UNIVERSITY OF ALBERTA

NURSING PRACTICES AND THE EXPERIENCE OF THE VERY ILL IN THE HOME

BY

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ABSTRACT

This is an interpretive philosophical inquiry into nursing practices and the experience of the very ill in the home. The study comprises a hermeneutic phenomenological exploration of the practices of palliative home care nurses and the experience of individuals receiving palliative home care in Canada. The following research questions guided the study "How do the very ill live through their experience? How do nurses engage with the very ill? How do the very ill reveal conceal dying? How does the global context relate to our understanding of the experience of the very ill?" In-depth experiential descriptions and interpretations of nursing moments gathered through on-site engagement and conversations with nurses and patients are woven throughout the entire text. Chapter one situates the inquiry in the world of nursing practices in the home. The notion of the home as a garment that sustains both nursing and the very ill is evoked. Chapter two involves a review of the texts of palliative care both in the North and the developing world and how these texts reveal conceal the experience of the very ill. Chapter three shows the fecundity of interpretive inquiry in undertaking research in the home. In chapter four, I elucidate an understanding of nursing practices in the home through an in-depth experiential description of a woman's experience and her nurse's engagement with her situation. Chapter five involves an exegesis of the stranger in contemporary society. How the otherness of the stranger relates to the otherness of the very ill is explored through the experience of a palliative patient in Chile. In chapter six I offer a detailed hermeneutic narrative of the experience of a young woman and the close engagement of her nurse. This account shows how the very ill reveal conceal dying and how nurses respectfully

enact their recognition of the inappropriability of death as they enable them to fully remain in life. In chapter seven I offer an interpretive approximation of how the nurse embodies ethics in the home. In the final chapter, I delineate primary understandings of this inquiry that call us to revisit policies unbefitting nursing practices and the very ill.

PROLOGUE

In his book *"Las intermitencias de la muerte,"* (the intermittencies of death) Jose Saramago (2005) tells the story of a country where as of midnight on a New Year's Eve, people no longer die. The country's initial reactions after the news that people have stopped dying are those of collective euphoria. Everywhere, people begin to celebrate the end of death.

Yet soon this euphoria turns into despair as sick people continue to get sick, and sicker and sicker as time goes on, being unable to die. In a few weeks, hospitals, nursing homes, and all kinds of health care institutions begin to collapse, overloaded with terminally ill and critically ill people. Health care staff faces a grave crisis as they become unable to respond to the urgent needs of so many sick people.

Taking measures to face the crisis, the government decides to return the now incurable sick to their family members. Families are now to look after their relatives in their own homes. As weeks and months go by, the situation becomes even more chaotic as the government is no longer able to continue to protect the good of the country. The *"maphia"* takes over taking advantage of the tragic situation of countless families. After the initial joyous responses, people in the country are now desperate for death to return.

The situation keeps deteriorating until a letter signed by death herself is received. In this letter, death announces her return to the country in a matter of hours. This time, as a sign of her consideration for everybody, death announces she will give a week notice to every person whose death is coming.

Once again people begin to die and in a few weeks, the country resumes its normal life. Yet life is no longer as normal as it used to be as now more and more people throughout the country fall in a state of despair as they begin to receive their 7-day death notice in a purple envelope sent directly by death herself.

Receiving the purple envelope turns into a tragedy for the population as people mourn in advance the loss of their own life or that of a loved one. Some decide to go on living just as they were living until now. Others decide to spend everything they have and celebrate day and night while others fall into despair unable to do anything at all. The endless rain of purple envelopes generates collective panic in the population.

Yet something unexpected takes death by surprise. One purple envelope keeps coming back to her working office. Intrigued and upset by this situation, death decides to leave her underworld and pay a visit to the addressee of this envelope. Things begin to change though the purple envelopes continue to be delivered in their usual way.

In a humorous and at times satiric manner, Saramago (2005) evokes throughout this novel our human responses in the face of mortality. The disappearance of death, the end of mortality, doesn't in the end bring about the anticipated happiness. Unable to die, very sick people experience day after day the dramatic decay of their bodies before the alarmed and helpless eyes of their families. I can just imagine how busy and overworked nurses must have been in this country.

The return of death doesn't seem to make things easier for the population. Now people are terrified to check their mailboxes knowing that a purple envelope might be awaiting them. The envelope brings home the direct realization of one's own mortality.

Not unlike the purple envelopes, the news of being very ill and that a cure is unlikely to happen is often if not always devastating. In daily life we go on seemingly oblivious of our own mortality. Yet in the very ill being able to remain oblivious like the rest is not easy and perhaps not even a choice. Their frail bodies constantly evoke their own mortality.

Yet even though in their situation the very ill experience in an almost everyday manner the embodied expressions of mortality they too are able to keep going with life, to somehow forget or leave aside the tragedy that the purple envelope evokes in Saramago's country. They continue to live in the face of their mortality. In the nearness of death, they are re-infused with a stronger and fuller sense of life.

How the very ill thrive in the midst of overwhelming situations was in this inquiry one of the most revealing elements of their experience. In their experience, the very ill evoke the need to on the one hand be attentive of the "*intermittencies*" of death borrowing Saramago's word, while on the other being able to keep going with life, to engage with whatever is going on in their lives, to have projects, to participate with others, to flourish. In a word, they need to be able to forget death.

The slow erasure from society that the very ill suffer as they go through their experience is so harmful of their integrity. Too easily we write them off. Too quickly we disappear from the scene. We flee away from the very ill, unable to face our common and *ownmost* mortality.

Here nursing shows itself as the constant and faithful partner of the very ill. In the face of the very ill, nursing remains always on the scene. Nurses are not afraid of mortality. Their embodied and skilled understanding of what the very ill go through enables nurses to fully sustain them in their experience, to the end. Nursing can never flee away from the sick.

Throughout the inquiry I was deeply taken by the nearness of nursing to the very ill. How one holds the other. The deeply committed and firm engagement of nurses to the very ill in the home and beyond was simply striking, extremely poignant. The purple envelope calls nursing into being.

Yet nursing doesn't stay with the news the envelope brings home. Nursing knows how to anchor the very ill in life. In their practices, nurses too move back and forth between the endless intermittencies of death and those of life. Nursing follows the rhythm of the very ill. Nurses enable the very ill to continue to thrive in the face of death.

In their relation with the very ill, nursing shows a path of solidarity that embodies an understanding of their situation that is very close to life. In the home, nurses work constantly to preserve the integrity of the very ill. Again and again they sew up the holes that non sensitive health care practices make in their garment. Nursing is indeed the garment of the very ill.

Nursing the very ill in the home involves skilled practices. Yet the complexity of nursing in the home often goes unnoticed. In the home the skilled nurse shows herself as the very ill's partner par eminence. Through the skilled nurse nursing shows itself as the most suitable home for the very ill. In nursing, the very ill are *at* home. Nursing and the very ill are home to one another.

I cannot finish without saying a few words on la *extraña* (the stranger). In Saramago's novel, once death begins to show up in the city, others look at her like an extraña. Even though outwardly she looks like others, meeting death feels to the greeter like meeting a stranger. Just like in this novel, in daily life death too evokes alterity, that which is unrecognizable before our eyes.

The situation of the very ill here and in the developing world evokes the alterity of the stranger. In their suffering corporeality the very ill too share the embodied suffering of those in exteriority, the poor and the marginalised of the world. In our contemporary world, we too tend to flee away from the stranger.

Both the stranger and the very ill pose upon us an ethical claim that wants to be heard. The struggle of the stranger is not unlike the struggle of the very ill. Their experiences reveal to us a deeply genuine and strong human desire to *exist*. Nursing understands the pain and the sweat of this labour and goes there.

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> *The world, in the full sense of the word, is not an object, for though it has an envelope of objective and determinate attributes, it has also fissures and gaps into which subjectivities slip and lodge themselves, or rather which are those subjectivities themselves (Merleau-Ponty, 1962, p. 333).*

BEGINNINGS

Understanding the experience of the very ill and nursing practices in the home has been a breath giving venture, animating, vigorous. It has meant entering a world where being reveals itself in its rawness, where our lived corporeality and our entire humanity express themselves in their fullness. In entering this world I came to experience anew the heartbeat of nursing. Through her very proximate relation with the very ill, nursing reveals elements of both the experience of the very ill and nursing that otherwise remain concealed to our eyes.

In trying to find an englobing way to comprehend the complexity of this world, I experienced the need to situate myself in the world of nursing as the place where the very ill can find themselves a home. I still remain overwhelmed by the explicit and tacit experiences ever present in this world and so integral to its very being. Situating the study in the world of nursing infused the study with vigour and was integral to its coming to fruition. Understanding the nursing world was a venture of primordial priority in trying to understand the experience of the very ill in the home.

In the home, nurses both attend to the complexity of the situation of the very ill and sustain to the best of their abilities their very subsistence. This has been the main path of this inquiry, going to the homes of the very ill, ringing the bell, entering the home, taking the shoes off, sitting in the living room, gathering around the kitchen table, following a nurse wherever she goes, being present to life as it reveals itself in the home and in the lives of so many unique individuals.

Below, I offer descriptions of nursing moments that emerged throughout the study as a way to show the path of nursing. Cameron (2004) writes of nursing moments as ethical moments that call for an ethical response. The concreteness of our life experiences, Cameron writes, expresses itself in these moments. While apparently of little significance such as asking "How are you?," Cameron remarks, these moments evoke a situated understanding that is integral to ethical nursing and health care practices. As the primary element of nursing practices, these moments were most integral to the being of this study.

First, I include a day with the palliative home care nurses as I follow them throughout their day. I begin with Claire who takes me to visit April, one of her own patients. Both Claire and April invite us to situate ourselves in the complex lifeworld of nursing and the very ill as we go through the roads to then enter

April's home. Following this, I initiate a conversation about the garment of the home as I describe two nursing situations following Alexa, another home care nurse. As she enters the homes of Jim and Magdalena's, Alexa shows how nurses are able to quickly make themselves at home in people's homes. Through her visits, she also takes us to the inside and often invisible world of the home where unique elements of the experience of the very ill reveal conceal themselves.

In the third section, I focus on the home and present my own vivencias of home as I myself experience a change of homes in moving to Canada. Revisiting my stories of home is a way to situate my own understandings as I undertake this work. In the last section, I describe my encounter with the Latin American world as I begin to visit my own country and take a piece of this work home. Finally, I present the story of Don Pedro, a palliative patient in Chile whose experience takes us to engage directly with the realities of the developing world. Don Pedro embodies both the drama of the very ill and the solidarity of the peoples in the midst of poverty in Latin America. I conclude this chapter presenting the question of nursing and the very ill as the primary question of this inquiry followed by a short section where I describe the structure of this dissertation.

A GLIMPSE INTO THE NURSING WORLD

> *Situating ourselves in the nursing lifeworld, where the daily lived drama of nursing takes place, calls us to accountability in a profound and ethical way. In these situations the ethical moment often catches us unawares. (Cameron, 2004, p. 55)*

Today, I am with Claire. She is a home care nurse who has been with the palliative home care team for quite a few years. I wait while she makes a few phone calls. She needs to reply to phone messages, call a family physician to discuss an increase in the pain medication of one of her patients, phone the lab to arrange for them to go to a patient's home to take blood tests, and phone some of her patients. I see this is very much the way nurses begin their days: retrieving phone messages, making phone calls to follow up on things that are in the process of being resolved from the day before, attending to situations that come up during the night, planning their visits for the day and for the next few days, answering their pagers, thinking through their patients' situations. Their nursing life is a continuous dialogue with others. So many things they attend at once that I get lost. And yet so very rooted in the moment they are.

Each nurse has her own desk with a phone separated from the other ones by a divider. This space greatly facilitates their nursing work. One can hear many phones ringing at once and many nurses speaking at once, and yet each attending to a very particular situation, immersed in somebody's unique world. Their concentration is high, apparently undisturbed by the parallel conversations that go on as they talk. 'Hi Mr Smith, how are you? This is your nurse from home care...' 'Hi Paul,' I hear another one, 'yes I can come at 1.00, that's Ok.' 'Hello Mrs

Chang, how are you? I just talked with your doctor…' I hear their voices, soothing, calming, reassuring. I sense their attentive engagement with their patients. It is indeed a conglomeration of parallel worlds. I see them furtively passing from one to the other and engaging with their patients in the concrete moment they face today.

'Anna,' Claire says, 'I am going to phone April and let her know I am coming with you. She likes to get up early so I know it's ok to phone her now.' 'Ok,' I say. Claire dials April's number. 'Hello, April? Hi April, it's Claire here, how are you? Good, I'm glad, did you go to the cancer clinic yesterday? Ok, I see, so they said now you will be mainly seeing your family physician? That's ok, I know that if he thinks you should see your oncologist, he will contact them. That will be ok. April, I am just finishing a few things here and then I will be on my way. I have a nurse from Chile with me today, her name is Anna. She is studying here at the university, would it be ok to bring her with me? Ok, thanks April. See you soon.'

'April says it's ok to come with you so that's good,' Claire says, 'let's go for coffee now and then we go.' 'Coffee time! Coffee time!' One of the nurses says calling the others. They summon each other to the table. They get their mugs and begin to walk to the staff lounge. 'Oh yes,' Alexa says, 'let's go for coffee, I need a break, I can't get John to hear me, he just won't take his laxatives, and now, of course, he is constipated, and needs an enema. It is hard to make him understand that unless he takes the laxatives he will end up constipated because of his medication. He hates these laxatives. I don't blame him, who really likes them? But they are better than having an enema every four days. Anyway, I think for now I better go for coffee.' I sense Alexa's concern as she speaks. John's situation really worries her. Palliative nurses know constipation can be a serious problem because opioids are so constipating. Yet they also know that taking or not the laxatives is their patient's own choice. But they don't give up. They work hard to find a middle point between what they know is best and what the patient wants to do.

There are two tables in the lounge, one larger than the other. This is a very bright L-shaped room with large windows facing east and south. On one corner, there is a fridge with a microwave on top of it, a counter with a sink, a large cupboard, and a dishwasher. A coffee-maker is already at work on the other side of the sink. A tiny kitchen to serve the needs of the home care staff. There is a locked door to come in from the hallway and a door that communicates with the teams' working areas, first palliative care and then long-term care. Doors that take us to the outside world and doors that take us to the health care world; an inside world that in many ways already holds the space of the home. '4-3-8-2,' is the keypad code, the team coordinator informs me as I enter this world for the first time. She gives me the key to freely enter this world.

I help myself with coffee and join the nurses sitting at the table. Slowly the whole team gathers around the table. Some will miss coffee today because they are already on visits or because their day is too busy. Yet most of them try to come. 'I really hate missing coffee,' one says to me, 'this is the only time of the day where we can talk and also help each other when we are having a hard time. Even when we are very busy, we always try to come even for a little while.' Coffee time is one of the most important times of the day for the team. The table is looking full. They talk to one another about an infinity of things. Here I hear a few talking about the latest news in the paper, there one nurse is telling the story of a frail lady living by herself who doesn't like the idea of moving to a hospice. On that corner, a few engage in a crossword puzzle.

A team member with a long sheet in her hands says they need to dish out a few visits. They volunteer. 'I can take Roberts,' says one, 'I met him already a few weeks ago.' 'And I can do Mills,' says another one, 'it is not too far from my area.' 'I got a full day,' says another, 'so I don't think I can take on extra visits.' After these visits and phone calls are arranged, they resume their conversations. Some stories draw everybody's attention. Some are hilarious and make everybody laugh. They laugh in unison, like a choir. They deal with extreme situations here. Laughter brings them back to the everydayness of life. They breathe out the tensions.

Claire is worried about one of her patients as she is not doing very well and is most of the day on her own. She lives with her daughter who looks after her after work. She does have a personal care attendant (PCA) coming to her home for a couple of hours a day.[1] Claire thinks she will likely need to move to a hospice soon. 'I don't think she really wants to leave her home and her daughter by herself,' Claire says, 'so it will not be easy to address this. Her daughter is only 19. Her husband left when her daughter was about three or four.' I sense Claire's concern for this woman. This situation evokes an ethical tension that grabs the nurse's attention. As her palliative nurse, Claire feels ethically implicated and knows the time to discuss this is coming. Yet she also knows how hard this conversation will be for this woman. Claire and the team will work hard to keep her at home for as long as possible. But they know that without family support she will need to be admitted to a palliative care facility soon.

On the Road: Sitting in the Co-pilot's Seat

After coffee, we rush to Claire's desk, get our coats, the client service records (CSR) of the patients she will visit today, and the nursing blue bag. Claire quickly checks her voice mail and we go. First, we go to the top floor to get extra supplies. Coming off the elevators, there is a reception desk with two operators who receive the phone calls to this office. I follow Claire to the left where the supplies room is located. Claire asks Louise, the supplies person, for a package of dressings for a week, tape, and a barrier cream. The supplies room is a large room with a great

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[1] Personal care attendants are home workers who assist people in their homes with their basic needs. In palliative home care, nurses can put in PCA services when necessary. PCA services are contracted by Capital Health.

variety of supplies, from tiny medication cups, syringes, and alcohol swabs to dressing trays and the most incredible kinds of dressings, catheters, tubings, and much more. Louise knows this space by heart as she quickly finds everything. Claire introduces us and she tells me of a Chilean dish she loves. I am met with hospitality wherever I go.

We take the elevator and go down to the parking level. It is underground parking so we need to watch our heads while we walk. A sign that reads "HOME CARE RESERVED PARKING" hangs on the walls of several parking places. 'I apologize that my car is so messy,' Claire says. Later on, I realize that all home care nurses who take me on their visits apologize for their cars being messy. They carry all kinds of stuff in their cars, their briefcase and work cell phone, nursing supplies, books, coffee mugs, snacks, etc. Their car is like a portable room that nurses carry back and forth every day. Their trunk is never empty. They load it with plastic containers holding a variety of things including gloves, saline solutions, fleet enemas, catheters, dressings, blue sheets, tubings, trays, diapers, and more. The trunk is a supply nursing room in full.

Nurses have their areas divided according to postal codes. Each nurse has about 10 to 18 patients at a time. They follow them up from the time of their admission to the palliative home care programme until their death or discharge to another setting. Claire goes to the north side of the city. 'It is very far, but I love it,' she says, 'I enjoy the landscape, the sun, the birds, nature. Driving around this area makes me feel renewed, rejuvenated, with new energies to engage with my families.' It is fall and the tree leaves are turning yellow and red. Trees with red leaves accompany us along the road. As we move towards the north I sense the horizon expanding and the city slowly receding behind us.

A loud and acute beep suddenly interrupts our conversation. 'They are paging me from the office,' she says looking at her pager. 'Would you mind passing me the cell phone that is on the back seat?' I give her the phone and she phones the office right away. 'Hi, this is Claire, you paged me... Yes, ok, she wants me to give her a call? ... Ok, sure, I'll give her a call in a few minutes, thanks, bye.' She hangs up and tells me it is a patient who needs to talk to her. She says she will phone as soon as we are off the highway. The road is quite busy here and I don't want to distract Claire while she drives. Yet she seems quite at ease driving and talking. Still, I keep an eye on the road all the time. It isn't easy to be in the co-pilot's seat, seeing everything with a pilot's eyes but the co-pilot's perspective. I wonder if this is what I will feel like throughout the study.

April

'April is about 46 years old,' Claire tells me while driving to her home. 'I have been seeing her for a few months. She was diagnosed with inoperable lung cancer last November. She did have radiation and has had chemotherapy treatments as well. She is now doing very well and I don't come to see her every week. I try not to come when she does not need me because I know that I am a reminder of her illness. Yet I also want her to know that I am here, so I come and see her as often as necessary. She is very independent and manages her illness very well. She leaves me phone messages like this: 'I am doing ok, my pain is about 2 to 3 and I am taking about 2 breakthroughs a day,[2] I am having bowel movements everyday, sleeping ok, and I am seeing the doctor next week.' She really gives very good reports. And she knows it.'

'I know she is exceeding the average time of patients in the programme, but I don't think it would be appropriate to discharge her to long term care. She is on methadone and has experienced severe crises in the last few months. She was in the process of being switched from morphine to hydromorphone when all of a sudden she had these awful cramps and pain. It was terrible to see her like that. And her husband was in such distress, thinking that she was going to die that moment. We phoned the regional team[3] and the regional nurse realized that her dose of hydromorphone was too small compared to the previous morphine dose. Eventually her pain and everything improved after taking the readjusted dose. She was then switched to methadone as her pain didn't respond well to hydromorphone either.'

As we approach April's house, at the very edge of the city, we see vast open fields turning yellow. 'Look at those beautiful birds!' Claire says, 'they are Canada Geese.' She slows down her car and opens the window, 'sometimes you can hear them singing.' We stay quiet for a few minutes hearing their chant, looking at their flight. It is a long way to April's house. The distance seems a necessary pause to get ready for April, her home, her situation. I feel like a pilgrim on her way towards a shrine. I am indeed a pilgrim here, a *peregrīnus*, a foreigner away from home (Skeat, 1963).

Entering April's Home

'We are almost there,' Claire says. From heading east, we turn right, then shortly after we turn left and after a few metres another left turn. April's alleyway is covered with yellow red leaves. A tiny blue house stands alone at the end of a field. As we approach the house, two dogs come close to the car. 'These are their dogs,' she says, 'they are very friendly so don't worry about them.' We get out of the car and pat the playful dogs. 'That one loves to be patted,' says April smiling. She has come out to greet us. 'Hi Claire!' April says. 'Hi April! How are you?' Claire says, 'this is Anna, the nurse from Chile I told you about on the phone. She is doing a study with us and she is with me today.' 'Hi Anna, nice to meet you,'

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[2] A breakthrough is an extra dose of pain medication in between doses scheduled around the clock. The breakthrough dose is about 5 to 20 percent of the total daily dose (Pereira et al., 2001, p. 17).

[3] The regional team is a team of nurses and physicians who act as palliative care consultants in the community. Family physicians can refer their palliative patients to this team when their symptoms are difficult to treat.

April says. 'Hi April, nice to meet you too,' I respond. 'Please come in,' she says. We follow her to the back door.

We enter her home and take our shoes off at the bottom of the stairs to the kitchen. Taking the shoes off to enter a home feels like a sign of reverence before holy ground. It is a gesture of respect for the vulnerability of the home. Our shoes carry fragments of the world and as I take them off, I have a sense I am leaving the outside world behind. Nurses know that keeping the shoes on is a recommended safety measure. Yet they also know that doing this may disrupt their relation with the patient and family in the home. I see they carry a clean pair of shoes to put them on when they enter a home. They work hard to find a balance between work demands and the implicit rules of the hospitality of the home.

We follow April upstairs to the kitchen. Claire moves with ease here. I can tell she knows April's home well. April invites us to sit around the kitchen table. Claire sits across April and I sit at the head. A light brown cat sleeps on the kitchen floor. April tells us that she has five cats and two dogs. I see a cat toy hanging close to one of the windows. Through a tiny window above one of the counters, I can see the landscape that surrounds her house. I feel a strange sense of familiarity in this home, a kind of intimacy that April's kitchen evokes. April has just brewed coffee and offers us a cup. 'Sure,' we say. She grabs two coffee mugs, milk, a sugar bowl, spoons, and napkins, and brings everything to the table. Her own coffee mug is already on the table.

'How are you April?' Claire says. 'I am ok,' she says, 'I have been doing ok these days. I am going to get the blue binder for you.' April leaves the table and starts looking for the blue binder.[4] I see her going back and forth as she searches for it. She goes in and out of her bedroom, the living room, another room, then she comes back to the kitchen. 'I can't believe I can't find it,' she says, 'I always leave it here but it isn't here today and I just can't remember where I put it.' She goes back to the rooms in another effort to find it. She is about to give up when her husband who is home after working a night shift joins her in her search. They find it in the closet of April's bedroom. She comes back with a big smile and gives the binder to Claire. 'I knew I had put it somewhere, but just couldn't remember where it was.'

Watching April going here and there, trying to find the blue binder makes me wonder what this shows about April's experience. Is her forgetting of the blue binder a forgetting of her own illness, a leaving of the world of illness momentarily aside that enables her to go on with life? The blue binder hides itself from April's awareness as she occupies herself in other matters. She has no need to be reminded of her illness through this blue binder. Yet the nurse's presence evokes its existence at the same time as she evokes April's illness. The nurse calls

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[4] The blue binder is the home care chart that is kept in the home.

to the fore a side of April's being that tends to conceal itself from people's awareness. She brings it into our midst.

Claire opens the blue binder, goes to the nursing flow sheet, and begins asking a few questions. 'How has the pain been April?' Claire asks. 'It's been ok,' April says, 'it starts hurting when I use my arm too much.' 'April's lung cancer is in her left lung. Her tumour is about 12 cm big,' Claire says looking at me, 'it has spread locally, infiltrating the surrounding tissues including her left underarm.' 'I don't feel my left underarm at all,' April says. 'That is probably because of nerve compression,' Claire says. 'I know I need to readjust what I can do now with my arm so I can control better the pain,' April says, 'I usually take a breakthrough before doing things where I will use my arm a lot.' 'April is very knowledgeable about pain control. She really went through hell when she had that terrible pain crisis,' Claire says, 'and she definitely does not want to go through it again.' April tells us she will not forget the day she had to have an enema because of her constipation and how difficult this was for her. 'I really don't want to be in troubles,' April says, 'and if there is anything I can do to avoid them, I will go for it.'

'Have you been to the lake lately?' Claire asks April. 'We were there for the long weekend and we had a very good time,' April replies. 'It must be so beautiful over there,' Claire says. 'This is another reason why April works hard to keep things well,' Claire says, 'she and Mark, her husband, enjoy a lot going out to the lake.' It is nice to see how knowledgeable April is and how she truly likes to be on top of things in matters of symptoms. Being symptom-free enables her to engage in other life activities. April claims ownership of her situation. She is quite interested in learning about her illness and very pro-active in preventing things. She is able to do this because there is a nurse who accompanies her through her experience.

Claire asks April a number of questions following the nursing flow sheet. April watches her with expectant attention as she writes down her answers. 'How much methadone are you taking now April?' – '24 mg three times a day and 8 mg for breakthroughs' – 'How many breakthroughs are you taking?' – 'Between two and three a day' – 'Have you seen your family doctor lately?' – 'I saw him last week' – 'Ok. How is your drinking?' – 'It's ok, I am drinking between 6 to 8 glasses a day' – 'That's good. Can I see your tongue?' – April sticks her tongue out – 'It looks really good, and your appetite?' – 'Not very good. But I am trying to eat well, at least one good meal a day' – 'Ok, are you having any shortness of breath?' – 'Not actually' – 'And any cough?' – 'No' – 'Are you having any troubles to void?' – 'No' – 'And are your bowels moving ok?' – 'Once a day and if not I will increase my laxatives' – 'How many are you taking now?' – 'Two in the morning and two in the evening and it is working well' – 'Ok.'

Claire moves now to the ESAS[5] graph sheet and asks April about each symptom. April already knows this sheet and gives her answers right away. Pain she says between a two and a three; appetite, a four or a five, and for the rest a zero or a one. 'Thanks April,' Claire says, 'we are done with this. Have you been to the cancer clinic lately?' 'I went there about two weeks ago,' April says, 'they told me that from now on I should only go to my family physician. The doctor said that there aren't any other treatments that they can offer me at this time as my cancer has stabilized. I consented to participate in a study about a vaccine, although I am part of the observation group only so I am not receiving it. But I still have to go every 6 weeks or so to have some tests done. I think it is good to at least have the tests done so I know how the tumour is doing.'

April gets a bit teary as she tells us about being discharged from the cancer clinic. She knows she is not on her own as she is with the palliative home care programme. She also sees her family physician quite regularly. Yet knowing that she is not eligible for further cancer treatments makes her feel like coming to a dead end. She does find a way to avoid this no exit road by consenting to participate in a research trial. This way she knows she will be able to keep going to the cancer clinic, see an oncologist, and have the tests done. This re-encourages her. Claire also assures her that her family physician will refer her back to the clinic should the need arise. Neither of them can stay with the thought of the dead end in mind. It suffocates life.

'I have always wanted to have a farm with lots of chickens,' Claire says, 'I always say to April that her place is not yet a farm until she has chickens, but she says that chickens are too much work. If I had a farm, I would also love having a little tea house where people can stop and have some tea and talk. How is the donkey April? I would really like to see him next time we come.' 'He is alright,' she says, 'our neighbour comes to feed him everyday. Next time you come, I'll take you to the barn.' 'There is a barn outside April's house where they keep two horses and a donkey,' Claire tells me. She is very excited about seeing the donkey and promises April that next time she will come very early so they can go to see the donkey. Claire leaves the world of illness and enters April's daily world where horses, donkeys, dogs, cats, and more are a daily preoccupation. Just as quickly as she brings us back to the world of illness, she is also able to take us away from it. She knows this is where April wants to be.

Our meeting comes to an end and we get ready to leave. We have been here about an hour and a half already. We are very close to lunch time. We thank April for her time and especially for letting me come in with Claire. She asks me about the study and says she would be interested in participating so I leave with her the

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[5] Edmonton Symptom Assessment Scale (Bruera, Kuehn, Miller et al., 1991). This is a symptom scale that health care professionals in the Edmonton Regional Palliative Care Programme employ to assess a number of symptoms including pain, activity, nausea, depression, anxiety, drowsiness, appetite, well-being, and shortness of breath. The ESAS assessment on each home visit is required according to programme guidelines.

information sheet about the study. I hesitate a bit as she has told us she is participating in a clinical trial at the cancer clinic. I share this concern with Claire after the visit. Claire assures me that if she really doesn't want to do it, she will say so. I stay with Claire's judgement as she knows April well. There is an ethical concern here as the very ill can so easily be overburdened. Yet I also know that the nurses will be the first to voice their concerns if they see the research is burdening their patients. In a way, engaging closely with the nurses safeguards the ethical integrity of the study. They watch us closely.

April comes to the door to say good bye. The dogs also join her, playfully demanding attention. 'See you soon April!' Claire shouts, 'I really want to see that donkey! I will give you a call before our next visit, bye bye.' Claire gets the car started and off we go to our next visit. 'I am very fond of April,' she tells me while driving. 'It will be very hard when she goes. Did you notice she got very teary when she was talking about the cancer clinic? Her tone was a bit like, 'and now what?' Feeling a bit abandoned I think. I can see why she would enrol in this vaccine study. It is her way of keeping them involved. She won't let them go easily.'

'I can see you have a very close relation with April,' I say, 'I enjoyed hearing you two talking about the barn and the lake and your dreams to have a farm. She engages with you very attentively.' 'I feel very close to her,' Claire says, 'and I enjoy coming to visit her. She has gone through a lot of things in her life and she is a very mature person. I also like talking about other things with my patients, not only their illness. It helps me understand their world better and their decisions. April is a very active woman. She was working full-time before her illness. She is very independent and needs to keep her independence. She is very strong. I know that April's two's for pain are not the same as the two's of other patients. When she says her pain is about two, she is having a lot of pain. Yet she decides when it is time to go for a breakthrough. And I will always respect her way of handling these things. When things are looked at from the outside, the picture is very different than when you are inside. This is their home and we are guests.'

I feel privileged to be able to enter patients' homes and be present to their experience during this time. I know I am able to do this thanks to the nurses who bring me along on their home visits. In their homes, the nursing world comes to life; the being of the nurse comes forth. As I enter this nursing world, I see myself entering the world of the very ill. These two worlds are inextricably united, one being the underside of the other. One leads to the other. As the day goes on, we continue to move in parallel worlds as we leave one home to go to another. I am glad the roads give us a brief pause between visits. In the car, we vent, make a phone call, answer a page, or simply tell a joke and laugh. We gather strength to engage yet with another world where nursing and the very ill meet one another. In the car, we gather ourselves again and move on.

TAKING ON THE GARMENT OF THE HOME

As I follow the nurses on their home visits, I am amused by their ease of movement in patients' homes. While each nurse has her unique way of being in the home, their manner in the home reveals a very embodied relation with the home that is common to them. Just as they have the ability to enter people's homes and sense what's going on in the home very quickly, they also have the ability to make themselves at home in a matter of moments. Van Lennep (1987a) writes that when we enter a room we take on the room as our garment. We never inhabit space in the mode of anonymity, he writes, but in degrees and forms of intimacy. As I see nurses entering the home home, I notice they put on the home like a garment.

Etymologically, palliative and garment are related. Palliative means to cloak, to cover and garment is related to robe, to protect. Garment is also related to garnish meaning to defend oneself, to fortify, and warning in the sense of guarding against, foresight, care (Skeat, 1963). Nurses enact these meanings as they engage with their patients in the home. They know the garment of the home protects our being; it defends us from the storms of life (Bachelard, 1958). They know how fortifying it is for patients to be in their own homes. They also understand the warning side of the garment of the home. There is a sense of being cautious, careful, watchful in entering a home. Mindful of these meanings, nurses put on the garment of the home and engage with their patients in a home-like manner.

Alexa Jim Magdalena

Jim is a man whom Alexa visits everyday to change his dressing. He is about 70 years old, a tall and skinny man. He has cancer of the larynx locally metastasized. Alexa tells me he is very much on his own. He has a son but he is not very close to him. Jim lives in an apartment building downtown. It is about 10.00 in the morning when we go to his home. Alexa parks her car, we get the nursing blue bag from the trunk, and go into the building. Inside the blue bag there is almost everything one can imagine: dressings, saline, catheters, a blood pressure cuff, a stethoscope, alcohol swabs, antiseptic solution, scissors, blank records, pens, a flash light, a thermometer, everything. Alexa's is a bit heavy. I volunteer to carry it upstairs and she takes Jim's records. She puts other people's records in the trunk so that they are not visible. I notice that nurses are always very careful about protecting the privacy of their patients. 'Ok,' Alexa says, 'everything is covered, let's go!'

'That's Jim's building,' Alexa says pointing to one of the buildings across the street. I enjoy her manner of speaking about her patients. She knows them by heart. We cross the street, go up a few stairs, and buzz in. '*Hello?*' We hear a low and hoarse voice through the speaker. 'Hi Jim, it's Alexa here.' The door opens and we go in. 'He smokes a lot,' she tells me on the elevator, 'and he complains all the time about this pain in his heel where his wound is, and I am sure it is a circulation problem. But he won't ever quit smoking, and he won't rest his leg as he needs. Anyway, he does what he wants.' I think to myself that this is one of the advantages of being at home, to do as one pleases. After all, we all do this and pay no heed to the warnings of our bodies. I see home care nurses often bear the consequences of our lack of attention to our own health. And yet nurses are so respectful of each person's right to make choices; they respect ownership: home ownership but also ownership of their own experience of health.

We reach the 5th floor, get off the elevator and turn left. The door is unlocked, Alexa opens it and we go in. I can tell Jim and Alexa already know each other. There is no need for locks here. 'Hi Jim, how are you?' Alexa says. 'Hi, come in,' Jim says. He is standing by the kitchen with a cigarette in his hand. Entering his home feels like entering a cloud of cigarette smoke. It isn't easy to breathe in here. The radio is on and Jim turns the volume slightly down. 'This is Anna, Jim,' Alexa says, 'she is the nurse I told you about this morning. She is from Chile.' 'Hi Anna,' he says. 'Hi Jim, nice to meet you,' I respond. Jim sits on the couch with a cigarette in his hand and begins to take his socks off. A used ashtray sits on the coffee table, waiting for more cigarette buts. I sit on a chair close to Jim.

The place is bright and sunny. I can see other apartment buildings through the balcony doors. 'I am going to wash my hands and will be right back,' Alexa says while going to the bathroom. I hear the tap running. She moves with ease in Jim's place. Her pace is fast and yet unhurried. The intentionality and directionality of her movements is quite amazing. She knows where things are and gets them quickly. She knows well the garment of Jim's home. She puts it on with ease.

Jim has a bag of dressing supplies in the kitchen and Alexa pulls it out from a drawer. The centre of the living room now looks like a nursing room. In a few minutes, Alexa has built her own nursing space to change Jim's dressing. One of the ends of the coffee table resembles a nursing tray. It holds gloves, sterile dressings, saline bottles, scissors, bandages, and a tube of cream. Everything is on top of a clean towel that Alexa put on this side of the table. 'Ok Jim, I am ready to do your dressing, how is the pain now?' She asks him while removing the bandages. 'Sometimes it hurts a lot, especially when I walk or stand too long,' he says, fumes of smoke come to Alexa's face as he speaks. There is no protection for Alexa here as she has no way of avoiding this toxic air. The garment of this home envelops her with both its safe and perilous sides.

'Have you been resting your foot during the day?' Alexa asks. 'Oh yeah, but I get tired,' Jim says. Alexa is kneeling on the carpet while changing the dressing, her own body quite close to Jim's foot. I see how nursing is an embodied relationality; in nursing we can never elude the body. 'Your wounds are getting smaller Jim,' Alexa says. The wounds on his right heel are deep, a mix of grey and yellow tissue. She irrigates them with saline, applies cream to the surrounding area, covers the wound with a dressing, and puts on a gauze bandage to hold the dressing. After finishing the dressing, she asks Jim to stand up to take care of a small wound on his coccyx. He gets up and pulls his pants down. The skinniness of his body stands out. His skin follows the contour of his bones, his abdomen is hollow. Alexa changes the dressing quickly. They talk about the latest news and laugh, *almost* forgetful of what they are doing.

Once she is done with the dressings, Alexa sits down and talks a little more with him. She knows this is one of the few times that Jim will talk to another person today. She stays a little longer even though cigarette smoke fills the room. They are both quite engaged in the conversation. 'We are ready to go, Jim,' Alexa says. She stands up, cleans up the table, throws the garbage away, and puts the supplies back in the kitchen. 'See you tomorrow then. Are you ok for the day?' She says. 'I am ok,' he says, 'hope my heel won't be too bad today.' 'Try to rest it a bit,' Alexa says. I say thank you to Jim for letting me come in with Alexa, we gather our nursing stuff and go. Jim stays on the couch, his foot on top of a stool and a cigarette in his hand.

'You know,' Alexa says on our way out, 'I have tried to cut down the visits to every other day but it won't work. He calls the office and says he needs a nurse because his dressing came off. He won't take care of his wounds. I think he also likes the visiting time as he is so lonely. He really doesn't have many people around and when we come, he can talk for a bit.' Jim's loneliness is difficult for the nurses. There are few supports other than the home care team to make his stay easier in the home. Here we see another side of this garment, the one closer to warning perhaps. The fortress that protects us in life can also isolate us from the exterior world. It can trap us in.

The loneliness of people like Jim strikes me as I follow Alexa and other home care nurses. Where are Jim's neighbours, family, friends? Yet I need to be cautious here as what in my Latin American eyes strikes me as loneliness can have another side, people's own privacy. Taylor (2004) writes of the high value of the private sphere in the modern West that grew partly out of the emphasis on family life. Keeping privacy in mind is important in trying to understand Jim's loneliness. How privacy hinges on loneliness here is not easy to discern. While in daily life we enjoy the comfort of retreating to our private lairs, withdrawing from the worldly noise, in severe illness, privacy closer to its originary meaning, can leave us bereft, "sundered from the rest" (Skeat, 1963). The privacy of the home can turn back on itself shutting us in at times of need. I sense my own cultural perspective surfacing here as I try to make sense of the alone-ness of the very ill.

Magdalena

After visiting Jim, we go to see Magdalena. 'She is a very nice lady,' Alexa says, 'she is from Europe but has lived in Canada for over thirty years. She has two sons but she lives on her own. One son lives in Red Deer and the other one is in town. The one in the city is very close to her.' It takes about five minutes from

Jim's place to Magdalena's. As we drive, I experience once again the nurse's passing from world to world. These parallel worlds hold such entirely distinctive personal situations and yet so existentially alike. The nurse's life seems to be an ongoing shifting of garments as she enters and leaves the homes, and yet she carries them all in her clothes.

We get out, open the trunk, get the blue bag and go into Magdalena's building. Alexa buzzes in and she lets us in right away. Her apartment is on the 7th floor. Alexa knocks on the door but we go in right away as the door is unlocked. Magdalena is standing by the door and greets us with smiling shiny eyes. She is in a red housecoat. 'Hi Magdalena, how are you?' Alexa says. 'Hi Alexa, it is nice to see you,' she responds in a very friendly tone. 'This is Anna, she is the nurse from Chile I told you about this morning.' 'Hi Anna, welcome here,' she says. 'Hi, thank you, nice to meet you,' I say. The kitchen is on our left side and the aroma of freshly brewed coffee reaches my nose in an instant. We take our shoes off and go in. I notice that nurses wear shoes that are very easy to take off. Mine have laces and it takes a while to take them off and put them back on. They think of every detail that can make their entry to the home easier, even their shoes!

'Coffee is ready,' Magdalena says, 'would you like a cup, Anna?' 'Sure,' I say. 'Magdalena knows that I love her coffee and she always brews dark coffee when I come,' Alexa says. 'Yeah, I don't drink coffee anymore, it doesn't appeal to me now,' Magdalena says, 'but I always like making it for Alexa. She is the only one who likes coffee,' Magdalena says while grabbing two cups from the cupboard. She invites us to help ourselves and goes to sit in the living room. We pour coffee in our cups and follow her. She offers us the hospitality of her home. Her coffee is an invitation to make ourselves at home in her home.

The living room is very bright and spacious. I can see the North Saskatchewan river through her windows. The view is gorgeous. Magdalena limps as she walks to the couch. She sits on one end with her left leg on top of it. Alexa sits on the other end and I sit on a chair close to Magdalena. 'I apologize Anna for sitting this way,' Magdalena says, 'but my leg is so sore, I can't stand it another way.' 'Please don't worry about it,' I say. Even though she knows we both are nurses and understand her situation, Magdalena apologizes for her manner of sitting. Even in pain and suffering, she continues to be the hostess in the home. The hospitality of the home weighs on her.

Alexa asks Magdalena how she is doing and she says the pain in her leg has been bothering her quite a bit. 'The doctors want me to have an MRI of the sore spot before they decide on the treatment so I am waiting to have it done,' Magdalena says, 'at the cancer clinic, they said I can have it in *two* months. They said they will call me if they have a cancellation.' 'Did the doctor from the regional team come to see you?' Alexa asks. 'Yes, she did, she was very nice,' she says, 'they are not sure about what's causing the pain and the swelling in my leg. Look Anna, can you see?' She pulls down her pants and shows us her swollen left thigh. She has no need to apologize for undressing before her guests. These guests are nurses. Indeed, Alexa is her *own* nurse.

'The regional doctor thought it might be a little fracture but it was hard to tell without the MRI,' Magdalena says, 'so I really need it urgently, but can you believe I have to wait two months to have it done?' 'Yeah,' says Alexa, 'I also phoned the cancer clinic and they were sorry to say they don't have any earlier opening, but they assured us they will call if they have one.' 'It is too bad I have to wait,' says Magdalena, 'because this waiting time is miserable time for me. I'm just sitting here, waiting and waiting till I get the results, till they can do something.' 'The thing is that they don't really know what's wrong with it,' says Alexa, 'and the doctor doesn't think it is cancer.' 'I myself have a sense it isn't cancer,' says Magdalena, 'maybe because I had bone cancer.'

Waiting takes a big part of Magdalena's life these days. She waits for the doctors to find out what's causing the pain in her leg. She waits for the cancer clinic to hopefully give her a call with an earlier booking. She waits for her pain to go. She waits until she is able to walk without pain, to sleep without pain, to go to the bathroom without pain, to live without pain. Pain overcomes her existence. This waiting is overwhelming, she tells us, especially not knowing what it is. Day and night she waits. This waiting is exhausting. Her pain increases when she moves and this makes it difficult to treat it as her pain needs can vary greatly depending upon her degree of movement.

'The hard thing is that she is spending a lot of time in bed now,' says Alexa. 'Yeah, I need to rest quite a bit because I get so tired and I can't move so easily,' Magdalena says, 'I always say to my friends, please don't phone me between noon and four. At noon, I am usually exhausted and I need to have a nap. I sleep for about two hours. And this is not how I used to be. People who know me, they know I would always be standing in the kitchen, cooking, making borscht or whatever. I was always cooking and giving lots away, to my neighbours. It is what I have enjoyed all my life. It is part of my living. But now I can no longer do it. I can't even eat.'

'How is your appetite?' Alexa asks gradually introducing her nursing questions, 'Not good, some things give me nausea just to look at them,' Magdalena says. 'The regional nurse who came in said you had a bit of thrush, have you been taking the medication they gave you for it?' Alexa asks. 'Yeah, but not any more, it was very hard to take it,' Magdalena responds, 'I would rinse my mouth with it and then spit it up. They say you can swallow it but there was no way I could.' 'And your bowels, are you having troubles?' Alexa asks. 'I actually went this morning, so it was ok, but some times it is very hard,' Magdalena says. 'Are you taking the laxatives?' Alexa asks. 'Yes, I am,' she says. 'And how are you sleeping?' Alexa asks. 'Sleep is ok,' she responds, 'I wake up early to take those pills, and I take a nap in the afternoons.' A pause follows this short dialogue as Alexa writes down in Magdalena's chart. We watch her in silence.

'Could you put some cream on my back, Alexa?' Magdalena asks. 'Sure,' she says, 'I'll just get ready.' Alexa goes to wash her hands. 'I have a spot on my back, look Anna,' she says taking off her housecoat and pulling down her top. I see a red bump of about 2 cm wide on the upper left side. 'I don't know what it is, but it doesn't bother me too much,' she tells me, 'it is a bit itchy sometimes. Alexa has been taking good care of it. It is so good to have her. Whenever I need her, I call the office and she will be here in an hour. But I try not to call very often.' Alexa comes back and puts cream on the red spot. 'I gave your number to one of my neighbours,' Magdalena tells Alexa, 'she has cancer and would like a nurse to come to her place. She says I am very lucky to have a nurse.' 'That's ok,' says Alexa. 'We are ready to go Magdalena, is there anything else that worries you at the moment?' Alexa asks. 'Just my leg,' Magdalena says, 'I really hope they call me soon.' 'I hope so too,' Alexa says, 'give me a call if you have any problems.' 'I will,' she says. We thank her for coffee and go. It is lunch time.

Pain has introduced a big shift in Magdalena's world. From being quite an active sociable person she is now mostly confined to her bed. Pain and disability are changing her very way of being. She feels demoralized unable to manage her situation. The shift is too dramatic. Her lack of appetite makes it worse as she loves cooking. Alexa encourages her. She tells her to try different things. She says they might call her sooner for her MRI. She helps her to make sense of her experience. They have an easy-going relation. They tell me they met about seven years ago when she had just been diagnosed with bone metastases and was admitted to home care. Alexa was her nurse then too. She was discharged and readmitted to palliative home care only recently.

Cancer is not new to Magdalena, she was diagnosed with breast cancer 16 years ago. She knows about the comings and goings of this illness. She has undergone several treatments throughout these years. Her last chemo treatment was about two years ago. She has been quite sick in the past. But now she feels this sickness overcoming her body; too much to handle at once. Her hopes are now with the MRI. Her waiting is exasperating. Etymologically to wait is to stay awake, to watch (Skeat, 1963). As she waits, Magdalena finds herself in a state of wretchedness. She watches for the slightest change in her pain. She watches her own body as she tries this or that to modify the pain. She is with it, *day in and day out*, as she says. She is forced into this constant state of wakefulness. How much more can she take?

Both Jim and Magdalena are suffering the insidious progression of their cancer and the gradual decline of their bodily strength. Inside their homes, their situation remains invisible to society. This is another side of the garment of the home; it can enclose suffering and hide it away from others. Yet Alexa is able to trespass this threshold of privacy; not in the sense of breaking in or intruding. Rather, trespassing in its originary sense of passing beyond, stretching (Skeat, 1963). Alexa stretches towards the inside world of the home to nursingly engage with their experience. Following Marcel's (1971) notion of experience as "straining towards" (p. 48), Cameron (1998) writes, "Much of our nursing awareness comes from just this straining towards understanding the particular lived moment" (p. 76). Alexa's straining is a decisive nursing act to continue to make their situation in the home liveable.

UNDERSTANDING THE GARMENTS OF HOME

Coming to Canada meant in a sense a change of garments. What I had from Chile was not warm enough for Canadian winter. My friends had warned me that I was coming to the world's freezer. I didn't weigh the consequences at the time. Yet while my exterior garments gradually began to change as I wrapped myself up in thick winter clothes and put on heavy snow boots to adventurously walk outside, there was an interior side of me that clung to my familiar Chilean ones. I felt unable to throw these ones away. I realized that these familiar garments were indeed like my second skin (Young, 1990); they were part of who I am; the Chilean fabric of my being. Not wearing these garments made me feel bereft, strange, other. Putting them aside to wear the northern garments alone felt like renouncing my own self. Slowly I began to take my old familiar garments out of the suitcase.

Striving to regain balance, I needed to find a meeting point where both the old and the new garments could come together. I resisted the thought of having to exchange one for the other. I needed my second skin. Yet I also needed to try on the new garments, learn to wear them and to walk in them, begin to recognize myself in these new clothes, and be able to enjoy the feeling of "freely swinging down the street in happy clothes, on my way" (Young, 1990, p. 178). Just as I worked to find a meeting point with regards to my clothes, I also experienced the need to find a point where the texts of home and the northern ones could meet one another. As I began to intensely engage with the northern texts I missed the texts of home; they too needed to come to the fore.

The etymological relation between text and weaving (Skeat, 1963) shows that texts are woven fabrics that we create and put on like garments. As I tried to understand the text of the very ill, I could not put on the northern garments alone and leave those of home in the drawer. This was like splitting myself off from who I am. Here engaging with the global text of the very ill was a way of integrating these garments as well as showing the need to coexist with a multiplicity of texts rather than one text alone. This global garment was the meeting point for the northern garments and the garments of home to come together.

Understanding the garments of home has meant understanding the place where I am from and my own path through life. It has meant returning to my country concretely and imaginarily and revisiting *vivencias* of home. It was in revisiting this fabric of vivencias that I came to the realization that they are the very garments through which I understand the world. They are indeed "the very condition of my understanding" (Burch, 1991, p. 42). What was it that I missed when I missed these garments? Was it that taken-for-granted sense of familiarity with my own things and my world? My world of relations? That world where I was pre-reflectively able to be myself? Yes all of this did I miss and even more. In truth what I first and foremost missed was this precious garment that sustains me through life, the garment of home.

How is it that we are able to experience home, vivenciar la casa, el hogar as our garment? Etymologically, home means both abode and to dwell (Skeat, 1963). Heidegger (1954/1993) shows this close relation between building and dwelling that the home itself embodies. Originally, to build means to dwell. We build because we are primarily dwellers, Heidegger writes, dwelling is how we are on the earth, it belongs to our very way of being. Yet dwelling is not so much about staying in a place as it is about keeping and preserving the world. "The basic character of dwelling is safeguarding," he writes (p. 352). We safeguard the earth, sky, divinities, and mortals. How does this safeguarding happen? Through building, Heidegger explains, which in preserving this fourfold realizes dwelling.

Is it in this safeguarding quality of the home and dwelling that we come to experience the home as a garment? In going back to the original meaning of home, there is another element that might show another side of this question. This time I have recourse to the Spanish language to examine the roots of home. Hogar, home, from the Latin "focāre," means fogón, fireplace, hearth (García de Diego, 1985). The hearth is the place around which people gather to cook a meal, tell stories, talk about their day, share intimate moments of their lives. The hearth is in many ways like the kitchen of the home, the place where we meet one another, "a place of warmth, sharing and conversation, fostering growth and fulfilling commitments" (Bergum, 1996, p. 6).

There is also another thing that used to go along with the talking around the hearth, weaving. Along with weaving stories, women wove a variety of things elemental for daily living, from personal clothing items to home implements so necessary to sustain the workings of the home. Around the hearth they wove the garments that protected life and the home. They wove containers to carry things home, "Before... the weapon, a late luxurious, superfluous tool; long before the useful knife and ax; right along with the indispensable whacker, grinder, and digger... we made the tool that brings energy home" (Le Guin, 1989a, p. 167). Indigenous women have safeguarded this ancient tradition and through their weaving they safeguard home and life, earth and sky. Day after day, they weave the garments of the home, making themselves at home through their weaving. For them, weaving and dwelling, garment and home, are one.

So in trying to understand the fabric of my garments, I needed to reread my vivencias of home, knowing that it was in their very threads that I would be able to find my mother tongue (Le Guin, 1989b), the language I learned at home and that little by little throughout the years I had learned to unlearn. I wanted to rediscover "what civilization has left out, what culture excludes, what the Dominants call animal, bestial, primitive, undeveloped, unauthentic—what has not been spoken, and when spoken, has not been heard" (Le Guin, 1989c, p. 163). I wanted to find my old (and yet new) robe and be able to put it back on, without shame or fear, and show it to the world.

I rediscovered my grandmother and her bags that I so hated when I was a teenager. I learned about the beauty of having your own bags to carry groceries home, to bring home the ingredients of her homemade meals that we all enjoyed. She carried the flavours, aromas, and tastes of home in her bags. I learned to appreciate dearly my great aunt's knitted bags to cover our hot water bottles. These colourful bags bore warmly the vitality of her aging hands. The creamy tasty soups of my oldest great aunt and her enthusiastic cooking spirits couldn't go amiss in these recollections. Indeed, in gathering vivencias in the kitchens of my grandmother and her two sisters I learned about their great love for life and their nurturing manner of being with others.

