All along the wife was asking things constantly like, "he's kicking his legs now, that must be a good sign." But anyway, once the tube was out, one of our nurses said that he said "Hi" to her appropriately. None of the doctors would believe her and teased her about it. But then his wife one day soon after was calling his name. She called about six times when another nurse was in the room. The man finally focused on her and she said "HI!" And he said hi to her and now even a couple of days later, he is quite mentally clear.

It's just that we are with the patients more and we know how they are, but now when we send them off to the showers before they are ready, you are not aware of changes in the same way. Another gentleman who was comatose for a long long while and the physicians did not think he would ever regain consciousness left the hospital two month later, not all there mentally mind you but enough functioning that he could live a normal life. You just never know with people and the human spirit can never be underestimated.

Brenda: Do you have more thoughts about nursing and the human spirit, a specific instance perhaps?

Moir: Well what is in my mind, are two gentlemen I nursed once. I had nursed them both through their heart attacks and knew them very well. And one day one of them came and got me because a cardiac arrest happened to one of them. He said his roommate's heart had stopped beating. I called a code immediately and we got him back and then took him to intensive care. Following this, I went in to see this man who called the code as often as I could because I knew they were quite close to each other and they had been together for about two weeks. So I went in and said, "Are you OK do you want to talk about it, I know you were close" and trying to help him that way. He talked a bit but told me that he was fine. Then I was down at supper at 530 PM and they called a code for my unit. I instantly knew it was that man who had helped the other and who was going home the next day and I got up and ran back to the unit as fast as I could. When I got there, there were two of us doing CPR waiting for the crash cart. We moved in to relieve and one of the nurses then tried to get a blood pressure and she yells at me, "He has no blood

pressure." And it was very tense. And then he was talking and saying "I feel so good, I just feel so good." He looked around and was just gone. He died.

That feeling about where do they go, do they go to Heaven... like he was on his way, but he was looking at us and he had such a beautiful smile on his face. He was so happy. I really did know this guy, I had the intuition that a lot of times comes from time spent with them, from bedbath times. We know them intimately and sometimes we can pin point things like what is wrong with them or that you saw "their left toe move today." Maybe nothing might have moved but you just have this awareness because you have gotten to know them that something is different. I know sometimes when we try to say these things to some others and to the medical hard cold facts, they think we are just telling "fuzzy feelings stories." They don't understand, like sometimes it is just a feeling and I'll say to the family, "He won't make it through the night" so I think you should stay..it is just well, I think a lot of times our intuition is pushed down. It's hard to talk about it and then when people ridicule it, you don't. You just act privately.

Brenda: Did you have a hunch about this second gentleman who died?

Moira: Yes and he died and the worst thing is, I was Charge Nurse that day and I was assigned these two rooms that were close to the desk. These two gentlemen were in one of these rooms. We called his sister because his mother hadn't seen him for 2 or 3 months because she was hospitalized in another institution. I felt terrible about this because the way things went there, the mother and sister got there very quickly. They went into the room before I could clean it up. After a code there is stuff strewn across the room, all the equipment for resuscitation is still there, it is a mess. I barely got there before she went into the room but she saw that it was a mess and there were no physicians around and I immediately went to her and talked to them, her and her daughter about the death. I had to tell her on her birthday that her only son had passed away and she hadn't seen him for 3 months. We literally carried her to the waiting room, it was just terrible.

I'll never forget those 2 gentlemen like never. They were very pleasant men. I had given them backrubs every night and I got to know them very well and they always teased me and I them. But there was obviously something here. I didn't mean to keep asking him if he was all right. It was getting to the point where he almost said, "no leave me alone" because I had been bugging him all day. The first person ran into difficulties probably about 10 oclock in the morning and over the next 6 hours I worried and obviously there was something inside me that knew something was going to happen. I couldn't put my finger on it but I knew I had to talk to him and keep checking him and I asked the resident to check him out too. But basically nothing helped; they said that he basically blew his entire left ventricle.

Brenda: Oh dear...this man helped the first one...

Moira: Yes, the first one was blue blue. He was one of those that have a cardiac arrest but stay awake, conscious with it. So he was lying there struggling for air. The roommate saw all this and saw it happen. The other nurse was busy and I was doing rounds with a physician so I didn't see it. Anyway, that man survived because of this man. He lives today.

Later, what balanced it out for me was when he said, "Oh I feel so good" as he was dying. This is probably the most bizarre thing spiritually that has ever happened to me. But because of that I was able to tell his mother the exact way he went. I don't know how much she heard but I know the sister heard and would be able to tell her later. And for me that was the wonderful thing about it; to be able to tell his mother this, about the smile on his face when he died. Even though he died young and tragically, it seemed he was going some place where he was very very peaceful and happy. It is hard to tell you this, but it was sort of like a religious or spiritual experience .

I've almost never seen anyone that happy; it was just shining from his whole body. It is hard to tell people. You had to really be there and I'm glad there were two of us to see it.

I have never seen anybody that happy with the birth of their child or marriage or anything. There was nothing like it. It was just like sunshine shining from the inside to outside of his body out to us. Like some people smile with their face but for him his whole body was smiling, his limbs, his torso. This is just really hard to describe. But this sticks with me so much. I have never seen that since, that peacefulness and joyfulness in anybody else. It was almost like how sometimes they depict Jesus where he is just radiating light or some of the saints radiating light. That is how it was. He was just radiating this joyfulness and peacefulness. It was just wonderful and kind of reinforced my own faith in an afterlife. Unfortunately I was sort of a wreck by the time that happened because it had been such a day. It was just at shift change too. By the time I got through my Charge Nurse things and dealt with the Mom again, I was exhausted. I went home. I don't know if I... well I guess I could of bathed him but it would have been very very emotional for me.

