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A Narrative Inquiry into the Experience of Women Seeking Professional Help with Severe Chronic Migraines

by

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TO

MOM AND DAD

WHO NURTURED AN INQUIRING MIND AND

WHO ENCOURAGED ME TO BE THE BEST I COULD BE

AND

TO MY HUSBAND GORDON

WHOSE LOVE AND FAITH IN ME SAW ME THROUGH TO THE END

Abstract

This narrative inquiry into the experiences of women seeking professional help with severe chronic migraines, helps us understand how suffering, disability, and illness influenced the timing and process of deciding to seek help, the choices made about where to turn for help, and the dynamics of nurse/person encounters. In the inquiry, understandings of seeking help with migraines grew as three women who suffered from migraines, two nurses and the researcher traced the pattern of social interaction of each woman from family to work to broader social context. Migraine is a social illness, difficult to live through without involving others because it often affects socially prescribed roles. The wider the circle of contacts and responsibilities, the more potential there is for impact on relationships and social roles. Looking in the opposite direction, the social narratives of culture, institutions, and families that surround the individual often dictate how illness is viewed and how migraine in particular is viewed and treated. The stories in this study revealed the private, personal side of migraines, the existential moments of pain and despair seldom shared and rarely seen. The women experienced the loneliness of suffering, the alienation of stigma and labeling, the fear of uncertainty, and the burden of chronicity. Side by side was the hope that they would not need outside help, that there would not be another headache, that people would not notice their pain, that people would notice they were in pain and would offer help. Family experience with migraines proved to be helpful to nurses in their work with women with migraines at both an evidence based and an intuitive level and in understanding the larger social issues that influence formal policies and procedures. The evocative nature of the stories and representations in this narrative inquiry illuminate the dynamics of nurse/person

interactions and the importance of recognizing the ethics of how we as a society care for our vulnerable members. As the layers of knowing that lead to meaningfulness in life are uncovered, there is potential for developing an ontological and epistemological basis for the process of seeking help.

Acknowledgement

I am indebt to many who contributed to the development of this dissertation. I would like to acknowledge the wonderful contribution of the women who participated in this study by sharing their life stories. Their experiential knowledge will be invaluable to others attempting to understand severe migraine headaches and the process of seeking help. My sincere thanks go out to my co-supervisors Dr. Brenda Cameron and Dr. Jean Clandinin whose wise counsel and regular input and encouragement kept me going and provided much needed direction. These are very wise women and it has been an honour to work with both of them.

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Chapter I Introduction to the Study

Nursing theories and conceptual models assist in defining the scope of nursing practice, or the theoretical enterprise of nursing, but it is in the art or practice of nursing where boundaries and obligations of relationships and ethical practice challenge and confound us. This is especially true when nurses face the intricacies of engaging in a shared discourse with those who seek help. Within individual's stories, lay the many "truths" and the depths of experience of individuals' who live with varying complexities of chronic illness and health over time. Within the context of nurse/person interactions, nurse researchers can be privy to the challenges faced by those seeking and those providing professional help. Here nurse researchers can also find evidence of the overall level of success of nurses, in understanding the experience of individuals living through illness over time, and nursing's success in recognizing and addressing suffering. The most common raison d'être for there being a discipline of nursing is that there are always vulnerable members in society who can benefit from nursing care. By placing nursing knowledge and understanding of help-seeking encounters, within a broader understanding of life stories, and merging this with nurse's understanding of relational ethics and the impact of illness, I believe there is potential for redefining how nurses understand and engage with those who seek their help.

Nursing practice is not just about life and death decisions in an Emergency room or the immediacy and urgency of acute care. Nurses and other caregivers frequently provide care for a growing population of individuals with one or more chronic conditions. Chronic illness presents different challenges than acute illness, both for the person suffering through it and for nurses who must meet the need for professional help. Based on variation in length of prognosis, rate of onset, level of disability and degree and nature of suffering, nurses, working with the chronically ill, may focus their efforts on managing symptoms, preventing exacerbations and disability, rehabilitation, health promotion or promoting a better quality of life. The roles nurses are faced with in chronic illness can be less dramatic than those in acute care, which the media likes to place before the public, and which governments fund the most (acute care, organ transplants, trauma care, and so forth). Nurses have reported chronic illness care as less exciting, valuable, and rewarding than the potentially dramatic roles in acute care where cure is the goal (Bryne

& Heyman, 1997). The pace of chronic care tends to be slower and longer-term implications should be considered for every decision made. Nonetheless, as in acute care, every decision made by nurses is really an answer to the ethical question of how you and I want to be treated (Bergum, 1999).

This is a research study in which I undertook to illuminate through narrative inquiry, both the experience of women who have sought expert help with severe chronic migraine headaches, and the experiences of nurses who have provided care to women seeking help with migraines. The theoretical premise behind this study was that "knowledge needed for ethical care must be constructed in the relationship between professional and patient who strive together to understand what meaning the disease factors have within the experience of the individual patient" (Bergum, 1994, p. 71).

In this dissertation, I first review the incidence of migraine, chronic pain, and chronic illness overall. Because migraine has been associated with considerable misdiagnosis (Kaniecki , 2002), under treatment (Holmes, W., MacGregor, A., & Dodick, D., 2001; Brookopp, Ryan, & Warden, 2003), and stigma (Joachim and Acorn, 2000; 2000), it is important to grasp some of the ideas we hold in our society, and in the profession of nursing, if we are to understand the current impact and potential challenges of chronic illness, current conceptualizations and ideas regarding chronic illness and chronic pain, and past and current approaches in nursing research on these topics. Both my thoughts on why narrative inquiry is an appropriate research method and way of thinking for this study as well as the procedures I used are explained. I explore the fit between chronic illness and narrative inquiry, in light of our understanding of ways of knowing in the discipline of nursing, in order to identify and highlight potential implications for health care delivery.

My approach, using narrative inquiry, allowed me to hear the voices of women seeking help with migraines and the voices of nurses who have provided care to women seeking help with this condition. The human and material cost of migraine in North America and other areas of the world is not insignificant and when placed in the context of how nurses conceptualize and approach the provision of care to the chronically ill, it has important implications for how we operationalize the values we hold as foundational to nursing work.

In the last 25 to 30 years, we have learned more about the human cost of chronic illness overall and the statistics on migraines may be surprising to some. In an early Canadian study, Edmeads, Findlay, Tugwell, et al. (1993) found that 31% of migraine sufferers reported having to cancel activities with family and 30% with friends due to migraine pain. Migraine disrupted family and social life, reduced work productivity, resulted in time off work, and affected the ability to complete education and hence limited earning power and quality of life (Holmes et al., 2001). A study conducted in Scotland revealed absenteeism from school and college was 7.8 days/yr for those with migraine compared with 3.7 days/yr for those without (Abu-Arefeh & Russell, 1994). Frequency of attacks was inversely related to function. Another study reviewed by Holmes et al. (2001) quoted 50% disruption of relationships. A UK study by Clarke, MacMillan, Sondhi, et al. (as cited in Holmes et al., 2001) indicated significant disruption of family life with impact on all family members and friends. Of interest is the fact that they also found that 50% of migraine sufferers had relationship problems with family, friends, and co-workers between attacks. It was speculated that anticipation of another attack could be a factor.

Holmes, et al. (2001) noted that changes in health-related quality of life showed migraine was a significant disorder, a statement that seems to imply that the impact of migraine may be underrated. Their study equated the suffering from migraine with that of other chronic illnesses such as asthma, congestive heart failure, and musculoskeletal pain. To determine the impact of migraine on all aspects of life, new instruments to measure disability have recently been developed. It is hoped that this will lead to improved diagnosis and more appropriate and effective treatment (Holmes, et al., 2001; Lipton, Stewart, Sawyer, & Edmeads 2001; Loeser, 2005; Maizels, & Burchette, 2002).

The dollar cost in terms of lost work productivity and absenteeism, direct costs of medical care, and indirect costs for such things as childcare, medications, help with housework jobs, additional costs incurred to manage work demands, the need for others to fill family and social roles are staggering. Fifty million people in the United States were reported to have chronic pain (Blomquist, 2003; Glajchen, 2001). When we look at migraine specifically, we find estimates of direct costs of $1 billion in the United States and $12.5 million in Sweden (Ferrari, 1998; Hu, Markson, Lipton et al., as cited in

Holmes et al., 2001). Two other studies on migraine indicated that indirect costs ranged from "$220 million in Australia, $732 million in Canada, $1.1 billion in Spain, $1.1 billion in the UK, $1.2 billion in the Netherlands, and $13 billion in the United States" (de Lissovoy, & Lazarus, as cited in Holmes et al. 2001; Stewart, Schechter, & Lipton, 1994).

It is important to consider the impact of prevalent understandings of the experience of chronic illness, on an individual and societal level, and on the ethical decisions, nurses and other health care professionals make in setting priorities and allotting resources. Chronic illness and, in particular, symptoms such as chronic pain are more often associated with misfortune, inappropriate lifestyle choices, failure to care for oneself, and punishment for life choices (Loeser, 2005). As a result, we often see stigma attached to these conditions, something that adds to the illness burden. It is essential that as nurses we engage in reflective practice and research, processes that can illuminate the values, beliefs and attitudes we hold about those with chronic illness. This understanding prepares nurses to think about nursing practice issues and the knowledge needed for ethical care.

I believe the findings of this study bring understanding to the experience of living through a migraine headache, to the vulnerability and risk women experience in seeking help, and to the importance of considering more than, where the individual is in her life at present. If we consider past experiences and future implications, we may gain a better understanding of self-care decision making and the role healthcare professionals directly or indirectly play in self-care. Nurse's stories provide insight into the experience of providing care to women seeking help with migraine. Because the findings provide both an emic and etic perspective on the total migraine experience, there is a potential for changing how all parties view the experience of living through migraines and seeking and providing help with them. Such insight has the potential to change how people think and this in turn can change how situations are approached. This study has application in developing standards of practice for nurses working with those with chronic illness, and in particular, migraine headaches. The findings of this study have wider application in the area of nurse/person interactions because they will construct knowledge that is produced and understood within the context of relationship and interaction. Relational knowledge illuminates the ethical obligations of nursing practice and provides an opportunity to make necessary and beneficial changes to how nurses define and carry out our practice.

Purpose of the Study

The purpose of this research is to study the experiences of women seeking professional help with severe chronic migraines, and the experiences of nurses whose mandate is to help meet the health related needs of this population. By listening to the voices of women with migraine headaches I present a more complete understanding of how suffering, disability, and experience with illness influence the timing and process of deciding to seek help, the choices individuals make about whom to turn to for help, and the actual dynamics, processes, and content of nurse/person encounters. Within this study I also provide an opportunity for nurses to share in depth, their narratives of experience composed around the above issues, their own beliefs and attitudes about those seeking help with chronic pain (women with migraines in particular), their thoughts and routine practices in the area of assessment, supportive interventions, and style of decision-making. I believe the evocative nature of the stories and representations in this study help readers recognize the importance of the dynamics, nature, and quality of nurse/person interactions. Inherent in our musings are questions about our responsibilities as individuals, as members of societies, and/or as members of a healthcare profession toward those with health related needs. I believe these are ethical issues and that nurses are called to ethical practice on a daily basis as persons with chronic conditions such as migraines make public their vulnerability, as they seek our help.

Coming to the Question ... Situating Myself in the Study

Whether we call it narrative or story, as a phenomenon, our ability to conceptualize and name our world through language is central to our conscious experience of life. It is through personal narratives and narratives related to such things as the workplace, social institutions, government, culture, and ethics that we make sense of situations, make decisions about how to live, and create meaning by integrating experiences into our lives. Hidden within intersecting personal, professional, and contextual narratives, are stories of our belief systems. Here is where we see how we have come to use language in ways that uplift, confer power, control, and value … illuminate oppression and vulnerability … or alternatively suppress, dismiss, or devalue experiences.

When we label our experience, we use words that are grounded in an historical and cultural context and understanding (in this case our western, increasingly multicultural milieu), in hopes of finding common threads but in fact, context often helps us reveal and appreciate *the unique, the particular, the personal.* We need to explore the temporal influences, the narrative (story) issues, the relational issues, the situated knowing that brings insight into another's world. Narrative inquiry takes us into the storied lives of individuals, lived on storied landscapes. Viewed in this way, narrative inquiry not only conveys information on a cognitive level, it becomes a way of thinking, an interpretive pathway bringing meaning through narrative histories (Clandinin & Connelly, 2000, p. 24).

Figure 1

Suffering, seeking help, consequences …listening for the question…seeing the question…feeling the question

Stories are also embodied memories and words are not the only way to express inherent knowing, the coming together of descriptive knowledge (subjective, how the individual is experiencing his or her life) and abstract knowledge (objective, universal, generalizable, disengaged) (Bergum, 1994). The above self-portrait I discovered while surfing self-help websites (actual source unknown); it presents a powerful image of how one woman viewed herself with a severe migraine. I see an urgency and franticness in her expression; energy seems to emanate from her face. Form, shading, lines, and colour in this picture speak to me on many levels. Each of us will see something different in her picture and it is only through dialogue that we would learn her understanding of it (Bergum, 1994).

Having lived with migraines all my life, I see the years of chronic pain etched in the deep lines in her face. Note the vertical lines between her brows, sometimes referred to as frown lines. I know them as pain lines and they speak to me of her years of chronic pain. Her clamped teeth, the hard set of her jaw line, and the tendons distended in her neck show her agony, frustration, and anger. Her fingers seem poised to pluck out the offending eye where the pain is focused. As her fingers curve inward around her eye, barely controlled tension is evident in the taut tendons from knuckles to wrist. Her eyes stare forward, almost blankly, not focused on something without but looking inward where the pain dwells, a living, breathing entity she cannot grasp and cannot ignore. It fills her head until she imagines it will explode. I know this face for it is also mine. I am fascinated at her choice of lifeless grays and blacks for depicting herself, while searing yellows and reds convey the power and quality of her pain. These bright red and yellow splashes of colour radiate away from her head. Perhaps the pain seems too great to contain, or is this the imagined exploding of her head. As readers look at this picture, I make sense of what they see by creating a story to match their interpretation. As readers wonder about her, they use their own context for insight. Bergum (1994), drawing on the 1986 work of Belenky, Clinchy, Golberger, & Tarule stated that, "All knowledge is a construction" and "truth is a matter of the context in which it is embedded" (as cited in Bergum, 1994, p. 72).

I did not like this picture when I came across it and yet something made me save it. Now after studying this picture, I have come to an understanding of this woman, have, in fact, given her an identity and a story in my own mind. I realize now that my initial negative reaction was because her picture resonated with me. Whenever we interact with another, or even with a representation of another, our reaction to that person or representation contributes another piece to their identity and to our own.

The cool edge of the toilet bowl brings some comfort to my sweat drenched face. I am exhausted ... shouldn't have eaten ... the migraine headache was too far along ... will I never learn? A painful shiver courses through my limbs and my arms shake as I lean into them to support my upper body. My legs are tucked under me and I notice the feeling is fading from my right foot. I breathe slowly through my nose in an effort to control the nausea that circles my throat. Blood pounds through the vessels at my temple. I push harder into the cold porcelain surface trying to stop the waves of pain so audible in my ear, like the sound of heavy surf pounding on a beach. Each beat is palpable through my chest and pulses even in my fingertips. The pain is a living breathing entity that I cannot escape and I feel trapped in a spectacle of vulnerability.

I find myself giving thanks for having cleaned the bathroom so thoroughly earlier in the day. What a ridiculous thought to have now ... am I trying to hold onto my dignity or is the nurse in me trying to find some control by inserting an aspect of normalcy. Then again, perhaps it is the mother in me, that can't quite let go of the caregiver role. I wish my mother were here, yet what I am experiencing seems too intimate to share even with her. Even as I acknowledge my desire for isolation, I know I have reached a point where I need help with the pain. Help means the hospital and oh, God I don't want to go there. At one time, the hospital was a refuge, but now I have a history and that history comes with me when I walk through those doors. Knowing the history should help, but instead of opening doors and easing the process, it just seems to create more barriers. How often have I faced nurses' unrealistic fears about the use of narcotics and addiction, poor triage when a status migraine was equated with a cold, and negative attitudes around patient expertise in chronic illness?

I am torn between my need for help and my fear of the reception I will get at the Emergency room, but even that fear is not the first barrier. I am the first barrier. I have to start ... have to call my husband ...the phone is so far away. I am not dressed ... where are my jeans ... my hair is standing on end.
Then there is that endless drive into town, where every pothole will be agony. Sitting on the bathroom floor I stare across the expanse of carpet I must cross to get to the

phone on my bedside table ... I see as a small child sees ... it's sooo... far. I am afraid to make any sudden move for fear my stomach will stage another revolt. Yet I have to move ... I carefully lower my head to the floor, and with forehead pressed against the tile breath slowly as I endeavour to gather my feet beneath me, gather my willpower. I can do it ... I will move ... in a moment ... I will ask for help. I just need a moment.

"It's me", I whisper. "I'm sick." "What number is it", he replies? "Eight"! "Ok I'll be right home". "Thanks". I clamp my shaking teeth together and force myself to breathe slowly through my nose as the nausea threatens to overwhelm me again. How many times have we used our code? It is a Godsend not having to explain that I have to go to the Emergency room ... just give a number and he knows what I need. He never complains, just comes, takes me, and then waits.

I am lying down in the back of our station wagon, a pillow under my head and a hot magic bag pressed tight against my temple. I have put two grocery bags together and hold them close to my mouth in case ... my teeth are clamped tight trying to hold back whatever may be left in my stomach. He tries to drive carefully but the potholes are winning and each dip is like driving a stake through my head. I am committed now... hoping the Emergency room will be quiet. I know I can't sit in the waiting room, can't even hold my head up, and can't face people watching me in my pain. If they don't have a bed, I'll lie on the floor if I have to. Will they understand that? Will they care? Do I care? How long will I have to wait?

I am lying quietly on a stretcher in the middle of a treatment room, waiting. Relaxation exercises have helped me stay still and rest but I can no longer focus on them ... I am so tired ... I feel the panic rising in my chest ... where is the doctor ... where is my nurse? It is so dark ... without my glasses it is hard for me to make out objects in the room ...only a sliver of hazy light is visible under the door. A small spot of red light shows the location of the ophthalmoscope on the wall. I carefully peer over the edge of the stretcher; it is like being in a lifeboat on a dark sea. The dark is soothing to my eyes but the pain is escalating. I am afraid. They have forgotten me.

The sides of the stretcher are up and I feel trapped; the nurse has forgotten to attach the call bell. My heart is beating faster and I know I am breathing too fast. My hands will go numb if I don't slow my breathing.

I know it has been at least two hours since I arrived. My husband has gone home to see to the children. I feel so alone. I close my eyes tightly in an effort to stop the tears that threaten. I will not cry ... I must not cry...it will make the pain so much worse. I am so tired. Why aren't they helping me? I don't know the name of my nurse. I call out "nurse", "nurse" several times. No one comes and I stop because it sounds so foolish ... did she tell me her name? Yet I have to get help. I have to get help!

I cannot see how to lower the side of the stretcher. You'd think a nurse could figure that out, but my brain is filled with mud. After minutes of fumbling in the dark, I finally feel the catch release. My head swims as I carefully sit up. With the rail down and so dark, I suddenly feel I may fall and hold the other rail for dear life until the feeling passes. As I search for the floor with my foot, I try and orient myself. I remember seeing the bell on the wall to my right when I arrived and so I carefully step in that direction in the dark ...I nearly fall as I trip over my shoes. Damn! Where is she? A small spark of anger strengthens my step. My hand finally clutches the cord and I pull. I am so weak ... I hurt so much ... I have to sit down ... I slide to a sitting position on the floor clutching the cord in my hand. A disembodied voice above me asks what I need. Please help me I say. I am a little child ... too tired, feeling abandoned, hurting so much, tired of waiting, and then this disembodied voice ... don't they know I am sick? I start to cry. I am curled up on the floor, cord in hand, and sobbing when the door bangs open admitting my nurse. She casts a stern shadow over me as she stops short and stares. Well, well ... what do we have here, she says.

Shame burns through me at being caught in this position. I hear the disapproval in her voice. Where is this coming from? There is no concern or caring here. She doesn't offer me a hand, simply flips on the lights and waits while I struggle to get to my feet and back to the stretcher.

I attempt to explain that the call bell was out of reach and I am so sick, but my words fall on deaf ears. As she locks me in the stretcher again, she says, "The doctor will be in in a minute". She flips out the lights and leaves. In an instant, I know I have become one of those "difficult patients".

Oh God, give me strength to get through this! I need my husband here ... I don't trust these people to help me ... I want to go home!

Figure 2 One of my stories

Améry (as cited in Frank, 1995) captures some of what I feel and understand about this one story from a lifetime of stories about migraine headaches: "...I had grasped well that there are situations in life where our body is our entire self and our fate. I was in my body and nothing else.... My body ...was my calamity. My body ...was my physical and metaphysical dignity" (Améry, as cited in Frank, 1995, p. 7). There is resonance for me in Améry's powerful testimonial on the nature of *her* experience of being in illness. A psychologist friend who read my story when I was writing it pointed out the gradual reduction of my world to one element, pain. I was totally in my body that day and it was my calamity. I look back and realize that there needed to be a dialogue that day with my nurse for without it she had only abstract knowledge on which to form an opinion. She could not know the depths of my pain, how much I feared coming to the hospital, that I had waited too long to come because of that fear, and that her reaction to me that day would always be with me, adding to my fear of seeking help even today.

There is another element to consider when we look at chronic illness. Yes, the body is often one's calamity, but consider Baron's description of the relationship between health and illness: "Health is the state of unselfconscious being that illness shatters" (Baron as cited in Leonard, 1997, p. 53). Baron's (as cited in Leonard, 1997) words are as evocative as Améry's, perhaps even more so, but, as a woman with chronic illness; this is not my experience of health. The use of the word "calamity" in Améry's narrative expression fittingly captures the notion of illness shattering the unselfconsciousness of health. Understood from within my narrative of experience, health is seldom unselfconscious. I revel in the moments when a sense of ease and peace replace pain and other symptoms, and an uncommon embodied awareness of well-being spreads throughout my body. When I can choose to work and play without holding back in effort or enthusiasm, without weighing every potential risk and benefit related to my illness, to engage in life until I am pleasantly tired without also being sick ... the wonder and freedom in those *moments of being*, go beyond words. To feel normal, to participate in meaningful roles and relationships again, to be conscious of harmony in my body, and wholeness in my spirit ... this is *my very self-conscious* experience of health, in a life so often constrained by chronic illness. This is what illness shatters! Thinking narratively, I understand how illness shatters this unfolding story. This is one of the pieces of insight missing from our knowledge base on chronic illness.

Along the same line, Montgomery-Whicher (1992) talked of the difference between drawing her sister as opposed to drawing a picture of her sister, with the former capturing more of the person, while a drawing objectifies and is mere representation. One can make a similar argument about the experience of a migraine headache. Citing empirical evidence, the signs and symptoms of a headache, even taking a picture of a person suffering from a headache, ultimately objectifies the experience. This partial frame of reference cannot capture what it is to *live through a migraine headache*. To understand we need more than one perspective and more than one form of knowing to appreciate the extent and meaning of the experience.

Leonard (1997) stated that illness is the breakdown of the embodied self in which we lose our "taken for granted" state of health and with it our ability to negotiate with the world (p. 53). In reflecting on Leonard's ideas, I wonder if healthcare professionals recognize that in seeking help, the ill individual is looking to overcome vulnerability, to reclaim that sense of embodiment and the ability to negotiate within our own worlds. When, as in the scenario I presented earlier, symptoms such as pain overwhelm me and I cannot help myself, it can feel like I am a child again, reliant on others to take away my pain. The early years of childhood are a time when we first experience the challenge of learning to control bodily functions and of using our bodies with skill in meeting our own needs. For each of us this is a unique experience in developing independence. How difficult is it to understand what it means to an adult to find him or herself in a similar state of vulnerability and need, the failure to manage evident to all who care to look? To understand these and other questions requires a variety of enquiry approaches, a telling and retelling, living and reliving of the experience to tease out the insight that we need to help us work with and provide care for those with chronic illness.

The questions within this study arise from my personal belief that the emotional and cognitive impact on each party within a nurse/person relationship carry over to future encounters. For years I have questioned, asking as a nurse and as an individual with chronic illness, what it is that makes for a successful or less successful nurse/person interaction? Becker, Janson-Bjerklie, Benner, Slobin, & Ferketich (1993) looked at this same issue with individuals with asthma. No matter how patients *presented* at a healthcare facility, some encounters were helpful and others fraught with misunderstanding, failure to recognize serious health problems, and interactions that reflected negative attitudes and frustration. My desire to explore the issues evident in the experiences of individuals with frequent severe exacerbations of migraine comes from a commitment to addressing the suffering of others, and from the moral stance, that provides the foundation for my work as a registered nurse. I believe we cannot change what we do not understand and a significant amount of research, see chapter 2, indicates that we do not understand the needs of the chronically ill or how we, as nurses, affect the process of seeking help. Nurses need to hear the voices of those living through chronic illness to help us understand our roles, in that experience, both positive and negative.

Research Questions

The primary research questions in this study are:

1. What is the experience of women, with a history of severe, frequent migraine headaches, seeking professional help from our health care system?
2. What is the experience of nurses working with women seeking professional help with severe migraine?

Summary

Chronic migraines are one of the increasingly complex arrays of chronic illnesses that are escalating in incidence and that require extensive healthcare resources. While we have made great strides in managing symptoms and prolonging life, there are more and more issues being raised about quality of life. It is essential to recognize that chronic migraines, like other chronic illnesses, often require ongoing intervention to help individuals manage day-to-day self-care in addition to acute exacerbations. This requires recognition of the tension created when persons are encouraged to engage in self-care and then have their rights to decision-making undermined when individuals come up against the paternalistic acute healthcare system, where their expertise may not be recognized or valued.

Ethical care is about the question of how we want to be treated and it is important at this time for us to consider the knowledge required for ethical practice, practice that addresses ethics as questions for both individuals with illness and for health care providers. Narrative inquiry provides a way to access the experiences of both of these groups and to visit the issues of ethical care from both perspectives. We need to identify the kinds of knowledge needed for ethical care of the vulnerable members of our society.

Chapter II Examining Relevant Literature

Introduction

How we think about particular concepts, and the way we define and convey meaning about them helps us understand the roots of our attitudes, beliefs, values, and norms. In this study, I consider seeking help with chronic migraines, looking in particular at the personal experiences of women with migraines and the experiences of registered nurses who provide care to this population. To understand the scope of this enquiry, key concepts such as migraine, pain, pain as disease, suffering, disability, the issue of burden in chronic illness, the larger context of chronic illness, temporality, seeking help, understanding seeking help, barriers to seeking help, and chronic illness as a narrative experience will be considered. In this chapter, I introduce the theoretical perspective from which I approach this study, show how this fits with narrative inquiry, and review the concepts listed above. My purpose is to demonstrate the need for this study and to place it within the context of narrative inquiry and relational ethics.

Theoretical Perspective

I come to this study from the theoretical perspective of relational ethics, based on the work by Bergum (1994; 1999) on ethical nursing practice. I believe that to ground ourselves in the basic premise that all nursing care and every nursing decision is an ethical one, is essential. This is the only way we as nurses can remain true to our mandate to care for those vulnerable members of our society, and support individuals, families, and communities as they traverse natural changes of growth and development, and adapt to sociopolitical and economic changes in their environments.

Bergum (1994) proposed that knowledge for ethical care, doing the right thing, for both caregiver and care recipient must be developed in relationship between the two. To treat individuals as objects is to disengage, isolate, and alienate them from their world, a move that results in missing the essence of the individual's way of being in the world. Through the discovery of inherent knowledge, collaboratively constructed through interaction within a nurse/person relationship, both groups have the opportunity to understand how the individual is living through the moment in question, what Bergum termed the "living 'I'" (p. 75). The opportunity also exists to bring to light actions on the part of the nurse that regardless of the intention may be helpful or may contribute to suffering in the moment and perhaps in the future. Bergum (1994) proposed that to develop knowledge for ethical care nurses need to move from dominance to collaboration, abstraction to context, and beneficence to nurturance (p. 74). Nurses assist individuals to make self-determined decisions and do so by helping them unify the abstract "body as object" with the subjective experience of the living "I" (p. 76). Through such collaboration, nurses can relate in a context of mutual respect and reciprocity where expertise and experiences are shared and valued. I agree with Bergum and feel this provides a sound ontological and epistemological perspective from which to examine the world of the chronically ill.