I remember those chilly days of our rainy winter in Chile when coming home after school, the first thing we tasted was a warm bowl of my mother's creamy tomato soup. I can see her standing by the stove slowly stirring the soup with a wooden spoon, fumes of steam emerging from the pot. My sister and I often regret not having learned her recipe. But we warmly treasure the unforgettable vivencias of her soup. My mother often took us to visit our aunt Judi, her sister, who lived in marginal barrios. I have fond memories of being in my aunt's home, biking in the neighbourhood, playing in the hills with other children, and eating her delicious tarta pascualina. My aunt's solidarity with the poor has been a profound vivencia in my life. Through her, I also continue to understand hidden threads of my mother's life, so early gone.

REDISCOVERING LATIN AMÉRICA

Revisiting vivencias of home also led me to revisit Latin America and her situation in the current world context. Here, the work of Enrique Dussel, a Latin American liberation philosopher, has been greatly relevant. Dussel (1996) writes that the being of Latin America "lies outside history" (p. 77). Modernity, he argues, has dismissed the Latin American lifeworld as immature, undeveloped, and primitive, confining this entire region, together with most of Africa and Asia, to the periphery of the world. The exteriorization of these largely populated regions, he writes, makes their path quite distinctive from the path of the dominating centre. Their path is an alternative path that finds its point of departure in the suffering, poverty, and oppression of its own peoples.

Dussel's philosophical elucidation of the situation of the poor in Latin America has been a guiding work in trying to elucidate the threads of my originary garment. His evocative insights on the "discovery" of Latin America (Dussel, 1994) and the origins and perpetuation of world inequalities (Dussel, 1996) have been the lenses that enabled me to reread the situation of Latin American peoples. His rereading of prevailing philosophical positions—heavily European in their definitions—also offers another way of understanding or approaching contemporary philosophical works. In a sense, the peripheral position of Latin America in world history, that Dussel so eloquently delineates, makes her a stranger in the eyes of those who a priori assume themselves as the centre. As a stranger, Latin America achieves only *quasi-communication* with the centre, her tongue being too other to be fully understood. This notion of quasi-communication that Dussel (1996) outlines, has also been quite helpful in understanding the marginal status of Latin America.

Having to try on a few Canadian garments has also made me revisit long learned and embodied understandings of world happenings. In wearing Canadian garments, I experienced the need to reshape and redesign (re-weave perhaps?) at least in part my old familiar garments. Bringing to surface garments acquired during the military dictatorship in Chile was part of this reweaving. Our country lost its democratic freedom and lived in an atmosphere of fear, authoritarianism, and military violence for seventeen years. This damaged our way of life to an unimaginable extent even for ourselves. New economic policies not only accentuated social inequities in Chile but also changed our understanding and value of both public services and the common good. The praise of the public so strong in Canada is a thread that I have tried to weave in as I redo my garments. Canada's climate of mutual respect, plurality, political and cultural diversity, and convivial living has in many ways been the inviting milieu for my revisiting and rediscovering experience.

Visiting my country has been a reviving experience throughout these years. My trips home were integral to recall vivencias of home and understand them yet again through other eyes. We had fun reweaving our stories of home with my sister and my brother and learning about our childhood secrets. I also began to cherish typical things of my country that I had not fully appreciated before. I began to enjoy la plaza, the corner stores everywhere, the bakeries and their daily crispy bread, the collective cabs, el Mercado, the handcrafts fairs, the smell and taste of our food. I enjoyed the fast pace of words rolling off my tongue as I became an avid talker after months of having spoken little Spanish. I enjoyed rediscovering our popular Chilean sayings and idioms so telling of who we are.

Undertaking a pilot study with a palliative team in a Consultorio in Concepci6n together with Dr Brenda Cameron was a way of reencountering our nursing and health care realities in Chile, especially after spending a year with the palliative team in Edmonton. Being able to be once again with patients and families in their homes in Concepci6n brought back to life my past and dearest vivencias of nursing. It was a reviving nursing experience. Having Dr Cameron visit Chile during the time of the study was a very precious vivencia. Her presence in Chile brought Canada a little closer to Latin America and our lifeworld a little closer to Canada. Below, I offer the story of Don Pedro, a palliative patient Brenda and I met in Chile. A few days before Brenda's arrival, I was able to meet him in his home.

Don Pedro

Don Pedro lives in a 2 x 2 metres room in the suburbs of Chiguayante. His room is inside a lot that holds several dwellings of similar condition. It is a very busy lot, kids playing with an old soccer ball, a dog sleeping by the sunshine, women going in and out, men talking. Life goes on inside the rusted walls of this tiny and crowded lot. As I enter Don Pedro's room, I feel like entering my own nursing past; images of visiting places such as his reverberate in my mind. And yet I am painfully aware that this is not my past, Don Pedro's room is his own very present.

I first heard about Don Pedro through Emilia and Carmen Luz, two nursing colleagues working in the Consultorio. 'I think Don Pedro would be quite happy to meet you,' Carmen Luz says, 'he has been with us for a while. He is quite frail now and spends most of his time in bed. He used to come here but now we go to visit him. He lives in a tiny room—una piecita—and is very much by himself as his only daughter lives in Santiago. I know he would enjoy talking with you.'

A few days later, I meet Laurie, the doctor from the palliative care programme and the first patient who comes to her mind is Don Pedro. 'He is a very lovely man and he is so lonesome now,' she says, 'he has an amazing sense of humour. He is about 70 years old and has prostate cancer with bone metastases. He lives in this very tiny room that he rents. He has always kept it very tidy but now you can tell he is feeling weaker. I feel very sorry for him as I know it is hard on him not to have his room as clean and tidy as he used to. But I know he would love to meet you. Let's go next week.'

The following week, I meet Laurie in the Consultorio to go to Don Pedro's. I join the people sitting in the waiting area while she finishes seeing her patients. There is a lot of activity in this place as people come and go. I enjoy observing the waiting crowd, mothers with their babies and playful and talkative children, a few youngsters, adults of all ages, and many seniors. Laurie comes out and says she is ready. We go to get his chart to the archives room and get in her car. She uses her own car as there isn't a vehicle in the consultorio to do home visits.

On our way to Don Pedro's we go from paved roads to dusty and bumpy ones. Modernity hasn't come to these roads yet, I think to myself. 'Here we are,' Laurie says pointing to Don Pedro's place. A metallic fence hides the lot from our view. We get out of the car and Laurie sneaks her hand through a whole to unlock the fence from within. I can tell she knows this place very well; there is no hesitation in her actions. 'Buenos días,' she says to the people around in the lot as we go in bending our heads, 'Vinimos a ver a Don Pedro!' 'Pase no más,' a woman says, with a look and a smile of recognition, as we walk towards Don Pedro's room.

'Permiso,' we say as we enter Don Pedro's room. 'Hola doctora, qué sorpresa,' Don Pedro says stirring in his bed. 'Hola Don Pedro, I came to see you with a visitor from Canada,' Laurie says. With a look of surprise and amusement, Don Pedro offers his hand to welcome us, 'I am sorry my place is so tiny,' he says looking at his room. 'Hi, Don Pedro,' I say, 'I am very glad to be here. I am actually from Chile, I study in Canada now. 'Oh,' he says, 'what brings you to these places?' 'She wants to do a study with us,' Laurie says, 'she is a palliative nurse. I thought you might like to meet her.' 'Oh, I always enjoy meeting people,' he says, 'just sorry about not being in better shape,' he adds with a mischievous smile, 'please have a sit.' Laurie stands near him and I stand at the foot of his bed.

As I stand here, I notice that Don Pedro's room is quite a room. Though the room is tiny, he has everything neatly arranged. His bed occupies a full third of this room. His clothes are kept in a small closet across from his bed. A two-burner stove holding a kettle sits on a tiny table by one of the walls. A cardboard box with dishes sits right beside the stove. A large wooden cabinet stands by the wall behind me and a small coffee table in front of it. On my left, right at Don Pedro's foot, a small window gives us glimpses of the world. The walls are decorated with colourful posters and figurines find their place atop every furnishing. There is no sense of anonymity in this room. Don Pedro inhabits every corner of this room. He is at home in this very tiny room.

'How are you Don Pedro?' Laurie asks. 'This pain in my belly is bothering me doctora,' he says, 'I am worried as I have not gone to the bathroom for a while.' 'When was the last time you went?' She asks. 'Three or four days ago I think,' he says. Laurie looks at his belly, listens to his bowel sounds, asks him to sit up and listens to his lungs. She taps his lower back and he exclaims, 'Ay doctora! Are you playing Martin Vargas today?' We laugh as Martin Vargas is a Chilean boxer. 'I want you to take this medication to help your bowels,' Laurie says, 'I don't think they are working well. If it doesn't work, we will have to give you an enema. Have you been taking your pain medication?' 'Yes, I have it right here on my night table,' he says pointing to a small brown bottle, 'my neighbours remind me to take it as well. But I don't forget.' 'That's good,' Laurie says, 'I don't want you to stop taking it because if you do you will be in pain.' 'No doctora,' he assures her, 'I will keep taking it.'

'Don Pedro,' Laurie says, 'Anna is doing a study with us about palliative care and she would like to talk with some patients as well. We thought that you might like to talk to her.' 'What would you like to talk about?' Don Pedro asks. 'About your own experience during the time of your illness,' I say, 'your difficulties or the things that have been important to you.' As I talk, I am conscious not to mention the word cancer. Laurie and Carmen Luz have already warned me that he is not aware of his diagnosis. They worry that he might get too sad if they tell him. They also say that he has not expressed interest in knowing further details about his illness. After leaving Don Pedro's home, Laurie confesses she feels an ethical tension here as she really doesn't know what to do about it. She asks me what they do in Edmonton. I also tell her what we used to do in the past with our patients and she finds it helpful. As we talk, I sense my nostalgia for this past time. Laurie and Don Pedro make me re-experience my nursing past once again.

Don Pedro says that he would like to talk as this might help him *'desahogarse.'* Desahogarse means to vent, to pour one's heart out, to relieve oneself. Literally it means to 'un-drown oneself.' It denotes a feeling of being overwhelmed, suffocated with a particular situation. Later on, Laurie says she was surprised to hear Don Pedro talk about desahogarse. I sense her concern for him. 'I am so glad you will be coming to see him,' she says. Don Pedro and his room stay with us as we drive back to the consultorio. I think of his tiny room holding him and his lifeworld in its entirety.

I notice Don Pedro feels very much at ease with Laurie. He even teases her by calling her 'Martin Vargas.' Laurie is also quite comfortable with Don Pedro. She addresses him in a very approachable manner. In Chile, this is not very common between a physician and a patient. Laurie embodies her concern for Don Pedro. She engages with him in the concreteness of his present situation. She enters Don Pedro's tiny room. Don Pedro's room feels quite crowded with all of us in there, overflowing really. The garment is quite tight. Yet Laurie is able to easily put it on.

Entering Don Pedro's room evokes a world of vivencias. As I look around in his room, I meet his own world, his past and his very present. I have a sense his whole world is contained within this tiny room. Also, as I see Laurie engaging with him, talking about his pain, laughing together, I meet Laurie's own world as a community physician. She reaches the patient in the home. I sense her enthusiasm as I follow her on her home visits. All this evokes my own nursing world from the past. Inside these worlds the questions of nursing and the very ill begin to form.

LIVING THE QUESTIONS

> *In all questions, it is we ourselves, our having and doing, thinking and being together, that is the principal matter at issue (Burch, 1986, p. 7)*

As stated above, these vivencias of home both in Edmonton and back home in Chile shaped the being of this inquiry. Integral to its being and emerging out of these vivencias were the questions of the study. The question of nursing and the very ill is in many ways the ethical stance of this inquiry. Bergum (1999) writes about the closeness of ethics to questioning, "Ethics as question not only looks to understand you, the you with a disease or health problem, but the you that connects with me even for a short time" (pp. 174, 175). Living the questions in this study involved forming a relation with the very ill and their nurses and engaging in a continuing dialogue about who we are. Living the questions was a way of remaining situated, embodied, in touch with the world of nursing and the very ill.

A pressing ethical concern before and throughout the study was how to ask a question to the very ill in a way that is both respectful of their experience and ethically responsible. As a palliative nurse, I often felt distressed by the ease of researchers to ask questions about death and dying to the very ill. Situating myself in the home and in each particular context was paramount to being able to ask questions that would not be disruptive of their moment. Nurses felt this concern throughout the study and expressed their appreciation. They know what it takes to be asked a question about dying when one is very ill. Living the questions meant engaging in an everyday manner with the very ill, attentive to the nuances of their daily life.

Living the questions involved a continued questioning throughout the study. Gadamer (1989) writes that in being able to persist in our questioning we preserve our "orientation toward openness" (p. 367). Questioning again and again elements of the experience of the very ill and nursing practices in the home as they came through during the study was a way of keeping the inquiry open. Remaining open was important to avoid hurried understandings and to preserve the dialogical manner of the study. It was the way to "let what is not yet present arrive into presencing" (Heidegger, 1977, p. 10).

The following research questions guided this study:

> How do the very ill live through their experience in the home?
> How do nurses engage with the very ill in the home?
> How do the very ill reveal conceal dying?

As a piece of this study took place in a developing country and being a health care professional from South América, I deemed it relevant and necessary to integrate in this study the following global question:

> How does the global context relate to our understanding of the experience of the very ill?

This global question was a way to situate the study questions above and the study itself in a broader context which binds the experience of the very ill here and in the developing world together. Through this question, I try to weave (if such adventure is possible) both the northern and Latin American garments into a piece that shows the originality of each place while also making present their human commonality. As a nurse from Latin América, I could not leave aside the global situation of the very ill. An understanding of how palliative care takes place in the developing world has great potential to enrich palliative care models in countries such as Canada where although universal access is a corner stone of health care, health care professionals can face significant challenges at the time of serving people living in marginal conditions. Developing countries are enacting practice modalities that often show in an inventive and effective manner how to reach these populations. Also, an awareness of the global situation of the very ill can assist health care professionals and the public in countries richer in resources to take action to on the one side mobilize resources towards impoverished regions of the world including lending their own knowledge and expertise and on the other promoting more global-oriented cost-sensitive initiatives in their local settings.

In sum, these research questions are a way of approaching the experience of the very ill and nursing practices in the home with love and respect. Love because these questions come from my own nursing world and my nursing nearness to the very ill in the home. Respect because through these questions I seek to recognize and make present the indeterminacy and *inappropriability* (Nancy, 1997a) of the experience of the very ill. In respecting this indeterminacy and inappropriability, we are able to be at home with nursing and the very ill.

Burch (1986) writes that questions involve "an issue that pertains to our very being in the world" (p. 6). In asking a question of nursing and the very ill, their question comes back to us. Who are the very ill? Who are we? How do *we* engage with the very ill in life? These questions concern our very being in the world. They invite us to revisit, to question, to ponder our own place in life. This is perhaps what after all living the questions of nursing and the very ill means.

STRUCTURE OF THE DISSERTATION

In the following chapters, I delineate the research questions above. In Chapter II, I examine the research text in palliative care both in the North and the developing world. Engaging with the global text of palliative care is a way of showing the garment of the very ill in the global context. Following this, I engage with the research texts of palliative care in the North and discuss how these woven garments reveal conceal the experience of the very ill. Both these global and northern garments of the very ill call us to reweave texts whose threads embody more strongly the fabric of vivencias of the very ill themselves.

In Chapter III, I focus on the human science tradition and interpretive inquiry as the philosophical and methodological bases of this research study. Here I show the enabling potential of interpretive inquiry as a research approach to undertake research in the home. I return to the garment of the home and explore how the rooms of the home reveal conceal elements of dying. I also outline methodological elements of the study highlighting the ones that were primary to developing an understanding of nursing and the very ill in the home.

Chapter IV is a delineation of nursing practices in the home of the very ill. Following Brenda Cameron's (1998) hermeneutical exegesis of nursing practices, I examine through an in-depth description of a patient's experience how nurses engage with the very ill in the home. Here I seek to show how nurses in the home are able to skilfully and relationally engage with the complexity of the experience of the very ill. Their nursing relation with both the very ill and their home reveals itself as a primordial element that enables nurses to continuously attune themselves to the shifting nuances of their experience as well as to engage with the otherness of the illness itself.

Chapter V introduces a slight (strange perhaps?) shift in the text as I bring the garment of Latin America into our midst. In trying to relate the global context to our understanding of the experience of the very ill, interrogating the socio-historical and political context of Latin America was extremely important. This context (not unlike the context of the poor and marginalized in other continents) has positioned Latin America as a stranger in the world context. This positioning affects how we relate to this part of the globe and how we understand the garment of their experience, for the situation of both the poor and the very ill finds its roots in how Latin America comes to be present in world history. Understanding the path of the stranger is also a way of understanding the path of the very ill in the global context and a way of refusing to stay with one garment alone. The status of the very ill both here and in the developing world is also evocative of the status of the stranger as they suffer the straightforward erasure of their own societies. In engaging with both the very ill and the stranger, we hear their ethical claim upon us and experience the need to reweave our own garments.

In Chapter VI, I return to April and Claire and situate the study in April's home. Here, we are present to how April herself is able to continuously shift back and forth between both the contingencies of her daily life and those of her health situation. Claire's engagement in April's experience reveals a nursing understanding of the experience of the very ill that holds close the ungraspability of dying itself. Through her engagement with her own situation, April reveals conceals primary elements of her experience as well as shows the persistent insistence of the centre of gravity of life itself. April's experience calls into question practice schemes and categories of thought unfitting the irreducibility and inappropriability of the experience of the very ill.

Ethics has shown itself as a primary thread of the garment of the very ill throughout the study. Moving towards the end, in Chapter VII I delineate the home care nurse's ethics in the home. Through a common nursing situation, I show how the nurse embodies an understanding of ethical practices in the context of the very ill. Home care nurses show an ethics that locates itself in the apparently most common and ordinary situations of everyday practice. This delineation follows primarily Cameron's (2004) exegesis of ethical moments in health care as well as Bergum's (1994) and Bergum and Dossetor's (2005) relational exegesis of health care ethics.

In the final chapter, I return to the various threads of this research study. Here I offer a prĕcis of the primary understandings of this inquiry. These understandings invite us to revisit our manner of relating to the very ill both locally and globally. They are a call to rethink and reshape health care practices that encumber the very ill who relentlessly and overwhelmingly strive to thrive in the face of death.

Throughout this work, the term *very ill* denotes individuals with late-stage incurable illness. Even though in the palliative care literature the terms dying or terminally ill are often used interchangeably, I found it difficult to refer to these individuals as *the dying*. In trying to find a respectful and non disruptive manner of approaching people in palliative care I found in *the very ill* a sensitive term that would not evoke unnecessary or unsought distress. Being careful about the term dying comes from the experiences of nurses and the people themselves. In practice, nurses tend to reserve the term dying for people who are in their very last few days of life. In Spanish the term dying is also used in this way and I felt extremely uncomfortable applying this term to palliative patients. While avoiding the term dying can be taken as continuing in a way our overall trend to avoid the topic of death in society, it is also a way of making present a primary element of their experience. It un-conceals the understanding that although these individuals are indeed *very* ill, they continue to be among the living and like every living being, they too strive to live.

CHAPTER II: ON THE PLETHORA OF TEXTS IN THE WORLD OF PALLIATIVE CARE

> *The cry, as noise, as clamor, as exclamation, proto-word still not articulated, which is interpreted in its sense and meaning by those "who have ears to hear," indicates simply that someone suffers, and that from out of their suffering they emit a wail, a howl, a supplication. (Dussel, 1996, p. 80)*

In keeping with the path of the study, I needed to engage with the existing texts of the very ill as a way to see how these texts delineate the experience of the very ill. These texts are woven fabrics that palliative care practitioners and researchers weave as they engage with the very ill during the course of their illness. In this chapter, I examine how the threads of these garments reveal conceal the experience of the very ill. As stated in Chapter I, here I engage with both the northern and global garments as a way of keeping present the texts of home as well as the texts of the north. The global garment reflects the woven text of the very ill in the developing world and the northern garment denotes mainly the woven texts of the very ill in high income countries.

In the Gadamerian sense, understanding a text involves the application of this text to our present situation. For a text to be rightly understood, it must be understood in the context of one's own particular situation (Schuchman, 1979). Application in this sense is an integral element of genuine understanding where through a questioning dialogue we are able to relate the text to our own perspective and thus unveil "our own horizon and the unsaid depths of the original text" (Schuchman, p. 42). Carson (1986) describes further the centrality of application to understanding in the hermeneutic process,

> To understand means that what is understood has a claim on us, we appropriate the meaning to our own thoughts and actions in some way... In a technical sense information may be picked up and used, or not used, depending on the discretion of the user. In a hermeneutic sense understanding is not completed unless we see what is understood as applying to us in some concrete way (Carson, 1986, p. 82).

In nursing the very ill, here and in the developing world, we come to situate ourselves both before the text of the person's particular situation and before the texts of palliative care. Engaging with these texts evokes a constant tension as we try to reconcile one with the other with as little disruption of the particular as possible. How are we to understand and address this tension? How are we to recognize the primary text and understand the applicability of the subsequent texts to this primordial one? These questions also apply to the nurse who in nursing the very ill here and in the South experiences a tension between the particularities of the home and the received text of palliative care. How is the palliative home care nurse to apply this text in the context of every particular home and individual at times even in sharp contradiction with the universal text?

Here, Dussel's (1996) exegesis of the text suggests a philosophical and practical possibility to understand the text. In discussing hermeneutics in the context of liberation philosophy, Dussel writes that the text of the marginalized, the oppressed, the poor, the slave, the exploited woman, the manipulated child, the massacred Amerindian, the ones in exteriority, is not the ethical or the political discourse but the daily non bread.

> In the background, hermeneutical phenomenology places the subject as a "reader" before a "text." Now, Liberation Philosophy discovers a "person in hunger" before a "no-bread" (that is to say, without a product for consumption, because of poverty or because of the robbery of the fruits of labour), or an "illiterate" before a "non-text" (which she cannot buy, or a culture which cannot express itself). (Dussel, 1996, p. 81)

As I tried to find a way to engage with the plethora of texts in the world of palliative care, I felt the need to engage first with the global text. This text offers a glimpse into the situation of the very ill and palliative care throughout the world with a focus in the developing world. Understanding the global garment was necessary before engaging with the texts of the North in order to situate these texts in the larger context. Speaking of phenomenological writing, van Manen (1997) refers to the tone of texts as the manner in which they "speak to us, address us" (p. 359). While not phenomenological, in engaging with the global and the northern texts, one can sense their tone and experience "visceral and corporeal" responses (van Manen, p. 364). The text that follows is a response to their manner of addressing us in the context of the experience of the very ill.

First, I offer an overview of the world's health situation followed by a look at the status of palliative care in the world. Next I describe the progress and the challenges of palliative care programmes in the developing world. I conclude the global text with a number of experiential studies that describe the situation of the very ill in developing countries where the no-bread shows itself repeatedly as the lack of food, health care, medications, and other life essentials. As I move back and forth between the global situation and local experiences, the discussion may seem repetitive at times. Yet in every case I try to show the situation from yet another slightly different perspective.

Following the global text, I offer an analysis of the research texts in the North. First, I briefly outline the state of palliative care research in the North. Then I focus on the symptom text, one of the major texts in the North, and discuss the need to revisit our understandings of the symptom experience. A summary of experiential studies in the North follows this discussion. In the last sections, I discuss the measurement comportment in the context of palliative care and revisit the limits of measurability. At the end of this chapter, I go back to the global text and raise the need to reweave garments that echo more strongly the experience of the very ill in their threads.

UNDERSTANDING THE TEXT OF THE DEVELOPING WORLD

An Overview of the World Health Situation

In this section, I illustrate the current global health situation and the disparities that are in place among and within high and low income countries. I focus primarily on the health situation of countries in the developing world as the burden of disease in these countries is far higher than in high income countries (De Lima & Hamzah, 2004). Global disparities and inequities are well documented in international public reports such as those emanating from the United Nations (UN) and the World Health Organization (WHO) as well as in individual publications. In this discussion therefore I do not present a comprehensive review of all these documents. Rather, I offer a brief overview of the global situation in an attempt to further contextualize the current practice of palliative care.

In contrast to the health situation of high income countries, the situation of developing countries is quite indicative of the severity of current global health disparities. In 2001, more than three quarters of the world's deaths occurred in developing countries (Torres & Lopez-Zetina, 2004). Life expectancy rates among the poorest countries are far below the world's rate of sixty-five years with sub Saharan countries showing the lowest rates. The life expectancy at birth in Zambia is a little more than thirty two years whereas Canada, Japan, and Sweden, among others, have a life expectancy higher than seventy nine years (De Lima & Hamzah, 2004). Yet far from awakening the serious commitment of affluent countries to reduce disparities, the burden of disease of the developing world seems to heighten world inequities. While the greatest health care needs are in poor and developing areas, most health care resources continue to be allocated in high income settings. Annual public spending on health per capita varies from US $6 in the poorest countries to US $1,356 in high income countries (De Lima & Hamzah).

The rapidly devastating situation of HIV/AIDS in Africa is one of the greatest tragedies of our times. Worldwide, the number of cases of HIV/AIDS and cancer are rapidly growing with most of them being in the developing world (Sepúlveda, Marlin, Yoshida, & Ulrich, 2002). While cancer and other non-communicable conditions account for over half of the world's deaths, HIV/AIDS is the leading cause of death in Africa (Torres & Lopez-Zetina, 2004). More than two thirds of the millions of children and adults suffering from HIV/AIDS live in sub-Saharan Africa where the persistent rise in HIV/AIDS rates counteracts the trend of Western countries (Olweny, Sepulveda, Merriman, et al., 2003; Wood, 2002). In the words of Stephen Lewis (2005), the UN special envoy for HIV/AIDS in Africa, the proportions of the HIV/AIDS epidemic are simply those of another holocaust. The African situation, he points out, ethically demands the world's attention and the immediate commitment of high income countries to provide the necessary financial assistance to reverse the disastrous consequences African peoples currently face.

Inequalities in health in Latin America and the Caribbean are also wide (Dachs, Ferrer, Florez, et al., 2002). While cardiovascular diseases occupy the leading cause of death in the region, the poorest countries including Bolivia, Nicaragua, and Haiti, experience high child and adult mortality due to infectious and parasitic diseases (Torres & Lopez-Zetina, 2004). Access to health care in this region also varies significantly across countries, with high income groups showing higher patterns of health care services utilization than low income groups even though both groups share similar morbidity profiles (Dachs et al.). In Chile, for example, wide income inequalities still persist despite continued growth and reduction in poverty rates with individuals from the lowest income strata showing poorer health outcomes than those from higher strata (Dachs et al, 2002; Vega, Hollstein, Delgado, et al., 2001; Vega, Bedregal, Jadue, & Delgado, 2003).

Cancer incidence also continues to grow in the Latin American region where the majority of cases are diagnosed at a late stage (De Lima & Hamzah, 2004; Pan American Health Organization, 1997a). This poses many challenges to health care providers and families as the resources allocated to health care are still insufficient (De Lima & Bruera, 2000). Similarly to other developing countries, cancer mortality in Chile has also shown a tendency to increase in the last few years (Medina & Kaempffer, 2000). Whereas in many affluent countries reductions in tobacco consumption have had an impact on lung cancer rates, there is an increasing risk of tobacco-related deaths in Latin America and the developing world due to the pervasive marketing of tobacco companies (Fornells, McGarrell, & Sala, 2004). Based on tobacco consumption trends, about a million individuals in the Latin American region will develop late-stage incurable cancer by the year 2020 (De Lima, Sakowski, Hill, & Bruera, 2001).

Global inequities in health and health care are generating a stark reversal in world's health improvements experienced in the past 150 years (Labonte, Schrecker, & Gupta, 2005). With the increasing global trend to privatize public services along with the belief that the private sector is more efficient than the public (McMurtry, 1998), the high costs of medical care are turning health care services into a privilege that the poor are unable to afford (De Lima & Hamzah, 2004). In many countries in Africa, the cost of HIV/AIDS treatment is the equivalent of their per capita gross national product (Wood, 2002). Also, the misallocation of health care resources to cover the costs of expensive yet little effective interventions results in lack of coverage for essential drugs and treatments as well as poor promotion of community health initiatives (De Lima &

Hamzah). All of this reduces the likelihood to ensure access to effective health care interventions for the economically disadvantaged and thus to a better health situation.

Prevailing corporate interests such as those of pharmaceutical companies have only worsened the world's health situation (Barnard, 2001). The legal actions pursued by thirty nine pharmaceutical companies against the South African government to prevent the import of generic versions of HIV/AIDS drugs, and the ensuing reduction in the companies own prices from $10,000 or 15,000 to $350 a year (Barnard), reveal the cruel machinery of corporations to control the global health care "market." As pharmaceutical companies target only potentially profitable drugs, they leave those in low income countries with little chances to gain access to drugs for the treatment of infectious diseases not prevalent in industrialized countries (Barnard, 2001; De Lima & Hamzah, 2004; Labonte et al., 2005). Current global disparities leave developing countries with little hope to achieve the UN (2000) Millennium Development Goals (MDGs)[6] by 2015 unless affluent countries make a firm commitment to increase their share of resources with the developing world (Lewis, 2005).

The health situation of the developing world is closely linked to the global economy (Labonte & Schrecker, 2004; Peter & Evans, 2001). According to World Bank estimates, nearly half of the world's population live on $2 or less per day (Labonte & Schrecker, 2004). In 1960, the wealth per capita of the ten richest nations of the world was 30 times higher than the combined wealth of the ten poorest nations; today, it is 72 times higher (Gergen, 2000). In Latin America, the systematic institution of neoliberal economic policies has also resulted in a dramatic increase in the number of persons living in poverty which reached around 210 million people in the mid 1990s (Korzeniewics & Smith, 2000). In the current economic context, the gap between the rich and the poor continues to widen while an ever-growing number of individuals are left behind (Chen & Berlinguer, 2001).

The capitalist market has had a deadly impact on the lives of the majority of the world (McMurtry, 1998). McMurtry discusses the pervasive and unchallenged tendency to identify the interests of the market economy with the public good, the "*moral foundation*" of the market. In the eyes of the market, the public good represents only the veiled interests of a few (the rich) to the detriment of most (the poor). The unending cycle of poverty and ill health demands urgent attention to broader social and economic determinants of health as the ethical approach to health equity (Peter & Evans, 2001). This includes close attention to prevailing

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[6] The UN MDGs represent the commitment of the world nations signed in the year 2000 (UN, 2000) to make development an achievable reality for all (UN, 2002). These include eradicate extreme poverty and hunger; achieve universal primary education; promote gender equality and empower woman; reduce child mortality; improve maternal health; combat HIV/AIDS, malaria, and other diseases; ensure environmental sustainability; and develop a global partnership for development.

economic models and their deleterious effects on the world's peoples. It is time to call these economic frameworks into question. We must attend to the situation of the poor in the South as well as within affluent countries if we are to bring about effective improvements in the world's health.

Labonte, Shrecker, and Gupta (2005) propose an agenda for the G8 countries to promote global health equity. This agenda includes increasing financial resources to support the control of communicable diseases in Africa; developing multilateral agreements to regulate the migration of health care professionals from sub-Saharan Africa and other regions of the world; recognizing the place of social and economic determinants of health, i.e., water, nutrition, education; allowing countries to utilize the resources according to their own needs and not economic agendas; expanding external debt cancellation; and promoting fairer trade policies.

Stephen Lewis (2005) makes an urgent appeal to the world nations to determinedly take action to stop the staggering suffering of the peoples in Africa. He also offers a number of alternative proposals to address the critical situation of African countries. It is time we engaged with the living text of the peoples in Africa and their silent (unheard) ethical claim. It is time we engaged with the text of the poor, the hungry, the unemployed, the illiterate, the homeless, the ones who suffer in their flesh the inequities of the world. They are the ones for whom access to proper treatment is often forbidden. It is time we saw their *no-bread* as *applying* in a very concrete manner to our own particular situation.

The Global Text of Palliative Care

Following the discussion of the global health situation above, I offer in this section a brief overview of the current situation of palliative care from a global perspective. In general, advances in palliative care throughout the world parallel in many ways the overall trend in the world's health. Since the founding of the internationally known St Christopher's Hospice by Cicely Saunders in the late 60's (Saunders, 1984), the development of hospice and palliative care services has been remarkable (Doyle, 2003). Yet the auspicious growth of these services in several countries is a sharp contrast with the lack of access to basic care in over hundred countries where the majority of deaths occur (Doyle). Today, Doyle remarks, most palliative care services exist in Western affluent countries whereas developing countries continue to struggle to provide basic health care to their populations. Despite worldwide efforts and progress in the care of the dying, there are many in the world still unable to reach the significant benefits of palliative care (Sepulveda et al., 2002).

Over the past few decades, the World Health Organization (WHO) has shown a marked commitment to the development of palliative care globally. The Three Step Analgesic Ladder (WHO 1990, 1996, 1998), a clinical guide for the management of malignant pain, has been extremely significant and useful in assisting physicians and nurses throughout the world to treat the pain of the terminally ill. The translation of the WHO's guide into more than ten languages (WHO, 1996) has enabled health care professionals across countries to use it widely. Global increases in morphine consumption (De Lima & Hamzah, 2004), one of the indicators of proper access to pain control, also denote a growing understanding of pain relief (Sepulveda et al., 2002). Yet morphine consumption in only six industrialized countries, including Canada, Australia, and the United States, accounts for over *three quarters* of global consumption while developing countries continue to show very low numbers despite the high incidence of late-stage incurable cancers in these regions (De Lima & Hamzah).

The delivery of proper care to the dying in the developing world faces several challenges. Poverty and insufficient health care resources pose grave constraints to governments and individuals to establish and sustain palliative care programmes in low resource settings (Olweny et al., 2003; Sepulveda, 2003). Other serious impediments include lack of knowledge and skills in palliative care, restrictive opioid legislations, limited drug availability, high cost of drugs, lack of infrastructure, political agendas, unaffordable housing, and lack of food and basic sanitation (Bertolino & Heller, 2001; Gupta, 2003; Kayita, 2003; Sepulveda, 2003; Wenk & Bertolino, 2002). Restricted access to health care services as well as to timely cancer and HIV/AIDS diagnostic services and treatments simply aggravates the situation of the terminally ill in the developing world (Aranda, 1999; Doyle, 2003; Olweny et al; Wood, 2002). These constraints are but just a few of the overwhelming realities developing countries face making both accessing and providing palliative care a continuous challenge in these settings.

The experiences of developing countries in the delivery of palliative care also vary widely within and among countries reflecting the existing disparities between developing and industrialized countries (Bruera & Sweeney, 2002; Burn, 2001). In terms of morphine consumption, for example, the latest world report indicated *fifty one* developing countries with no recorded morphine consumption (De Lima & Hamzah, 2004). In Latin America, Argentina shows a high morphine consumption rate while Peru and Mexico show very low rates (De Lima et al., 2001). Nine of the fifty one countries indicated above are in Latin America (Pan American Health Organization, 1997a). In Africa vast inequalities among countries have led to the recommendation of a differentiated and pragmatic approach to HIV/AIDS and cancer ranging from pain and symptom relief in the poorest countries (the majority) to full HIV/AIDS and cancer treatment in those able to afford it (Olweny et al., 2003). In India, most resources for cancer are allocated on curative efforts while more than three quarters of the cancer population are diagnosed at a late stage (Gupta, 2003). Less than three percent of the population in India are able to access pain relief (Rajagopal & Palat, 2002). WHO's recommendation that most health care resources in the treatment of cancer in developing countries be allocated to palliative care due to late diagnosis is far from being a reality.

The Palliative Care Text in the Developing World: Progress and Challenges

In the midst of their scarcity of resources, health care professionals in the developing world strive to develop local initiatives to ensure access to pain and symptom relief to the terminally ill. The experience and expertise of Western countries has often provided a basis for the development of these programmes (Speck, 1999) although developing countries are growing critical about the import of Western models into their settings (Doyle, 2003). The sharp disparities in resources as well as the many contextual differences are moving individuals, institutions, and governments in low and middle income countries to build affordable programmes within their existing health care systems (Sepulveda et al., 2002). Taking these disparities into account, North-South collaborative initiatives are a significant and necessary venue to strengthen local initiatives in the South (Sepulveda, 2003). South-South partnerships are also emerging as a strategy to enhance the development of programmes that share similar realities (Sebuyira, 2004).

In line with the 1978 Alma Ata declaration on primary health care (WHO, 1978) and recent WHO recommendations (Sepulveda et al., 2002), developing countries are following a community health approach in the provision of palliative care. Community and home-based palliative care has shown to be a low cost effective initiative to increase access to palliative care for the very poor (Sepulveda, 2003). In Uganda developments in palliative care since the early 90's have placed the country among one of the leaders in the African region (Kayita, 2003; Ramsay, 2001). Here an intersectoral collaborative approach has been one of the key elements in the sustained development of palliative care services for people with HIV/AIDS (Kayita). The African project led by the WHO Programme on Cancer Control (Sepulveda et al., 2002; Sepulveda, 2003; Sepulveda, Habiyambere, Amandua, et al., 2003) involving five countries has shown team collaboration and recognition of local capacities as well as a strong public health care approach as the key ingredients to strengthen palliative care services in these settings.

In India, despite striking poverty rates and the allocation of most resources to curative treatments, there have been considerable developments in palliative care in the last decade (Burn, 2001; Rajagopal & Palat, 2002). Training initiatives and the creation of palliative care centres have gone hand in hand thanks to the involvement of WHO and Cancer Relief India, an organization from the UK, and the eager interest and commitment of local physicians, nurses, and allied health care professionals (Burn). Intersectoral joint efforts have been critical to increasing morphine availability in the country and to improve access to proper pain relief to the terminally ill (Rajagopal, Joranson, & Gilson, 2001). The promotion of low cost programmes and regional cooperation together with community initiatives to secure financial support has also been important to the continued progress of palliative care in India (Rajagopal & Palat). These advances are encouraging for the future as much remains to be done in the country to ensure access to palliative care for the majority of the population (Rajagopal et al.).

In Latin America, the commitment of the Pan American Health Organization (PAHO) to palliative care has greatly supported the development of these services (WHO, 2002a). Palliative care denotes an ethical approach to those diagnosed with late-stage incurable cancer in Latin America and the Caribbean (PAHO, 1997b). PAHO has made palliative care one of the main components of their cancer control initiative since 1997 (De Lima & Bruera, 2000). The heterogeneous development of palliative care in Latin America and the Caribbean region has led PAHO to support demonstration projects to increase access to palliative care in the region (De Lima, 2001). PAHO has recommended several strategies to ensure access to palliative care including a public health approach, decentralization of services, development of a national policy, drug availability, opioid legislation changes where needed, and training of health care professionals (De Lima & Bruera). The provision of palliative care through primary health care has also been promoted by PAHO as one of the main strategies to increase access to these services in the region (De Lima, 2001).

In Chile, a National Pain Relief and Palliative Care Programme was established by the Ministry of Health in the mid 1990's following recommendations from a National Palliative Care Working Group (Fernández & Acuña, 1996). Since then, palliative care programmes began to be introduced in the public health care system in the country (Rico, 1997). In the Province of Concepción, the programme was first developed in rural areas and low complexity urban hospitals in the early 1990's (Fernández & Acuña). In 1998, the programme was introduced in all primary health care centres in the city of Concepción. The provision of palliative care through primary health care has shown to be an effective and affordable community-based initiative that ensures access to the population on an ample basis (Fernández & Acuña). Currently, the national programme covers about 47% of the population with late-stage incurable cancer (Ministerio de Salud Chile, 2002). These numbers are expected to grow in the 2000-2010 decade as the government has expressed a strong commitment to increase access to palliative care in the country (Ministerio de Salud, 2002, 2004). With more than two thirds of the cancer population diagnosed with late stage cancer in Chile, most cancer resources allocated to curative treatments, and the cancer mortality trend on the rise in the country, the challenges to ensure access to palliative care for everyone are not few.

The Experiential Text of the Developing World: Documenting the Experiences of Health Care Professionals and Patients in Developing Countries

Research and programme reports from developing countries are eloquent in describing the suffering of the very ill in these zones. In this section, I present a number of experiential studies from developing countries. Although studies documenting the experience of health care providers and patients in these settings are not many, they bring to the fore local perspectives that increase our rather limited understanding of the global situation. They also provide further evidence about the complex situations that health care professionals and people suffering from a terminal illness in low resource settings face. The research text from the developing world shows a face that differs in many ways from the research text in the North. It is a text that embodies the developing character of palliative care in these areas as well as that of the settings themselves. The research text of the developing world provides a venue to engage the international community in issues of global magnitude and mobilize efforts towards areas in great need of assistance.

Kikule (2003) undertook an exploratory study in Kampala, Uganda to describe the needs of a group of terminally ill patients receiving care in the home. Severe symptoms such as pain, vomiting, and diarrhoea were among the most common needs of these patients, the majority of whom had a diagnosis of HIV/AIDS. Serious financial constraints were also a common experience resulting in difficulties to cover basic expenses including food, school, and housing. Patients in the study often experienced feelings of fear, stigma, and abandonment. With a third of the population living in absolute poverty and with limited access to health care for nearly two thirds of the population (Kikule), the advent of a terminal illness in Uganda can have a disastrous effect in people's households as well as in the local communities. Indeed, understanding cancer as a catastrophic illness reflects the tremendous financial burden of this illness in families of the developing world (Robles, 2005).

The experiences of patients in Kikule's (2003) study have many commonalities with the experiences of patients from rural Kenya (Grant, Murray, Grant, & Brown, 2003). Severe pain was a predominant theme in the experience of terminally ill Kenyan patients participating in Grant et al.'s study. Stigma and fear of being a financial burden were also part of their experiences. The high cost of health care services and of medications for symptom control together with patients and families' extremely limited financial capacity prevented them from accessing timely and effective symptom relief. The experience of unremitting pain and other disturbing symptoms was overwhelming for patients and families. Lack of basic sanitation services, insufficient home care support, and their own cultural traditions about death made their experience in the home even more difficult. The support of community groups in the home together with their own spiritual traditions was very important in assisting patients and families to go through this experience. Based on findings from this study, the authors make an urgent call to join world efforts to reduce poverty. Until the resources to meet the most pressing needs of these patients and proper relief from pain and other symptoms are in place, a good death, they remark, is unlikely to happen.

Sepúlveda et al. (2003) report the results of preliminary surveys with terminally ill people or their family members in the five countries participating in the WHO African project, including Botswana, Ethiopia, Uganda, Tanzania, and Zimbabwe. The most pressing needs of patients across the five countries included relief from pain and other symptoms, accessibility to drugs, lack of food, financial assistance, and home care support. Loss of income and employment due to the ill condition of their relative was a common experience among family members in these countries. Based on these findings, the authors emphasize the need for community-based initiatives and team development to ensure accessibility to palliative care services. The basic components of a palliative care intervention, they suggest, should include at least drugs for pain and symptom relief, food, and family support. The burden of HIV/AIDS or cancer in these countries demands the immediate implementation of such initiatives so that immediate relief can be assured.

Uys (2002) describes the experiences of community caregivers looking after people with HIV/AIDS in the home in South Africa. Community caregivers were able to assist patients with their daily needs, assess emerging situations, and provide advice. In their experience, their work was rewarding as they felt it made a significant difference in the lives of patients. Yet the daily realities of poverty they faced increased the complexity of their work as they felt unable to solve the great economic needs of the families. In this regard, the support of community organizations was a relief for the workers. Resources were so scarce that at times nobody would take charge of burial services. The future of orphan children was cause of great concern for these workers and registered nurses. Lack of transportation, communication technologies, and lack of recognition from health care staff also was experienced as a hindrance to their work. The support of nurses and hospice staff on the contrary was very important to enhancing their work. The study highlights the significance of home-based care and community caregivers to provide significant comfort to the terminally ill in their last months of life.

In Argentina, home-based care has also shown to be an affordable initiative that suits well the cultural and economic context of the country (Wenk, 2000). In the year 2000, there were 25 supportive care or palliative care teams in Argentina, most of them in Buenos Aires (Bertolino & Heller, 2001). In 2002, a larger number of palliative care teams were identified primarily located in major or middle-sized urban settings (Wenk & Bertolino, 2002). Wenk (2000) reports the impact of their local domiciliary palliative care programme. Most patients admitted to the programme over a one-year period were able to remain at home during the course of their illness with few hospitalisations. Both good symptom control and the continued support of family members were most important in facilitating a home death. Two physicians and one nurse with training in palliative care and extended clinical experience were also crucial in the delivery of timely and effective care. The provision of services and medications at no cost to people with few financial resources increased accessibility to these services. The overall low cost of care of this programme as well as the good outcomes make domiciliary care a feasible alternative for the Argentinean health care system to serve well the terminally ill population of the country.

Our pilot study in Chile (Cameron & Santos Salas, 2003) assisted us to understand the provision of palliative care in the community in Concepci6n province. The goal of the study was to delineate elements of the experience of patients and primary health care professionals from a low resource setting including barriers to access and provide palliative care. Data collection methods included hermeneutic conversations with palliative patients, family members, and primary health care professionals as well as participant observation of home visits. Overall, patients and families were quite content with the palliative services provided by the primary health care centre. Although they were able to receive palliative services available at no cost, their lack of resources limited their access to home supports such as mobility enhancing equipment, mattresses, or nutritional supplements. The commitment of health care professionals to provide palliative care with so very few resources as well as the support of neighbours and family members to care for the sick person were truly remarkable. While lack of training and insufficient time allocation to palliative care were among the main difficulties health care professionals faced, these were not experienced as severe hindrances in their practice with palliative patients. The study showed that the provision of palliative care in the primary health care setting is an effective strategy to ensure timely access to palliative care in low resource areas.

In sum, the experiential text of the developing world shows the lived drama people face in the context of a terminal illness. The experiences of patients, families, and health care professionals in developing countries reflect the tremendous impact of a terminal illness in the context of scarce resources, poignantly in Africa. They also show how families and communities mobilize themselves to secure the means to provide at least minimum comfort to the sick person. Developing countries are weaving a text that embodies the pain and the sweat of the peoples, a living text whose threads hold their very lives. Sepúlveda et al. (2003) write, "The extent of human suffering associated with HIV/AIDS and cancer in Africa today is tragic. The provision of palliative care is an urgent, unavoidable humanitarian responsibility. In many ways palliative care transcends medicine and reflects the values of society, both locally and globally" (p. 212). Understanding the text of the developing world takes us necessarily to revisit our values and priorities in the current times, to move ethics into life. The developing text of those in poverty reveals the state of the world. The time has come to rewrite this text.

UNDERSTANDING THE RESEARCH TEXTS IN THE NORTH

Coming from a Latin American perspective (and a nursing one from the developing world), finding a way to engage with the written text in the North has been difficult. The tone of this text evokes a different response. The tone of the global text addresses health care professionals, patients, families, and communities as they engage in the daily contingencies of life in Latin America and the developing world. The northern text speaks to us in another manner. Below, I present an overview of the northern texts and focus on those texts that relate more directly to this work.

Advances in palliative care research in the North have been quite significant in the last few decades with an increasing number of researchers focusing their attention on the terminally ill and funding agencies also recognizing the need to allocate research funds to this field. In Canada, the Canadian Institutes of Health Research (CIHR) have recently created the Palliative and End of Life Care Peer Review Committee (CIHR, 2005) in an effort to promote the conduct of high quality research to address the needs of the dying in Canada. This is undoubtedly a milestone in palliative care research development in Canada and the world that would not have been possible without the continuous advocating efforts of clinicians, researchers, and politicians as evidenced in the Canadian Senate's (2000) *Report on Quality End of Life Care* and important national events addressing the development of end-of-life care in Canada (Fainsinger, 2002). Indeed, research publications and national and international research conferences in Canada reflect the emergence of a vibrant research community greatly committed to the development of palliative and end of life care in the country.

Research and programme developments in palliative care in Canada make the country one of the leaders in the field internationally. The United Kingdom is also a well-known international leader in palliative care and the country credited with the beginnings of the modern hospice and palliative care movement. International leadership in palliative care is also shared by a number of other countries including the United States, Italy, Australia, Spain, Sweden, the Netherlands, and Ireland. In literature reviews published in palliative care journals, the majority of articles tend to come from papers published in American, Canadian, and British journals. This denotes not only the leadership of these countries in this field but also the predominance of the English language in the palliative care research international community. Publications in other languages including Spanish, Italian, French, Asian languages, and others are destined to remain within the communities that speak the language and are often left outside by English speaking authors due to language or accessibility limitations.

WHO has defined palliative care as "an approach that improves the quality of life of patients and their families facing the problems associated with life threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual" (WHO, 2002b, p. 84). In following WHO's mandate, research on pain and symptom control has been one of the main foci of palliative care research. The current world cancer situation with the majority of individuals diagnosed at a late stage (WHO, 1990, 1996, 1998, 2002b) has prompted WHO to work closely with palliative care experts from throughout the world to develop clinical guidelines for pain and symptom control (WHO, 1990, 1996, 1998). This has enabled health care professionals in many countries to provide proper treatment to the terminally ill. Yet as discussed above, a vast majority of individuals continue to be unable to access palliative care due mainly to insufficient drug availability, lack of resources, and of trained health care personnel (Sepulveda et al., 2003). Pain and other distressing symptoms are still a common experience and major problem for the terminally ill around the world.

The symptom text in palliative care

Research on symptom control shows that the prevalence of symptoms in the terminally ill continues to be high even in countries where palliative care is well developed (Emanuel, Fairclough, Slutsman, et al., 1999; Hockley, Dunlop, & Davies, 1988; Lichter & Hunt, 1990; McCarthy, Phillips, Zhong, et al., 2000; Morita, Tsunoda, Inoue, & Chihara, 1999 a, b; Power & Kearney, 1992; SUPPORT, 1995; Ventafridda, Ripamonti, De Conno et al., 1990; Tranmer, Heyland, Dugeon, et al., 2003). Symptoms are indeed one of the main threads of the palliative care text as their defying presence in the terminally ill continuously claims the attention of clinicians and researchers. Below, I present selected research studies that show the high incidence of symptoms in the terminally ill. While the amount of research studies on symptom control is quite large, the studies included in this section are mainly those that report the symptom profile of a large segment of the population. I have also included studies from different countries as a way to show an international perspective regarding the symptom experience in various populations.

The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT, 1995) is a well-known large-scale American study undertaken to improve the care of hospitalized individuals with life-threatening illnesses. Research findings from the first phase of the study showed that among individuals able to communicate in their last days of life, half of them experienced moderate or severe pain most of the time. In this group, over a quarter of those who died of cancer (1063) experienced severe pain three to six months before their death and more than forty percent during their last three days of life (McCarthy et al, 2000). The study showed several shortcomings regarding the care of these individuals. Study outcomes provided evidence of how difficult it was to significantly improve the overall situation of care following a two-year intervention (SUPPORT). The authors conclude that access to necessary and desired end-of-life care in hospital settings is not easy to achieve despite the implementation of interventions.

The prevalence of symptoms in the SUPPORT (1995) study among the critically ill is similar to that of a population-based retrospective survey conducted in the UK (Addington-Hall & McCarthy, 1995). This research study revealed that nearly ninety percent of the people who died of cancer experienced pain in their last year of life as well as in their last week of life. Over half of this group experienced other physical symptoms such as constipation, vomiting or nausea, and breathlessness among others. Symptom prevalence in this group was also similar to that of individuals who died of heart disease (McCarthy, Lay, & Addington-Hall, 1996) and dementia in the UK (McCarthy, Addington-Hall, & Altmann, 1997) although symptoms differed from one group to the other. Findings from these studies show that even in a country with a long trajectory in palliative care, access to symptom relief is not necessarily a granted right for every individual.

A large Canadian study involving hospitalised seriously ill individuals with cancer and non-cancer diagnoses also reported a high prevalence of symptoms among this population (Tranmer et al., 2003). In this study, patients with cancer reported high prevalence of pain, nausea, unpleasant taste, constipation, and vomiting whereas patients with a diagnosis other than cancer reported high prevalence of shortness of breath and cough. Prevalence of psychological symptoms including feeling worried, difficulty sleeping, feeling sad, difficulty concentrating, and feeling nervous were also high in both groups. In general, symptom prevalence was high in both groups with an average number of ten symptoms per group. Taking into consideration that the majority of patients in Canada die in the hospital (Heyland, Lavery, Tranmer, et al., 2000) the high prevalence of symptoms in this study may also be indicative of the severity of the symptom experience among the dying in Canada. The study also shows that access to palliative services in acute settings in Canada is far from optimal.

The experience of distressing symptoms is also common in individuals receiving palliative care. A multicentric Italian research study with persons with cancer receiving palliative care in the home (Peruselli, Di Giulio, Toscani, et al., 1999) revealed that a fifth of these individuals experienced severe and/or continuous pain during their last week of life. Over a third of the population in this study had severe or continuous symptoms during their last week of life and another third had at least one symptom at the moment of death. In a retrospective study conducted in London, UK to examine the prevalence of symptoms in patients referred to four palliative care settings, the most common symptom was pain, followed by anorexia, constipation, weakness, and dyspnea (Potter, Hami, Bryan, & Quigley, 2003). The mean number of symptoms per patient ranged from nearly three in outpatients and hospital patients to seven in hospice and community patients with an overall average of five symptoms per patient. Also, although the most common symptoms varied across settings, pain was the first most common in three settings and the second most common after weakness in community patients. These findings in countries with demonstrated leadership in palliative care show that the treatment of symptoms in the terminally ill is a common and continuous challenge.