Brenda: We do get really close to patients don't we? I mean, how can we help it when you describe what you just did? What you just said is very very beautiful and I think very unique to nursing this closeness...

Moir: True. It is so often such an uneven relationship. The patient is just sort of left there with no personal power; really at the whim of the disciplines interacting with him. It is the nature of medical knowledge that it is so specialized, we all have to listen and take heed. But as nurses, we spend a lot of time diminishing things that other disciplines have said or done that have hurt or concerned the patient. That's what I mean about uneven relationships. The disciplines take a lot of charge over the patient, some nurses try to control the person's day more than others. Patients are so vulnerable and you have to spend a lot of time managing that.

But what I started to say, with your closeness idea is that because patients are so vulnerable and we are all "over" them so to speak, this closeness of nursing is almost a way of them getting back themselves, their dignity, re-establishing an even foot in the relationship...like the one of nursing being the authority and the patient being the one everything is done to. When you are able to connect body to body with someone it is almost like you have an even relationship again as adults. It changes it somehow. Instead of an adult and a patient you are two human beings together.

Patients need this. Especially when they are elderly and they don't have a lot of family or their family is scattered all over the world, that one hug might mean the difference. Even when you bedbath them or even when I shower them...you know like you wash their hair, you are in there with his scalp and you give him a scalp massage depending on how able they are; when you are washing their groin area or their bottom or something, that is very vulnerable space especially as we grow up we are told that this is your private area and you don't let anybody touch it...To go in there and do those things for people, you take a big chance. You need to ask them "can you wash your groin area yourself?", and if they say yes they can then I give them a few minutes to do it. I try to do their back in the shower and their legs especially as they can't bend over to their feet. Afterwards, it might take five of us to get them transferred back into a chair or the bed in the room, but I always give them that choice.

We nurses are lucky to have this body to body contact, it is a wonderful way to transmit how you care as a nurse to them. Instead of being really rough and aggressive and quick with the wash cloth which makes patients feel terrible. To come along after a person has been bathed like this, his body pulled and mauled, is to see them broken up into pieces. They are really a wreck as a person. Then it takes so much time just to get them back, like we say "we got them back" after

they have a cardiac arrest, well I mean here, it is like I have to work hard to get them back here, I mean their personal self back after being treated like that. To get them back is to put them in themselves again. You know, people shudder sometimes over seeing bodies and unsightly things and blood and stuff that are just part of a body. But to see this sort of self left with no connection to the self, I don't know, it is worse somehow for a nurse. Like you can fix their body and do these concrete things and help a lot that way. But when the parts that make up who that person is are floating around somewhere because someone has diminished them, it's terrible.

No, you have to be gentle and when you are washing their back you talk to them at the same time. It's not just a bath, it is a relationship. It is a difference between those who nurse and those who don't...I've cried and hugged patients and families after their loved one has died and I have had staff say to me, "I would have never have done that" and I answer, " Well I have not lost anything by crying with them and hugging them." If anything I have gained because I've started to go through that grieving process too and I've gained from knowledge of the fact that they appreciated me in what I was able to do for their loved one. I've given them nursing, something important, and I haven't lost anything by it.

Brenda: I talked recently to a hospital chaplain and she has told me that she has people from all the disciplines come into her office, close the door and weep. She believes that as health care professionals we have to look at personal issues and why we have to be in control of relationships with patients. And she pointed said, "It is a paradox I know to most people, but I want to tell you that when I am connected with people I'm OK and when I am not connected I'm not. I burn out." And she thinks this is a very important aspect of working with people in health care. She also believes that with our smaller staff now, no one can connect with anything as everyone runs around getting things done and not often the most important things. At least that is what the patients tell her.

Moira: The last six weeks I have been taking a course and worked fewer nursing hours. The course is finished now and I'm back to my normal working schedule. But I haven't probably in the last 6 weeks really developed any new relationships with any new patients. In my fatigue and preoccupation and too with all the changes by the Design team on the unit, I didn't look forward to going to work other than this one patient through all that time, the 6 weeks...he is comatose and his wife is a few years older than myself and I quite connect with her. She leaves me notes and asks questions and I leave her little notes answering and adding pep talks and stuff. It does help to know someone is there. You walk away being revitalized at the end of the day when you have even made just one connection with somebody. But when you don't make any, it's like "Oh dear it has been so draining even after three twelve hour shifts." Whereas if I have had a good time at work where I have really connected with the patients, I'm not burned out. I really agree with the Chaplain. When you don't connect with people whether it is patients, staff or anyone, it is difficult to work. Really it shows respect for other people and when you show respect you are more comfortable with yourself. Like certain kinds of touching doesn't make a person feel comfortable, so beforehand you come to that patient and say "I need to do this and this is how it will go." If you just keep an awareness of your own self and what it would be like to have this done, then you can transfer all these feelings of awareness, which is just human awareness really, to others, to respecting other people, no matter how difficult they might be to care for. I hope nursing never disappears. I really believe in what we do.

Brenda: Can you think of an example of someone who is difficult to care for?

Moira: Well we have this one man on our extended unit who has probably been there for about 6 months because sometimes they wait for placement. He irritates everybody on the floor probably because of how long he has been there. What I mean is sometimes we get abusive people,



abusive people to the nursing staff and if it is short term we can manage to deal with it. You rotate these patients among each other, like "I've had him for 2 days and I don't want him anymore" so you try to take the pressure off staff that way.