According to Bergum (1994), inherent knowledge must be the starting point and collaboration is the only way to construct inherent knowledge. She noted that there is a need to understand not just the abstract fragmented world of observations and measurable characteristics (abstract knowledge), but to also incorporate descriptive knowledge. This entails including the meaning and effect of signs and symptoms and the actual experience as an individual lives through, not just with, the challenges of change and transition that make up past life experiences. Gadow's statement that only the individual can "supply true meanings for the empiricist's collage of facts, the essentialist's categories, and the observer's reading of signs and noting of symptoms" (as cited in Bergum, 1994, p. 75) is particularly fitting here.

The need to understand the individual's perspective ties into Bergum's (1994) thoughts about moral decision-making. I too believe that nurses must recognize moral decision-making as dynamic and set within relationship; we must be prepared to be flexible, to remember, that the many truths of life are contextual and contingent. As Bergum reflected, a relational dialectical process often involves raising questions or finding the question to fit the answer. Dialogue may be open and sometimes it is silent but it must be initiated. Here is where we see a tie between narrative inquiry as a means to knowing and relational ethical practice, for while narrative is often verbal, it can take many other forms, many of which are silent. Consider the picture presented in chapter one and the interpretation I supplied based on the context of my life experience with chronic severe migraines. Each of us could develop a story, a narrative to fit what is conveyed in the picture, but for a more complete understanding, each of us would need to establish a dialogue in relationship with this woman. This way of knowing provides an epistemological foundation for exploring the experience of migraines, chronic illness, and seeking help, using narrative inquiry.

Understanding Migraine and Situating it in the Realm of Experience

Having considered how stories as experience can be represented and interpreted through multiple interactive processes, it is necessary to review some of the key concepts in this proposed study. The ties among these concepts create a contextual matrix that I believe is essential to consider as each life narrative is explored within such a matrix for participants in the study.

Migraine.

Migraine is not like other headaches in etiology, symptomatology, treatment, or debility. The etiology of a headache is usually the basis for medical diagnoses such as migraine headache. Treatment is tied to the diagnosis, the designation of the problem as acute or chronic, the severity of pain, and to the presence or changes in vital signs and neurological signs and symptoms. One key factor in seeking help is the variability of symptoms and severity of pain. Many individuals go undiagnosed because of insufficient knowledge on exactly what is a migraine. Kaniecki (2002) stated that diagnosis of migraine was difficult as many types of headache have overlapping symptoms. He referred to migraine as a wolf disguised in sheep's clothing, as misdiagnosis is common, especially if other types of headache are present.

One medical definition of migraine is "a heterogeneous disorder characterized by attacks that vary in frequency, duration, severity, and symptomatology" (Holmes, et al., 2001, p. 2), with headache the most common symptom. To understand the full experience of migraine headaches one needs to understand that pain located in the head is only part of the experience. Migraine headaches are often accompanied by nausea and vomiting, numbness, paresthesia (pins and needles), weakness, speech difficulties, and for some the presence of aura [an abnormal sensation experienced before a migraine or seizure - more specifically a complex of focal (localized) neurologic symptoms] (Holmes, et al., 2001; Cady, Schreiber, & Farmer, 2004).

In other words, migraine is a neurological disorder involving much more than just pain in the head. This condition affects the sympathetic nervous system (SNS) producing a variety of symptoms, resulting from altered SNS function (Peroutka, 2004), with the potential to create unpleasant feelings and altered function throughout the body. For about 20% of the migraine population episodic migraine eventually evolves to a chronic headache disorder (Cady et al., 2004).

While most migraine patients experience head pain, some individuals (particularly children) experience abdominal pain; other people experience only the prodromal symptoms (aura). The cause of migraines is not completely understood, but is believed to involve a complex process leading to modified circulation within the head, inflammatory changes, and altered function of neurotransmitters that influence many functions within the body. There is often a strong family history of migraine. Migraines can result in significant disability affecting all aspects of an individual's life. They are difficult to treat and the range of treatments includes medications, stress management modalities, and a variety of alternative therapies (Aukerman, Knutson, & Miser, 2002).

Schwartz, Stewart, & Lipton (1997) conducted a large quantitative study in the United States employing a telephone survey method in which 13,343 individuals between the ages of 18 and 65 were interviewed about the impact of headache on work loss and disability at work. Individuals lost on average 4.2 days of work per year and 70% of the impact of migraine was in the form of reduced effectiveness in their jobs. The major impact of headaches at work is thus disability (inability to fulfill roles), not actual missed days of work. Migraine accounted for more lost days, 8.3 (mean) and 2.0 (median) per year for women, than for men 3.8 (mean) and one (median). The authors concluded that indirect costs of headache far exceed the direct cost of medical care, diagnostic testing, medication and so forth. I found this study interesting because the articles I had reviewed on disability showed that disability is one of the things seldom and poorly assessed when individuals with chronic conditions seek medical help. Here are two issues (burden and disability), highly interdependent, and yet the importance of connecting this data to how assessments are done has generally not been acted upon.

A population based study on migraine headaches conducted by Van Korff, Stewart, Simon, and Lipton (1998) filled in some of the gaps regarding the indirect cost of migraine headaches and headaches of other types in terms of the workplace. Since a headache is not something for which workers are compensated, it was found to be rarely reported and so this is really a hidden effect. Since women suffer from migraine more than men do, 18% in women compared with 6% in men, this is also a gender issue. In this study, 800 subjects were recruited, with 225 meeting the diagnostic criteria for migraine and 174 actually completing diaries for 11 weeks. This study addressed individuals working full time. The authors noted that the indirect cost of headache in non-paid work (in the home and for volunteers) should also be assessed. Of headaches reported on 8.1 workdays, 2.2 met the criteria for migraine. The authors concluded that frequent headaches could lead to decreased participation in the paid labor force, especially for those with migraines.

Treatment of migraine presents another challenge. Rodriguez reported that, "Nurses continue to assess pain inappropriately, they under-medicate, and provide inadequate documentation of pain assessment and management, (as cited in Brookopp, et al., 2003, p. 409). Brookopp, et al. (2003) stated that nurses willingness to spend time and energy on treating chronic pain varied with the nurse's perception of the individual involved.

Pain

It is appropriate at this point to consider the topic of pain, for this is the symptom that causes the most disability in migraine. To appreciate our current view of pain and pain assessment and treatment, it is helpful to review the history of pain management. Donovan (1989) provided insight into how ideas about pain have changed. Early beliefs linked pain to punishment by God. Interfering with pain was considered interfering with *Divine Will.* In the 4th century, Aristotle linked pain to emotions thus opening new avenues for treatment. By the 19th century, technological advances helped researchers undertake sophisticated research leading to identification of the roles of neurotransmission in pain (Donovan, 1989). Despite such advances, it was not until the early 1940's, that inflammatory processes and pain were linked. Given the subjective nature of pain and the rush to explore the body, researchers took advantage of new technologies to study other symptoms and body processes that were easier to quantify. It would not be until the last 30 to 40 years of the 20th century that new conceptualizations of pain and a holistic approach to assessment and treatment would arise. The number of articles on *the difficult chronic pain patient* and the *risk of addiction* demonstrated that attitudes with underlying social and moral values influenced the research undertaken on pain. Placebo effects were another issue that contributed to negative feelings toward chronic pain patients. Latham (1983) noted that, "if doctors and nurses set about to relieve discomfort with sincerity and competence, their intention alone brings ease" (p. 54).

The most common reason that patients seek medical attention is pain (Schim & Stang, 2005), yet the first major medical textbook on pain, by John Bonica, was not written until 1953. It was not until the last quarter of the 20th century that there was a significant increase in pain research, the development of scientific journals on pain, and the establishment of numerous societies devoted to the study of pain and pain management (Loeser, 2005). This suggests that pain was not a priority in medicine, or other factors were deemed more important. While nurses spend much of their time on pain management, as in the discipline of medicine, they have been slow to incorporate in depth knowledge about pain, pain assessment, and pain management into nursing education programs.

The subjective nature of pain is not easily accepted by healthcare providers steeped in the biomedical model. McCaffery, a well known nurse researcher in the field of pain, defined pain as "whatever the experiencing person says it is, existing whenever he (sic) says it does" (as cited in McCaffery & Pasero, 1999, p. 5). If we look to the word pain for insight we find that it derives its early meaning from the Middle English word *peine* meaning punishment, torture, or pain, from the Latin word *poena* referring to penalty or pain, and the Greek word *poiné* meaning penalty (Costello, 1996, p. 972). The recurring theme of punishment or penalty suggests that humans have tried to find a reason for pain, seeing it as a response to something, and in many cases viewing that something as some form of personal or moral failing.

The development of the Melzack-Wall Gate Hypothesis in 1965 changed how pain was conceptualized and "modulation, both upstream and downstream, was soon to be recognized as the dominant functional mode in the nervous system" (Loeser, 2005, p. 78). This was a significant step for healthcare, for professionals then realized that the perception of pain could be modulated by factors such as previous experience with pain. This is a key issue when one considers the time element in chronic pain.

In 1973, Melzack and Chapman stated their belief that pain is second only to the fear of death and that pain is one of the main reasons individuals seek medical assistance. In 2005, Melzack proposed the Neuromatrix Theory of Pain. He noted that this evolution from the Gate Control Theory of Pain provides a new conceptual framework for examining chronic pain syndromes, previously poorly understood. Melzack described how phantom pain interferes with leading a normal life and stated, "similarly, most backaches, headaches, muscle pains, nerve pains, and facial pains serve no discernable purpose, are difficult to treat, and are a disaster for the people who suffer them" (p. 86). He concluded that chronic pains are not a useful warning system of danger to the body but rather are, "the result of neural mechanisms gone awry" (p. 86). Melzack reminded us that, "our brains are built to produce" qualities of experience (p. 87). In other words, experience is not something exterior to us, waiting for us to encounter or feel. Experience is an internal construction of the interaction of mind, body and environment. Melzack further emphasized the importance of recognizing the complex stress response that pain initiates in the body as vastly expanding the puzzle of pain (p. 89). His work will help explain some of the elements of chronic pain that have often been attributed to psychological cause, resulting not only in negative labeling of individuals, but also in negative stereotypical expectations of behavior and motivation.

During the 32 years between Melzack's two articles, researchers have documented a lack of knowledge, misconceptions about pain and its treatment, and problem attitudes toward the assessment and treatment of pain, on the part of nurses and doctors (Marks & Sachar, 1973; Weis, Sriwatanakul, Alloza, Weintraub, & Lasagna, 1983; Foley, 1989). Despite intervention with analgesics, many patients in acute care settings continued to suffer moderate to severe pain with varying degrees of distress (Marks & Sachar, 1973, Foley, 1989; Stratton, 1989). Diamond and Grauer (1986) reported that negative feelings about chronic pain patients could also compromise care.

While treatment modalities, other than pharmaceuticals, have been incorporated into medicine and nursing, health care professionals continue to rely heavily on drugs for managing acute and chronic pain. In chronic care, however, there is a general reluctance to use strong analgesics, even for acute exacerbations of pain. Physicians and nurses are more receptive to trying milder drugs together with lifestyle changes and psychosocial modalities, for example, exercise, stress reduction, relaxation therapy, therapeutic touch, or autogenics. While research is now being conducted on alternative therapies and there is considerable anecdotal evidence to support their use, most have to be learned or used when pain is subacute and are not appropriate for severe pain. Once again, the time factor of chronicity plays a role. In my own experience, it took 2 months to become proficient at progressive relaxation and 6 weeks to learn autogenics. While I find these useful therapies, they require concentration, something that is not always possible when one is in acute pain and in particular, when that pain is located in the head, the centre of thought. They also require ongoing practice to be effective. The other issue is the need to recognize that chronic pain is not always less intense than acute pain.

Healthcare providers are faced with an ethical dilemma regarding whether to use potentially addictive substances to treat acute exacerbations of chronic pain conditions, or force these individuals to endure significant pain for longer periods. As a nurse and an individual with chronic pain I feel an ethical obligation to pose the question, is it ethical to deny chronic pain patients strong analgesics when they are in acute pain, just because of an underlying chronic condition? We know that *few* people with chronic illness become psychologically addicted to narcotic analgesics. The issue here is why the individual is taking the medication. Physical dependency is an entirely different issue. With increasing numbers of individuals facing chronic pain, we may have to have a more open debate over what is the humane course of action in pain management.

Pain as disease.

Loeser (2005) in the John Bonica Lecture presented at the Third World Congress of the World Institute of Pain, Barcelona 2004, provided an interesting discussion of the similarities between how we define and conceptualize both pain and disease. It has been suggested that chronic pain should be considered a disease in itself (Loeser, 2005; Niv & Devor, 2004). In examining definitions of disease from the Oxford English Dictionary (Hoad, 1996), Loeser showed how descriptions evolved. In the 14th century, descriptions focused on experiential words such as discomfort, uneasiness, and disturbance. By the 16th century, disease was considered a condition of the body or some organ or part of the body, with the idea that disease meant a change in function, in state of health and a departure from the norm (p. 79). Loeser (2005) examined the difference in definitions of disease from "an impairment of the normal state of an organism" as cited in Encyclopedia Britannica, to phrases such as "interruption or perversion of function of any of the organs" and " abnormal state of the body as a whole", taken from Stedman's Medical Dictionary (Loeser, 2005, p. 79). Loeser's position was that disease, like pain, is a condition of the whole body for one would not be able to discern the state of chronic pain by examining a damaged nerve. Illness results from the interaction of the patient's world and disease. Pain can also cause illness. His point was that removing or repairing an organ or tissue would not necessarily remove the patient's disease or pain. Loeser commented on the importance of the new use of narrative in medicine and other disciplines to gain insight into the experience of pain. He stated, "The fusion of story telling and medicine is the recognition that disease is resident in the person and that only by listening to the patient's story can we understand the importance and meaning of symptoms" (p. 79).

If as Loeser (2005) believed, pain and disease are experiences of the body, then those who work with individuals suffering from pain, such as that experienced in migraine, must understand the implications of pain as an embodied holistic phenomenon. The International Association for the Study of Pain's (IASP) definition of pain is extensive but can be stated briefly as "an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage" (as cited in Carter, 2004, p. 211; American Pain Foundation website). In an article on pain narrative and the use of narrative in practice, Carter commented that the IASP's frequently quoted definition, failed to capture the individual essence of the pain experience and the permanent changes it can cause in people's lives. I am reminded of Bleeker and Mulderij's (1992) words that "the presence of a handicap colours one's existence" (p. 1). The pain of a headache may not sound like a handicap, but the chronic nature and increasing severity of my own experience with migraine headaches would in time present a significant handicap, one that continues to colour my world. In Carter's (2004) words relating to the generic quality of the IASP definition, "Pain dramatically shifts and forever changes the landscape of a person's world and their positioning in it" (p. 211).

The dominant narrative around pain has been reductionist in nature with many researchers working to develop assessment tools that are effective for particular groups of individuals, such as children or older adults. Carter (2004) concluded however that this approach while useful does not capture the holistic nature of pain. By combining the use of tools, technology, science, and narrative there is less chance of "experiences being drowned out by the clamour of science and protocol, by the 'chart talk' health care professionals so easily slip into" (Frank as cited in Carter, 2004, p. 211).

Carter (2004), while writing an article about working with children, introduced some basic ideals that I believe are just as relative to working with adults with pain. Drawing on the early work on care by Nodding, Carter introduced the need to "acknowledge an ethic of care" in narrative practice, for individual's stories come forth when an atmosphere of trust is established and when a story is listened to *with* the teller versus listening *to* the teller. In other words, caregivers share the meaning and experience of pain when engaged or in-relation with individuals. Such engagement does put the practitioner at risk for potentially negative consequences for some stories are difficult to hear and, as Carter stated, it means being prepared to "risk something of ourselves" (p. 214). Carter takes us from a definition of pain, to an understanding that stories are authentic and credible. Understanding pain requires engagement and a view from inside the experience. When intervention takes the form of something tangible such as medication, healthcare providers need to remember that the individual needs not just relief from the physical symptom, but understanding of "what the pain was, where it came from, why it happened, what it means, whether it will come back". In addressing these questions, we are able to facilitate healing (Carter, 2004, p. 214).

The ideas expressed in Carter's (2004) article lead into an issue raised by Loeser (2005) about our lack of data on "the natural history of those who live with hurt" (p. 80) and the "long term effects on health care on their functional status and self reported pain" (p. 81). I agree with Loeser that until caregivers come to terms with the fact that chronic pain is not just a result of somatic malfunction, we will not even understand, let alone be able to intervene to address the human and material cost of chronic pain.

In reflecting on my own experience with chronic pain, I find resonance with the ideas presented by Carter (2004) and Loeser (2005), and the meanings embedded in the word pain. I often see migraine as the enemy with whom I must engage ... and to fail to overcome the pain does seem like a personal failure. It is difficult to maintain hope and move forward when feelings of guilt or failure continually pull one back into the abyss of suffering. When others, especially health care professionals fail to grasp the totality of my chronic pain experience, I not only lose hope, but I also experience a profound sense of being alone in my suffering.

Suffering

To gaze into the face of one with chronic illness is to see the face of suffering. It may be covered by a smile, dismissed with a laugh, suppressed in activity, but that does not make it any less real. People learn to cover up suffering as they strive to appear normal and avoid stigma (Joachim & Acorn, 2000). Suffering is defined by Cassell (1991) as "the state of distress brought about by an actual or perceived threat to the integrity or continued existence of the whole person" (Cassell as cited in Younger, 1995, p. 3). Younger (1995) noted that the root meaning of suffering is the "idea of submitting or being forced to submit to some particular set of circumstances, forced to admit to an existence that is not under our control or to the intrusion of an activity operating under another law than ours. Thus, it makes us not ourselves, and it is a threat to our integrity" (Younger, 1995, p. 3). The individual with a chronic illness, such as migraine, then experiences one of life's great paradoxes, the alienation of the sufferer. "The suffering that accompanies adversity is compounded by suffering of a second type: the loss of community and the sense of connectedness it entails" (Marris as cited in Younger, 1995, p. 2). In a similar vein John Donne stated, "As Sickness is the greatest misery, so the greatest misery of sickness is solitude ...Solitude is a torment which is not threatened in hell it selfe" (Donne, 1987, p. 106).

Younger (1995) introduced an interesting take on suffering and pain ...that suffering is "what we choose to do with pain" (p. 4). As such, suffering becomes a source of experience, one in which we may "endure, hold out, resist, or sustain" (p. 4). Is it possible, that in moving through an experience of suffering, we seek to find meaning in why we are being hurt (Weil as cited in Younger, 1995, p. 4), and, through this, find our very selves modified? Am I a different person because of my experience in living with migraines? Do I see myself as separate from this illness or have I integrated my embodied experience into the person I am. How does this affect my ability to interact with others? Perhaps one of the key roles for nurses is helping patients discover a new identity, with new possibilities. I think this is an important place to address the question of planning, provision of care, and coordination of care. Loss or change in function requires learning to live in a different way and nurses have a key role in assessing needs and helping people to plan how to meet those needs. Discharge planning, as a concept important in coordinating care, should be done in any healthcare setting. This is a key issue in chronic illness for most people manage their illness at home. Nurses are in an ideal position to help coordinate care among various agencies involved in providing needed and helpful services. The need for assistance is really about disability, the next concept to be examined.

Disability

It is difficult to know how many people have disabilities and if these are related to chronic illness, since many disabilities are not readily apparent. A lack of sensory cues to disability may reflect the nature of the disability, the degree of suffering, skill at covering impairment or difference, or the fact that an individual has learned to live through the experience and, at least in that moment, is managing. Disability also isolates and marginalizes through stereotyping, labeling, stigma, ignorance, and fear. I think part of the issue of disability can reside in each of us in terms of whether we are willing to help, to advocate, to acknowledge the needs of another.

How many children have never been diagnosed with a learning disability when one exists; how many individuals deal with chronic pain, respiratory problems, and cognitive deficits such as short-term memory loss? The intricacies of reasoning that lead to not wanting to share our needs and perceived inadequacies and, on the other side, the hesitation, even determination, not to acknowledge what we may sense, not to engage with another or inquire as in Cameron's (1992) "How are you?", in case we feel called to act are difficult to untangle. Do we dissociate from those with chronic illness such as migraine and disability? As Bergum (1994) suggested, our answer may be to become disembodied from the experience, seeing the other as object and in that process, ourselves becoming object. To understand the lived "I", Bergum (1994) said, "nurses must be re-embodied, must experience their bodies as part of their own subjectivity rather than as unfeeling instruments" (p. 76).

Definitions of disability vary with location, culture, sociopolitical structure, stability in a state, religion, age, and other factors. They are affected by social policies and can have a profound effect on those who are labeled by others or by themselves as chronically ill or disabled. Wendell (1996) noted that issues such as legal status and access to services are far ranging from the need for help with basic needs such as food and shelter, access to medical treatment, medications, physical aids for mobility, communication, and so forth. Barriers to accessing basis resources and opportunities such as education and employment present tremendous problems that impact identity as well as quality of life. Access to affordable migraine specific medications is one of the problems migraine patients face. Problems with lost school and workdays can limit the socioeconomic level individuals with migraines are able to attain and thus affects their quality of life.

Validation of disability is a key to health and wellness for recognition of the reality of one's life experience is part of acceptance into a community. Without such acceptance, when there is a lack of belief in one's experience, individuals are at risk for ridicule, isolation, lack of support, and inappropriate treatment. How a person thinks of himself or herself is tied to how others react to them and to evidence of disability or illness. Wendell (1996) asked us to consider what standard we use to judge disability. What is the norm for mobility for instance and how would this need to be modified based on growth and development, age and social circumstances, gender and other factors. Do we recognize how much standards of structure, function and ability are tied to culture, location, gender, sociopolitical factors and history? Disability is also often judged on the ability to earn money. What then is the fate of disabled women in the home? Amundson (as cited in Wendell, 1996) poses the question, is illness disability?

The disabled do not always require healthcare assistance; that is, there can be discontinuities in both the disability and the need if any for intervention. Wendell (1996), drawing on her own experience with chronic fatigue syndrome, noted that for her the key issue was the need to "identify the difficulties people face in surviving and contributing to societies" (p. 22). Some of her questions are thought provoking: Who defines disability in our profession, and for what purpose? One of the comments I liked most as I read Wendell's book was a paragraph from Fine and Asch (as cited in Wendell, 1996) in which they said that what people with disabilities really share is similar treatment by a disability phobic society. Wendell believed that as long as there is oppression and marginalization based on disability, then the term disability has value and we, as a society, have an ethical obligation to address what it means to be disabled.

The worth placed in the moments of living in which we cannot or have difficulty participating, can affect the sense of loss and distress experienced. Is the provision of resources and support and symptom management enough to alleviate suffering? This is one area of particular importance to migraine patients. Is that enough to reach the roots of suffering which I think can lie in paradigmatic thinking that is skewed in favour of dominant norms in various societies...being different from what is held up as normal, what is expected as normal appearance, function, roles. These are experiential questions and must be addressed as such. Narrative inquiry is one way to access the experiential answers.

The Issue of Burden in Chronic Illness

One can ask if chronic illness has a recognized place in society or if it is still largely hidden. When working with chronically ill individuals in the hospital over my years of nursing practice, I often felt a sense of wonder at the seclusion of the entire hospital experience. It seemed to me that the world of the chronically ill was generally unknown within society. As I have shared my personal narrative from chapter one, with colleagues, family and friends I have been admired for being brave and unafraid to really put it out there. I feel a little uncertain as to how I should react to these comments, for on reflection I wonder if they were not providing a clear view of the continued notion that illness experience is best kept to oneself.

Following this line of thinking one can also ask if society is prepared to sustain support for illness that can last a lifetime. Bleeker and Muylderij (1992), like Baron, noted that in the experience of chronic illness the body is no longer silent but calls attention to itself. Whether actively symptomatic or not, there is a constant awareness of suffering or the potential for suffering, and with this a loss of spontaneity in living. Weighing the risk of potential suffering and need for treatment against the benefits of an activity, be it physical, psychosocial or spiritual, is a part of daily living for the chronically ill. How do societies in general and health care professionals in particular help people to live with this continued uncertainty, this burden?

Another way of considering the burden of chronic illness is to look strictly at the numbers ... the cost of informal care giving. In an American study by Langa, Chernew, Kabeto, Herzog, Ofstedal, Willis et al., 2001), the national annual cost of informal care for elderly individuals with dementia was estimated at over 18 billion dollars. The researchers used data from the 1993 Asset and Health Dynamics Study, which they state was a nationally representative survey of people age 70 years or older (N=7,443). They looked at the number of hours of informal care required for individuals with mild, moderate, and severe dementia and then calculated the potential cost using 1998 wage figures for a home health aid, to estimate the cost of informal care. While this is not a Canadian study, the numbers are staggering and it does make one think about the extent of the financial burden chronic illness places on families and society. When I think about the fact that most informal care in Canada for illnesses such as dementia or chronic pain is provided in the home, and where disability increases and occurs over an extended period, I have to wonder how long families will be able to handle such demands. The majority of care-giving still falls to women in our society and women are forced to give up jobs or take leave to care for those who are ill. The assumptions underlying government policies, e.g. that family (i.e. women in many cases) will be there to care for those who have chronic conditions, will be willing to do it for no pay, will be willing to give up their own careers and personal goals to do this, are likely to come under some serious review (Wuest, 1993). This kind of care was never included in the original design of Medicare and never before have we needed as much support for caregivers as we do today and will in the near future as our population continues to age.

Harrison and Neufeld (1997) in a study on social support stated, "The concern for burden on others can be interpreted as giving priority to relationship maintenance over personal needs" (p. 600). They were talking about women using this rationale of sparing others for whom they care, such as children or spouses, in making decisions about requesting support or not. These facts point to the complexity of chronic illness and disability, a fact that individuals may or may not choose to share with others. As Chinn

(1996) suggested, we need to develop new approaches to dealing with chronic illness and this means including the voices of the patients and caregivers in policy and procedure discussions and decisions. We need a new discourse to help us understand the possibilities and vision when cure is not possible. This means a shift in framework to one that "brings everyone's thinking to include an image of how to engage this type of discourse, what the discourse consists of, and who could and would stay given any number of possible discourses" (Chinn, 1996, p. 2).

The Larger Context of Chronic Illness

Since recurrence is part of the diagnostic criteria for migraine, it is important to consider migraine in the larger context of chronic illness. Chronic illness is a highly complex topic and many questions arise as we consider what we know and understand about it, and to what we are really referring? Cameron and Gregor (1987) believed that chronic illness is a lived experience and included in their definition of chronic illness, "permanent deviation from the normal, caused by unalterable pathological change" (p. 672). Inherent in the notion of normalcy is the social construction of norms and the beliefs and values on which they are founded. Benner and Wrubel (1989) spoke of the human experience of loss or dysfunction in chronic illness as a reality in itself, while Jerrett (1994) focused on the permanent changes in how one lives, defines health and sets attainable life goals. Price (1996) reminded us that quality of life measures reflect social norms of the healthy and may not provide useful or meaningful goals for chronically ill persons.

These definitions provide only a partial understanding of chronic illness. Thorne (2000) noted that we no longer have a solid foundation on which to deal with and understand the increasing complexities of chronic illness. In her 1999 article, Thorne (as cited in Thorne, 2000, p. 6) stated that focusing on individuals and their experiences with illness presents an incomplete picture. We must also acknowledge and study the "socially constructed world" in which the experience of chronic illness is embedded (p. 6). She called for a wider vision in which we can start to understand the relevance of focused, directive inquiries, "in a much more comprehensive and complex kind of science" (Thorne, as cited in Thorne, 2000, p. 6).

Therefore, what do we know about chronic illness and how do we know it? Are there units of measurement involved? Is the experience of knowing related to words such as intensity, frequency, cause, intervention, or assessment? Do we define chronic illness in terms of suffering and disability? Where are the voices of individuals telling their stories of living the experience? Do we consider chronic illness from a process perspective where we identify signs and symptoms, come up with a diagnosis, treatment plan, self-care and rehabilitation options? Are we aware of contextual issues such as the impact of social norms, basic beliefs about health, illness, and disease, underlying assumptions about role fulfillment, identity, vulnerability and the need for help, and how we assign worth to human life? Have we found a way to define and measure life with chronic illness in terms of length, quality, and purpose? Do we fulfill the definition of knowing by identifying and addressing issues of marginalization, loss, choice, economics impact, and burden?

When we consider chronic illness, is our perspective biophysical, psychosocial, spiritual, cultural, or political? A biophysical perspective is often associated with a mechanistic view of the body, with measurement, and a mind/body dichotomy. The metaphor of body as machine is inadequate when trying to understand chronic illness, an experience affects mind, body, and spirit as a whole. If we use a process perspective, this does little to help us appreciate the experience of suffering or the temporal implications of chronicity. Human valuing is the basis for resource allocation and priority setting, key issues in health care delivery. How often do we consider the basis we use to assign worth in our society, or the ties between labels, such as disabled, and access to resources?