Findings from another large scale study exploring the needs of dying persons in several cities in the United States (Emanuel, Fairclough, Slutsman, et al., 1999; Weiss, Emanuel, Fairclough &Emanuel, 2001) revealed that half of the study population reported moderate to severe pain. In this study, more than two thirds of the population experienced shortness of breath when walking, a third of this group had urinary or fecal incontinence, and nearly a fifth of the research participants had symptoms of depression. Of note here is that while the needs of this group were quite high, only a third was under hospice care or home health care. This shows that access to proper care is a continuous challenge for the terminally ill. It is disturbing to know that even in countries with a wealth of resources, many continue to experience needless suffering in their last months of life. In Australia, a similar situation occurs as many individuals suffering from progressive illnesses other than cancer are not receiving palliative care (Kristjanson, 2005). In general, individuals with a cancer diagnosis are becoming a privileged group compared to people with other end-stage diseases as the former are the ones most often able to reach palliative care (Emanuel et al.; Kristjanson).

A research study conducted in Toronto to explore symptom distress in patients with advanced cancer referred to palliative radiotherapy over a three-year period (Bradley, Davis, & Chow, 2005) reported a high level of symptom distress among patients. Symptoms were assessed through the Edmonton Symptom Assessment System (ESAS), a scale commonly utilized in the assessment of symptoms in the terminally ill (Bruera, Kuehn, Miller, et al., 1991). Fatigue was the most common symptom in the group followed by impaired sense of well-being, pain, and poor appetite. On average, patients reported between five and seven symptoms at the time of the assessment and very few patients denied any symptoms at all. Nearly a fifth of the patients reported either severe pain or severe fatigue. Also, patients with lower performance status scores (denoting deterioration in patients' functional capacities to engage in daily life activities) tended to report a greater number of symptoms and higher symptom distress than patients with higher performance scores. This latter finding shows that the patient's experience of symptoms usually intensifies as death approaches.

Indeed, symptom prevalence in the terminally ill is known to increase as death approaches (Oi-Ling, Man-Wah, & Kam-Hung, 2005). Studies focusing on the last days of life show a close relation between certain symptoms such as dyspnea and delirium and the closeness of death (Caraceni, Nanni, Maltoni, et al., 2000; Morita, Tsunoda, Inoue, & Chihara, 1999b). A retrospective Australian study examining symptom prevalence in the last three days of life found that the majority of patients had had on average between two and three major symptoms (Turner, Chye, Aggarwal, et al., 1996). Pain was the most common symptom in this study with nearly half of the patients reporting only moderate pain control. The symptom experience in the last days of life constitutes a double challenge as not only the patient's relief is at play here but also the bereavement of family members. The high prevalence of symptoms in the last hours of life is a concern here as this may have a deleterious impact on the family members' own bereavement experience.

A population study conducted in the Netherlands to examine symptom burden in the last week of life among cancer and non cancer older patients (Klinkenberg, Willems, van der Wal, & Deeg, 2004) reported the majority of patients experienced fatigue as the most common symptom followed by shortness of breath and pain. Confusion, depression, and anxiety were present in about a third of the patients. Nausea and vomiting were also common in twenty five percent of the population. Most patients in Klinkenberg et al.'s study experienced on average nearly three symptoms during their last week of life. The authors conclude that freedom from pain and other distressing symptoms was not a common experience among the older population in the Netherlands regardless of the place of death.

In sum, findings from studies on the symptom experience show that the terminally ill across countries and settings continue to suffer distress to a significant degree. In the South, they suffer because of little or no access to symptom relief. In the North, symptom relief, though available for many, is reaching only a few. In many ways, the terminally ill throughout the world are perhaps in solidarity with one another. The ones in the North share in their own bodies the suffering of the ones in the developing world. They bear the suffering of one another; an embodied solidarity so to speak; the kind of solidarity that only suffering in the face of death evokes.

Rethinking the symptom text in palliative care

> *To put it in Heideggerian terms, perhaps we are lacking an existential analytic of pain, an existentiale of painfulness, but one that would not supply pain with a sacrificial justification of any sort. (Nancy, 1997b, p. 99)*

As noted above, studies on symptom control in the terminally ill reveal that a large segment of this population continues to experience pain and other distressing symptoms even in the affluent countries where palliative care services are well developed. This situation leaves these countries also far from achieving one of the main goals of palliative care, i.e., to provide pain and symptom relief to those suffering from a life-threatening illness (WHO, 2002b). After conducting a research review to examine the extent to which WHO goals of palliative care were being met, Johnston and Abraham (1995) concluded that pain and symptom control in palliative patients was still showing undesirable results. A decade later, this conclusion still rings true both globally and in the industrialized world. Cicely Saunders' (1984) urgent appeal to alleviate the pain and suffering of the terminally ill remains as urgent as before.

What makes symptom relief such a challenge despite the numerous research advances to elucidate the underlying mechanisms of pain and other distressing symptoms in the terminally ill? The question resonates with the one about advances in cancer control in the industrialized world where despite the enormity of cancer research efforts cancer mortality rates have been only slightly reduced. Prevention and early detection rather than expensive cancer treatments have been the main strategies to reduce cancer mortality in North America (Canadian Broadcasting Corporation, 2005). Admittedly, cancer survival rates in affluent countries are higher than in the past, yet this also results in longer periods of suffering with limited access to proper relief. Globally, symptom relief is a tragic problem due to poverty and inaccessibility to basic treatments (Sepulveda et al., 2003; WHO, 2004). In affluent settings, similarly to a few years ago (Olweny, 1994), only a select group of the population has access to good symptom relief. Is symptom relief the privilege of a few? Are current approaches to symptom relief proving somewhat problematic in that they reach only a few of the suffering? Is there a hidden text underneath the text of symptoms? Is the symptom text covering a deeper, less graspable, unpresentable[7] text?

It is important to recognize that the development of palliative care services throughout the world has had an overall impact on the lives of the terminally ill. Studies reporting programme outcomes show shifts in the place of death from acute to long term care settings and the home (Bruera, Neumann, Gagnon, et al., 1999), earlier referral to palliative care services which facilitates earlier symptom control (Santos Salas, Acuña, Sepulchre & Arriagada, 2000), satisfaction with care (Wilkinson, Salisbury, Bosanquet, et al., 1999), and overall significantly better outcomes when a palliative care team is in place (Hearn & Higginson, 1998). Yet research evidence in palliative care is still developing and this makes it difficult to evaluate the overall efficacy of palliative care services (Hearn & Higginson; Wilkinson et al.) as well as to determine the most appropriate evaluation indicators (Stewart, Teno, Patrick, & Lynn, 1999; Teno, Byock, & Field, 1999). In general, the situation of the very ill around the world, including disadvantaged communities in affluent countries and those suffering from progressive illnesses other than cancer, reveals that several steps need yet to be taken for palliative care to achieve a significant global impact.

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[7] Drawing on Lyotard's (1984) notion of the unpresentable, Cameron (2006) offers a nursing philosophical elucidation of the unpresentable in nursing practices. I discuss this later in this chapter.

The difficulties in both gaining access to and providing good symptom relief as referred to above speak of the complexity of the symptom experience in the very ill. A number of elements co-participate in this experience making symptoms a rather obscure and challenging phenomenon. The symptom experience shows significant variation across individuals due to biological diversity, type of cancer, and accessibility to oncology and palliative treatments, among others. Individual responsiveness to the illness itself and the treatments together with patients' own historical, familial, and social situation are other important elements that also configure this symptom experience. The political, economic, and cultural context of the individual is also another critical element that adds to the complexity of the patient's experience. All of this together with the variety and diversity of elements that often emerge in the particular situation make the assessment, treatment, and evaluation of the symptom experience in the very ill quite a challenge in clinical practice.

The recommendation to pay careful attention to the physical, psychological, social, and spiritual dimensions of pain and other symptoms (Saunders, Baines, & Dunlop, 1995; Twycross, 2003) has assisted health care professionals over the years to develop a broader understanding of these symptoms as well as to treat them more effectively. The notion of total pain (Saunders, Baines, & Dunlop), where total denotes the various dimensions of pain, has also shown the significance of an interdisciplinary approach to palliative care interventions. Yet the current situation of the very ill shows that this approach alone does not suffice to achieve good symptom relief both globally and locally. An approach that takes into account the complexity of both the individual and the global situation, and provides us also with the opportunity to critically understand and address the economic and political determinants of pain and other distressing symptoms, is urgently needed if we are to generate a significant change in the current global trend.

In the past few years, research approaches that take into account the complexity of the patient's situation have gained growing recognition in palliative care (Bailey, Froggatt, Field, & Krishnasamy, 2002; Munday, Johnson, & Griffiths, 2003). Along with providing a more contextual understanding of experience, these approaches also assist health care professionals in developing effective palliative care practices (Canadian Senate, 2000). Below I present an overview of selected qualitative studies of the very ill. I return later to a discussion on measurement in the context of the very ill and its limitations in clinical practice.

The experiential text in the North

In their efforts to enhance quality end of life care, palliative care researchers are giving more attention to patients' perspectives in their research studies (Cohen, Macneil, & Mount, 1997; Fowler, Coppola, & Teno, 1999; Singer, Martin, & Kelner, 1999). In general, the tendency to privilege measurement research in palliative care and the scarcity of qualitative, narrative, and interpretive studies evokes the need to make these research approaches one of the priorities in the palliative care research agenda for the 21st century (Seymour & Clark, 1998; Walshe, Caress, Chew-Graham, & Todd, 2004).

In contrast to the experiential text of the developing world, the experiential text in the North denotes a more sophisticated approach to examine the experience of individuals in the context of a terminal illness. In developing countries, the goal of experiential studies is often to document the current status of patients and family members from their own perspective as well as to examine the need for palliative care interventions and revise those currently in place. In more affluent settings, the goals of experiential studies are often around the development of categorizations that represent the experience under study. Here, experiential research studies seek to generate conceptualizations that outline experience in more abstract (permanent and generalizable perhaps?) terms. There are also a number of recently published studies that offer a narrative account of the experience of dying individuals (Barnard, Towers, Boston, & Lambrinidou, 2000; Kuhl, 2002; Lawton, 2000).

The focus of the experiential text in the North is very diverse. There are studies that explore the overall experience of dying in the terminally ill (Barnard, Towers, Boston, & Lambrinidou, 2000; Bolsmjö, 2000; Carter, MacLeod, Brander, & McPherson, 2004; Engle, Fox-Hill, & Graney, 1998; Friedrichsen, Strang, & Carlsson, 2002; Lawton, 2000; McKinlay, 2001; Yardley & Davis, 2001; Yedidia and MacGregor, 2001). Other studies focus on one particular phenomenon. These include for example studies on dignity (Chochinov, Hack, McClement, et al., 2002; Street & Kissane, 2001); studies on hope (Herth, 1990, 1993; Benzein & Saveman, 1998; Benzein, Norberg, & Saveman, 2001); and studies on the meanings of a "good death" (Leichtentritt & Rettig, 2000; Payne, Langley-Evans, & Hillier, 1996; Tong, McGraw, Dobihal, et al, 2003; Walters, 2004). Below, I offer a review of selected studies that focus on the patient's experience. The title of each section reflects the experiential focus of the study.

The Text of Dignity

Dignity at the end of life has been a topic of interest in palliative care (Abiven, 1991; Johnson, 1998; Street & Kissane, 2001). To date, our knowledge of patients' perspectives on dignity is very limited (Chochinov, Hack, et al., 2004). Chochinov et al. (2002) conducted a qualitative study to explore the meaning of dignity for persons with advanced cancer and develop an initial conceptual framework for dignity from the perspective of these individuals. Three major dignity categories were identified including, illness-related concerns, dignity conserving repertoire, and social dignity inventory. The *illness-related concerns* category included patients' concerns about the effects of the illness on their sense of dignity. Level of independence and symptom distress were the major themes in this category. The *dignity conserving repertoire* category included matters that foster patients' sense of dignity. Dignity conserving perspectives (i.e., hopefulness, resilience, maintenance of pride) and dignity conserving practices (i.e., living in the moment, maintaining normalcy, and seeking spiritual comfort) were the themes of this category. The *social dignity inventory* category involved social or relational experiences that might compromise or enhance the patient's sense of dignity. Privacy boundaries, social support, care tenor, burden to others, and aftermath concerns were themes of this category.

Following the findings from the study above, Chochinov et al. (2002) proposed a developing conceptual model of dignity where dignity results from the interrelatedness of the above three categories. The authors suggest this model offers clinicians a means to expand the range of dignity enhancing interventions as they provide relief to terminally ill patients. The exploration of dignity from the perspective of patients in this study suggests in a sense a more experiential understanding of dignity. The qualitative nature of the study offers some insights into the patient's experience. Yet the text of complex categories, themes, and sub-themes of the model denotes a shift from the experiential text of the individual. This makes the application of this dignity model difficult in clinical practice.

Street and Kissane (2001) examined the relational and embodied aspects of dignity at the end of life. Participants in this study expressed their continuous struggle to be treated with respect and not as objects to preserve their sense of dignity. The loss of bodily capacities was often associated with the loss of dignity. Practices to cover up the body such as changing the smell of malignant wounds preserved patients' sense of dignity. The integrity of the body was very close to the individuals' sense of dignity. Their relations with others were closely related to their sense of dignity. For some patients making the lives of their loved ones miserable as a result of their illness affected their own dignity. For some family members, bodily closeness with their loved ones was significant to maintain their dignity. The authors conclude that a broader understanding of dignity is needed in palliative care practice. They invite palliative care providers to be mindful of the kinds of dignified death that are meaningful for the terminally ill and their family members.

While understanding the experience of dignity is important, we must be careful not to transform the lived notion of dignity into a clean model that leaves this lived sense aside. In practice, health care professionals face complex situations where several elements are concurrently at play. The unpredictability of a symptom or the sudden changes in the condition of a patient are lived tensions that embody the complexities of a practice. The world of practice is full of uncertainties and ambiguities; here life is lived not as a chain of events but a web of relations, a structure in which no part has priority over the other (Gadamer, 1998). Our world of practice requires approaches that are attentive to the swings of life. Shifting from the text of experience to the text of categories displaces practice and experience to the margins. The resulting text distances us from the lived realities of practice. It leaves us bereft.

The Text of Hope

The study of hope at the end of life has also attracted the interest of palliative care providers (Herth, 1990, 1993; Benzein & Saveman, 1998). Here, I include a qualitative study (Benzein, Norberg, & Saveman, 2001) in which the lived experience of hope was explored from the perspective of individuals with cancer receiving palliative care in the home. Participants were invited to talk about their experience of living with incurable cancer as well as about situations in which they had experienced hope. Participants' experiences of hope included hope for being cured, hope for living as normally as possible, the presence of reassuring relationships, and being at peace with life and death. Participants' symptoms often made their hope for a cure less strong. Their struggles to live a normal life and not being stigmatized because of their illness were also important for their sense of hope. Being at home was also an important component of hope as it enabled them to participate in decisions related to their care and their everyday life. Being well prepared for death was also important for their experience of hope.

Benzein et al. (2001) state that the findings of this study reveal the lived experience of hope as a multidimensional experience in which the tensions between hoping for something (i.e., cure) and living *in* hope in the face of death coexist. This study contributes to our understanding of hope from the perspectives of patients. The study also elicits insights about the experience of the very ill. The deterioration of the body was a common theme in participants' responses. Bodily deterioration was also closely related to the individuals' sense of dignity in the studies discussed above. Even though these studies focus on a particular experience, their results evoke questions that relate to the overall experience of the terminally ill. How do they experience their own bodies during this time? How does the body reveal conceal itself? How do nurses engage with this experience?

The Text of Pain

The large number of studies of pain in persons with cancer has resulted in significant improvements in pain management for this group (WHO, 1996). While not being the most common symptom pain is one of the most feared ones in the last few months of life. I present here a grounded theory study (Duggleby, 2000) that explored the pain experience of elderly individuals with late stage cancer. For participants in this study, suffering was "the pain." Their experience of pain included both physical and psychological pain as a result of loss of physical function, helplessness, and dependency. Enduring was identified as the way participants dealt with their suffering. Enduring involved maintaining hope and adjusting to the pain. Maintaining hope for pain relief as well as for life after death was important for participants to endure their suffering. Trusting in a higher being and finding meaning in life also contributed to their sense of hope. Participants identified dealing with the uncertainty of pain, accepting the pain, and minimizing the pain as ways of adjusting to their pain.

Duggleby's (2000) study helps us understand the experience of pain from the patient's perspective. Enduring the pain was important for these individuals. It enabled them to live through their suffering and pain. In Cameron's (1993) inquiry into the meaning of comfort, patients often spoke of enduring their illness. Here enduring involved a sense of waiting, waiting to recover as well as learning to integrate this experience into their lives (Cameron). One wonders about the theoretical representation of enduring and the extent to which it modifies our lived understandings of this experience. While Duggleby's study offers insights into the personal experience of pain, the delineation of this experience in theoretical terms also introduces an element that is strenuous to the experiential understanding of pain. The text of experience hides behind the theoretical text.

The Text of Experience

In this section, I include a number of studies that explore the perspective of individuals with a terminal illness in relation to their experience of illness. As most studies refer to their experience as *the experience of dying,* in citing these studies I keep the authors' way of referring to the patient's experience.

Singer, Martin, and Kelner (1999) undertook a secondary analysis of data gathered through a study on advanced directives to explore the meaning of quality end-of-life care from the point of view of persons suffering from advanced chronic illnesses. The authors identified five end-of-life care domains that were relevant for the participants. These included receiving adequate pain and symptom management, avoiding inappropriate prolongation of dying, achieving a sense of control, relieving burden, and strengthening relationships with loved ones. These domains, Singer et al. state, are simpler and more specific than professionals' models and reveal important differences between healthcare professionals' and dying patients' perspectives. The authors highlight the need to incorporate patients' views in our efforts to improve end-of-life care to ensure that their concerns are addressed.

Payne, Langley-Evans, and Hiller (1996) conducted a study to explore the perceptions of a good death among terminally ill patients and palliative care professionals. The results showed differences in their views in relation to what makes a "good" death. Patients' views were more related to the way of dying, i.e. dying in one's sleep or dying quietly, whereas health care professionals' views were more focused on symptom control. Payne et al. suggest that health care professionals' concern with symptom control may reflect the influence of the medical model in their understanding of a good death as it relates so directly to the interventions they are able to offer.

Engle, Fox-Hill, and Graney (1998) explored qualitatively the experience of living-dying in residents of nursing homes. Thirteen residents suffering from advanced cancer participated in the study. The findings were organized in two conceptual models, a resident model and a nursing home environmental model. The resident model represents the residents' experience and includes the concepts of dying, pain, nutrition, religion, caregiving, care receiving, and coping. Study participants often spoke about being more focused on living than on dying in the nursing home. Common themes related to dying included *"thinking of dying," "having little or no fear of dying,"* and *"finding comfort in their religious faith."* A few participants also reported anxiety about dying or about their thoughts of dying.

Black residents in Engle et al.'s (1998) study reported moderate to severe pain as well as poor pain relief more frequently than white residents. Participants also talked about their loss of appetite and pleasure eating food. They spoke about their religious beliefs and practices, i.e. believing in God or attending church. Looking after other residents in the nursing home was reported as a very meaningful activity. Residents also referred to the various ways health care providers had to approach them. Some participants described their difficulties to understand the technical language of their attending physicians. Residents described several ways of coping with their situations including anger, withdrawal from the situation, direct confrontation, humour, and talking with the nursing home staff.

Based on their study findings, Engle et al. (1998) offer several recommendations for the participants' nursing homes. In doing this, they remind us that one of the ultimate goals of clinical research is to offer a meaningful contribution to the world of practice. The translation of research findings into knowledge that is potentially applicable in the practice setting makes the world of research closer to the world of practice and practitioners. It restores their originary relation. Engle et al. assist us to bring these worlds closer to one another.

Another qualitative study on the experience of dying is that of Yedidia and MacGregor (2001). The goal of this study was to explore the perspectives of *dying* individuals. The majority of participants had late-stage cancer. During the interviews, participants were invited to describe their experience of being seriously ill. The interviews also included questions about "what provides strength, what is meaningful, what is difficult, how they view the future, and how they perceive death" (p. 810). Based on their findings, the authors outlined seven motifs characterizing how participants viewed their experience and their approaching death. These motifs also reflected the ways in which participants tended to face their previous life experiences. The motifs identified included the struggle motif, the dissonance motif, the endurance motif, the incorporation motif, the coping motif, the quest motif, and the volatile motif. I briefly describe them below.

The struggle motif, *living and dying is a struggle,* characterized the experiences of participants who had already gone through many difficulties in their lives and for whom dying represented one more struggle. The dissonance motif, *dying is not living,* represented the experiences of those whose current situation was a sharp contrast with their past life experiences. For them, dying was not part of their life but constituted the end of it. The endurance motif, *triumph of inner strength,* described the experiences of those whose inner strength had always enabled them to face difficult events in their lives. The incorporation motif, *belief system accommodates death,* represented the experience of those who strove to understand their dying within their own frame of beliefs. For them, their experiences were part of a larger plan that was in the hands of a higher being. The coping motif, *working to find a new balance,* outlined the experiences of those individuals who sought other sources of strength to face their dying as positively as possible. The quest motif, *seeking meaning in dying,* characterized the experiences of those for whom a constant search for meaning enabled them to live through their experience. The last motif identified by the authors (Yedidia & MacGregor, 2001), the volatile motif, *unresolved and unresigned,* described the experiences of those whose illness situation was an overcoming experience difficult to resolve.

Yedidia and MacGregor (2001) state that the motifs above delineate the personal stories of their participants. The relevance of these motifs in the authors' view is that along with describing the participants' perspectives they provide a venue for healthcare professionals to respond creatively to the wide range of experiences of these individuals. The value of these motifs is that they situate the experience of people with late-stage disease in the context of their own life experiences. The authors show the significance of understanding people's experiences of illness within their own life context. When we are able to see patients' experiences beyond the context of the disease to reach the context of their lives, we come to realize the immensity that lies behind each individual (Cameron, 1998).

Yedidia and MacGregor (2001) state that the motifs above are not meant as a model to be applied to all people suffering from a terminal illness. Rather they offer them as a way to expand our understanding of this human experience. The study shows a genuine concern to stay close to the participants' world. One wonders about the categorical text of the motifs. Is it a step away from the experiential text of participants? Here we see the tension that staying close to lived experience evokes. On the one side we engage in an open and conversational manner with the people themselves. On the other, prevailing thinking modes in academia force us to transform the text of experience into a set of categories, motifs in this case, seemingly (and deceivingly) good equivalents of experience.

Bolmsjö (2000) reports the results from a qualitative study on the existential concerns of persons with cancer in palliative care. Interviews with study participants included questions about their present situation, the future, meaning, remorse, respect, information, and confidence. The authors developed six categories including dignity, autonomy, meaning, guilt, relations, and communication. *Dignity* described the individual's need to be seen as a living person to the end. Physical symptoms and loss of control over bodily functions were related to participants' sense of dignity. *Autonomy* was another concern for study participants. They spoke about their fears of losing their capacity to make decisions and depending on others as well as on machines. The *meaning* category described participants' need to engage in meaningful activities. This involved being with their children and grandchildren or doing ordinary things such as stroking the cat, going for a walk, or talking with a friend. Not giving up, struggling for life, and having something worth striving for also helped these individuals to find meaning in their experience.

The *guilt* category in Bolmsjö's (2000) study reflected participants' feelings of guilt. They experienced guilt when they attributed their illness to their actions in the past or when they saw their children sad. Some participants did not show interest in addressing this topic. The *relations* category described participants' concerns about their relations with others. The need to be at peace with everybody was a common concern. They also expressed concerns about leaving alone their loved ones. Finally, the *communication* category reflected issues of communication between patients and health care providers. For some, how they had been told about their condition generated great confusion in their lives. Some described their decision-making conflicts after hearing contradictory information from staff members. Based on the study findings, Bolmsjö highlights the need to address in clinical practice the existential concerns of palliative patients.

The findings from Bolmsjö's (2000) study reflect common concerns in the experience of palliative patients. Similarly to other studies (Chochinov et al., 2002; Engle et al., 1998), participants in this study voiced their need to be treated as a person to the end. The decline of the body together with the experience of physical symptoms also emerged as important concerns. Bolmsjö's study also shows what helps patients to make their experience meaningful. This involved at times doing very small things. While this is perhaps common knowledge among palliative care providers, there are many who die in acute settings where these concerns tend to be forgotten. Bolmsjö's findings can be of help in these settings. Bolmsjö also invites health care providers to speak with tenderness to patients as they are quite sensitive and vulnerable during this time of their lives. Etymologically, "tender" means easily broken or injured (Hoad, 1996) and is also related to tend, tender, or offer unto (Skeat, 1963). Tenderness invites attentiveness to the fragility of the very ill. Participants' voices in this study are a claim to tend to their fragility.

Gray, Sinding, and Fitch (2001) discuss their experience with the production of a research play about women with metastatic cancer. The authors describe the difficulties the theatre group (researchers, women with breast cancer, and actors) faced to acknowledge the seriousness of metastatic breast cancer. Seeing the women with breast cancer as women rather than victims of disease was a central theme during the production. Letting hope coexist with the difficulties of metastatic cancer was also a significant theme. Isolation from others was a common experience for the women as people tended to treat them in a different manner than usual. One of the goals of the play is to raise awareness about the isolation these women experience in society as a result of people's difficulties to engage with suffering and fragility.

Gray et al. (2001) describe the tensions these women experience while facing the need to live a normal, ordinary life and also the need for others to acknowledge their illness experience. They write about the shifting contexts of these women's experiences and remark the need to remain attentive to the changing character of their experience. Through their work, Gray et al.'s call healthcare professionals, family members, and society in general to never take for granted the meanings of the experience of metastatic cancer. They also highlight the women's drama facing their own mortality at the same time as striving to live as normally as possible. Their work shows the woman who in the midst of illness struggles to be a person. Gray et al.'s research work stays close to experience. Like a festival (Gadamer, 1989), a drama gathers people together and situates them in the world of human experience. Through drama, the authors re-ground the study in life.

In sum, the experiential text in the North offers insights into the experience of the very ill. These experiential studies are the beginning steps to develop an understanding of the experience of the very ill that is close to life. They also show how difficult it is to remain close to experience. The tendency to envelop the experiential text of participants with categories that keep us at a distance from the lived text is discouraging. Categorical conceptualizations reduce the complexity of the experience of the very ill. This in turn limits their applicability to the world of practice. The lived text conceals itself behind these representations.

Gadamer (1989) writes, "The spoken word interprets itself to an astonishing degree, by the manner of speaking, the tone of voice, the tempo, and so on, and also by the circumstances in which it is spoken" (p. 393). In contrast, the challenge of the written text, he writes, is that it needs "to be transformed back into speech and meaning" (p. 393). In writing down the text of experience, we must strive to show the meanings of experience as they reveal themselves in a particular context. We must create texts that evoke the primordial threads of the lived text of experience, texts that *apply* to our own particular situation.

ON THE MEASUREMENT COMPORTMENT IN THE PALLIATIVE CARE TEXT

> *The relationship of the human being to measure is not entirely comprehended by quantitative measurability. Indeed, it is not even raised as a question. The relationship of the human being to what gives a measure is a fundamental relationship to what is. It belongs to the understanding of being itself. (Heidegger, 2001, p. 100)*

One of the most common features of palliative care research in the North has been the trend to develop and utilize measures to assess primarily the symptom experience in the very ill as well as other related events. The utilization of instruments in the palliative care setting serves several purposes including to describe and compare in a systematic manner people's experiences at the end of life (Stewart et al., 1999), to effectively assess illness-related symptoms (Mazzocato, Stiefel, Jonge, et al., 2000), to speak a common and universal language among practitioners (Bruera, Schoeller, Wenk, et al., 1995; Bruera & Pereira, 1998), to help clinicians keep accurate and objective records (Bruera & Lawlor, 1997; Zhukovsky, Abdullah, Richardson, & Walsh, 2000), to evaluate patients' response to clinical trials (Caraceni, Brunelli, Martini, et al., 2005; Pickering, 2002), to ensure quality end-of-life care (Zhukovsky et al.), and to generate *robust* evidence about palliative care interventions (Jubb, 2002). Also and perhaps most importantly in the clinical setting, the utilization of instruments has shown to be helpful in the early detection and treatment of symptoms as well as in the assessment of complex clinical episodes that involve the superposition of several other dimensions along with the physical component of the illness.

There are a wide variety of measures available in palliative care for use in research and practice. These range from single-item measures such as the visual analogue scale, numeric, or verbal scales to assess pain or other distressing symptoms to multi-item multidimensional measures (Pereira, Otfinowski, et al., 2001). The Edmonton Symptom Assessment System (ESAS) is a well-known multidimensional instrument that assesses on a scale from zero to ten the intensity of nine symptoms including pain, nausea, depression, anxiety, drowsiness, appetite, shortness of breath, activity, and well-being. (Bruera et al., 1991). The ESAS has proved very effective in assisting health care professionals to assess the symptom experience of the palliative patient as well as to consider other areas in the patient's symptom experience (McKinnon, undated). In general, the palliative care text shows that measurement instruments are indeed one of the primary methods of assessment in the palliative population.

Although the utilization of measurement instruments with the palliative care population can be advantageous in clinical practice, their application also faces several limitations. First, while the number of measures available in palliative care is quite large, evidence that they indeed measure what they are intended to measure is not large enough (Pickering, 2002). Second, as these instruments are not yet as well established as other commonly used measures in health care, i.e., the Glasgow Coma Scale or the APGAR scale, their acceptance is often limited to the circles familiarized with their usage (Pickering). Third, the rapidly progressive nature of the clinical condition of the terminally ill makes it difficult for patients to answer these questionnaires on an ongoing basis and often results in proxies or health care professionals answering on their behalf (Broberger, Tishelman, & von Essen, 2005; Higginson, Wade, and McCarthy, 1990; Maguire, Walsh, Jeacok, & Kingston, 1999). Fourth, similarly to the situation of many in developing countries (Higginson & Bruera, 2002), low literacy levels among the older and language barriers in immigrant populations in affluent countries including their unfamiliarity with the format of these questionnaires can also act as impediments to their proper utilization. Last but not least, the high degree of weariness of the very ill may also result in these measures adding an extra burden to their already burdened bodily situation (personal communication with palliative home care nurses).

Measurement approaches in palliative care research also meet with several difficulties. Randomized controlled trials and psychometric research often fail to meet statistical requirements to achieve significance (Jubb, 2002). Low accrual rates (Addington-Hall, 2002; Entwistle, Tritter, & Calnan, 2002, Kelvin, 2000), high attrition rates due to illness progression and death of participants (Jordhøy, Kaasa, Fayers, et al., 1999), and participants' failure to fill out the measures according to the research protocols (Pickering, 2002) are common experiences for measurement researchers in palliative care. Also, the use of proxies in retrospective studies examining the last weeks of life of their family member raises methodological concerns regarding the accuracy of their ratings (Bucher, Trostle, & Moore, 1999; Higginson, Priest, & McCarthy, 1994). Along with these limitations, the use of instruments such as lengthy and complicated questionnaires in palliative care research also evokes several ethical concerns that require careful examination at the proposal stage as well as throughout the entire research process (Cameron, Santos Salas, & deMoissac, 2004; Ross, Cameron, Santos Salas, & Whelly-Southwell, 2003). These limitations are also prompting researchers to find approaches that take into consideration the complexity of end of life situations (Munday, Johnson, & Griffiths, 2003; Walshe, Caress, Chew-Graham, & Todd, 2004).

On the Measurability of the Bodily Experience in the Very ill

The array of limitations in the utilization of measurement devices in the palliative care population as discussed above shows that measurement approaches in the terminally ill can be quite problematic. This poses the following question, are these limitations in themselves just a *symptom* of the problem or the problem itself? Wherein lies the real difficulty in the utilization of measurement in palliative care? A closer look at these limitations shows that many of these originate in the bodily situation of the very ill themselves. Often they are too ill and too tired to fill out a questionnaire. Their progressive bodily decline prevents them from keeping up with research protocols over time. Bodily speaking, they are unable to remain the same over time. As their illness progresses, they experience a turn to the worse. This alone is one of the greatest obstacles to measurement and the evaluation of interventions in palliative care. Is it in the body itself where the resistance to measuring is found in the first place?

In discussing the phenomenon of the body, Heidegger (2001) raises the question of measurability and measuring. He discusses measurability as a property of things as well as a quality inherent to the human comportment toward things where we continuously measure up to what we have before us. "In all comprehending of something as something, for instance, of the table as a table, I myself measure up to what I have comprehended" (p. 100). This measuring up, in Heidegger's terms, is ontologically different from quantitative measuring as observed in science. In fact, he remarks, quantitative measuring finds its own roots in measuring up as a structural element of human comportment. In measuring a thing, Heidegger explains, we come to represent the thing as an object with measurable properties, i.e., width and height. Yet this numerical information does not show the being of the thing as it exists in the world. In this sense, measuring in a quantitative sense alters the presencing of the thing and our manner of relating to its very being.

In addressing the question of the body and the question of the conflictive distinction between *soma* and *psyche*, Heidegger (2001) remarks the character of measuring as a way of access to a domain of being. Through his analysis, he takes us to the question of method which in its etymological roots already denotes our way toward something. "Method is the way leading to a subject matter—to a subject field. It is the way we pursue a subject matter" (pp. 101, 102). The relation between the way toward something and the subject matter itself, he observes, cannot be decided in advance and depends ultimately on the own being's manner of being. This takes Heidegger to discuss the close interrelation between the question of measurability and the question of method as a necessary step to address the question of the body. This way of addressing the question is a way "to see how the phenomenon of the body resists measurability and what entirely different method the determination and interpretation of the body's bodying forth are required in and of themselves" (p. 102).

Heidegger's (2001) discussion above illuminates our efforts to comprehend the measurement comportment in the text of palliative care. His discussion provides a way to understand the difficulties that this comportment presents in the context of the very ill and in the face of their distinctive bodily situation. It also raises the question of whether measurability as the prevailing way toward comprehending the phenomenon of the body in the very ill has altered or has the potential to alter our manner of relating to the experience of the very ill as a whole. Below I discuss the tension that measurability evokes in palliative care in the context of the experience of delirium in the very ill.

Delirium is an event quite evocative of the intensity of the bodily experience in the very ill. Characterized as a cognitive disorder, delirium is known to develop in the majority of patients who are terminally ill in their last weeks of life (Bruera & Pereira, 1998; Caraceni, Nanni, Maltoni, et al., 2000; Lawlor, Gagnon, Mancini, et al., 2000). This high incidence of delirium has led palliative care researchers to pay close attention to this complex and distressing event to elucidate treatment approaches that prove effective in the stabilization and potential reversal of this condition (Centeno, Sanz, & Bruera, 2004). Studies have shown that when detected earlier in the illness trajectory, the chances to reverse delirium are higher than in the last days of life (Fayers, Hjermstad, Ranhoff, et al., 2005). Its prognostic value (Lawlor et al.) together with its potential reversibility (Centeno et al.) makes the study of delirium a significant research endeavour. Also, the high value placed on clarity of mind and cognitive autonomy in the industrialized countries (Fainsinger, deMoissac, Mancini, & Oneschuk, 2000) makes the study and treatment of delirium an important priority in the palliative care research agenda.

One of the hallmarks in the study of delirium has been the development and refinement of assessment methods (Hjermstad, Loge, & Kaasa, 2004). These methods often involve the assessment of cognitive functions through measurement questionnaires. The Mini-Mental State Examination (MMSE), a screening instrument to assess cognitive status in the elderly (Folstein, Folstein, & McHugh, 1975) is one of the instruments most commonly utilized as a screening tool in the assessment of delirium in palliative care (Fayers et al., 2005). The utilization of this instrument is considered a useful method in the early detection of delirium in the terminally ill (Centeno et al., 2004; Fayers et al.) and it is widely recommended (Fainsinger & Young, 1991; WHO, 1998). In fact, research studies have shown that variations in MMSE scores can indicate the initial development of delirium and thus facilitate early treatment of underlying causes and prevention of further complications (Lawlor, Gagnon, Mancini, et al., 2000).

The utilization of the MMSE is also recommended in combination with delirium-specific questionnaires (Pereira et al., 1997). Several instruments have been reported in the literature including the Agitation Distress Scale, the Confusion Assessment Method (CAM), the Memorial Delirium Assessment Scale (MDAS), the Confusion Rating Scale, and the Delirium Rating Scale, among others (Centeno et al., 2004; Hjermstad et al., 2004). Hjermstad et al. conducted a study to examine common methods of assessment of cognitive failure or delirium in palliative patients. The MMSE was the most commonly utilized instrument alone or in combination with other scales. The MDAS followed by the CAM were the second and third most frequently utilized scales respectively. The authors point out the need for further research studies of assessment methods of delirium that both suit the clinical condition of palliative patients and facilitate its early detection and treatment.

The utilization of instruments in the detection and evaluation of delirium such as the ones indicated above also faces several limitations. In the case of the MMSE for example, even though its appraisal is quite good among palliative care experts, its utilization still evokes several concerns. Its length raises the question regarding its appropriateness in severely ill individuals (Fayers et al., 2005). Its application is at times considered cumbersome among clinicians (Hjermstad et al., 2004) and nurses (personal communication with palliative home care nurses). Its sensitivity to detect minor cognitive changes is not clear (Hjermstad et al.). The lack of simplicity in these questionnaires, many of which involve the performance of complex tasks such as mathematical calculations or dexterity demonstrations, also limits their applicability in seriously compromised patients (Hjermstad et al.). Another limitation is that evidence regarding the validity of these questionnaires is at various stages of development (Fayers et al.; Hjermstad et al.). In addition, evidence to date is mostly based on studies with patients admitted to palliative care units (Hjermstad et al.) whose conditions tend to be more complex than those in the home (Fainsinger et al., 2000).

On the Limits of Measurability

> *What the photograph reproduces to infinity has occurred only once: The photograph mechanically repeats what could never be repeated existentially (Barthes, 1981, p. 4)*

Along with the limitations indicated above, there is one rarely questioned in palliative care, namely the a priori assumption that the delirious event is measurable. Measurement has established itself as the primary way of access to the delirious event. Yet in granting methodological primacy to this way of access, we run the risk of reducing our understanding of delirium. We reduce delirium to one *representation,* i.e., that of a pathologically complex brain syndrome graspable and confinable within the limits of science. Experience itself remains concealed behind our measurement comportment towards delirium.

This is not to question the value of pathology in the palliative care approach. The pathological lens is indeed of great value in clinical practice as it assists physicians and nurses to provide competent and timely treatment to the very ill. It is a necessary component of palliative care. The potential reversibility of delirium when detected early in the illness trajectory demands attention to the underlying pathological mechanisms before deciding on the most suitable course of action. Yet this lens alone cannot provide a full understanding of the experience of delirium. There are several experiential elements that this knowledge system leaves aside. Taking it as the main knowledge system to approach delirium leaves patients and families bereft.

Brenda Cameron (1998, 2006) relates the story of a man who becomes delirious during the night shift in an oncology ward. The night nurse describes this episode during morning report.

> 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. (Cameron, 1998, p. 220)

Through her text, Cameron shows nurses thinking through this episode. We hear the night nurse's concern as she and the resident tried to figure out this episode. In the end, she mostly stayed in the room with Mr Phillips, reassuring him now and then, making sure he was safe. The day nurses are also able to relate to the night nurse's concern. They know this episode marks a vital moment in Mr Phillips' life. They engage in a dialogue about his present situation, they discuss his lab tests and his treatments. But they know this information is not enough to explain this night episode. They talk about his wife, his life as an esteemed author, his relapse, his isolation from others, their difficulties to engage in conversation with him. Cameron shows how careful the nurses are not to rush to conclusions about Mr Phillips's delirious episode. While not leaving out the pathological text, they add other layers to the story. They know this night might be Mr Phillips's way of facing his near future.

In her hermeneutic analysis of Mr. Phillips's episode, Cameron (2006) shows the many texts co-present in this situation. Delirium as a psychological emergency or a metabolic disorder, she remarks, is only the first reading of this situation. While necessary, staying with this text alone, Cameron writes, would keep the co-texts of this situation hidden. These are the texts the night and day nurses try to understand as they talk during their change-of-shift report. Mr Phillips's episode shows something deeper than an organic imbalance. The sky falling down before his very eyes reveals the fragility of his own existence, his looking directly at his own mortality. Nurses understand these concealed texts and engage with the utter *alterity* of this human experience.

Cameron (2006) refers to this episode as an "*eruption of being*" that bears the "*unpresentable*" of life, that which is other, strange, unrecognizable. This "eruption of the unpresentable into our very midst" (p. 28) evokes the need to engage directly with experience, to stay with it before any lenses are applied to it. Mr Phillips's nurse recognizes the otherness of his delirious episode. She sees more than a metabolic disorder, more than a brain dysfunction. She recognizes the suffering of a human being in the face of death, in front of what is truly Other (Levinas, 1987). This existential recognition, Cameron writes, enables the nurse to hold this episode in its otherness.

In their daily practices, nurses learn to recognize and engage with the otherness of disease. Skilled nurses are able to quickly grasp the many nuances of a particular moment and enact their nursing judgement in a competent and ethical manner. The complexity of this nursing judgement is irreducible to categorical terms. It is a matter of concern when the language of instruments begins to replace the language of the practitioner and more so when these instruments become the mediators of experience in clinical practice. While nurses appreciate the clinical utility of instruments such as the MMSQ, they also feel concerned when the frequency of this instrument is dictated in practice (personal communication with palliative home care nurses). They know that numerical language alone can flatten the full scope of their patients' experience.

Is the Measurement Comportment Problematic in Practice?

While recognizing the clinical value of assessment instruments in palliative care such as the ESAS, it is also important to raise the question of measurability in the context of the very ill. In his essay "*The Question Concerning Technology,*" Heidegger (1977) raises the question of technology and shakes our common understanding of it as simply a "means to an end" or a "human activity" (p. 4). He discusses the ultimate character of technology as a mode of revealing that shows things as standing-reserve, "ordered to stand by, to be immediately at hand" (p. 17). Burch (1986) explains this mode of revealing further as technology's power to grant "a perspective through which we do control and order the world" (p. 10). Technology's character, Burch remarks, shows the presumption that lies at the heart of contemporary Western thinking as expressed in Western societies' "conviction... that in principle *nothing* escapes our grasp, and hence that reality belongs to us more than we do to it" (pp. 5, 6, emphasis mine).

How does the discussion concerning technology relate to our discussion on measurement? How are these two topics related? In a sense, the question of measurement is related to the question of technology. Measurement as a way of access to reality shares the same roots and aims of technology itself. It is a mode of revealing that similarly to technology, "conditions in fundamental ways, our self-understanding, and our relations to other human beings; our whole experience of the world" (Burch, 1986, p. 15). Burch's philosophical analysis of technology elucidates further the relation between technology and measurement. Burch's contrary-to-conventional-notions *nonneutrality thesis* about technology brings a philosophical perspective to instrumentality that reveals unchallenged and unquestioned assumptions within the prevailing scientific-technological framework.

> The thesis of nonneutrality claims instead that merely to have a tool ready to hand is in itself, *whether for better or for worse*, already a transformation of experience... Reality itself is changed because of the possibilities the instrument grants. In their mediation,

> instruments effect both material changes and existential-ontological transformations. The use of tools is a form of our being in the world, and thus, a fundamental mode of the original disclosure of things, that is, of how the world comes to be for us as a world in the first place (Burch, 1986, p. 15).

What do instruments conceal reveal about our practice with the very ill? In what way do they transform experience? Heidegger (2001) reminds us that the prevailing scientific way of thinking has numbed our capacity to be astonished before the simple, that which is before our very eyes. Delirium as a bodily way of being in the world in the face of death has little appeal to the scientific mind. *Delirium* as a lived bodily expression in the nearness of death is transformed into psychiatric and somatic measurable fragments. Our understanding of delirium as an expression that englobes much more than a chemical or metabolic disorder is irreversibly lost.

What makes measurement comportment problematic in our practice with the very ill? Admittedly, clinicians do not rely exclusively on measurement instruments as the only method of assessment in the context of the very ill. Also, along with the utilization of these instruments in clinical practice, the expertise and judgement of the clinician always comes forth. Yet it is a concern to see how easily the language of instruments substitutes the experiential language of the practitioner and makes it acceptable, common, *universal*. Going back to Burch's (1986) nonneutrality thesis, this apparently innocuous substitution already implies an existential-ontological transformation of experience. We must continuously revisit measurement approaches in the context of the very ill and their potential to impoverish experience before our eyes.

In sum, while measurement as a method of assessment shows benefits in clinical practice, granting methodological primacy to this method can also prove problematic. In presuming the neutrality of measurement we forget the various hidden yet present co texts of experience unreadable through the method of science (incomprehensible perhaps?). Also, in assuming the language of measurement to communicate our clinical findings, we sever experience from the world where it reveals itself. This has potential to have a deleterious impact on our manner of relating to the very ill and their experience. In the next section, I briefly discuss limitations of measurement in clinical practice. I end this chapter taking the palliative text in the North back to the global text.

A WAY FORWARD

One of the first times April was asked to describe her back pain, she described it like having slept all night with her back on a bump on the ground. She soon realized that her answer did not help the health care professional in front of her. She was then asked to rate her pain on a scale from zero to ten. As a new patient, she couldn't figure out the meanings of these numbers. What does a five or a two mean? She wondered. Later on, she became familiar with this way of assessing her symptoms. She learned to speak in these terms. She wanted to make sure she was understood. She knew these numeric signs legitimized her experience before others. Her own lived sense turned into something anecdotal, subjective, unreliable.

April's anecdote in the cancer clinic shows how granting measurement methods a position of privilege in clinical practice has potential to transform our manner of relating to the very ill. In the context of modernity, Taylor (1991) writes that individualism has harmed our capacity to relate to others and now we are often in need of mediators to relate to one another. This difficulty to relate to others has permeated all spheres of our life. One wonders if the introduction of assessment instruments in our practice with the very ill is reflective of our modern need for mediators. They mediate the experience of the very ill distilling its meanings into acceptable categories before the palliative care community. Yet at the same time these mediators distance us from the person of the very ill. They make us forget how to engage with the unrepeatable particularities of each individual.

Gadamer (1989) speaks of the secondary relevance of application to the discovery of knowledge in the eyes of the modern scientist. Severing knowledge from the textual quality of experience, Gadamer writes, leads science to dismiss knowledge that falls outside the scope of its methods. In the same vein, the predominance of the methods of science in palliative care practice has led to the devaluation of the experiential understanding of the practitioner. This has had a constraining effect in the everyday practices of nurses. Lack of recognition of nursing ways of understanding experience, i.e., nursing dialogue, embodiment, engagement (Benner, 2000; Cameron, 1998, 2006; Gadow, 1980, 1989) has potential to trap nursing practices inside a categorical care plan unbefitting the situation of the very ill.

Etymologically, to assess means sitting near (Skeat, 1963). It also relates to attend or apply oneself to something (Hoad, 1996). To sit is to situate oneself (Hoad). In keeping its originary meaning, assessing the experience of the very ill involves sitting near the person and situating ourselves before their experience. What better way of understanding their experience than sitting near the very ill themselves? Sitting near is to be face to face with our neighbour, the stranger or the friend. It is to have the capacity to look directly into the face of another human being and recognize the *inappropriability* of their experience.

In going back to the global text, one senses a tension in relation to the Northern text. Their tones are too dissimilar. While one embodies the drama of the very ill in the context of poverty, the other seems alarmingly indifferent, apathetic to these realities. The northern garment has turned into an insulating layer that keeps us away from the experience of the very ill here and in the developing world. The global text remains outside the categories of the research text in the North. The no-bread text cannot trespass its thickly woven layers.

As I engage with northern and global texts, the question of how to remain close to the world of nursing and the very ill continues to be present. In the context of education, Jardine (1992) writes about the fecundity of the particular instance in understanding elements of pedagogy. In trying to understand the experience of the very ill, we need to be mindful of the fecundity of these particular instances. These instances "can have a generative and re-enlivening effect on the interweaving texts and textures of human life" (p. 51). They are indeed the very threads of the garments we weave. The infinity of instances of human life reminds us of the dangers of holding onto one universal text that rules over emerging texts. This ruling suffocates life. These instances call us to weave garments that fit the myriad sizes of the experience of the very ill.

The etymological relation between the words palliative and cloak invites us to look once again at the global and northern garments. How do these woven fabrics assist us in enacting the originary meaning of palliative? A cloak covers, veils, protects. It is the garment that safeguards us at times of need. This safeguarding is what inheres in our palliative practices with the very ill. We seek to safeguard the integrity of the very ill. As we weave these garments, we need to continuously ponder the weight of the garments we are to lay upon the shoulders of the very ill.

CHAPTER III: THE FECUNDITY OF INTERPRETIVE INQUIRY UNDERTAKING RESEARCH IN THE HOME

> *We do not understand what recognition is in its profoundest nature if we only regard it as knowing something again that we know already – i.e., what is familiar is recognized again. The joy of recognition is rather the joy of knowing more than is already familiar. In recognition what we know emerges, as if illuminated, from all the contingent and variable circumstances that condition it. (Gadamer, 1989, p. 114)*

THE WAY OF THE INQUIRY

A few days after visiting the palliative home care team with Brenda to present the study to the team, I went back to the office to make the arrangements to begin. I felt a bit nervous initially as I didn't know how things would evolve with the study. I knew very little of the palliative home care programme and did not know the nurses at all. A couple of years earlier I had spent a month visiting several settings of the Regional Palliative Care Programme in Edmonton and came to their two-hour team meeting while following a regional nurse consultant. These two hours was all the time I had ever had with this team. After meeting with programme managers to discuss the feasibility of the study, I was happy to hear home care would be the best setting to undertake this research. I knew right away I wanted to go back to this team.

After having gone now through the processes of ethics and administrative approvals, the time had come to get going with the research itself, to begin. How would the nurses engage with the study? How would the team feel about having me around during work hours? What would people think of having their nurses come with an extra guest to their homes? How was I as a nurse-researcher to engage with patients, families, and the team? All these questions kept going back and forth in my mind on my way to the home care office. I could only imagine possible situations. But in truth, I had not even the faintest idea of what was going to happen.

Both the nurses and the team's responses to the study went truly beyond imagination. I felt immediately welcomed on their team and quickly began to partake in their daily life. At the beginning of the study there was a sense of ambiguity in the morning as I did not know who was taking me on home visits. But they took care to resolve this during coffee time. 'Who is taking Anna today?' One of them would ask. There was always a nurse who volunteered to take me with her. As I began to spend most of the time with the team and go out with the nurses on their visits, we began together to develop a sense of one another and of the study itself. Slowly, the nurses and the team began to weave the study and myself into the weft of their daily home care practices.

Nurses engaged fully with the study from its very beginnings. They felt this study gave room to talk about nursing, their own experiences with patients and families in the home, those things that one cannot 'measure' as one of the nurses expressed. They also sensed the difficulties of doing this and were very supportive. They grasped what the study was about immediately. I enjoyed hearing them talk about the study to colleagues from other teams or patients and families. They re-interpreted the study for myself. They knew nursing was at the heart of this inquiry and that they would be main actors throughout the study. This was encouraging. They started talking to me about their experiences right away, when they felt like nurses or like strangers in the home, when they got tired and everything irritated them, when they needed to stop and ask another team member to take over, when they were unable to nurse, when they chose to go an 'extra mile' with a patient. They showed me their personal treasures they kept from patients, a thank you card, an obituary, a picture, an article from the paper, a letter, a poem. I heard the stories they wove around these treasures. They graciously opened their nursing world to the study and let me in. I felt honoured.

As the days went on, nurses began to suggest participants for the study. They explained the study to them and took me to their homes once they gave their consent. Nurses were very generous to take me in their cars. I became the nurse's co-pilot for the duration of the study and felt happy to be so. We drove all over the north side of the city. My initial thought had been to follow participants in the downtown area so that they would be within reach for a bus-dependent researcher. But these nurses changed all my schemes. In a few days, they had expanded my horizons and the horizons of the study. Thanks to their enthusiasm and support to get the study going, visiting people in a far away corner of the city or in a chilly winter day was far from being a limitation for this study. They would even make arrangements to meet me after I was done with a nurse to go on another visit. The nurses' hospitality and the hospitality of the team were immense. I quickly began to feel at home in their home.

One of the most enjoyable moments of the team's life was their interdisciplinary team meetings. Once a week they gathered around the table to talk about their practice. The meeting always included breakfast as they took turns to bring food. I became a regular member of these meetings as they invited me to join the team during these times. They talked about recent deaths, shared their emotions with the team, voiced concerns about patients' situations, did follow-up of past situations, shared ideas and suggestions, learned about the latest news in the programme, discussed research studies, laughed, and enjoyed the food. These meetings were a time for team members to vent as well as to renew themselves. During team meetings one could really experience their circular and dialogical manner of approaching practice situations. Indeed, the food turning around the table during the meetings showed in many ways their communal manner of working things through and understanding situations of practice.