But we have had this one man for the last 6 months so the last 6 weeks. He used to rattle his side rails and he wasn't really all there cognitively so we would go in and ask what is wrong, reposition him, rub his back, give him a drink of water, talk to him, soothe him stroking his arm. But to no avail. No matter what you did you could not do enough. I guess because cognitively he wasn't there very much, he wasn't able to communicate what he really wanted. It is very frustrating because you cannot settle him at all. Like there is nothing you can do to make him content. Nurses find that frustrating. So I ask myself "Why I am frustrated with that what is he doing?" Because you have to be self aware; you have to know why what they do makes you feel like you do. It could be that the behaviour you see is something, or makes you aware of something, you don't like in yourself, for instance, I don't like to feel frustrated and that my efforts at nursing are not effective and then you think, "Well maybe I'm not a good nurse" or something like that. And a lot of times the behaviour is the same as something about yourself you don't like. A lot of times you have this same thing yourself and don't want it and that really disturbs you.

I guess there is a fine line between overdemanding people and your own ability to handle your frustration. When people are overdemanding when I am going flat out getting the work done and I say "I am doing the best I can. I will back in one hour" and I say it in a voice that says, "Don't push it." Well what can happen is that they become even more demanding as if the overdemandingness makes me back off. It is like they've put ice on the relationship. Patients know they can do certain things and I like all nurses, encourage self care. You try to get them to do as much as they can for themselves. So a lot of times, because of the cutbacks to staff and everything else right now, I can become resentful of the time they ask for if they really don't need it and their neighbor does. It's just that you can't explain to them why you spend that time with the neighbor and not with them. Well, you can say, "He's really sick right now", but if you are into demanding care, you won't listen to that. Nursing tries to do the best they can for everyone. It is our mandate. But for some people it is not enough and it is almost as if it brings back all my little childhood issues...you know where you grow up and do things and for others it is just not good enough? So when I couldn't do enough for him even after all the care listed above and this behaviour happens about every fifteen minutes through the shift, you back off. And for some nurses they say, "I can't do anything more now" and "I choose not to do anything more right now for him because he pushed certain buttons" and I need to go and deal with that. It is a hard thing to admit but these things are true. Now above I speak of a slightly cognitive impaired man and you make allowances for that. But I want to tell you there are a lot of people in society that act that way when they are sick. Just think of the variety of people in society and then think about how people have different ways to cope when they are ill. Nurses have to deal with other's sometimes outrageous behaviour.

Brenda: Nurses don't like to admit these things. Some of the things that are realities for nurses are sort of our silent thing isn't it, the thing you do not want to admit to, you don't want to tell other people.

Moir: Well as you know, nurses have coping behaviours too. We try to get past all of the above by taking turns, sending different people in because certain people can relate to certain types of difficult people better. We used to always work as a team and know each other's strengths. Now with the fragmentation of staffing, you never know what kind of staff person you are going to get.

Brenda: I heard a nurse say the other day that there was no way "in" to know a certain difficult person and he just gets more demanding every day. She told me, "There is no way in to know him."

Moira: You know when I get into a situation like this sort of demanding patient who is cognitively all there, I do a couple of things: sometimes I just call them on it, because sometimes I don't know if they are aware of it and I'll say, "When you do this it upsets me because I (and then whatever is happening) and I'm trying to do the best I can." This often will be enough. Now they know what their behaviour causes and sometimes they are embarrassed because they did not know its consequences. They were not aware of it. So you can never assume that people know the effect of their behaviour on others, on situations. Sometimes like the cognitively impaired man above, all he wants is someone to hold his hand, to stay with him. And it did calm him to have me sitting in the room with him and of course, you schedule this into your shift, but you can't do it for long these days. My last shift there were only two staff total on and we were needed out on the floor with sicker patients and couldn't sit with this patient. So what you in effect do is prioritize him lower because he is technically stable medically and clean and waiting for placement which isn't fair to him. We tried talking to the family to have one of them stay and we tried for more staff but both failed. All he needs is someone to stay with him all the time and he would be calm. So you can call them on it but sometimes that backfires and they get worse and we have had patients who try everything to see what they can get away with...speaking of the nurse's childhood issues, patients have the same sort of behaviours and can become very rude and obnoxious. Don't get me wrong. There are people in the system who are not getting the care they need now and I'm not referring to them. I refer to people who could engage in self care but won't or patients who have all the nursing they need but it is not enough.

Brenda: Is there anything you don't like about nursing? We do take a lot of abuse from patients and families sometimes.

Moira: What is interesting on our unit is that patients and families always report nurses to the Administration but they never report the physicians and there have been instances where they should have. In these instances, the nurses were held accountable too.

But to answer your question, no. I really like nursing despite the above and patients who become demanding are probably the worst part of nursing. It is like they show you up that you can't do enough for them and often we can't do enough for people, but we do what we can.

Brenda: Is there anything more you would like to say about nursing before we stop?

Moira: I'd like to say that the two men I spoke of moved me most out of my nursing experience. And I wish I could just nurse, you know, nurse...do what I can do well without all the impediments to it in the institution. We need to shift that. It is all politics not patients. It goes against our code of ethics to see some things these days. Even our own nursing organizations allow nurses without cardiac expertise to come to our unit. We have one nurse that bumped in to our intensive cardiac care unit from a long term facility. There is nothing wrong with her but she is not safe. I know I said above that you can get angry with patients but if I could just go and do my job without having to jump through all these administrative and political hoops, I think I would enjoy nursing that much more.