It is important to consider if our view of chronic illness is that of a generic experience (single reality) or an experience unique to each condition and individual (multiple realities). Are we aware that if we employ reductionist or realist methods in developing knowledge about chronic illness, this represents an ontological swing between a mechanistic and a holistic view of individuals? I think we can recognize similar functions to those of machines within the body but this in no way helps us see the inherent holistic nature of people and their experience of life.

Metaphors have always helped us grasp complex ideas. Thorne (2000) briefly discussed health care reform and the changing metaphors that underlie much of the discourse in healthcare, and how these factors affect care for the chronically ill. We know that erosion of traditional services that have supported the chronically ill and their families has paralleled downsizing and changes in healthcare delivery in response to difficult economic times. Thorne stated that, "the relationship between information and power in health care decision-making has altered with the information age and access to the Internet" (p. 6). With the rise of consumerism as a guiding metaphor, many individuals have explored alternative methods of care on their own, in a quest for wellness, a state based on a more holistic and innovative approach to health. This introduced the notion of wellness within illness as a possibility, an idea that moved us beyond the rather tired and inadequate concept of coping. Overall then we have seen a significant change in ways of conceptualizing and treating illness and in the goals being set for quality of life; however, this does little to help us appreciate the experience of suffering or the temporal implications of chronicity.

Thorne, Nyhlin, & Paterson (2000) lay a foundation for considering meaning and impact in chronic illness with the following stated assumptions on health care relationships: "that the professional is the expert, that the healthcare system is the legitimate gatekeeper for socially supported health care services, and that the ideal patient is both compliant and self-reliant" (p. 303). They noted that discrepancies exist between these assumptions and the reality of chronic illness. Over time, the expertise of the *patient* may exceed that of the professional (Brown & Piper as cited in Thorne, et al., 2000). The chronically ill individual may look to long-term goals of improved health, seeking help in a system that focuses on acute illness and efficiency in moving people through the system as quickly as possible. The third problem arises when compliance comes up against self-reliance (Thorne as cited in Thorne et al., 2000). Decisions individuals make, based on their intimate knowledge of their embodied experience of illness, may run counter to advice from health professionals, resulting in the negative label of non-compliant. Caring for the chronically ill is very different from caring for those with acute, short-term illness. Professionals need to engage with the patient and acknowledge the individual's intimate understanding of how the illness affects his or her personhood, and work together toward solutions.

Thorne et al. (2000) introduced the notion of having to prove illness exists and then negotiate for care. How does one find meaning in such contradictions? What is the impact on identity and self-esteem? I cannot help but think of the dilemma for individuals who have chronic illness with acute episodic exacerbations, such as asthma, migraines, multiple sclerosis, and rheumatoid arthritis, given the different philosophies underlying the care of acute and chronic illness. Does our healthcare system parallel our justice system where individuals are presumed innocent until proven guilty or healthy until proven ill by a healthcare professional? If this is the case, the state of innocence and health are both subject to the same assumption of deviation from normalcy, as a social construction. Thorne et al. (2000) stated that in considering the need for respect, trust and control within healthcare relationships with those who are chronically ill, "our failure to afford systematic attention to their significance complicates and accentuates the burden of chronic illness for those afflicted" (p. 309).

Thorne noted that Joachim and Acorn analyzed our individual complicity in "the larger context of how we understand chronic illness", stressing that we need to recognize that our interpretation of chronic illness research is based on assumptions, the origin of which we may not recognize (as cited in Thorne, 2000, p. 6). Joachim and Acorn (2000) discussed the interface of stigma and normalization in chronic illness experience, and included "medically diagnosed diseases as well as chronic states such as disabilities" (p. 38) in their definition of chronic illness, noting the "psychological stress imposed by society as a result of how it views the conditions" (Joachim & Acorn, 2000, p. 37). According to these authors, understanding of the chronic illness experience is enhanced if we consider the interdependence of processes that either set individuals apart as different, or promote normalization. They challenged us to step back and consider the epistemological and ontological basis for what we think we know about the experience of chronic illness and disability and its place in society.

Temporality

Time is a key concept in chronic illness, referring to a "limited stretch of continued existence; period or point in the course of this" (Hoad, 1996, p. 494). I believe that reflecting on personal stories, snapshots of the experience of living with chronic illness over time, will provide a clearer understanding of the impact of social responses to persons with chronic illness, in their relationships with others. Merleau-Ponty (1962) suggested that "our experiences, inasmuch as they are ours, arrange themselves in terms of before and after, because temporality, in Kantian language, is the form taken by our inner sense, and because it is the most general characteristic of 'psychic facts'"(p. 477). However, he noted that individuals cannot be a series of psychic events since the subject and time must communicate from within the individual. Accordingly, it is in the study of the intersection of dimensions or attributes, e.g. temporal, sexual, spatial, that insight into the subject as a whole is possible. Subjectivity is temporality and he stated that, "I can take a certain period of my past life by unfolding it anew according to its own tempo" (Merleau-Ponty, 1962, p. 491). The temporal element of chronic illness can only be addressed through narrative, a concept where time is a central characteristic.

There are obvious implications in the area of self-identity when we consider chronicity. Because we know some conditions, for example diabetes, are chronic, preconceptions about the condition are often immediately applied to the individual upon diagnosis. These may be positive or negative depending on how society views the illness. However, we still need to consider what happens when an individual lives with an illness for a long time. Years of experience living with chronic illness builds up complex multiple identities as individuals work to find meaning in living through the challenges chronic illness presents. Layers of meaning come not only from within, but also from stories others tell about individuals with chronic illness.

Seeking help

The inability to manage usual tasks and roles due to pain or limits on mobility or impaired breathing, is one factor that may influence the decision to seek professional help, although disability seldom appears on assessment forms or plays a major role in diagnosis. Embedded within disability is the reason for these limitations, the presence of noxious symptoms and the psychological and emotional distress they cause, i.e. suffering. The experience of such symptoms and distress can increase or even be the root cause for some symptoms. One could ask if suffering then, is as much the disability as the impairment of function or contextual factors that interfere with full participation in life. Perhaps living through disability is what suffering is all about.

Programs of research around self-care decision making and compliance have provided some insight into help seeking behavior but relatively little is known of the experiential daily decisions required in living with chronic illness. To understand the experience of *seeking help* it is necessary to reconceptualize it as "personally constructed, changing over time and in various situations, entailing a complex interplay of mediating and contextual influences, and arising from authoritative knowledge that evolves in living with the disease over time" (Paterson, Russell, & Thorne, 2001, p.7).

Research using models around seeking help, often reflected early conceptualizations of chronic illness, e.g. Health Belief Model (Walsh, 1995), Theory of Care Seeking (Bourgault & Gratton, 2001), Theory of Reasoned Action (Howland, 1997), Self-Regulatory Model of Health and Illness (Kersh et al., 2001), with little or no attention to the individual experience of seeking help. While studies on factors such as stigma (Joachim & Acorn, 2000), normalization (Patrick, Knafl, & Murphy-Moore, 1999), health care delivery issues (Byrne, G., & Heyman, R. (1997), and attitudes toward patient expertise (Thorne, et al., 2000), provided insight into when and how individuals seek help, real understanding can only come from the voices of patients and nurses immersed in the experience. It is through their voices that we as a society will come to understand how factors such as uncertainty and suffering in chronic illness affect the process of seeking help.

Understanding seeking help.

Seeking help with illness is really about suffering, finding comfort, and healing. It taps into how each of us conceptualizes health and illness and how we understand and feel about those who ask for help in addition to how we as a society choose to address the needs of those who are vulnerable. People with any chronic illness often develop a set regime of self-care and, as this begins to fail, can be faced with the prospect of seeking help. Seeking help at that moment is often not just about oneself. Somewhere within the experience of increasing illness, one has to decide when others must take on our responsibilities. Whether the individual recognizes it or not, this represents a gradual loss of control and a change in identity.

To understand an individual's response, when seeking help, one has to consider the context. "Understanding the relational and configurational context allows for a more appropriate interpretation of what significance things have for a person (Leonard, 1997, p. 51). The significance of the reception at a hospital Emergency room or a clinic remains unknown unless one attends to the relationship at that moment and places it in the larger context of the individual's life. Significance is tied to past experiences and projections into the future, not just the now. Heidegger (as cited in Leonard, 1997) used the term temporality rather than the more linear concept of time, describing it as directional and relational, a space that can be filled. This space has a "dimensional content" (Heidegger as cited in Leonard, 1997, p. 54). Leonard (1997) noted that "Being-in-time, on the other hand, cannot be studied except within the context of its having-been-ness and being-expectant, it's past and future, by which it is constituted" (p. 54). To use my own experience as an example, the experience of handing over responsibilities and seeking help requires both an understanding of the having-been-ness of those responsibilities, the concerns about childcare or present work commitments, and the being-expectant elements, e.g. would I be able to work tomorrow?

Another way to deepen our understanding of seeking help is to consider what meanings people apply to the terms. What does it mean to seek help? In a traditional sense, the word "help" refers to providing assistance or "what is necessary to accomplish a task or meet a need" (Costello, 1996, p. 623). A less positive frame may occur to us with the word "help" suggesting a lack of something or a need for assistance. We may think of helping someone meet a goal or fulfill a desire. In this case, help is viewed as a positive action or a provision of material assistance that facilitates movement toward a chosen goal. Help as filling a void that threatens in some way or creates a need rouses a less positive connotation. It is true that some needs are associated with "normal" processes such as giving birth or tending to our frail elders. Such acts are not only sanctioned by society but are expected. In other cases needs are equated with personal failure, with challenges to culturally and socially defined norms of behavior, with bad luck or even the will of God. Responses to needing help can range from the marshalling of material and human resources through friends, family, and community services to an immediate or gradual reaction that ostracizes people and pushing them to the margins of society. The response to the need for help in chronic illness runs the full gamut.

To "seek" means to, "try to find or obtain" (Hoad, 1996, p. 427) and implies a conscious attending to a need by looking for and endeavouring to attain assistance. For an individual to seek help involves recognizing that they have a need, that they cannot fulfill this need themselves, that help is accessible, that the cost of sharing one's vulnerability is bearable, and that they have the ability to take action to seek that help. It implies a belief that help probably exists, and a hope that it can be found. Whether we take action on behalf of others, or ourselves, seeking help means taking on new responsibility. To seek help for another involves less risk for, in western society, people generally believe that care for the vulnerable is a social responsibility. Who is deemed legitimately vulnerable is culturally defined, with children and the elderly most acceptable as people who need help. However, for a young or middle-aged adult seeking help society is less charitable, falling back on our value of independence, our admiration of stoicism, and our fear of the face of suffering and its call for action. To seek help from another is to bring attention to human mortality and with this the evocative call to responsibility for another human being.

Barriers to seeking help.

To open one's life to others, revealing personal liabilities, is to create new vulnerability. Yet is that not the challenge that haunts each one of us when we are in need of help, to trust enough to risk exposure? As patients we have only a minimal understanding of how the experience of living with uncertainty, vulnerability, and suffering in chronic illness, a reality that can earn individuals the label of a threatening "other", impacts nurse-person interactions. Add to this the uncertainty about the reaction of others to our call for help and you have a better idea of the fear that can be associated with seeking help.

Today “help” is often combined with the term "self", i.e. "self-help", with an implied meaning of being responsible for helping oneself. In this view, the individual is expected to learn skills or make lifestyle changes that prevent, ameliorate, or solve conditions of need. Finding this balance between personal and situational tensions is part of the experience of chronic illness. However, chronic illness also encompasses an element of "otherness", a label applied, felt and lived. The individual experiences being out of step with the rest of the world, separate from and yet part of the general life milieu, accepted and yet marginalized. The impact of suffering and the self-imposed label of otherness in all its colours can create the strongest barrier to the individual seeking help.

There are many ways to ask for help. There is the reasoned request for help *"I've had this heavy pain in my chest for three hours. I'm a bit short of breath. I haven't eaten since early this morning and anyway it's different from indigestion".* There can be the loud cry *"Help ... help me"*, panicked words shouted for all to hear! There is the whispered plea by someone hoping for a receptive ear, *"Help me, oh please help me!"* Then there is the silent cry for help that is only visible through the embodiment of suffering, *"Why aren't you helping me; can't you see I need help?"* Why do we listen to the reasoned voice of some and not to others? Why can some call openly for assistance while others feel they must voice their needs in hushed tones? Is the one who can shout to all, a strong resilient individual or does such voice reflect a socially acceptable state of need? Are we more likely to get help when the threat may extend to those in a position to provide help? What kind of vulnerability is revealed in the whispered cry? Is this the voice of suffering or the voice of marginalization? For those whose need must be inferred, is this the sound of stigma, of fear, of the hidden world of suffering?

Our understanding of the impact of uncertainty and suffering in chronic illness on seeking help and on nurse/person interactions is minimal. Assessment of the individual's suffering, the level of disability a condition is causing, and the burden of a chronic illness on all aspects of an individual's life has been neglected in some areas of chronic illness such as migraine (Loeser, 2005).

Benner (2000) reminded us that human beings succumb to sickness, not just to diseases, and in so doing may lose the ability to connect with others. Nursing is about "the social sentient body that dwells in finite human worlds, the lived body that gets sick and recovers; suffers and is altered during illness and pain and engages with the world differently upon recovery" (Benner, 2000, p. 5). While attending to suffering is inherent in the philosophy of nursing practice, the governing process under which most nurses provide health care is directed at the medical goal of cure. When we think of those with chronic illness, where cure is often not an option, we need to give careful thought to what we need to know about the chronic illness experience to meet the needs of those who ask for our help.

Chronic Illness, a Narrative Experience

The idea of story as history suggests the continuity inherent in experience and from this the sense of temporality. Dewey (as cited in Clandinin & Connelly, 2000) saw experience as both personal and social, with continuity meaning that experiences grow out of one another. These ideas are central to the work in narrative inquiry conducted by Clandinin and Connelly. They undertake narrative inquiry within a framework consisting of a metaphorical three-dimensional narrative inquiry space, a framework that addresses the three dimensions of context as place, temporality, and personal/social dimensions.

By tapping into the history of individual and family experiences of health and illness through the medium of narrative, nurses can know their patients better and understand the meaning attached to experiences. As Bergum's (1994) work on relational ethics helps us appreciate, knowledge about an individual's unique experience with health or illness (inherent knowledge) does assist us to understand the issues that influence these happenings. It is in understanding the perspective of others, and how their viewpoint evolved and continues to change, that we start to appreciate the possibilities for intervention that are both right and appropriate for the situation. Bergum (as cited in Marck, 2000) suggested that we can best understand our ethical commitments, in relationship, alluding to Gadow's (1995) idea that we need to frame nurse/person relationships, "from a place where illness is a 'situation to be lived through', not a problem to be solved" (p. 7).

Perhaps the experience the chronically ill have most in common is dealing with a common health care system; every healthcare system is subject to contextual, historical, and human forces, all of which shape the personal experience of illness (Kleinman, 1996). Gadow (2000) suggested that we need to understand the significance of the present, for more than its current significance. We have to consider individual experience as situated and continuously unfolding anew when present events are revisited and reinterpreted in light of past experience. Narratives of the present help us see the past from different perspectives and in much the same way open new possibilities for understanding the future. The notion of understanding as always situated helps us see the possibility for multiple realities. Gadow (2000) reminded us that there is no uninterpreted location from which to make comparisons of experiences. As she said, without a viewing point, all we have is fiction.

Whether my viewing point is through a personal or professional lens, I believe the issues, that confront me as a woman living with chronic migraines and as a registered nurse, are experiential and ethical in nature. When I consider the professional perspective, I am caught by Gadow's (2000) idea that we are inescapably situated. As I have pondered the day-to-day discussion of nursing practice by nurses, to which I have been privy, I see the importance of understanding the perspective of each story. For example, I have seldom heard nurses using terms generally associated with ethics. Instead, my experience has been that nurses frequently express their ethical concerns about quality nursing care in terms of grievance over understaffing, insufficient resources, excessive workload, and unsafe working conditions. This suggests to me that concern for patients is at the heart of nurses' thinking, but the impact of the current system on nurses has become the discourse through which these concerns are expressed. This is an important dialogue but I suggest it moves the discussion one-step away from the underlying concern for those we serve.

Many researchers have considered the experience of chronic illness and the nature of the nurse-person relationship when the patient is seeking help with chronic illness. Questions about the nature, scope, and object of nursing, nursing knowledge, and nursing practice are philosophic questions amenable to scientific study (Kikuchi, 1999). Yet, while many concepts related to specific chronic illnesses, responses to illness, and nursing interventions have been identified, a dearth of research on the "totality of the experience or on the theoretical connections among these concepts" exists (Thorne & Paterson, 1998, p. 2). Also missing is a thoughtful look at the experience of health and illness in individuals situated and embodied in physical and psychosocial contexts that are not stable, but rather continually changing over time. It is in the stories, the narratives of individual and social histories where understanding may lie.

If we consider Gadow's (2000) voiced idea that understanding is situated, it becomes important to consider the viewpoints within research. Thorne and Paterson (1998) described a recent shift in perspective within research studies of chronic illness, from that of the outsider to an insider perspective, with most studies focusing on specific concepts and populations. According to Gerhardt (1990), an insider perspective "represents patients as analysts of their chronic illness experience, articulates disease management within the context of a more general life management and, more recently, depicts patients as active agents in attaining a desired outcome" (p. 2). Placing questions of disease management within a life context is placing it within life stories. This also indicates an increasing belief that professional health caregivers are limited in their expertise within the area of illness experience. Mutual recognition and valuing of expertise, be it based on the lived experience of illness or professional healthcare practice, provides a foundation for working with patients as partners rather than passive recipients of care. The unfolding of life stories provides a useful epistemological approach to learning about the ontology of chronic illness. To presume an understanding of chronic illness outside of life stories strikes me as similar to trying to judge a book by its cover.

Given the trend in research toward holism and the search for more effective and efficient provision of care, one can ask why we continue to be concerned with individual traits, for example, hardiness. Hardiness by itself is not a useful concept in planning and implementing care. Do we not recognize the incongruence between this kind of approach and our stated ideals about holistic practice? In my opinion, concepts such as coping are closed ended ideas. Coping means getting by and managing, it does not promote personal grow, wellness or feeling a sense of hope. As someone with a chronic illness, I find terms, such as adaptation and hardiness tend to objectify people, place limits on expectation in life, and do little to promote quality of life. In short, they marginalize people and can be at the heart of ethical dilemmas faced by nurses in practice.

Healthcare literature contains many accounts of the challenges and ethical dilemmas of chronic illness ranging from managing complex treatment regimes, to dealing with side effects and stigma, preventing loss of function, and so forth (Cameron, 1998; Gadow, 1994, Joachim & Acorn, 2000; Paterson, et al., 2001; Spiers, 2000). The risk for psychosocial and spiritual dysfunction in chronic illness is significant; the need for social support, and material and human resources is endless (Anderson, Dyke, Lynam, 1997; Asbring, 2001; Auria, Christian, & Richardson, 1997; Coe & Neufeld, 1997). Even when we place a positive spin on a situation and look at illness as providing an opportunity for personal growth, this harkens back to the old saying of adversity building character. Is this how we really want to view illness?

If we bring narrative to bear on issues of suffering and self-care we are able to bring to light the possibilities for quality in one's life, but at the same time we need to recognize that narrative will also illuminate the challenges. We must always consider that suffering may be far too intense to allow for the potential for growth during a crisis, so personal growth is not always a reasonable goal. Our current conceptualization of self-care decision making has often resulted in patients being blamed for their health problems and a failure to recognize the impact of the individual's life context on how health decisions are made (Garro, 1998). The result is that healthcare treatment decisions are made using an incomplete picture of the actual experience of living through the illness. I think this shows a fundamental lack of understanding of the embodied experience of living through chronic illness.

An example of the importance of a holistic approach can be seen in the area of assessment. Since migraine can mask other serious health conditions, assessment is a key to both diagnosis and treatment. While in-depth assessment is best handled in community settings, when the individual is not in severe distress, neurological assessments should always be carried out in Emergency room and critical care settings to rule out life-threatening problems. Given that healthcare providers use new drugs very specific to the treatment of migraine pain today, it has become even more important to ensure that migraine is accurately diagnosed. However, there is little evidence in the literature of consistency of approach to assessment; for example, using a pain measurement instrument, doing neurological assessments, or consistency in how often or when assessments are done. A focus on physiological measures with little attention to patient narratives, especially in the area of disability is common. Chronic pain is about pain over time and assessment needs to be tied to this idea. Assessment approaches, such as listening to patient stories that tap into the temporal ongoing state of experience are critical if nurses are to meet the needs of our patients.

Some authors report that patients are generally symptom free between migraine attacks. I wonder how true this is. When I search my own experiences and that of others I know who have migraines, I think symptoms such as fatigue that follows a migraine or the sense that the pain is just under the surface, a feelings that can result in a reduction in activity for fear of bringing the headache back, are important. I do not consider this symptom free. So what does symptom free mean? The answer lies in personal narratives.

One of the interesting issues in the Holmes, et al. (2001) article was the discussion on whether or not disability was a part of assessments done by physicians. The authors concluded that many physicians do not assess for disability and many patients do not offer this information. Given that disability, resulting from pain, is one of the reasons that people seek help in the first place and that it should be a consideration in treatment decisions, this is an appalling finding. These authors concluded that migraine is under diagnosed and under treated, in part due to a significant communication gap. Patients unhappy with treatment results stop consulting. Physicians and nurses are sometimes uninformed and lack skill in engaging with patients. Dissatisfaction was defined by patients as "lack of overall relief, delay in onset of relief, and incidence of side effects" (Holmes, et al., 2001, p. 8). The question becomes one of communication or institutional policies. Does a problem arise because physicians are unfamiliar with current migraine treatment, or is the problem lack of consultation time? A narrative approach to practice has the potential to bring out key issues that if unrecognized can severely compromise care.

We know that many problems in chronic illness are the result of social determinants of health and access to healthcare. We need to advocate for research aimed at addressing these issues, in addition to looking at individual characteristics that contribute to illness and promote health. I believe part of the reason we fail to champion the cause of chronic illness is because it means a lengthy commitment. Chronic illness is seldom fast paced, often not immediately life threatening, and just does not hold up to the exciting world of acute care the media loves to portray and governments love to fund. In a study on nurses' communication with accident and Emergency department patients, one Emergency room nurse stated about major trauma, "It's what I think we're here for" (Byrne & Heyman, 1997, p. 7). These authors noted that major trauma patients "provided nurses with an opportunity to feel both technically expert and rewardingly useful" (p. 7). So who decides what is useful? I conclude from this study, that being skilled in performing tasks and feeling useful are important prerequisites for job satisfaction. I can acknowledge the rush that comes with saving lives and fast-paced intervention. Perhaps what we need in chronic illness is a good public relations campaign to help healthcare providers realize that an Emergency room visit, for a woman with a severe migraine, is a real crisis. The difference is that the acute trauma event is often a one-time event, whereas the migraine patient knows this could and probably will happen again. The difficulty of facing this reality over and over is hard to comprehend. We need the voices of those in the midst of the experience to help us grasp the desperation this can create. Once again, the need for a narrative approach to care is highlighted.

The perception that tasks and technology are valued and are more important than the relational work of nursing is validated when we hold up as heroic and rewarding, the fast paced, exciting, life and death world of Emergency nursing. As a society, we place high value on the heroic efforts of those who protect and care for the public. We are amazed when significant injuries are fixed or organ function restored. We see these as life and death situations and what is at stake is obvious. Chronic illness can certainly be life threatening, but the timeframe is longer and the disease process can be less visible. I can see a potential for trivializing patient needs requiring non-technical interventions such as psychosocial care or education. In a discussion of the role of narrative in ethical decision-making, Charon and Montello (2002) stated that "narrative approaches to ethics recognize that the singular case emerges only in the act of narrating it and that duties are incurred in the act of hearing it" (p. vix). The issue of how social value and worth are determined is an ethical dilemma nurses need to consider. Nurses need to understand the situation narratively in the context of a life unfolding.

This ties into Levinas's (1985) notion about the call to responsibility that arises when we see the face of the other. Issues around provision of care, resource allocation, preservation of dignity & autonomy are choices typically made by healthcare providers & ethicists. Yet patients are the true ethicists, making the choices with which they will have to live (Bruner, 2002).

Medical and technological advances have created the need to balance the advantages of greater longevity against the real possibility that most of us will experience one or more chronic conditions in our lifetime. As we struggle with ethical dilemmas around resource allocation, quality of life issues, and the increasing complexity of health care needs, we need to hear from all perspectives. A number of studies have hinted at the negative impact of limited resources and changes in staff mix and numbers on how healthcare professionals are able to practice. Rather than continue to put all of our efforts into increasing resources, I suggest that how care is delivered and how each of us cares for ourselves are equally important issues to address.

Narrative is evident in all aspects of nursing practice, in patient stories, notes made during shift change reports, charts, test results, stories families tell, and in the words of other health professionals. These stories are interpreted in light of our scientific knowledge, personal experience, anecdotes and previous cases, and the social and cultural narratives with which we are familiar through the arts, mass media, literature and so forth. It is important to realize how often our thoughts on right or wrong are influenced by sources such as television and newspapers, each with a particular storyline that is obvious when reflected upon. Zoloth and Charon (2002) remind us that case studies used in the case based approach to ethics known as casuistry are based on an assumption that "the world of the other is true" (p. 3). When an individual enters the life world of another through narrative, it is essential to know what world is being entered. What are the norms, values, and beliefs at play? It is important to recognize who has power and who are the decision makers and the moral agents, for they may not be the same individuals? How are decisions made in this world and how are ideas such as personhood and the good life defined?

Narrative discourse records place and passage within the context of time. It also records calls to responsibility in discussions of options for action. Within those discussions, are the consequences for the lives of others considered if one course of action is chosen over another? What if the other is not included in those discussions? Zoloth and Charon (2002) emphasized the importance of narrative competence in illuminating the "meant from the said, the said from the heard, and the heard from the understood" (p. 24).

Zoloth and Charon (2002) saw the identity of the moral agent resting within the encounter between patient and clinician. Levinas (as cited in Zoloth & Charon, 2002, p.

28) believed that the encounter with the other (other than self) results in a claim placed on us to be responsible for the other. The call to responsibility is in the face of the other, and in our shared discourse is a record of that call and our response or lack of response to it. Ethical decisions vary in urgency, intensity, and consequences and as Zoloth and Charon noted, can involve numerous conversations as various options are discussed. The story of this ethical discourse is then recorded over time. Every decision in nursing practice reflects a moral stance. Narrative is being used in place of or as adjunct to principle based decision making in many disciplines including history, sociology, anthropology, law, education, and psychoanalysis (Charon, Banks, Hawkins, Hunter, Jones, Montello, & Poirier, 1995). Narrative is valued in decision-making, as a complement to deductive and inductive thinking, and as a method of inquiry in nursing. Recently we are seeing nursing looking to ethical decision-making models that make use of narrative. Charon et al. (1995) stated that through the telling and retelling of stories, the complexity of events unfolds and "unlike logico-scientific knowledge, narrative knowledge configures singular events befalling human beings or human surrogates into meaningful stories" (p. 601). The application of narrative concepts such as plot and intention can help in posing and confirming hypotheses (Charon et al., 1995). Analytical approaches have tended to problematize human life. Narrative methods draw out the cultural and biographical context, placing the ethical issues in the context of the patient's life (Jones, 1988, as cited in Charon et al., 1995). In addition to providing a better way to conceptualize and understand moral dilemmas, the aim of narrative ethics is early recognition and intervention to prevent ethical quandaries.

Summary

Chronic illness is of primary importance in healthcare planning today. Migraine, while one of many serious conditions, affects a large population with staggering direct and indirect costs in both human and material terms. Despite considerable advances in our understanding of pain and our ability to treat it, we continue to find individuals experiencing significant problems in attaining relief from migraine pain. I believe the world of the chronically ill is largely unknown to many, including nurses. There is no way to really measure suffering and the voices of those immersed in the experience of chronic illness or in the experience of providing care to those who are chronically ill have seldom been heard. It is time to embrace other epistemological viewpoints, such as narrative as experience, in order to gain the knowledge healthcare providers need for ethical care. This study is what I hope will be the first of many to uncover the world of chronic illness and provide a richer, more authentic basis for planning care for the growing number of individuals with various chronic conditions. By listening to the stories of those who seek help, we as nurses, are privy to the context of their health and illness experiences and through the interactive process of narrative have an opportunity to realize how the care we provide is contingent on our stories as well as the stories of those who seek our help.