As the weeks went by, the study began to insert itself more fully in the world of nursing practices in the home. I began to follow consenting nurses on their home visits to patients who also consented to participate in the study. I accompanied the nurses as often as possible on these visits. Along with becoming a regular co-pilot in the nurse's car, I became an almost regular guest in patients' homes at the time of the nurse's visit. In patients' homes, I often followed the rhythm of the nursing visit and the engagement of nurse, patient, and family members when someone was present. Occasionally, we planned visits to talk about their experience together with their nurse but in general staying with the nursing visit itself was best. I carried a tiny tape-recorder all the time and recorded some of the visits and some of the conversations with the nurses. I tried to be judicious in using the tape-recorder as at times I felt it was too disruptive or intrusive to the moment. While having the transcripts was helpful for analysis and interpretation, in the end I found that being there during the nurse's visit, going with the flow of the moment, was the most significant element of the study.

Conversations with the nurses often happened in their cars, on our way to patients' homes or right after a home visit. While driving, we would go again over the patient's situation and talk about alternative ways or how to put pieces together. I also asked them questions about how they came to this or that decision or about something I noticed during the visit. Nurses talked their selves out in the cars. They began talking about one situation and would end up telling me their nursing stories with patients they had had in the past and intertwined them with their own personal stories. They seemed to re-live these stories as they shared them with me. I came to see their personal side in these stories, all they carry with them while nursing others. Along with the stories came the emotions, the pain, the joy, the frustrations, or the sadness of the moment. Suffering from the co-pilot's syndrome, I got worried at times about the driving. But nurses knew how far to go with the story.

Being there with the nurses as they go about their day was one of the most integral threads of this study. Nurses appreciated this as they felt it showed a commitment to stay tuned to their practices. They also enjoyed being able to put a face to the research, to engage directly with it, to discuss pros and cons of the study, to shape the inquiry itself. It was through being there that the inquiry began to show itself. Being there gave all of us a sense of the way of the inquiry itself. Slowly, the inquiry was opening itself to the world of nursing practices in the home and opening a way to find nursing and the very ill in their home.

I began the inquiry engaging with the palliative home care team and the nurses on a daily basis for a two-week period. After this initial period, I spent about two to three days a week with the nurses as I followed them to participants' homes. This period lasted about a year until I went on a research trip to Chile for a period of two months. After my return, I continued my engagement with the team on a weekly basis while I followed those participants who continued to be in the programme although no new participants entered the study. This period took nearly another year. In total, four palliative home care nurses participated in the study and eight individuals receiving palliative care in the home, most of them with a diagnosis of late-stage cancer. In Chile, one primary health care nurse and one primary health care physician participated in the study and three individuals receiving palliative care in their homes.

THE APPROACH TO THE INQUIRY

> *An adventure lets life be felt as a whole, in its breadth and in its strength. Here lies the fascination of an adventure... It ventures out into the uncertain. (Gadamer, 1989, p. 69)*

The approach to the study was in many ways an adventure, in the original sense of the word. Etymologically, adventure is to approach (Skeat, 1963). The adventure of this study was finding a way to respectfully approach the world of nursing and the very ill as it opened itself to the inquiry. It was in living through this adventure, venturing out together with the nurses into the uncertainty of what lay ahead of us that I experienced the fecundity of interpretive inquiry in approaching this world. Gadamer (1989) and Jardine (1992) use the term fecundity to show how the particular case richly contributes to our understanding. Fecundity is related to both *fēcundus* meaning fruitful, and *fētus,* which means a bringing forth, offspring and is allied to generate, produce (Skeat, 1963). As we embarked on this adventure, interpretive inquiry began to show itself as a fecund approach in understanding the wide diversity of particular instances so proper of the world of nursing and the very ill. Interpretive inquiry lent itself to open a way to bring forth what in its beginnings was an incipient thought, a pregnant question, a waiting-to-be understanding.

I was initiated in the human science philosophical tradition and interpretive inquiry in nursing through my doctoral supervisor, Dr Brenda Cameron. Through her comprehensive hermeneutical exegesis of nursing and its practices (Cameron, 1998, 2004, 2006), Dr Cameron shows the relevance of this research tradition in understanding the practices of nursing and the complexities of human experience. Dr Vangie Bergum's research work on mothering (Bergum, 1989, 1997) and her comprehensive delineation of relational ethics (Bergum & Dossetor, 2005) have also contributed to enhance my understanding of interpretive inquiry and its relevance to nursing. Dr Robert Burch's scholarship in continental philosophy has helped me deepen my understanding of the philosophical roots of the human science tradition and the work of 20th century continental philosophers.

In seeking a way to understand nursing and the experience of the very ill, I found in interpretive inquiry as expressed in the hermeneutic phenomenological tradition a venue to openly approach this world that was inclusive, thoughtful, respectful, and humane. Bergum (1991) writes, "Phenomenological research, a research method that explores the humanness of a being in the world, is a drama, an interactive involvement of both the 'researcher' and the 'researched'" (p. 55). Together with the nurses, we lived Bergum's notion of phenomenological research as a drama. We shared the pain of seeing patients quickly declining. We accompanied one another as we saw them approaching their death. We went to the hospital or the hospice for a last good-bye. We went to the patient's funeral or visited a family member afterwards. Nurses stay with the patient's experience to the very end. They don't let the garment go until it's time.

Understanding nursing practices and the experience of the very ill in the home was the élan vital of this inquiry. Nurses and patients fed this élan vital with their ongoing enthusiasm and generous commitment to the study. Arendt (1994) writes that understanding "is a complicated process which never produces unequivocal results... Understanding is unending and therefore cannot produce final results... Understanding begins with birth and ends with death" (pp. 307, 308). The way of understanding was the way of the inquiry itself, fragile, elusive, circular, open, and unending. Through our conversations, we were never able to arrive at a conclusive truth. Rather, we tended to bring forward possible thoughts, adding to our stories "another more plausible, more revealing story" (Burch, 1989, p. 211).

David Smith (2000) invites us to discover our shared truth together. Truth, he writes, "is nothing else than the practice of finding oneself at home in the world" (p. 24). It is about reconciling ourselves to one another and to the world. This is perhaps the prime task of understanding (Arendt, 1994). As I followed nurses, I saw them engaging daily in situations that bear the extremes of the human condition. They do their best to make these situations a little more bearable for their patients and families. They work together with them to make sense of their situations "in such a way that life can go on" (Smith, 1994, p. 125) for them. They embody the task of understanding. Through their nursing ability to reconcile life with its fragile edges, they infused the inquiry with a sense of understanding as finding together a home for the fragility of life itself.

The Conversational Quality of the Inquiry

> *To reach an understanding in a dialogue is not merely a matter of putting oneself forward and successfully asserting one's own point of view, but being transformed into a communion in which we do not remain what we were (Gadamer, 1989, p. 379).*

Throughout the study, understanding showed itself as a conversational venture. Smith (1994) writes of understanding as a creative act "rooted, hermeneutically speaking, in a sense of the dialogical, intersubjective, and conversational nature of human experience" (p. 108). The inquiry itself became a conversation as together with patients and nurses we tried to make sense of past, present and emerging situations. Conversation from the Latin *conuersārī* means to dwell with or to dwell together and it is also allied to convert (Skeat, 1963). Conversations offered us a space to be with one another, "to share experience, and to make connections"

(Bergum, 1997, p. 6). Through conversations we were able to transform, *convert* our preliminary understandings into more revealing understandings of nursing practices and the experience of the very ill.

Instances to talk were of varied nature. One of our favourite ones with the nurses was with a cup of coffee and a snack in a coffee shop. Sometimes we went straight to a coffee shop after a long or tense home visit, or at lunch time, or at the end of the day after they finished work. Coffee time in the mornings was also a common space for the team to engage in lively conversations of practice. Nurses talk about things over coffee. A cup of coffee gives them a moment to gather their thoughts, think things through, integrate different pieces of the puzzle. The experience of coffee for nurses is real sustenance because of the magnitude of their work. It is time to rest, to sit your body down. It brings a sense of closure and relief after a difficult situation. Coffee time provides a safe space to release tensions, to turn away from the seriousness of practice situations. Yet in this turning away, they also re-think situations and envision new ways of approaching them. Doing crosswords or bringing a note of humour to the conversation during coffee time gave nurses and other team members a break from the intensity of their work and also opened a space for new understandings to come forward.

Gadamer (1989) writes that engaging in conversation is about letting ourselves be lead by the subject matter of the conversation. He highlights the hermeneutic quality of conversation, "In dialogue spoken language—in the process of question and answer, giving and taking, talking at cross purposes and seeing each other's point—performs the communication of meaning" (p. 368). This back and forth movement that a conversation evokes gave us the possibility to continue talking about a particular instance throughout time. Sometimes on the following home visit, we resumed our past conversation with the nurse and the patient and reinterpreted our understandings to one another. Other times, there was no time to talk as too many pressing things needed attention. But whenever there was a respite we went back to our conversations. In the car, in the patient's home, in the office, in a coffee shop, on the street, weekdays and weekends, we kept weaving our understandings together.

In searching for understandings, sometimes I experienced a lack of words to express these. In part this was due to my unfamiliarity with common or popular ways of saying things in English. I needed to go back to my mother tongue and figure out a way of translating our common expressions back into English. Here nurses and patients were extremely helpful in assisting me to find words. They enjoyed talking to me about words and I enjoyed learning the hideouts of their mother tongue. Finding words was not always easy and at times we were left with a sense being unable to put a word to our understanding. Chasing words to describe the ineffable was an ongoing adventure.

Conversations with my supervisor Dr Brenda Cameron throughout the entire inquiry were integral to move further in our understandings. She followed very closely the path of the inquiry, the world of nursing practices in the home and participants' experiences. Our ongoing back and forth dialogue was vital to safeguarding the vibrancy of the inquiry. Through her questions and thoughts about particular situations and her respectful suggestions about how to approach this or that situation, she guided the way of the inquiry and kept moving the horizons of understanding to unforeseen places. Her direct and dialogical engagement with this research work has been a constant invitation "to find nursing in its world of practice… to apprehend nursing as it happens" (Cameron, 1998, p. 18).

Conversations with patients about their personal experience tended to be very emotional for patients and I felt concerned about evoking unnecessary pain. Most of the time, nurses also participated during these conversations although they let patients lead the conversations. The nurses' presence was very significant as they were able to add their nursing perspective to the patient's experience of their situation. Looking at their experience through the nurse's eyes evoked a sense of comfort in patients. It softened the intensity of their pain. The nurse's perspective assisted them to settle down during the conversation. While having these conversations was meaningful for patients and nurses as they themselves expressed, I tended mostly to participate in the conversation that took place during the nurse's home visit itself asking a question here and there when I thought it pertinent.

As time went on, we got deeper in our interpretations of nursing and patients' situations and conversations took on a very interpretative tone. Bollnow (1979) writes that interpretation is the creative co-creation of meaning. It carries the insights and understandings of others while at the same time seeking to enlarge those understandings. Interpretations in this work have often been communal so to speak; communal in the sense of being the fruit of shared work to which many have contributed with their thoughts, understandings, and insights. Nurses were very generous to also engage with the writings of practice situations coming from this study and contribute their insightful interpretations, broadening and deepening the horizons of this inquiry. Revisiting past nursing experiences was painful at times for the nurses. In the conversations around the text we talked about this pain, we reread the story to ourselves, we were able to make sense of it together.

Nurses often expressed that conversations about nursing situations brought about new possibilities for their practices. At times, they shared how a previous conversation had helped them see or experience a particular situation in a different way. Carson (1986) writes about the power of conversational research to create communities of cooperative research where distinctions between "researchers" and "practitioners" are blurred. Conversations, Carson writes, bring about the possibility to explore practice questions together with participants and arrive at new understandings that in turn have the potential to be immediately applicable into practice.

> The practice of conducting conversations with participants is in itself a form of action which helps forge a reformed practice. By engaging in conversation researchers are helping to create spaces... for thoughtful reflection oriented towards improving practice (Carson, 1986, p. 84)

Throughout the time of the inquiry, I was able to continuously experience the transformational power of conversation. In dialogue with nurses and the very ill, we felt "bound to one another in a new community" (Gadamer, 1989, p. 379) of practice that enabled all of us to look forward into our practice and present situations with renewed eyes and strength. Having a sense of community was indeed the soil where the élan vital of this inquiry kept thriving.

Throughout its various stages, ensuring the rigor and credibility of this research study was also an important consideration. Meleis (1996) identifies eight criteria to evaluate the credibility of research studies with vulnerable and marginalised populations. As the very ill constitute a very vulnerable group, I followed most of Meleis's criteria to enhance the credibility and rigor of this study.[8] These included contextuality, relevance, respect for language,[9] disclosure, and reciprocity.[10] Achieving *contextuality* involved constant attentiveness to the context of participants' experiences, i.e., the home and the palliative home care setting as the primary contexts where their experiences took place. The interest and ongoing engagement of participants in this study was a sign of the *relevance* of this inquiry to them. As stated above, nurses often expressed how the inquiry responded to their interests and concerns. On several occasions, patients also expressed how this study opened a way to share their experiences and perspectives.

Respect for language was a primary concern throughout the study. Engaging in conversations with nurses and patients on a regular basis, taking notes following the home visits, and staying as close as possible to experience in the writing of practice situations trying not to overlay their experiences with too many layers were ways of respecting the language of participants' experiences. *Disclosure* required thoughtful carefulness in showing participants' experiences and also respect for the vulnerability of nurses and patients. Being able to share with participants emerging and revised interpretations of their experiences in conversations and in writing was also helpful in ensuring that the understandings of this inquiry remained true to their experiences. Ensuring *reciprocity* was a constant concern during the study. This involved finding out about participants'

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[8] The following criteria are not included: Awareness of identity and power differential, empowerment, and time.

[9] Meleis calls this criterion *communication styles*. Communication styles indicate the need that our studies reflect an understanding of people's language. Respect for language gives language a more central place.

[10] Meleis calls this criterion *reciprocation*.

expectations with the study and the extent to which these were met as the study went on. Involving nurses in research presentations and research discussions enhanced the reciprocity of the study. Following the nurses' judgement in approaching participants and letting participants' interests and concerns guide the conversations were also ways of promoting reciprocity.

While these criteria above were most important in enhancing the credibility and rigor of this research study, the continued on-site engagement with nurses and patients throughout the inquiry was the primary way to ensure its rigor and credibility. How researchers engage with the setting and the participants throughout the research should be one of the main criteria to evaluate the credibility of research studies that follow the tradition of interpretive inquiry. The intensity of the researcher's engagement is the main and most vital way of showing rigor as well as deep respect for the time participants so generously give to the inquiry at the time of undertaking interpretive research.

Looking with the Co-pilot's Eyes

> *My point of view is for me not so much a limitation of my experience as a way I have of infiltrating into the world in its entirety (Merleau-Ponty, 1962, p. 329).*

Cameron (1998) writes, "Carrying the research question on your body in its very honesty... and openness, opens doors and pathways that don't open easily" (p. 140). I was often overcome with a sense of awe at the openness of nurses to this inquiry. I learned quickly that this is very much their way of being with others. But they also are very careful with research studies and researchers. They "discern research that is beneficial to their patients and that which is to their minds, questionable" (Cameron, p. 141). I sensed nurses' watchfulness with the study for the first little while and later on in our conversations they acknowledged this. It didn't last long as they sensed in the study a genuine concern to understand their world of practice and not to overwhelm patients with research activities. The doors of the nurses' cars were among the first ones to open.

Sitting in the co-pilot's seat in the nurse's car became an everyday experience in the study. Along with enjoying the conversations with the nurses while driving on the roads, the driver in myself began to make itself present. I started experiencing the tensions of the road as though I was the one driving the car. Van Lennep (1987b) describes well what I experienced in the nurse's car. Writing about co-drivers, van Lennep shows how they "*see* the road situation with *the pedals and the wheel*" (p. 221). Sitting in the co-pilot's seat, I felt the need to pay attention to "the total road-situation with its trees, crossroads, pedestrians, bicycles, drives, curves, traffic signs, and so on" (van Lennep, p. 217). The difference was that I did not have any access to the pedals and the wheel. Looking at the road with the co-pilot's eyes was both enjoyable and miserable at the same time. While gaining a beautiful perspective to the outside world, I also missed the driver's singular perspective to the road.

As I accompanied nurses to their patients' homes, I quickly began to experience a feeling like the one I had in their cars although musically speaking in the home I was able to play variations of the theme. As the nurse's guest, I often felt like a spectator of whatever was going on in the home visit. Gadamer (1989) writes that spectators are involved in a play "in such a way that, despite the distance… the spectator still belongs to the play" (p. 116). So while being a spectator in the home, I also felt involved in the situation itself, it called my being out. As a spectator I was pulled to participate in the situation. Gadamer evokes the true meaning of participation as "not something active but something passive (pathos), namely being totally involved in and carried away by what one sees" (p. 125). Like the spectator of a play, here too, I was fully drawn into the drama of the situation itself.

Yet even though as a spectator I felt quite involved in the situation, at times I also felt like a spectre, a ghost, a "fly-on-the-wall" (Cameron, 1998, p. 224) in the home. This was an ongoing tension throughout the inquiry. Like the spectator, I also wanted to be an actor, to perform. I wanted to be *the* nurse and actively take part in this "*shared* world of discourse and action" (Burch, 1989, p. 209) that plays itself out in the home visit. True, as a spectator, I had another perspective to the situation; my perceptual field was one that involved patient and nurse together. Like in the co-pilot's seat, here too "the figure-ground relation ha[d] fundamentally changed" (van Lennep, 1987b, p. 221) from the one I was familiar with as the nurse. Another figure and another ground were now at play.

Slowly, figure and ground began to change as I myself experienced slight changes in perspective. In certain situations, nurses called the nurse in myself to the fore. Here and there I offered my nursing thoughts and experience. Sometimes I even caught myself asking a nursing question to patients. At times I needed to let go the garment of researcher and the research questions and take on the garment of the nurse and be a nurse with the nurse. After all, this is who I am. Being there with the nurse did "not simply mean being there along with something else that is there at the same time" (Gadamer, 1989, p. 124). It meant being attentive to the fullness of the situation to be able to act. As a nursing *colleague*, originally meaning to bind together (Skeat, 1963), I was bound to participate in the play together with the nurse. Nurses themselves made this possible.

RUTH AND THE ETHOS OF THE HOME

In going to patients' homes with the nurses, I noticed how nurses can have a sense of the home in a matter of instants. I saw how tiny changes in a home put them on the alert as they knew these could be indicative of a turn in the patient's health status. I saw that just as they are able to quickly make themselves at home during a home visit, they often can tell what's going on through the way the garment of the home presents itself in the moment. A door that didn't open was rarely a reason to turn away and go. On the contrary, they went to the back door, called the home, phoned a patient's contact, or even got close to a window calling the patient directly. The ethos of the home activated their nursing being so to speak.

Initially ethos meant the abode of human beings and from this originary sense ethos came later on to be understood as our way of being at home in the world (Schuchman, 1979). Who we are and how we find ourselves in the world is contained under the word ethos. As the study went on, the ethos of the home showed itself as a primary element in understanding a patient's situation. The status of a home, each of its rooms were revealing of how patients were in a particular moment. What follows is a nursing situation where I accompany Claire to Ruth's home.[11] The ethos of Ruth's home as it shows itself in the rooms of her home "calls us to accountability in a profound way" (Cameron, 1998, p. 142). Here the nursing 'how are you?' question (Cameron, 1992, 2001, 2004) evokes a profound ethical poignancy as now the home itself involves us in the question.

Ruth

It is about 0200 in the afternoon and Claire and I are on our way to see April as she was throwing up this morning. Claire wants to check on her as she knows April wants to go away for a few days. 'April knows very well how to manage these situations,' Claire says, 'and when she calls in it means it is a very big crisis, so it is good to visit her even though she just told me she is already feeling better. We had a little chat on the phone before we left. I just need to make a quick stop at another patient's home, her name is Ruth, for a dressing change and then we are on our way to April's.' As she drives, Claire tells me that Ruth is a 61 year old lady with cancer of the pancreas. She also says that although she is 61, she looks as if she was 75. 'She has had a really tough life,' Claire says. We get out of the car, the day is very chilly and I shiver. Claire grabs her nursing bag and we go into the building. We press the buzzer and there is no answer but we are able to go in quickly as someone comes out. We take the elevator to the fifth floor. Ruth's apartment is a few steps across from the elevator.

Claire knocks on the door and nobody answers. She knocks again but there is no answer. Claire checks the door handle and it is unlocked so we go in. The home is very silent, cloaked in silence. We stand in the entry hall and Claire starts calling out Ruth loudly, 'Ruth we are here, it's Claire! Ruth! Ruth!' No response. Claire's face shows concern. She decides to go in. She takes her shoes off and walks into the rooms. I stay in the entry. I hear Claire's voice 'Ruth! Ruth!' She goes back and forth from room to room. She makes her way to the bedroom and finds Ruth there. I hear her saying in a slightly loud voice, 'Hi Ruth, how are you? I came to do your dressing.' I can't hear Ruth's voice. Claire comes back and asks me to

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[11] An earlier version of this writing was presented at the 15th Canadian Annual Home Care Conference (Santos Salas & Cameron, 2004).

come in, her face quite pale. She whispers, 'I thought she was dead… It took me a while to wake her up.' As a nurse, I can feel Claire's heart is pounding. I take my shoes off and follow her.

I walk behind Claire toward Ruth's bedroom, the place is dim and very still. I enter the bedroom and see a white haired skinny woman lying on the edge of a double bed. 'Ruth, this is Anna, she is a nurse from Chile,' Claire says. 'Hi Anna' she replies speaking with a very thick tongue. 'Hi Ruth,' I respond. Her face is very pale and her eyes are barely open. On the night table I see medications, a glass nearly empty, a jug of orange juice, plastic bags with some stuff in them and a telephone. There is also a wheelchair beside the bed. Daylight comes in through a window on the other side of the bed. I see cardboard boxes all over the place, piles of clothing on top of them. They just moved in a couple of weeks ago Claire tells me later and they haven't been able to fully unpack yet.

'I came to do your dressing' Claire says. Ruth is having daily dressings as she has several ulcers in both legs. 'Thank you,' she responds. 'How are you? You seem to be a bit drowsy today,' Claire says. 'Yeah, I feel very sleepy,' she says, 'it is these pills that make me sleep.' It is hard to understand her words as her voice is soft and her tongue dry. Claire grabs the medication bottle; the label reads Tylenol #3. 'How are you taking these pills?' She asks. 'I have been taking them every time I feel pain,' Ruth responds. 'How often have you been taking them?' Claire asks. 'It depends,' she says, 'I took one this morning, then another one, and I think I took one at about 200.' 'Have you been having a lot of pain?' Claire asks. 'Yeah, last night I had a lot of pain in my belly,' Ruth answers pointing to her abdomen with her left hand, moving it slowly. Ruth's abdomen is quite prominent under the bed covers; a very large abdomen for such a skinny body. 'What time is your husband coming?' Claire asks. 'Around six I think,' Ruth says. Ruth and her husband have a laundry in the city and Ruth used to be there all day but now she has not been able to go as she has not been feeling that well. 'Ok, I will do your dressing first and then I will check your medications and phone your doctor, is that ok?' Claire says. 'Yes,' Ruth says in a very low voice.

Claire opens her blue bag and takes dressing supplies. Ruth also has supplies in one of the plastic bags on the night table. She uncovers Ruth's legs and takes the bandages off. Her legs are swollen and one of the ulcers is dripping a bit. I assist opening saline bottles, dressing packages, and holding Ruth's leg when needed. 'Your ulcers seem to be getting better. This one is really smaller. This one on your ankle is the only one that hasn't changed much. This is good!' Claire says and I see a faint smile in Ruth's face. Once Claire finishes the dressings, she checks Ruth's abdomen. We cover her legs and she uncovers her abdomen. Ruth has a diaper on. 'How long ago did you change your diaper?' Claire asks. 'This morning, before my husband went to work,' she says. 'We can help you change before we go,' Claire says. 'Thank you,' Ruth says. Her abdomen is quite large and tense and there seems to be a lot of fluid in it. 'Your abdomen is a bit bigger than before and you may have more fluid in it now. I will tell the doctor and see what he suggests. I am worried about your pain and your pain medication as there is no need for you to be in pain all the time. If you want, I could also put some services in and have somebody come in to assist you for two hours a day. 'What time would that be,' Ruth asks. 'We can accommodate the schedule to your needs,' Claire says. 'I think that would be good,' she responds. 'Would you like us to help you change now?' Claire asks. 'Yes please,' Ruth says, 'I would like to go to the bathroom.' 'Sure, we'll go there.'

Ruth sits on the bed very slowly, her swollen feet seeking support on the floor. Claire is on one side and I am on the other. We help her get up and start walking slowly to the bathroom, each holding one arm. Ruth's skinny body moves with difficulty. The bathroom is small and three people in here feels like a crowd. Standing by the toilet seat, Ruth lifts up her gown while Claire takes off her diaper. The diaper is full of diarrhoea and a strong stench impregnates the room. Ruth's pubic area is covered with diarrhoea. Her labia are very swollen, hanging about eight centimetres below her pubis. Claire grabs a cloth, wets it in the sink and begins washing her up. I hold Ruth's arm while she stands.

Claire moves back and forth between Ruth's body and the sink. She washes Ruth's pubic area, her swollen labia, the inner side of her thighs. She asks her to turn around and washes her bum. She washes again and again as traces of diarrhoea are all over her skin. Claire is entirely immersed in action, her sleeves rolled up, gloves in her hands, her body close to Ruth's body in this tiny bathroom as she works hard to clean her up. She knows April is waiting in her home. But she also knows that if things weren't going well, April would have phoned the office. At the moment, she cannot leave this home. Ruth's home holds Claire up and does not let her go. The smell is everywhere. Ruth remains silent, mortified. Yet there is something in Claire's actions that makes this moment a little more bearable; something in this nursing act that turns this horrific moment into a more liveable human experience.

After leaving Ruth clean and comfortable in her bed, we go to the living room as Claire needs to make several arrangements. She needs to phone Ruth's doctor to revise her pain medications and discuss her ascitis, call the pharmacy to request the delivery of the medications to Ruth's home, and write down her nursing notes. But first of all she needs to phone the evening nurse to ask her to please go to April's home as it is now very late. It is hard to reach the living room as boxes are all over the place. After crawling over a few boxes, we find a spot in a corner by the dining table. I go to the kitchen to get Ruth a glass of fresh water. The kitchen seems to have been forgotten for ages.

Entering Ruth's home evokes a state of watchfulness in the nurse right away. This home is too still. Claire senses something is seriously wrong here as nobody comes to the door and now nobody responds to her callings. The silence in this home is unsettling. It summons Claire to take action. She must search for Ruth in the home. Her entry into Ruth's home is an intentional and purposeful act quite different from the way one would usually enter a home. She refuses to stay in complicity with this silence. Yet her decision to enter this home turns her into an accomplice of the home. Accomplice means originally to weave together (Skeat, 1963). Here we see Claire weaving herself together with Ruth's home. She takes the risk to enter not knowing what awaits her. The ethos of this home holds sway.

Claire's searching for Ruth is insistent and urgent; the lack of response to her calling makes it even more urgent. In going from room to room she also senses the unresponsive state of the home itself, unpacked boxes everywhere. The rooms themselves already bespeak Ruth's state. She has sunk into deep unresponsiveness; to the point that Claire thinks she is dead. Every room in Ruth's home deepens Claire's sense of what's going on at this moment, each confirming in its own particular way her deepest concerns. In each of the rooms, Claire gathers further pieces of this puzzling situation. These rooms call strongly her nursing self to the fore. She is bound to respond.

How Ruth finds herself at the moment is contained in each of these rooms.[12] The large quantity of boxes in the living room makes it really uninhabitable at the moment. There is no room here to entertain guests; no room to engage with others, to have a moment of fun. She is too ill to care. The kitchen looks like a deserted place, alien to Ruth's world, now reduced "to the size of her room" (de Beauvoir, 1965, p. 73). In truth, her whole house is in a state of abandonment, there is no Ruth in these rooms; no "enveloping warmth" (Bachelard, 1958, p. 7) in this home. But nowhere is this more poignant than in her own bedroom where she herself lies down in a state of exhaustion. Piles of clothes on top of crowded boxes reveal the extreme frailty of her body. Her broken body holds her to her bed. She lies on the edge, as if reaching the edges of her very existence.

Claire enters Ruth's home even though her home is not yet ready, not yet prepared to receive the exterior world. This yet-to-be home calls the nurse in herself. She puts on the garment of Ruth's home as she seeks out Ruth, engages hands-on with her present situation, and even finds herself a corner to make all the nursing arrangements. Bergum (1996) calls us back to the kitchen as the place where we can turn our attention to human experience. She makes us attentive of space as she invites us to be mindful of the *trapdoors* of technology. Claire's attentiveness to the rooms of Ruth's home shows a profound nursing concern for Ruth herself. Her decision to enter her home is also her decision to enter Ruth's experience and partake in whatever it takes to respond to the nursing call of this moment.

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[12] Our efforts to elucidate the relation between the rooms of the home and the experience of the very ill began a few years ago (Santos Salas & Cameron, 2001; Cameron & Santos Salas, 2002).

In a way, when a nurse enters a patient's home she also asks the nursing 'how are you?' to the home itself. Cameron (1992) writes, "The nurse enters and asks 'How are you?' She is one of the few who can truly ask. She needs to ask and she needs to know" (p. 184). The nurse's 'how are you?' upon the home shows the nurse's decisive act to engage with this home. Her nursing 'how are you?' turns her into an ethical guardian of the home. Once she asks the question, she is ethically bound to respond. The nurse's ethical complicity with the home evokes the close relation between ethics and home. Ethics in its originary sense "ponders the abode of the human being" (Heidegger, 1998, p. 271). In asking 'how are you?' the nurse hears the ethical claim of the home and acts. This claim "is not itself a fixed demand" (Gadamer, 1989, p. 127). Rather, it poses itself as a call that bids the nurse's being to come forward.

CHAPTER IV: UNDERSTANDING NURSING PRACTICES IN THE HOME

> *A call summons nurses to immediacy. It is an appeal to come forth into the very now... 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... But too, nursing hears a call within a call. Possibilities hover and await one's response, one's acting. (Cameron, 1998, pp. 199, 200)*

Undertaking this research study with individuals who are very ill in the home and with nurses who often face a myriad demands emanating from the condition of patients themselves, their families, and the health care system has meant constant attentiveness to the daily nuances of these spaces. The lifeworld of the very ill is a world loaded with interruptions, medical visits, oncology treatments, diagnostic tests, home visits from health care professionals and support workers, daily phone calls, not to mention family members' and friends' inquiries and visits, or the funeral arrangements that at times they themselves decide to make in advance. All of this together with the endless bodily changes they experience originates fissures in their world that claim a sudden shift of attention from taken-for-granted life to life that makes itself unrelentingly present.

In nursing the very ill, nurses strive to attune themselves and their practices to the complexities that infiltrate the lifeworld of the very ill. Again and again they are faced with the challenges that meet them at times unexpectedly as they engage with patients and families, and as they work with the health care system to provide the best care to the very ill. In the home, nurses develop very unique and complex skills that nursing very ill individuals in their own homes requires. They are skilled practitioners who throughout years of practice have also developed a very distinctive skill, unique to working in the home, that of entering a home with immense respect, attentiveness, and recognition.

There is a poignancy about entering somebody's home, inhabited space filled with smells, sounds, dust; filled with breath. How boring it is to enter a new home. There is no breath as yet. No smell but for those toxic smells that come from painting, carpeting, and constructing; "To be without scent is an act of violence. To be without scent is not corporeal" (Cameron, 1998, p. 209). Inhabited space bears the trace of existence, of a past, cumulative and collective breath. When we enter a home, we are present to somebody's existence. We are already implicated. We partake in the home's breath.

> 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 (Cameron, 1998, p. 214).

Bachelard (1958) writes that the house is "our corner of the world" (p. 4). He evokes inhabited space where the experience of home reveals itself. The house, he writes, is our protective space, the place where we are able "to dream in peace" (p. 6). The house is "the human being's first world… a large cradle" (p. 7) where we begin our life and come back from time to time. It is in the intimacy and primitiveness of this cradle where I come to meet the very ill, their loved ones, and their palliative home care nurses. Here the home stands as the first and primordial space that sustains, reaffirms, and re-creates us as we pass through the most vital life experiences. It is a space with a life of its own, a space that resists and grants, embraces and takes distance, hides and uncovers, holds and lets go, revives and limits. The home is the place where life manifests itself in its manifold edges.

In this writing, I begin a conversation about nursing practices in the home. Through this, I seek to elucidate an understanding of the palliative home care nurse's engagement with the very ill in the home. In this analysis, I follow Brenda Cameron's (1998) exegesis of nursing and its practices as it reveals itself in the complex world of nursing practices. In her work, Cameron develops a humane and poignant philosophical approximation to nursing practices as it reveals itself moment by moment in the, at times, dire situations practicing nurses face. She speaks the vibrancy of nursing practices. She brings us closer to the nursing moment where the nurse in the midst of complex situations, with patients often nearing death, skilfully enacts nursing, that very short-lived moment where nursing is waiting to be born.

> Lived expressions of nursing show that nursing is often in a state of gestation and as such it is warranted to be so… 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 practices of nursing. (Cameron, 1998, p. 253)

As she undertakes her research work with nurses and patients in a highly complex oncology unit, Cameron embodies the tension between staying close to the being of nursing-as-it-happens in daily practice and showing nursing as lived in a text. She writes a lived text of nursing where she shows the lived-ness of nursing practices. Cameron struggles to preserve the heart beat of the nursing lifeworld in the text; its very breath, its rhythms, its flow. In writing her text, she carries "an internal agitation, an excitement, a certain labour too, the pressure of the unspeakable which wants to be spoken" (Barthes, 1981, p. 19). She embeds this tension in her writing and holds the unspeakability of the nursing moment in our midst.

In trying to understand nursing practices in the home, I need to say that Cameron's existential elucidation of nursing practices is at the very root of this work. Cameron's work shows a tight closeness between nursing and mortality that reveals itself more prominently as death approaches. She evokes this closeness in Rozalia's story (Cameron, 1998), a young woman who dies of cancer in the hospital. Rozalia finds a home in death through nursing. In the home, the closeness of the nurse to the very ill sustains them through this time. Here, nursing too shows itself as the home of the very ill, the place where the very ill find a home in death. Nursing is a primordial thread in the experience of the very ill. When there is no nursing, the very ill suffer enormously.

IRIS

I meet Iris while following June on her home visits. Iris is a 67 year old woman who suffers from advanced colon cancer. She was diagnosed about three years ago with bowel cancer and following surgery received a few cycles of chemotherapy. In the last few months, she experienced tumour growth in her abdomen and received palliative radiation with partial response. Her abdominal tumour continues to slowly grow and has now broken the skin forming a small wound that now requires daily dressings. Iris was recently transferred from the STIT (Short Term Intervention Team) home care team to the palliative home care team and June is her palliative home care nurse. We stop at her house on our way to the home of another patient.

We arrive in Iris's home at about 1030 in the morning. After parking on Iris's driveway and grabbing the nursing blue bag, a tiny plastic bag with supplies for a week, and Iris's info sheet (CSR), we go in. The door is unlocked and we go in right away. An elderly woman sits at the head of the kitchen table reading the paper with her back to the window. June says hi and introduces me to her while we take our shoes off. 'This is Iris's Aunt Alice,' she tells me. She says hi to us in a soft voice and tells June that Iris is in her bedroom waiting. She points to the room with a very slow and almost rigid movement of her right arm. Then she quietly turns her gaze back to the paper. Later on, June tells me that Alice suffers from severe rheumatoid arthritis. She is about 83 and has lived with Iris for quite a few years.

June goes to the bedroom to see Iris while I wait in the kitchen. I see a small garden through the kitchen window at Alice's back. The day is sunny and the sunlight comes in warming Alice's body. June comes back and says that Iris would like to meet me. She says it is ok to come to her bedroom. I pass through a narrow hallway that connects the kitchen with Iris's room. On my way there, I notice a sink and a small toilette on the side. I enter Iris's bedroom which in contrast to the bright kitchen, is quite dark as there is scarcely any natural light. The curtains are drawn and the room light is on. Piles of clothes sit on top of a double dresser by the wall. I cross the room and stand close to June's side as she stands beside Iris's bed. 'Iris, this is Anna, she is a nurse from Chile,' June says. 'Hi Anna, nice to meet you,' Iris says in a loud voice. 'Hello Iris, nice to meet you too,' I reply.

Iris is lying on the edge of a queen size bed. At first glance she seems to be the other way around on her bed as her head is at what looks like the foot of the bed. But soon I realize that she has arranged the bed this way. The foot of the bed is by the wall where the covered window is. There is an indoor area on the other side of the window and through a tiny edge I can also see a little bit of the garden. There is a change of perspective here as I meet Iris. I keep thinking she is positioned the wrong way and I find myself consciously making an effort to re-orient myself in this space. Also, she is lying on the bed and I am standing. Her bedclothes are drawn back and her belly is uncovered for June to do her dressing. I sense asymmetry here as I meet her in her quasi-nakedness while she meets me in my fully-clothedness.

There is something intimate about meeting a person in the bedroom. Here myself a stranger suddenly entering one of Iris's most private spaces. Yet I too am a nurse; a stranger-nurse so to speak. But I have been granted entry to this room because I am with June, Iris's nurse. June has already built a space in Iris's home that makes possible my entry to her home and her bedroom. It is within June's relation with Iris that I can enter this moment. I feel suddenly drawn by nurse and nursed together as a co participant in Iris's vulnerable and fragile health situation.

'I am going to wash my hands to do your dressing,' June says. 'I also will wash mine,' I say and follow June toward the sink in the hallway outside Iris's room. 'The red towel is your towel, June!' Iris shouts while we wash our hands. 'I see it!' June responds. 'She puts this soap for me to wash my hands and also this very nice cream. She has a fairly large business with beauty products and knows a lot about these things,' June tells me. Towel, soap, and cream sit beside the sink, ready to be used by the nurse. I see Iris in her own home also building a space for her nurse. We dry our hands and go back to the room. A variety of nursing supplies including dressings, tape, bandages, scissors, saline bottles, gloves, and plastic bags sit on top of a small table by the wall close to Iris's bed. It resembles a large nursing tray. Everything is ready for the nurse to take care of Iris's wound. This is June's nursing space, carefully built to enable her nursing actions, and those of other nurses to come.

June places a towel on the bed along Iris's left side to prevent the bed from getting wet when she irrigates her wound. She puts gloves on, opens a saline bottle, and soaks the thin gauze that covers the wound. Then she pulls the gauze out. A voluminous mass occupies part of Iris's lower abdomen, a large tumour pushing hard from underneath the skin. On its surface, a small circular area of raw tissue is now exposed after June takes off the gauze, a mix of black and red tissue with irregular edges. In truth, this tumour reminds me of a volcano with a red/black crater revealing its hidden activity. Yet this volcano is Iris's very flesh, slowly erupting from within her own body.

'Iris had a very severe reaction to the antibiotics she had to take for her wound infection,' June tells me, 'she had a generalized skin rash and severe edema as well. You could hardly see her eyes. You can still see a bit of it around her right eye.' 'I am very sensitive to many things so I need to be very careful with what I take,' Iris says, 'I ended up in emergency because of this reaction, the rash was really terrible.' 'So much of this redness you see around her wound is part of the rash,' June says looking at Iris's wound, 'although this is really nothing compared to what she had last week.' 'I still have some redness beneath my breast,' Iris says pulling her shirt up to show us the skin irritation. The skin surrounding the tumour is almost covered with fading red patches that stretch towards her upper body.

Iris holds a mirror in her hand and looks at the skin around the tumour. 'It is getting better,' she says giving the mirror a scrutinizing look, as if interrogating the mirror itself. 'I am afraid that I might get another wound around here,' she says and points with her left finger to a pinkish shiny spot beneath the wound. Here her translucent skin seems to have stretched to its maximum capacity, making room for this pushy tumour. 'It has been like this for a while and it might stay just like this,' June says, 'your skin is really looking better.' Iris puts the mirror aside and watches June as she changes the dressing. She follows June's every movement, telling her here and there how best to put this or that. June takes her directions. She wants Iris to be content with her dressing.

June grabs a transparent circular measuring sheet especially designed to measure wounds. She holds it very close to the wound. This helps her assess how the wound is evolving. 'It is about two centimetres wide,' she says. Then she measures the tumour's transverse and vertical diameters. 'Fifteen centimetres here and,' she pauses as she measures, 'eighteen centimetres here,' she says. I write down the numbers. Her face gets close to the wound as she measures it. Her closeness to the wound shows no signs of repulsion. On the contrary, she does this as though she is doing a very common thing, nothing out of the ordinary. She makes a very complex nursing act look like an ordinary life event. She nurses this erupting wound in a way that enables Iris to face a future.

After measuring, June begins to palpate Iris's abdomen. 'I think there is still a bit of fluid in your belly,' she says to Iris. 'I can feel it,' Iris says, 'my labia are a bit swollen as well.' 'I will talk to your doctor and tell her about this,' June says, 'she might prescribe something for you although it isn't really a lot.' She turns towards me and says, 'Anna, why don't you see as well?' June takes me by surprise as she invites me to palpate Iris's abdomen. She calls the nurse in me. 'Ok,' I say, 'if Iris is ok with it.' 'Of course,' Iris says, 'I have no problem.' I stand up and palpate Iris's abdomen. Her belly is moderately distended and there is resistance when I exert pressure. I gently push from the right side and a small wave reaches my left hand. I push it back and it goes back to my right hand. 'I can sense the fluid,' I say, 'although it doesn't seem to be a lot.' 'Yeah,' June says, 'I'll phone your doctor when I get back to the office.'

June irrigates the wound with saline and then covers it with a vaseline-impregnated gauze. She grabs a white bottle from the table and opens it. 'This is the cortisone cream they prescribed for Iris at the hospital for her rash,' she says, 'we are applying it twice a day.' She uses a wooden stick to get some cream, puts it on her gloved hand and proceeds to spread it on the red areas around the tumour. Then she covers the skin around the wound with white gauze. On top of it she puts a thick absorbing dressing and fixes it to the skin with paper tape, the only one Iris's skin tolerates. She is very careful to choose areas where the skin is not irritated to tape the dressing while Iris keeps an eye on her.

June tells Iris about my studies at the university and the ongoing study with the team. 'What is your study about?' She asks with interest. I tell her. 'I would like to participate in this study,' she hurries to say before we ask her if she would be interested. 'I have had a terrible experience with the health care system and I would like to talk to you about it,' she says, 'I was in emergency about three times before they were able to tell me I had colon cancer. They told me I had a cold, to go home and rest. Imagine! I always wonder if I would be like this if they had detected the cancer right away, when I started going to the hospital.' She speaks in a loud and sharp voice as she recalls her difficulties with the health care system, the tension of her muscles showing in the tightness of her cheeks. We hear her in silence.

'We are done,' June says and Iris begins to dress herself. She pulls up very loose underwear that covers the tumour and the dressing. She holds it with a loose elastic band around her waist. She props herself up and sits on the bed, grabs a pair of pants from a chair nearby and puts them on. They too are very loose on the top. 'You are very tall!' I say as I assist her to stand up. How different it is to meet somebody standing. It is as though one evokes another sense of presence. Much remains hidden in the bed. Now I see her clothes hanging around her skinny body.

June and I move over to the living room while Iris finishes up dressing herself. 'I'll meet you there in a moment,' she says. We stop in the kitchen to grab June's bag. 'It is nice to be sitting by the sun,' June says to Alice. She smiles and says, 'Oh yeah, it is very nice for my old bones.' 'Have you had a chance to be out for a while these days?' June asks her. 'I have been out in the garden,' she says, 'days are warming up, so it is very nice.' Warm days feel like a blessing after enduring the long and cold Edmontonian winter. I notice people here seem to walk in a different mood when spring begins to announce itself in these first few warm and sunny days.

Iris is back in the kitchen and offers us a cup of tea. We decline and move over to the living room. Walking slowly, Iris reaches a comfortable chair where she can pull up feet support. June sits on the sofa beside the chair and I beside her. A large shelf with several cosmetic products sits close to one of the walls and another one close to the entry door. A large mirror hangs above this shelf. On top of the TV I see an enlarged picture of three women. 'That's me,' says Iris. She is standing beside the owner of the cosmetic company she has worked in for several years. It takes me a few instants to recognize her in the picture. She is perhaps double her current size on this picture. She looks radiant, happy, and well. Her hair is beautifully done. 'It was a special event,' she tells us. Her picture speaks of a past that now seems hard to recover. This photograph shows pieces of Iris's missing world. Yet pieces that in the face of mortality lose bits of their attractiveness. A whole world of beauty so close and vibrant in the past seems now so distant from Iris's present situation.

Simone de Beauvoir (1965) evokes the felt ludicrousness of these worlds as she passes through the fashion streets of Paris after being with her dying mother.

> How desolate I was, that Wednesday evening, in the cab that was taking me away! I knew this journey through the fashionable quarters by heart... I saw ridiculously elegant hats, waistcoats, scarves, slippers, shoes... Scents, furs, lingerie, jewels: the sumptuous arrogance of a world in which death had no place: but it was there, lurking behind this façade, in the grey secrecy of nursing-homes, hospitals, sick rooms (Simone de Beauvoir, 1965, p. 78).

Iris tells us how much she has enjoyed working in this cosmetic company. She can't do much anymore, she says, as she is too tired although now and then she tries. She says working in this company has been a big support for her not only economically but also personally. Her appreciation of this company comes up in our conversations as she tells us about the stories of her past. I think of Iris's wound and of how hard it must be for her, dedicated to bodily beauty for years, to bear now the hard-to-cover ugliness of this flesh-eating tumour. *'Dead meat,'* she calls it at times. She hopes it will heal, that this *'little pudding mass will be able to get squished out of there.'* She suffers the growth of this malignancy, both visible and invisible. Her own flesh is now erupting into the exterior world. This is very difficult to endure.

June asks Iris her nursing questions including the ESAS. Iris refers little pain at the moment. She complains about the loss of strength in her right arm but says that her visits to the chiropractor are helping her to regain muscle force. June asks, 'Are you having any nausea or vomiting?' 'No,' Iris responds. 'How are you sleeping?' June asks. 'I wake up at night with a bit of pain, but then I go back to sleep again,' Iris replies, 'when I get these pains, I just put my hands on there and kind of grin and bear it, and get over it that way.' June replies, 'It would probably be good to take a Tylenol for those pains.' 'Yeah,' Iris says, 'I have done that occasionally, but I just haven't in the last maybe week, or couple of weeks.' June says, 'But you don't realize how much the pain wears you out, too.' 'Oh Yeah,' Iris says, 'you do realize.' 'So it's good to take Tylenol,' June says. 'But isn't that more like a headache pill?' Iris asks. 'It's for pain, any kind of pain,' June replies.

'The trouble with those painkillers,' Iris says, 'is that there are always side effects of some kind. So the more you take, then you've got to put up with the side effects.' 'Tylenol probably isn't bad,' June says, 'it is one of the weak ones.' 'But some of those painkillers are constipating,' Iris says. 'Certainly,' June responds, 'once you get into the ones with codeine.' 'Well,' Iris says, 'I don't need any more constipation problems; I'm already taking laxatives to the hilt.' 'And you take just one a day?' June asks. 'Yeah,' Iris says. 'You can always increase it if you need it,' June says, 'you could easily take it two or three times a day.' 'Oh, I know,' Iris says. 'So if you need the Tylenol, it's worthwhile taking it,' June says. 'I don't know,' Iris responds.

'How is your Appetite?' June asks. 'You know, I'm really funny now,' Iris responds, 'I'll eat, and I don't know what I want to eat. Nothing seems to taste good. Then I eat, and I should be good for a while. Then in a little while, I sort of feel hungry again, and again, I don't know what I want. It's awful. I think the heat has something to do with it.' 'Can you eat fresh fruit?' June asks. 'Well, they told me because of the colitis to limit anything acidic,' Iris responds, 'I find that when I have acidic, I break out in my mouth right away with those sores. My worst problem is that I'm bleeding all the time. See, they give me these blood transfusions, but I'm losing that blood faster than it's going into my system. Ever since I had this transfusion, all that's happening is the blood is just redder coming out of there.'

Iris's loss of blood through her bowels is a concern. She has had anaemia in the past and has received a few blood transfusions. June is very aware of this situation. 'What colour is your bowel movement?' She asks. 'Like bloody,' Iris says. 'Is it black or red?' June asks. 'Red,' Iris responds. 'Is it like fresh blood?' June asks. 'Yeah,' Iris says. 'How long has that been?' June asks. 'Oh, for a long time,' Iris says, 'and sometimes, I'll get a bowel movement that's not red, it's just sort of greenish colour. But there's always some red accompanying it.' 'Is there ever black?' June asks. 'A lot of times,' Iris says. 'Is it ever kind of a brown colour, like a regular kind of a bowel movement?' June asks. 'Occasionally,' Iris says.

'You said you have a little wee bit every day, would that be like a small finger?' June asks. 'Yeah,' Iris says, 'but it's every day, four or five times in a day, and sometimes, it's not even like that.' 'Do you ever have pain with a bowel movement?' June asks. 'Yeah,' Iris responds, 'I have to force it out most of the time and at least get a plug out of there. Then I feel relieved a little bit more. What a subject! I hope it improves soon, because it gets pretty depressing.' 'When are you seeing your family doctor again?' June asks. 'Next week,' Iris says. 'She will probably order some new blood tests to see if you need a new transfusion, have you been very tired lately?' June asks. 'Yeah, I feel I can't do very much as I get so tired,' Iris replies. 'Have you had difficulty breathing?' June asks. 'Not much really unless I exert myself,' Iris responds.

June does a very comprehensive assessment of Iris's condition. Her nursing questions assist her to understand Iris's situation and to offer advice, today regarding the management of her pain. She does this in a very respectful and non invasive manner. She makes every effort to speak to the benefits of taking the pain medication but she also knows that Iris after balancing personal benefits and disadvantages will make her own choice. June's main concern at the moment is to determine the urgency of a blood transfusion. She knows Iris will eventually need one as it has happened in the past. She knows that another blood count will assist her doctor to know whether it is time for a new transfusion. Yet she too knows that Iris's clinical condition is most vital in deciding the timeliness of the transfusion. She carefully assesses Iris's bowel movements. Dyspnoea or severe fatigue due to anaemia are among clinical indicators of the need for a transfusion in the very ill (Pereira et al., 2001; Twycross, 2003). June knows Iris is visiting her family physician the following week and given Iris's current status waiting till then is fine. She also knows that she will be seeing Iris every day this week because of her daily dressings. Should things change, she would be able to quickly contact the doctor.

The assessment period goes on until June finishes her questions. I notice patients tend not to interrupt these questions. They know there is time to talk about other concerns afterwards or before, when the nurse arrives in the home. I sense a silent expectation during this time as the nurse asks, the patient responds, the nurse writes down the answer. It is a very characteristic moment of the palliative home care nurse's visit. This standard assessment occasions a shift in the flow of the visit from a conversational mode to a more question-and-answer mode. The visit takes on a different quality, a certain formality that the questions themselves evoke. The nurse also assumes a serious stance as she concentrates on the questions and listens carefully to the patient's answer. She knows a subtle variation in a response compared to past answers may indicate a change in the patient's status that needs close follow up.

Nurses follow a number of parameters during their assessment in the home, i.e., mouth and skin status, fluid and food intake, nausea and vomiting, bowel routine (constipation is very common in the very ill), breathing, pain, medications, cognitive status, among others. They use a nursing flow sheet as their main assessment guide and a few scales including the ESAS and the Mini Mental Status Questionnaire. I enjoy the nursing questions from the nursing flow sheet as they invite an open response. The numbers only come in at the time of doing the ESAS where they ask patients to rate their symptoms or when they see the need to do the mini mental test. I see the nurses do not give great emphasis to these scales. The numeric questions disrupt engagement, their lived relation with the person in the home. They do use them regularly on their visits and do take into account the patient's ratings. Yet their main focus is on the story. They privilege dialogue with the patient. They know that dialogue is the venue to understand the patient's situation and decisions more fully.

> 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 patient calls, the nurse responds. The nurse calls, the patient responds... Through dialogue we increase our understanding of things. (Cameron, 1998, p. 223)

In nursing the very ill, nurses know they need to keep a close watch on their patients as things can change quickly. This involves periodic assessments of their patients' clinical status. Doing this requires skill, knowledge, clinical judgement. It too requires the capacity to shift the planned focus of a visit to wherever an emerging situation takes the nurse at the moment. Here dialogue shows itself as central to the nurse's assessment of the very ill. Engaging in a continuous dialogue with the patient in the home is integral to understanding the changes they experience from the inside. The nursing dialogue is a primary element of nursing practices in the home. Through this continuous dialogue, the ethos of the home visit and of nursing practices in the home reveals itself.