But out of all, a lot of the good memories are of comatose patients. You probably think that is strange, but I know that I make a difference with them. When they walk out of the hospital, I rejoice. On the floor, and I'm tooting my own horn here which nurses are not supposed to do but I've probably more than any other nurse on the floor had other nurses, physicians, families come up to me and say or write a letter to me or put on a card to the staff with special thanks to me

about how happy they were that I was their nurse because I treated them with respect. I talk to them and treat them as a person even though they are comatose, like, "Now David or Mr. Jones or Mr. Smith, we are going to wash you or I have to start an intravenous", or things like that and basically who knows if they can hear or not. But they are human beings and not just lifeless bodies or a body without movement. I've seen enough lifeless bodies to know. I really like working with them and their families. I know how to support them.

This woman I already spoke of, where it is not known yet whether her husband will remain in a persistent vegetative state. He has not made any significant changes in 6 weeks and medically speaking the person must make some changes in a month or it is not good. But she still hopes he will walk out of the hospital. And she asked me, "What do you think is going to happen?" I'm not going to take away her hope and so I said to her, "You know I hope for you that something is going to happen because that is the best you love him, but I am not God and I can't tell you." But I always add, "In my nursing career this has happened and that has happened but we can't say one way or the other yet. But thinking about him getting better and hope is getting you through every day and it gets through to him too."

Brenda: I hope you Moira are around when I need some nursing care

Moira: I hope to be in nursing for a long time to come. I'm not in jeopardy of getting bumped out of my unit. It is cardiac and it is specialized nursing care. But we have that patient care design team and they want to replace nurses with the multiskilled worker so when that happens I will be gone for sure with all my expertise and knowledge, just gone, wiped out...

### **The Voice of the Patient**

Brenda: Leigh, do you think an interview like this can give any insights at all into a patient's world?

Leigh: Well yes, in some ways. If this is all we've got, it is better than nothing. But you know I was a math teacher for many years and I know that if you really want to see what it is to be a student learning math, you needed to be right there with me when I was teaching it to him or her. It didn't matter what came out in terms of teaching mathematics better, the teacher still had to teach it, you know what I mean, bring it to life or something like that.

But here you have been with the nurses here seeing what they do so I know that what I can more easily explain things to you, well not explain really, try to show I guess.

Brenda: You told me that the most important thing about nurses is that they "live it with you."

Leigh: Yes and I would still say that after all these months. In fact they helped me live my disease, my treatments, my health. In fact, I know more about my body than I ever did in youth and health, even in my pregnancies when you really know what your body can do and you are constantly surprised. Did I ever think that my breasts would leak milk like that? Not in my wildest dreams coming to womanhood. And that movement in my belly, yikes...that was something surreal and yet it was my body.

So here it is almost the same. I didn't know that disease, leukemia, could be so destroying of my body, my whole life really. In a matter of hours, 48 to be exact, here I was at this big institution getting ready to put chemicals into my body that would kill my skin cells if a drop of it should spill on my hand. It's unbelievable really. This illness and its nastiness was totally unpredictable; like there it was one day and I still felt well. I felt well right up until the chemotherapy, first sickness I had was after the chemotherapy.

But too, I've now known the wondrousness of the human body in the face of the onslaught of disease like this...the way it keeps coming back after the treatments. And now one of my cardiac valves has been effected by the chemo, it is not working as well as it should, but still I have life and my heart ticks on. The bone marrow transplant too was a horror. Yet as I found my body getting into trouble with my identical twin sister's marrow, I was angry; I mean we were one egg once, one egg, imagine that. And yet I have leukemia and she doesn't. (Long silence here)

Brenda: I see you a bit differently though. I see you living this whole episode with dignity and grace...as one who has negotiated care and meaning all the way through. You did not ever abdicate your responsibility in this illness.

Leigh: Yes well, you have choices to make and no one lives this disease the same way. I think that is what is so difficult for the nurses; whoever has this responds differently and so the nurse can never operate from a step by step approach. Actually if they try to and I have had a couple, not many, but you see them after about four hours in a dreadful state of not-knowing what is going on, not being able to interpret things. You know in teaching, I just kept working things through with a student until I would see what step in the logical progression of mathematics he kept missing. I know nursing is not a logical progression like math, well not often anyway and what is nursing for me is different than for my neighbor Helen. But the analogy for me is that the nurse keeps working things through too until something happens that is right for the person. When you being with a step by step plan as a nurse, well that something can't get through I think. The more I drilled in the steps of mathematical progression, the worse the student got because of a missing piece of understanding and so he would get nervous and lose the whole thing. Well sorry, I speak of math here and don't mean to.

Brenda: Tell me once more about living-it-with-you please.

Leigh: I think anytime you are sick, no one else can be in the same place you are, the same symptoms, the same feelings that you have, your body reacting a certain way...you know the nurses tell you about certain side effects and how they can manage them, but not everyone gets them. We are all unique. But because no one can be in the same place you are, it makes being very sick a very lonely type of thing because you are the only one going through this.

But nurses are right here, part of my whole life now, they know your symptoms, your responses, they know where you are. They live their life with you or they live my life with theirs. They are kind of on the front lines of any controlling disease like this, I know front line is war terminology, but it is a kind of way, a war against this disease. They care about getting you out of here and whole. They want you at home as much as you can be because they know that is renewing of our spirits.