Chapter III Methodology

Choosing a Methodology

Choosing a methodology for this study was the natural outcome of considering my topic, *the experience of women seeking professional help with severe chronic migraines*, and my taking two different methods courses. It became obvious that Narrative Inquiry would provide the most appropriate framework for exploring experiences that unfold over time with the telling, and memories that are embodied, not just cognitive and emotional. In this chapter, I review narrative inquiry, as a way of thinking and as a reflective relational research methodology, and the fit with a study on seeking help with a chronic illness. I then present a section with the logistics of the study, how ethical considerations were addressed, and how the issue of credibility in a qualitative study of this nature was handled. The entire chapter is written with the underlying foundational belief that seeking help is an ethical issue, that nurses are called to ethical practice, and that the knowledge needed to understand chronic illness is inherent knowledge, a result of the collaboration of nurse and patient in relationship determining how best to treat the patient.

In an editorial commentary, Chinn (1996) challenged us with the following question: "Why in the face of clear inability to 'cure' a disease do nurses and other medical care providers continue to move within a frame of reference oriented toward cure?" (p. vi). As a starting point in addressing this question, she clearly stated that any viable framework (and I believe this applies to research as well as nursing practice) must have the "interests, the experience, and the voice of the person with chronic illness in the center" (p. vi). Such a framework would illuminate issues directly related to the person as an individual with a particular philosophical and ethical perspective, a life story that includes the experience of chronic illness, the hopes of this individual, and the roles of others who are part of the ongoing narrative of what the ill person is facing. The challenge would be to uncover, understand, and find meaning in how everyone involved sees the situation. Chinn saw this as an opportunity for a truly shared discourse in which needs and desires could be highlighted with appropriate resources and interventions explored.

Thorne and Paterson (1998) commented that research on chronic illness has moved in the direction of a more psychosocial understanding and away from biomedical oriented models. Having established chronic illness as a dynamic process and a generic specialty within the discipline of nursing, the focus has shifted to a contextual, more person-centered approach. While research into specific conditions is needed, knowledge development on chronic illness as a concept in itself is being addressed through more collaborative research methods. Greater accessibility of healthcare information, consumerism, healthcare reform, a stronger sense of self-care agency in achieving health on the part of individuals, availability of alternative and complementary therapies ... all of these changes have impacted the experience of chronic illness (Thorne & Paterson, 1998). With this, nurses must change how we conceptualize chronic illness and the role nurses take in providing care for those who suffer from such conditions.

As I planned my study into the experience of women seeking professional help with severe chronic migraines, I chose narrative inquiry as a research method because I believed the heart of the chronic illness experience lay in the relational interactions individuals live through. Finding meaning in these experiences and incorporating changes in lifestyle, personal abilities and goals, changes in function and perhaps appearance ... these are complex processes that cannot be captured in one time interviews, surveys, or through the use of instruments. They are part of the individual's life narrative and it is through the telling and retelling of their stories that I believe insight into the experience lies. I wanted to bring the experience of living with chronic illness to light, in a relational context, explore it in terms of personal and professional/individual experiences, and the relational experiential context of the inquiry, which would help the participants and myself collaboratively find meaning in what we think we know.

Reflective Relational Research

Narrative inquiry.

Narrative inquiry is a recent addition to the methodologies nurses use in researching human living. We live "storied lives on storied landscapes" (Clandinin & Connelly, 2000, p. 8) and what better way to access lived experiences, and provide visibility, value, order, and meaning to our own and the experiences of others than through narrative. By listening and writing stories of experiences, reliving those experiences in the telling, and then rewriting the stories again as we inquire into them, researchers gain insight. Writing is not merely a record of what is said; rather to write is to present an organized and considered argument (Rolfe, 1997). Less spontaneous and subjective in nature than speech, our written thoughts are given a distance that provides a perspective that facilitates analysis of the thoughts, words, feelings, actions, and embodied memories.

In general, metaphor, a narrative element, underlies how we think about many issues, and its use has both the potential to widen or narrow our perspective. In striving to consider both the particular and the universal, the pull of different views demands personal engagement to help untangle the complexity (Zoloth and Charon, 2002). Engagement is another key element in narrative inquiry for a story always involves interaction with oneself, the environment, or another individual ... it requires an audience and that audience is engaged even as it is named. Those who undertake narrative inquiry respect personal experience, recognize the relational source of identity, and engage in revealing the complexity of life situations and choices. With an emphasis on exploring the social context of a situation, important principles are revealed, as is more of the individual's identity. Nelson (2002) explained that identity and perception are key elements that influence reaction. Unlike the juridical approach that stresses the present, narrative allows an exploration of the past (explanatory) and the future (action guiding) perspectives. The juridical approach, in Nelson's words, looks sideways, and can only "flesh out the here and now" (p. 40). Narrative inquiry helps establish mutual understanding that is justified by being embedded in the stories of the past, present, and future. Through narrative inquiry, knowledge is constructed and interpreted within a relational space where issues of voice and power can be raised, thus addressing some of the institutional barriers to ethical practice. It provides a way to explore conflicts among ethical principles, address the realities and practicalities of clinical practice, brings out matters of context and the specifics of relationships and provides rich detail that helps clarify ethical issues (Nicholas & Gillet, 1997, p. 295).

Narrative inquiry is a relational methodology and the researcher enters the field with the intent of establishing a safe and supportive relational space or forum in which to explore the phenomenon of interest. The researcher negotiates her ongoing presence in the field and moves in and out of this context over a period to provide time to immerse herself in the phenomenon and then to reflect on and write about what has been learned (Clandinin & Connelly, 2001). Using narrative inquiry the researcher can apply innovative strategies for data collection (e.g. interviewing, participant observation, and the use of memory boxes, diaries, letters, and art forms), allowing for multiple ways of knowing participant experiences.

Researchers, philosophers, educators, administrators, and practitioners in nursing have followed the lead of other practice professions such as education and medicine in recognizing narrative inquiry as a means to access and understand the everyday experience of practice and the experience of being a recipient of care. Narrative inquiry has the potential to illuminate the challenge of recognizing suffering, finding meaning in human living, and understanding the call to moral action within practice. The use of narrative elements such as telling, listening, hearing, feeling, and being moved to action are useful in constructing and interpreting knowledge; language contains the power of description and definition, and exposes "what human beings see and can know" (Charon & Montello, 2002, p. x).

The Importance of Researching Chronic Illness

Epping-Jordan, Pruitt, Bengoa, & Wagner (2004) discussed the increasing primary concern of world healthcare systems over chronic illness. A new framework for care, from a global perspective, the Innovative Care for Chronic Conditions (ICCC) framework has been developed through collaboration of the World Health Organization and the MacColl Institute for Healthcare Innovation. It includes changes at the micro (patient and family), meso (healthcare organization and community), and macro (policy) levels to help develop more flexible delivery systems congruent with local needs and resources (Epping-Jordon et al., 2004, p. 299).

Chronic illness has become a major concern in health care, not just because of increasing incidence (Hoffman, Rice, & Sung, 1996) and the complexities presented by more comorbidity resulting from technological advances and changes in the demographic profile of many populations (Centers for Disease Control and Prevention, 2003; Nadkarni, 2004), but because most healthcare systems were designed to deal primarily with acute illness (Gask, 2004). The discord between philosophies and approaches to acute and chronic illness care and the escalating economic burden for both families and societies that comes with higher rates of chronic illness, poses a threat to both the economic, sociopolitical, and conceptual foundations of healthcare delivery systems. Indirect costs of chronic illness due to decreased productivity, long term disability, individuals leaving the workplace to care for chronically ill family members, and the impact of stress on lay caregivers, many of whom are older adults, is also placing significant pressure on available human and material resources (Wuest, 1998).

The meaning of living with illness is embedded in a sociopolitical and cultural context. It reflects changes in society and health care systems. There have been significant shifts in the focus of nursing research related to chronic illness based on changing understandings of concepts such as health and person. As one of the more recent methodologies used for investigating chronic illness experiences, narrative inquiry has the potential to uncover the cultural, social, and institutional narratives in which nurses and patients are embedded and the resulting layers of meaning that over time have been used to construct ways of conceptualizing the experience of human living. For the individual with chronic illness, knowing comes about through living the experience, researching the illness, and listening to others with knowledge of the medical condition and of the reality of living with the illness. One of the challenges in chronic illness is to have an individual's expertise recognized and valued by professional health care providers. I believe we need to think of self-care decisions made by patients as clinical decisions. We also need to examine the threat patient expertise seems to pose to nursing identity, a situation that may account for some of the reticence to acknowledge patient expertise in nurse/person interactions.

Ways of Knowing

Whether referring to professional or lay expertise, the question is, is it sufficient to use knowledge of facts, procedures, risks and potential benefits as a basis for intervention decisions. Is it enough to know about chronic illness in a taken-for-granted manner without considering how we know and in what way we know, or even the potential for further knowing? What is it that nurses and patients with chronic illness need to know to provide care or self-manage their illness? This question is about more than an overview of facts relating to the chronic illness experience. It concerns a deeper level of understanding where we examine how chronic illness is conceptualized. Through narrative inquiry, one can articulate the assumptions giving rise to abstractions and patterns of knowing in nursing (first identified by Carper (1978) with additional development by Heath, 1998; Munhill, 1993; White, 1995; and others). These can be applied to chronic illness, to different perspectives on knowing (Drew, 1988), to beliefs about health in light of our relationship as human beings with the world in which we live (Kleinman, 1996), and to actions and knowledge that help us see and find meaning in life experiences (Koch, 1995).

Many researchers have considered the experience of chronic illness and the nature of the nurse-person relationship when the patient is an individual seeking help with a question related to that chronic condition. While the importance of dominant belief systems and health system ideologies on how chronic illness is experienced and managed was evident in past research, these factors were rarely considered in analysis of data. Based on their meta-study on 158 research studies on chronic illness, Thorne and Paterson (1998) described a shift in viewpoint from that of the outsider to an insider perspective on chronic illness, with most studies focusing on specific concepts and populations. According to Gerhardt (1990), an insider perspective "represents patients as analysts of their chronic illness experience, articulates disease management within the context of a more general life management and, more recently, depicts patients as active agents in attaining a desired outcome" (p. 2). The insider perspective also reveals a belief that professional health caregivers are limited in their expertise within the area of illness experience. Mutual recognition and valuing of expertise, be it based on the lived experience of illness or professional healthcare practice, provides a foundation for working with patients as partners rather than passive recipients of care.

Thorne and Paterson (1998) noted that the more traditional view of chronic illness in terms of loss, suffering, and burden has been challenged in more recent work by a view that emphasizes "aspects of chronic illness that are healthy, transformative, and positive" (p. 5). In light of this shift in thinking and the increasing recognition of the expertise of the chronically ill regarding their own health, they raise an important issue: "in representing chronically ill individuals as the authority in their own illness and articulating a partnership model of health care relationships as the new ideal, the current literature seems to be heading in the direction of systematically ignoring the continuing need that many people with chronic illnesses have to seek and expect help from experts" (Thorne & Paterson, 1998, p. 7). Assuming that every person with chronic illness desires and is able to participate fully with health care providers in managing illness is tantamount to ignoring the complexity of the chronic illness experience and the importance of the particular experience and circumstances of the individual. Benner (2000) reminded us that human beings succumb to sickness, not just to diseases, and in so doing may lose the ability to connect with others. Nursing is about "the social sentient body that dwells in finite human worlds, the lived body that gets sick and recovers; suffers and is altered during illness and pain and engages with the world differently upon recovery" (Benner, 2000, p. 5). While attending to total suffering is inherent in the philosophy of nursing practice, the governing process under which most nurses provide health care continues to be directed at the medical goal of symptom management and cure.

Whether we are exploring the expertise of nurses or individuals with a chronic condition, nurse/person interactions, conceptualizations of chronic illness, or goals of care, we need a research methodology that can capture the particular and the universal, the dynamic and the static, the abstract and the concrete, and the temporal context of each. Narrative inquiry provides such a methodology because it draws on human stories and stories are more than a chronological list of facts. The relational aspect of narrative inquiry, that assumes a teller and an audience, a stimulus and a response, a meaning evolving in the relational and collaborative moment, is a tremendous strength of this method of inquiry. Narrative inquiry is also a way of thinking that spawns new insights each time a story is recounted. The reflective nature of this method helps us change perspective as we study a topic, thus producing new insights and the potential for innovative action.

Chinn (1996) challenged nurses to consider how a cure orientation limits the participation of individuals in decisions that affect not only suffering but also how they come to understand and live with the reality of chronic illness. She emphasized the need for a shared discourse on the patient's beliefs, values, needs, and goals (that is the patient's story), being central to the process. Thorne and Paterson (1998) pointed out that such a partnership also requires an understanding of the ability of partners to engage in the process. For the chronically ill, that ability may be compromised by virtue of the illness experience itself.

While nurses are taught to identify many features of chronic illness, understanding the patient's perspective on living with their chronic illness is the key to establishing the patient's trust in the nurse as a caregiver (Price, 1996). Stories patients tell of their personal experience of chronic illness help nurses understand the ontological and epistemological beliefs underlying formal definitions as well as the beliefs reflected in their own and their patient's perspectives.

Narrative Inquiry

Coles (1989), in writing about his own experiences as a medical student, repeated the words of one of his mentors, "the people who come to see us bring us their stories. They hope they tell them well enough so that we understand the truth of their lives. They hope we know how to interpret their stories correctly. We have to remember that what we hear is their story" (p. 7). This brings to mind the words of Bruner (as cited in Carter, 1993) when he said that in effect, we think our way through life in story form and that this helps us bring order, develop understanding, find a way to share experience, deal with obstacles and conflict, identify causality, and so forth. It is natural for people to seek help by sharing their stories. Carter (1993) stated that story provides a place for exploring ambiguity and dilemma, something more traditional inquiry processes do not accommodate. Carter is writing about teacher education but there are many parallels here with nursing. Inquiry through narrative has the advantage of helping us examine intrinsic multiplicity of meaning, capture the complexity of meaning, explore sequence of events and perhaps gain insight into a person's construction of causality (Carter, 1993).

Carr (1986) explored the use of narrative, in particular, around the issue of identity. His discussion moved into moral dimensions when he said that we must consider what story (ies) we are part of in order to ask questions about what to do. Nurses have many roles, both personal and professional and each can be explored through story. Do we make choices from one perspective only? Carr raised the question of authenticity as self-choice. He stated that our story is our responsibility and it is based on choice, whether that is a conscious act or one of default or inadvertence (p. 94). I wonder how often we choose by default because of uncertainty over the consequences of a conscious choice.

Perhaps one of the more interesting, albeit challenging elements of employing narrative inquiry is ethical in that researchers never come into a story at the beginning. Lives are always in progress and narrative allows us to move backward to get the history and forward to consider future implications as well as the present circumstances. While individuals are a work in progress, through narrative inquiry, we can gain a sense of the wholeness of the individual and this brings a sense of ease to the situation. The story is not finished but it can be seen as whole.

Carr (1986) stated that narrative was not only an organizing principle for experience and action, but also, that it held the same function for the self as experiencing and acting (p. 73). Narrative provides access to metaphysical, epistemological, and moral aspects of identity. Schapp (as cited in Carr, 1986) says we are able to learn about the self through one's life story. Both Husserl and MacIntyre's work (as cited in Carr, 1986) addressed not just the story of a life but also, the importance of the unity of life and coherence of a life story (p. 74). Life is made up of multiple events that we may categorize as our experiences or as actions we take. In order to grasp the wholeness of identity it would seem necessary to weave such elements together into a kind of narrative. As individuals, then, we find ourselves as central characters in/and authors of, our life stories.

Life stories include past, present, and imagined future unified, not just on a temporal plane, but through a process of reflexivity which has the potential to create the self, as unified whole. Carr (1986) noted that reflection can inspire moments of transformation as the individual gains new insight or a new perspective. Whether such transitions result from distinct or unique events or normal developmental changes, the individual is then able to reassign labels and significance to past experiences as each story finds its place and purpose in our life-stories. According to Dilthey (as cited in Carr, 1986), understanding is a product of coherence around "values, purpose, and meaning or significance" (p. 76). If, as Dilthey proposed, values and related purposes only form a coherent purpose in the presence of meaning, then seeking understanding is how we find coherence in our lives. Since our perspective is always from within an ongoing life, as one of its parts, full understanding of the whole of our identity is not possible. Meaning is, therefore, never set or stagnant, is bound by our place as part of a whole and as belonging to the whole, and changes constantly with each new purpose we undertake. Dilthey's remarks are connected with autobiography and reflect the narrative structure of "backward reference", "temporal relations between whole and parts", and "the idea that we are at once the spectators of, agents in, and tellers of a story, which in this case, is a life-story" (Dilthey as cited in Carr, 1986, p. 78). While connections we may find among actions or experiences within a life may be related, life is far too complex for us to see a life-story as having a single-minded purpose. The single connecting factor is that all events, actions, and experiences involve one individual.

Bringing Narrative Inquiry to the Study

In chapter I, I told a story from my experience that provides a clear example of the evocative nature of narrative. It captures the temporal elements of how past, present and anticipated future consequences of seeking help have impacted my life and how the perception of time can change when one is suffering. By sharing my experience in the form of a story, the reader is privy not only to an account of consecutive events as they unfold but to the thought processes and embodied memories of the experience. The story is about the process of seeking help but it also reveals not only the decision making process but the barriers that are raised by physical and emotional suffering and how nurses' reactions can influence the experience of vulnerability and the capacity to place one's trust in another.

Our lives are made up of a series of both concurrent and sequential stories that present a chronological account of multiple encounters, experiences, choices, and actions, some of which are shared with others and some known only to us. While we may not often consider our daily experiences in terms of life narratives, we are in fact adding to our life stories every day through our relationships with others, our inner experiences of self, and our interactions with the environment in which we live. Experience as text or narrative is lived in a variety of contexts and is expressed in our everyday lives in personal conversations, notes, letters to a loved one, emails sent to friends or colleagues, and so forth. Narrative is equally present in the birthday gift just mailed to your mother, in time spent coaching a youth soccer team, in the offer of help to someone in need, in regular attendance at a church service, or in many years of dedicated work in or outside of the home. As a nurse, I know my stories are both embedded in and revealed through my work with others, by way of the relationships I have helped establish wherein which stories can be told and retold. However, narratives are not always easy to hear or be part of and nurses are often privy to stories of adversity and challenge in the face of illness, disability, loss, and impending death. It is both our privilege and our responsibility as nurses to be present with others in a manner that facilitates the making of both everyday choices and extraordinary ones in hopes that the most appropriate actions are taken. Zoloth and Charon (2002) noted that in such encounters each idea has both a social and a moral meaning that often requires a response; as a result, these interactions become moral encounters with the decision-making process storied through language and actions.

Bruner (2002) noted that people live and relate by stories and that illness disrupts their life narrative. The notion of seeing the face of another or hearing their life narrative creating a sense of obligation, suggests to me that relationships and responses that individuals experience during interactions contribute to the development of identity. Bruner moves from the influence of the social narrative to a consideration of the roots of identity as found in culture, relationships with family and friends, and membership in small communities to which we make commitments. The stories we tell and our use of metaphor or other narrative features help us envision our path, our goals, and our choices. Life is not just about abstract forces; selfhood relies on a story in which the individual is the agent (Bruner, 2002, p. 7). Agency within relationship plays out as a knowing of each other's intentions to some extent and a coming together of subjectivity and objectivity that is intersubjectivity.

Agency comes through often in the voice of individuals telling their stories of living an experience. While case studies may capture the story of the self, research findings are often conveyed in light of themes to address. While themes are frequently supported with direct quotes from the data collected, it is impossible to include the entire context and so the result is still subject to reductionism, fragmentation, and decontextualization. Also lost or untapped is the change in experience over time and the ability to see how the past, present, and future are intertwined, interdependent, and always a part of experience.

Ways of Knowing and Understanding

Whether we consider the experience of individuals living with chronic illness, or the experience of health care providers in meeting the needs of this population, it is crucial to have a basic understanding of issues around knowing. In nursing, our ability to recognize, tap into, appreciate, understand, and find meaning in human living experience is a function of how we know our world. How we conceptualize reality, what we think is possible to know and the methodology by which we can come to that knowing, beliefs held about the truth and value in ways of knowing … these form the ethical connection between knowing and action that provides the foundation for both the call to action and the actual provision of nursing care.

To understand this reality of nursing practice when we find a synthesis of knowledge and human qualities such as empathy, moral responsibility, and care result in health care interactions that facilitate the sharing of the complexities of human living within the context of chronic illness. In the past, we have studied health care interactions under the concepts of communication, compliance, and patient education. We have concentrated on knowing facts, recognizing patterns, developing skills, applying interventions, and measuring outcomes, with little regard for the how and what of our knowing or the possibility of what we do not know. If we become less paranoid about sharing our own expertise and the unique knowledge that places us in a position of power over patients, seeking instead to work with patients as equals, we create a relational context where mutuality and reciprocity can permeate a discourse on the challenges of chronic illness. When we recognize the sociopolitical, ethical, and contextual issues that influence how we see our world, it is easier to uncover the ontological and epistemological basis for our taken-for-granted ideas about chronic illness and our beliefs about how to provide for vulnerable members of our society.

Study context.

The study took place in the community and involved women with a long history of migraines and nurses with experience in caring for this population. In this context, I listened to the stories of nursing practice and stories of being the recipient of nursing care. The stories were seen as complex, interwoven, relational and contextually framed, not in terms of binary opposites such as positive or negative.

Study procedures.

The study was conducted within the framework of narrative inquiry as described by Clandinin and Connelly (2000) as a metaphorical three-dimensional narrative inquiry space. This framework assisted in addressing experience within an all-encompassing context of place, temporality, and personal and social dimensions and allowed conversation to flow inward and outward as it tapped into inner "feelings, hopes, aesthetic reactions, and moral dispositions" and "existential conditions" (or environment) along the personal social dimension. Movement backward and forward made possible the illumination of memories and experiences from the past to the present and into a projected future. While Clandinin and Connelly included place within environment in their earlier work, they now refer to place as the "specific concrete physical and topological boundaries of inquiry landscapes" (Clandinin & Connelly, 2000, p. 51), making it the third dimension of the narrative inquiry space, thus capturing context. The study was also informed by a theoretical perspective of relational ethics (Bergum, 1994, 1999) since understanding the meaning of experience leads to the call for ethical practice.

Setting.

Conversations and other participant/researcher interactions took place in participants' homes or at a place of their choosing.

Participants

Selecting participants.

Ads were placed in local newspapers; flyers were placed in a pain clinic and a medical clinic to recruit participants. No healthcare facilities were formally involved in recruiting participants. Several ways to contact me were put in the ads and flyers. Some participants were recruited by word of mouth. One participant was recruited from another study in which I was an interviewer. Participants were enrolled in the study once they had read the information sheet and consent form, and initialed and signed them to indicate their understanding of the study and their agreement to participate.

Number of participants.

Three women with a history of severe migraines and two nurses with experience providing nursing care for women with migraines, were recruited.

Inclusion and exclusion criteria.

Women participants, with migraines, had to be at least 35 years old, have been diagnosed with chronic severe migraines by a physician, have suffered from migraine for at least 10 years, and have sought help in the management of migraines in at least one community setting (e.g. clinic where nurses are part of the care team) and one acute care facility (e.g. Emergency room where nurses are part of the care team). Participants had to be able to read and speak English and had to have lived in Canada during the time they suffered from migraines.

Nurse participants had to be at least 35 years old, have a minimum of 10 years experience of nursing practice in either a hospital and /or community based facility where they had had the opportunity to work with women seeking help with severe migraines. Participants had to be able to read and speak English and have worked in the Canadian healthcare system during the minimum ten years of practice.

One of the women with migraines did not meet the criteria of having had migraines for 10 years. She had had them for 6 years at the time I interviewed her and had always had to seek help with them. Given the severity of her migraines and the fact that I was having difficulty finding participants, I decided to include her as the final participant in the study. One of the women with migraines had not sought help with her migraines at an acute care facility although she had considered it many times. The medications she was taking and a life long history of migraines convinced me that she would be a valuable source of experiential knowledge for the study.

Composing Field Texts

Given that narrative inquiry is a relational research methodology, there were several planned meetings with participants and additional contacts as research texts were developed and negotiated collaboratively. Collaboration was limited by the fact that I had moved to another province after completing data collection and had to make contact by email and telephone. It is important to consider the positioning of field texts within the three-dimensional inquiry space. Clandinin and Connelly (2000) noted that for epistemological credibility and integrity, it is important that field texts be clearly positioned so the source and interpretation of data can be clear (p. 118).

Conversation as field texts.

Each participant took part in conversations with the researcher at times and places where the participant was comfortable. The logistics and time commitment were mutually negotiated between participants and researcher. The purpose of the conversations were to provide an opportunity for participants to tell their personal experience stories of seeking help with severe migraines and/or of providing nursing care to women with migraines. Conversations were structured using Clandinin and Connelly's (2000) metaphorical three-dimensional narrative inquiry space.

Memory box narrative as field text.

For the second planned meeting between each participant and researcher, each participant was asked to put together a memory box, comprised of items that had meaning for them and that related to their experience with migraines and seeking help and/or with providing care for women with migraines. During our initial conversation, I explained what a memory box was and gave examples of what I might choose to put in one, so the participant would understand the concept. The purpose of the items was to stimulate memories and provide another format for representing participant experiences. Our discussion of the memory boxes items was also taped and transcribed verbatim by myself or a hired transcriber. Pictures were taken using a digital camera and were processed by myself. All pictures included in the final dissertation, presentations, articles or any other forms of dissemination are included with written participant consent.

Aesthetic representations as field text.

Participants were invited to use their choice of an aesthetic form of representation to share their stories of chronic illness and seeking help and /or providing care to women with migraines. Representations could take various art forms such as drawing, painting, or making a collage. A written representative form of journaling could also be chosen. The choice was negotiated between the participant and the researcher. Participants explained/demonstrated their work at a third meeting. Participants were asked to assist the researcher in interpreting their representation as needed.

Field notes as field texts.

Field notes were made immediately following each interaction and later allowing for the movement, as Clandinin and Connelly (2000) stated, "between intimacy with field participants and a reflective stance" (p. 95). Extensive ongoing writing about field notes, participant narratives, as told using words, objects, and art forms, and my own experiences with seeking help with migraines was planned but somewhat limited due to illness on the part of the researcher.

Data Analysis and Interpretation

Research texts.

A narrative account of the research was gradually constructed (research texts) using a format that seemed appropriate to the nature of the study. I initially composed accounts of each woman's experiences. This was followed by identifying and writing about resonance across individual narratives. This is a difficult process that takes you back and forth between the words and experiences of the women in the study. For example in developing narrative thread two on the perception of the self with a migraine, I had been writing about Grace and how she equated herself with the vulture when she had the headache. This took me to the idea that that the vulture was cruel and so was the headache and did she really want to own the headache if it was cruel. The question was, is the headache really a part of me or not, and who is in control. This idea struck a cord with me for Claire had talked about her headache as being ugly, telling her colleagues that they did not want to see it because when it got bad it was really ugly. She wanted to protect them from that sight and to protect herself from that humiliation of being exposed at that time. Again, there was the notion of an external force taking control of her. As I thought about these elements of their stories, they resonated with perceptions of the self with a migraine. As I searched through the transcripts, I found more stories of both particular and social forces that resonated back and forth and ultimately fit with the idea of how each participant came to see herself with a migraine. These insights were gradually incorporated with my own stories and the story of the inquiry itself. Participants interpreted their creative projects in collaboration with me. These interpretations added depth to our understanding of their experiences and in some cases added new stories as new memories were triggered. Participants had the opportunity for input before the research texts were finalized. Some changes were made based on their input. Interpretation brought a sense of meaning and understanding to the stories that have been shared and to the new stories of the experience of the inquiry. The complexities of interaction and relationship have been considered and incorporated throughout this and each activity of this study. Reflecting on all sources of field texts, incorporation of knowledge from disciplinary theory and literature, and referral back to the research questions, helped to bring out some of the personal and social significance of the inquiry.

Ethical Considerations

A certificate of written ethical approval from the University of Alberta Health Research Ethics Board (panel B: Health Research) committee was obtained before data collection began. Informed consent was ensured before each participant was enrolled in the study. Participants were informed how privacy, anonymity and confidentiality would be ensured; that they could refuse to participate in any activity or part of an activity and that they could withdraw from the study at any time. Women with migraines were assured that their health care would not be affected by their participation. I assured nurses that their narratives would have no impact on their work. All computer and paper files, audiotapes, and computer storage devices (CD's, DVD's, and floppy disks) were coded for identification in order to protect anonymity and retained in a locked filing cabinet in my home. Access was limited to my dissertation supervisors and me.

There was no direct risk to participants in this study. No interventions were undertaken. Sharing intimate details of one's life did evoke strong emotions but no participant became upset. No follow-up was necessary with any participant. No direct benefits were anticipated from participation in the study, however some individuals did find it validating and stated it was satisfying to have the opportunity to share their experiences with someone who understood what they went through.