The home visit is the palliative home care nurse's embodied expression of her clinical and ethical attentiveness to the situation of the very ill in the home. Etymologically, to visit is go to see, to behold (Skeat, 1963). Through the home visit, the palliative home care nurse is able to directly behold the very ill. Here she attends to their current situation in a manner that is attentive of the particularities of their lifeworld. The home visit is the nurse's decisive act to understand and attend to the emerging needs of the very ill. In Spanish, both entender (understand) and atender (attend) are etymologically related, meaning a stretching towards something (Gómez de Silva, 1985). The home visit is the nurse's intentional movement to enter the home. Through this stretching towards the home, the nurse apprehends the web of elements that take part in a situation.

Gadamer (1996) regrets the gradual invasion of "technological forms of thought" (p. 137) in our languages and how these have led us to "conceive of language as a form of rule following" (p. 137). He writes about engaging in genuine dialogue in the therapeutic relationship with patients and remarks the need to have these dialogues in the manner of a conversation. Through genuine dialogue, he writes, we awaken each other's inner activity without losing our own individual ways. In the home, nurses cultivate their nursing relation with the very ill and their family members through dialogue.

> What takes place here... is a form of attentiveness, namely the ability to sense the demands of an individual person at a particular moment and to respond to those demands in an appropriate manner, it is in these terms that we must understand what is involved in therapeutic dialogue... It is an attempt to set in motion once again the communicative flow of the patient's life experience and to re-establish that contact with others from which the person is so tragically excluded. (Gadamer, 1996, p. 138)

In the home, nurses sense the primordial need of dialogue to comprehend the fine pieces of the situation of the very ill and to respond appropriately. In the home nurse and patient meet one another's world through conversation. The conversational quality of the home itself is what gives conversation such a significant place in the nursing relation with the very ill. It also makes the use of numeric tools particularly difficult at times. The shift in language that tools demand makes the tool rather incongruous with the dialogical flow of the home visit. Conversation is the nurse's manner to partake in the world of the very ill and inhabit their experience as it reveals itself in the home.

Knowledge and skill are a vital component of the nursing dialogue. The nurse engages in a conversation with the intent to find out about the patient's status. Having a cup of coffee facilitates this conversation at times. Yet far from being merely socializing as the scene might look like to an outsider, over a cup of coffee the nurse observes the cues that come forward and are revealing of the status of this person. In the eyes of others, June and Iris sitting in the living room looks like a common scene. One cannot appreciate the clinical significance of their conversation. Visiting in the living room denotes a clinical complexity that is difficult to grasp. "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" (Cameron, 1998, p. 223). Second guessing does take place. Yet their second guessing is based on patient cues, embodied knowledge, nursing expertise.

After June finishes her assessment, we get ready to go. June asks Iris if she has any questions before we go and she says she is fine. June tells her she left supplies for a week so she shouldn't have any problems with this. Nurses always make sure their patients have enough supplies to cover their needs for a few days at least. A good stock of supplies expedites nursing work. Iris is having dressing changes twice a day so the evening nurse comes in the evening. June thinks it is time to go down to only one nursing visit a day as the wound and the surrounding skin are in better condition. Yet when she suggests cutting down one nursing visit Iris responds strongly that she doesn't think it is time to do so. She is concerned she will be unable to change the dressing herself because of her lack of strength in her right arm. 'Ok,' says June deciding not to insist. She suggests re-evaluating it at the end of the week. Iris asks me when I will be coming and we arrange to meet with her and June in about two weeks.

In the car, June says she really doesn't think Iris needs the nurse to come twice a day to do her dressing. 'I just couldn't insist at the moment because she got so upset right away,' she says. 'What do you think?' She asks me. I appreciate her recognition of the nurse in myself and enjoy participating in her thinking forward of Iris's situation. I say that Iris's skin doesn't look too bad and a dressing a day would probably be fine. She decides to discuss this with the team and the evening nurse. Team dialogue is another vital part of their practices. I notice they seek each other out to think together how best to approach complex situations. Nurses support each other through dialogue. They enact their knowledge and practices through dialogue.

THE NEXT VISIT

Two weeks later, after the team meeting, June and I go to Iris's home together. Before we leave, June phones the patients she will visit today to confirm her visit. I see nurses are very respectful of their patients' time. They make appointments in advance and then make every effort to arrive on time. They know time is very precious for their patients. It is also precious in the nurse's eyes. They try to accommodate patient's preferences. After making sure nobody needs an urgent visit today, June gives Iris a quick call to let her know we are on our way. She leaves a message as there is no answer. 'Let's go,' she says and we leave. I already went to the supplies room to get a bag of dressing supplies for Iris. We go straight to the parking area.

On our way to Iris's, June tells me they are now down to one visit a day only. She says that after discussing Iris's situation with the team, they proposed to have a personal care attendant come in the evenings to apply the cream on her skin. Iris was in principle agreeable with this although she insisted the doctor had said the nurse had to do this. June also talked to one of the nurses in the doctor's clinic to discuss this as there was no real need to have a nurse come twice a day. The situation was resolved and everything is working fine now. June also says Iris just had a blood transfusion at the beginning of this week. 'That was another trouble,' she says, 'because she couldn't have it done at the cancer clinic. They informed her family doctor she was "no further recall" over there and her doctor had to refer her to another hospital for the transfusion.'

"No further recall" means the patient is definitely discharged from the cancer clinic. Patients who are no longer eligible for further cancer treatments given the progression of their disease can be classified as "no further recall." They continue to be seen by their family physicians and by palliative care practitioners. Their family physician can refer them back to the cancer clinic to request an oncology assessment. 'This news was devastating to Iris,' June says, 'she is truly mad about this. She can't believe her oncologist didn't inform her directly she would be discharged from the cancer clinic. She says her family doctor was as surprised as her. The thing is that in the past she always had the blood transfusions at the cancer clinic. But now they were adamant that she could not have it there.'

'Her doctor suggested that Iris goes to another hospital for the transfusion,' June says, 'but she refused to have it there because of her past experiences. I called other places and in the end she went to a community health care centre to have it done. I hope she feels better after the transfusion as she was feeling quite tired last week.' In Iris's neighbourhood, June says, 'I just missed the turn. I think I had to turn left over there. Oh well, we aren't too far anyway. I always forget which one is the turn to get to Iris's home.' We turn around. 'It is funny,' she says, 'I have come here so many times already. But I keep missing the turn.' 'I wonder what it means,' I say, 'you rarely miss your turns.' June isn't really lost, she just forgets the turn. The turn to Iris's home keeps slipping away from her attention. She lets it slip away.

The door in Iris's home is locked and Aunt Alice lets us in. The slow and rigid movements of her arms and legs reveal the arthritic state of her joints. She walks with the rigidity of a mannequin. 'Iris is in her bedroom,' she says. We take our shoes off and go straight to her bedroom. 'Hi Iris,' June says. 'Hi June,' she replies. She is lying down, ready for June to do her dressing. 'Hi Anna, good to see you again,' she says. 'Hi Iris,' I respond, 'good to see you too.' 'How are you?' June asks Iris. 'I am ok,' Iris says, 'I am feeling better after the transfusion. I was really dragging my legs before it, but now I can walk for a bit and still feel ok.' 'I am glad,' June says, 'shall I do your dressing right away?' 'Yes, sure,' Iris says pulling down the bed covers.

June and I go to wash our hands and are back in a few moments. June takes off the dressing and looks at the surrounding skin. I say, 'Your skin is better than the last time I saw you.' 'Yes, the rash is almost gone,' June says. Iris looks at her skin through her mirror. 'Yes, it really looks better,' she says, 'I am worried about this spot here. It looks like I'll get another wound there.' 'It looks the same as before,' June says. 'I feel it the same way I felt this other one before it opened,' Iris says, 'it feels very mushy.' 'It might be the fluid you have in your belly,' June says, 'did your doctor give you anything for it?' 'Yes she did,' Iris says, 'Now I don't feel my labia as swollen as before.' 'That's good,' June says irrigating the gauze with saline before taking it off.

Iris's wound looks the same size as the last time I saw it but the tissue looks blacker. As I look at her wound, I think of this tumour slowly eating her own flesh, hungrily malignant. Its insatiable hunger takes over the living tissues of Iris's body. Yet what is this tumour but her flesh turning inside out, angrily erupting into the world? This flesh once harmonious with itself has now turned against itself (Burch, personal communication). Her flesh has lost the capacity to recognize itself as one of its own. Now in eating itself it grows, invading other places. It overcomes what is no longer itself but Other. Iris's own flesh has now turned into a stranger to herself.

Kristeva's (1991) notion of the stranger in ourselves is helpful here. In her book *"Strangers to Ourselves,"* Kristeva undertakes a comprehensive philosophical analysis of the place of the stranger in the history of humanity. She shows how strangers have always been a part of societies and how societies in one or another way have despised and dismissed the stranger. Through her psychoanalytical exegesis of the stranger, Kristeva brings us to the (uncomfortable and uncanny) realization of the stranger within ourselves. She calls us to be conscious of the other as our "(own and proper) unconscious" (p. 183). This realization, Kristeva writes, moves us to address foreignness, to admit the stranger we ourselves hold in us.

> To discover our disturbing otherness, for that indeed is what bursts in to confront that "demon," that threat, that apprehension generated by the projective apparition of the other at the heart of what we persist in maintaining as a proper, solid "us." (Kristeva, 1991, p. 192)

Iris's body reveals in a striking way an uncanny presence of the stranger in ourselves. This flesh now evokes an embodied awareness of the invisible, unconscious perhaps? Otherwise invisible this flesh erupts into the exterior world forcing us to look at its rawness, to remain conscious of it. It is difficult to look at this wounded flesh. Its appearance is utterly other to us. We cannot easily reconcile ourselves to this dramatic presentation of Otherness in our body, unrecognizable. And yet, uncannily, this stranger is also Iris herself.

It is hard for Iris to assimilate the otherness of this flesh inside herself. This tumour is an "it" in her life, a strange object, foreign to her. It remains other, '*dead meat,*' as she herself calls it, a thing with a life of its own, unpredictable. She lives under its constant threat to burst open in new places. June's nursing presence enables Iris to live with this repugnant wound. She has the nursing skill to engage with the otherness of Iris's body. She makes it liveable for Iris, endurable. The otherness of Iris's flesh calls the nurse into being. It claims the nurse into action. Strangely, the stranger in Iris evokes the presence of the nurse as though nurse and stranger called one another. Precisely the moment when nurses are called in to Iris's home is right after the tumour bursts open for the first time. The eruption of this "disturbing otherness" (Kristeva, 1991, p. 192) gives birth to the nurse.

As I see June nursing Iris's wound, I think of the exquisite combination of knowledge and skill that doing this involves. She activates the knowledge systems that support her nursing practice. Through her knowledge of physiology and pathophysiology she understands the formation of wounds and their progression towards healing or impairment. Her knowledge of microbiology assists her to manage and prevent further infection. Pharmacology is always in her mind as Iris discusses with her the side effects of her medications and potential drug interactions. She regularly consults her drugs book and makes every effort to answer Iris's questions. Her knowledge of the cancer process itself is also very important. June knows this is a malignant wound and the likelihood it will heal is very low. She is careful not to infuse a false hope in Iris. Yet she also knows she cannot take away Iris's own hope that it will eventually heal. Doing this, she knows, would be harmful to Iris's integrity.

As she changes Iris's dressing, June integrates all the above with her nursing knowledge and skill. The movements of her hands are specific and directional. She knows what to do here. Her nursing actions are a back and forth movement between Iris's situation today and her knowledge systems. She has the ability to let her situated understanding of Iris activate her knowledge. Above all, her finest nursing skill is her capacity to so directly engage with the striking otherness of Iris's wound. Through her embodied nursing engagement with this tissue so foreign to Iris, so unpresentable (Cameron, 2006), June makes it less foreign, less other, less strange, presentable. In doing this, June gives back to Iris her wholeness.

HOME IN ANGER

'My daughter is coming in a bit,' Iris says as June finishes up her dressing. 'She wants to talk with you,' she adds. 'Oh Ok,' June says. The news takes her by surprise as Iris had not mentioned this before. 'She wants to talk with you about the transfusion,' Iris says, 'I don't think she is very happy with the cancer clinic decision to discharge me. She thinks something has to be done about it.' 'I know,' June says, 'it is hard. I really tried to have you go there for your transfusion. Your doctor also tried but we couldn't make it happen. How did it go in the centre where you went to have it done?' 'I don't think they ever had done a transfusion before,' Iris says, 'I am sure I was the first one. They didn't seem to know anything.' Iris's voice gets sharper as she talks. 'But my daughter will tell you the story,' Iris says, 'she was with me over there.' 'Ok,' June says, 'it will be good to talk with her. It doesn't sound you had a very good experience.' 'Not at all,' Iris responds. 'I am sorry about this,' June says, 'we really thought it was going to work well for you.'

'Shall we go to the living room or would you like to stay here?' June asks. 'No, let's go to the living room,' Iris says while getting up. I help Iris get dressed while June leaves everything in order on her now nursing table. We wash our hands on our way to the living room. 'Would you care for a cup of tea?' Iris asks in the kitchen. 'Sure,' we say. Iris puts the kettle on and offers us a few choices. We pick out herbal tea. 'You have been canning', June says looking at carrot and rhubarb jars on the kitchen counter. 'Just a little bit,' Iris says, 'I like pickled carrots although these ones are very mild. I can't have them too strong because of my bowels.' 'They look good,' June says, 'I also have been canning a lot these days. I am almost running out of jars.' I enjoy how June talks about her home life with Iris. She lets her gardener side come out. For a few moments, the world of veggies, gardens, and trees makes us forget the world of wounds and tumours.

We get our tea cups and move on to the living room. Alice reads the paper by the kitchen table. I wonder about her as we go. She seems left outside Iris's situation, and yet she is so inside it. She is present in an invisible way. 'How is it working for you with the PCA coming in the evenings?' June asks Iris. 'Fine,' Iris says, 'she is very good, she puts cream on my legs also. I usually get out of the shower just before she comes. But she has fished me out of the shower a few times.' 'What about the one on weekends,' June asks. 'She is in and out very fast, because I guess they are very busy on the weekend.' 'Yeah,' June says, 'I'm glad this arrangement is working for you. We will keep the PCA coming for as long as you need it.' 'Thanks,' says Iris, 'I really don't think I can do it myself.' June's nursing judgement is central to deciding the services Iris needs. She regularly re-evaluates Iris's needs. Her nursing relation with Iris helps her decisions.

Iris's daughter arrives and June finishes her assessment quickly. Her daughter apologizes for being late. Her face looks red as though she has been in a hurry all morning. She takes her sandals off and comes to the living room. She sits on the couch beside June. Iris is sitting in her large chair with her feet up and I am sitting on a chair beside her. June introduces me and we exchange a quick greeting. The atmosphere in the room has changed to one of serious expectation. 'Iris told me you want to talk with me,' June says. 'Yes,' she responds in a sharp tone, 'I want to talk with you about my mother. I will not stand anymore all these horrible situations that she has had to face with the health care system. So I want you to do something about this. The problem with the transfusion is the last thing that could happen.' June hears Iris's daughter attentively. She senses her anger coming out through her sharp voice and piercing gaze. She is sitting on the edge of the couch turning towards June, her trunk slightly forward. The tightness of her face muscles and of her whole body can hardly contain her tension. June is sitting very close to the back of the couch, her arms on her lap, her hands holding one another.

- 'Would you like to talk about the last transfusion Iris had?' June asks Iris's daughter.

- 'Of course I want to, but first of all, I want to tell you that what they did to my mother in the cancer clinic is unacceptable. How could they just dismiss her without even talking to her? I think the way she learned about this is shocking. They crossed her out without even saying a word to her.'

- 'I know, I am truly sorry about this,' June says.

- Iris adds, 'I just cannot understand how they can do that to a person, it's like they're saying to me, 'Just go home and die, and don't bother us any more.' What kind of care is that?' Iris's face looks paler than a few moments ago; her eyes mirror her daughter's eyes.

- 'This is ridiculous, we keep fighting the medical system all the time, I cannot see my mother go through this again,' her daughter says.

- 'I know,' June replies softly.

- 'These guys, I don't know what they're thinking to just say a thing like that, especially to my doctor,' Iris says.

- 'That's how they care about people? They sort of 'Go home; we're done with you.' What kind of care is that, can you tell me?' Iris's daughter says. Her voice is loud, she is nearly yelling.

- 'And this excuse that the mail just didn't get through. They're supposed to notify me that I'm off their list. I don't think that they ever will notify me,' Iris says, her tone getting sharper and louder.

- June responds, 'I think they must have had something in the computer for them to tell you that when the doctor phoned. There had to have been something there already.'

- 'Yeah, well, they probably had in there, 'This old biddy, we don't need her here any more. Just keep her out of here.' That's probably it,' Iris says.

- 'I know, it is hard to understand, especially when you've been going to the cancer clinic for quite a while, and you get kind of connected with the doctors there,' June says.

- 'It's three years; it was three years in May since I was diagnosed,' Iris says.

- 'And the least they could do to my mother after all this time is to let her continue to come there. This is the very least. It is our right,' her daughter adds.

- Iris says, 'I don't want to see them more than I have to. Don't get me wrong. But at least they could say, 'We'll see you six months from now,' or whatever, instead of telling you, 'We didn't expect you to be around any more.'

- 'How could they say that to her?' Her daughter says.

- 'Yeah, how can anybody predict when somebody will be around and when they won't? You know? You can have a perfectly healthy body, and today, they're here, tomorrow they're gone,' Iris says.

-'And thanks to them and their rigid rules, she had to have this transfusion in this other health care centre. I want you to make sure that my mother is not going there any more,' her daughter says. She expels anger as she breathes out.

- 'I don't think the girl had ever done a blood transfusion. She couldn't even find my veins,' Iris says.

- 'And when we got there, they didn't even have a place for my mother. They put her right by the garbage, at the very end. And I asked them if they couldn't find a better place and they said that was all they had,' her daughter says.

- 'I see,' June says, almost in a whisper.

- 'Why would you ever send her there if they don't even know how to do transfusions?' Her daughter asks.

- 'They assured us that they would be able to do the transfusion. Otherwise we wouldn't have sent you there,' June says.

- 'Oh yeah, and my mother had to pay for their inexperience. I cannot tolerate this anymore. If this happens again, I tell you I am suing the system right away, I really am,' her daughter responds.

- 'I really hope you don't have to go through this experience again,' June says.

- 'And I want you to take care of this, because you are part of the system and you know very well what I am talking about,' Iris's daughter says.

- 'I will call your doctor and discuss with her this situation. We will assist Iris as best as we can during this time,' June responds.

As Iris and her daughter speak, they boost each other's anger. The louder her daughter speaks, the louder Iris speaks. And the louder they talk, the softer June speaks. They seem to hardly hear her. Iris's daughter wants June to hear all her complaints. She wants to make sure she understands her demands and threats. At the moment, she seems hardly interested in a response. Her anger makes her unable to hear. She is caught in her own outburst of anger. As they talk, Iris's home fills up with anger. Anger bounces back and forth between the walls. June is in the midst of it. She breathes it in. Yet she remains calm, even calmer than usual.

Iris's daughter is truly furious, outraged. She seems so inside this anger that at times I fear for June's safety. Although both of us are here, I don't seem to exist in Iris's daughter's mind. June is the only focus of her attention, her target. Her hands and arms shake as she speaks, her trunk stiffens. Her red face accentuates the intensity of her rage, her eyeballs about to jump out. She hardly takes her eyes off June. This is indeed a violent episode. Something we would have hardly expected on our way to Iris's. Iris's daughter's anger makes me wonder if we should leave. But June has no intention to leave. She makes no movement in this direction. She knows that leaving now would make Iris's daughter more furious. She knows it would not be helpful. Staying is her nursing response. Inside this moment, she has a sense this is how she needs to act. She takes the cues from this moment. She let's Iris's daughter vent her anger. Yet she won't let her escalating anger take over.

Home care nurses know that once they enter a home, they need to stay there until things that need immediate attention are settled. This is the ethical claim of the home. The nurse's attentiveness to this claim activates her ethical response. June will not leave unless in her judgement her safety and personal integrity are in real danger. She assumes an attitude of serenity before Iris's daughter's agitation. Her response is respectful of Iris and her daughter, and Alice who is quietly present in the kitchen. She offers her understanding mind to her. She listens attentively to her complaints and threats. She doesn't argue with her, she doesn't challenge her points. She knows there is a lot more to this anger episode than what we see at the moment. She sees the hidden layers behind this anger. She knows something deeper lurks behind this outburst of anger.

Etymologically, anger is related to the Latin *angere,* to choke (Skeat, 1963). There is an element of choking in Iris's daughter's expressed anger at the system. Her words come out in short quick breaths. She speaks her words in staccato manner. As she expels her words, her chest tightens and not much air goes back in. The redness of her face bespeaks her lack of air. What is it that makes her choke? What is it that triggers such a constriction of her airway? Anger and anguish (*angustia* in Spanish, angst) are related (Skeat). Is this outburst of anger the disguised eruption of Iris's daughter's deepest fears, the restlessness of an angst that can no longer conceal itself? June knows that this torrent of harsh emotion involves something more serious and painful than their disappointment with the health care system. She acknowledges their frustration with the recall policies at the cancer clinic. She knows this is often demoralizing for palliative patients. Yet she senses here an anger that goes beyond this frustration, a pervasive anger that pierces their very selves.

There is accumulated anger here. Ever since she met Iris, June has heard Iris's complaints about the health care system. Iris often recalls her negative experiences with the system, at the time of the diagnosis (after she and her daughter refused to leave the Emergency Department), at the time of her surgery (when the assured bed was not immediately available), later on while having chemotherapy (when she had an allergic reaction to the central line), and lately with the radiation and the bursting open of her wound. Her allergic reaction to the antibiotics for the wound infection aggravated her anger. Yet even though these experiences have been frustrating and upsetting, her anger in her also surpasses these events. In a sense, her anger is not merely an emotion she experiences occasionally or a "stage" in the course of her terminal illness. Anger here has become a mode of being in the world. It pervades her entire life.

After Iris's daughter finishes venting her disappointments and frustrations, June says she will give her a call after she talks with Iris's family doctor. She and Iris have calmed down and June knows it is time to leave. She asks them if they have any questions and they say no. They both look numbed after this conversation. And so do we. June looks rather pale. Anger is anaesthetizing. It blocks our senses, our sense of relation. It leaves us bereft. As the recipient of this anger, June has done her best to hold it in peace, to not let it bounce back to others. Through listening, she has been able to calm down Iris's daughter, to pacify her. She has brought her back to a wakeful state. Iris looks tired. June says we are going. She reminds her daughter to contact her anytime to discuss her mother's situation with her. She leaves the door open for the future. She knows this daughter is the closest relative of Iris's and her collaboration is needed to facilitate Iris's care and well being. June knows she needs to work in partnership with her.

In the car, June and I look at each other and exhale a big sigh. 'Whew,' she says, 'that was hard. She was so mad. For a moment, I thought she was not going to calm down. And Iris had told me nothing about this. And she got so mad as well.' We are already driving away. 'What a day,' June says, 'I really need a break. We should go for lunch. I think there are a lot of things unsaid between these two, so much anger!' We both feel disturbed after this visit. It was difficult to bear Iris's daughter's yelling, her anger coming out in big chunks, to see such disrespect for the nurse, ethically disturbing. We stop at the first *Tim Hortons* coffee shop on our way. As we drink our coffee, we go again over Iris's daughter's words. We bring back our fresh and lived memories of this visit. We exchange our views. We vent. 'I am glad you were there,' June says, 'glad you witnessed this. I think I have to three star Iris.[13] Nurses coming out must be aware of her daughter's anger. I will also put her for case reviews next week.' As we talk, we breathe out the anger that entered our bodies, until slowly we are able to come out of it. Until we feel ready for the next visit.

THE VISIT AFTER

On our next visit, after June changes Iris's dressing and does her nursing assessment, we sit in the living room and have a conversation about Iris's experience. Iris continues to be upset for having been classified as no further recall at the cancer clinic. She had hoped the situation would reverse, but it didn't. She takes it as the consequence of having acted in a very demanding manner during one of her visits to the cancer clinic. She tells us she upset the nurse and the doctor at the clinic after being tired of waiting for hours.

Iris says, 'we were there early in the morning and it was getting to be way past lunchtime. I was hungry and I was getting cranky, and I wanted *out* of there. I was sitting in the wheelchair all bent up. So I just went and told the nurse at the desk, 'You might as well make a morgue out of this place.' She put me in a room right away. Then I thought we would be there for hours but the doctor came in very quickly. Then I complained to him about not having ordered all the blood tests I needed and about the lab technicians who wouldn't add the tests I was requesting. He wasn't very sympathetic and I ended up telling him off right there. I apologized after, but I was so upset. You think he would understand that you're upset. But he took a very big offence to it, I think. He softened up after; he took

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[13] Three star denotes there are safety concerns in the home. It is a precaution sign for home care team members.

my hand a little, 'Yeah,' he says, 'I know.' I figured, 'Yeah, do you?' but I didn't say too much after.'

Iris's anger at having been discharged from the cancer clinic in such an irrevocable way has a degree of reasonability. She interprets this situation in a way that helps her to make sense of it. It is difficult for her to believe other reasons, also plausible in the current health care context in Alberta. Her own situation makes it difficult to understand the no further recall policy at the cancer clinic. Being unable to go back to this clinic means closing the door to treat the cancer itself; this cancer that still is inside her body, showing itself in her wound. Iris's anger is the embodied expression of her despair. She shares with us her suffering and the restless anguish of having already been written off. She bears alone her despair as well as the long self-ignored specialist's despair in the face of the untreatable.

Iris shares with us pieces of her personal life that also help us understand her anger. She has gone through many hardships throughout the years. She married at a very young age and had her only daughter early in her life. She has endured serious family conflicts in the past. She carries these unresolved conflicts that continue to evoke anger in her today. There are many broken ties in her life. This is painful. As she recalls these events, she re-lives the emotions they evoke. She re-experiences the anger these events generated in the past. This anger is truly suffocating.

Iris tells us it is painful for her not to be able to forgive. She asks how to forgive when it is so difficult. 'Perhaps part of it is just being able to forgive ourselves for not being able to forgive,' June responds. Iris is appreciative of this advice. It is hard to offer words in the face of such difficult experiences. June and I mainly hear. Iris regrets all the suffering her daughter has gone through as a consequence of these family conflicts. 'She was young,' she says, 'when all this happened.' She talks about raising her daughter on her own. She worries she didn't give her all the time she needed because of work. 'I hope she forgives me,' she says, 'if I did anything wrong I thought it was right at the time.' She appreciates her daughter's support in her sickness. She is the only family member left. Aunt Alice remains outside.

As we hear Iris's stories, we understand her anger as well as her daughter's from another perspective, one that resonates with the nuances of Iris's own existence. Anger has had a predominant place in her life, consuming her being as conflict after conflict have demanded most of her attention throughout the years. Her daughter has absorbed this anger through her skin, her lungs, her ears, her mouth, every part of her body. She has appropriated anger as a way of speaking to the world. Anger has been Iris's mode of attuning herself to the world, her mode of being with others in the world. Anger sets her in motion. She moves forward through anger. It gives her the courage to go through the challenges she has faced in life, including this cancer. Anger is the passion of her being.

ANGER AS LIVED EMOTION, RESPONSE AND CLAIM

In his analysis of blushing, Heidegger (2001) says blushing is a gesture that shows our relatedness with others. Blushing happens in the context of one's relation with others, not in isolation from other human beings. In a similar manner, we can look at Iris's anger in the context of her relation with others. Our being in relation with others, Heidegger writes, means a being together in the world, a sojourning together. In a sense, anger is Iris's mode of sojourning with others in the world. Her anger is not an isolated emotion that comes from the depths of her own being, something like an irrational urge or an instinctive biological response to external stimuli. Rather, anger reverberates in and through her interrelatedness with others. Through her being in relation with others, in this sojourning with other human beings, anger has become an intrinsic part of her very being, an incarnate emotion so to speak.

Alison Jaggar (1989) offers a perspective that shows the significance of emotions in our understanding of the world. She discusses the rationalist approach of the Western philosophical tradition and its systematic dismissal of emotions as "nonrational and often irrational urges" (p. 130). Jaggar shows how the tendency to privilege rationality over emotionality in the generation of knowledge pervasively permeates all spheres of life. It generates a generalized interpretation of emotions as marginal (or superfluous) elements in our understanding of human experience. In contrast to the general conception of emotion as "presocial, instinctive responses, determined by our biological constitution" (p. 134), Jaggar writes emotions are socially constructed within the idiosyncratic character of particular cultures and societies and cannot be experienced in isolation from others. Emotions, she remarks, are ways through which we engage in the world. They are the fuel of life.

Jaggar (1989) urges us to recognize the primordial place of emotion in our experience of the world. She refers to "outlaw" emotions as those that are rather unconventional within determinate societies. She shows the need for such emotions in changing our traditional ways of perceiving the world. Outlaw emotions give us the courage to challenge domineering forms that exploit and oppress marginal groups. Jaggar says we need to pay careful attention to the perspectives of these groups as through their own situations of oppression and marginalization, they have access to a lived (and emotional) understanding of unjust societal forms. She writes, "the emotional responses of oppressed people in general, and often of women in particular, are more likely to be appropriate than the emotional responses of the dominant class. That is, they are more likely to incorporate reliable appraisals of situations" (p. 146).

While Iris's anger finds its roots in a larger context than her current health situation alone, her anger also evokes the need to revisit conventional practices in the health care system. As an outlaw emotion, Iris's anger occasions a disruption in her relationship with others, particularly with health care professionals. Yet her anger is also an emotional response to her being left out of an important part of the health care system, the cancer clinic. Her anger is also a response to in her eyes the negligence of the system in the course of her illness, i.e., having been twice diagnosed in emergency with the flu instead of having had a timely and thorough investigation of her condition.

Iris's anger is an invitation to revise current health care policies. Iris speaks from a marginal position. She is part of one of the most vulnerable (and marginal) groups in society. She is very ill. Her bodily fragility makes her even more vulnerable. Iris brings to the fore a perspective that the apparently healthy cannot articulate (and experience). How many others share Iris's disappointment and frustration? How many others whose voices remain invisible in the confines of the home? Iris's voice carries the voices of those unable to join her in her desperate claim to us. Is this not what ultimately her anger is? Her anger is a claim to create a more just and humane society where everybody can thrive. Her anger is ultimately a political claim.

THE AFTERMATH

We end our visits together to Iris's home towards the end of the summer as I go on a research trip to Chile. On my last visit to her home, we say goodbye until I come back. It is not easy to leave my continued engagement with Iris and June as we have slowly built a relationship together. In a way, I am disappearing from the scene. June stays. She continues her nursing relation with Iris. Nurses carry on to the end. They do go at times, vacation time, sick time, personal time. They know this is hard on their patients. When they go, other nurses on the team take over. Nurses never disappear from the scene. They are always on stage. Researchers play secondary roles. Nurses know this.

When I return, June tells me Iris has been recently admitted to hospice. Iris declined quickly in the past few months and spent most of the time in bed. Her family doctor visited her weekly. She also tells me that Iris's tumour and wound continued to grow and this was very demoralizing for Iris. She says she has gone to the hospice to visit Iris a couple of times. This is something palliative home care nurses often do once their patients have been transferred to another setting, especially when they have come to know them for a while. Through these visits, nurses continue to honour their relation with their patients. Even though brief, patients also appreciate these visits. They are a gesture of recognition. Seeing their (former) nurse assures the patient that she or he still exists. These visits are a human and humane act of solidarity with the patient's suffering, an acknowledgment of their own situation.

June and I arrange a time to go to see Iris as she is quickly deteriorating. It has been a few months since the last time I saw her and I feel an internal hesitation about seeing her. Yet I also know I need to go. 'Her anger has not gone,' June says as we take the elevator to her room, 'and her family still doesn't know that she is so ill. Iris decided not to let them know. It is sad really.' We go in the hospice and go straight to Iris's room as June already knows where she is. On our way, we greet one of the nurses in the hallway. They recognize June.

The door is open and June knocks on it very softly. Knocking on the door is such a typical gesture of the home care nurse. Even here, her nursing approach to the home continues. We hear a faint come in. We enter and turn our faces towards the bed. Iris is lying on her back, covered with bedclothes, and hooked up to a few tubings. An infusion pump busily working stands beside her bed and a urine bag hangs on the bed frame. The room is impregnated with a strong stench, a mix of fungating wound, urine, and hospital odours. What is most impressive is Iris's state itself. Her abdomen protrudes through the bed sheets in a voluminous manner. Its size is three or four times the size of a few months ago, utterly disproportionate with the size of her body.

Iris faintly opens her eyes and looks at us. Her pale and tiny face barely emerge out of the bed covers. She says 'hi June,' in a low voice, her dry lips try to emulate a smile. 'Hi Iris,' June says holding her hand. She bends down and kisses her on her forehead. They stay holding hands for a few moments. 'How are you?' June asks. 'Not very well,' Iris responds, her voice tired. 'I came with Anna today,' June says moving backwards. 'Hi Iris,' I say reaching her arm. 'I can hardly remember you,' she responds, 'her tired eyes looking at me.' 'I am the nurse from Chile,' I say, 'I'm sorry I couldn't come to see you earlier.' Iris closes her eyes and says she feels very sleepy. June and I stand in silence for a few minutes beside her bed.

Iris's room is large. A couch with a pile of bedclothes on top gives the impression somebody stayed overnight. The smell in the room makes it difficult to breathe. I think of Iris breathing it in day and night. Her breathing is superficial; the large size of her abdomen doesn't make it easier. The nasogastric tube coming out through one of her nostrils relieves her abdominal discomfort. It is a cruel image to look at her disfigured body, to see her in this hospital bed hooked up to a few things, so far from the familiarity of her own home, so alone. The malignancy of this tumour respects nothing. How different the image of her in her own bed from this one. She was still herself, whole, able. Now she looks so severed from her world. It is hard to reconcile my past images of Iris with the sharp strangeness of this room

After a few minutes watching Iris dozing off, we decide to leave. 'We are going,' June says to Iris touching her arm. She half opens her eyes. 'Ok,' she says, 'thanks for coming.' 'It is good to see you,' June says. Iris goes back to her sleepy state. As we get on the elevator, June says, 'that was hard, the smell in the room was so strong, I am not really good with these smells.' 'It was,' I say, sharing the relief to leave it behind. 'She is not doing well at all,' June says, 'I think she will go very soon.' 'I wonder if her daughter is staying with her overnight,' I say. 'I doubt it,' June says, 'she could hardly wait to have her mother admitted here.' 'I am sad she has no family with her,' I say, 'what happened to Alice?' 'I talked to her the other day,' June says, 'she was happy because she was moving to a Seniors Lodge that she really liked.' 'I am glad to hear that,' I say. 'Shall we go for a quick coffee?' June asks. 'Sure,' I say. It is very chilly outside and the cold makes us walk fast to the car. It helps us move on. In the car, June shifts her mind to her next home visits. She checks her voicemail and writes down a few notes. After a warm and reviving cup of coffee, we part.

CHAPTER V: LA EXTRAÑA/L'ÉTRANGER/THE STRANGER

> *How could one tolerate a stranger if one did not know one was a stranger to oneself? And to think that it has taken such a long time for that small truth, which transverses or even runs against religious uniformist tendencies, to enlighten the people of our time! Will it allow them to put up with one another as irreducible, because they are desiring, desirable, mortal, and death-bearing? (Kristeva, 1991, p. 182)*

The situation of the very ill poses in many ways the question of the stranger in front of us. Growing and smelly wounds that expose their raw flesh to the world as we see in Iris bring forth a strangeness difficult to integrate in our daily lives even for the very ill. Yet the very ill are bound to continually face this strangeness as they begin to experience the transformation of their own bodies. Their flesh evokes the stranger amidst us; *inside* ourselves, the one to whom Kristeva (1991) claims our attention, yet here an embodied one. The situation of the very ill raises again Kristeva's question, "How could one tolerate a stranger if one did not know one was a stranger to oneself?" (p. 182). Here the very ill themselves raise the question of the stranger and invite us to sojourn "into the strangeness of the other and of oneself, toward an ethics of respect for the irreconcilable" (p. 182).

In hearing the question of the stranger that the very ill pose before us together with my own personal experience as a foreigner/stranger in Canada, I felt the need to incorporate in this work developing thoughts about the stranger. This takes me to first of all revisit Latin America's entry into the Western world as "the beginning of an age in which the Other, the stranger was systematically concealed" (Santos Salas, 2005, pp. 17, 18). Revisiting the story of the Indigenous peoples of Latin America who have embodied the status of strangers in their countries is also important to this work. Here Kristeva's (1991) analytical work on foreignness provides invaluable insights to understanding the question of the stranger.

Kristeva's (1991) analysis of foreignness and the often ambiguous position of foreigners in society is evocative of the struggle of the stranger. Following the discussion above, I include a section on the struggle of Indigenous peoples of Latin America as their struggle is so revealing of the realities of those confined to strangeness in the world (and of the struggle of the very ill perhaps?). This struggle challenges our contemporary understandings of communal life and shows the need to be *in solidarity* with one another as a way to build more just and equitable societies. I conclude this chapter going back to the very ill in whose experience we hear the ethical claim of the stranger. Here I return to Don Pedro and his room where the realities of Latin America and the very ill seize us fully.

THE QUESTION OF THE STRANGER

Who is the stranger in our lives? Quién es la/el extraña/o? L'étranger? Is it the merchant from overseas? The foreigner who lands in our country? The refugee who flees from persecution? The prisoner? The homeless man? The street child? The one who speaks our home language with a foreign *accent*? The one with a different skin colour? The one with another sexual orientation? The working class woman/man? The illiterate? The one who suffers disability? The terrorist? The enemy? What do they bring into our midst? They bring difference, disruption, questions, openings, beginnings. They disturb the common (but not community in its originary sense). Strangers are a call to repair our bonds with humanity, to *re-turn* our face to our neighbour, to claim back our notion of the common.

Étranger translates as *extranjero/a* in Spanish. In English, extranjero/a translates as both *foreigner* and *stranger*. Stranger also translates back into Spanish as extraña/o, a subtle (political?) variation from extranjero. Extraña comes from the Latin *extrāneus* meaning on the outside. *Extra* means "beyond what is necessary" and relates to the Latin *exter* (Skeat, 1963). Exter is at the root of exteriority. A world of extrañas and extraños form exteriority. It is the world of "that-which-has-no-place (ouk-tópos)," (Dussel, 1996, p. 7). *Ouk-topias*, Dussel writes, "are the non-beings, who nevertheless have *reality*" (p. 7). This negation of the other who exists and coexists in the world, writes Dussel, reflects the irrational foundation of modern times. The modern age founds itself in this exclusion of the other. The excluded are those shut out from the world (from the Latin *exclūdere*, to shut out), the impoverished, the abused, the exploited. The excluded are the extrañas/os wilfully confined to exteriority.

Throughout the course of my doctoral studies and while undertaking this research study, I have experienced the need to pay attention to the situation of Latin American peoples and to recognize the position of our peoples in the world context. So here I would like to begin a dialogue on the realities people face in this part of the globe. Gadamer (1989) writes of dialogue as a transformative experience through which together with others we are able to arrive at new understandings that in turn transform who we are. Dialogue is an invitation to immerse ourselves in each other's world. Genuine dialogue is an effort to reach the other, the stranger, the foreigner, and the condition of the possibility perhaps to understand the world of the other. So long an *extraña* to many, Latin América claims today her position in world history.

There are ethical, philosophical, as well as practical concerns that I would like to address in this dialogue. The ethical concerns have to do with the continuing world inequities that result in striking disparities for the peoples from the South as outlined in Chapter II. Too often, economic and political agendas in granting well being to the wealthy continue to impoverish the poor. These severe differences, within and among countries, call for the development of new understandings that incorporate in their roots the ethics of the poor, one we have yet to understand. We need to turn our minds towards the poor and learn about their lived solidarity between the common and the different.

The philosophical concerns have to do with the ways in which the realities of Latin American peoples urge us to elucidate new categories of thinking (Dussel, 1996). They also pose the need to rethink our current philosophical understandings in light of the lived experience of the peoples of the developing world. The practical concerns have to do with health care as well as nursing practices. The poor in Latin América often face serious constraints accessing services in an expedite manner (a visit to a specialist, an x-ray, an ultrasound, a CT scan, a magnetic resonance image, or medications among others). The privatization of health care services, a common practice in Latin American countries in the last few decades, has mostly affected the poor. The rising cost of health care is making the poor poorer and others fall below the poverty line in the face of a severe health crisis. The financial impact of the so called catastrophic illnesses such as cancer on Latin American families (Robles, 2005) is evidence of the impoverishing effect of private health care. Disparities in health outcomes between the poor and the affluent (Vega, 2001) show the uneven impact of privatizing health care.

The situation above demands the revision of our current health care systems in Latin América. It is time we claim back our value for the public. It is time we stop the pervasive intrusion of the private in our societies. Our lives have been sadly colonized by the fake goodness of the private. We must envision structures that are supportive of the health of our peoples; structures that protect the good and well-being of the individual, the community, the country, and the earth. This also calls for a form of collaboration with countries and individuals who value public and equal access to health care such as Canada. Nurses, physicians, and allied health care professionals in Latin America and many other countries are in a position to reclaim and enhance the value of the public.

1492 AND THE NEW CONTINENT: ENTRAÑAS TURNING INTO EXTRAÑAS

> Vosotros dijísteis que nosotros *no conocemos* al Señor-de-lo-íntimo-que-nos-rodea, aquel de quien son los-cielos-y-la-tierra... Dijisteis que no eran *verdaderos* nuestros dioses... Nuestra respuesta es ésta: Estamos perturbados, estamos molestos por lo que habláis, porque nuestros progenitores, los que han sido, los que han vivido sobre la tierra no solían hablar así... No podemos estar tranquilos, y ciertamente no creemos aún, no tomamos por *verdad* lo [que nos habéis dicho], aun cuando os ofendamos.[14]

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[14] Dialogue between the Tlamatinime—indigenous from América Latina and twelve Franciscan missionaries just arrived in their land, quoted in Dussel (1994). Brackets in the original text. Translation mine.

> You said that we *do not know* the Lord-of-the-intimate-that-surrounds-us, the one to whom the-heavens-and-the-earth belong... You said that our gods were not *true*... Our response is this: We are perturbed, we are disturbed for what you say, because our ancestors, the ones who have been, the ones who have lived on the earth did not speak that way... We cannot be at peace and certainly we still do not believe, we do not take for *truth* what [you have told us], even when we offend you. (In Dussel, 1994, pp. 142-143)

Dussel (1996) writes that the being of Latin América has long remained outside history. In a way, Latin América still remains an ouk-topia, una extraña in the world. War conflicts in the Middle East, terrorist attacks in high-income countries, and security developments are today the main centre of attention. Little paper or coverage is dedicated to the dramatic situation of many others in the world. They are confined to the periphery, to exteriority. Thousands die everyday from HIV/AIDS in Africa. The healthcare situation in Haiti is among the poorest in the world. The economic crises in Latin América are leaving thousands without a job. All this takes place while developing countries under external economic pressures continue to privatize what belongs to the common good of their peoples. Health, education, housing, water, electricity, and indigenous lands to name a few, are all for sale in the developing world.

The word *entrañas* is closely related to the English word *entrails*. Entrañas is used in Spanish to refer symbolically to the inner parts of a woman, i.e., the womb. Both, the Spanish and the English words derive from the Latin *intrānea* meaning inward. The common expression *"tú eres el hijo de mis entrañas"* (you are the child of my womb) that mothers use in Latin América shows an embodied usage of *entrañas* in our context. We, the people born in Latin América are the children of her entrañas. Yet too often these entrañas remain unknown or ignored; unknown to her own children and unknown to the world. Is it in the being of Latin América to conceal herself and remain una extraña to the world? Below, I present an overview of the events that mark the origins of Latin América in the modern age. It is not my intent to provide a comprehensive account of these events. Rather, I discuss them with a view to further understand our current situation in the Latin American continent.

The arrival of the conquistadores in Latin América on October 12, 1492 marks the beginning of an age of violence and destruction for the indigenous peoples of the hitherto unnamed continent. Until then, Latin América and the lifeworld of indigenous peoples did not exist; at least in the existing categories of the European world. Initially interpreted as a sign from their gods (Dussel, 1994), the arrival of Spaniards turned into a catastrophic event for the Indigenous peoples of this continent. Suffering the cruel destruction of their ancient and sacred civilization and of their own peoples led them to take these events as the end of the world. Dussel (1994) describes the sharp contrast between the malevolence of the conquistadores and the genuine hospitality of indigenous peoples.

> Once the valiant "resistance" ended, they accepted with tragic resignation the "end of the world." Having this taken place, it was now necessary to face the new situation. The story is told that "three Tlamatinime from Ehécatl, from Tezcocano origen, were eaten by dogs... They just came to surrender. Nobody had forced them. They carried just their canvas with paintings... They were four, one escaped; three were attacked there in Coyocán." Only today are we able to imagine the humiliation, disrespect, the tragedy of those wise men who pretended to give to the "invaders"—often illiterate, brutal, and uneducated—the most precious of their culture, of their mystic vision of existence, as it was their tradition. (Dussel, 1994, p. 138)[15]

The arrival of Colón and his fleet of barbaric conquistadores in the so called new continent meant to them a great opportunity to expand their kingdom and amass a promising wealthy future. For Church representatives, the *"discovery"* of this continent also presented them with the opportunity to convert people to their faith. Thus, in the name of God or the queen, these newcomers granted themselves leave to systematically and forcefully take over these newly *discovered* lands. Spring (1998) describes this Roman-European-Western obsessive desire to convert and civilize the peoples of the world, "Rome was the model for the culture and moral of the empire. In this context, those living outside the Roman empire were without culture and morals; those outside the empire were considered irrational barbarians or natural slaves" (p. 9). The conquest of the new world meant a political, moral, and religious enterprise that finds in itself the justification for Indigenous genocide.

In his philosophical exegesis on the colonization of the indigenous peoples in Latin América, Dussel (1994) writes that modernity arises out of an irrational myth in which violence finds its moral justification in reason. Modern reason, he states, founds itself upon this irrational myth. These are the origins of the modern age, Dussel states, the invasion, destruction, and appropriation of lands, peoples, and civilizations that has taken place since 1492. Violence was the necessary and morally justifiable means to domesticate the *"savage"* and expand European *"civilization"* and the European empire. Dussel (1994) takes this event back to its original and hidden intention. He writes of the *"descubrimiento"* (discovery) of these lands as nothing else but the systematic and pervasive *encubrimiento* (covering up) of the Other. The initial action of *des-cubrir* turns into an *en-cubrir* the other, the different, lo extraño. Entrañas turn now into extrañas (on the surface, the exterior side). This insidious encubrimiento of the other is the most

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[15] Original in Spanish, translation mine.

significant and appalling expression of the cruelty of the too often celebrated discovery of the Americas, the vivid embodiment of the irrational face of modernity.

STRANGERS IN THEIR OWN LAND

The European occupation of indigenous lands in Latin América brings about the abrupt eruption of the Other in the eyes of the conquistadores. The irony and irrationality of this situation is that the colonizer, the first stranger, the *Winka*, the Non-Mapuche, the stranger or outsider in Mapudungun (Catrileo, 1995) turns into the centre, the dominator, the illicit owner of the land. The Winka assume themselves *a priori* as the prototype against whom every other one is measured while the Aborigines, *ab origine*, the ones from the beginning, "*the ones who have been, the ones who have lived on the earth*" (Dussel, 1994, p. 142) turn into strangers, extraños and extrañas in their own land. Los pueblos *originarios*, the originary peoples are now entrañados[16] (estranged) from their own place; exiled within the very entrañas of their land.

> The 11 Ahuau Katun, first that we count, is the initial katun [...] It was the seat of the Katun in which the strangers of reddish beards arrived, the sons of the sun, the men of white colour. Ay! Let us be sad because they arrived! From the East they came when these bearded men arrived in this land [...] Ay! Let us be sad because they came, because the great pilers of stones arrived [...] who blow fire at the end of their arms![17]

The entry of the newcomers in the warm entrañas of Latin América is a vital threat to the lifeworld of Indigenous peoples. The Spanish conquest was fought hard by the Indigenous peoples of the continent. This indigenous fight was the living expression of the courage and braveness of their leaders and their peoples as well as their great love for their land and traditions. Caupolicán was an Araucano leader and warrior who fought the conquest to his death. Yet not even the horrendous manner of death to which he was condemned while captive in the hands of the Spaniards was reason enough to shake his personal integrity. Alonso de Ercilla (1961), a Spanish witness of the Chilean conquest, narrates in *"La Araucana,"* a classical epic poem of the time, the death of the native leader Caupolicán.

> Descalzo, destocado, a pie, desnudo, [Barefoot, uncapped, afoot, naked]
> dos pesadas cadenas arrastrando, [dragging two heavy chains]
> con una soga al cuello y grueso nudo [a rope around the neck and thick knot]
> de la cual el verdugo iba tirando... [which the executor was pulling]

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[16] Entrañamiento (estrangement) is the exchange of a jail sentence for exile in certain cases of political imprisonment.
[17] Mayan excerpt quoted in Dussel (1994, p. 144). Brackets in the original text. Translation mine.

> No el aguzado palo penetrante, [not even the sharp penetrating stick]
> por más que las entrañas le rompiese [that torn down his entrails]
> barrenándole el cuerpo, fue bastante [chopping his body, was enough]
> a que al dolor intenso se rindiese; [for him to surrender to intense pain]
> que con sereno término y semblante, [that with peaceful end and face]
> sin que labio ni ceja retorciese, [not twisting lip or eyebrow]
> sosegado quedó de la manera [quietly did he stay as though]
> que si asentado en tálamo estuviera. [sitting on a tree he were] (De Ercilla, 1961, pp. 153-155)[18]

Since the conquest times, there also emerged individuals who fought strongly for the indigenous cause. Gutiérrez (1993) identifies a number of individuals who saw the injustices done to the native peoples in the Americas such as Cristóbal Rodríguez, Pedro de Lumbreras, Pedro de Rentería, or Pedro de Isla. The Spanish Fray Bartolomé de las Casas was one of the strongest advocates of Indigenous peoples before the Church and the King. In his writings, Las Casas incessantly called the newcomers, the crown, and the church to recognize and respect the life and traditions of indigenous peoples (Dussel, 1994; Gutiérrez, 1993). He saw in them fellow human beings who were entitled to respect, freedom, and justice. For Las Casas, native peoples were not strangers, barbarians but human beings who also enjoyed the love of God and the rights of the children of God. His incessant plea to the authorities of the time was to stop the abuses and to approach indigenous peoples in peace, cognizant and respectful of their capacity to understand and engage in dialogue.

Yet the cruelty of the conquistadores went on in spite of the advocacy efforts of people like Las Casas. Following the conquest, during the colonial times "governors and commissioners, members of the Holy Office, foremen and landowners... made a public spectacle of tortures and broken limbs in the name of the King and of God" (Gonzalez Stephan, 2003, pp. 188, 189). Over the centuries, indigenous peoples in Latin América continued to fight the conquest and the systematic appropriation of their lands. The republican times in the late 1700's and early 1800's in Latin America far from bringing them better conditions, perpetuated their oppression and marginalization. Here, the educated came to occupy positions of power and domination leaving the illiterate, the poor, women, peasants, and indigenous peoples as the *barbarians* of society. The Indigenous peoples of the *new* continent, the inhabitants of the land, continued to experience the destruction of their civilization on an ongoing basis.

> During the "divine" colony, they shared the best lands and valleys out among themselves, cultivated for millennia with love and respect. The hacienda of the feudal system continued for a long time. Even the apparent freedom of the colonial yoke, the famous political

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[18] The poem is written in Old Spanish. Translation mine.

> independence, was an absolute farce covered with racism. For the autochthonous peoples, abuse was perpetuated and the apparently patriots took over the lands stolen by their Spanish ancestors. Our women and girls continued to be abused and our men alcoholised, for alcohol was a form of payment for the mandatory work of servants. (Vizcarra, 2001)

Kristeva (1991) remarks the altruistic aims of a number of European travellers who thought it necessary to share their own *civilization* with the world (or the uncivilized barbarians). "Undoubtedly colonialism was already beginning, but the initial intent was a cultural expansion of which all men are worthy" (p. 124). Kristeva identifies a few explorers whose writings reflect their sense of wonder and respect before the strangers of other lands. Quoting the French explorer Michel de Montaigne she writes, "Montaigne cannot help observing them, but he hesitates to call them 'barbarians,': 'So we may well call these people barbarians, in respect to the rules of reason, but not in respect to ourselves, who surpass them in every kind of barbarity'" (p. 121). Kristeva writes about the cosmopolitan endeavours of individuals such as Guillaume Postel and their praise of other civilizations. Yet their strong support of Christianity as the major umbrella of religions and cultures, Kristeva notes, makes also one wonder about the sincerity of such praise. She raises the question whether the generous acceptance of others that these individuals show also denotes an ulterior attempt to absorb their unique particularities into a hegemonic whole.

While arguably universalism or cosmopolitanism may have been the ultimate aims of a few, in the case of Latin América, the original intent of the Spanish conquistadores to reach the Indies and bring fortunes to the Crown is widely known. In the end, distinctions about the original intents of the explorers made little difference to the *"explored"* or *" discovered"* ones. What began as a cultural, civic, religious, political, or economic enterprise turned into a massacre of unimaginable and horrendous dimensions; an enterprise fed on the greedy ambitions of men, their cruelty, and their incomprehensible horror before the stranger. An enterprise founded upon their own incapability to recognize humankind in the face of the stranger.