The nurses also tell you things. They always tell you what is going on. I mean it is our body and nurses know that here. That it is you that is directly involved and that you should be the first person to know exactly what is going on in your body, even the good or the bad, you should know.

I had a few hours before my very first chemo was ready to start and so I joked with them and said, "Oh this is nice so that I can get to know you so when I start my chemo I won't have to do anything. I'll just yell for you, you see." They laughed and said, "Yes but we are getting to know you well too. So when we want you to get out of bed because we don't want you to have pneumonia or because we want you to have exercise, we are just going to say, "Leigh, get out of bed now!"

It is this rapport, when you build up this rapport with us patients, you can ask them to do things that patients would be very reluctant to do otherwise because of how they feel. But when they

know the nurses and that the nurses have their best interests at heart, then they get up and move or swallow things you would die to know about how awful they are. But you do it because you trust the nurses. I have had nurses other places that only come in for a few hours and you can't trust them in the same way. They cannot keep track of things or know you. Really they just run around doing these things to patients, disconnected things and so they are often not helpful and I often don't let them do it or I watch very carefully. And then you have the ones who aren't nurses who are doing nursing things now; that is frightening. Once I almost called the RCMP, the police, I was so scared of one of these people who was trying to put someone else's blood into me. You don't realize until you hit something like this how much you need skilled and honest people around, people who don't fake. You need confidence in them because remember, when this was happening, I had a fever of 39 plus C, I mean I was not in much condition to watch, to monitor things.

But no, back to nursing. That is not nursing. You know, a good nurse knows you have a fever before you do. Here they have caught it many times. You see, here they are the ones who take care of you, they change your broviac dressings, take your blood pressure, help you to the bathroom. They get to know you and the body of the person. They know because they can tell by the eyes how you react or talk or how you are feeling because they know you. They know just by looking at you whether you are better or whether you are worse. So that's the thing, they get to know you. I know it is a chore for them to always be writing things down, but because they do, another nurse can come right in and follow on...it is an amazing things really. Not even teachers, well math teaching is my field, not even teachers can follow on like this...it is a phenomena in itself really.

I think you must have a calling to be a nurse really, at least a nurse who is at the bedside has to have a calling I think. And you know in terms of education, I have a friend who teaches nursing and she talks about the dummy manikins in labs students practice on. I say, get them out of the lab. I've had too many of them where they tell you they haven't done it on a person yet and they are already finished their program. Why not get them out with us as soon as possible? They should ask us who are sick about nursing like you are and then get it into the programs. I know that politics determine health care and they do not want to hear from us. Somehow sick people who people who have been ill a lot are not stakeholders, that word they use, stakeholders in the same way a healthy, non-diseased person is. They think because we are sick we have nothing to add because we will be biased or have certain bandwagons we are on. Maybe there is some truth in this, and maybe if I was in the position I would push for more cancer care. But I don't think so. When you are ill, you are ill and need appropriate care and there is no one like a sick person to be able to tell you about this. Now I don't see myself sick now. I see myself treated and improving all the time. I was just using sick here to show you. But it is true about stakeholders. I know this from my MLA at home.

But I want to tell you this one more thing. When I came in, I was so upset about getting the treatments, the disease, oh terrible things, terrible horrific horror in the mind, I tell you, it was awful. But they said, "Don't worry about the treatment. You just worry about your heart, soul and mind. We will look after the physical part of the treatment and we will get you out of here. We'll get you out of the front door!" And I said, "More like the back door, I think." And they said, "No! We will get you out the front door and you are going to be on your feet walking out of here and we will make certain that you will."

And I have walked out the front door several times and I will again tomorrow.

Brenda: Any more Leigh?

Leigh: No, just that life is too short to just be a hypocrisy. You have to be who you really are and nurses come through as being real people and they really share part of their life with you. They ask you about your life and who is important to you, what types of things you do at home. They tell you too about theirs sometimes, their children, their hobbies and that makes you want to share more with them because they offer you a part of theirs. I don't mean the ones that talk all the time about themselves; they are those who are not nurses or not nursing particularly well that day and that happens too. When you are sick, you want to be treated like a real human being, like a person. We need that recognition. We have to be recognized as breathing, doing others and not just this lump of clay with this disease. Nurses do that, not just the physical, but all of it, feelings, emotions. They are a link to humanity, to life. You are not just another body lined up in a row...

## **APPENDIX TWO: INFORMED CONSENT DOCUMENTS**

### **CONSENT FORM FOR PATIENTS FOR TAPE RECORDED INTERVIEWS**

This consent form, a copy of which has been given to you, is only a part of the process of informed consent. It should give you the basic idea of what the research project is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

This study is designed to help nurses understand what types of nursing care are essential and important to patients when they are ill. If you agree to participate in this study, you will be asked to participate in a tape recorded interview with the researcher. You will be interviewed at a time and a place that is convenient for you. It will last approximately 1 hour. During the interview you will be asked to describe your experience of being cared for by a nurse. The questions you will be asked are "what is it like to be cared for by a nurse?" and "will you please describe to me what kinds of nursing care are important to you when you are ill?" You may answer these questions in any manner that you like.

You do not have to be in this study if you do not wish to be. If you decide to be in the study, you may drop out at any time by telling the researcher. You do not have to answer any questions or discuss any subject in the interview if you do not want to. You can stop the interview at any time if you wish. Taking part in this study or dropping out will not affect your care in the hospital.