Substance and Rigor

In an article on culturally competent scholarship, Meleis (1996) encouraged researchers, theoreticians, and reviewers to address eight criteria to ensure rigor and credibility in scholarship: contextuality, relevance, communication styles, awareness of identity and power differentials, disclosure, reciprocation, empowerment, and time (p. 1). Since her definition of culturally competent care addressed "issues related to diversity, marginalization, and vulnerability due to culture, race, gender, and sexual orientation" (p. 2), these criteria were applied to the question of rigor and credibility in this study.

Women are not only more susceptible to migraines and to psychological diagnoses (often linked to stigma), but those with frequent and severe migraines find themselves marginalized by ensuing disability and suffering and live in a unique cultural milieu of uncertainty, vulnerability, burden, and suffering that affects their entire lifestyle and quality of life. The research method of narrative inquiry, addresses context and issues of relevance to all participants and interactions are grounded in negotiated comfort levels that help address power differentials. Since the researcher's inquiry story is part of the data, reciprocity and disclosure are part of the process. The criteria of time is particularly apropos, not only in that experience is always grounded in time, in past experience, and in projections about the future, but also because migraine is a chronic illness and the effects over time on self-care activities such as seeking help are I believe crucial in this study.

I am committed to helping to give voice to this group of women and to the nurses whose stories of providing care are often hidden for fear of reprisals in the workplace if criticisms are made openly. I undertook this study with some trepidation of my own in terms of both my vulnerability as a woman with an ongoing problem with migraines and as a nurse who is conscious of the excellent care many nurses provide, but equally aware that we do not always critically reflect on how we might improve care and care giving conditions for marginalized groups.

Chapter IV Grace's Stories

In this chapter, we hear stories of one woman's experiences of migraines over time as she first had them through to her most recent experiences with them. As I narratively inquire into them I begin to see how her stories to live by (Connelly & Clandinin, 1999), her identity, is shaped by her experiences with migraines and how who she is, and is becoming, has shaped how she has sought help with her migraines.

Entering the Field

She reminds me of my mother … quiet and a bit reserved about her yet welcoming, friendly, and interested in others … I feel that somewhat outdated term, a "real lady" applies to her as it did to my mother. I was very close to my mother and this is probably one of the things that drew me to this woman. She favours long skirted clothes that flatter her slender figure. Her soft brown curls are never in disarray, and her smooth skin belies her 70 years. Of course, our ideas about what 70 year olds look like are rapidly changing today. She has a ready smile and a gentle way about her and I will call her Grace for this seems to capture her way of being in this world.

As I prepared for my first meeting with Grace, I thought back to the first time I saw her. I met Grace when I joined the senior choir at the church I was attending. To say I knew her well would be exaggerating but I knew her well enough to know she had suffered from migraines most of her life and that it was a significant problem for her. Several people suggested I approach Grace as a potential participant, when they heard of my study. I wondered if she would meet my criteria of severe migraines. Grace never seemed outwardly disabled by a migraine nor to my knowledge did she miss choir practices or church services due to migraines. I had never noticed telltale signs of illness, such as rubbing her forehead, wrinkling her brow, being quieter than usual, complaining of a headache or not taking part in activities. The only thing that ironically could have suggested chronic headaches was the very careful, graceful way in which she moved and did things. Oversensitivity to sight, sound, movement, and other stimuli is a large part of the migraine experience. I know I, as an individual with chronic severe migraines, have learned to undertake activities carefully, to avoid jarring my head. I also modulate my environment to promote calmness, avoid bright lights and loud or unpleasant noises. I even drive as smoothly as possible. Most people would be unaware of this level of adaptation. I wondered if what I had seen as her careful, graceful way of moving was her way of living with her migraines. Thinking about this I felt eager to hear Grace's stories.

I noted that Grace often reads scripture in church and this amazed me. Reading can be difficult with a migraine and one never knows when a migraine will strike. I wondered how she dealt with that uncertainty when making commitments. I used to read in church but had to give it up because I could not count on being well enough to be there, let alone to read. I have become afraid to make commitments of this nature and I wondered if she felt this way about any activities.

It was a short drive to Grace's home and I had no difficulty finding her place. The sun was shining, the air was crisp, and there was snow under foot on that January afternoon. I spent a few extra minutes in my car rechecking my bag to see I had not forgotten my tape recorder, tapes, or forms. I think the time was really more for gathering my nerve for this was the start of my fieldwork, and I was a little nervous. This was it!

Grace lives in an attractive bungalow in a subdivision constructed in the early sixties. She has lived in the same place for a long time and her home reflects this. Her home is newer than the one I grew up in but the décor immediately took me back in time to my childhood home that was also filled with things collected over time and events, that is, with family pictures and memorabilia. Her house, too, was warm and comfortable, very much a family home. It had the same level of cleanliness and order that I associated with how people lived in the generation in which I grew up. It made me think how much more casual yet complicated our lives are today. There was a sense of things staying the same in Grace's home, one I struggle to find sometimes in my own home where things seemed constantly in flux.

I was not surprised to see such an orderly home as Grace has a softly polished appearance and the house gleamed in the same way. Assuming Grace kept the house that way was buying into the old stereotype that individuals with migraines are perfectionists. That stereotype was put to rest long ago. I shared these observations with Grace during our second meeting and she laughingly noted she was no perfectionist and told me the living room was generally used when company came and was tidied up with that in mind.

What I saw of the rest of her home looked very tidy. I continue to wonder if, like me, she benefits from order in her surroundings in dealing with her migraines.

When I arrived for the first visit, Grace's husband was getting coffee in the kitchen and I said hello to him. He gave me a nice smile and a welcoming nod and left a short while later. Grace invited me to sit in the living room. The room had formal floral covered couches and I was reminded of my grandmother's parlor that was used for formal entertaining only. I wondered if the formality of the room would hinder our connecting with one another. I was entering a space that was Grace's and it was up to me to negotiate with her the rules of engagement in establishing a safe relationship in which sharing of storied experiences and discovery could take place.

I looked around for a place to set up my tape machine. I discovered there were no three prong plugs in that room. I had a few moments of panic, realized I had my battery-powered tape recorder with me ... relief ... then realized I had no large tapes for it ... panic returned. Fortunately, we found the dining room section of the L shaped dining-living room area did have updated wiring. Grace seemed a little distressed that there were not current outlets in the living room, as if it was some kind of personal failure. We moved on and quickly settled at the massive dining room table. Now I could relate to this room. Perhaps it was the huge table that reminded me of years of celebrations growing up. I could not help but imagine many happy family parties in this room, the table laden with hot and cold dishes of food. In my mind, I saw noisy family members packed around the table celebrating birthdays, Christmas and other holidays.

I pulled myself back to the present, noting Grace had settled opposite where I had plugged in the tape recorder. Instead of angling the tape recorder, I sat opposite her. This was a poor decision as it had us eye to eye the whole time. In our next visits I made sure we sat at a more comfortable angle to one another. We went over the information letter and as she read it she said, "Oh I meet all the criteria". As a result, I did not go over each item and we were well into the conversation before I realized Grace had never been treated in hospital with a migraine. I decided to push forward, and in the end, I think her contrasting experience proved valuable for it provides a glimpse of the wide spectrum of experience women with severe migraines have.

Grace had considered going to Emergency rooms numerous times over the years. This combined with the kinds of medications she took over the years certainly confirmed that she has severe migraines and most certainly would have benefited from hospital intervention. However every time Grace was faced with the choice of going to the hospital for help, the thought of a long wait in a hospital waiting room, when the migraine was so severe, was always too much for her. That time of suffering provided a barrier too strong for her to overcome. I wondered if some of this was related to lack of family support for one needs help to get to an Emergency room when this stage is reached. I also realized that when Grace was a young woman, a headache was probably seen as even less of an emergency than it is today. Some of the stories that follow will suggest both individual and social reasons that may have held Grace back from availing herself of this source of help.

It seemed as we talked that Grace's stories of her experiences with migraines tended to be very short with her describing the events in a sentence or two. Her memories came to her in a piece meal fashion during the course of our talks and we struggled a bit to put some of her experiences together into something of a timeline of how her migraines and her search for help had evolved. As I reviewed them later, they seemed more continuous, an interesting difference perhaps between having a conversation and reading a conversation set out as a whole.

During our initial conversation, I felt it was very much a question and answer session. In later talks, we had a much more flowing narrative as we talked over tea. Our ease with each other was more obvious in later conversations and with ease came a greater depth of detail in Grace's stories as well as more emotion. I found myself using fewer prompts. Yet in the actual process of looking at transcripts, which are written out in separate lines with each section attributed to a particular speaker breaking the flow of conversation, I found it was not until I put the words into paragraph form that I really discovered the stories. It was an interesting revelation to me in terms of method.

My First Migraine

> "I was 18 when I had my first migraine", Grace stated. "I remember it vividly; I was at work." "This was in my hometown and I had to go home from work … and I really didn't understand why I was having such a terrible headache

> … I'd had headaches all my life but just ones that an aspirin would get rid of ... but this was much more than that … but it didn't last very long", she explained. "I remember taking a 222, in those days I don't believe we had Tylenol", she said, "and it got rid of it". "Nowadays it would be like eating candy". Grace laughed at this and I joined her. "That sounds familiar", I remarked. "So did you have more right away after that or …" "I don't remember that so much in those days", Grace responded, "It seems like I didn't have so many until after I had children. I was 25 I believe when I had my first child and it seems like I had them more after that … I may have had some but not to a great degree". "So when you had the first one, did you seek any medical help? Help at all or did you just go home and go to bed?" I asked. "I just went home and went to bed", Grace said. "Ok ... and what about later on, …now …" I wondered. "Since then", she asked? Laughing, she said, "I have sought very much help … as much as I could find … but ah and some has helped and some has not".

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In our initial conversation, Grace described the memory of her first migraine, at 18, as "vivid". At first it seemed as if this was her first headache but then she went on to say, in an offhand way, that she had had headaches all her life but nothing like this one which required a 222 (a combination of Aspirin and Codeine), rather than her usual remedy of an Aspirin. She noted that taking 222's today would be like "eating candy". This comment raised questions for me later because she takes extra strength Tylenol today for her migraines and I am assuming this would not be much different from Aspirin. Two twenty-two's would probably be a step up from this and more comparable to a Tylenol number one or number two. The comparison to eating candy seemed to imply that she took a lot since they were not overly effective individually.

The Experience of Being Diagnosed

As Grace and I continued to talk about her headaches and where she had turned to for help, she told me that she went to the "X" Clinic and met a doctor there who first diagnosed her with migraine.

> "So tell me some of the places where you've looked for help", I said.
>
> "Ok, well I can remember going to the X. clinic to a doctor there and he was the
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> one that first diagnosed them as migraine … he tested me out with some pills which didn't work at all and I think they must have been a placebo because they didn't do anything… I didn't feel groggy or anything with them so I just felt he must have used a placebo", Grace responded. She continued, "So I went back and he put me on something called Gravergol and I found by taking the Gravergol, but I had to take Tylenol with them to make them work". "Gravergol", I repeated. "Gravergol, yes", she said. "Never heard of it", I said. "Ah they don't, I'm sure they're not available anymore, Grace replied. "Umm hmm, but took Tylenol with it", I murmured. "And I, for some reason I discovered that they would, they worked if I took a Tylenol with it, otherwise it didn't work" she said. "So I took those for many years and it kept them under control".

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Grace's recollection of the doctor who diagnosed her with migraines was that his approach to testing her for migraines was to try placebos in case the ailment was all in her head. The fact that Grace did not see this as a problem, if the use of placebos was indeed his true practice, was distressing to me as the ethics of such practice is certainly problematic. It did, however, start to show what became more and more evident over time spent with Grace, which is that she relied on physical evidence to validate her own illness. Her faith in the doctor and her lack of knowledge about her medication reflected the very paternalistic mode of medical practice at that particular time. I eventually found information on Gravergol, an ergotamine compound used for the treatment of moderate to severe migraine (Drug Information Online, 2006) Ergotamine compounds are usually highly effective in treating the body processes in causing migraines although they can have a rebound effect. I am not sure why she needed the Tylenol, unless the Gravergol did not completely help the pain and she needed an analgesic to supplement the Gravergol. It struck me that the Tylenol could have been helping the most. This combination, which she took for many years, would take the headaches away if she took them soon enough.

I was surprised that Grace was not upset that the doctor might have given her a placebo. I hesitated to ask about it as I did not want to plant ideas. I related to her words as I remember as a child, our own family doctor telling my mother that I was a nervous
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little thing and that my own headaches would go away if I just relaxed. This experience made me feel responsible for the pain and planted the notion that I could control it. Grace did not see this implication in her own situation and I did not point it out. Knowledgeable practitioners about pain today do not question its existence, do not think of pain as something a person has dreamed up, since we cannot prove it does not exist and must rely on the patient's word. Accepting the idea that it might be something she dreamed up is tantamount to blaming herself for the pain (feelings of guilt, questioning her own pain), and reflects the over application of psychiatric diagnoses used with women in pain over the years and the devaluing of women's health problems in general.

I Still Got Them

As Grace and I continued to talk about her headaches in our first conversation, she said,

> "I still got them … they were mostly during my periods. I would get two headaches, one on each side, during that time. It would start on one side and last for a couple of, well not a couple of days, it didn't last that long, and then it would just move over to the other side. And one was always coming up the back of my neck (points to left side) and the other one was always in my eye or just above my eye (points to right side). It was the most severe one or it lasted longer anyway. The other one didn't tickle, it was pretty severe too but that one…"Grace trailed off and shook her head. I nodded and said, "I always find ones that get in your eye seem harder to take some how". "And you hear about them being throbbing headaches but mine are not throbbing, they are continual", Grace pointed out, "there's no throb to them at all". "Oh ok", I said. "The doctor who diagnosed them said they were atypical so I'm not sure if that's the reason or why he called them atypical", she noted. "Well throbbing is one of the criteria that they do look for", I stated. "Yes, but mine don't throb, they just come and they stay there", said Grace. "Right. So how did you feel when the doctor supposedly gave you a placebo?" I asked. "Well I just… I wasn't upset … I just thought well that's good … he tried it out to see if it was all something that I had dreamed up. I think they like to do that to check before they really do give you something that maybe you don't need. So it didn't upset me at all", she concluded. "Ok … so you took the

> Gravergol, Gravergol?" I asked. "Gravergol", she affirmed. "And when did you change to something else?", I asked. "It must have it was when the Imitrex came out", she replied. "Oh", I said, "so it was a long time?" "Yeah, I did take them for a long time", she said.

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The Look

Grace continued to have some headaches, generally associated with her menstrual cycle. This is a common trigger for women due to the cycling of hormone levels (Stewart, Lipton, Chee, Sawyer, & Silberstein, 1999). She described two primary types of migraine that she experienced, noting that she would have both kinds with her periods. The headaches are on opposite sides of her head. One lasts several days. Then the other type takes over for a few days. It was obvious from how she emphasized her description that she fears the right sided ones more. She noted that her headaches do not throb, a symptom very typical of migraine, and most likely the reason for her physician's labeling them atypical. We both agreed that eye pain is hard to take and talked about how the picture of the woman, in Chapter 1 of my dissertation, showing her reaching toward her eye as if to pluck it out resonated with both of us. Talking about that picture took us into a short discussion of how one looks with a migraine. We noted that both of us had similar lines on our foreheads to the woman in the picture … pain lines.

> "…but I've got them", Grace said. "I do too", I replied. "You've got them", she affirmed. "Those are pain lines", I pointed out. "I thought it was cause I was elderly", Grace said. "Noo, no", I corrected. "I've been out in the sun too much. I've had these for ever", she suggested. "Well I've had them for a long time too. Yeah, … those are pain lines. And to me she looks like she just wants to take that eye and just pluck it out of her head", I concluded. I added, "Yeah, that's just where I get mine. Because, that's, the pain is so intense here….and you look at her jaw. Yeah, clenched … her teeth. Teeth are clenched and the bright burning, burning sort of colours that she's chosen and yet she's in black and white". "Yeah, that's right", Grace said. "She's in a dark place", I stated. "Un huh", Grace murmured. I told Grace, "There are just so many things that I wrote about as I looked at that and I think it would be very interesting to
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take your own picture, when you're really sick, when you're really having a bad day, you know and you've had your ice pack on your, on your hair … and so consequently your hair is standing out like this". (Laughing and nodding in affirmation). And you have no makeup on and you know … things like that … your glasses are off". Grace mused, "I remember when I had my knee done in the hospital, I got a migraine, and I asked for an ice pack … well they didn't have any…so they brought me ice in a towel. And it melted all over my head and then, of course, the doctors saw me like this and I was so embarrassed, as if he cared you know … they teased me about that so much you know".

In our conversations, Grace talked about her headaches in what seemed to be a matter of fact way, using descriptive terms, but expressing minimum emotion. I wondered about the amount of laughter when I listened to the tapes later. She used words like "terrible" or "awful" but I could not detect distress in her voice or in her face. When I hear or use these words, I relate them to pain levels I consider awful or terrible. I wondered if those from whom she might seek help might not understand Grace's pain levels when her words did not seem to connect to visible physical expressions of pain.

Addiction to Tylenol?

"... I had gone to pain clinics, Grace said. I remember two different pain clinics and the one I went to this doctor put needles in, like an injection in my forehead. And I went there one time with a migraine just to see if it would work but it didn't work, it didn't work at all so I didn't continue that and then I went to one, it was at the H. Center, they had a pain clinic there. And they, was that the one? One of them anyway I went to wanted to take me off Tylenol completely for three weeks because they felt I was addicted to it. I'm not sure if that was the clinic ... I've forgotten now". "That you were addicted to it?" I asked. "That I was addicted to it and that I should come off it for three weeks", she replied. "Well I just about cried when I heard that because I thought, what am I going to do, you know, if I get a headache … I will just .. it's just unbearable if I don't take something, so finally I decided well I guess I've got to try it and I did try it and the first night I got a headache. I think it must have been the power of suggestion and I was just deathly sick. Normally I don't get sick to my stomach but without the Tylenol, I did. I was so ill, it was just unbearable and the headache went on and on and on. But I stuck it out and I finally got rid of it. And ah then for 13 days I didn't have a headache… and I thought this is the answer, that's what the problem is … but about ten days later I, no, after 13 days I got another headache and again I was so ill and I, my head was just unbearable. And they had said 'well if you really can't stand it take something' and so I just had to … I couldn't stand it any longer…and I did take something then but when I went back, the doctor thought 'well you're probably off the addiction now anyway' but the headaches just came back.. and I can remember having such a stiff neck afterwards but I think it was just from the pain and I was holding my neck so stiff … well I was right in bed, I couldn't get up it was just so so awful. So I didn't want to try that again".

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Grace attended two pain clinics. At one, she had injections of something in her forehead (not acupuncture). This apparently did not work. The second clinic was where she had the experience described above regarding addiction to Tylenol. That this was a difficult suggestion was evident in her tone of voice and in how she told me about this suggestion. While the body can get used to Tylenol and there is always the possibility of what is called rebound headache from taking a medication, one cannot become addicted to Tylenol. Addiction to a drug usually involves taking it for the wrong reasons and a strong psychological dependence. It also involves extreme worry and a lot of time spent ensuring that the drug is always available. This was not the case here. This word was misused and Grace found herself being blamed for her problem. She told me how much the idea of not having Tylenol to take affected her. She did rely on it but only because she had nothing else to take for her migraines. To suggest taking her off Tylenol without providing other ideas for how she was to deal with her headaches was naturally upsetting. I have had a similar experience and I remember the sense of panic I felt wondering how I would look after my children, go to work, and function at all… not to mention get through the pain.

It was interesting to hear her talk of how she finally decided to try going off the Tylenol, on her own. In other words, she decided when to do it. I did the same thing and when I consider this, I see that we both took control by choosing our own timing for this trial. We both had terrible headaches without the medication, then a period of relief, then a return of the headaches. Grace was able to go back to the Tylenol and her doctor told
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her that she was probably over the addiction (again I question the use of this word) and the headaches had simply returned. I am surprised Grace did not end up in the hospital as she described the pain as unbearable and talked of being very ill, sick to her stomach and having a very stiff neck. She was unable to get out of bed and stated she did not want to try going off the Tylenol again. This was the most graphic description of a migraine that Grace had made up to this time. In contrast to her earlier reference to migraines as awful, in the above transcript she detailed her signs and symptoms of migraines.

How Much Do Migraines Interfere with My Life?

I asked Grace, "How much would you say migraines have interfered with your life"?

> "Well, as I say, I always went to work and sometimes my mind is a little sharper when I have a headache", she said. (Laughing) She continued, "I don't know why but I have noticed that. It's very strange .... I've been able to eat... sometimes my stomach does feel a little queasy but not usually ... I'm usually able to eat. I'm not particularly enjoying life when I have one but I guess I have tried not to let them interfere too much". "So have there, you say you haven't missed work. Have there been times when you've missed social events or family events?" I ask her. "I can remember one time, this was a long, long time ago though I, my ah brother-in law and sister-in-law were here and ah well we'd been out doing something around town and I got a headache and I don't know if I wasn't taking Tylenol at that time or what, but I supposedly was going to have supper for them afterwards and when we came back I had to go to bed ... I couldn't make supper for them ... I can't remember what happened but I just couldn't ... I was feeling quite sick that time ... I do remember that was one time it interfered".

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In the above story, Grace focused primarily on her social and family roles in evaluating whether migraines interfered with her life. Her comment about being a little sharper sometimes with a migraine probably relates to the increased sensitivity to stimuli that many experience.
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In this story, Grace focused on social roles. I consider eating as a social role as well for, while it can be an individual problem, there can be a lot of pressure and negative feedback if one does not eat, for example, while at work, during family meals, while entertaining friends. As she often did in our conversations, Grace mentioned the possibility that the migraine was due to her not taking her Tylenol. Treatment of her headaches is a common way of speaking to her migraines. The only internal experiential remark in this story is her brief referral to the fact that she was not particularly enjoying life while she was out with her family that day. As I listened to Grace, I saw her pushing herself to fulfill what she probably saw as both things she wanted to do and things that were social obligations despite the presence of a migraine. In this case, she was unable to overcome the severity of the pain and complete the latter. I wonder what her family would have thought if they had realized the extent of will power it took for her to participate at all that day. I wonder if Grace was more concerned over her inability to fulfill her role as host than over having a bad headache. I wonder about how illness is viewed by Grace and others. Is it seen as a personal failure when someone cannot fulfill a social role? Sometimes not fulfilling a social role is seen as a moral issue, especially concerning women's roles. For example, a good woman may be viewed as one who takes care of her family, produces and protects healthy children, and so forth. Failure to fulfill any of these roles can lead to a woman being labeled as a bad mother, a poor housekeeper, and so forth. While it may be acceptable not to fulfill social roles for a short time because of acute illness, this is not the case when chronic illness makes one redefine social roles over long periods of time.

I was beginning to get a sense of a woman who managed her chronic headaches on her own in silent suffering for the most part. It seemed to this point that she had had minimal success in getting professional help. I needed to get a better feel for who had been involved in helping her.

"OD' ing" on Imitrex

> "So did they send you to a neurologist?" I asked. "Yes, yes I had seen a neurologist who I was not pleased with … apparently a very good neurologist but lacking bedside manner (laughed). "Tell me more", I encouraged. "I'd actually gone to one before him too but then I got sent to him. I'm not just sure what to

> say about him but I know that I went to him when I had the stroke (I knew Grace had had a stroke and planned to follow up on this later) and the seizures because it was felt it was caused from OD'ing on Imitrex. I was having 3 to 4 headaches a week by that time and I was 65 at the time and if you read the instructions on the Imitrex it says not to take them after 65 but he allowed me to continue to take them ... said there shouldn't be a problem ... and in a matter of just a few months after my 65th birthday this happened so ... he still didn't agree that it could have been the Imitrex but other doctors did... and I felt that way too... and looking on the internet too...my family were very active in that regard trying to figure this thing out and it was probably more than my body could handle for my age", Grace recounted. "Well migraines are implicated with strokes", I explained, "ah you do see them, you know migraine can result in a stroke". "I see", Grace acknowledged. "So it could be a number of factors. There might have been several things going on", I said. "Yeah, it could have been", she agreed. "So the .. these neurologists, now they didn't suggest you change your medication at all?" I wondered. "No he didn't, no no .. he didn't ... I think he would let me continue on even after the stroke and the seizures but there was no way I was going to do that", she said.

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Grace's stroke and seizures occurred shortly after she turned 65 and were attributed to her "OD'ing" on Imitrex. I wondered about how Grace stated the problem for this seemed to blame her, the patient, for taking too much medication when she was simply following the prescription guidelines. While overdosing on medications can be a problem with older adults, Grace is very cognizant of the proper dosages for her medications and the risks of taking too much medication.

Perhaps her healthcare providers were upset with her for taking a lot of medication for migraines but no one asked about the alternative. Grace was frequently in terrible pain, she did not exceed the guidelines, and she simply had too many headaches (3-4 a week). This may have resulted in a large amount of Imitrex in her system, but there is no way to prove this caused her stroke. She noted that the instructions said not to take Imitrex after age 65, but her doctors did not agree on this either.
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Since migraines tend to decrease following menopause, I wondered if the testing of Imitrex on this age group is as extensive as on younger populations. Grace felt that Imitrex was the problem however and said her family was very active on the internet researching the issue. The conclusion, on her and their part, seemed to be that her body could not handle the Imitrex at her age. In talking with Grace my feeling was that the seizures frightened her more than the stroke. Again, these two conditions are related. When Grace talked about her family getting very involved in finding information on Imitrex and strokes, etc., I knew exactly the kind of information they would find for I have spent many hours researching such conditions on the internet. There are cardiovascular risks in taking Imitrex. I personally switched to another version of this drug because my neurologist was afraid I would have a heart attack due to the amount of drug required to keep my migraines under control. As noted earlier, under control means I am able to function. The only reason I stopped Imitrex was that other similar medications became available. I am also familiar from my clinical experience and from having taught pharmacology to nurses with how often risks are overruled in prescribing medications. Family members can have a significant influence when it comes to health decision, especially for older adults, and I got the feeling from Grace's tone of voice that the decision was a family one. I wondered about all the choices Grace may not have had because of her condition over the years. The neurologist would have had Grace continue on the Imitrex but she stated that she and other doctors felt the Imitrex was the cause of her stroke and seizures and she did not intend to continue to take it.

The Memory Box

For our second visit, I asked Grace to make up a memory box using items that evoked specific memories for her around migraines and seeking help. Both Grace and I were more relaxed this time as we both knew what to expect and were better acquainted. Grace did not have a little reminder checklist of topics to tell me about this time. She immediately invited me back into the dining area where we had talked before and asked if I would like tea. I said yes and she busied herself in the kitchen while I set up the equipment. I made sure I picked a chair at an angle to hers this time so our eye contact would be more natural. Once set up I followed her out into the kitchen and noted she had a cake and a bowl of icing all set up for putting together later. She said they were celebrating a birthday and, because of our meeting, she had things done ahead of time. I pointed out later that while she did not consider herself a planner, she nonetheless had done some planning with my visit and their celebration in mind. Planning can be one way of dealing with the uncertainty of migraines.

As we settled in with our tea, I noticed she had a shoebox full of items on the table (Figure 3) and assumed it was her memory box. After one false start with the tape recorder, we were off exploring the items in her box. There were only a few items but each triggered additional information to add to her story.

Figure 3 Grace's Memory Box

The first item was a small box of chocolate candies. She included these because this was something she had to give up since chocolate is a migraine trigger for her.

No chocolate.

"So do you react immediately to chocolate?" I asked. "Oh it takes a few hours and then I'll get the headache up the back of my neck up to the top of my

> head", she said. "Right", I murmured. "Yeah, so … you don't want that so it's better not to want the chocolate". "Yes, yes but that is a favourite treat so that's one of the tough ones", I suggested. "Well it isn't for me, thank goodness", Grace replied.

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Most people would have complained but Grace noted several times that it did not bother her at all. It was better not to have the headaches. One thing she noted was that chocolate triggers the headache that comes up through her neck. This was the one we had questions about earlier as to its origin – migraine or tension processes. Her sensitivity to chocolate seemed to bear out that this too was a migraine headache.

This ready acceptance of what life handed her seemed typical of what I already knew of Grace. Our conversation continued to reinforce this impression.

The second item she showed me was a well-used, older style ice pack. The cover, one she had made, was worn with several small holes growing in the sides. These were testimony to the many years of use.

The ice pack.

> As she patted the ice pack, she commented "Well, this is my ice bag in it's little case because it's always too cold to just have it … it's one that I made years ago and it's got a few holes in it now because I've used it so much". "I was gonna say that cloth's been well used", I responded. "And it's still being used I'm afraid", she lamented. "See, so you always liked the cold?" I asked. "Yes", she stated. "Have you ever tried …?" "I don't like hot", Grace immediately added. "You don't like hot?" I confirmed. "No, no, I prefer the cold", she said. "No I always use the hot", I contested. "Isn't that funny", Grace said, "I've heard of other people that do too. And sometimes I do put the hot form or hot bean bag around my neck". "Your neck, right" I said. "It doesn't do it, doesn't really ease the pain whereas the cold does", Grace reiterated.