WHO IS THE STRANGER? ¿QUIÉN ES LA EXTRAÑA/EL EXTRAÑO?

And the gods do take on the look of strangers
dropping in from abroad (Homer, p. 370)

Although a common and wide phenomenon during the colonization times with the arrival of European explorers/conquistadores in the Americas, Africa, and Asia, from the fifteen century onwards, the eruption of the stranger before others and the subsequent abuses emanating from the ones in power is not a phenomenon unique to these times. In *"The Odyssey,"* (Homer) Odysseus, the great adventurer, returns after a long absence as a stranger to his own home in

Ithaca. Dressed in rags, Odysseus refuses to disclose his identity before verifying the loyalty of those he had left behind. Unable to recognize him, people treat him like a plain and insignificant stranger showing at the same time their own prejudices toward strangers. On his way home, a man addresses him in the following manner.

> Stranger, how would you like to work for me
> if I took you on—I'd give you decent wages—
> picking the stones to lay a tight dry wall
> or planting tall trees on the edge of my state?
> I'd give you rations to last you year-round,
> clothes for your body, sandals for your feet.
> Oh no, you've learned your lazy ways too well,
> You've got no itch to stick to good hard work,
> You'd rather go scrounging round the countryside,
> Begging for crusts to stuff your greedy gut! (Homer, p. 387)

In her philosophical analysis of the place of the stranger throughout the times, Kristeva (1991) shows how since ancient times, there have been individuals confined to the position of strangers in society. She writes of the Danaïdes, daughters of Iō, the lover of Zeus, as the first foreigners. According to the legend, these Egyptian women of Greek descent fled their land escaping from the brutal hands of their cousins, the sons of Aegyptus, after killing them in their wedding night. They arrived in Argos where they refused to join the local community through marriage thus remaining foreigners in the land. Although entitled to the protection of the *proxenus* who granted them the right to settle in the city, the Danaïdes, Kristeva writes, were never fully integrated into the polis remaining as both citizens and foreigners before the locals.

Kristeva (1991) tracks the use of the term *Barbarian* back to the late 400's early 500's in the Greek Polis. Initially used to refer to foreigners, the term began to be applied to "*Greeks and non-Greeks* having a slow, thick, or improper speech" (p. 51). Greek philosophy and its strong emphasis on the *logos*, she writes, came to accentuate the marginal place of barbarians in the Greek polis in virtue of their language and cultural traditions so foreign to Greek custom. Later on, meanings of cruelty, moral inferiority, and savageness would be associated to the term barbarian and would reflect the hostility of Greek society towards foreigners.

Foreigners in the Greek polis included those passing by as well as those settled in the land (Kristeva, 1991). Kristeva writes that while Greek society made a distinction between these two categories, settlers from foreign lands were considered of an inferior status compared to Greek citizens. Along with being heavily taxed, they were also deprived of citizenship rights. While kept away from civic and political life in the polis, settled foreigners (Metics), Kristeva notes, were used to the economic benefit of the state. Through her analysis of Plato's

Laws, Kristeva exemplifies the Greek attitude towards foreigners. Along with suggesting a friendly relation with *visiting* foreigners (so they shall always go back to their country), Plato's writing also reflects an a priori moral superiority of the Greek citizen in relation to foreigners.

Kristeva identifies the efforts of Hellenistic cosmopolitans and ancient Stoics as a way to promote the integration of the foreigner in the polis. Yet their philosophical arguments, she writes, remained primarily an intellectual endeavour. Based on the principle of human universality, Stoics called to love others regardless of their ethnic origin making the distinctions between foreigners and citizens, slaves and free persons, men and women blur. Unfortunately, Kristeva writes, this egalitarian approach to human society was unattainable in reality. Behind this egalitarian attitude, "an elitism of the reasonable wise man was unfurled" (p. 58). Under the flag of equality, stoicism produced "a new class of foreigners: those who did not attain virtue, did not live according to the law, or talked non-sense" (p. 58). What was achievable in the mind was unachievable in the body.

While advances in cosmopolitanism were common in Hellenistic Greece as evidenced in the emergence of international law and the development of multiethnic cities, foreigners, Kristeva writes, continued to be considered a separate class who did not enjoy the rights of citizens. Cosmopolitanism however with its acceptance of foreigners in the community opened the way for the expansion of Christianism in the societies of the time. The first followers of Christianism found in foreigners, merchants and those from the margins of society a rich soil to their teachings. The birth of Christianism, Kristeva writes, gives rise to the *Ecclesia*, the new community no longer confined with the boundaries of the polis.

Foreignness also emerges as a significant thread in the biblical account of the history of salvation. Kristeva (1991) quotes several biblical excerpts where the people of Israel, being reminded of their former status as strangers in Egypt, are called to be hospitable to foreigners and treat them with respect. She takes the story of Ruth the Moabite to exemplify the participation of foreigners in the history of the *chosen* people. Ruth was the daughter-in-law of Elimelech, a Jew who having settled in the foreign country of Moab, was considered a traitor by his people. Elimelech's death was followed by the death of his two sons leaving his wife Naomi and two daughters-in-law Orpah and Ruth as the only survivors.

Ruth accompanies her mother-in-law Naomi back to Bethlehem who following the Hebrew tradition tries to find for Ruth the relative who would second her deceased husband. Working in the wheat fields of his property, Ruth meets Boaz, an 80 year old cousin of her deceased husband who marries her. Tradition tells that Boaz died on the wedding night leaving Ruth pregnant with a child who would be the paternal ancestor of David. The story of Ruth gives foreignness a central place in the history of the Israelites.

> Ruth the foreigner is there to remind those unable to read that the divine revelation often requires a lapse, the acceptance of radical otherness, the recognition of a foreignness that one might have tended at the very first to consider the most degraded. This was not an encouragement to deviate or proselytize but an invitation to consider the fertility of the other (Kristeva, 1991, p. 75).

This fertility of the other in the history of salvation finds its culmination in Christ who born in poverty and through his teachings comes to challenge the learned of his time, members of his own tradition. In engaging with women, foreigners, beggars, prostitutes, fishermen, the sick, and the poor, he breaks the notion of *the* chosen people as one nation only, to institute a New Covenant where the poor, the persecuted, the hungry, the sick, the oppressed, the foreigner, without distinction of race... "are God's favorites because they find themselves in a situation altogether contrary to the divine design, which is a design for life. For God, the despised of this world come first" (Gutiérrez, 1993, p. 18). The proclamation of the beatitudes in the sermon of the mountain is an expression of this predilection of the God of the New Covenant for the poor and the oppressed.[19]

While Christianism formed a community that in going beyond the borders of nations was accepting of foreigners, Christian cosmopolitanism, Kristeva (1991) writes, gave rise to a new kind of foreigner, the one who does not believe in Christ. Foreign pilgrims, she states, were entitled to the hospitality of the town provided they were able to attest to their Christian status while non-Christians were not eligible for such treatment. The *hospitia,* Kristeva writes, were buildings built in the towns to provide shelter exclusively to Christian pilgrims. In the end, she writes, these hospitality policies prompted numerous individuals to become Christians so that they might be able to stay in these shelters while travelling.

Kristeva (1991) questions the extent to which the integration of foreigners into the Jewish tradition meant the assimilation of the other into the values of the dominant community. As a foreigner, she writes, Ruth adhered fully to the Jewish tradition. Yet in absorbing her otherness, tradition also asserts itself in its supremacy before others. Erasure of otherness was not alien to the cosmopolitanism of the Christian tradition as it sought to establish itself throughout the world. In fact, the overcoming of the stranger was a central feature of the (Christian) invasion (and *conversion*) of the so called new world.

At the 2004 University of Alberta Human Rights Lectureship, Bishop Samuel Ruiz García, a retired catholic Bishop from Chiapas, Mexico, spoke against the

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[19] See the beatitudes in Mathew 5, 1-12.

Westernization of the Church and the imposition of the Western way to practice the Christian faith on the Indigenous peoples of Latin America. Not only during the conquest times but still today, Bishop Ruiz García affirmed, the Church follows a Western agenda that does not serve the realities of Latin American peoples. He highlighted the need for the Church to be locally acculturated as the way to build the Church of the people. Unfortunately, this was not a matter of concern for the *"pilers of stones"* as the Mayans refer to the conquistadores. On the contrary, these conquistadores along with a number of Church representatives (with the exception of a few as indicated above) sought untiringly to erase the strangeness that individuals from this continent evoked. There was no place for foreignness or strangeness here. Not a glimpse of cosmopolitan Christianism where the foreigner is welcome. Welcome only under the unidirectional conditions of the European agenda.

Throughout the centuries to date the stranger continues to erupt into our midst. From the quasi-integration of barbarians during the Roman Empire to the limited privileges of the *aubain* in the middle ages to the conflicted status of those born in foreign land under *Jus Sanguinis,* distinctions between citizens and foreigners continue to emerge often granting the latter restricted privileges with regards to the former (Kristeva, 1991). While Western contemporary countries show a tendency to acknowledge the civil rights of foreigners (to a degree), Kristeva writes, they remain excluded from political rights.

> Either *rechtlos*—without a single right—or enjoying certain rights that the political power from which he is excluded is willing to grant him, the foreigner is thought of in terms of political power and legal rights. Such a condition, which, in spite of its variations, has never been belied throughout the course of history, may be observed in all its purity today (Kristeva, 1991, p. 96).

Literary art, voyages, philosophy, politics, throughout the centuries, Kristeva writes, have all influenced our contemporary approach to foreigners. Montesquieu's universalistic stance on the rights of people would have moved us today to preserve the political, the social, and the private space of everyone and promote what Kristeva calls a "union of singularities" (p. 134). Unfortunately this was not the way the *in principle* egalitarian principles evolved. The *Declaration of the Rights of Man and Citizen* in 1789, Kristeva analyses, was influential in generating a (subtle) political split so to speak between man and the citizen of the nation and their corresponding rights. The result was "the demand for the national rights of peoples, not the universality of mankind" (p. 151). These nationalistic principles, Kristeva states following Hannah Arendt, served as the moral basis and justification of the Nazi crimes. The irrational face of modernity (Dussel, 1994, 1996) emerges once again, this time under the disguise of rational universal egalitarian principles.

Kristeva's reading of the birth of the nation-state and the rights of man and citizen and its influence in later political developments throughout the European continent (and the world) leads one also to wonder about the origins of political regimes that have sought in many ways to exterminate the other. Political dictatorships in Latin America in the 1970s and 1980s and their systematic persecution of those considered a (political/ideological) *"threat"* to the nation-state are a clear example of regimes that justify their criminal acts as necessary steps to *protect* and *safeguard* the nation-state. The increased focus on state security in many industrialized countries (with the corresponding reallocation of national budget to meet high security requirements) is a frightening matter that not only endangers popular sovereignty (and the needs of the peoples) but also places the foreigner and the stranger in a state of uttermost vulnerability.

Kristeva (1991) concludes her philosophical exegesis of foreignness in the history of humankind raising the question of the other in ourselves. Recognizing the stranger within us evokes the *otherness-foreignness* which is before and within us. Tolerance of foreignness should follow recognition of our common and shared strangeness, Kristeva suggests; and perhaps political, economic, and social integration into the common while also preserving difference, particularity, privacy. This is the challenge that societies face in the current socio-political context as they grow more than ever cosmopolitan. Kristeva proposes two elements to address this challenge: a balance between the rights of citizens and those of foreigners and an ethics of human dignity that includes strangeness as a core element. Until these elements are recognized and integrated into the social and political machinery of contemporary societies, the struggle of foreigners/strangers will not cease.

THE STRUGGLE CONTINUES

> The interpellation is an originary speech act, with which the pauper erupts into the real community... and makes them accountable, demands a universal right...; and, in addition, expects to transform it by means of a liberation praxis (which is also frequently a struggle), into a future, possibly more just society. It is the excluded one who appears from a certain *nothing* to create a *new* moment in the history of the community. He/she erupts... as the excluded from life, from production and consumption, in misery, poverty, hunger, and imminent death. (Dussel, 1996, p. 36).

Hilaria Supa Huaman, a Quechua leader tells the story of her life as an Indigenous woman in Peru (Supa Huaman, 2001). Suffering and struggle are ongoing threads throughout her life. From growing up in poverty, exploitation, and abandonment, having an abusive husband, raising children on her own with no money, developing a disabling illness at a very young age to experiencing a profound sense of displacement while living in the suburbs of the capital, Hilaria comes to the realization that these experiences are not isolated events in her life. They are common life experiences of many Indigenous women in her country. They hold the struggle of Indigenous peoples throughout the world.

> Yo no cuento mi historia para que me digan: "Ay pobrecita, todo lo que le ha pasado" sino porque la historia de mi infancia y juventud es la historia de muchas mujeres indígenas de mi tierra (Supa Huaman, 2001, p. 1)

I met Hilaria in November 2004 in Edmonton at a Human Rights Conference in the Faculty of Education at the University of Alberta. In her keynote, she spoke about the oppression of hundreds of thousands of Indigenous women in Peru who underwent forced sterilization as a consequence of government-imposed natality policies. She spoke about the struggles of Indigenous peoples in Peru most of whom live in extreme poverty. Hilaria called us to be respectful of the earth, to love the trees and the water, the mountains and the wind. Her message was one of reconciliation; she called us to reconcile ourselves with the world and live in peace with all living beings. She is a woman of peace.

In her book, Hilaria talks about her process of rediscovering her Indigenous roots (Supa Huaman, 2001). Claiming back her tradition, she says, has been integral to her coming out of a position of resignation and exploitation. Together with other women from her community, and the support of non governmental organisations, she became an active leader in promoting Indigenous women and their communities. This emancipatory work has involved ongoing struggles: the struggle to overcome society's strong and long-standing prejudices against Indigenous women, the struggle to prevent her own women from falling into despair in the midst of poverty and endless difficulties, the struggle against machismo within her communities, the struggle to keep their children close to their tradition, and the struggle to work in harmony with her communities and supporting organizations. These have been a daily experience in working for the advancement of her own peoples. The struggles are endless.

Like Hilaria Supa Huaman, Indigenous peoples in Latin America (and throughout the world) live through severe difficulties that turn their lives into an ongoing struggle for life. A United Nations report on the situation of Indigenous peoples around the world (UN, 2005) states, "in most regions of the world indigenous people continue to face powerful obstacles hindering the full and effective enjoyment of their rights and to endure grave violations of their fundamental rights" (p. 10). The report remarks on the precarious situation of Indigenous peoples as well as their continuous exposure to ethnic discrimination which deprives them from accessing social and public services including clean water, food, health, education, housing, and employment, among others. According to this report, the overwhelming poverty of Indigenous peoples results in their exclusion from "the benefits of economic, social and human development to which they are entitled" (p. 14).

In Chile, the political struggle of Indigenous peoples fighting their subjugation to the established system and claiming back their (political and geographical) territory has been ongoing (since 1512 with the arrival of the Spaniards in Chile). Conflicts over land ownership together with the indiscriminate exploitation of ancient Indigenous lands in the hands of the private sector have intensified their struggle. While recent governments have taken formal steps to address their situation, the lack of political will to grant the *Pueblos Originarios* constitutional status, the consequent denial of their right to self-determination, and the application of dictatorship-inherited anti-terrorist laws to placate their ardent struggle have aggravated the existing tensions. The overall lack of attention to the Indigenous claim in the country and the piecemeal approach to address their urgent needs have simply contributed to accentuate the condition of impoverishment and domination of Indigenous peoples.

The current situation of Indigenous peoples is not alien to those who live in the margins of society throughout the world. Confined to exteriority (Dussel, 1996), they live under conditions of poverty and exploitation that dominant communities (and the global economy) perpetuate. Speaking of the impact of world economic trends on the developing world, Spring (1998) writes, "Left out of the global economy, large parts of Africa face a future of mass starvation and epidemics" (p. 7). Exclusion from public good and human development, he writes, is affecting an ever growing number of world inhabitants. The fate of the poor and the marginalised in industrialized countries is not far from those in the developing world. Thrown into exteriority, the poor of the world share their common struggle to be heard. Their claim is an *act of interpellation* through which strangers "erupt into the real community" (Dussel, 1996, p. 36), demanding their universal right to exist.

TOWARDS A CULTURE OF SOLIDARITY

Speaking of the ideal of authenticity in contemporary society, Charles Taylor (1991) suggests that we give up debates about the usefulness or uselessness of the culture of authenticity and its corresponding practices. Instead, he proposes that we revisit our current practices in the context of the originary ideal behind them.

> What we ought to be doing is fighting over the meaning of authenticity... The struggle ought not to be *over* authenticity, for or against, but *about* it, defining its proper meaning. We ought to be trying to lift the culture back up, closer to its motivating ideal. (Taylor, 1991, pp. 72, 73)

Undertaking this proposal above, Taylor writes, evokes a difficult tension. The tension originates in the contrast between the ideal and the extent to which current authenticity practices meet this ideal. The struggle that this tension occasions, Taylor remarks, reveals that neither trend in the culture of authenticity is permanent or irreversible. A full turn towards either end can never be assured. Self-destruction or steadfast improvements are not guaranteed. The struggle between these two poles is ongoing in contemporary societies. We are not irrevocably caught in this net.

Taylor's analysis of the culture of authenticity in contemporary societies and the tensions that this culture evokes shows the significance of struggle in working out these tensions. Struggles enable societies to continue to move ahead, to change, to grow, to live a fuller life. They bring about new life. They are sustenance to keep going in the face of adversity. They sustain us in life. In a way, as Taylor suggests, struggles sustain societies amidst conflicting positions that put their very approach to life at stake. They are the living sign that we are not trapped in an unchangeable path.

In this context, the struggle of strangers seems to acquire yet another significance in the life of societies. How does the struggle of the stranger sustain the life of societies themselves? In her analysis of Ruth's story, Kristeva (1991) writes about the *fertility of the other* (p. 75). The path of Ruth, the foreigner, becomes a necessary path in the history of salvation. In the same vein, one might wonder about the fertility of the stranger in the life of contemporary societies. Is their struggle a fertile one? Is it a sign that we are not caught in a definite chain of events that confines strangers to exteriority?

Arendt (1994) writes, "The so-called chain of happenings... is interrupted every minute by the birth of a new human being bringing a new beginning into the world" (p. 326). I would like to say that the struggle of the stranger also interrupts this chain as it relentlessly challenges society to revisit our common practices and the grounds that sustain them. Their struggle brings about new fruits into our midst as it gives birth to new life-giving and life-sustaining practices. The struggle of the stranger teaches us to rethink and reclaim our notion of the collective.

Solidarity is one of the core elements of the struggle of the stranger. Through solidarity they subsist and strengthen themselves. Solidarity keeps their struggle going. Hilaria Supa Huaman (2001) talks about organizing a *comedor* to feed their children, a community dining room where meals are served to those in need. *La olla común* is another solidarity practice common among people in low resource neighbourhoods or workers on strike in Latin America. They cook their meals together in a large common pot sharing the ingredients they have. *La Escuela Mapuche* is a Mapuche-led initiative for Mapuche children to learn their own tradition. Hilaria talks about her *Escuelita Quechua,* their own initiative to teach the Quechua tradition to their children.

In Argentina, the establishment of *cooperativas* (co-ops) is helping thousands of workers to find the means to subsist in the midst of a severe economic crisis

(Raimbeau, 2005). The Zapatista movement in Chiapas, Mexico has been central to advances in the protection and recognition of Indigenous rights (Herrera Lima, 2003). In Bolivia, the people's struggle for their rights blocked the government's privatization policies. The recent election of an Indigenous president is also considered a victory of the Indigenous movement in this country. These initiatives are a strong sign of the fertility of the stranger. They are the result of the solidarity of the peoples who in the midst of poverty, oppression, and marginalisation give life to communities of bread and action that sustain them in their ongoing struggle to exist.

Solidarity practices are commonplace among the poor of the world. During a conversation about how the poor support one another when they are sick, Claire tells the story of a patient she took care of in a former job. He lived in a tiny shack located in a parking slot and shared it with his friends during the cold winter times. In his hospital room, he used to keep on his night table a big piece of smoked ham and enjoyed sharing it with all his friends. Claire evokes her fond memories of him as she recalls the day she entered his room and was presented right away with a thick slice of smoked ham he had just cut with his own pocket knife.

The solidarity of people who have lived through extremely tough at times unthinkable circumstances is often striking. In their common struggle they are in solidarity with one another, and their solidarity sustains them in their struggle. It is this renewed sense of solidarity in struggle that our societies need to follow to make our being with one another more liveable (and more sustainable). Smith (2003) writes, "unless the rules of engagement for human procedure can be rethought in ways that are more equitable, fair and just, what lies ahead may be unthinkable" (p. 501). The struggle of the stranger, the peasant who sells the fruit of her labour in the city market, the woman who trades sex for money, the child who works for hunger wages, the temporary fruit worker, the unprotected miner, and many more is the struggle to make our societies more just and more equitable. Their struggle is an urgent call to build societies more *solidarias* with one another. In solidarity we are not afraid of the stranger in the midst of us.

THE QUESTION OF THE VERY ILL

> *Even in death, the body evokes the 'how are you?' The ethical question still remains. (Cameron, 2004, p. 60)*

Who are the strangers in our midst? Who is this other "whom we perceive by means of sight, hearing, smell, but do not 'frame' within our consciousness" (Kristeva, 1991, p. 187)? Kristeva openly declares the difficulties we face to identify ourselves with the stranger. She shows us the uncomfortable feeling that the stranger arouses in us and takes us to the disquieting discovery of the stranger within us. And she presents this discovery as a necessary condition of solidarity and "the ultimate condition of our being with others" (p. 192). In bringing the question of the stranger into our midst, Kristeva summons us to reconcile ourselves with otherness and admit our own and *proper* stranger.

In a sense, the above is also the summons and the question of the very ill. It is Iris's question upon us as her wound bursts open before our eyes. It is Ruth's question as she falls pray of her corporeal exhaustion. The very ill bring into presence this disquieting discovery of the other before (and inside) us. They embody an otherness that grabs our whole attention. Is this the ethical claim of the very ill? To engage with this otherness so strangely *present* in the midst of us? Below I go back to Don Pedro and his room. Here the question and the claim of the very ill come back to presence.

The visit after Brenda goes

After Brenda goes I go back to visit Don Pedro. I get off the bus and walk a couple of blocks towards the river. I think of Carmen Luz walking as she goes to visit her patients in the home. She reaches her nursing world afoot I think to myself. 'Buenos días,' I say to a young woman in the yard as I enter Don Pedro's lot. 'Buenos días,' she says, 'Adelante.' I knock softly on Don Pedro's semi open door and go in. 'Hola Don Pedro! I came to see you,' I say. 'Hola Señorita, ¿Cómo le va?' He says grabbing an extra pillow to sit up in his bed, 'have a sit por favor.' 'Gracias,' I say moving the chair closer to his bed and sitting down. I notice Brenda's little bear on top of his tiny TV, a golden chain with a teeny bell around his neck. 'I see you are getting this little guy ready for Christmas,' I say. 'Oh yeah,' he says, 'he is such a good boy!' And we laugh.

'¿Cómo está la niñita?' Don Pedro asks, wondering about Brenda. 'She went back to Canada last week,' I say. 'That's too bad,' he says, 'I wanted to give her a poster. She liked these posters on the walls so much.' 'Yes,' I say, 'and she enjoyed very much visiting you here.' 'I wrote down her name here,' he says showing me his tiny blue notebook where he keeps track of everybody who visits him. Laurie and Carmen Luz's names are also here, and mine too! There is a short story after each name. 'I also write down my debts here. See? *Las cuentas claras conservan la amistad,*' he says showing me his carefully written columns of numbers. He really keeps his accounts in order. Don Pedro tells me, 'Sometimes the girls come and say, Don Pedro, could I borrow a few pesos to buy a cigarette? They know I get my pension. Anyway, I always treat them as they also give me a hand, so I say sure, here you are!'

'They came yesterday from the Consultorio to deliver my medications,' Don Pedro says pointing to a few bags on top of his night table. He stretches to reach a cream bottle on the shelf behind his bed with his arm over his head. He is quick to find it. No need for eyes in the back of his head. He moves at ease in his bed. He is used to this new spatial orientation. 'La doctora Laurie gave me this cream and she says I need to use it very often,' he tells me while putting cream on his skinny arms. 'It is a very good cream. She is so kind with me. See these pillows?' He says pointing to a few pillows on the side of his bed. 'She brought them here. She also gave me two nice suits and I have them in my closet. People treat me so well,' he says and gets teary. 'I think people love you very much,' I say, 'I have heard about you ever since I came to the Consultorio.' He smiles, wiping his tears away.

I notice Don Pedro is a bit subdued today and I ask him about it. He tells me he is worried about his daughter, 'she is in the city and came here a few days ago. I heard she broke her leg falling downstairs in her friend's home. So I don't know what to do. I know she doesn't want me to know but I need to know. I asked my neighbour to phone her but I haven't heard back.' He tells me she is his only daughter. 'My mother and I looked after her since she was a few months old after my wife left home,' he says, 'I enjoy so much when she comes. She has a son with Down's syndrome and always brings him with her. He lies down here right beside me. She worries a lot about him and now about me on top of it. She wants me to go to Santiago but I don't want to go. I know it would be a problem for her. She must be so worried now being unable to get here.' Don Pedro gets very teary as he talks about his daughter. He tells me he doesn't even know where she is staying. He is unable to reach her and he finds this very hard to bear.

'I wish she could stay with me,' he says, 'but my room is so tiny. I found myself this room a couple of years ago. I am very good in here. It was close to work. I didn't like the neighbours I had upstairs. One day I thought the ceiling was breaking down. It was leaking right on top of my bed. I was happy when they moved out. My new neighbours are very good. They are helping me a lot now that I can't do much. The owner is also very good. Now that I am sick he won't let me pay the rent. He just won't take it. So I haven't paid the rent for a few months. I give these pesos to my daughter as I know she needs them.'

I ask Don Pedro about his friends and he tells me he hasn't seen them for a while. 'We used to be very good mates,' he says, 'there was one who went with me every day to the hospital when I was having the treatments. After I was done, we went to our favourite restaurant here in Chiguayante and had a cup of coffee and a sandwich together. You should try it. They make a very good cazuela. Now and then I also used to go to a bar close by with a few friends. After I got sick, I didn't go anymore. But they are not coming to visit me. They only want to have fun but now I can no longer have fun with them. One came the other day. He was drunk. I think he didn't know what to say. So I am very much by myself.' Don Pedro gets teary as he talks about his friends. Being unable to go out is hard on him. Some days, he tells me, he feels completely '*botado*,' abandoned, as not a soul shows up through his door.

Slowly Don Pedro comes back to himself leaving his sadness behind. I notice this as he takes back his tool and resumes his work with a chain. He is decorating everything in his room with golden chains. Christmas is approaching and he is getting his room ready. His artiste's heart enjoys making the world more beautiful. 'How come such a short visit?' He asks when I tell him I am about to go. We have been talking for about an hour and a half. I say that I need to go but I promise to be back soon. Inside myself, I find it very hard to leave him. I think of the nurses in Edmonton who sometimes have no choice but to leave the very ill on their own. Don Pedro's garment clings tenaciously to me. I cannot get rid of this garment.

Don Pedro brings both the world of Latin America and the world of the very ill into our midst. He embodies both the face of poverty and the drama of being very ill. His situation is extreme. Alone, very poor, and sick, Don Pedro shows a world alien to many. Yet this foreign and difficult to conceive world is Don Pedro's ownmost world. He is fully inside this world just as he is fully inside his tiny room. He is entirely bound to this room. Alone in his experience. Others are able to come and go. Nothing holds him in the fullness of this moment of his life. Nothing but his room. Yet in a strange way the extremeness of his situation, the poignancy of his experience clings to us. Like his room, Don Pedro makes us unable to turn away from him. Don Pedro evokes the desire to stay with his situation (while also the urge to flee from it).

Inside Don Pedro's room we have a sense of who he is. His figurines, his posters, his tiny TV, his blue notebook, and now even his little bear, they all hold pieces of Don Pedro's life. The *who* of Don Pedro reveals itself in every corner of this room. This room reminds us that even in the face of poverty, marginalisation, and hardship the who of Don Pedro "still *exists*" (Cameron, 1992, p. 184). No need to ask '*who* is Don Pedro?' inside his room. Here we experience an immediate understanding of his who. Don Pedro's "living I" (Bergum, 1994) greets us right away.

Etymologically, to greet is related to address (Skeat, 1963). In hearing the greeting of Don Pedro's who, his own who immediately addresses us and asks, '*Who* are you?' The who of Don Pedro calls our own who "to come forward into the moment" (Cameron, 2004, p. 54). In his room he interrogates who we are. Hearing his question is to be directly involved with Don Pedro and his room. In the midst of his room, "we ourselves are seized" (Levinas, 1987, p. 71). 'Who are you?' is the ethical question of the stranger and the very ill. They call our very being into question. Their question is an ethical claim that demands an *authentic* response, authentic in the sense of original, formed with our own hands (Skeat). Their question is a call "to stand under the claim of one another's presence and enact ethics in its original sense" (Cameron, p. 61).

CHAPTER VI: WOMAN OF STRENGTH

> *Open your lips; don't open them simply. I don't open them simply. We – you/I – are neither open nor closed. We never separate simply: a single word cannot be pronounced, produced, uttered by our mouths. Between our lips, yours and mine, several voices, several ways of speaking resound endlessly, back and forth. (Irigaray, 1985, p. 209)*

APRIL

The phone call

Just a few moments after arriving home, I notice I have a phone message. I press the blue green button of the answering machine and hear.

> *You have one new message, first new message, Tuesday, 2.41 PM.*
>
> Hi Anna, this is Claire. I am so sorry, you know, I was going to the hospital to see April as they are talking about discharging her and I wanted to phone you to come as well. But I couldn't find your number so I couldn't call you. I am on my way back to the office now. April is completely paralysed from her chest down, it will be permanent. She received seven radiation treatments but the tumour literally wrapped itself around the cord and there is no chance of surgery.
>
> She is true to April. She is taking it at her own rhythm. We are now looking at ways to have her at home. Mark wants to take her home next week. I suggested that we wait until we have all the equipment in place. I really don't want her to go home until Mark is ready and the home is ready. Her mom came as well and she doesn't look too well.
>
> I feel as if I had my stomach kicked and feel really low so I will stop and have a cup of tea and sip and think. She is still good, the rest of her is good. Talk to you soon.
>
> *End of message. No new messages.*

It is late in the day and I can't call Claire back as by now she has surely left the office. I know April is in the hospital as Claire phoned me as soon as she was admitted. The news of April being totally paralysed from her breasts down is shocking. I re-play the message as if to convince myself. I regret not having been able to accompany Claire to the cancer hospital. At least I could have shared with her a cup of tea afterwards. We would have vented together. Claire has always known a moment like this would come. But we kept pushing the thought away. Even now, the thought of her being paralysed is hard to digest.

The last time I saw April was shortly before their long awaited holiday trip with Mark, her husband. They were going away for about three weeks, first south to Colorado and then back home through Vancouver and the Rocky Mountains. They had delayed this trip ever since April was diagnosed with lung cancer about two and a half years ago. Following the initial treatments (including palliative radiation and chemotherapy), she was on and off a number of clinical trials and she was unable to have a holiday. But now that she is no longer eligible for further trials was a good time to go away. It was decided, they would start their trip early May or shortly after. On this last visit to her home before they went away, as we are leaving Mark shows us his brand new car. He bought it especially for this trip, a beautiful car where April can sit very comfortably or adjust the seat to almost lie down if she needs so.

On this last visit before their holiday, April tells Claire that she is taking about 6 breakthroughs a day as the pain on her upper back has been bothering her a lot. 'I am almost taking a breakthrough together with the regular dose,' she says, 'but it doesn't last long.' April's pain has involved her left shoulder, underarm, and the area between the scapulas ever since she was diagnosed. Her latest tests also show that her cancer is beginning to metastasize to her chest bones including the ribs and spine. She tells us that the pain between her shoulder blades has been giving her a hard time. 'What did the oncologist say about this pain?' Claire asks. 'He told me that I could not receive any more radiation in that zone as I already had the maximum dose,'[20] she responds. A shadow of sadness shows in her face as she recalls her doctor's words.

April has managed her pain with oral methadone for most of the time of her illness. Her pain has been refractory from the beginnings and she has needed progressive increases in the doses of methadone. Claire is concerned about April's needing several breakthroughs a day. April's daily dose of methadone is also high. But she is achieving only partial relief. The amount of methadone she is taking could increase the risk of neurotoxic effects associated with this drug (i.e., cognitive impairment, hallucinations). In fact, Mark, who is standing behind April during this visit, tells us April is having a lot of nightmares, speaks incoherent things during the night, and wakes up soaked in sweat.

As we talk, Claire notices April's eyelids drooping. 'You are drowsy,' Claire exclaims. 'No, I am not,' April quickly replies. Yet her eyelids belie her. Claire notices April is drowsy as this is not her usual self. Indeed, this is the first time that I see her eyelids drifting off while talking. Claire has been April's nurse for the past two years. She knows that now she cannot push April's drowsiness as she denies it. But there is definitely something wrong and she will follow it up. Claire

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[20] Palliative radiation may be used in palliative patients to palliate pain, reduce the need for pain medication, improve ambulation, or prevent complications of spinal cord compression and pathological fractures (Vogel, Wilson, & Melvin, 2004). There are safety dosage limits and April has reached these as she received radiation to this area in the past.

knows that insisting on April's drowsiness will make April feel questioned in her judgement. At this moment, she shows respect through her recognition of April's capacity to stay in control of her personal health. She preserves the being of April-*at*-home.

April asks Claire if she could see the regional doctor she saw at the time of the big crisis. Claire says she will call April's family doctor and suggest a referral to the regional team before she goes away on her holidays. 'I think it will be good to have them come as your pain is not responding well,' Claire says. April and Mark agree with this. 'I will give you a call after I talk to your doctor and put a referral in,' Claire says. 'I am so excited about your trip. So glad you will have your holiday!' Claire tells them. Mark's face shows both joy at the thought of their coming holiday and big concern for April's condition.

On our way out, Mark shows us his new car while April stands at the door. He has arranged everything to go away. 'Ok, I'll be in touch with you soon!' Claire says as we get in the car, the dogs playfully jumping around us. On our way out, she says she will call the doctor right away. She hopes the regional doctor can see her as soon as possible. 'They will ask you for her mini mental score for sure,' I say. 'Oh yes, I know,' she replies, 'but there was no way I could have done a mini mental after she denied being drowsy. I just couldn't do it to her. I really hope she can go on her trip. They deserve so much to have this time away and Mark has waited for this holiday for so long. It will be good for both of them. And it will help Mark to get ready.'

The holiday trip

Following consultations with the regional doctor, April is started right away on biweekly infusions of clodronate, a medication used in the treatment of metastatic bone pain. Her methadone dose is also increased. The blood tests show her potassium is high and she goes to emergency for treatment. April's pain begins to improve as well as her overall status. After her second dose of clodronate, Mark and April are ready for their holiday trip. In the car goes a carefully prepared package including a good stock of butterfly needle sets, syringes, dressings, tape, alcohol swabs, tubings, saline, and a few vials of anti-emetics. Both Mark and April know how to insert a subcutaneous butterfly needle, load a syringe, and administer saline infusion and medication via the butterfly when April experiences nausea and vomiting. Claire taught them how to do this a while ago as they like to go to their cabin in the lake. This way they could deal with a crisis right away.

As it turned out, there was no need to use this package. Two days after they begin their holiday trip, Sherrie one of the nurses on the team, picks up an urgent phone call. Mark is calling from Montana. He tells Sherrie that April can't walk very well and has lost sensation when she goes to the bathroom. Sherrie reviews April's chart as Claire is not in the office and tells him she will call the regional doctor right away. 'Where are you?' She asks before hanging up. 'We are about two hours from the Alberta border,' he says. 'Ok, call me back in about fifteen minutes. I will have talked to the doctor by then and I will tell you what she says.' She talks in a calm and reassuring voice. Sherrie calls the doctor immediately. She knows this situation is urgent given April's clinical history. When Mark calls back, she has talked to the doctor and has a plan of action ready.

'Mark,' she says, 'the doctor suggests that you take April to the closest hospital. Because of her symptoms, she thinks she may have a problem related to her spinal cord. This can happen in people with cancer and it needs immediate attention. In the hospital they can examine her and start her on a treatment. Then if necessary they can transfer her back to Edmonton. As you are not too far from the border, it might be easier to take her to the hospital on the Alberta side. Then the regional doctor will call the emergency doctor to that hospital and discuss April's condition once she is there.' Mark agrees with this plan of action and says he will call back as soon as they are in the hospital. 'Take your time to get to the hospital. Drive safe,' Sherrie says as she senses Mark's deep anxiety through his voice.

At the hospital on the Alberta border, April receives a high dose of dexamethasone. The doctors suspect a cord compression is in progress. After being a few hours in this hospital, Mark drives April back to Edmonton. Upon their arrival, they go straight to the cancer hospital. The regional doctor has talked with the doctor from the hospital at the border and has also contacted April's oncologist in the city. The oncologist knows April is on her way to the cancer hospital. A hospital bed needs to be negotiated for her as they expect her to be admitted. The news of having to leave April in the hospital is shocking to Mark. He was hoping to take her back home after a few hours. This is the first time during her illness that April is admitted to a hospital. The first time she will be *in* bed.

GOING BACK TO THE BEGINNINGS

Meeting April's home

A couple of weeks after meeting April for the first time, Claire and I go to visit her as she has consented to participate in the study. April has coffee ready when we get to her home and offers us a cup right away. We sit around her kitchen table holding a mug in our hands. 'April,' Claire says, 'I met your mother and your grandmother the other day.' 'Yeah, she told me she met you in granny's home,' April says. 'I was on evenings and they called in so I went. I know you told me about your granny but I had not made the connection that she was with our palliative home care team as well. I almost froze when I realized who she was.' 'And granny hasn't been doing very well lately and it's been hard on my mother,' April says, 'we are thinking of hospice but she is not ready, she doesn't want to leave her home. So we have been organizing ourselves to give her a hand at home.' Claire replies, 'There were a few people there when I visited her that night. But I was very glad to meet your mother. Not the happiest of the circumstances, I said, but it was good to talk for a bit.'

As I hear April and Claire talk about April's grandmother and mother, I get distracted by two painted wooden wall plaques hanging on the wall across myself, each of them with a phrase painted in decorative letters.

Only boring women have immaculate houses

M stands for mother not for maid

An image of April quickly forms in my mind as I read these wooden plaques. She is surely far from being boring. As she talks about her grandmother, I wonder about her and April. She tells us she is both first daughter and first granddaughter, same as her mother and her grandmother. She tells us she grew up together with both mother and grandmother so she feels quite close to her grandmother. I can imagine her as a little girl "working with her in her garden, helping her cook, and doing the wash" (McAlister, 1999, p. 18). I can tell she carries her grandmother in herself. I look at these wall plaques again and an image of these three women together in their home greets my eyes.

'How have *you* been?' Claire asks April. 'I have been painting and redecorating my room,' April says, 'So I was very busy all the weekend. Would you like to have a look?' 'I'd love to see it,' Claire says. 'Come in,' April says taking us to her bedroom. Her bedroom is a few steps from the kitchen and we stand at the door. Lamps, curtains, bedclothes, rugs, and pillows are all in various shades of blue. Even the walls are in blue tones. She has just painted them and put stripes of wallpaper across the walls. There are lots of pillows on top of her queen size bed. 'I know I will spend more time in my bedroom as I get sicker,' she says, 'so I want it to be very beautiful.' "You are an artist,' Claire says. April's room is truly artistically decorated. It takes our breath away.

'My next goal is to rearrange this room,' April says moving to the room across from her bedroom. The room is bright and spacious. A tiny window looks out to April's alleyway and trees. There is a closet covered with a dark green curtain. 'This is my dressing room and I want it to be my room for when I need to stay in bed longer,' April says, 'I don't want to spend all day in my bedroom because Mark will need his space. And I don't like the idea of using the living room as a *sick* room.' Her face shows her dislike at this thought. 'So I want to spend the time here, reading or whatever. I want to have it in peach tones. Basically, it's going to have many pillows.'

Entering April's bedroom is poignant. Hearing her talking in her own bedroom about the days ahead moves me deeply. Our bedroom is a space of intimacy, nakedness, secrecy, relation. Here we bear witness to another side of her experience; one that conceals itself from others. She shares her future with us, this naked future that resists thought. Then she takes us to her dressing room, the room where she can be by herself, find herself perhaps? She talks about not converting her living room into a sick room. She needs to preserve each room in its own being. She inhabits them. She safeguards her rooms as they are. They are the "body and soul" (Bachelard, 1958, p. 7) of her home.

We go back to the kitchen and April refills our mugs. The cat sleeps on the floor. 'How is your pain?' Claire asks April opening the blue chart. 'I increased the methadone and have been taking about 2 breakthroughs a day,' she responds, 'I was about to take a breakthrough when you came.' 'You should go and take it right away then,' Claire suggests. April goes to her bedroom and comes back with a pill in her hand. She gets a glass of water and takes it. 'I know that when I work too much, I have pain. I know I can't do as much as I used to but it is hard and sometimes I just keep going,' April says, 'I think it was the painting of the bedroom that made the pain worse. Moving things here and there, I don't think of my left arm.' 'Are the breakthroughs helping?' Claire asks. 'Yes, after I take a breakthrough the pain goes,' she says.

'I think I gained a bit of weight,' April says after Claire finishes her nursing assessment. 'They weighed me at the cancer clinic and I gained a few pounds. But I have actually lost a lot of weight. I notice it with my clothes. I have lots of clothes because one of my aunts used to give me fancy clothes for work. But now that I decided I am not going back to work I gave all my nice clothes to my sister. She just got a job in a place where she has to dress up every day. So I said to her just come and take my clothes. I thought, 'April, you're never going to wear those clothes again. Why keep them?' And it's not just a case of losing weight and gaining it back again. It's a case of I never will wear those clothes again, so why not pass them on now? Why wait? So she came and took a whole bunch and was very happy but she also was very sad to be taking my clothes away. She cried and I tried to calm her down saying that it's better to do this now when I am alive. In the end she gave me a hug and we were both a bit teary.'

April gets a bit teary towards the end of her story but quickly wipes her tears away. Just as she shows us her newly decorated bedroom and speaks of her days ahead, here again she talks about her future in a very calm manner. April is able to give away her own garments. The same garments I was unable to give up. She sheds weight, lightens a burden. She is courageous to give away her very shields. But she gives them to her sister. She protects her, cloaks her, helps her to get ready for the future. Heidegger (2001) writes, "Mortals are hardly aware and capable even of their own mortality" (p. 94). Yet "while we are all going on undyingly" (Rilke, 1984, p. 165), forgetting death and our own mortality, April cannot. Her own mortality moves her to action. She is capable of preparing herself and others for the future.

The visit is coming to an end and we get ready to go. Mark joins us for the last part of the visit and is uncomfortable hearing April talking about her clothes. Claire knows it is time for them to return to the daily rhythm of their lives. We mark the date for another visit and exchange a few words with April and Mark while putting our shoes on. 'Thank you for your time!' Claire says, 'We'll see you in two weeks! Have a good time at the lake!' In a few minutes, we are driving through these roads on our way to other patients' homes. April's home stays behind. Yet the garment of her home stays with us as we go.

April's Diagnosis: When All Hell Broke Loose

April is working full time in a business company when she falls sick. She has worked since the age of 12 when she helped her mother serving tables in her coffee shop. Then she works as a waitress for several years supporting herself and her only child until she finds a job with this company. She tells us with pride that her first job here was to measure the size of ads. Then she moved to a financial management position. She earns promotions quickly. She enjoys a good job when the pain in her shoulder begins to bother her, a couple of years ago. She keeps hoping her pain will recede so that she doesn't need to see a doctor. But her pain gets worse. After a few months, she finally decides to consult a doctor.

'I started feeling the pain and the hurt almost in June. At the end of August I thought I had damaged it again by pulling something in my chest, because I was carrying heavy trays when I was helping at a wedding. I was carrying a lot of things up above my head, like waitress style. So I was using my left arm a lot. By September, the pain really, really starts to hamper me and bother me. But I still keep insisting that I pulled a muscle. I did it myself, and there is nothing you can do with a pulled muscle except let it heal. It was so sore that the week after, I could hardly lift anything. I thought, 'Gee.' Then it kind of went down a bit, and I thought, 'Okay.' It wasn't getting worse, so I thought, 'Okay, it's going to heal on its own.'

'Then getting into October, it starts getting bad enough and Mark says, 'You've *got* to go to a doctor!' 'Yeah, yeah, yeah, yeah,' I say. Then during a weekend at the lake, we are moving some stuff from the truck to the house and then suddenly I am unable to carry anything else because of the pain, so that was it. I just couldn't do much with my arm. So now, I decide to see a doctor. But then at work, I can't take the time off because someone is on holidays and someone else is sick, and I have to cover on the switchboard. So I sit for 4 days at work not using this arm at all. If I had to use it on the computer, I was really favouring it. But I kept thinking that it was a pulled muscle.'

'After all this, I finally go to the medicentre and say, 'We'd better x-ray this, because something's wrong. It's been there for well over a month now, and it's not getting better, it's getting worse.' My family doctor sends me for the x-rays right next door and after I return to his office, he says looking at the x-rays, 'I see congestion in the lung there, so I'm sending you directly to a lung specialist.' In 3 days, I am in another doctor's office, and then 3 days, in another hospital, and from then on, it's been very fast and very steady. When I see the lung doctor, he says, 'Yes, there's definitely what looks to be cancer there.' So he sends me in for the CAT scan and the biopsy. A few days later, I am in the hospital and the following week, I have my results and the diagnosis, and from there, I go straight to the oncologist. Just from November 19th to December 4th, that three-week period, all hell broke loose. All of a sudden, it was cancer, it was there. By the middle of December, I already know it is inoperable. In January, I am in radiation. It was just *bang, bang, bang.*'

'If I'd listened to my body, I probably should have had it looked at right at the beginning of September. I should have said, 'Even if it is just a pulled muscle, let's go and make sure.' No, not April; I'm the one who says, 'You don't have to go to a doctor yet, so you don't go yet.' But when the pain started increasing, I thought, 'Okay, if it's getting worse, maybe it's a pinched nerve,' which indeed it was, because the tumour was pinching the nerve. So that is when I came to the conclusion that, 'Okay, this is definitely not an athletic injury, because it's not going away. It's something more than that.' But cancer, cancer was the last thing on my mind.'

Claire and I remain mostly silent while April tells us how it all started. Claire responds to April's regret at not having gone to the doctor earlier. 'It was more a pulled muscle feeling, too, wasn't it?' She asks, 'did you ever have any shortness of breath or a cold in there at any point?' 'No,' says April. 'So in lots of ways, I think your symptoms were very masked,' Claire says. 'Yeah,' says April, 'even the lung doctor said they still might not have found it even if they had looked at me in June. And I kept thinking it was a pulled muscle because of the pain.' 'But I can see that line of thinking,' Claire says, 'I just would not think cancer at that point.' Claire offers her nursing eyes to April. Her perspective is reassuring, comforting. She tries to make sense of it for April.

On this day, just before hearing April's beginnings, she and Claire talk about how the ice in the rivers thaws out during early spring in the north. They tell me about the times of the gold rush in Canada in the late 1870's and how explorers suffered all kinds of accidents not knowing about the ice in the north. 'When spring came, they didn't know what it was like when rivers break up, up north,' Claire says, 'when the Slave River broke up, you would wake up in the middle of the night because it sounded like booms going off.' April adds, 'It is almost like thunder or dynamite; like a big explosion.' 'In the night, the ice would break,' Claire says, 'but then it would come crashing up the hill on the sides of the water. It would move way further than what they realized. They thought if you're on shore, you're safe. But you have to be well back from the big rivers with the deep ice. Because the water breaks through and just pushes the ice in front of it.' 'Almost like a bulldozer,' April says.

April talking about her beginnings brings my mind back to the breaking up of the rivers after the long winter freeze. Hearing how she finds out she has an inoperable cancer sounds like hearing these big booms going off. All of a sudden, an uncontrollable torrent of events floods her life, just like the river furiously breaking up the ice, taking over everything in its path. She has no time to think in between, to digest her own diagnosis. She acts, takes on what's next, and keeps going. No sense in going against the flow of this river. The news of her diagnosis, etymologically meaning a distinguishing (Skeat, 1963), breaks through her entire life making ice and shores undistinguishable from one another.

Life Goes On: Visiting the Barn

Shortly after meeting April, she invites us to visit their barn, a few metres outside their home. April and Mark are taking care of their neighbour's two horses and donkey here. It was Claire's dream to visit the barn and feed the animals and April and Mark are excited about taking us there. The day arrives and we get to April's home very early. We go to the barn right away. The day is chilly so we keep our coats and mittens on. April wears a pinkish jacket that brightens her hair and skin colours. 'I got the candies,' she says showing her bag of carrots. Mark goes to the barn and lets the horses and the donkey out. The donkey is the first to come out and April pats him. 'Hi Buddy,' she says, 'here, have a carrot. And these are Sarah and Amigo,' she says pointing to the brown and black horses coming behind the donkey.

'Anna, you feed him now,' April says passing me a carrot. She notices my hesitation to get near the donkey. 'You think he would be coarse,' she says, 'but he's very soft.' Claire also confesses she is afraid of horses. April reassures both of us that they are very friendly. She talks to them, gives them carrots, and tells us stories about each of them. I give the carrot to the donkey and he eats it right away. 'He is so sweet,' Claire says. 'You are pretty,' she says to him, 'this is the first time I ever saw a donkey up so close that I could touch.' One of the horses makes his way towards April. 'Okay, don't get so pushy guys. Boy, you have manners; you have manners,' she says to them. 'Here, you have this carrot,' April says passing me the last carrot in the bag. I give it to the horse. The donkey lets us pat his head and his neck all the time. They say that donkeys are very patient. This one embodies patience.

We follow April and Mark to the barn. A strong barn smell greets us right away as we go in. 'I love this smell!' Claire says. She is truly transported. April shows us around and tells us about their diet and the barn chores. 'What we feed them is about an ice-cream pail full of food and some straw,' she says, 'and then all you do is you take the fork and just shovel out any of the crap, but there isn't any in here. So they weren't even in overnight.' She takes us to the area where they keep the alfalfa pellets. She handles buckets and tools with amazing agility. No exterior signs of her shoulder pain here. It has sunk into concealment, forgotten perhaps?

'This is for Buddy, this one for Amigo, and this one for Sarah,' she says showing us the feeding buckets. She fills the buckets and takes them to the stalls. 'You are always feeding everybody,' I say, 'even the animals.' We laugh. 'C'mon, Amigo!' she says trying to get the donkey out of Amigo's way. 'Sorry we didn't have anything for you to shovel!' April says to Claire making us laugh. Claire had assured April she would shovel the barn on this visit. We leave the animals eating and go outside. April and Mark take us to a shed where a friend of theirs used to keep pigeons. 'He used to train them as homing pigeons,' Mark says, 'but in the end he let them all loose, about a hundred of them. They really built a pigeon condo as far as I am concerned,' he says laughing.

Stories about birds and animals take on a life of their own as we visit the barn and the shed. Claire talks about the two pigeons she took care of several years ago. April talks about a couple of pigeons that live on the roof of the barn. Mark talks about the dogs and the cats being scared to death when two foxes came near the house a couple of weeks ago. Claire seals this moment telling us about her adventure after being locked in with a whole bunch of chickens in a chicken coop. I enjoy hearing their stories. Being in the barn, surrounded by straw, horses, donkey, smells, cats, and dogs, seems to have taken all of us to an imaginary world. We seem to have forgotten the world of illness and disability, even if for a few instants.

FORGETTING

Shortly before Christmas, we find April in the midst of a kitchen operation as we arrive. She has been baking Christmas cookies for hours. Her kitchen smells like cookies and cookie trays are all over the place. She opens the oven and pulls out another tray. The warm smell of cookies in the oven reaches us right away. She says she is grumpy because a full tray of cookies got burned. In truth, they look browner than the others but they look good. She tells us she likes to give cookies to her family, friends, and neighbours at Christmas. She enjoys treating others with her cooking. A cookie plate is already on the table and I can hardly wait to try them.

April is a very fine cook. She is always trying this or that recipe. She likes to innovate when she cooks. Kitchen talk comes to our conversations on all our visits. Claire is also a very good cook and she and April can forget the world talking about cooking. Claire enjoys April's suggestions. I enjoy hearing both of them exchanging their kitchen ideas and learning about Canadian recipes. Looking at April in the kitchen surrounded by cookie trays, we see an April far away from pain and illness. This is the April of everyday life. April's being stands out in the kitchen. She finds herself at home in the kitchen. She regenerates herself in the kitchen. She forgets herself in the kitchen.

Forgetting helps April to keep going with life. She is able to get going with other things. Staying inside her pain and diagnosis is disabling. She needs to forget it, hide it, conceal it. Continental philosophers write about self-forgetfulness in daily life. Merleau-Ponty (1962) shows how we take for granted our bodies as we move, do things, think. Heidegger (1998) remarks the self-forgetful quality of our being in the world. Feminist philosophers have called self-forgetfulness into question (Irigaray, 1999; Young, 1998). Delineating women's experience of embodiment, they show that we are never fully able to forget our bodies. They are critical of male philosophical discourse and evoke the need for "a discovery, recovery, and invention of women's culture" (Young, 1990, p. 181).