Confidentiality will be respected at all times. Only a code number will appear on any forms associated with the study. All identifying data will be kept separate from these documents. The researcher will erase your name and any other identifying material from the tapes. All records will be kept in a locked cabinet in the researcher's office at the Faculty of Nursing at the University of Alberta, with the identifying data locked in a separate cabinet in the researcher's office. The tapes will be destroyed after the study is completed. The typed interview and notes will remain in a locked file. Only the researcher will have access to all research material. All data obtained from this study will be stored and may be used for future analysis without obtaining further consent from you. However, each study arising as a result of information obtained in this study will be submitted for ethics approval.

The information and findings of this study may be published or presented at conferences, but your name or material that may identify you will not be used.

Taking part in this project will be of no direct benefit to you. However, it is hoped that the results of this study will assist nurses to give comprehensive and competent nursing care.

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Initials of Patient

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Date

### **UNDERSTANDING OF PATIENTS**

I acknowledge that the research project has been explained to me and that any pertinent questions I have asked have been answered to my satisfaction. My signature on this form indicates that I have understood to my satisfaction the information regarding my participation in the research project, and agree to

participate as a subject. In no way does this waive my legal rights nor release the researcher, sponsors, or involved institutions from their legal and professional responsibilities.

I have been informed of the alternatives to participation in this study. I understand that Brenda Leigh Cameron (492-6412 or 492-2902 or 962-3025) will answer any additional questions that I have about the research project.

I am free to withdraw from the study at any time without jeopardizing my health care. Should I decide at any time during the study that I do not want any information about my experiences to be used, the information will be withdrawn and destroyed immediately.

If at any time during the course of this study I feel that I have been inadequately informed of the risks, benefits, or alternatives, or that I have been encouraged to continue in this study beyond my wish to do so, I can contact the Patient Advocate at (403) 492-8585.

I have been assured that confidentiality will be respected at all times.

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Name of Subject

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Signature of Subject

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Name of Witness

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Signature of Witness

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Name of Researcher

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Signature of Researcher

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Date



## **CONSENT FORM FOR PATIENTS FOR PARTICIPANT OBSERVATION**

This consent form, a copy of which has been given to you, is only a part of the process of informed consent. It should give you the basic idea of what the research project is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

This study is designed to help nurses understand what types of nursing care are essential and important to patients when they are ill. If you agree to participate in this study, you will be asked to consent to allow the researcher to observe and participate in your care along with your assigned nurse. The researcher is a registered nurse with several years of nursing practice and teaching experience. These observation times will be negotiated with you and your assigned nurse in terms of what is most convenient and appropriate for you. The researcher will respect patient and nurse privacy at all times. You can ask the researcher to leave at any time if you wish. Following the observation time you will be invited to participate in a tape recorded interview. You will sign an additional consent form for the tape recorded interview.

You do not have to be in this study if you do not wish to be. If you decide to be in the study, you may drop out at any time by telling the researcher. You do not have to answer any questions or discuss any subject in the interview if you do not want to. Taking part in this study or dropping out will not affect your care in the hospital.

Confidentiality will be respected at all times. Only a code number will appear on any forms associated with the study. All identifying data will be kept separate from these documents. The researcher will erase your name and any other identifying material from any written or typed notes taken at the observation times. All records will be kept in a locked cabinet in the researcher's office at the Faculty of Nursing at the University of Alberta, with the identifying data locked in a separate cabinet in the researcher's office. The notes will remain in a locked file. Only the researcher will have access to all research material. All data obtained from this study will be stored and may be used for future analysis without obtaining further consent from you. However, each study arising as a result of information obtained in this study will be submitted for ethics approval.

The information and findings of this study may be published or presented at conferences, but your name or material that may identify you will not be used.

Taking part in this project may be of no direct benefit to you. However, it is hoped that the results of this study will assist nurses to give comprehensive and competent nursing care.

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Initials of Patient

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Date

## **UNDERSTANDING OF PATIENTS**

I acknowledge that the research project has been explained to me and that any pertinent questions I have asked have been answered to my satisfaction. My signature on this form indicates that I have understood to my satisfaction the information regarding my participation in the research project, and agree to

participate as a subject. In no way does this waive my legal rights nor release the researcher, sponsors, or involved institutions from their legal and professional responsibilities.

I have been informed of the alternatives to participation in this study. I understand that Brenda Leigh Cameron (492-6412 or 492-2902 or 962-3025) will answer any additional questions that I have about the research project.

I am free to withdraw from the study at any time without jeopardizing my health care. Should I decide at any time during the study that I do not want any information about my experiences to be used, the information will be withdrawn and destroyed immediately.

If at any time during the course of this study I feel that I have been inadequately informed of the risks, benefits, or alternatives, or that I have been encouraged to continue in this study beyond my wish to do so, I can contact the Patient Advocate at (403) 492-8585.

I have been assured that confidentiality will be respected at all times.

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Name of Subject

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Signature of Subject

---

Name of Witness

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Signature of Witness

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Name of Researcher

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Signature of Researcher

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Date

## CONSENT FORM FOR NURSES FOR TAPE RECORDED INTERVIEWS

This consent form, a copy of which has been given to you, is only a part of the process of informed consent. It should give you the basic idea of what the research project is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

This study is designed to help nurses understand what types of nursing care are essential and important to patients when they are ill, especially when they are ill with a potentially life threatening disease. If you agree to participate in this study, you will be asked to participate in a tape recorded interview with the researcher. You will be interviewed at a time and a place that is convenient for you. It will last approximately 1 hour. During the interview you will be asked to describe your experience of taking care of patients and perhaps asked about taking care of a particular patient. The questions you will be asked are "what was it like to care for that particular patient?" , or "will you please describe to me what you think are the essential qualities involved in nursing patients with a potentially life threatening disease?" You may answer these questions in any manner that you like.