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This conversation brought out some of her actual day-to-day suffering caused by living with migraines and the importance of self-help. Grace seemed to convey a sense of regret for all the suffering, despite her otherwise general acceptance of her condition.

The way she touched the ice pack conveyed the idea that it was like an old, reliable friend. The ice pack reminded me of my first hot water bottle and the many heating pads, gel packs, and magic bags I have used and worn out over the years. We discussed the merits of cold versus hot, a conversation that spoke to the need to individualize care for these treatments, which while both based on temperature, are extreme opposites.

The bottle of Tylenol.

Also included in her memory box was a large bottle of Tylenol, her "faithful old Tylenol", and a medication that had been a staple for her since the beginning of her migraines.

> "But I still take Tylenol and I probably take too much of it when I'm having a headache … I'm trying to cut back", Grace says. "How much of it would you take?" I asked. "I had been taking two of the strong Tylenol every four hours, extra strength Tylenol every four hours which made … six (Counting in her head)… that was a lot in the day and I should extend it to every six hours to get an amount that isn't too much", she replied. "But I was just talking to my pharmacist yesterday about that and he said well as long as you're getting your liver checked every six months you should be all right ... but I really am trying to extend it and finding that I can so maybe just mind over matter", Grace stated with determination.
>
> "So you're now on a seizure drug", I mentioned. "Yes, I have been for five years", Grace replied. "And that's helping?" I asked. "Yes definitely I only get … the one on my right side that's over my eye I probably would only get about one a month now where I was getting maybe five or six a month and the one on the left side ... it's probably about the same and I was getting probably yeah probably about the same …so I haven't got that in front of me right now … so yes it has helped and I also take Nadalol which is a blood pressure pill which is supposed to help to eliminate headaches … and I think it helps some too. So with those two medications it has improved my life immensely", Grace explained.

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I found it interesting that her staple drug is an analgesic. Taking the edge off the pain is the priority. Grace does not see the anti-seizure and antihypertension medications
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as the same priority although she appreciates that they do help. Much of the work in migraine research is directed at prevention and I wondered if there should be more attention paid to comfort.

Beside the Tylenol was a small bottle of peppermint oil, an alternative therapy she had tried. I also use a peppermint oil compound to help relieve migraine pain so could relate to this item. Grace just waved her hand briefly at this item as if it was just something tried in passing. It took me back to several stories from our first conversation where other alternative therapies were mentioned.

Less Traditional Treatment

Peppermint oil.

> "Well sometimes I use the peppermint aroma therapy, you know if it's really …"Grace said. "Oh yeah, yeah, I've tried that rubbing it in", I replied. "Does that help?" I asked. "Well just temporarily. I think it does but maybe that's all in the mind too but ah", she sighed. "Oh no, I have a little bottle of oil that has peppermint and things … yeah … in it and I put it on my temples and the back of my neck and I think it helps" I affirmed. "Ah ha … everything's worth a try", Grace conceded.

Massage, chiropractic, laser, acupuncture.

> "I do take massage. I started that about a year ago hoping that that might help, but it doesn't help the headache. It is very pleasant but it doesn't help the headaches. And I have gone to a chiropractor but that was for my neck and for the headaches and one day I was in there … I'd had the massage … and then went to the chiropractor because they were in the same office and I had the headache and it did go away in just a matter of a few hours it went away and I thought wow this is great ..I've found the answer", Grace said. "But I've tried it again or just going to the chiropractor and it didn't work that time at all so okay. It's hard to know. He even did some kind of treatment by putting his finger and pressing on the roof of my mouth and I don't know what that does", she continued. "That's a new one! I've never heard of that", I said. "That's what the doctor said too, Grace noted, and well he did other things too to try and get rid of it and the first time it worked and ah the second time though it didn't, so I haven't tried that

> again". "Any other things that you've tried?" I asked. "Well", she started, "I'm taking laser treatment on my neck right now hoping that's going to help the arthritis. It was recommended to me by a friend who had gone there with arthritis in her back and it has really helped her. But it doesn't seem to be helping me but they did say it should help migraines too. Now I haven't gone long enough to know if it really is going to help the migraines ... Seems to me there was something else. I'll think of it later probably". "Acupuncture?", I asked. "Yeah, that's what, that's it. I'm taking acupuncture right now and that's for my neck too but its also would help the migraines because they put needles in to do all sorts of different things and um so I am taking that at the present time", she said. "So where are they putting the needles for that?" I questioned. "In my head" she explained. "In your head?" I queried. "Yeah and my neck. So I'm going to doctor A, whose supposed to be the very, very best and I've had seven treatments I think and he said they usually start to help after about six", she said. "Umm hmm", I encouraged. "And I've not, it was helping after 6 and then I started the laser treatment and that made it worse", she mused. "Some treatments irritate first and ultimately help", I suggested. "Yeah, that's what I'm hoping, that it might help. Anyway the rheumatologist that I went to the other day prescribed medication for pain", Grace finished.

* * *

Grace told me of several other attempts to seek help, trying massage therapy and seeing a chiropractor for her neck pain and headaches. She noted that massage did not help the headache and neither did the chiropractic treatment. I should note that Grace's husband strongly believes in the benefit of massage and this creates some tension for her since massage did not help her headaches. As she continued to talk about the array of different treatments I thought, this is quite an array of overlapping treatments which makes it difficult to tell the impact of any one treatment. I do not know if her family physician knows about all of the things Grace is trying. I know from my experience that many people use alternative therapies without telling their physicians. I have noticed in my work as a nurse that people are usually more willing to share these self-help measures with nurses. Perhaps the appeal of alternative therapists is that they frequently spend more time with patients. I wondered if Grace had considered an interdisciplinary team approach with someone assigned to help her coordinate and evaluate the various treatments.

We talked about the effectiveness of treatment on her different headaches. The Imitrex helped her right sided headache but not the one she gets on the left side. She noted the acupuncturist encouraged her to keep trying new things. Grace continues to live with a lot of pain as evidenced by her openness to new therapies.

It seems that seeking help with migraines has involved a trial and error approach for Grace. She believes help is out there but, at the same time, it seems that apparent help is not always a sure thing, nor is it readily available or visible. Grace seemed to accept her suffering and the failure to get help at times. I did not sense anger or disappointment, just a feeling that suffering is part of life and that she had to deal with it. This is not unlike the attitude my mother had about her many health problems. While my mother did not have that same complacence about my health problems, I wonder if this speaks to how women, in particular mothers, view their health. I wonder if mothers place a lower priority on their health, trying to meet the needs of their families despite their own illness. We talked later about Grace's children and their experiences with headaches. This was the second time that guilt surfaced as an issue. The first time guilt entered the conversation, it revolved around her initial diagnosis with migraines.

Grace had been having frequent migraines for some time before her stroke, was working at the time, and as she noted, "it (the Imitrex) took the headache away and it's gonna work, you're gonna take it". This is in fact a way of looking at risk versus benefits. This again raised the issue of what is the alternative and what is causing the migraines. Without the Imitrex, she might not have been able to work and I do not know the implications of that. Some of these issues are difficult to approach without suggesting things that reflect social beliefs, e.g. stress and work cause migraines, women do not need to work, women's work is not important so they can just quit if it is causing health problems, and so forth.

Seeing is Believing

The final item in her memory box was a series of small books in which she had recorded her migraines from May 1998 to February 2000, just shortly after her stroke and first seizure.

> "Yeah… And here are some books that I kept track of my migraines in", she said, "I don't know if they're right full or not ... no I guess they are … and I tried to put in all the details when they started. It goes from 98, May 1998 to February of 2000, and that's when I ...well it was just a few months before that I think ... no it was after that I believe that I had the stroke and the seizures and the seizure medication helped so much that I didn't write in it anymore. Maybe that started February 2000, yeah it did, right up to Wednesday October the 4th, yeah, yeah … in there I've written I had one and a half Imitrex and a half a Tylenol that day … seizure at 1030 pm and that was my first seizure". "What kind of seizure did you have?" I asked. "It was a grand, grand mal", Grace responded. "Grand mal", I repeated. "Yeah … it gripped me, well I could feel it coming up from my abdomen and then all of a sudden my mouth just twisted so badly and I was able to go and look in the mirror and it was just horrible it was just twisted all up and really interfered with my breathing". "Did you fall?" I wondered. "Well I ran downstairs. R. was in the bathroom downstairs, and I knew I needed help and I got down just … he had the bathroom door closed and I was in front of the bathroom door, and I guess I was scrabbling, and he heard me, and wondered what was going on, and then I just remember falling over backwards, and I hit my head quite hard. And he phoned 911 and the ambulance … had to come downstairs, it was a little awkward because there wasn't that much room". "Right", I encouraged. "Course he was told to turn me on my side and he couldn't get me on my side … I guess I wasn't cooperating and the funny thing about it was that the girl on 911 happened to be a girl that was raised down the street from us, who was my daughter's best friend". " Oh it's that's interesting", I replied. "So she knew what was happening", Grace said. "Oh she'd be having a fit", I added. "She was when she saw it come in from our place, yeah", Grace noted, "anyway she came to see me the next day which was nice".

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When Grace talked about the first seizure she had had, it was as if she had switched to talking about something much more legitimate than a migraine. Before this, she said little in terms of bodily descriptions of illness. Describing the start of the seizure she remembered, "it griped me ... well I could feel it coming up from my abdomen and then all of a sudden my mouth just twisted so badly and I was able to go and look in the mirror and it was just horrible ... it was just twisted all up and really interfered with my breathing". Her description made me think of something being done to her. Each word came out with passion and emphasis. As I listened I was amazed that Grace would take time to look in the mirror to verify what was going on before seeking help, especially since the apparent twisting of her mouth was interfering with her breathing. Even though she later told me the bathroom mirror was just across the hall from where she was, this was one more time when she seemed to rely on physical evidence over her own body feelings. I remembered Grace telling me at another time that after a migraine had gone she often felt so well she wondered if she had really had a headache. This kind of questioning of the reality of the event was something I had never experienced. Migraines can come and go very quickly. Some individuals have a prodrome (symptoms that precede the migraine) and a slow onset of migraine symptoms while for others or at other times the onset of the headache and accompanying symptoms such as nausea, vomiting, and photophobia is sudden and very intense. The migraine can leave just as suddenly. Given the potential intensity of these symptoms it is not surprising that it is hard to believe this is possible.

After Grace told me about her stroke we discussed the records she kept in her books a bit more, for this again spoke to how she thought about her migraines.

> "So what types of thing ... give me an example of what you would put in the book when you had a headache?" I asked. "Ok, alright, September 27, morning – slight headache. Half an Imitrex and half a Tylenol. Evening – it was on the right side, er the right and it was slight and again I took half an Imitrex and half a Tylenol. The next day .... No two days later the right side in the afternoon, one Imitrex, one Tylenol. So that's what I what I would put, where the headache was and what I took for it", Grace explained. "... and what you took for it", I
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echoed. "… and I took a lot of Imitrex", she agreed nodding her head solemnly. "So you didn't write down what, what worked?" I asked. "Well the Imitrex worked on the right forehead. The one's in the back of my head it didn't work nearly as well. For some reason. Now here I kept track during the month, like the month of September before I had the seizure I had taken 13 ½ Imitrex and 16 1/2 Tylenol. So I kept a monthly count as well", she recounted.

Her records included when she had a headache, some comments about the severity, and what medications she had taken. What interested me was the absence of any comment about whether or not she gained relief. The focus was really on incidence and treatment, not suffering, a focus mirrored in our healthcare system where disability and suffering take second place to incidence and treatment.

With the stroke and the seizures that came with and after it, there was a major revision of Graces's medication regime for migraines. I was reminded first of Grace's simple statement about not wanting headaches and so giving up eating chocolate. Then I thought of her other comment about Imitrex, how if it works, you are going to take it. In this case she was being asked to stop taking Imitrex and to go back to relying on Tylenol. This was a frightening thought for her. Knowing how much Imitrex can help, and how debilitating and disabling migraines can be, I felt for Grace having to make this decision. She had not tried any prophylactic medications that I know of at this point or other versions of the triptin medications and so she was back to Tylenol. The Gravergol seemed to be out of the picture by then. I do not have a good feel for the sequence of medications she has taken as she finds it hard to remember when she took various drugs. Tylenol is a poor substitute for Imitrex and, without it, her quality of life would have been in for a significant drop. Still Grace told me all of this calmly and without apparent distress. Fortunately the anti-seizure and anti-hypertensive medications Grace was placed on after the stoke are also helpful in preventing migraines and this has helped fill the void left by the Imitrex.

By this point Grace had told me of getting help from a family physician, a neurologist, her family, and a pharmacist. The help has primarily centered on medications, an approach consistent with the medical model of care which views the body in a mechanistic manner and illness as caused by broken or malfunctioning parts.

For problems such as migraines, where symptoms cannot always be measured in concrete terms, the medical model can prove inadequate. A more holistic approach is often required. Grace's family supported her trial of massage therapy as one alternative way of addressing her migraines. Grace did not talk about physical care or comfort measures other than her own self-care. She did say her family and friends provided advice, ideas on new therapies to try, and emotional support for her. Unfortunately her daughters are too busy with their families to call often.

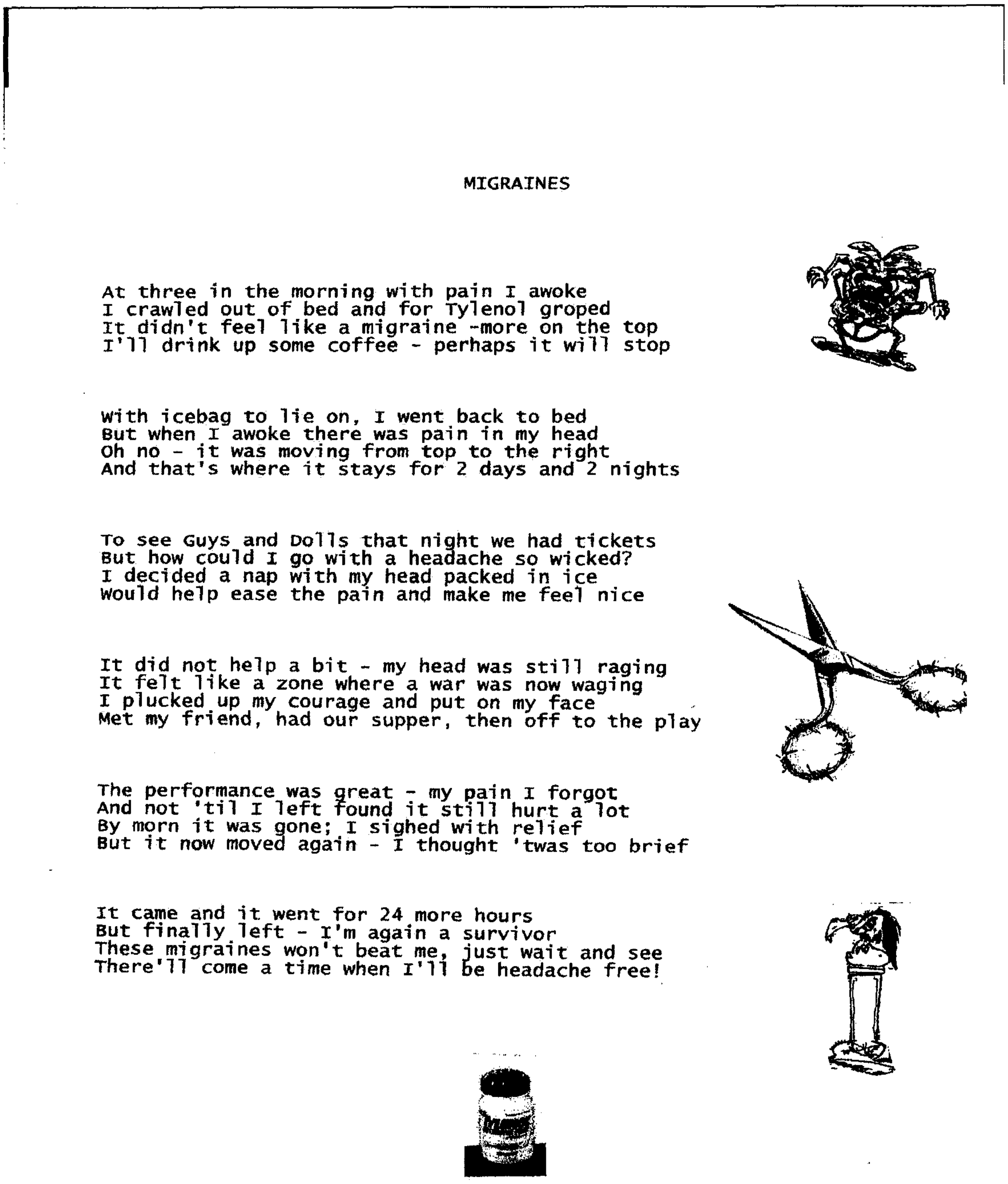
Her description of her headaches was somewhat sparse in terms of physical detail but she had addressed frequency, regularity, one potential cause, and severity. She mentioned carrying on with work and the frequent use of mind over matter. To me this suggests questions about the acceptability of the health problem of migraines, and whether there is an understanding in society of the disability, and the level of suffering that can accompany migraine. She would later tell me that she seldom missed anything because of her migraines but she really did not address her quality of life much. There seemed to be an acceptance of the inevitability of pain in her life.

Our discussion continued to the seizure drug Grace has been on for five years. She agreed it was helping as the frequency of her headaches (both kinds) is down to roughly one a month from five or six a month. Then, as an aside, she noted she was on Nadalol, a blood pressure medication that can also help prevent migraines. Blood pressure medications, in particular beta-blockers, and more recently anti-seizure medications are common choices for prophylactic treatment of migraines. Grace thought the Nadalol helped some and noted the two medications improved her life immensely. This was a strong statement for her but again given in general terms rather than specifics. She continues to use Tylenol for headaches stating that it prevents nausea and makes her headaches "more bearable". This reference to bearing the headache touches on suffering and quality of life, but it also speaks to social narratives and the expectation that those with chronic illness must bear with a certain level of suffering. I think our expectations for acute illness are much different. We expect interventions to control our suffering while we recover and expect that there will be an endpoint to suffering. Grace noted again that she never has to go to bed with her headaches and has never missed work because of them. Distraction from keeping busy helps her forget them. This latter statement is interesting for in the past healthcare professionals viewed pain relief from distraction as an indication that pain was mild or absent rather than relieved by the distraction process. The ability to sleep was likewise seen as absence of pain rather then exhaustion.

Overall, Grace seems to view Tylenol as the main medication for treating her migraines and sees the seizure drug and blood pressure drug (these both taken for their primary purpose) as helping prevent her headaches but as very much a secondary treatment.

Grace's Poem

For our final visit I had asked Grace to come up with a creative representation of her experience with migraines and seeking help. She was free to use any creative process with which she was comfortable. The use of a memory box had helped open up many new aspects of Grace's experience and had made it more real, more physical, more touchable. In the same way, when Grace used her creative nature to come up with a representation of her experience of seeking help with a migraine headache, it uncovered more layers of experience. Her words over the course of our discussions had become more personal, more gritty, more passionate. With them came a finer tuned picture of the experience of a migraine for her and of the identity that having migraines had helped create for her.



MIGRAINES

At three in the morning with pain I awoke
I crawled out of bed and for Tylenol groped
It didn't feel like a migraine -more on the top
I'll drink up some coffee - perhaps it will stop

With icebag to lie on, I went back to bed
But when I awoke there was pain in my head
Oh no - it was moving from top to the right
And that's where it stays for 2 days and 2 nights

To see Guys and Dolls that night we had tickets
But how could I go with a headache so wicked?
I decided a nap with my head packed in ice
Would help ease the pain and make me feel nice

It did not help a bit - my head was still raging
It felt like a zone where a war was now waging
I plucked up my courage and put on my face
Met my friend, had our supper, then off to the play

The performance was great - my pain I forgot
And not 'til I left found it still hurt a lot
By morn it was gone; I sighed with relief
But it now moved again - I thought 'twas too brief

It came and it went for 24 more hours
But finally left - I'm again a survivor
These migraines won't beat me, just wait and see
There'll come a time when I'll be headache free!

Figure 4 Grace's Poem

The headache she wrote of in her poem helps capture the migraine and the days that followed. It shows the personal and the social nature of migraine, and how it can disrupt one's life and that of others. The many things people use for self-help are touched on as is the severity of her suffering. Perhaps one of the most meaningful pieces for me in this work is when Grace describes putting on her makeup. Although she told me it was really just putting on makeup, for me it evoked the image of the hundreds of times I have used that activity to hide my pain and gather my courage before going out to undertake some activity despite my pain. It is like a metaphor for putting on armor and gathering one's courage to do battle with an enemy.

What Do You See?

I loved the passion expressed in this poem and it was fascinating to hear Grace's explanation of the pictures that surrounded the verses. She pointed at the vulture and said, "And I think that maybe that's me down there at the bottom, that ugly vulture. Kind of feel like an ugly vulture when you have one". Our conversation turned to how we sometimes feel guilty or embarrassed because of the way we look with a bad headache while at other times it seems we are too good at hiding our pain.

> "It's, it, that's kind of interesting, yesterday morning I went to play golf and I'd had a, well I got up with a headache … and it's in back and it can get really very painful but it went anyway … and I'd only had about three hours sleep so I wasn't feeling very perky, but one of the uh, the workers out there at the pro shop he says, 'Well you're out here looking great today, young lady!' (Laughs), you know, something nice like that", Grace explains. I said, "Yeah, sure I am, I only had three hours sleep last night." "You are looking good", he said. "So you know, maybe it was guilt, she continued, "Yeah. I thought I shouldn't be looking good, so I mustn't be looking good. But uh, anyway…". "Well that's an interesting notion, yes, that we shouldn't look excellent. Yeah, when you're feeling so much pain, how can you look good?" I asked. "Uh huh, no I figured I must have big bags under my eyes but he apparently didn't notice them or he was just being super kind", Grace mused. "Yeah, well I've had that happen too, when I've really had quite a headache and, and I was always amazed that people didn't see it", I said. "Um hmm", Grace murmured. "You know", I stated. "I guess you get used to covering up", Grace suggested. "You get used to covering up, yeah, you put your makeup on, and you, and you know, and do the best you can and uh, and then they don't know", I said. "Yeah, and they … well people I know just

> didn't see anyway, even if you do say you have a headache ... they're not interested in it, they've forgotten about it ...after a while", Grace finished.

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Grace's story shows us some of the contrasting elements in how the private and public worlds of living with the pain and the aftermath of migraines can shape how an individual builds identity. Grace pictured herself as ugly and as having large bags under her eyes. She did not feel perky and there is an implied idea that the pro shop worker should have seen that. At a time when she needed empathy for feeling unwell, he provided what appeared to be undeserved flattery. Like Grace I have had many moments when others have not seen my pain for I have learned that pain is generally not acceptable in society and I hide it well. With this unfortunately comes a loneliness that I think only those who live with pain in isolation can truly appreciate. I sensed this especially in Grace's final words about people not being interested in one's pain after a while, in fact forgetting "after a while".

Separate or One?

When I asked Grace about the little character at the top of the page with her poem she said,

> "Well I think I would think of it as the headache, as being very cruel. You know?" "Oh okay. So you, would you say that you see the headache as somewhat separate from yourself?" I asked. "Separate entity. Um, I guess not, because I always refer to them as my headaches and not as them. They, my headaches can still be separate", she explained. "Yeah?" I pondered. "I don't know if I do or not.

The power of a migraine to turn off our abilities one by one seems to endow it with the powers of an entity. Perhaps this is one of the reasons some of us struggle with this issue of is the migraine a part of me or is it separate? Given that a migraine is pain and agony of many kinds, why would any woman want it to be a part of herself? Perhaps it is easier to live with picturing those negative forces and experiences if you push them outside of the self.

> "I sometimes think I'm at war with, with this thing" she stated. "Um hmm", I murmured. "And I mention that too, that I feel like a soldier, at war with
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them", she continued. "Well right, and now, yeah, and you used the words right there. So it is kind of separating out from yourself", I affirmed.

I went on to talk about war terminology used in medicine and how I thought that in this case that made the headache the bad guy. Grace and I found this interesting to contemplate for as I said to her,

> "If it's, if it's not really part of me, then am I doing anything that causes it or do I bring it on... Um hmm. ...you know, we, we could have a conversation about it and uh, and I". And if there is a bad guy is there a good guy and am I part of both I wonder? "which brings a moral issue, you know?" I said to Grace. "Right, I see", she said.

This brought us around to the question of guilt again. Did I do something to bring this on, and do I have the power to rid myself of it? These are powerful questions with significant consequences for women with migraines.

Grace had included a picture of a pair of scissors with barbed wire wrapped around the handles. This was significant for her as it represented hurt. As a young girl growing up on a farm she had become entangled in a barbed wire fence and still had scars on her back from that painful experience. She related that pain to that experienced with her migraines. The only positive picture was her Tylenol bottle, a recurring theme throughout out conversations. The one figure she told me she forgot to add was a smiley face to represent her constant determination to be a survivor.

In this chapter Grace's stories of past and recent experiences with migraines have painted a picture of the evolution of a woman increasingly challenged by a chronic, progressive disease. Through storied events and storied words we have dipped into the streams of her life waters sampling the complexities of the balancing act that is living with frequent pain while trying to live a 'normal' life. Grace and I laid out issues that she had not questioned before and it brought us insight into the many visible and invisible ways in which the public and private worlds collide and help shape our identity and our ability to act in certain ways, for example to seek help. Grace's experiences have been played out in a relatively stable place. In the next chapter, place will have a more prominent impact as we continue to narratively inquire into the experiences of women seeking help with severe migraine headaches.

Chapter V Nina's Stories

In this chapter we meet Nina, a delightful, middle aged woman of South American heritage. Severe migraines coloured her world for most of the first forty years of her life. Now she lives virtually migraine free but deals with serious heart disease. As we consider Nina's stories using Clandinin and Connelly's (2000) three-dimensional inquiry space, 'situation' takes on greater significance for Nina looks at things very much from the situation of family cross-referenced through time. She recounts stories of her migraine experience almost entirely in terms of relationships. Our conversations were indeed storied and as we talked we not only shared our experiences of illness, we also talked about our own and each other's experiences.

I met Nina while interviewing participants in a cardiovascular study and in the course of that interview discovered she had had severe migraines. She agreed to participate in my study as well. She is a very vivacious, outgoing person with dark hair and sparkling dark eyes. Her interest in health matters is very evident and I had enjoyed talking with her. I looked forward to seeing her again as I pulled up across from her townhouse condominium for our first meeting. Nina's home was colourful and attractive like herself and she greeted me warmly. We were soon settled in her cozy kitchen over a cup of tea. We were into health matters before we could even get the paperwork done so I hastily set up and started the tape recorder so as not to lose any ideas. I was mindful of her health as we spoke as I did not want to tire her for I knew her heart condition was somewhat unstable. As events unfolded, we only met twice because of her health and my preparations to move to another province. Nina was not well enough to undertake the projects of a memory box and a creative representation of migraines and seeking help. Therefore, during our second meeting I had Nina use her creative energy and imagination to think through what she might have collected in a memory box. For the creative project I asked her to imagine what pictures she might have taken if I had given her a camera to use to capture her experiences with seeking help with migraine headaches. Nina found it easy to use her imagination to picture how she might have done these projects.

They Lived Everything I Lived

Nina started talking about how difficult it was having migraines over a long period of time, when she was always dealing with different people and being in different places and situations.

> "And then, as different people who it, they don't have that, they, it's hard to understand how bad the headache is and you, when you try to explain you get even in more pain because you …and you can't explain that uh, you feel so bad you, your eyes hurt, that you feel like you're going to throw up and you, you ask help, like I, like my greatest fear when I have headaches, was that, in the back of my mind, I always had the um, the memory of one of my, my aunts uh, my Dad's sister, who got up in the middle of the night and went into the bathroom to get an aspirin and she never came back to the room and she, it's because she had a, you know, such a bad headache and uh, she died in the bathroom", Nina explained. "Ohh", I exclaimed. "So my Mother used to be very worried every time we had migraine, it's like I told you the other day, I had two sisters and one brother who, they still suffer from migraine headaches. Except for me that I took the treatment but when I had them, uh, they were so bad that my family, my husband and my two daughters, they knew, well it's coming, because they would, they, they lived with me and they lived everything I lived, uh, with the pain, so they knew what they had to do. The TV was very, you know, very low, the volume, um, we had curtains, so we can close the curtains, turn the lights off, be quiet because Mummy's having a headache. Um, my husband used to cook and he used to take care of the girls because they were really young, since I suffered this since I was, as long as I can remember, I mean, I remember when I was four or five I was, we would travel um, on holidays or I, one of my uncles or my Grandmother would take me to the town where they lived and, and we'd have to get the first seat, seat in the bus because if I sat in the second or third, in the middle, then I would get sick. I would get headaches. Um, so they knew and sometime we had to travel by train because the train didn't give me the same uh, car-sickness and buses and yeah. My father used to, I remember my father used to take taxis or cabs, how you call it here, to bring me home because if I got sick in the buses", she concluded.