While recognizing these philosophical tensions above and assuming that we, as embodied beings, can never entirely forget our corporeality, I would like to discuss how April shows a kind of forgetting (let's call it this way for now) as she lives through her experience. How April leaves her own situation temporarily aside to engage with other things in life shows her personal strength and also an enduring force that keeps her in life, even in the face of a mortal diagnosis. She can't forget her body, the one she was able to ignore before her diagnosis. She takes her pain medications around the clock and the laxatives. This aside, she forgets. This temporary forgetting enables her to go on.

April's forgetting is always partial and temporary, never definite. Being pain free helps her to forget. Excruciating pain or discomfort would send her to bed, unable to forget. Her shoulder pain brings her ill body back to her awareness. It reminds her she needs to stop and take a breakthrough. She has to pace herself. Otherwise she forgets. Had she been in pain the day we visited the barn, we would have been unable to go out, feed the animals, enjoy this outdoors moment. In pain, she would have been unable to bake so many cookies at Christmas time. She would have been unable to look after her grandmother. Relief from bodily suffering enables her to forget. She regains her capacity to be able.

April shows an immense capacity to engage in life and to respond to the needs of others. Her son asks her to give him a hand with his meals. He is diabetic, is working double shift, and is concerned about eating properly. April cooks and brings him meals. She helps him get organized. Her mother's heart knows no limits, even in illness. She looks after her grandmother at home and later on visits her often in the hospice. She accompanies her until she dies. Then she volunteers to clean up her house. She holds life in its fullness, the interruptions of her ill body and those that come forward in life. She is well aware of her diagnosis. She knows that death is coming, that she is *'on the way out, slowly dying, that it is happening'* as she herself tells us in a conversation. She does not forget she is sick. She waits for her nurse to come to her home. She doesn't miss her medical appointments. She enrols in research trials in the hope of slowing down the growth of her cancer. She undergoes the treatments. Yet she does not stay in illness.

April's forgetting is not a dismissal of her situation. April tells us that her engaging in other things is not a mere acting to cover her condition. Her message, in her words, is not like *'Hey, everything's all better. I'm fine, the pain is under control, I can paint and wallpaper for a month.'* She is not interested in staying in the world of sickness. But she tries to go there from time to time, almost casually, for her husband. She doesn't want another crisis like the one she had a year ago, to catch Mark unawares. She wants him to be ready. She says, *'I don't want you to forget it, and then all of a sudden, crumble when I get sick again. We've got to be prepared for that to come, but we aren't rushing it along, that's for sure.'*

April strives to find a balance between doing things as usual and also gently reminding Mark and others that she is sick. *'I don't overdo it,'* she says, *'it's not something I press every day to remind him that I am dying. At the same time, I don't want him to forget it, I don't want him to get that false sense of security and lose it again. I'm just realistic about it. No one can give me a date, but I live day to day.'* As she refers to herself as a *'dying woman,'* April laughs. It sounds ridiculous; too intense to make it real. Laughter vents the emotion. But also, the label *dying* doesn't really fit April. She is such a vibrant woman. To call her a *dying woman* is a misplaced metaphor. The label *dying* is disabling. It takes life away from her. It hinders forgetting.

Heidegger (2001) writes that to understand forgetting we need to look at our way of being in the world. He refers to forgetting as "ways and manners of how something withdraws from oneself, how it conceals itself" (p. 168). Forgetting is composed of the prefix *for* "away or from" and the word *get* "to seize" (Skeat, 1963). Etymologically, forgetting is the negative of seizing, the letting go of something from our awareness. In Spanish to forget is *olvidar*, from the Latin *oblivisci, ob* "away" and *liv* "to slip" (Gómez de Silva, 1985). Something slips away from us when we forget. Olvidar shares its roots with oblivious, to be unaware of something, forgetful (Canadian Oxford Dictionary).

Heidegger (2001) goes to the Greek meaning of forgetting to show it further. Here forgetting denotes concealment, "Something in my relationship to something remains concealed to me" (p. 170). April's forgetting reveals a concealing. Just like health concealing itself from our awareness (Gadamer, 1996), here April's lack of health also conceals itself, to a degree. This forgetting is not a deliberate act. Rather, concealing belongs to the experience of health itself. The gravity of her health situation slips away. Even now as she experiences a gradual decline of her bodily strength, April's body conceals itself. This embodied concealing forgetting enables her to live.

Gadamer (1996) reminds us of the enigmatic character of health, "this condition of not noticing, of being unhindered, of being ready for and open to everything," (p. 73). He describes how illness disrupts this state. Yet even though here illness stands out and reminds us of what we are now lacking, he writes, the state of being healthy continues to have primacy. We strive to regain health, to go back to this state where health conceals itself. This concealing "shelters and saves the concealed for what it is" (Heidegger, 1992, p. 62). What does this concealing preserve here? Etymologically health means whole (Skeat, 1963). Concealing safeguards April's wholeness. It enables her being in the world, her being *at home* in the world.

April's forgetting is a concealing revealing. She experiences her body as both a concealing and a revealing; simultaneously. She forgets it she brings it to presence. Both occur together. The way women experience their bodies. Like the way women's lips touch each other, "Within herself, she is already two—but not divisible into one(s)—that caress each other" (Irigaray, 1999, p. 354). Like in pregnancy, "where the transparent unity of self dissolves" (Young, 1998, p. 274) and health becomes a growing presence. For April, health is never entirely a concealing nor is it a revealing. In her, each touches the other continuously, "Body shared, undivided... Both at once... Neither one nor two" (Irigaray, 1985, pp. 206, 207).

April cooks takes a breakthrough goes to her doctor looks after her grandmother cooks for her son goes to the lake with Mark stays up late playing cards takes laxatives talks to her nurse gardens for she is a gardener too loses weight gains weight takes her pain pill reads the paper cleans up her closet feeds the horses the donkey picks up the mail bakes cookies cans jam veggies salsa all kinds of things from her own garden decorates her room paints the walls takes another pain pill renovates her bathroom cooks again throws up her shoulder pain bothers her goes on trials doesn't let them write her off loses her hair wears a wig a cap looks after her son in the hospital eats pop corn goes out for coffee shovels the barn the pain comes back she ignores it stops takes a breakthrough makes supper eats little takes her mother to the doctor cleans up her grandmother's house never ends she is a woman who touches is touched simultaneously.

Like woman's experience of touch, April's revealing concealing "is far more diversified, more multiple in its differences, more complex, more subtle, than is commonly imagined—in an imaginary rather too narrowly focused on sameness" (Irigaray, 1999, p. 357). Speaking of revealing *and* concealing is misleading. She cannot split herself in two. Introducing the *and* here would be disruptive of how she experiences herself. Irigaray reminds us how poorly our culture's obsessive desire to count, to separate, to split suits woman. Her lips keep "woman in touch with herself, but without any possibility of distinguishing what is touching from what is touched" (p. 355). Health for women is not a concealing (or a revealing). It is wholeness. The wholeness that her lips form together.

RETURNING HOME IN A PARALYSED BODY

After two weeks in the cancer hospital, following her short holiday trip, April is discharged home. Claire, the occupational therapist, and Mark have worked closely all this time rearranging the home so that April can manage as well as possible. Her body is paralysed from her breasts down. A hospital bed, a trapeze to ease her movements in bed, a commode, and a high-back wheelchair are all in place. Even wheelchair access to the home has been addressed as Mark has just finished building an entry ramp that goes straight to the living room. He is desperate to have her home.

April is coming in an ambulance but the time is uncertain. Mark goes back and forth between the home and the hospital and keeps in touch with Cynthia, the occupational therapist who wants to be home when April arrives. Claire is on evening shift so she will visit April tonight. Mark wants to look after April on his own and has taken time off work. Cynthia invites me to go with her and we wait together for Mark's call. After a while, I decide to go as it is getting late. It turns out April's arrival happens very late and they are both exhausted after a long day of waiting. Claire goes to see April in the evening and her visit is very short as she realizes how worn out they are. She wants to say hi, let them know she is there, and make sure everything is working. Then she goes.

A couple of weeks later, Claire and I arrange a time to visit April together. April has not wanted many visitors after coming home and has just begun to let her family come. 'She asked me about you on my last visit and says she would be happy to see you,' Claire says. 'Her new situation has meant a whole readjustment for both of them,' she says, 'but I notice they are settling down. Mark is there day and night looking after her. He helps her to the commode, changes her diapers, and does everything she needs. We are visiting her everyday because she came home from the hospital with a bedsore and needs daily dressings. It isn't very big but it gets wet easily as it is so close to her bottom.'

I feel a mix of expectation and ache in my stomach as we drive towards April's home. I have not seen her since the visit before they went away on their holiday. This is the first time I will visit her in the bedroom. This bedroom she carefully decorated in blue colours for 'those days ahead.' 'She is using her wheelchair,' Claire says, 'and moves about her home quite easily. Mark has rearranged all the furniture to make room. He can also take her out thanks to the ramp. When she is tired, he takes her to bed. She alternates time in bed and time in the wheelchair. She is not letting herself stay in bed.' 'How is her mother doing?' I ask. April's mother was diagnosed with inoperable lung cancer only a few months before their holiday trip. She was on chemotherapy for a while. April often accompanied her to the cancer hospital. 'She is ok,' Claire says, 'April's situation has been very hard on her. She is off chemo at the moment and has visited her in the home a few times. I think of the days ahead and my heart pounds.'

We drive slowly towards April's house. Everything is green around us. Claire parks her car and their two dogs playfully jump around. We go in through the back door as usual and Mark comes to the kitchen. 'Hi Mark,' Claire says, a loud 'Hi April,' follows. 'Hi Claire,' Mark says. 'Hi Claire,' I hear April's voice. Claire stops in the kitchen and talks to Mark for a few moments. I stay with her. 'Go see April,' she says. 'Is it ok?' I ask. 'Of course,' Mark says, 'she is in the bedroom.' I walk in to the bedroom. I realize April is actually in her dressing room. 'Hi Anna,' April says, with her arms widely open and a big smile in her face. 'Hi April, it is so good to see you!' I say bending forward to hug her. She hugs me with such vigour. 'How are you?' I say holding her hand and sitting down on the chair besides her bed.

'I am alright,' April says, 'we knew this was going to happen, it is the next stage. It was coming. But I still have my arms and I am so happy that I can move them,' she says moving her arms freely. 'It would have been terrible if I was paralysed from my neck down, then I couldn't do much really. But this way I still can do lots. I am learning,' she says. April is in a hospital bed. A trapeze sits behind her bed and goes up above her head. April grabs it with her arms and repositions herself while we talk. 'You are learning quickly,' I say seeing her ease at manoeuvring the trapeze. 'Well, I have strong arms as I have done all kinds of work with my arms. So this is now helping me,' she says. I remember her stories carrying 80-pound boxes over her shoulder while cleaning out an accounting storage room at work. She could do it with no troubles at all. Now the strength of her long and skinny arms is her great advantage. I think of her arms as both arms and legs. They are now her only bodily support.

'Hi April,' Claire says as she enters the room. 'Hi Claire,' April responds. 'How are you?' Claire asks. 'I am good, thanks,' April says. 'I came to do your dressing,' she says. 'Sure, would you like to do it right away?' 'Yes, if possible, I hope I didn't interrupt your conversation with Anna.' 'Oh no, no problem,' I say, 'we had a chance to visit for a little while.' 'All the supplies are right there,' April says pointing to the shelf at the foot of the bed. 'I'll need a soaker also to change the one you have now,' Claire says looking around. 'There is none here,' she says. 'Perhaps in the closet,' April says. Claire looks into the closet. 'No, I don't think there is any here,' she says. 'Where could they be?' Mark says. 'Check the laundry,' April says. Mark goes away and comes back with a soaker in his hands. He hands it to Claire. 'Ok, we are ready,' Claire says. She asks April to turn on her side and pulls down the bed covers. 'Anna, why don't you go and get a cup of coffee?' April says, 'I think coffee is ready.' 'Ok,' I say and leave the room.

How difficult it is to be in April's kitchen without April. Her brown cat sleeps on the floor. Mark goes back and forth between the bedroom and the kitchen. The phone rings, he answers, says he is with the nurses, hangs up, and goes back to the room. Several coffee mugs are in the sink soaking in dish soap. I make myself a cup of coffee and stand looking out to the barn. I decide to rinse the cups in the sink. 'Don't bother,' Mark says, 'I'll do them later.' 'It is nothing really,' I say, 'you have so much to look after.' 'We are trying to manage,' Mark says, his tired face showing his few hours of sleep.

April's bed

I go back to the bedroom as Claire is finishing April's dressing. 'We need to keep the dressing dry,' Claire says. 'Yeah,' Mark says, 'I am very worried about that. I change her diaper as often as needed. But that thing comes off very easily, it won't stay there, that's the problem.' 'I know,' Claire says, 'I am also putting tape on the edges so that it doesn't come off right away. If there are any troubles or if it gets wet, you need to let us know.' 'Oh yeah,' Mark says, 'I'll phone the office right away. I can help April as much as I can but not with the wound.' 'Good,' Claire says, 'a nurse will come out as soon as possible and change the dressing. Ok April, I am ready, I'll put the clean soaker and then you can turn over.' 'Ok,' April says lying on her left side with her back to us. I move to April's side, Claire puts the soaker, April turns over, and I get the other end; our movements in synchrony with one another. We straighten the sheets and cover her.

After all the times meeting with April in her kitchen, seeing her now in bed is difficult. She is confined to this bed. She can take breaks as she sits in her wheelchair. But this metallic bed is almost inseparable from her. I think of how she so carefully redecorated her bedroom a while ago for this time. Now she cannot enjoy her own room. Her dressing room has now become her bedroom and the *wound* dressing room as here nurses do her daily dressings. How does she feel in here? Has she come to experience "that peculiarly distressing feeling common to the sick... as if the walls and ceiling were closing in upon them, and they becoming sandwiches between floor and ceiling?" (Nightingale, 1860/1969, p. 82). Van den Berg (1980) writes about the experience of the sickbed: our horizons narrow, our spatial planes move around, the world turns over. April's sickbed is no longer the space where she can thrust aside the daily contingencies of her life. Her "sickbed is not a promise, not a waiting, but a permanent confinement" (Van den Berg, p. 63).

In this bed, April cannot "sink into the healing sleep of forgetfulness" (Gadamer, 1996, p. 138). This bed is not the nest where she can forget past, present, and future. Forgetting can be harmful here. It would jeopardize her bodily integrity. Yet how can she remember her anesthetised body? From her breasts down, she cannot experience the numbness that bothers us when we press for too long a leg or an arm. April and Mark know she needs to turn over as often as possible. They need to stay watchful, awake, to guard this obstinately asleep body. The perils of her anesthetised body are too many to sink into forgetful sleep. The garment of this bed has transformed itself into a dangerous one. Yet her paralysed body makes her unable to take it off.

The bed by the window

As we drive away from April's home, I say to Claire, 'April told me about her experience in the hospital. She talked about being hurt.' 'That's a sad story,' she says. 'She was in a double room and her bed was by the wall. The day the patient next to her was discharged, she expressed her wish to be by the window to a staff member. You know how April is; she never asks for anything, she always puts other people's needs first. The staff person told April's wish to her nurse right away. They were close by and April was able to hear their conversation. All she heard was the nurse complaining about patients being so demanding and how hard it was to make them happy. April was very hurt and started crying inconsolably. You know she rarely cries, she always puts up with difficult situations, but here she couldn't. When the oncologist came, he noticed her distress and wanted to find out what happened. The nice thing was that at the end of the day the nurse came to see April and apologized. April felt better afterwards.

'It was a hard day for April,' Claire says, 'but I think it was good for her to cry. She needed to have a good cry. It was good that she gave herself permission to cry. This incident was the straw that broke the camel's back. She had been keeping too many things to herself. She was able to let her emotions out. They did move her to the window so that was also good. It was very nice on the nurse's part to talk with her and apologize. It helped April. She has gone through such a tough time these last few weeks.' 'She is in such a good spirit,' I say, 'I admire her strength. I am so glad Mark has been so supportive of her.' 'Yes,' Claire says, 'he is everything for her.' 'And so is April for him,' I say.

We leave April's situation behind us as we drive back to the office. Claire still needs to coordinate a few things related to her care. They have now accepted to have a personal care attendant to assist her with her bath. She also needs to contact the physiotherapist to inform her about April. Slowly we shift our minds to other commitments that await us. There are also other patients and families in need of Claire today. I go back to the university. Yet it is hard to shift to these other worlds. "Others are not in the throes of life and death... Out there... there seems to be little concern for living well, for the fragility of life, for the thankfulness to be disease-free" (Cameron, 1998, p. 186). April's world claims us; the gravity of her situation draws us to its centre.

CADENCE

Low sugar

A few weeks after visiting April at home after her discharge from the cancer hospital, Claire gives me a call to tell me that April is on her way to emergency. 'She is not very responsive,' she says, 'and her family doctor advised Mark to take her to emergency.' A few hours later I go to the emergency department to see April. As I arrive, a woman comes out of her room together with a young man. They are April's sister and son. We introduce ourselves as this is the first time we see each other. I have a sense I already know them. April is lying on a stretcher, her eyes closed. Mark stands close to her. 'Hi Anna,' he says, 'thank you for coming.' He looks worried and extremely tired. 'April,' he says calling her loudly, 'this is Anna.' April barely opens her eyes and says, 'Hi Anna,' drifting off quickly, her face pale and sweaty.

'Have a seat,' Mark says. I sit down and look around. 'Did they see her already?' I ask. 'The doctor just came and ordered blood tests. He will call the plastic surgeon to have a look at her wound. She has had a lot of diarrhoea these past few days. I tried to put her in the commode and change her diaper as often as possible but keeping her wound clean was nearly impossible. I kept phoning the nurses to come in, but the diarrhoea was there all the time.' This morning in the office Claire told me that April's wound isn't good. The diarrhoea is causing problems. The wound is infected and they are doing their best to keep it clean but it was difficult as a nurse can't always come right away. Claire is distressed as she feels the tension between keeping April at home and providing the best care for her wound. Mark is also wearing off. As I hear Mark telling me about these last few days, I can smell April's infected wound in the room.

A registered nurse comes to the room and explains to April and her family that she will start an IV and take blood samples. She says that once the results are back they will decide what to do. She will also go for an x-ray. April tries hard to keep her eyes open but the weight of her eyelids wins her over. The nurse helps April reposition her body before she starts the IV. She gets a facecloth, bends close to April, and softly dries her forehead and face. She straightens April's sheets. How many things a nurse can do in just a few seconds I think to myself. These small nursing gestures comfort April and her family, anxiously awaiting the resolution of this moment. 'Just a poke,' she says inserting the IV needle. 'Are you ok?' she asks before going. April faintly nods.

'You recovered very well after your accident,' I say to April's son, 'April told us all you went through. You spent a long time in hospitals, eh?' 'Yeah,' he says, 'I was really lucky to survive the accident.' 'Show her your scars,' April's sister says. He pulls up his pants and shows me the scars on his right leg. One looks like a very deep crack running through from knee to ankle. Several surgical scars show all that had to be done to practically reconstitute his leg. He points to all the spots in his body where he carries screws. He wears a very solid boot that assists him in his walking. After lengthy treatments and rehabilitation, he says he is now fine. 'Are you motorcycling yet? I ask. 'No,' he says, 'no way.'

April was on chemotherapy at the time of her son's motorcycle accident. He was in ICU for several weeks. April's days were split between her chemo cycles and time in the hospital for months. She stayed at her son's bedside all the time, first in the acute setting and then in the rehabilitation hospital. She was hardly at home during this time. Once he was discharged to the rehab hospital, we met her there in a coffee shop. She was wearing a cap as she had lost all her hair with the chemo treatments. She told us about the drama of her son's accident and his gradual recovery, his slow advances, his outbursts of anger at the nurses, the medical efforts to stabilize his glucose levels and to save his leg, her exhaustion at not being able to have a good night's sleep. April had a great part in her son's recovery. She spoke of her son's recovery as a miracle. It was also a miracle she herself survived.

The nurse comes in and asks Mark if April is diabetic. He says no. She tells him her blood sugar is very low. She says she will give her glucose through her IV right away. As the nurse gives April an IV push of glucose, April wakes up and looks around her. Mark's face lightens up in a few seconds. He is so happy to see April coming back to her own self. 'Hi Anna,' April says, 'I didn't realize you were here.' 'I came about half an hour ago,' I say, 'I'm very glad to see you.' Mark wipes her face with a facecloth. The nurse says she will bring her some juice and comes back with an assortment of juice cans. She asks Mark to make sure April keeps drinking. Mark opens a can, puts a straw in it, and gives it to April. She holds it in her hands and drinks right away.

'It's good to see you awake,' April's sister says to her with a smile. 'I don't know what happened,' she says regaining control. 'Your sugar went down a lot,' her sister says. 'Really?' April says. 'Has she been eating at home?' I ask Mark. 'Not very well these last couple of days,' he says. 'She didn't want to eat much because of the diarrhoea. We have also been so busy that we hardly have any time to eat. So many people are coming to the house that we can't eat our meals on time. The other day we had supper at 10 in the night. The whole afternoon was one person after another. We were about to eat when the evening nurse called to know if she could come in to change the dressing.' As I hear Mark's story, I realize how overwhelmed Mark and April are. Her bodily reserves are too scarce to compensate for her meagre intake these last few days. The gravity of April's illness has taken over their entire life.

The wound

Two physicians enter the room, one with a large package in his hands. They introduce themselves as the plastic surgeon and the resident. The surgeon says he came to clean her wound. He asks questions about April's condition. Mark tells him about April's lung cancer, her recent cord compression, and their problems with the wound. The surgeon explains to April what he is about to do and how he will do it. He is very kind and explains things carefully to them. He makes sure April has no sensation in this area and asks her to turn on her left side. Mark and I quickly help her to turn over. As soon as he removes the wound dressing, a strong nauseous smell fills the room.

The surgeon begins his work right away. I hear the surgical scissors cutting through April's tissue. Her sister stands by the surgeon and stares at the wound; her son has gone out. Mark and I sit on April's side. April is on the edge of the stretcher; her tiny face comes out through the bed rails, her right arm holding onto the rail. The surgeon asks her how she is doing and she says she is okay. She follows the sounds of the surgeon's scissors. Mark offers her a sip of juice and she drinks. Blood-soaked gauzes come out of her wound. The cutting goes on. April's lack of sensation makes it hard for her to apprehend this wound. Thank God. All she is able to sense is its horrific smell.

I hesitate to look at April's wound. The image is too disruptive of April's integrity. Her sister sits down. I gather nursing strength and move closer to the surgeon's side. He is nearly done. A deep chill runs through my body as I stare at her wound. It bears no resemblance with the wound I saw the last time I was in her home. This looks like a deep crater, to the bones really. Pockets of dead tissue hide inside this bottomless whole. The bleeding is profuse. The surgeon packs the wound with gauze to stop the bleeding, waits, removes it, and packs it again with saline soaked gauze. His fingers grope inside April's wound as they push in the gauze, filling every corner until the wound edges get bumpy. Several metres of gauze are needed here. He covers it with a thick dressing. He says he will see April in two weeks and goes.

We help April to a comfortable position. She looks tired. A few minutes later, they take her for an x-ray. I stay with Mark until April is back. I suggest that he gets something to eat. But he doesn't want to go. He tells me he is very worried about April. He is afraid of taking her home tonight. He says he has hardly had any sleep these last few nights. But this is not his concern. He is afraid she will get unresponsive again. I think of Claire and her distress about April's wound. The care of her wound in the home is reaching the limits. And April's limits too. This wound needs a close nurse's watch. And so does April. How much longer can she bear this wound?

I go home right after April comes back from her x-ray. She is in a good mood. Her sister has gone out so April and Mark are alone in the room. Tonight they wait. I think of her wound as I go, finding it hard to reconcile this mass of rotten tissue with April. This wound is pushing her body's limits. How far can it go? Later on we learn that whenever April sat in the commode, she rocked her body back and forth to ease her bowel movement, rubbing her wound on the edges of the toilette seat, hurting it without being able to notice. Etymologically wound and hurt are related (Skeat, 1963). To hurt is to dash against, to injure, to press on (Skeat). Now this hurt wound is pressing April's life to the edges.

Back to the hospital

April goes home after spending another couple of hours in emergency. She has an appointment to see the plastic surgeon in two weeks. The following days are not easy at home. She gets feverish. Her wound worsens. Nurses are going to her home about twice a day to change her dressing. Claire feels April's wound needs special care now. She keeps in touch with the plastic surgery department. They provide advice. She works hard to secure a special bed for April at home, one that would keep turning her, constantly. But this is not easy. She faces a number of administrative hurdles. April's status deteriorates quickly. She calls back plastic surgery. They tell her to send April to emergency to do an assessment. April comes back to emergency a week after she was here. She is admitted to the hospital.

Claire calls me right away to let me know April has been admitted to the hospital. She is in the plastic surgery department. 'I spoke with Mark today. She is in a single room and in a very particular kind of bed,' she says, 'the one that keeps turning. So she and Mark are very happy about that. They are treating her with such care. I also spoke with the nurse. She says April is dying. She was very kind. I just find it very hard to believe. I know April wants to come back home. I know she hasn't been doing well. But she didn't look that sick when she left home. I don't think she is dying yet. I really don't.' We arrange to visit April on the following day.

The next day, we meet in the hospital cafeteria and go straight to April's room in the plastic surgery department. We find her room quickly, her door is open and we go in. Mark is with her. 'Hi April,' Claire says getting closer to April. 'Hi Claire,' April says smiling. 'Good to see you,' Mark says looking at us. 'Hi April,' I say, 'Hi Anna,' she responds, 'I'm glad to see you.' April is in a motor-operated bed that makes a constant noise. The mattress is huge. She looks so tiny in this high bed; the size of her face so small. 'How are you?' Claire says. 'I feel better,' April says, 'the doctor says I have an infection and they are giving me antibiotics. This bed is fantastic. It keeps moving. Now we don't need to worry about turning. The nurses also come in all the time to make sure I am comfortable.'

'Do you think we can get a bed like this at home?' Mark asks. 'I'm working on it,' Claire says, moving closer to Mark, 'I think we can. We need to make sure April's infection is treated first. It is good for a little while to have her in the hospital as she is also getting 24-hour nursing care.' 'Yeah, I'm very glad about that,' Mark says. 'They are also taking good care of her wound,' Claire says, 'and I am so glad about this.' As I hear Mark and Claire talking and making plans for an eventual discharge home, I notice April tries to remain engaged, her head moves back and forth as she tries to follow the conversation. But she begins to drift off. She resists her drowsiness. She tries hard to keep her eyes open, to stay alert. This conversation is all about her. She needs to participate. Yet her exhausted body wins her over. Sleep comes. She lets go.

After a little while, we get ready to go. April is awake. 'I'll be in touch with you,' Claire says. 'Yeah,' I'll let you know any news,' Mark says. She gets closer to April. 'Give me a hug,' she says to her bending forward to hug her. April hugs her back. I move closer to April after Claire. I hold her hand up in my hands, feeling the heat of her feverish body. 'Thanks Anna for coming,' she says. 'Thank *you* April for all you have done. It's been such a gift to meet you.' 'When are you going to Chile?' She asks, remembering my trip home is coming. We talked about it in emergency. 'On the weekend,' I say, 'I'll see you again before I go, for sure.' 'Yeah, that would be nice,' she says smiling. We leave April's room and go for coffee. April reverberates in our minds.

April's flowerpots

A few days before April is admitted to the hospital, I see April at home during a visit for a dressing change. Mark comes out to greet us and as we go in, I get distracted by colourful flowerpots just outside their house. I stop to look at them. 'Are these the pots April planted?' I ask Mark. 'Yes,' he says, 'those are the last ones she did. After that she didn't have the strength to get up.' In emergency, Mark had told me about April planting flowers in the kitchen. He brought the pots in, put the dirt in the pots, and April planted the flowers. Now I was looking directly at her flowerpots. They are right here looking at me, happily standing on the edge of the deck.

April's flowerpots have cute animal shapes. There are a few cows, a sheep, a duck, a swan with its long black neck, a dog, and a little pinkie pig, the whole farm. On their backs, these animal pots hold blooming flowers of all kinds. I imagine April in the kitchen planting her flowers in these pots, sitting in her wheelchair, a belt around her chest, her table covered with dirt. So many kitchen moments come to mind in an instant. This kitchen holds the fullness of April. She replenishes her élan vital in this kitchen. And now she finds the strength to plant these beautiful flowerpots. She garnishes the world in her kitchen.

After seeing April, I go home with an image of her flowerpots in my mind. They are so revealing of April. I think of her rag doll-like legs and her strong arms. Her capacity to keep going is truly beyond measure. Her élan vital infuses her with life, breath. No text can ever apprehend this vital force in April. Gustavo Gutiérrez (2003) writes that the poor learn to appreciate every gift of life. In the experience of deep pain that is part of their existence, they learn to be content. This is perhaps one of the greatest gifts of life, that in the face of overwhelming suffering, human beings can be truly content. April radiates this gift to others.

The last visit

Two days after our visit to April in the plastic surgery ward, Claire calls. Her voice is serious, her tone sad. 'April is in a coma,' she says, 'I just spoke with the nurse on the unit. She says April has lost consciousness. She has been like this for several hours. She *is* dying. She thinks she will be in this state for a few days. She says April looks comfortable. No signs of pain or distress. So that's good. When are you going home?' 'On Saturday,' I say. 'Shall we go see her tomorrow?' She asks. 'Would that work for you?' I ask. I know tomorrow is Claire's last day of work as she is also going away for a couple of weeks. 'Oh yes,' she says, 'I also want to see her before I go. I couldn't go without seeing her.' We agree to meet next day late in the morning.

We meet in the hospital coffee shop and go upstairs to see April. Claire's morning has been quite busy and she is a few minutes late. I am glad to see her as I was afraid she wouldn't be able to make it. We enter the plastic surgery ward and the nurses recognize her right away. They greet her as we go in. One nurse comes close to talk to her. 'How is she doing?' Claire asks. 'No major changes,' the nurse responds, 'Her husband and family have been taking turns so she is never alone.' 'I'm glad to hear that,' Claire says, 'thank you for all the care you have given her. I know this was the best choice for her.' 'Go see her,' the nurse says. We go in.

April's room is very quiet; the noise of her motor-operated bed and the infusion pump is all we can hear. Her sister is sitting in a chair, resting. We greet her in a whisper. She tells us Mark has gone home to rest. We look at April. She is lying on her left side, quietly breathing. Tiny drops of sweat on her forehead. Her bed is tidy. Her body hides underneath the bed covers. Claire gets closer to her. 'Hi April,' she says softly touching her body. She waits. She moves away. 'Hi April,' I say, touching her shoulder. She looks comfortable in this bed. This is such a unique bed. I am so glad she can have it. It is a bed for April.

Claire whispers a few words to April's sister. She asks about her son, her mother. 'They are all around,' she says, 'coming and going.' Suddenly, April begins moaning. Claire notices it right away. 'Was she moaning when we came in? I don't think so,' Claire says. 'No,' April's sister says, 'she was very quiet.' April's moaning turns more intense. Her moaning is moving. Claire moves closer to April and touches her. She stays at her side. We stay in silence. April moans. 'I think she feels our presence,' Claire says. 'I think so,' April's sister says, 'you were with her for such a long time. She always spoke so well of you. You were *her* nurse.' Claire hears in silence. After a few moments, we decide to go. 'Bye April,' Claire says bending forward close to April's ear. April moans. 'Bye April,' I say in a whisper. We leave.

A nurse approaches us outside April's room. Claire speaks to her. 'This is very hard,' Claire says. Her voice breaks as she speaks. She looks at me in watery eyes. Looking at her is heartbreaking. This is April's nurse, grieving April. 'I have known her for so long,' she says to the nurse, 'she is such a woman.' 'I know,' the nurse says. She touches her arm. 'Thanks,' Claire says walking backwards. We feel an urgency to go. We walk fast. Once outside the unit, we slow down. We breathe. Our chests feel tight. We find a spot in the cafeteria and sit down. We get coffee. It is hard to talk. We take sips. April goes.

APRIL'S KITCHEN

April's kitchen is the hearth of April's home. She thrives in her kitchen. She feeds the spark of life in this hearth, *"la chispa de la vida,"* the spark that animates who we are. We enjoy infinite moments in her kitchen. The day she tries on her new chestnut curly wig as she is losing her hair with the chemo treatments. How we laugh hearing her stories about learning to wear it, walking with the wig out of place, the constant itch, her fingers craving to scratch her head. On our way to the door this day, after listening to April's story of her wig askew, April and I burst out laughing as Claire suddenly turns around with her eyes hanging out. She has put on a pair of glasses with fake eyes. We laugh to tears looking at this funny Claire.

We are April's personal guests in her kitchen. She doesn't think twice about making coffee and putting a plate of cookies on her table. She enjoys making others feel invited, closer, regardless of their background. She looks past the face. For her offering food to others is like giving them a gift. She welcomes others in her home with her gift of food. David Smith (1999) writes that true gifts are simply given. This is "the essential gratuity of giftedness" (p. 143). April simply gives. This is her gift. April's gift is hospitality.

On one of our visits, April runs down the stairs and comes back with a few jars in her hands. She hands me a jar of salsa and one of strawberry jam. She takes me by surprise and I hesitate about accepting her gift. She is adamant that I take it. I go home holding her gifts. A few weeks later, I tell April her salsa and her jam are just delicious. I tell her how much I have enjoyed both of them. I say that I would love to have her salsa recipe. She promises she will have it ready next time. On our next visit, as soon as we arrive she hands me a piece of paper. I read.

April's Salsa Recipe

For Anna

Club Salsa Sauce:

3 HOT PEPPERS (I USED THE GREEN JALAPENO)
12 RIPE TOMATOES (AGAIN, THE PINKIE/NOT QUITE RIPE FILLED IN WHAT I NEEDED)
1 ONION
2 LG GREEN PEPPERS
2 LG RED PEPPERS
1 CUP WHITE SUGAR
2 CUPS CIDER VINEGAR
2 TBSP. PICKLING SALT.

1) Peel tomatoes. Add sugar, vinegar & salt, & hot peppers.
2) Boil till thick.
3) Add green & red sweet peppers.
4) Cook till tender.
5) Pour into sealers & tighten while hot.

Makes 2-3 Quarts. Turns out very thick vegetable wise, but sauce is watery (The longer you cook, thicker it gets!).

Taste is a "MEDIUM" hot, that sneaks up on you!!
P.S. I threw in about ½ - ¾ chopped celery too.

April bestows us her gift. Her gift is the spark of life, *la chispa de la vida*. She feeds this spark in us. She feeds us. She is in solidarity with a world in hunger. In her kitchen, she feeds the hearth of life. She gives birth to life. In the midst of her labour, this hearth insistently claims her back. Life's centre of gravity draws her to the hearth. Here she finds the spark, *la chispa*, to keep going, to live, to die, to nurture the vibrancy of life. Death finds no room in her life. Her labour is the labour of life. Her life is a "*MEDIUM*" hot, that sneaks up on us.

CHAPTER VII: EMBODYING ETHICS IN THE HOME

> *What matters about each of us is not (only) some abstract capacity but the fact that we are the specific concrete individuals that we are. (Dillon, 1992, p. 115)*

In situations of health care, we are often witness to the myriad expressions of human life. As agents of care, health care professionals find themselves in the midst of concrete and particular circumstances that call for their attention (Cameron, 2004). How we respond and engage in these situations evokes an understanding of ethics that transcends prevailing theoretical frameworks. Bergum (1994) writes that ethics is about "deciding 'what is the right thing to do?' or deciding 'how should I act?' " (p. 72). While the graveness of some individual situations raises these questions immediately, it is in the everydayness of clinical practice that we encounter a genuine understanding of ethics and face the need to enact these questions (Cameron, 2004). How nurses respond to a situation denotes in many ways an understanding of ethics that is embedded in their practices. Here nurses already reveal primary elements of ethics that we find in exegeses of ethical practices. They embody an originary sense of ethics so to speak.

Cameron (2004) delineates an understanding of ethics that situates itself in the immediacy of the moment in clinical practice. She shows "the nursing 'how are you?' as an ethical question" (p. 54) that makes us ethically accountable in the face of human vulnerability. Bergum (1994, 1999) and Bergum and Dossetor (2005) in their comprehensive delineation of relational ethics call our attention to the relationship between health care provider and person as a necessary condition to enact ethics in health care. Bergum and Dossetor remark the need for health care professionals to engage relationally with patients and families as a way to foster respectful and mutual understandings of each person's situation that in turn enable them to act ethically.

Schultz and Carnevale (1996) call into question the medical view that "responsible care requires objectivity and therefore distance from the patient and his or her experience" (p. 190). They suggest that while ethical principles and guidelines are helpful in health care, health care professionals need to attain an understanding of "what is going on" (p. 192) in a particular situation before being able to make ethical decisions. This understanding, they write, is achieved through a continuous and open engagement with the patient's own experience of suffering as they go through it. In a similar vein, Cassell (1991) writes about the ethical need to recognize both the wholeness of each individual and their suffering in injury and illness. To learn to do so, he writes, we need "a shift away from a virtually exclusive concern with the body and disease toward a primary concern with the sick person" (p. 31).

In what follows, I present a nursing situation in the home as a way to delineate this understanding of ethics that nurses embody in their daily practices with the very ill. In embodying ethics, nurses participate in their patients' experience "as a 'whole' person" (Gadow, 1980, p. 87), embodied, vulnerable, subject to pain (Gadow, 1989). Through their embodied relation, nurses and patients "work together to create meaning out of the experience" (Wilde, 1999, p. 31). I have divided this situation in three parts as a way to highlight elements of the nurse's ethics in the home. I finish this chapter with developing thoughts on the nurse's way of embodying ethics in the home.

THE BREAKTHROUGH

Erna is a short and effusive 76 year old woman who has been with the palliative home care team for a few months. She lives in a seniors' lodge on the north side of the city. She suffers bone pain due to her multiple bone metastases secondary to her breast cancer. She receives biweekly subcutaneous infusions of clodronate as an adjuvant in the treatment of her bone pain. Sherrie is her home care nurse. She visits Erna every two weeks, on the day the clodronate is due. As we drive to Erna's home, Sherrie tells me she is concerned about her as she has been in a lot of pain these past few days. She has spent a fair bit of time on the phone with her. 'She just won't take the breakthrough when she needs it,' Sherrie says, 'she waits too long to take it and she ends up in very bad pain.'

We get out of Sherrie's car, get the nursing blue bag and go to Erna's apartment. We get off the elevator and walk toward her place. She is waiting for us at the door with her housecoat on, her hair beautifully done. 'Hi girls, how are you? I am so happy to see you.' She says and gives us a kiss. 'Come in, come in, I am ready,' she says. We go in, take our shoes off, hang our coats, and walk to her living room. Erna is sitting on the couch and an IV pole stands right beside her. Sherrie washes her hands and gets the clodronate infusion going very quickly. Then she grabs the blue binder from the kitchen table, moves a chair to the living room, and sits beside Erna, watching now and then the infusion. I sit on a small stool on the other side.

'Erna has been getting the clodronate for a few months and it helps with her bone pain, doesn't it?' - 'Oh, does it ever help! Last time, remember, I was in so much pain; a few days before, I could hardly even walk, but I didn't give in; after the clodronate was finished, I said, Oh, boy, now I'm going to feel good. The next day I felt like a million dollars' - 'Erna, when it does start to wear off like that, that's when you need to take the breakthrough, because you shouldn't be in a *lot* of pain' - 'That's what I did; because my daughter is like a policeman; she always phones and asks, You take your breakthrough? How much pain? Oh, I'm in a lot of pain, I said' - 'But you don't have to be in a lot of pain. We've talked about this a lot. You know it's there for you, and you use it. Maybe you're not taking enough of the pain medication, because it should really take that sharp pain away.'

'Sometimes, I'm just scared. I think that maybe I take too many and it's going to hurt it more, whatever it is' - 'But you know what? You have to put confidence in the doctor and how' – 'I do' – 'they order things, so with the pain medication, all of our patients have a dose like you do, every 4 hours, but they always have this extra, this breakthrough dose, and the doctor orders it every hour as needed, until that pain is' – 'See, that's something *new*' – 'No' – 'Maybe it's been around for a long time, but I didn't have to use it, this is the first time that I'm using it, that's why it seems that maybe I'm taking too many; maybe I will do more damage than good' – 'And like we talked yesterday, it won't, all you have to do is write down when you take one, because that's what's going to direct the doctor as to how he should change that every 4 hour dose, if that's what's going to be required' – 'Well, my doctor always stresses, 'Make sure you use your breakthroughs.' I *do*, well he wants to see me again tomorrow, mainly about the pain.'

As I hear Sherrie and Erna talking, I sense their friendly openness to express their concerns to one another. Sherrie is concerned that Erna is suffering unnecessary pain. She knows the breakthrough dose can help her manage her outbursts of pain. She has tried to address this in the past to no avail. Erna on the other side is afraid of taking these *extra* doses of pain medication. She rather waits a little longer in the hope that her pain will recede on its own or until the time for her next regular dose. Yet these pain times in between that Erna experiences are the ones that very much concern Sherrie. She knows they are taking a big toll on Erna and on her as well, as her nurse. There is a tension here as Erna's pain situation has reached a critical moment and Sherrie senses the urgency to revisit the breakthrough once again. This tension evokes Sherrie's close nursing engagement as she tries together with Erna to find a way to ease her pain.

Breakthrough I

'You know what I think we'll do today, Erna? You know this chart where you tell me how you rate certain things, like pain, from 0 to 10, like, 0 being no pain, and 10 being really bad crying pain; right now, what would you say your pain would be at?' – 'My back pain is about 6. I'd say 6. That's my back pain, and it goes all the way down to where the breast is; that pain is just like a ball; it hurts. You can't straighten out; you just have to go down like this; even you can't get up, because usually I get up and I just stand this way, all hollowed up' – 'Is it in the ribs? Does it feel like it's in the rib area?' – 'Yeah, yeah, right; but then after I take the pill, about 15 minutes, it goes away. Do you know how nice it is not to have the pain? I don't mind pain that's pain; you learn how to accept it; but oh, my God!' – 'Erna, like we were saying, that medication that you have is there for you to use for that pain. So with the breakthrough, the doctors always like to make sure that you have that little extra so that you don't have that really bad excruciating pain' – 'That's right, even the pharmacy; they're so attentive. They phone me, they ask me how I'm feeling; they're so concerned; that makes me feel so good.'

'When I go tomorrow, I'm going to drop in and pick up the pill pack, because they deliver every Friday. But when I go to see my doctor, it's only a few blocks away, so we just drop in. A few weeks ago, I went to see the doctor and then to get my pain killer; while waiting there, I fool around with the rest of the staff there; of course, John my driver, he's *90* years old!' – 'Very good, eh?' – 'We talk, we joke around and all that, and I came home without my pill pack' –' Oh, you were talking too much?' – 'So I phoned right away and I told them. So now I make sure I don't forget. Yeah, he's 90 years old; he drives for the seniors driving association, they're all old like me. Their tickets are $5 for 2 hours, because they stay with you' – 'That's a wonderful service to have' – 'Oh, is it ever! Last week, John phoned me and said, I can't pick you up tomorrow, I got an emergency at home. I said that's fine. So they sent this lady and she's just about as old as John, clicking 90. I thought, Oh, my God! How's she going to drive? You'd be surprised, they drive so cautiously. My doctor's office and the pharmacy, they saw John wasn't there, and boy, they just about strung me up. They asked me, what did you do with John? I told them. They said, Oh, we thought you fired him, you pushed him out.'

'So now, Erna, shall we get back to this?' – 'Okay, let's get back to that' – 'Tiredness; how would you rate your tiredness? Zero, you wouldn't be feeling tired at all' – 'No, I don't feel tired' – 'What about nausea?' – 'No, I never get that' – 'That's a blessing; depression?' – 'No' – 'Good, good; anxious?' – 'Anxious?' – 'Anxiety, feeling nervous' – 'No, no; I feel good and happy; I do, you know' – 'No drowsiness; appetite, good appetite?' – 'Oh, yeah, pretty good, the normal' – 'We'll put that as a 0 then, being normal; you're eating all your meals. Well-being? That's having a good day today; things are going smoothly for you?' – 'Oh, yeah' – 'No shortness of breath?' – 'No, no; I'd like to go out for a walk, but it's icy, and I'm scared, even with my *Cadillac* over there. Yesterday, it was so beautiful out, I took the garbage out, and I went around a few times. Okay, go ahead' – 'It's good even in the hallways' – 'Oh, I know; it's good all over. I love it; it sure is a help, you know. I go many times without it, but not very far; you have to be careful you don't fall down.'

'What about your bowels, Erna?' – 'Oh, they're good' – 'Are you going every day?' – 'Yeah, sometimes twice; yesterday, I went twice' – 'And it's nice and formed, it's not hard?' – 'No, no' – 'Is peeing no problem?' – 'Oh, good, yeah, no problem' – 'How about your sleeping? Do you have a good sleep?' – 'Oh, yeah, I sleep good; ten o'clock, usually, unless I watch some good movie' – 'Now, what we'll do is' – 'My legs are good, yes; see?' – 'Yeah, they are good, they look really good' – 'They hurt once in a while, you know, arthritis. But then I guess the pain killers work on that, too, eh? I used to have so much trouble; my knees hurt, arthritis. But now that I'm taking the pain killers, I'm sure my doctor said they work on that.' – 'How's your mouth? Stick your tongue out; oh, it's good; nice and moist.'

'With the increased pain that you have, Erna, you've had that since last week?' – 'Yeah, all last week; and it was right in my chest; see how you cough? *Aahemmm,* I can do it now. I couldn't before because it was so painful. I could feel all this like when you're getting a cold or you got a cold and you want to cough the stuff out, and I couldn't, because it seemed like the whole rib cage was breaking, it was so sore. So I'd hold myself down, *ahemmm*, and now it's good; now this week is good. I'm so happy, because that makes a big difference, you know. If you want to even cough a little like this, you know, it means a lot many times. But my doctor said I had a touch of the flu; he'll be happy when he sees me, because I'm much, much better' - 'And you say the clodronate always makes you feel a little bit?' - 'Oh, does it ever, yeah!' - 'Good for your system; so you sound like you're on the upward swing again, Erna.'

Sherrie wants to do an assessment of Erna's symptoms and she gently introduces the ESAS questions into the conversation. She knows Erna is familiar with these questions yet she explains to her once again how to go over them. She knows the clodronate infusion takes Erna's attention for a while until she settles with the drip and the burning sensation it generates in her upper chest. Erna's pain status also reduces her level of attention. Sherrie knows Erna is not at her best today and she integrates this knowledge into how she does her nursing assessment. In asking the questions, she also doesn't expect a straightforward answer, a plain number, and moves on to the next question. Rather, she stays with Erna's manner of responding to her questions. She listens to the story Erna wants to offer.

Vangie Bergum (1994) identifies three kinds of knowledge necessary to provide ethical care, descriptive, abstract, and inherent knowledge. Descriptive knowledge has to do with the person's subjective experience of illness; abstract knowledge refers to the disengaged and objective evaluation of one's illness through physical examination, lab tests, imaging, and so on. Bergum writes that while both descriptive and abstract knowledge are useful in clinical practice they are also limited as the first offers a partial understanding of the person's health situation and the second, a rather fragmented and technological approximation to the same. She proposes inherent knowledge as the kind of knowledge that reflects an understanding of the person as "a living person where body and self are one" (p. 73). Inherent knowledge, Bergum writes, integrates both descriptive and abstract knowledge into the person's own context and lived understanding of her situation. The person's "living I" (p. 73) is safeguarded through inherent knowledge.

As she does her assessment, Sherrie is attentive of the various kinds of knowledge that Bergum (1994) describes. She hears Erna's description of her pain, how it limits her movements or keeps her from coughing. She also knows Erna's pain has an underlying cause. She has bone metastases in several places including her rib cage and her leg bones. Yet above all Sherrie makes room for Erna's living I to come forward. Erna tells stories of her doctor and her pharmacy, her 90 year old driver, and even the walker that she so mischievously calls her *Cadillac*. Erna shows Sherrie her world of relations, *who* she is in this world, how she goes about her daily life. To the external eye it might look like Erna goes all over the place with Sherrie's questions. Yet inside the moment, one notices that there is no detour in here. This is how the conversation flows. Sherrie transforms the ESAS questions into a dialogue, a way into Erna's lived world.

Breakthrough II

'Thank you Sherrie for giving me that push that I needed. I know my doctor said that if I take the breakthroughs whenever I need them, but I don't need them as often. I didn't at that time, but then I started to get a little worse. I didn't think, at that point, gee, maybe I took too many or something' - 'You know Erna how you take them every 4 hours? You'd never ever miss those 4 hour doses' - 'Yeah, I remember that' - 'Even if you take, let's say, a breakthrough dose an hour before your next regular dose. You'd still take that regular dose. The breakthrough dose is just to take that edge off the pain, to keep it from getting really bad. What happens sometimes, people will bite the bullet. They think, I can wait until that 4 hours, and take it' - 'Yeah, yeah, I know what you mean' - 'But then the pain gets so bad that when they do take the pill, it doesn't control it the same.'

(Phone rings) 'Hello? Yes, come in, I am on the third floor, I'll let you in. It's the pharmacy, what were we talking about?' - 'You know what, Erna? Did I ever draw you the little diagram? Here, I'll just show you on here' - 'Hi, dear! I'm attached to a thing here. I guess I owe you some money. I got the cheque ready. Anna, would you mind passing me that cheque? There on the wall, thank you. Here you are, what is your name?' 'Doris.' 'Oh Doris, Okay, I like to know what to call you. I got it dated yesterday Doris.' 'That's Okay, as long as it's not 6 months from now,' Doris says. 'No, Oh, heavens! When are you picking up this pole? Tonight?' 'Probably not till tomorrow,' Doris says. 'Tomorrow is fine. I am seeing my doctor so I won't be home between noon and three.' 'If I know I'm going to be late then, I'll come the following day,' Doris says. 'Okay Doris, thank you very much, please have a candy; have a good day, watch, don't fall, because it's slippery.'

'Okay, Erna, I'm just trying to' - 'Hi Paul! How are you doing? That's Meals on Wheels. Just put it on the table.' 'You're not having your hair done, are you?' Paul asks. 'No, I'm getting a needle in there; see? I never have my hair done; it's on my own.' 'Just on your own?' Paul says - 'You do such a good job yourself Erna' Sherrie says - 'Okay, see you next week,' Paul says. 'Are you going to the football game?' Erna asks. 'No, I'm not, but I'm going to be watching it, are you going to be watching?' He says. 'Oh, yeah, I have no choice; what else is there? There'll be nothing but football. Okay, you be good boy, I'll be a good girl if you're going to be a good boy.' 'That's fair enough,' Paul says. 'Okay, we'll see you; you have a good day.'

'I'm just going to update your little bag here, with your supplies Erna, make sure that you have enough. Do you have any questions for Erna, Anna?' - 'I was wondering if you would like to talk a bit more about your pain?' I say, 'what does your pain, all that it involves, mean?' – 'It involves the main part of your body; it's like your mid-section, right, Sherrie? It's right in the middle and the back, even up here. It seems to involve everything' – 'You know, when you have pain, Erna, how frustrating it can be,' Sherrie says, 'what happens to you when you have pain like that? Like you know, does it curtail what you do or maybe are you thinking differently about what's happening to you?' – 'Well, it does come to mind, you know, you think, I wonder how much longer I'll be able to take this pain, because that pain is very hard. You take something in your hands, you hold it; sometimes you have to let go because that pain is so hard. Yesterday, everything was falling out of my hands. I had so many phone calls, and I got the phone here, all my bookings, everything; and every time I picked up the pen, it would fall down. And when you're in so much pain, you wonder, maybe that's the end. Because you don't know; you don't know. But when the pain starts to subside, then you feel better.'

(Phone rings) 'Hello? Hi John, how are you? I'm not too bad. I got the nurses here; they're giving me my infusion, my needle. You are going to pick me up tomorrow? Yes, between 1200 and 1230 is good. Just come at 1230, that's good. No, no, pick me up at 12:30. They'll all be happy to see you. They just about strung me up last week because they figured I fired you. Okay, John, how are feeling? Not too bad. Listen, you watch; don't fall, okay? Ok, you take care, don't fall. Bye bye. That was John, my driver, he was confirming the trip to the doctor, so where were we?'

As Sherrie tries to bring the breakthrough back to the conversation, she faces a number of interruptions that take Erna's attention away. Sherrie doesn't disengage from these moments. Rather, she stays with whatever goes on in here. She knows Erna is covered by a palliative plan and expresses her concern about the amount Erna is paying. Doris clarifies it for her. Sherrie's concern engages all of us in a dialogue about the high cost of drugs. '*Here goes my washing machine; here goes my drier,*' Doris says as she tells us her home delivery stories and the cost of medications. Then Sherrie engages in a conversation about beauty shops and hairdos as Erna responds to Paul's joke at seeing her sitting so still on the couch. While these interruptions seem to take us away from our focus here, Sherrie knows that they are also threads of Erna's world. Engaging with these moments is a way of affirming the *person* of Erna in her home; it is Sherrie's "personal responsiveness" (Gadow, 1999, p. 63) to Erna's storied experience.