Please understand that the researcher is not evaluating your nursing care. Rather she is attempting to determine the essential nursing qualities that are present in nursing care, particularly the nursing care of patients with cancer.

You do not have to be in this study if you do not wish to be. If you decide to be in the study, you may drop out at any time by telling the researcher. You do not have to answer any questions or discuss any subject in the interview if you do not want to. You can stop the interview at any time if you wish.

Confidentiality will be respected at all times. Only a code number will appear on any forms. All identifying data will be kept separate from these documents. The researcher will erase your name and any other identifying material from the tapes. All records will be kept in a locked cabinet in the researcher's office in the Faculty of Nursing at the University of Alberta, with the identifying data locked in a different cabinet also in the researcher's office. The tapes will be destroyed after the study is completed. The typed interview and notes will remain in a locked file. Only the researcher will have access to all research material. All data obtained from this study will be stored and may be used for future analysis without obtaining further consent from you. However, each study arising as a result of information obtained in this study will be submitted for ethics approval.

The information and findings of this study may be published in refereed professional journals, and/or presented at conferences, but your name or material that may identify you will not be used.

Taking part in this project will be of no direct benefit to you. However perhaps the time spent reflecting with the researcher on what it is that happens between a nurse and a patient may enhance your personal nursing practice. It is also sincerely hoped that the results of this study will not only add to professional nursing's theory base, but also provide a body of literature that refers to the specificities of what types of nursing care are essential to caring for patients with cancer.

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Initials of Nurse

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Date

### UNDERSTANDING OF PARTICIPANTS

I acknowledge that the research project has been explained to me and that any pertinent questions I have asked have been answered to my satisfaction. My signature on this form indicates that I have understood

to my satisfaction the information regarding my participation in the research project, and agree to participate as a subject. In no way does this waive my legal rights nor release the researcher, sponsors, or involved institutions from their legal and professional responsibilities.

I have been informed of the alternatives to participation in this study. I understand that Brenda Leigh Cameron (492-6412 or 492-2902 or 962-3025) will answer any additional questions that I have about the research project.

I am free to withdraw from the study at any time without jeopardizing my employment. Should I decide at any time during the study that I do not want any information about my experiences to be used, the information will be withdrawn and destroyed immediately.

If at any time during the course of this study I feel that I have been inadequately informed of the risks, benefits, or alternatives, or that I have been encouraged to continue in this study beyond my wish to do so, I can contact the Chairman of the Alberta Cancer Board Research Ethics Committee at (403) 482-9366.

A copy of this consent form will be given to me to keep for my records and future reference.

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Name of Subject

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Signature of Subject

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Name of Witness

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Signature of Witness

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Name of Researcher

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Signature of Researcher

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Date

## CONSENT FORM FOR NURSES FOR PARTICIPANT OBSERVATION

This consent form, a copy of which has been given to you, is only a part of the process of informed consent. It should give you the basic idea of what the research project is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

This study is designed to help nurses understand what types of nursing care are essential and important to patients when they are ill, especially when they are ill with a potentially life threatening disease. If you agree to participate in this study, you will be asked to consent to allowing the researcher to observe and perhaps at times under your direction, assist you with your nursing care. These observation times will be negotiated with you in terms of what is most convenient and appropriate for you and for your patients. The researcher will respect patient and nurse privacy at all times. You can ask the researcher to leave the nursing situation at any time if you wish. Following the observation times, you will be invited to participate in a tape recorded interview. You will sign an additional consent form for the tape recorded interview.

Please understand that the researcher is not evaluating your nursing care. Rather she is attempting to determine the essential nursing qualities that are present in nursing care, particularly the nursing care of patients with cancer.

You do not have to be in this study if you do not wish to be. If you decide not to be in the study, you may drop out at any time by telling the researcher.

Confidentiality will be respected at all times. Only a code number will appear on any forms associated with the study. All identifying data will be kept separate from these documents. The researcher will erase your name and any other identifying material from any written or typed notes taken at the observation times. All records will be kept in a locked cabinet in the researcher's office at the Faculty of Nursing at the University of Alberta, with the identifying data locked in a separate cabinet in the researcher's office. The notes will remain in a locked file. Only the researcher will have access to all research material. All data obtained from this study will be stored and may be used for future analysis without obtaining further consent from you. However, each study arising as a result of information obtained in this study will be submitted for ethics approval.

Taking part in this project may be of no direct benefit to you. However perhaps the time spent reflecting with the researcher on what it is that happens between a nurse and a patient may enhance your personal nursing practice. It is also sincerely hoped that the results of this study will not only add to professional nursing's theory base, but also provide a body of literature that refers to the specificities of what types of nursing care are essential to caring for patients with cancer.

The information and findings of this study may be published in refereed professional journals, and/or presented at conferences, but your name or material that may identify you will not be used.

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Initials of Nurse

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Date

### UNDERSTANDING OF PARTICIPANTS

I acknowledge that the research project has been explained to me and that any pertinent questions I have asked have been answered to my satisfaction. My signature on this form indicates that I have understood to my satisfaction the information regarding my participation in the research project, and agree to

participate as a subject. In no way does this waive my legal rights nor release the researcher, sponsors, or involved institutions from their legal and professional responsibilities.