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This was an amazing story to me. I could hardly warrant what it was like for a mother to have 4 children with migraines and to have had the experience of losing a relative to a migraine. I am aware that migraines can cause strokes and can be fatal on rare occasions. However Nina's comment about her mother's fear that one of her children would die from the pain itself is something I could relate to without having had a relative die from a migraine. I remember several times when I thought I was going to die, the pain was so intense and I was so sick. For a whole family to deal with such a fear openly was new for me. This was not a fear I shared with my family and it was obvious that it was a shared fear in her family. As I think about her parents I wonder if there was ever blame placed on Nina's mother. The lengths to which Nina's family had to go to adapt to her illness was also interesting. I remember my sister always getting car sick as a child and how we always took towels, wet face cloths, and a change of clothes with us on even short trips. It was common for us to stop at the home of a stranger on our way to get some water to help with cleanups. When I think of this now I think of how easy it seemed to ask for help with a child. Perhaps people's response to children is to understand their needs. This apparently was the same in Chile. When Nina grew up in Chile, her extended family took great pains to help with a very obvious and frequent problem.

I remember that, as a child, I was more open about my headaches, telling my mother as she always provided unconditional help. I did not have to prove that I needed help. For Nina it was the same. As I grew older, it became less acceptable to be chronically ill and I learned to hide my pain as well as to hide the measures I took to ease my pain, such as taking Aspirin. Here there seemed to be a difference in Nina's world. Her family was very aware of her headaches throughout her life and was very involved in caring for her. Even when she married and had young children, her illness was a family affair and her husband was very involved in helping care for her. I wonder how much of this is cultural and how much is individual.

Nina told me that male and female roles followed traditional patterns in Chile. In her words, "women stay home and take care of the children and they have to serve their husband who spent the day outside working and so they just sat there and you had to
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bring the plates with the dinner and blah, blah, blah and then clean up after them". She noted that even when people were newly immigrated to Canada, women stayed home with the children to "clean and cook and they do the jar work and the farm work and …". While she was glad to be away from those traditional roles she still felt very guilty when she was unable to care for her children and do things like make dinner. Her husband took on these roles willingly but this role reversal was hard for Nina. Nina praised her husband for helping her. It seemed that, in her family, the notion of family took precedence at all times.

Daddy Cut Potatoes, Mummy Has a Headache

> "…they become involved in any, any illness you would have because they have to be in charge when you can't. When you're out for one, two days, three days, with a headache. And you can't…", she said. "Don't, don't you find it, or do you find it, that's similar to your heart disease?" I asked. "Yes. It is", Nina replied. "Everybody's, a chronic illness is exactly…", I started to say. "That's what I'm saying, any kind of illness, the family is also, they also have the symptoms, I mean they don't feel the symptoms of the illness but it's like they are involved. Like me, with the headache, if I had to um, if I had to uh, be in bed and be quiet and, and you know, it's important to get the support and my daughters got involved in, in getting me cold stuff on my head, um, bringing me a pail just in case I was gonna throw up, they covered my feet because they were too hot or too cold and this is new probably, and you're gonna laugh about it but back home in Chile, every time somebody had a headache, you go and cut a potato and slice it, just, don't peel it up, just wash it, cut it in very thin slices and you put it on the head. Around your forehead, on the, on the um, temples and um…", Nina interjected. "Ohh. That sounds very familiar…", I said. "or like little cucumbers", Nina added. "I think I may have heard something like that", I agreed. "Well, and, and you know what, it takes, I don't know, I think it's the temperature in your forehead, that that gives you so much um, alleviates the pain, it takes that pressure out, I don't know what it is, but if you put it on, and you will see the potatoes turn…", she said. I stated, "I'll have to try that". "The potatoes turn black. They turn dark because they, the heat from your forehead", she

> continued. “They turn, the colour changes”, she hesitated. “I wonder if that’s a chemical reaction that...?” I started. “I don’t know what it is, but in Chile people still use slices of potato on the forehead. It’s like here I think people put cucumbers on their eyes when they have it, right?” Nina asked. “Yes”, I replied. “Because it’s really cool. If you, if you...”, she went on. “Yeah, and some people use a cloth soaked in vinegar for migraine” I said. “Yeah, okay, but for me, my, I remember my daughters used to ask my husband to cut potatoes, so that we can put it on Mummy’s head. So that’s, yeah, and they keep peeling, I mean, they took them and put new ones on and...”, Nina continued. “Right”, I added. “... and they, we have fresh. And do you have them, like I put my potatoes in the fridge all the time. I don’t keep them outside ... um, so they’re always nice and cool. Cause, not because I have any headache now, but it’s, it’s, I always keep the potatoes, they last longer, you know? They last longer in the fridge than when you have them outside” Nina explained. “Um hmm”, I murmured. “So yeah, they were always cold, and my husband used to cut them and the girls kind of felt, they did, helping Mummy to get better”, she concluded.

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This story not only highlights a cultural practice for treating pain, that is, using cut potatoes to alleviate pain, it again places the spotlight on the importance of a family approach to care. As we continued to talk about seeking help, Nina talked about the rest of her family and then went into more details of the struggle to get help when she was so sick. I loved the picture she paints of her whole family, even the children helping to make mummy better. It brings to mind days when my young children would go get my heating pad for me and would then sit by the couch where I was resting and play with their toys. Their presence was a comfort and it seemed as if they felt better watching over me. I also remember the day I had to take them with me to the Emergency room for my husband was out of town. They sat quietly and watched while medication and fluids dripped into my arm over several hours until I could go home. I will never forget their worried little faces as we all waited for the pain to fade. Once home, I fed them supper, got them ready for bed and asked a neighbour to come in and check that they were in bed later, then put myself to bed. As I listened to Nina describe the support of an extended
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family I thought about how I had yearned for such support.

It Isn't Fair

> Nina explained, "See in my family, my sisters have gone to neurologists, they think it could be depression, they, I mean and they keep, they're still having headaches. They're still taking medication, you know? And, I don't know. And like I said, when my Mum, uh, one of us had a headache, uh, she was always worried about us having an aneurism or really something so severe um, so she was always afraid one of us can die from the pain because she saw us, you know, throwing up and getting pale and your blood pressure went down and I don't know, you got cold, you got hot, and so she went through that with us". "It, how did you feel about it?" I asked, "Well, did you ever worry about dying?" "Um, sometimes I used to think about it, because the throbbing pain, you know, you think your head is gonna explode and then you're gonna die of uh, I don't know. Yeah, I did get scared, many, many times. And I thought, I'm too young! Not that I'm special but I used, then I was young, you know, my daughters were young and they were, they were three, four, but then, you know, until they were about, it's in the nineteen nineties, so its been sixteen years, so still it was about fourteen, sixteen last time I got my headache, but before that, it was, it was every, they started on Thursdays, I don't know why. They started on Thursday, Friday, Saturday, Sunday and then the, the afterward of the pain, it was like, I don't know where my head was, it was a feeling of emptiness, my stomach was really weird because of all the medication and you don't want to eat and if you eat you get sick and yeah. I'm so glad that I don't have it anymore!" "Yeah, that's very true that the, it takes a couple of days afterwards", I agreed. "Yeah, to get better. To get...", Nina said, "...to get better". Nina continued, "it's a whole body, I don't know, it's sort of like...". "The headache is, it's gonna, it's just there", I suggested. "Yes, yes", she agreed. It's almost coming back and you're so afraid it's gonna come back, you know? I used to cry so much, and that'd make it worse. "Yes", I agreed. "That made it worse", Nina said. "That was the worst thing I can do is cry", I said. "I'd cry and I'd cry and I couldn't understand why and where they came from and many times I felt guilty because you have to drop

> everything and you have to go and lay down" Nina explained. "Um hmm" I murmured. "And you, you miss, sometimes, socializing with family, friends, your children. You miss work. And sometimes you know, I, not in every workplace they understand what's going on, what's going on with you, they may think you made, you're making it up, you know? So it's not fair", she finished.

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Every time Nina told a story about her migraines she situated it in relation to her family as she was growing up, or her own family when she was married, and even in relation to her work life. Throughout the discussions, she gave more details of the actual experience of having a migraine. I found her use of language was very passionate and descriptive and filled with meaning for both of us. When she is talking about her fear of dying and she says "I'm too young!" I was not surprised that her next words were about her daughters. As a young mother with migraines, my first thought was always whom can I get to look after the children when I needed to seek outside help with a headache. They were always my priority. We talked about some of the less talked about things about suffering in migraines, for instance, how crying makes the pain so much worse. This led Nina into talking about crying in frustration because of the loss of time with family and friends and of time at work. When she spoke of work, where they might not "understand what's going on with you", was her first mention of the problem of not being trusted or believed. Headaches tend to be used as an excuse for getting out of things and, unfortunately, those who have migraines are also seen as trying to get out of work. Because of this, people may think "you're making it up". Nina's words "So it's not fair" seemed to me to refer to many things: the headaches themselves, the many losses that resulted, and the labeling and stigma that could result. It was the first hint of the very social nature of the illness.

The Look

> "Yes. And you don't look good. I mean, I remember my eyes, they uh, people knew that something was wrong with me because my eyes, I had a different look", Nina explained. "A different look?" I questioned. "It's a different look and your eyes kind of, my eyes, you know, uh, look like they go inward and, and you don't have a, shiny eyes anymore, they're different. And…", she said.
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"Yeah", I encouraged. "And you find, you know, that those, the two lines here (pointing to her forehead), that when I had the headaches and I go like this, see?" "Yeah", I agreed. "That's when I have some headaches", she said. "Yeah, I can look at that and I know that that's migraine 'cause those two little lines there…" Nina interjected. "Yeah!" I agreed. "Yeah, because you…" Nina continued. "You know, I mean, normally we say they're frown lines but if you have migraines, they're pain lines", I stated. "Yeah. Yeah, 'cause uh, yeah, it's pain. I remember that, it's pain. It pained so much, that uh, all you do is rub your forehead and, and you, I remember that. Yeah. So people always, 'You don't feel good, what's wrong with you?' Yeah. Well, the usual thing, 'Oh, your headache' Yeah. So you have to leave early if you were with friends, you have to, you know, couldn't socialize anymore and yeah, so…" she finished.

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While many people become adept at covering their pain, there is a 'look' that is often difficult to hide. Nina describes some of the aspects of the look in detail. She mentions how her eyes "they go inward and, and you don't have a, shiny eyes anymore, they're different". Then she talks about two vertical lines that form above her nose when she has a migraine. While some might refer to them as frown lines, for those with migraines, they are pain lines. Nina's friends are familiar with the look when she is not well. The simple words, "oh your headache", with an unspoken "again" capture some of the frustration others feel when you are ill frequently. Nina noted, "So you have to leave early if you were with friends, you have to, you know, couldn't socialize anymore and yeah, so…". And so we see the social aspect of migraines, the relational aspect, and how often this is jeopardized, for one must rely on the understanding of one's friends and family or one's co-workers.

It Takes a Village

Nina started to explain, "… I just got married and I remember I got the flu, uh, it was the fall in Chile, and I got the flu and I felt so sick and my mother came to visit and I was in bed with laryngitis or something and I felt really, my body ached and everything and my Mother told me, and I think that's why, you know, we get things in the back of your mind there's always messages that you get when
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you're young. My mother said to me, 'Try to take care of yourself and not getting, not being sick too much because men get tired of it. They don't like women who get sick a lot.'" "Oh! I can't, I just knew you were gonna say that! (laughs) You know, I had a doctor tell me that?", I said. "A doctor telling you that?", she questioned. "Just before I got married. Uh, my doctor said to me this one day, 'You know, men get tired of women who are sick all the time.'" I answered. "Yeah. And that's why…", she started. "And I've never forgotten it", I finished, "it's stuck in my head and it was just…". "It's probably, that's where you probably feel so guilty because you already got the message, long, long time ago. I got married when I was twenty", Nina stated. "Yeah", I agreed. "So it had been in my head for so long, and when I got my heart attacks and I was unable to do anything for myself and I, I, my husband had to bring breakfast to me upstairs and he made me lunch and I felt like, I think of my mind, my Mum's voice was just, just ringing in my ears, you know, 'Men get tired of women getting sick'… They want to have, especially in, in South America, because of the culture, years ago, now it is different, but I'm so glad that it's different because women put up with so much before. Even here maybe when people just get immigrated to Canada, women stay home with the children and they clean and cook and they do the jar work and the farm work and, and…", she finished. "Oh sure", I said. "And then, in Chile, it was, okay, women stay home and take care of the children and they have to serve their husband who spent the day outside working and so they just sat in there and you had to bring the plates with the dinner and blah, blah, blah and then clean up after them and you know, it's like years and years ago…", she said. "It hasn't changed that much", I noted. "My Mother, my mother uh, I'm so glad that I move away from Chile", Nina says. (laughs) (phone conversation) "…my very best friend, she works at the university" she starts. "Oh", I muse. "Yeah, and um, uh, what I was saying, and then I'm glad that I'm not, I wasn't there when I had most of my headaches, because uh, we move away and um, they, they, that's when you feel guilty because of your background, your culture and, and then I always thought, "Okay, he's gonna get tired of me and he's gonna get tired and he's gonna just leave me and thank God he hasn't", Nina

> concludes. "Um hmm", I murmured. "Um, and he's very good. I mean, he helps a lot. He used to help with the headaches, and now he helps with the heart. So everybody, oh, and the other thing is, hopefully, if anybody finds the uh, the solution to get rid of the headaches, they will get the family support because it take a village like uh, Mrs. Hillary Clinton said, when uh, 'It takes a village'.

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This story really took me by surprise, not only because of the similarity of our experience, but because of the intensity of our reaction to the same message. Nina and I both took these warnings seriously. For Nina, it has been in the back of her mind her entire life and with her increasing need for help with her migraines as she had children her worry swelled. Even though her husband readily helped her, she continued to worry about whether he would leave her. "Okay, he's gonna get tired of me and he's gonna get tired and he's gonna just leave me and thank God he hasn't", Nina told me. In her story she immediately hurries on to tell me how much he helps her as if to convince me and herself that he will always be there for her. She no longer has headaches but needs his help now because of serious cardiac disease. I think how lucky Nina is that she has someone who stands by her and I recognize how difficult a role her husband has to play. Partnerships cannot always stand the stress of chronic illness. Mine did not and as the stories of my second marriage evolve there is an underlying fear of being left and a determination to not let this happen again. The words of that doctor long ago continue to haunt me and I have learned that messages we get from people whose opinion we value can have lasting effects.

There is a social narrative underlying Nina's story, one that tells of role expectations for women. It is a narrative that shapes how illness in women is sometimes viewed. We also learn that men are storied in this social narrative and in a professional narrative as sometimes "not liking women who are ill". We do learn about role expectations in this story, about how illness in women is sometimes viewed, and about the importance of family support. Nina is very specific at the end in her story that it really takes family support to deal with chronic illness.

When Nina says it takes a village, she moved her story to the social arena. Nina went on to tell me how important she felt it was that everyone not push you into taking
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risks when an activity or food makes you prone to headaches. “Lots of people force people to, they, they don’t force you, force you, but they really push you to change your mind, ‘Have a drink, it won’t affect you’. But some people get headaches because they drink”, she said. “’Have a coffee, you know, have coffee cream in your coffee’. ‘No, I can’t have cream in my coffee because I might get a headache’. ‘Oh but it’s so good’. You know, people, they need their support. Funny it’s all like people don’t hear”, Nina concluded. Nina explained how she had gone on a radical dietary change for a month supplemented by various herbal supplements prescribed by an alternative therapist to stop her migraines. This was another narrative, an alternative way of pursuing health not always accepted by society in general. She and her family then ate a very healthy well balanced diet avoiding any foods that she learned from the diet might trigger a migraine. Nina is very much into self-help and she stories her friends as trying to sabotage her efforts in an unthinking manner. I could understand her frustration for I think many of us are ready for self-help in principle only. The reality of seeing it played out in front of us takes it into our court as well and that can be very personal and threatening. Perhaps this is why Nina’s friends do not always realize the unfair pressure they place on her to conform to social norms.

It’s Really Scary

I asked Nina about her experiences in healthcare settings.

> “I went to the Emergency room so many times that I, they knew me already by name”, she started. “They knew me and um, well you know, you get to Emergency and you, you’re probably at the bottom of the list because it’s not that important for them because it’s just a headache. Which they call, ‘Just a Headache’ which is not just a headache. It’s been proven that sometimes people are having a headache because they’re having uh, a blockage in their brain or they’re having aneurysm uh …”, she continued. “Right”, I agreed. “They’re having, uh, gall bladder problems which also give you a headache. Some people have vision problems who can also, you know, also give you headache. Um, if you ate something that it wasn’t good, you can also get a headache. I mean, there are so many different ways you can get a headache”, Nina stated. “Um hmm”, I affirmed. “But they don’t understand that”, she said, “even when you have

> migraine …". "It isn't always a migraine, it isn't necessarily", I said. "Yeah, and, and well, yeah ... I, and, like for myself was um, I did it so many times, that they can go into my records at the P. Hospital or X.Y. Hospital, they will find history of all the headaches that I had and all the needles that I had and um, yeah, so well, they give you a needle and they say, 'Well you can go home and sleep it out now,' you know, it just, go home and if it keeps coming back, then come back and we'll do some tests. But, they know, they're not, not always they do testing", Nina concluded. "So how did it feel when they told you 'Go home'?" I asked. "Well, you don't look forward to it because in my case, I was afraid that it would be something bigger and that I could die. I would have thought, I'm gonna go home and I may have one of my brain veins or whatever, they can burst on my way home and I can die. But that, 'cause the pain's so severe that you think that you may die of hemorrhage", she explained. "Um hmm." I murmured. "Did you worry about it coming back again or did they keep you long enough to … so the pain sort of calmed down and then, then send you home?" I asked. "Of coming back after the pain went away or…?"she questioned. "Umm" I affirmed. "Well yeah, I was always afraid of getting the headaches and going to the Emergency cause uh, you always think that maybe next time it will happen. It, you will, they will find a brain tumor or they will, no, it's really scary!" she exclaimed.

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The Emergency room presented another situation that challenged Nina. She tells us that the staff knew her by name, which should have been a comfort, but she felt she was better known by the category "Just a headache", which in her mind was anything but "Just a headache". Nina knew that headaches were associated with "a blockage in their brain" or "they're having an aneurysm" and other serious medical conditions. The migraine was bad enough but the memory of her aunt dying while having a migraine was always with her and so the fear of dying was always with her. Thinking that the staff were placing her at the bottom of the priority list was very frightening for Nina.

Nina thought back to the many times she had been in two particular hospitals and knew there were many records of her visits and the treatments she was given. At this point in her story, Nina suddenly switches topics and tells us that treatments consisted of
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a needle and being told to go home and sleep it out. She would be advised to return for tests if the headache returned. Then she commented, "but they know, they're not, not always, they do testing". I got the definite feeling that, while records existed, they were seldom used. Perhaps there was information in them that could have led to more effective or faster treatment. When she talked about the treatment, her voice was rich with disgust. I could tell she felt she was too easily dismissed from the hospital and that promises of tests were just that, promises. I could hear her conflicting thoughts about going home … looking forward to it for it meant the pain was under control and at the same time fearing the pain might return or she might suffer a serious condition such as an aneurysm on the way home. There was little comfort in such ambiguity.

It is interesting to reflect on how differently Nina spoke of her treatment in hospital for her migraines and for her cardiac problems. Going to the Emergency room was not something Nina took lightly. She used every self-help measure she knew to handle her headaches before giving in and asking for professional help. In terms of suffering, the migraines were probably equal to her cardiac events and yet the treatment was so much less supportive. I wonder, do we have to be in a life-threatening situation to warrant real support. Does suffering count anymore?

I Don't Want to Be a Burden

> "Cause you don't wanna get sick. You know, uh, and that's my problem. That's one of my problems, that I don't like to say every time I don't feel good, I don't like to be a burden and I don't want to be uh, I, I don't know. But that's how I felt when I had a headache. I put up with it, I put up with it, until I couldn't handle it anymore. Then I said, 'Please take me to the hospital'. My husband used to ask me, 'Do you want me to take you to the Emergency?' And I'm, 'No let's wait a little, it may go away, it may go away' and can be hours", Nina explained. "I would say the same thing", I said. "I had my daughter write, write a little bit, when I was writing a paper about this and, and uh, she wrote, you know, 'Mummy, why don't you want to go to the hospital? Mummy, you need to go to the hospital…". "Umm. Yeah" Nina interjected. "She doesn't want to go to the hospital and I don't understand why", my daughter wrote. "That's being grown up. That's what it is, being responsible and you want to be self sufficient and, and

be…", Nina started. "That's what we learn growing up", I said. "Yeah, yeah", she agreed. "It, it's a social thing that it's important to be um…", I began. "Willing and able all the time", Nina finished. "Yes, willing and able all the time" I agreed. "All the time, yeah", she repeated". "That's a good way to put it", I said. "Yeah, and I know, yeah, and you feel guilty if the house is not clean, if dinner is, I'm very blessed because my husband is a good person in that way, he, he cooks, he goes shopping, he cleans, he takes the garbage, he does the vacuuming, I, he's done it all the time, he helped me a lot through, um, all our marriage, I would say, because we had two little girls, one after the other and if they were, diapers and bottles all the time and yeah, he, when I had a headache, I remember I had such a bad headaches when they were young, that my husband give them baths, put their pajamas on, make the bottles, you know, prepare the bottles, put them to bed and then, everything was quiet. He used to close the door, my bedroom door and say, 'Mummy is sick so now we're going to leave Mummy alone, leave Mummy alone and then we're going to go somewhere'. And he took them outside so I wouldn't hear any, you know when they're two and three, what can you do?"

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I think the key sentence in this story is the first one, "cause you don't wanna get sick". You never want that headache to happen again and to admit that you do not feel well or worse that you have a headache is to make it real. As soon as it is real, then the possibility that you may need help is also real and with it comes the feeling of obligation, of being a burden, of guilt. So as Nina says you put up with it until you cannot handle it anymore. Then you say, "please take me to the hospital". I think it is important to think about what it means to put up with something until you are so sick you require hospitalization. Many people will never be that ill until they are dying. Yet women with severe chronic migraines go through this over and over again.

Nina shows us what the waiting is like. Her husband offers to take her to Emergency and she says "no let's wait a little, it may go away, it may go away". Then she admits it can be hours. If she is anything like me she probably knows it is not going away, she is just putting off the trip to the Emergency room because she never knew what
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the reception would be like, how long the wait would be, what kind of treatment would be tried, how successful the treatment would be. I tell Nina about having my grown daughter write about what she remembers of my headaches when she was a young teenager. Her storied account was about me not wanting to go to the hospital, about hiding in my bed. She did not understand at the time why I did not go when it was obvious I needed help. But Nina knew why. It is being grown up and responsible she says. It is part of the social narrative we had learned, to be self sufficient, willing and able all the time.

Nina mentions feeling guilty when the house is not clean and dinner is not made. Then she goes on to describe how her husband takes over her roles when she is ill. Here again we get a strong sense of the obligation attached to gender roles and the guilt and feelings of burden that come when illness makes it impossible to fulfill role expectations. Nina saw this as taking responsibility as one matures and I agree with this but, at the same time, I see that for both of us it presented a barrier to seeking help. We both tried to keep going too long before seeking help, something which can lead to the need for greater intervention. I wonder at the strength of the social narrative that held us both to this pattern of behavior in the face of such suffering.

It Should Be a Partnership

In talking about her hospital experiences Nina also explained her viewpoint on the kind of partnership that must exist between patients and healthcare providers, especially nurses.

> “I know there are people that are worse than me probably, probably people that are bleeding to death and they need to be looked after first, you know. But some people doesn’t understand that. So it, it has to do with your, your humanity I think, in, within you. The, the essence of the human being, because some people it’s so, maybe they never had that. The loving care of their family, your children, your husband, I don’t know. There’s some people that’s really bitter”, Nina explained. “Um hmm”, I agreed. “And they go into that store, then they go into the hospital and they, I know it’s a lot of pain, but they’re trying to help you, unless the doctor comes and tells them what to do, they can’t just do it. You

> know what you need. If I go to the hospital with a headache, I know that I need Demerol and Gravol. But unless the Doctor signs the paper, the nurses won't give it to me, she said. "Well no, they can't", I said. Nina continued, "They can't. So you have to understand that, but pe, some people doesn't. I know that its fifty fifty. I know that it's you have to put up fifty and they have to go the other fifty. We have to meet in the middle. "Right", I agreed. "Right? ...but so...", she started. "It's a partnership", I suggested. "It's, yeah, and some people are very impatient. To me, sometime, I even feel guilty if I want to push that button and tell them I'm not feeling too good. Because I know, I can hear other people screaming, and yelling and crying in the other room, you should hear it! And you say 'well mine is not that bad'", she continued. "Um hmm", I murmured. "Yeah", she said, "Yeah, you don't want to be a bother".

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This story contrasts with earlier ones that address the fear and suffering experienced when hospitalized with a migraine. In this story, Nina first compares herself to others, "people that are worse than me probably, probably people that are bleeding to death and they need to be looked after first , you know". Then she steps back and talks about her thoughts on healthcare in general and the importance of understanding that everyone has a turn and everyone needs to respect the needs of others and the limitations placed on staff. This is the "essence of humanity" for Nina as she holds a strong belief in the equality of individuals. Once again she brings in the issue of family as the root source of this understanding of the importance of caring for others. This has been a story to live by for her. As she takes us back into the particular of her story, Nina's fear and uncertainty about where she fits within the priority list for care services, surfaces again. She tries to justify having to wait for care by talking about the constraints on nurses who must wait for doctors' orders before giving her medications. I wonder if nurses provide any non-medical comfort measures to her during these waits. Nina concludes that it must be a fifty-fifty partnership in the hospital with patients meeting staff halfway in terms of being patient and understanding. She finds the impatience of others hard to understand. Part of her finding a way to that partnership is to say to herself, "well, mine is not that bad". Another way is to say I "don't want to be a bother". It seems to me that these are
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ways of devaluing her suffering and I wonder if this is necessary as a coping mechanism. Perhaps we do ourselves a disservice when we fail to call attention to our suffering and needs. I wonder if staff do not need to hear our stories as we live them, instead of a watered down version of what we think they want to hear.

Taking Health for Granted

> "Yeah, and then you think about how could you take so much pain? How your body is able to take so much pain?" Nina asked. "Yeah", I answered. "That's what, that's what, every time I got rid of my headache, or after I felt better, she said, 'How my, how my body take so much pain?'" "Yeah. And still alive", I commented. "And still, yeah", Nina confirmed. "Yeah", I agreed. "How? When, when you feel sick to your stomach and you said, you ask yourself, 'How my stomach, how my body, my muscles can take so much?'", she wondered. "Um hmm", I murmured. "You know, it's like you dehydrated and, and you feel so sick that then, it's like a new life after you...", she started. "When you've felt so bad", I added. "...like you've been in a coma or something" she finished. "Yeah", I agreed. "That, that's how I felt and it's like, thank God it's gone, because you feel so light and you feel, like you said, it's, you think the headache is right there and it's gonna come back any minute. You feel expectant all the time", Nina stated. "Yes, yes. There is that threat", I added. "You feel so good that you, you, it's like you're scared that it's gonna come back and you're gonna feel sick again. I remember those feelings. I remember that. Please God, I don't want to get a headache because I have this to do and I have that to do and I have to take the girls here and I have to, and I know, I always thought about what I have to do ...", she explained, ...and I didn't want to be responsible. So, suffering from headaches, it's a lot of work. It's, it's a burden that you have", Nina concluded. "It's a huge burden", I said. "Yes", she agreed, "Because your life stops. Like we take for granted everything we have when you're, when you're well. You take for granted".

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In this story Nina paints a series of pictures for us, each of which tells us something about the experience of having a migraine. She relates it to severe illness,
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"like you've been in a coma or something". As she thought about the violence of the vomiting she went through she wondered, "how my body, my muscles can take so much?". When the migraine is gone the sense of wellness is so profound it is , "like a new life after". But along with that wonderful sense of newness was the threat of another migraine, "having a constant sense of expectancy". Nina talked about being scared that a migraine would come back, not just because she did not want to be sick again, but because of the threat it posed to her everyday responsibilities. Nina talked about her girls and how they were always in her mind. She concluded that a migraine is a lot of work, "it's, it's a burden that you have" , "because your life stops". The brighter side of this for Nina was that when the migraine was gone she felt like she had a new life, despite the uncertainty. The relief of pain was so great that the appreciation of her conscious state of health was accentuated.