Even though brief, these interruptions take Erna's full attention. In pain, she still needs to attend to a world of things, book transportation, pay for pharmacy services, attend to the person who delivers her meals, answer the phone; all this on top of being "*hooked up*" to an infusion and having the nurses in the home. She is very sociable in her engagement with others. She likes to know their names, chats about ordinary things, warns them about the ice on the roads, and even takes a moment to offer a candy. She makes friends with everybody. One could say that she enjoys these short visits or interruptions even though these are not easy things to do when one is in pain. As soon as she tries to get back to the conversation, another interruption takes her attention away. Sherrie wants to talk with her about the breakthrough but these interruptions get on the way.

How do people who are ill experience these interruptions in the home? Stajduhar (2003) describes the concerns of family members of palliative patients about the high volume of interruptions in their homes. While family members recognized the significance of in-home support, they also felt this affected their own sense of privacy and autonomy in the home. They experienced a sense of disruption of their family identity. In a way, these family members felt *robbed* of their own space in the home as others began to take over the care of their sick relative.

The etymological meaning of interruption is to rob (Skeat, 1963). In relation to this meaning, one might ask, are home interruptions like an act of robbery? Joan, another participant in this study, feels that June, her nurse steals her time when she visits her. June is aware of her feeling and makes every effort to time her visits, spending most of the time with Joan's sister. In another situation, June herself feels like robbing Mr. Kim's air in the home. Mr. Kim suffers from very advanced pulmonary fibrosis and is extremely short of breath. He is on a very high dose of oxygen. Conscious of Mr. Kim's need for air, June, his nurse, tries to make brief visits to his home. She also tries to reduce the frequency of her visits to Mr. Kim's home as much as she can.

Erna doesn't seem concerned about her home privacy with so many interruptions. In fact, she seems to have integrated these interruptions into her daily life. While these interruptions do rob her of her time and energy, they also keep her in touch with the world; this world she is now only able to reach as far as her *Cadillac* can go. One could say that these interruptions are perhaps like breakthroughs in Erna's life. They take her away from pain and illness, even if momentarily. As we try to bring the breakthrough back to the conversation, here we find ourselves inside the breakthrough itself. One might even say that Sherrie herself is like a breakthrough as she brings her nursing knowledge and attentiveness to understand and relieve Erna's pain in her home.

Breakthrough III

'Erna, I was going to show you the drawing; do you want to?' – 'You want paper? I got lots of paper' – 'No, it's okay, Erna; I can just use the back of this thing. If it's big, I get creative and draw big pictures' – 'Oh, you go ahead; artist number 1, doctor number 1, artist, she is, you know!' – 'Okay Erna, these would represent your 4-hour doses, what time do you take them?' – 'Okay, I have everything stabilized, and now it's much easier. I'll start with 5:00 in the morning: 5:00 a.m., 9:00 a.m., 1:00 p.m., and then 5:00 again, and 10 o'clock for the Gava' – 'Gavapenten. Okay, so what happens, at 5 o'clock, you take your pill, and you swallow it, your liver starts to break it down so that your body can use it, and the pain medication starts to become effective; it's breaking down, it's controlling the pain. Then it starts to diminish in your system; it starts lessening, right? And it's coming down like this, see this curve going down? So at 9 o'clock, it isn't out of your system yet, but the effectiveness isn't as strong; so at 9 o'clock is your next dose, which you start taking, the body breaks it down, it starts to become effective, it goes up like this. They cross over right here, where one is becoming effective and the other one is decreasing in effectiveness, see these curves here? But it's not out of your system yet; so it controls it; the pain is always controlled for sure at this level, because this is where it's coming down, here, and it comes down like this; so it's always crossing over here.'

'But let's say it's 8 o'clock in the morning, you're feeling quite uncomfortable; maybe you've moved around more, you've had a shower, you've got a cough, you feel like there's more pain there. This is where you want it. Let's say at 8 o'clock now, you're thinking, I don't want to wait until 9:00 to take my next dose, because I have a lot of pain right now. You take the breakthrough so here, it starts to become effective, and it controls the pain at that point, rather than it going all the way down here. So the pain is always nicely controlled in this area. Your body is never without some medication to help with that pain. But sometimes, it will spike up. It'll feel worse than other times, and that's when you need an extra one, just to keep a cap on it so it doesn't get out of hand' - 'You're right' - 'Sometimes people bite the bullet, or let's say you go out and you forget your pain medication, and now you're not taking it, let's say, until 11 o'clock. Well, by then, it's totally out of your system and the pain is way up here somewhere; the pain isn't controlled at all. That's why the doctors usually order medication every 4 hours, to keep a nice and steady dose' - 'Well, that's good; that's good.'

'So whenever you use one of these breakthroughs, all you have to do is note the time down that you took it, because they're easy to forget, because you also have the regular doses. So when I phone you and say, Erna, how many breakthroughs did you need? You can say, Sherrie, hold on, you grab your sheet, because you're good at keeping records; and it's good to write it in red; you can do the other stuff in regular pen, but the breakthrough ones in red, and then they stand out nice and easily, and you can just count them up. So let's say you're using from none to three a day, within 24 hours. That main dose would be considered a good dose for you; the doctor wouldn't change anything' - 'Like yesterday, I took three' - 'But let's say things change, and the pain is bothering you even more, and you're using maybe five or six breakthroughs in 24 hours. We'd let the doctor know that, and he'd count up the milligrams that you used, and he'd divide up amongst your 4-hour regular doses. So he's eliminating the breakthrough doses. But you're getting that increased amount of medication attached to each 4-hour dose. That way, it keeps it more regular; but it directs him; it lets him know how much you're really needing to control that pain' - 'That's right, that's right.'

'That's the modern way, nowadays, we never had anything like that in the past' - 'But they've done a lot of research, you know' - 'That's what I mean, they've done a lot of research, a lot of studying. Just imagine all the work put into that in order to get to see what I'm going through now; and if I don't use it, I need a good licking' - 'Yeah, we'll come and give you one!' - 'You do that; because if I only knew how many people suffered in order to get help for me in this respect, and I turn my nose at it, that's not right' - 'Like I say, the medication is just to make you feel as normal as possible' - 'I know' - 'Sometimes people worry, like you were saying, what if I take too much? But the way the doctor has it ordered, you won't. And if you get over the three a day, that's when you phone me, and you let me know, okay, and then we'll just see what's going on' - 'Yeah, okay; well, gee, thank you *so* much, Sherrie' - 'You're welcome' - 'Honestly, you know, you're such an understanding person; you know, she showed me that before, but for some reason, my brain didn't want to; why is it that sometimes the brain has to be told so many times?'

'Sometimes, Erna, I think you have to make sense out of it yourself, and when you've seen the benefit of doing it, like you did yesterday by taking that extra one, it made you feel better. Now maybe if this happens again, you'll say, Okay, I know I need to take the breakthrough, it will make me feel better and take that bad pain away. So sometimes it's just a process that we all go through, that we have to kind of try it for ourselves, and then you see the benefit of it; but you know now' - 'That's right; this will stay with me forever. It will, you know, because that's what you call education. And the way Sherrie explained it yesterday on the phone, it couldn't have been done more clear or anything. You got the best teacher in the world, I'm telling you! Boy, she is great.'

After the interruptions are over, we resume our conversation. This time, Sherrie is able to talk in detail about the breakthrough with Erna. She has already brought it to the conversation a couple of times, slowly approaching the topic. She is unable to leave Erna's home before having discussed the breakthrough, until this matter is settled. The breakthrough has become an ethical question here as this malignant pain takes over Erna's existence. In seeing Sherrie addressing this question, one senses her respect for Erna, her situation, her manner of dealing with things. Robin Dillon (1992) writes that respect is about "recognizing our power to make and unmake each other as persons and exercising this power wisely and carefully" (p. 116). As she talks with Erna, Sherrie enacts this lived notion of respect. She is dialogical in approaching the question of the breakthrough. Her manner is re-affirming, practical, engaging. She brings forward Erna's own capabilities.

Later on, I ask Sherrie about her manner of approaching patients in the home. She tells me she likes to give patients a sense that she is there for them but she doesn't like 'to get in their face.' She is strong in saying that she doesn't like to make decisions for them. But she likes them to know what is available. 'Sometimes they just need a little extra time,' she says, 'it's sort of a self-limiting process, and if they make a different choice, that's my tough luck. I still have to respect their decision.' Sherrie calls this *taking the mystery away,* reassuring patients in their current situation, explaining things step by step, following their own time. This is what Sherrie does today with Erna. She wants to make sure Erna understands the breakthrough, she draws it for her. The breakthrough is not an imposition; she offers it as a possibility. There is no coercion here. Coercion would be the "removal of the possibility of relationship" (Gadow, 1994, p. 305); the end of the nursing relation. Sherrie takes the mystery away and waits.

Bergum (1994) proposes three moves necessary to developing knowledge for ethical care, from dominance to collaboration, from abstraction to context, and from beneficence to nurturance. In making these moves, Bergum writes, we introduce a shift in our current understandings of ethics in health care. Here, prevailing medical and ethical frameworks are replaced by a "relational narrative" (Gadow, 1994, 1999) where "ethical certainties fail, and nothing remains except possible engagement between nurse and patient" (Gadow, 1999, p. 64). Sherrie enacts an understanding of ethics that resonates with Bergum's and Gadow's relational exegeses of ethical practices. She doesn't offer her knowledge of the breakthrough in an abstract, scientific way that knows no reasons *not* to be utilized when needed. Rather, she makes this knowledge "irreplaceable and unique to *this* relationship, *this* patient and *this* professional" (Bergum, 1994, p. 74). She makes it *applicable* in the context of this particular Erna.

Here we see the nurse embodying an ethics of respect as she engages with Erna, her illness situation, her pain, how she makes sense of it, her fears. Dillon (1992) reminds us of the original meaning of respect, "to look back at," "to look again" (p. 108). Respect, she writes, involves attention to the concrete particularities of each person. Attention, writes Iris Murdoch (cited in Dillon), is the "just and loving gaze directed upon an individual reality" (p. 120). Sherrie directs her nursing gaze upon Erna's particular reality. This gaze is "neither the coolly detached and emotionless stare that objectifies and depersonalizes, nor the coolly appraising look that can be invasive, presumptive, and diminishing even when it is admiring" (Dillon, p. 124). Rather, Sherrie's gaze is one of respect and recognition of the concrete person she has before her eyes.

Joan Liaschenko (1994) describes the gaze of nursing as that which "looks not to the biomedical model of disease but to what it means to have a life" (p. 25). One might add to have a life in the face of adversity and failing health. This is the ethical stance of nursing, to direct our nursing gaze upon a human being and recognize in this being the person who strives to thrive and to remain whole when things are falling apart. To recognize is "to know again," "to know together, fully" (Skeat, 1963). Through her nursing gaze, Sherrie knows once again *together* with Erna, who Erna is; in a fuller, more whole way. She brings back the self of Erna that "is injured in illness and lost in suffering" (Cassell, 1991, p. 25).

Respect and recognition are core elements in embodying ethics in the home. They are interwoven into the "ethical fabric" (Nelson, 1982, p. 1) of nursing practices. Charles Taylor (1994) names the deleterious consequences of refusing recognition, it "can be a form of oppression, imprisoning someone in a false, distorted, and reduced mode of being" (p. 25). In health care situations, nurses and other health care professionals can choose a distancing disengaged stance where, borrowing Carole Taylor's (1993) terms, the other is positioned as an object of care while professionals position themselves as the subjects of care. The alternative *"is not its opposite"* (Gadow, 1980, p. 94) but it opposes it. The alternative is about being engaged and embodied; mindful of our "power to make or unmake others" (Dillon, 1992, p. 128). It is about creating a "relational space" (Bergum & Dossetor, 2005) where respect and recognition are the gifts we bestow on one another. The home is a space of possibilities where realizing these gifts is an awaiting project. Nurses venture into the openness of such project.

THE END OF THE BREAKTHROUGH

> *"If you go flying on a flying trapeze," said his mother,*
> *"I will be a tightrope walker,*
> *and I will walk across the air to you." (Brown, 1972, excerpt from The Runaway Bunny)*

The visit has come to an end and Sherrie and I are ready to go. Erna is settled sitting comfortably on the couch, her infusion going. Everything is within reach on the coffee table right in front of her, the phone, a glass of juice, a few magazines, her pills, and the TV remote control. Erna and her home are also ready.

'So how's your clodronate?' - 'Oh, it's hurting a little bit; let's see how's it going? Oh, it's dripping; it's normal' - 'But it'll settle down a bit; you need to have a good, steamy movie on to take your mind off it' - 'I watch *"Who's the Boss?"* Are you going already? Sherrie see those oranges and apples there? You take one, whatever you like, orange or apple, and one for Anna' - 'Oh, wow! What would you like, Anna?' - 'Orange' - 'There are mandarin oranges or regular oranges' - 'The regular ones' - 'Can you catch?' - 'I think so!' - 'That's in case you get thirsty or whatever' - 'Thank you very much' - 'Is there anything you want to say before we go?' - 'Oh, no, no, I'm fine; I've asked all the questions; I've turned Sherrie's hair gray!' - 'Anyway, if you *did*, I would just go and get it dyed; get another dye job done' - 'I'll have to get mine done soon; I want to get myself a perm, and I'm deciding; there's a beauty shop in the lodge, and there's a beauty shop in the corner here. I keep asking some of the ladies which is better. Some go here, some go there' - 'You'll have to try them both out and decide which one you like' - 'Maybe I'll have no hair left by that time, who knows?'

In a cheerful manner, Erna expresses her concern to Sherrie about having turned her hair gray. She recognizes the intensity of her nurse's engagement. Sherrie's response to Erna reminds me of the story of *The Runaway Bunny* (Brown, 1972). To each of her son's proposals to run away from her, the bunny's mother gave him the most kind and loving response. Sherrie gives Erna a reassuring response, one that takes away any fears or concerns. What better answer than this? Her response embodies a deeply respectful sense of being human and humane. With the image of Erna in the beauty shop and a couple of nice oranges in our hands we go. Sherrie's hair did not turn gray in the end. If it did, we would have followed Erna's steps to the beauty shop and keep going. This is the beauty of nursing.

CHAPTER VIII: ONWARD THOUGHTS

> *Meaning does not have the sense of an answer, and not even of a question; in this sense, it has no meaning. But it is the event of an opening. It brings no salvation, but greets (calls) the to-come and the end-less. It does not gather community or bring about intimacy, but relentlessly exposes a common exteriority, a spacing, a coappearance of strangers. (Nancy, 1997a, p. 78)*

Bringing experience into a text without losing the lived-ness of its coming to presence in life has evoked an ongoing tension throughout this work. The weight of human experience is un-weighable. Nancy (1997a) evokes the close relation between thinking and weighing, "The act of thinking *is* an actual weighing; it is the very weighing of the world, of things, of the *real as meaning*" (p. 76). In showing thinking as weighing, Nancy evokes the inaccessibility of both the thought of weight and the weight of a thought. It is this inaccessibility that makes us think. We continuously weigh the weight of meaning. Yet as the weight of the heaviness of existence, meaning escapes appropriation. Meaning is thick, impenetrable, consistent, resistant, inappropriable. This *inappropriability* of meaning, of existence constitutes *"the weight of a thought"* (p. 80).

Brenda Cameron (2006) evokes this inappropriability of meaning as she writes about the unpresentable in nursing practices. She shows how difficult it is to bring the unpresentable to language. Recent world events and current economic trends in health care that view nursing as another commodity in the global market, Cameron writes, call us to turn to the unpresentable in nursing as well as to ponder (weigh) how our nursing discourse is responding to these unpresentable realities. She asks, "How do we bring to our presence these mostly unspeakable unpresentable things, these acts that defy any representations or any comforting means to be applied to them?" (p. 25). Like the weight of a thought (and the thought of weight), the unpresentable in nursing "*resists* representation" (p. 25, emphasis mine). Cameron urges us to hold the unpresentable in our midst. This is our ethical demand.

How to bring into text these weighty unpresentable things that come to be in the life of the nurse is a continuous challenge. We lack words to show their weight. Language irremediably fails us. Their weight is the weight of experience which constantly conceals reveals "the inappropriable gravity of meaning" (Nancy, 1997a, p. 82). The weight of experience forces us to admit that in trying to ponder it we always fall short of thoughts. We experience its resistance, its impenetrability, its thickness. Thought cannot apprehend it. It can only *endure* its own weight. Like the way nurses endure the unpresentable in their daily practices (Cameron, 2006). Like the way the very ill endure the unweighable (*impesable*) and unthinkable (*impensable*) weight of their experience. In nursing the very ill, nursing endures the weight of dying, together with the very ill. The weight of dying becomes lighter or heavier as it goes.

Throughout the inquiry, I have come to realize that the longer we try to appropriate the meaning of dying the more difficult the task becomes. The thought of dying is hard to appropriate, even in the very ill. It "pushes, presses heavily into the head and into the belly, throughout the whole body, with the force of a fall or a tearing" (Nancy, 1997a, p. 77). Just like the thought of dying young. One is always young when one dies. In their experience, the very ill show that we can never presume to appropriate dying. As they go through their experience, they conceal reveal this *inappropriability*, as April shows it. This is not to say that they forget or deny death. This is the last thing April wants to do. On the contrary, the knowledge of her coming death moves her to live well, fully, to immerse herself in life. Being respectful of the inappropriability of dying is about learning to follow the rhythm of the very ill as they go back and forth between the realization of their own dying and their deep desire to fully engage in life. Just like nurses do in their practices.

Some participants in this study died at a very young age. April is not yet fifty when she dies. Lorene in Chile dies at age thirty four. Unfortunately, having young patients in palliative care is not uncommon. These young deaths should also move health care professionals, policy makers, and the public here and in the developing world to interrogate the larger context where these deaths take place as well as to implement and endorse strong public health measures directed to cancer prevention. We still witness too many young deaths in the world. The weight of these "early and unjust deaths" (Gutiérrez, 2003) is hard on individuals, their families, communities, and their countries. We cannot remain indifferent before these young deaths. The need for stronger protective and preventive measures is urgent.

Poverty adds an extra weight to the experience of the very ill. As Don Pedro's experience shows, being poor makes it difficult to afford things that can bring necessary comfort to the sick such as proper housing, food, clean water, mobility-enhancing equipment, or at times medications not covered under the public health care system. Poverty reveals the "underside of modernity" (Dussel, 1996), its other face. The otherness of poverty is unpresentable. It "is what cannot become a content… it is uncontainable, it leads you beyond" (Levinas, 1985, pp. 86, 87). The "no-bread" (Dussel, p. 81) of poverty deepens the suffering of the very ill. *"I am hungry"* (Dussel, p. 35) is also the ethical claim of the very ill in the face of poverty.

Most participants in this study were mothers. Bergum (1997) writes that mothers evoke a shift "toward thinking of the other person as well as oneself—the move from *me, me, me* to *us*" (p. 133). In their experience of being very ill, mothers too continue to enact this move. Magdalena worries constantly for her youngest faithful son after she dies. Joan suffers not knowing what will happen to her young daughter who lives in a group home after her death. Rose mourns the early death of her son and cries for her remaining daughters at the thought of leaving them. Like these mothers, very ill mothers suffer enormously as they anticipate their absence in the lives of their children in the near future. The African saying goes, "A human being is a human being is a human being, simply by being a human being" (Tangwa, 2000, p. 39). Following the saying we say, mothers are mothers are mothers, simply by being mothers; to the end. The thought of dying tightens a mother's heart. It evokes distance, "an incalculable distance/that cannot be measured in hours or in inches/nor miles, semesters, or sizes..." (Benedetti, 2002, p.62).

There were also fathers in the study. "The sound of a man crying the knowledge of his death" (Laurence, 1988, p. 471) is barely audible. Don Pedro suffers for his daughter and grandchild. Being unable to provide mortifies him. He has been father and mother to her. He carries this weight alone. There is no mother here. Don Leo is a father of three. He misses the ones living abroad. Their absence weighs on him. His wife takes care of him, day after day. She comforts him with love. Mr. Kim is a father of three daughters. His wife is his oxygen to him. His breathing is even harder when she is away. One of his granddaughters is pregnant. She will give birth to his first great grandchild. He doesn't live to hold the baby girl in his hands.

Throughout the inquiry, the home revealed itself as an integral element to the experience of the very ill. Indeed, the garment of the home sustains the very ill as they go through their experience. It cloaks them as they go. Losing the garment of their home was a very difficult experience for participants in this study. They felt bereft. Even though those who were admitted to a palliative care facility felt comfortable there, they missed the space of their homes. The home revealed itself as the hearth of the very ill, el *hogar*; the place where they thrive. The hearth is "a world in which being is not given but rather emerges over time" (Merleau-Ponty, 1948/2004, p. 54). It is flesh (Merleau-Ponty, 1968). Like the kitchen, the hearth of the home attracts us to its centre. Inside this garment, the very ill experience a deep sense of protection. Even the tiniest garment like Don Pedro's embodies this sense. Being in one's home strengthens the very ill in their experience. It fortifies their integrity.

The utilization of tools in palliative care practice while beneficial to practitioners in the assessment of symptoms has also potential to be on occasions detrimental to the very ill or the health care professional's relation with the very ill. When applied in every particular situation regardless of context, the utilization of measurement tools with the very ill can impose another burden to the experience of these patients for whom at times "even doing the ESAS is too much," as one of the nurses in the study expressed. Also, tools can bring about a revealing that is disabling for the very ill as they evoke elements of their experience that they do not necessarily want to revisit in a particular moment. In this sense, tools can disable forgetting. They force the very ill to remain in illness. We need to enable the very ill to forget, to reveal conceal as they go.

In their practices in the home, nurses show a very patient- and context-sensitive manner of enacting the tools. As revealed throughout this text, in their nursing assessments nurses have the ability to transform the questions of the tools into questions that enhance the nursing dialogue with the very ill as well as their clinical understanding of the patient's situation in a particular moment. In the home, nurses evoke a way of applying these scales in a manner that is not disruptive of the moment. They enact the tool in a very respectful and judicious manner that takes into consideration other elements of the patient's experience also present in the moment. In the home, nurses show an exquisite ability to insert the tools within their dialogue with the very ill.

The *no-further-recall* policy at the cancer institution added a heavy weight to the experience of most patients in this research study. On the patient's side, being classified as *no further recall* feels like entering a dead-end road, like hearing "There is nothing to be done" (Saunders, 1984). It evokes pain, anger, powerlessness, sadness, hopelessness. These emotions weigh on the very ill and on their nurses in the home. *No further recall* is disruptive of relation. It makes no sense to an individual who *still* has the cancer inside. The *No further recall* policy in the context of palliative patients unresponsive to cancer treatments needs to be revisited. A more flexible policy which takes into account the shortage of resources as well as the patient's experience would ease the passage from curative to palliative. The thought of being fully and only palliative is hard to bear. We are never ready.

On the other side, recommending cancer treatments to individuals with little or no chances of recovery can be very harmful. In developing countries, unscrupulous specialists in the private sector often take advantage of the situation of the terminally ill and their families by offering expensive cancer treatments that only bring disastrous financial, personal, and familial consequences. In affluent countries, the excessive number of research trials targeting the very ill is a matter for ethical concern. While it is important to be able to participate in these kinds of research studies, patients should also be fully enabled to weigh the desirable and undesirable consequences that enrolling in a research trial would entail. Undesirable effects can be quite taxing on the very ill. They often rob the very ill of precious time (and of resources that at least in the developing world many do not have).

Medical researchers should consider the overall impact of their research trials on individuals in the palliative stage. Oncologists and specialists hold an ethical responsibility before the very ill and their families at the time of suggesting a research trial or a cancer treatment that has little potential to do any good. In virtue of their expertise and knowledge, oncologists should provide honest, informed, and comprehensive advice to patients and assist them as they make their decision. Specialists cannot send patients home to make their choices on their own. The patient's best interest should always guide these treatment decisions. Covert research or profit interests have an alarming potential to be harmful to the very ill. Taking advantage of the extreme vulnerability of the very ill and their human and legitimate desire to live is an ethical scandal.

The cost of medications in the context of palliative care evoked rich discussions in this study. Nurses and patients often talked about the excessive cost of drugs. While in Edmonton palliative patients are entitled to a palliative drug coverage plan, they expressed their awareness that others in the city, the country and the world would be simply unable to afford the high cost of these drugs. Also, viewed from a global perspective, the high amount of resources spent on drugs in affluent settings contributes to increase local and global inequities. Pharmaceutical companies' thirst for profit can know no limits. Health care professionals in the developing world are showing that good palliative care can be at work with low cost medications and little technological support. In contrast to expensive long acting brand-name drugs, morphine powder alone is already making a difference in the lives of many in low resource settings. An over reliance on diagnostic technologies can also affect the experience of the very ill. Long waiting lists and the high cost of these technologies both in Canada and the developing world can make timely access very difficult and in turn delay proper relief.

Even though in Chile there are limitations in terms of palliative care resources, the support Don Pedro receives in his home from his community health care centre enables him to stay home to the end. The generous commitment of his physician to his well being also makes his experience less harsh. Even though she has little, she is able to creatively lighten Don Pedro's experience making his situation a little more bearable. She offers Don Pedro a garment that guards him as he goes. The support of family, friends, and neighbours can also make a big difference in the experience of the very ill both in Canada and Chile. Loneliness is difficult to bear when one is very ill. Before the face of the very ill, the public cannot "simply remain there, contemplating it" (Levinas, 1985, pp. 88, 89). We must respond, act, be there.

Scarcity of resources should not be an obstacle to reach good pain and symptom relief. We must take action to develop and strengthen initiatives to ensure access to palliative care services to everyone in Canada and developing countries. This also includes reaching individuals with late-stage illnesses other than cancer. These continue to be marginalised in the world of palliative care. "We as nurses must struggle to see these differences" (Hall, 2004, p. 42) and bring these people into our discourse and action. Ensuring access to both continued palliative care training for health care professionals working with marginalised communities and basic medications for symptom relief is urgent. We must envision and implement inexpensive home-based modes of palliative care delivery. Palliative care cannot remain the luxury of a few. This calls our ethics into question. It demands immediate action.

We must revisit palliative care practices that have potential to rend the fabric of nursing practices and the very ill. We need to deeply understand what happens to the very ill when we tear their garment. Research trials, tools, technology, no further recall policies, insensitive interactions, profit agendas have all potential to make holes in this garment. Tearing the garment is disruptive of the experience of the very ill. We need to continuously interrogate our practices and bring our attention back to the originary mandate of palliative care, to relieve suffering. This is our ethical mandate. In the home, nurses often bear witness to the holes health care practices make in the garment of the very ill. Nurses are constantly sewing up these holes; weaving their "text with the text of the unpresentable" (Cameron, 2006, p. 34). Through this weaving they enable the very ill to regain their wholeness, to re-cover their integrity. Nurses know the garment of the very ill cannot hold a weighty hole. They lighten the weight again and again.

The support of the palliative home care team to nurses and team colleagues from other disciplines was always recognized as extraordinary. Indeed, nurses often expressed they felt invigorated and renewed as members of this team. How the team enhanced nursing practices in the home was palpable during coffee time, their weekly team meetings, their ongoing conversations with one another as well as during home visits where nurses put immediately to practice ideas and suggestions coming from the team. The support team members offered to one another on this team and their high level of expertise were among the most vital ingredients to enacting best practices in the home. While the team as a whole was not part of this study their openness and engagement with the research and the research questions enhanced the being of the inquiry to an incredible extent.

While my stance before qualitative research studies that generate categorizations of the experience of the very ill is perhaps too critical, I need to recognize that the growing interest in qualitative research in palliative care is showing recognition of the need for approaches that are more context-sensitive in this field. It also shows a serious commitment to bring the complexity of the patient's experience to the fore. In practice, nurses and other health care professionals are often appreciative of studies that show another side of the patient's experience. In general they appreciate the contributions of emerging models and categories that have a direct applicability into their practice. They also often express their great appreciation for studies that remain close to the language of the world of practice.

In this research study, interpretive inquiry showed itself as a fecund and fruitful research approach in understanding nursing practices and the experience of the very ill in the home. Throughout the inquiry, nurses and other team members saw in this research approach a respectful and sensitive way to engage with the very ill in the home. They also often expressed their appreciation for the attentiveness to the complexity of their practices that they sensed as the inquiry took place. Following the tradition of interpretive inquiry was integral to bringing this inquiry to fruition as well as to remain faithful to the experiences of nurses and the very ill in the home. Just like nurses are as they nurse the very ill in the home.

PERFORMING NURSING IN THE HOME

Nurses perform nursing wherever they go. They embody the drama of nursing. Cameron (1998) evokes the nurse's ability to perform nursing in lived life. Just like a musician who is able to play an instrument and perform before others in a very distinctive manner unique to this musician, Cameron writes, so does the nurse perform nursing in a way that is "unique to the particular nurse, the particular person, the particular nursing event required" (pp. 266, 267). In performing nursing, she writes, the nurse is able to put together embodied knowledge, expertise, and skills with her own nursing qualities. In the daily world of practice, the nurse enacts the lived-ness of nursing. She brings forth nursing. She "(re)presents" it for us (Cameron, 2006).

In the home, the nurse performs nursing in a way that is unique to this particular individual, this family, and this home. Her performance is private and yet public; her audience small and yet multitudinous. Like an actor's performance in a play, the nurse's performance involves a nursing attentiveness to the many texts present in the home. She has the ability to read the existing and emerging scripts so to speak. She blends the standard scripts of practice with those that come to presence in the moment. As she reads and acts, her nursing script transpires. She has the ability to reweave these scripts together into an irreplaceable and unrepeatable one. As she performs, she weaves a garment (a fabric, a text) that fits the "unique nonrepeatable properties" (Nussbaum, 1990, p. 320) of this home. She creates a nursing garment that holds the experience of the very ill.

In performing nursing, nurses bring nursing to life in the home. Gadamer (1989) writes that the work of a play comes to existence as it presents itself to others. The play is a bringing forth, a presentation where text, actors, and spectators themselves all come together. The performance of the play, Gadamer says, is as integral to the play as the play itself. In understanding how nurses practice nursing in the home, we can say that just as the play "cannot simply be isolated from the 'contingency' of the chance conditions in which it appears" (Gadamer, 1989, p. 116) so cannot nursing be severed from what is going on in the moment. Here as the nurse acts, "suddenly the gesture itself is nursing itself, wholly there, wholly present" (Cameron, 1998, p. 267).

Performing nursing in the home is never following "a mere schema of rules or prescribed approaches" (Gadamer, 1989, p. 116). This is destructive of the drama of nursing. Performing nursing is the reweaving of a garment that holds the very ill in their wholeness. The home becomes a stage where nurses are able to act. On this stage, the nurse puts on the home like a garment and acts. She has an ability to let go other garments. She lets the unpresentable garment direct her performance. She lets it reveal conceal itself without transforming it into a set of prescribed technologies. She does not appropriate this garment. She knows it is "*inappropriable*" (Nancy, 1997a, p. 80). On stage, she doesn't ponder the weight dying. She already knows its weight. Rather, she weighs the weight of life. In the home she nurses the labour of life.

HOLDING THE FACE

> *What better example of the play of concealment and un-concealment, of closure and dis-closure, than the play of the face? It conceals what we want to hide and un-conceals what we were trying to keep under wraps. (Caputo, 1987, p. 273)*

The face exposes itself to the world "without defense" (Levinas, 1985, p. 86). It leaves *us* without defense. The face holds us. The nearness of the face of another human being brings us back to life. It roots us in the moment (Cameron, 2004). The face is a showing, an epiphany of humanness that exceeds meaning. Looking at the face we learn to recognize the vulnerability that makes us equals. Holding the face of another human being we are present to our vulnerability in a way that cannot be forgotten or resisted. In holding the face we are in solidarity with one another. We are in solidarity with the fragility of being human.

> I had a very young patient once, Sherrie tells me. She was nineteen, a little Vietnamese girl. All she wanted to do was go back to Math class. Her family doctor had me in tears. We were both in her home at the same time and she says, 'I just want to get better. I just want to go back to school. I want to go to my Math class.' He sits down in her bed, takes this little girl's face, cupping her face in his hands, and says, 'I'm sorry, I can't make you well.' He was teary, I was teary. We had children her age. He was so tender and gentle with her. She died a few weeks after that. Nineteen was she.

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APPENDIX ONE: LETTERS OF INFORMATION

INFORMATION LETTER FOR PALLIATIVE HOME CARE NURSES IN CANADA

Title of Study	**In Dialogue with the Very Ill: Towards Understanding Their Experience**	
Investigators	Anna Santos Salas, RN, MN Doctoral Candidate Faculty of Nursing University of Alberta Phone: 492-8185	Brenda L. Cameron, RN, PhD Doctoral Supervisor Associate Professor Faculty of Nursing University of Alberta Phone: 492-6412

Purpose of the Study

The purpose of this study is to increase our understanding of persons' experience of serious illness. A related aim is to understand how nurses participate in the care of the very ill. This study is part of doctoral studies in the Faculty of Nursing at the University of Alberta.

Background to the Study

To date, there are a significant number of studies about the nature of advanced cancer. These studies have facilitated the provision of treatment to the very ill. Yet we still know very little about people's experiences from their perspectives. This knowledge will assist us to further develop palliative care practices that respond to people's priorities during this time of their lives. Because of their close relation to the very ill, palliative care nurses may contribute in a unique and meaningful way to deepen our understanding of persons' experience of progressive illness.

Procedures

Your being in this study will involve

1. Being accompanied by Anna Santos Salas on your visits to patients who have consented to the study. Anna will keep notes from these visits. These will not exceed three.
2. Being observed by Anna during your visits to patients' homes. The number of visits will be decided in dialogue with you and the patient. Anna will negotiate the observation times with you in terms of what is most convenient and appropriate for you and your patients.
3. Voluntarily participating in audio-taped conversations with Anna. During these conversations, Anna will invite you to describe your experience of taking care of persons who are very ill and perhaps of nursing a particular person. Anna will ask you the following questions:
    a) What is it like to nurse persons who are very ill?
    b) Can you describe your experience with persons who are very ill?
    c) What is it like to care for this particular person?

    You may answer these questions in any manner that you like. These conversations will take place while Anna accompanies you on your visits to the home.
4. A request to voluntarily participate in one conversation with Anna and patients from the study to discuss interpretations of the findings. This conversation will last approximately 45 minutes to one hour.

Voluntary Participation

Benefits: There are no anticipated direct benefits to participants in the study. However, through conversations about your nursing experience you may gain further insight about your relation with the very ill. We also sincerely hope that the results of this study will enhance nursing and palliative care practices with the very ill.

Risks: Being in this study is your choice. There are no known risks. At any time during the observation period if you or the patient decide that Anna should leave, she will comply. Respect for patients' and your privacy will be our priority. You may request at any time no tape recording of the conversations or no field notes from the observation periods.

Confidentiality and anonymity: All information will be held private, except when professional codes of ethics or the law requires reporting. We will keep tapes and written material resulting from conversations and observations in a locked filing cabinet. Only Anna's doctoral supervisor, her supervisory committee, and herself will have access to these data. A typist will have temporary access to the tapes. We will delete your name from all the records. We will assign a number to each tape, transcript, and to any other material that results from your participation in this study. We will keep the tapes and consent forms for at least five years after the study is completed. Consent forms will be stored separate from the tapes.

Given that palliative home care nurses are not a large group in Edmonton, we cannot guarantee full anonymity. Steps to safeguard anonymity will be taken. Research findings may not relate to one particular nurse but to a number of them. As well, some of the data collected with participants may not be used for this study.

Freedom to withdraw: Even if you enter the study, you do not have to answer any questions or discuss any subject in the conversations if you do not want to. You may withdraw from the study at any time by telling the researcher. Taking part in this study or dropping out will not affect your status within palliative home care and will not be communicated to your superior.

Future use of data: We may report findings from this study in conferences or published material. Your name will not appear in any report. We may also use information collected in this study in future studies. Before doing so, we will request permission from the appropriate ethics committee.

Additional contacts: Should you have any questions about this study, you can contact Anna Santos Salas (492-8185) or Dr Brenda Cameron (492-6412). If you have any concerns about the research, you may also contact Dr Jane Drummond, Associate Dean of Research, Faculty of Nursing at 492-6410.

If you agree to take part in this study, please contact Anna Santos Salas at (780) 492-8185 at your earliest convenience.

INFORMATION LETTER FOR PERSONS RECEIVING PALLIATIVE HOME CARE IN CANADA

Title of Study **In Dialogue with the Very Ill: Towards Understanding Their Experience**

Investigators	Anna Santos Salas, RN, MN Doctoral Candidate Faculty of Nursing University of Alberta Phone: 492-8185	Brenda L. Cameron, RN, PhD Doctoral Supervisor Associate Professor Faculty of Nursing University of Alberta Phone: 492-6412

Purpose of the Study

Our purpose is to understand what it is like for you to be very ill. This study is part of doctoral work in the Faculty of Nursing at the University of Alberta.

Background to the Study

Many studies about cancer have been conducted. These have helped improve treatment for the very ill. Yet we still know little about how people experience their illness. This knowledge will assist us to provide better care for the very ill.

Procedures

1) You will take part in conversations with Anna Santos Salas. She will invite you to talk about your experience of being ill. You may wish to talk about a particular experience you have had. Anna will ask you the following questions:
   a) How do you experience your illness at this moment?
   b) What is it like to be at home when you are very ill?
   c) How have others in your life responded to your experience?

   The conversations will last about 45 minutes to one hour. They will take place as often and for as long as you wish. The number of these will not exceed four. Anna will meet you in your home or in a place of your convenience at a time that is good for you. Conversations will be audio-taped and typed.
2) Anna will accompany your nurse on some of her visits. These will not exceed three. This will take place at a time convenient for you and the nurse. Anna will make notes about these visits.
3) Should you be admitted to a hospital, with your consent, Anna will visit you there.
4) Anna may invite you and your nurse to talk about the study findings. This conversation will last about 45 minutes to one hour. This conversation will be audio-taped and typed.
5) With your consent, we may access your chart. We will do so only if we need to clarify the drugs that you are currently receiving.
6) Should any of your family members express their desire to participate in your conversations with the researcher, they will be requested to sign the form at the end of the consent form attached to this letter. They can only participate if you agree.

Voluntary Participation

Benefits: This study may be of no benefit for you. However, through conversations you may gain new insights about your illness. We also hope that the results of this study will assist us to give better care to the very ill.

Risks: Being in this study is your choice. There are no known risks. At any time during the study if you or the nurse need privacy, Anna will leave the room. Respect for your privacy will be our priority at all times. You may request at any time no tape recording of the conversations or no notes from observation periods. This study will not interfere at any time with your treatment. Should you become distressed during a conversation with the researcher, tape-recording will stop. The researcher will stay with you until you feel comfortable. If necessary, your home care nurse will be contacted for further assistance with your permission.

Confidentiality and anonymity: All information will be held private, except when professional codes of ethics or the law requires reporting. We will keep tapes and written material from the study in a locked filing cabinet. Only Anna's supervisor, her committee, and herself will have access to these data. A typist will have temporary access to the tapes. We will delete your name from all the records. We will assign a number to each tape, transcript, and to any other material that results from your participation in this study. We will keep the tapes for at least five years after the study is completed. Consent forms will be stored separate from the tapes. We will keep consents for at least five years.

Freedom to withdraw: In the conversations, you do not have to answer any questions or discuss any subject if you do not want to. You may withdraw from the study at any time. Taking part in this study or dropping out will not affect your care in any way.

Future use of data: We may present findings from this study in conferences. We may also publish some of the findings. Your name will not appear in any report. Information collected in this study may be used in future studies. If so, we will request permission from an ethics committee.

Additional contacts: For additional information, you can contact Anna Santos Salas (492-8185) or Dr Brenda Cameron (492-6412). If you have any concerns, you can contact the Patient Concerns Office of the Capital Health Authority at 407-1040. You may also contact Dr Jane Drummond, Associate Dean of Research, Faculty of Nursing, at 492-6410.

If you agree to take part in this study, please sign the consent form attached to this letter.

INFORMATION LETTER FOR PRIMARY HEALTH CARE PROFESSIONALS IN CHILE

Información Sobre el Estudio para Enfermeras u Otros Profesionales

Título del Estudio **Conversando con personas en cuidados paliativos: Hacia un entendimiento de su experiencia**

Investigadoras	Anna Santos Salas, EU, ME Candidata Doctoral Facultad de Enfermería Universidad de Alberta Edmonton, Alberta, Canadá Teléfono (Concepción): 204823	Brenda L. Cameron, RN, PhD Doctoral Supervisor Profesora Asociada Facultad de Enfermería Universidad de Alberta Edmonton, Alberta, Canadá Teléfono: 204823

Introducción

Hoy en día se cuenta con un número importante de estudios sobre la naturaleza del cáncer. Estos estudios han permitido mejorar la atención de cuidados paliativos a personas con cáncer. Información sobre la perspectiva de los enfermos, sin embargo, es relativamente escasa. Esta información nos permitirá a futuro continuar desarrollando los cuidados paliativos en Chile así como también responder a las prioridades de los enfermos durante este tiempo. Dado que la enfermera y otros profesionales de la salud juegan un papel importante en el trabajo con enfermos en cuidados paliativos, su participación en este estudio constituye un aporte significativo a nuestro entendimiento de esta experiencia.

Objetivos

El objetivo de este estudio es comprender la experiencia personal de vivir con un cáncer en fase avanzada. Un objetivo adicional es comprender como las enfermeras y otros profesionales de la salud participan en el cuidado de los enfermos que reciben cuidados paliativos. Este estudio forma parte de los estudios de doctorado de Anna Santos Salas en la Facultad de Enfermería de la Universidad de Alberta en Edmonton, Canadá.

Actividades

Su participación en este estudio comprenderá

1. Ser acompañada por Anna Santos Salas en sus visitas a domicilio a enfermos que han aceptado participar en el estudio. El número de visitas será decidido en acuerdo con Ud. y los pacientes que participen en el estudio. El tiempo y la duración de cada visita se planificará de acuerdo a lo que sea más conveniente para Ud. y los enfermos. Anna observará su interacción con los enfermos durante estas visitas y tomará notas sobre estas observaciones.
2. Participación voluntaria en conversaciones con Anna. Con su consentimiento estas conversaciones serán grabadas. En estas conversaciones, Anna le invitará a describir su experiencia con personas en cuidados paliativos y tal vez con alguna persona en particular. Anna le hará las siguientes preguntas:

   ¿Cómo describiría su experiencia con enfermos en cuidados paliativos?
   ¿Cuáles han sido algunos de los obstáculos para entregar cuidados paliativos?

   Ud. puede responder a estas preguntas de la manera que Ud. estime conveniente. No existe una respuesta ideal. Estas conversaciones tomarán lugar durante sus visitas a domicilio con Anna o en el momento que Ud. estime conveniente.

3. Participación voluntaria en una conversación con Anna y un(a) paciente para conversar sobre los hallazgos del estudio. Esta conversación tomará aproximadamente entre 45 minutos y una hora.

Participación Voluntaria

Beneficios: Este estudio no ofrece ningún beneficio directo a quienes deseen participar en él. Sin embargo, conversar sobre su experiencia con enfermos de cuidados paliativos puede significar un nuevo aporte a su práctica profesional. Es también nuestro deseo que los resultados de este estudio contribuyan a la práctica de enfermería y de los cuidados paliativos en Chile.

Riesgos: La decisión de participar o no en este estudio es completamente personal. Su participación no involucra ningún riesgo conocido. Durante los periodos de observación, si Ud. o los pacientes lo estiman conveniente, Anna no participará en la visita. Respeto por la privacidad de los enfermos y la suya propia constituirá nuestra prioridad en todo momento. Ud. también puede solicitar que Anna no utilice la grabadora o no tome notas sobre la visita a domicilio.

Confidencialidad y anonimato: Toda la información recolectada en este estudio será considerada confidencial, excepto en los casos en que de acuerdo a los códigos de ética o la ley sea necesario proporcionarla a las autoridades correspondientes. Todos los cassettes y el material escrito proveniente de este estudio serán mantenidos con llave. Las únicas personas que tendrán acceso a este material son Anna, su profesora guía y su comité de doctorado. La persona que transcriba los cassettes tendrá acceso transitorio a este material. Su nombre será borrado de todos los registros relacionados con este estudio. Un numero será asignado a cada cassette, transcripción y cualquier tipo de material que resulte de su participación en este estudio. Los cassettes y consentimientos serán conservados por al menos 5 años luego que el estudio haya finalizado. Los consentimientos serán guardados en un lugar distinto al de los cassettes.

Dado que el número de profesionales de la salud que trabaja en cuidados paliativos en Concepción no es grande, no nos es posible garantizar totalmente el anonimato. Para cautelar el anonimato, los resultados del estudio no se relacionarán con una persona en particular sino con un número de ellas. Asimismo, parte de los datos recolectados en este estudio pueden no ser utilizados para esta investigación.

Libertad para retirarse del estudio: Su participación en este estudio es completamente voluntaria. Ud. no está obligado a responder a todas las preguntas o a conversar sobre temas que no desea abordar. Ud. puede retirarse del estudio en cualquier momento que estime conveniente. Su participación en este estudio o su retiro voluntario no afectarán su cargo profesional de ninguna manera y no será informado a su jefe correspondiente.

Uso futuro de los datos: Los hallazgos de este estudio serán presentados en congresos o publicaciones. Su nombre no será informado en ningún caso. Información recolectada en este estudio puede ser utilizada en futuros estudios. Para este efecto de solicitará nuevamente la aprobación del comité de ética que corresponda.

Otros contactos: Si Ud. tiene alguna consulta sobre este estudio, por favor llame a Anna Santos Salas al número 204823. Si Ud. tiene alguna duda o queja sobre este estudio, llame al 364823.

Si Ud. acepta participar en este estudio por favor llame a Anna Santos Salas al 204823 en el momento que estime conveniente.

INFORMATION LETTER FOR PERSONS RECEIVING PALLIATIVE CARE IN CHILE

Información Sobre el Estudio para Personas en Cuidados Paliativos

Título del Estudio	**Conversando con personas en cuidados paliativos: Hacia un entendimiento de su experiencia**

Investigadoras	Anna Santos Salas, EU, ME Candidata Doctoral Facultad de Enfermería Universidad de Alberta Edmonton, Alberta, Canadá Teléfono (Concepción): 204823	Brenda L. Cameron, RN, PhD Doctoral Supervisor Profesora Asociada Facultad de Enfermería Universidad de Alberta Edmonton, Alberta, Canadá Teléfono: 204823

Introducción

Hoy en día se cuenta con un número importante de estudios de investigación los cuales han permitido desarrollar y mejorar la atención de cuidados paliativos. Información sobre la perspectiva de los enfermos, sin embargo, es relativamente escasa. Esta información nos permitirá a futuro continuar desarrollando los cuidados paliativos en Chile así como también responder a las prioridades de los enfermos durante este tiempo.

Objetivos

El objetivo de este estudio es comprender su experiencia personal de vivir con una enfermedad avanzada. Este estudio forma parte de los estudios de doctorado de Anna Santos Salas en la Facultad de Enfermería de la Universidad de Alberta en Edmonton, Canadá.

Actividades

Su participación en este estudio comprenderá

1. Permitir que Anna Santos Salas acompañe su enfermera en algunas de las visitas a su domicilio. El número de visitas será decidido con Ud. y su enfermera. El tiempo y la duración de cada visita se planificará de acuerdo a lo que sea más conveniente para Ud. y su enfermera. Anna tomará notas sobre su interacción con la enfermera durante estas visitas.

2. Participación voluntaria en conversaciones con Anna. En estas conversaciones, Anna le invitará a describir su experiencia durante este tiempo. Ud. puede desear hablar sobre algún momento en particular. Anna le hará las siguientes preguntas:
    a) ¿Cómo ha sido su experiencia durante este tiempo?
    b) ¿Qué ha significado el estar enferma(o) en la casa?
    c) ¿Cómo han respondido otras personas a su experiencia?

    Cada conversación durará aproximadamente 45 minutos. Si Ud. lo permite, las conversaciones con Anna serán grabadas y posteriormente tipeadas.

3. En caso que Ud. sea admitido a algún hospital, si Ud. lo permite Anna le visitará en ese hospital.
4. Participación voluntaria en una conversación con Anna y su enfermera para conversar sobre los hallazgos del estudio. Esta conversación tomará aproximadamente 45 minutos.

5. Con su consentimiento, Anna revisará su ficha clínica en el consultorio sólo en caso que se necesite información sobre el tratamiento que Ud. recibe actualmente.
6. Si alguno de sus familiares desea participar en las conversaciones que Ud. tendrá con Anna, se les solicitará su consentimiento para participar en el estudio.

Participación Voluntaria

Beneficios: Este estudio no ofrece ningún beneficio directo a quienes deseen participar en él. Sin embargo, el conversar sobre su experiencia puede ofrecer un nuevo entendimiento sobre su enfermedad. Es también nuestro deseo que los resultados de este estudio contribuyan a la práctica de enfermería y de los cuidados paliativos en Chile.

Riesgos: La decisión de participar o no en este estudio es completamente personal. Su participación no involucra ningún riesgo conocido. Durante los períodos en que Anna acompañe su enfermera, si Ud. o ella lo estiman conveniente, Anna no participará en la visita. Respeto por su privacidad constituirá nuestra prioridad en todo momento. Ud. también puede solicitar que Anna no utilice la grabadora o que no tome notas de la visita a domicilio. Este estudio no interferirá de ninguna manera con sus tratamientos. En caso que Ud. experimentara algún malestar físico o emocional, Anna detendrá la entrevista. Anna permanecerá con Ud. hasta que Ud. se sienta mejor. Con su autorización, Anna contactará su enfermera si se necesitara mayor asistencia.

Confidencialidad y anonimato: Toda la información recolectada en este estudio será considerada confidencial, excepto en los casos en que de acuerdo a los códigos de ética o la ley sea necesario proporcionarla a las autoridades correspondientes. Todos los cassettes y el material escrito proveniente de este estudio serán mantenidos con llave. Las únicas personas que tendrán acceso a este material son Anna, su profesora guía y su comité de doctorado. La persona que tipee los cassettes tendrá acceso transitorio a este material. Su nombre será borrado de todos los registros relacionados con este estudio. Un número será asignado a cada cassette, texto y a cualquier tipo de material que resulte de su participación en este estudio. Los cassettes y consentimientos serán conservados por al menos 5 años luego que el estudio haya finalizado. Los consentimientos serán guardados en un lugar distinto al de los cassettes.

Libertad para retirarse del estudio: Su participación en este estudio es completamente voluntaria. Ud. no está obligado a conversar sobre temas que no desea abordar. Ud. puede retirarse del estudio en cualquier momento que estime conveniente. Su participación en este estudio o su retiro voluntario no afectarán su tratamiento de ninguna manera.

Uso futuro de los datos: Los hallazgos de este estudio serán presentados en congresos o publicaciones. Su nombre no será informado en ningún caso. Información recolectada en este estudio puede ser utilizada en futuros estudios. Para este efecto se solicitará nuevamente la aprobación del comité de ética que corresponda.

Otros contactos: Si Ud. tiene alguna consulta sobre este estudio, por favor llame a Anna Santos Salas al número 204823. Si Ud. tiene alguna duda o queja sobre este estudio puede llamar al 364823.

Si Ud. acepta participar en este estudio, por favor complete el consentimiento que se adjunta a esta hoja.

CONSENT FORM TO ENTER THE HOME OF PERSONS RECEIVING PALLIATIVE HOME CARE DURING INITIAL PARTICIPANT OBSERVATION PERIOD IN CANADA

Title of Study	**In Dialogue with the Very Ill: Towards Understanding Their Experience**	
Investigators	Anna Santos Salas, RN, MN Doctoral Candidate Faculty of Nursing University of Alberta Phone: 492-8185	Brenda L. Cameron, RN, PhD Doctoral Supervisor Associate Professor Faculty of Nursing University of Alberta Phone: 492-6412

This letter is to request your consent for Anna Santos Salas to enter your home. Anna is beginning a study with persons in palliative care and their home care nurses. The purpose of this study is to increase our understanding of persons' experience of serious illness. A related aim is to understand how nurses participate in the care of the very ill. This study is part of doctoral studies in the Faculty of Nursing at the University of Alberta.

The first part of this study involves Anna's accompanying a home care nurse on her visits to people's homes for a two week period. The purpose of this time is to observe palliative home care nursing in practice. During this time, Anna will observe the home care nurse on her visits to people's homes. Anna will keep notes from these visits.

If you consent for Anna to accompany your home care nurse to your home, Anna will observe the nurse's interactions with you during her visit. Anna will keep notes of the nurse's activities during her visit. She may also keep notes of your involvement with the nurse during her visit. Your identity will not appear on any records. You may request that while Anna is in your home, no notes be taken from your interaction with the nurse.

You are free to refuse this request. Doing so will not affect your care in any way. You may also agree to be contacted in the future to take part in this study.

I hereby give permission for Anna Santos Salas to accompany my home care nurse on her visits to my home during the initial participant observation period of this study.

Patient's Signature	**Date**	**Signature of Witness**
Print name		**Print name**