I have been informed of the alternatives to participation in this study. I understand that Brenda Leigh Cameron (492-6412 or 492-2902 or 962-3025) will answer any additional questions that I have about the research project.

I am free to withdraw from the study at any time without jeopardizing my employment. Should I decide at any time during the study that I do not want any information about my experiences to be used, the information will be withdrawn and destroyed immediately.

If at any time during the course of this study I feel that I have been inadequately informed of the risks, benefits, or alternatives, or that I have been encouraged to continue in this study beyond my wish to do so, I can contact the Chairman of the Alberta Cancer Board Research Ethics Committee at (403) 482-9366.

A copy of this consent form will be given to me to keep for my records and future reference.

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Name of Subject

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Signature of Subject

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Name of Witness

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Signature of Witness

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Name of Researcher

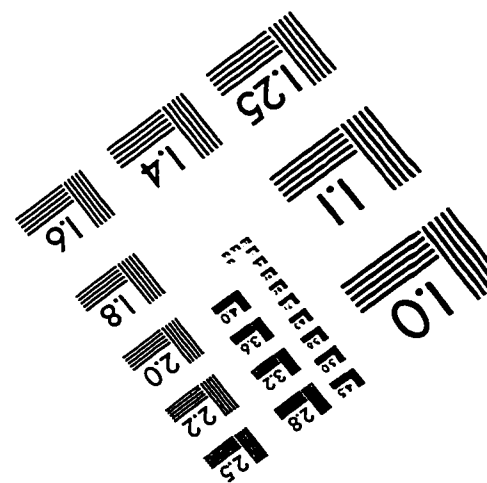
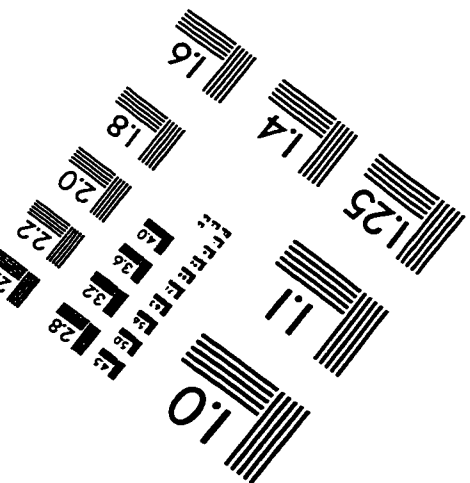
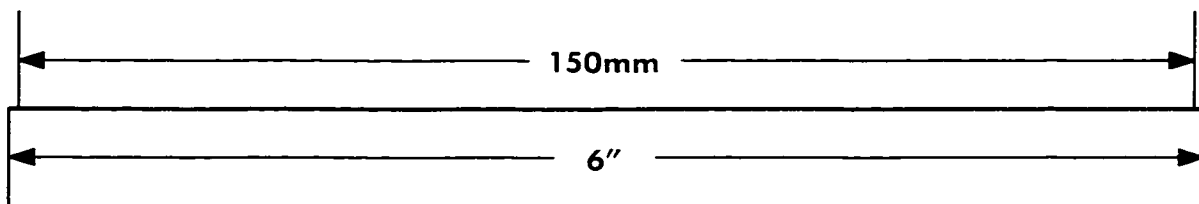
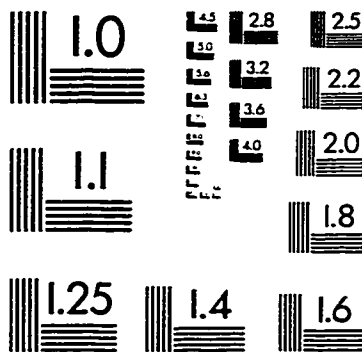
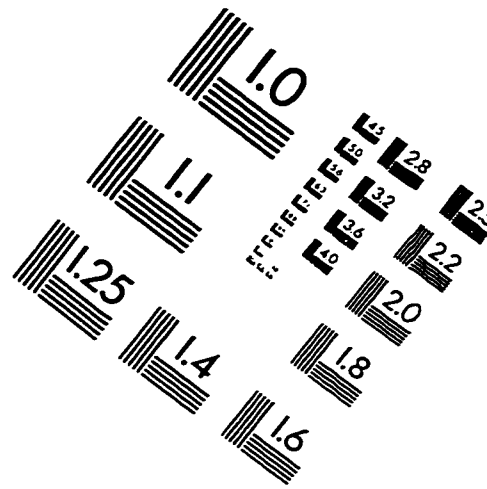
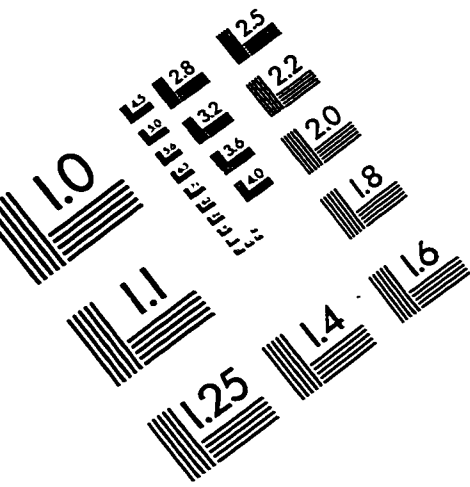
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Signature of Researcher

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Date

# IMAGE EVALUATION TEST TARGET (QA-3)



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1653 East Main Street  
Rochester, NY 14609 USA  
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Fax: 716/288-5989

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