Stigma

Nina talked about the stigma sometimes attached to migraines as stressful and hurtful.

> "Yeah, and the other thing is that some people, let's say at work, lots of people have problems because they don't believe them, that they have a headache. Some people call them hypochondriacs because, "Oh there's always something wrong with you. You always have a headache, you al…" "So it's a hard life for people with headaches. Because do you, people will think that you're lying, you want to go home and probably you have other plans and, you know?" she asked. "Um hmm", I replied. "And all you want is to go home and sleep, you know? Lay down and sleep". She said. "Right, right", I agreed. "And take something so that you can take the pain away. But I, I remember that I used to stay at work, I used to stay and I'd hang in there, hang in there, until I could come, it was time to come home. As soon as I got home, my family knew, or I'd phone and I'd say, 'I'm gonna go home now, I have a headache, so you know, you make the dinner' … But all I want, and my, my daughters and my husband understood because they've seen me in such a bad shape all the time that they knew that I wasn't pretending", she explained. "Um hmm", I affirmed. "You know. So um, yeah. But I, I hardly ever missed work because of the headaches. Probably I woke up

> with a headache, I went to work with a headache, and I came home with a headache. But I didn't want people to think that I was lazy, I was using an excuse and then that puts a lot of stress on you", she stated.

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This was not the only time Nina talked about stigma. Labeling of individuals as "hypochondriacs" and comments such as "oh there's always something wrong with you" directed at others had made Nina very aware of the potential stigma attached to chronic illness. She knew that her chronic headaches would be seen in a negative light and so she learned to endure, "I'd hang in there, hang in there, until I could come, it was time to come home". Despite her headaches she says she hardly ever missed work, often waking with a headache, going to work with it, and coming home with it. She noted, "I didn't want people to think that I was lazy, I was using an excuse and then that puts a lot of stress on you". I agree that it does put a lot of stress on you. In my own life I think I always felt the need to excel to make up for the few times when I missed work because of a migraine. I set my standard too high most of the time because I worried I might be performing at a decreased level of function because of chronic migraines. Like Nina, my family were the only ones who really understood and home was where I could let down and be sick without fearing stigmatizing words. I wonder as I consider Nina's words if stigma is not often just the result of not questioning the assumptions that underlie daily decisions. Assumptions are often based on cultural values, beliefs, and norms as well. Chronically ill individuals and their families are often subject to stigma and labeling (Joachim & Acorn, 2000). As we hear the storied account of Nina's life I think we gain a better narrative understanding of the potential for stigmatization in chronic illness.

The Memory Box

As noted earlier, Nina thought her way through the memory box project. When we started to do this, she immediately said

> "Uh, the tools for somebody with a migraine headache would be um, having a wet cloth at hand and probably a pail, if you were, if you think you were gonna throw up. Close the curtains and turn the lights off um...what I did, I had um, the Imitrex uh, syringe close. Um, water, if I had to take something, when I
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> used to take the Imitrex through pills. Um, sometime I got really cold, so my husband and my daughters, if they were here, they would give me uh, a hot water bottle to put on my feet because the headache will probably, the medication will lower my blood pressure so I felt really cold.

With that quick list she was finished … and then she thought of her pillow and she paused a moment for deeper memories had been evoked.

My pillow.

> "I remember I started taking my own pillow and if I didn't remember, my daughters would". Nina said. "Mum, here's your pillow, we're gonna take your pillow. So while they were driving me to the Emergency, I remember I put my pillow by the window and I, I put my head on the side, so, because it felt like I was more comfortable not with my head up straight because I got dizzy, I got carsick, yeah. So yeah, my pillow goes everywhere", she concluded. "Stays the same", I said. "Yeah", she replied. "Having it against the window. Yeah. So my pillow goes everywhere and…she continued. "Did you wear anything in particular?" I asked. "Hmm, well comfortable clothes because um, like jeans are too hard but it would be soft clothes, uh, clothing because um, when you have a headache, I remember that even the buttons against my skin would bug me", she mused. "Um hmm" I encouraged. "Um, any hard seams around me would, would bug me and will get the headache worse. I mean, yeah, everything bugs you. And um…, she went on". "Just get very sensitized to everything", I stated. "Yeah. Yeah. I remember that. It's and it's um, its, I don't know, it's something that you know you want. You want not to feel that it's there", she stated.
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> "It's there, its, I remember one time we were, went to uh, when I was in High School, we went to the end of the year trip with my class. We went uh, like about an hour and a half, two hours away from the city to the ocean", Nina started. "Right", I said "But as soon as we got there, I had a headache, migraine headache. I didn't enjoy anything, everybody was playing volleyball, they were playing, you know, basketball, I remember on the beach and I can, I can see them, but I felt so sick, I couldn't eat and on my way back, on our way back, I remember my best friend Glenda, she was wearing a jacket that it had a, a kind of

> strap on the shoulders and, and it had a button on. And she said, 'If you had a headache, just lay on my shoulder' and of course I didn't have my pillow because it was High School and you know, I never thought about it and it was for the date, I mean, for the day, uh, it wasn't a trip that we had to stay, so we had to go, we had to head back after eight o'clock in the evening, because it was so close to the city, so we didn't have to leave early", she recounted. "Right, right", I said. "Besides, it was December and, and it's hot in Chile so on top of that, I had a headache. With that heat, and then she said, 'You can lay your head on my shoulder' and I got so mad at her because she had that button that I couldn't put my head on her shoulder because it hurt more and I couldn't get comfortable and um, by the window, I couldn't put my head on the window because it was a bumpy ride, right, and, and it wasn't like, it wasn't a smooth ride. Because we went up and down the hills and, and then, oh God, I, all I wanted was to get off that bus and, I don't know how to get home, I had no idea but it was so, I missed so many things, before I got married, after I got married, I missed so many things because of the headaches. Parties with my friends, you know, um, and people, when people doesn't have headache that bad, they don't know, they can't understand why you cancel on them. And your social life is ruined because of the headaches", she stated emphatically.

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Once again we see the benefit of considering the memories attached to an object. The pillow was both a source of comfort for Nina and a reminder of the extreme physical sensitivity she experienced with a migraine. This is a common symptom in my experience and I often wonder why it is not discussed more in the literature on migraines. As Nina thinks more about her pillow it triggers another story from her childhood, a year end class trip when she was in high school. She tells us that, "as soon as we got there, I had a headache, migraine headache". While everyone else was playing games and enjoying themselves, she couldn't even eat she felt so sick. I can imagine how she felt being a two hour drive away from home and having a migraine. Usually I just want to lie down and instead she was faced with a whole day away and then a long trip home on a bus. Nina tells of her friend's offer to use her shoulder as a resting place for her head but
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the discomfort caused by a button on her friend's jacket makes this impossible. She misses her pillow at that moment. She tells us "it was December and, and its hot in Chile so on top of that, I had a headache". Heat always makes my headaches worse, especially if it is humid and I felt for her on that day. She could not put her head against the window "because it was a bumpy ride" as the terrain was hilly. I could hear the memory of her frustration in her words, "oh God, I, all I wanted was to get off that bus and, I don't know how to get home, I had no idea". This was an intensely physical memory for Nina and I could hear the emotion in her voice.

As I pictured Nina in agony on that bus, it took me back to a ride home from a weekend track meet I attended in high school. I had managed my headaches during the weekend but was totally overwhelmed by one on the ride home. It was a 4 hour drive on a hot day and I was sitting in the middle of the back seat of a car. With the pain in the side of my head I needed desperately to press my head against something, like a window, but, being a typical teenager, I did not even want to admit that I was ill. About midway through the trip the young man sitting to my right complained that I looked like a thundercloud, asked why I was not talking, and concluded that I was not much fun considering how great a weekend we had all had. My control broke with these words of judgment and tears flooded down my face. I was forced to explain my predicament. The couple driving us home were very supportive and I was able to sit by the window the rest of the way home. The pressure of the cool glass against my temple provided some relief. I was never so glad to get home and was tucked in bed with my hot water bottle within minutes of arriving. I remember many drives like that one. Sometimes I was able to take medication, sometimes my parents stopped and found a place for me to rest. As an adult, I have missed parties, cancelled flights, had to check into motels in the middle of trips to deal with a headache, and visited hospitals around the country. Migraines do have a way of ruining your social life. The amazing thing I find is that individuals like Nina and I keep trying to have a social life. I sometimes wonder what drives us. I wish people knew how hard it can be for us.

Pictures Worth a Thousand Words

> "Probably the first one I would take would be me in front of a mirror with that face that it tells how much it hurts. That would be the first thing I would do",

Nina mused. Because, when I have the headaches, I turn so yellow, my eyes were different, and I remember that I can feel that I was, it was like, it was an out of, of my body experience because it hurt so much that I look at the person in the mirror and it, it was like it wasn't me. That would be the first one, probably. I think that would be, to register, you know, the beginning of something that it would stay with you for hours and maybe two days and three days, you know, and, and then um, probably it would be, it would be the medication on my end table, the glass of water, the pail, the uh, the cloth, uh, you know, blanket, because I, when I got so cold and um, probably my room with the curtains closed and everything kind of dark", she continued. "Um hmm", I encouraged. "And um, and probably I would take a picture of, if I was all alone, I would take picture probably, of my thigh where I, when I was putting my Imitrex in my thigh", she said, you know, um, yeah, I think that's what I would do ... to, to show and probably I would, if my family came home I would ask them to take picture of me laying on my bed or if I was getting sick and I had to kneel by the toilet, I don't know, things that you go through, and then, when you have to have help from somebody to, to get back to bed because you ran out of energy. You know what, the one time I passed out, I remember in the bathroom, I passed out when throwing up and my husband, I, I called my husband and he ran upstairs and I fainted. I remember because it was so severe and I was throwing up so much that I lost conscious, I think for a minute or two, I don't know, but my husband took me back to the bed and I was shaking and, and I felt so sick", she said. "Um hmm", I murmured. "I, I remember that", Nina finished. "I, I think I'd want a picture of you with the potato slices on your head", I said. "Oh yeah! Yeah, well that, my next one was to tell you that, some of what, when I said, if my husband, my, my family came home, the first pictures would be by myself probably, but then, the next one would be my daughters putting wet cloth or potato slices on my forehead. Or cucumbers, which ever's handy. But usually wet potatoes. Like, 'Dad, cut potatoes, Mum has a headache!' And my husband started cutting the, the potatoes", Nina explained. "When I, when I think about stories that you've told me, um, about how your family has to do things for you, I would think, to capture your experience, you might take a

> picture, them cooking supper and not you", I suggested, "especially if you're looking from far away. "You know, but yeah, they are, and the other thing they would uh, I remember, 'Mum, you have to eat something because you threw up too much so you need something to eat'. And they would make chicken noodle, they would bring me chicken noodle and um, 'Mum, do you want some tea?' and I, they, they always uh, did something. And my husband took the, charge of the kitchen, you know, for supper and sometimes at breakfast because I, I woke up with a headache so I didn't get up. So they, they, he took over on weekends and they went grocery shopping. Mum what do you need, what we can do, you know, you need more medication, and yeah, it was a whole family thing. Like I said before, um, it's a family, it's a family matter when uh, when somebody is having a headache. You know, because…", she trailed off. "Well in many cases, pictures of normal family activities, but you not there. That would tell a story" I said. "That's right", Nina smiled. "In itself", I suggested, says a little bit…. "Oh yeah, oh yeah" Nina agreed."…sitting there…alone", I wondered. "Yeah, every, everything, like I said, I missed so much, so many things because I'd feel, and like I said, sometime we did go to be present for certain things and then I would say, you know, 'I'm so sorry, I have to go. I don't feel good'".

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Nina was not able to undertake a creative project to represent seeking help with migraines using a different format. Instead we used our imagination to think of what she might have done with a camera to capture the experience. This proved to be an easy task for Nina. The imagined photographs flowed freely from her and I readily followed her as we gazed at her face in the mirror, seeing the 'look' that was so foreign it was like an "out of body experience". She told me of "that face that it tells how much it hurts". It turns yellow and her eyes are "different". As she looked at the person in the mirror "it was like it wasn't me". These were powerful images of something that, as she said "would stay with you for hours and maybe two days and three days". She then pictured the tools of someone with migraines as she had spoken of them before, medications on her bedside table, a pail, water, a face cloth, a blanket. I could see the darkened room and her lying on the bed. Anyone who watches television advertisements for migraine medications will be familiar with the fact that individuals with migraines are sensitive to the light. As she described taking a picture of her thigh where she would inject herself with Imitrex, I thought that tells a story some people would not think of, a headache bad enough that it requires an injection of something. It took me back to when I used injectable Imitrex. It is wonderfully effective for migraines but the medication burns when you inject it. It comes with a self-injection device and all you have to do is load the syringe and push a button to inject it. I remember sitting on the side of the bed trying to get up the nerve to push that button in anticipation of the burn that I knew would come. In public I would have to take the medication in a washroom and I felt like a junkie getting my fix as I gave myself an injection hoping no one would hear the click of the injector when I pushed the button. Even I was buying into some of the stereotyping that was attached to migraine patients.

Nina went on to tell of vomiting that is so severe that she loses consciousness and has to be carried back to bed. That would have really frightened me. Both Nina and I have experienced severe dehydration with migraines because of nausea and vomiting. Intravenous (IV) replacement of fluids is a normal part of my treatment regime. How I came to fear having those IV's. They hurt so much going in as my veins tend to collapse when I have a migraine and are hard to find.

I loved the idea of a picture of Nina's children putting potato slices on her forehead. This story captures not only a culturally specific folk remedy for headaches but also one way her family deals with her migraines. They all contribute to helping her get well. The migraines are seen as a family illness and this is very special for it relieves Nina of some of the loneliness that can accompany a chronic illness.

My thought when we talked of family pictures of them cooking meals without her was of her absence and I came to see that that thought reflected my own experience and my own experience of loneliness in my illness. I soon realized that Nina saw those same pictures as her family making things for her, something to eat for her, "chicken noodle they would bring me" and "Mum, do you want some tea?". If she was sick on a weekend and her family went shopping without her they would ask, "Mum what do you need, what we can do, you know, you need more medication, and yeah, it was a whole family thing". Nina says, "it's a family matter with us, when somebody is having a headache". What a wonderful attitude. Nina did say she missed many things or had to come home early from some events. The family pictures of her children and husband helping her and going about life without her paint a realistic picture of the social nature of this illness. In its severe form, migraine, as experienced by Nina, is not like a cold that can be managed without help, it involves others in one's family and social circle.

It was exciting how effective this project was for we called on more than just words to find meaning in Nina's stories. We called on our own ability to use our imagination to picture what the words represented and with those representations we naturally pulled other memories and meanings from our own experiences that fleshed out the pictures and gave them life and a multiplicity and depth of meaning.

Chapter VI Claire's Stories

It was late June and I was feeling desperate as I had not been able to find a third woman with migraines for my study and time was running short as I was moving to Nova Scotia in August. Ads in newspapers and flyers at the pain clinic were having no effect. Then someone from our Tuesday Research Issues Discussion Group gave me a name and I met Claire. She said yes immediately and said she would be just as happy to come to my house for our chats. She first stepped through my door one sunny July morning. Tall and slim, with a multitude of tiny, tight, long blond braids and a small piercing in her nose making a slight statement of alternative style, this young woman was filled with energy and her blue eyes shone with expectation. She slipped off her sandals and we walked upstairs to my living room and settled ourselves on my sectional. With one leg tucked under the other, Claire looked very relaxed. Claire told me she was a teacher, had been teaching in a local high school for the last ten years and that her specialty was theatre.

Head Flu?

While filling out the usual forms I found that Claire had had migraines for 6 years, not the 10 years set out in my inclusion criteria, but I had been having great difficulty getting participants and decided to include her in the study. It would turn out that her migraines were very severe and that she always needed outside help with them and so this decision proved appropriate. She started by telling me about her first migraine.

> "The first time I had a migraine, I wasn't sure what it was because I was so sick. Um and I just knew that it felt like my head was going to split open and, and I thought there's head flu or something horrible. Um, and could not get into my regular doctor so I went into a Medi-centre, and finally after, probably an hour and a half of waiting and sitting there, trying to find out what was wrong with me … with the nurse on staff had administered Demerol to me and uh, and of course, you know, within about twenty minutes from that, I was passed out in my husband's car", Claire explained. "Um hmm", I encouraged. "And sleeping. Uh, and then after, I went to, to my family doctor and she said there was potential that I, you know, had a migraine and that it could be recurring", she said. "Right", I

acknowledged.

“And so that, like the first year, probably one or two times a month, it would come on and often they would come on after a really busy day at work or something, or a stressful situation. And so my regular doctor not being open, I would have to go to a Medi-centre and uh, dealing, sort of dealing with them, saying I’m here for a migraine, but couldn’t actually voice that because I was in so much pain, and I’d be curled up in a ball in the waiting room and just being treated very differently because I don’t think they knew how to handle it. Um, and …”, she continued. “Did you find it um, was hard to actually find the words, form your words?” I asked. “Absolutely. Yeah and I’m also, I’m one of those migraine sufferers who, as you, you know, I throw up. I’m throwing up until I can’t throw up anymore”, she added. “Right”, I agreed. “And so, you know, I, I think when they see me coming too, it’s like, ‘Oh there’s that woman again’ (Laughs) You know?”, she says. “Yeah”, I nod. “There’s that one we don’t know what’s wrong with her but um, we have to give her a shot. Um, so yeah, and then uh, it was, I mean it was, you just are trying so hard to say, ‘My face is caving in’, um, my, ‘can’t, I can’t open my eyes’ ‘The sound of your breathing is affecting me’, like all of those things? she stated. “Right, right”, I encouraged. “Yeah and um, and you know, just feeling, actually feeling kind of like a freak the first year, I think, because I think it was because I was dealing predominantly with Medi-centres thought”, she finished.

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Claire’s description of a migraine resonated with my own experience. At first I almost chuckled at her reference to a head flu but then I realized that I was listening from the perspective of someone who had always had headaches and here was this woman who had never had them. Under those circumstances I might have imagined I had a bad flu or worse was having a stroke or something equally severe. As she talked about how sedated she was by medication I thought of the implications of this in terms of time needed for recovery and the need for someone to be with you while you recover. Then she talked about her experience at the Medi-centre and I was awed by her description for it really captured the hypersensitivity I experienced with a severe migraine. I had never
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heard anyone put into words the fact that someone's breathing can be too loud but her description resonated with my experience. I too have felt I could hardly get my eyes open and that my face was caving in. Sadly, I have referred to myself as 'that woman' who comes for help, that woman who does not seem to be welcome, who feels like she is a bother or who is in the wrong place. I have wondered as Claire did if there was a particular way of thinking behind these perceived responses and if so what might the origin of these thought processes be.

It's Torture

> "So it is, it's voicing it and I, for sure, that first, yeah, first year I felt really, it's like I said, I felt like a freak because they, you know, I felt like they were just, they didn't understand what, how severe it was, number one", Claire told me. "Um hmm" I encourage. "Um, and I don't think my husband understood how severe it was too, until the, the lucky night he came, he had to pick me up because I could feel it coming on and I knew I had to deal with it um and by the time I got to the Medi-centre I was just a wreck … 'cause I shouldn't be driving … 'cause I can't even open, I barely open my eyes", she explained. "Um hmm", I agreed. "But I think, 'I've got to get myself someplace'. So um, he came to pick me up and they had just given me this new medication through the nose …" she said, "…a spray …". "Right", I nodded. "…yeah, and uh, I said, 'It's not working, it's not working and I feel sicker than before.' And my husband had come into the, the little room that we were in and, and I threw up, from the table to the sink, like he was, and he was like, 'Oh my God, you really are sick'", Clare finished. "You know, my God, yeah!" she laughed. "And that's when the nurse too, she said, 'Well I guess we'll … now we'll have to give you your shot.' I thought well, yeah, the only thing that's working, you can't just keep trying these new things on me that you think might work, because I, it's torture. It's absolute torture!", Claire said. "Yeah", I agreed. "So I mean, I've had a lot of, I'm a dancer and have a lot of injuries in my life…", Claire continued. "Um hmm", I murmured. "…um but there's not a lot that equates to that same amount of pain. You know, like it overtakes everything", she said.

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Again Claire gave me new insight into the extreme suffering that accompanies a migraine headache, pain that is greater than a lot of injuries she has sustained as a dancer, “pain that overtakes everything”. I also saw the systemic nature of her experience as she described projectile vomiting, from the table (Claire’s term for the stretcher) to the sink that accompanies her migraines. One of the less obvious kinds of pain is the pain that comes from others not recognizing the extent of physical illness. Her husband had not realized how ill she was until he saw a physical manifestation of illness in her extreme vomiting. Even the nurse seemed to need to see this sign before she finally says it is time to give Claire an injection of medication and Claire says that yes to keep trying other things is nothing but torture for her when she knows the injection will work.

Claire’s experience reminded me of similar experiences over the years. Just a few short weeks ago, I was in an Emergency room with a migraine and the doctor asked what usually worked. I answered that Dehydroxyergotamine or DHE was the most effective treatment. The doctor said okay, then proceeded to try two other things unsuccessfully before giving me the DHE. In the end, I had to have the DHE twice before the headache was under control. I felt like Claire, it was torture to have to try other treatments that I had had before, often unsuccessfully, when I knew what would work. If they could have looked at my records, they would have seen that DHE was my standard treatment.

Going to the Emergency Room

I wondered how clinic care compared with that given in Emergency rooms and asked Claire about her experiences.

“Yeah, um, I work very close to the X.Y. hospital, so I’m two blocks away from there. And so I have gone there a few times and, and um, I’ve, I’ve found that they’ve, it was a little ex …, it was a little more expedient um, and I don’t know if it’s because of the type of hospital that is? They deal with a lot of things very quickly, very efficiently because it’s right in the core of downtown. I don’t know, yeah, so it was, it wasn’t too bad. Um …” she started. “Was there a difference in um, interactions with people or the approaches they took?” I asked. “Well, no not really, I think they, I just felt like I didn’t wait as long there. But, I think it’s still, you know, get this done. Just get this done, kind of thing”, she concluded. “Right”, I responded. “So there wasn’t any…”, she began. “Was that your feeling, or theirs?” I asked. “Um, that’s my feeling, for sure, that’s from my perspective. Those, okay, let's just deal with this so we can move on, 'cause it's a very busy hospital", she stated. "Umm, I pondered. "Um, so yeah, and there was never a time when anyone went beyond and said, you know, 'How often does this happen?'", Claire said. It was just "Okay, I've got a migraine. All right, we'll give you a shot. Are you okay to go home? Go home. Like that was always how it was", she said. "That was it?" I asked. "That's it. Always the way ... Yeah, yeah, so it wasn't until I sought help from my doctor that, you know, because I was dealing with this too much …", she hesitated. "Um hmm", I encouraged. "That, you know, it got beyond and we, you know, did all the tests and things and it was okay. What's going on, you know", she finished.

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Claire's experience of a busy downtown hospital Emergency room was that it was efficient, a little faster than the clinics she sometimes went to, and very immediate in terms of the care. What she describes in terms of their approach "let's just deal with this so we can move on" really reflects the acute care focus of any Emergency room for this is the primary purpose of these facilities. It would not be surprising if staff reflected this mindset and the need to deal with many patients in the run of a day. As she talked about her experience in terms of "Okay, I've got a migraine. Alright, we'll give you a shot. Are you okay to go home? Go home", I thought it sounded like a formula and I could almost see the standard nursing care plan, one plan that fits all. The problem is that every migraine may not be the same from person to person and even from time to time.

Claire recognized that her headaches were happening too often and I could sense in her voice a feeling of something close to disappointment or feeling let down when staff failed to follow up further than handling her immediate needs. She had to take the initiative and see her own physician to look at her problems from a long term perspective. This perspective was that of chronic care, and she found this more satisfactory. One of the unique things about migraines is that they are both chronic and acute and so need to be addressed from both chronic and acute perspectives to be fully understood. Claire and I have both been in the position of wondering where to turn to get help that is holistic enough to meet the needs of both elements of this illness.

Where Do I Start?
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I asked Claire if she had run into any particular barriers or anything that particularly facilitated her seeking help? I reminded her that she had mentioned a couple of problems, the severity of her condition, difficulty explaining her condition to people, and individuals not necessarily understanding how over sensitive her body was at the time. I said I found it really interesting to think about somebody's breathing bothering her and that most people would never, ever imagine that this could be a problem.

> "Um hmm. Yeah, yeah, well just even footsteps, like the footsteps of, of someone coming over, when you're curled up on that table and there's footsteps and that is like making your bones rattle, you know?" she said. "Yeah." I answered. "Like it's, yeah, um, I just, I'm thinking like, I know my doctor's been very helpful, but it did take time to get there, to that point, because initially, it was, it was always about, and I think partly could have been my not understanding what I was going through too, it's that, it was, 'Fix it now' and then, it wasn't until it happens again, that you go, 'Okay, this is recurring, I need to know more about it.' But it was never in that process until I had sought out my own doctor that anyone had said, 'Okay we need to, you need to see somebody about this.' It was just, 'Fix it.'", she explained. "Right", I nodded. "And I think that's a big issue because, and it's funny because I never thought about this until now. You know, you just, I think you realize you just got to do stuff to, to make your life better, but yeah, it wasn't until I said, 'Okay, this is too, there's too much, it's happening too frequently' Um, all my body's feeling wiped out, like the next day is even hard, right? "Oh yeah", I agreed. "It's, you know...", she started. "Several days", I suggested. "...it's hard and, you know, like two nights ago, well you called me yesterday and I'd had a horrible migraine, was so sick the night before um, had been highly medicated. Yesterday I kind of went through the day feeling fragile, right? Like it was, go slow, go through the day feeling like I've got to sort of be in a little cocoon and you're just not...", Claire continued. "Yeah, the headache's almost there...", I said. "Yeah!" Claire agreed. "...you're just barely holding it at bay", I continued. "Exactly, you know, and it's, I mean, that in itself is hard to deal with but it was, yeah, it was me pursuing other people to help me because no one had, you know, and I guess maybe it's not

> their responsibility to take the initiative, but you think after going to the same Medi-centre, you know, eight times in two months, that someone would say to you, 'Yeah, there's a problem here.'" she stated. "We've seen you before" I added. "Then they look at your file and…" she began. "Yeah", I nodded. Claire said, "Yeah, but I don't, and this is why I don't like, I'm not a big fan of Medi-centres, is that they're not really consistent with, with what they do there. Right, it's write a prescription and go and here's that lady, let's give her her shot so she can go home. So yeah, yeah, it was definitely me pursuing it and bringing it up to my doctor too, like I know, and I had to tell her, "I've now had to go to the Medi-centre three times this month, to get, because these headaches keep coming." "Um hmm", I murmured. "So yeah, so I would think that's a barrier, for sure. And, and sort of being able to, to voice that and say, "Okay, this is an issue, what do I do, who do I go to for help, where do I start?", she said, "You know?" "Right", I agreed. "Yeah, yeah, that's a big step, 'cause that, that took some time, for sure", she finished.

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As I pictured Claire curled up on "that table" it was not difficult for my imagination to take me to a hard surface and footsteps that are "like making your bones rattle". Stretchers are never very comfortable for long periods of time and I really liked the image of it as a table for it conveyed some of the reality of hours spent in an Emergency room with a migraine, in an over sensitized body trying to get comfortable on a narrow stretcher.

As she went on to tell her story of seeking help from her doctor, she contrasted the early repetitive narrative, "fix it", "fix it now", from the medical side with her own concerns, "okay this is recurring, I need to know more about it", "okay this is too, there's too much, it's happening too frequently", "all my body's feeling wiped out, like the next day is even hard". Then she takes us into a metaphorical picture of the after effects of a migraine as she compares it to being in a cocoon, a state of "almost not being there". One can picture the fragility of a butterfly that is protected in a cocoon until it is ready to emerge and fly or in Claire's case to fly again.
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The rest of this story is about who takes responsibility for initiating the process of help. For Claire it had been at her initiative that things had been done and she wondered why this was so. She pondered why staff at Medi-centres did not recognize the need for follow-up when she had been there so often. Even with her family physician she was the one who brought up the issue, "I've now had to go to the Medi-centre three times this month, to get, because these headaches keep coming". For her then, finding the who, the what, the where of seeking help was a definite barrier, a barrier that in her words "took some time, for sure".

That Woman

One of the things I have always struggled with around my migraines is this sense of otherness that seems to be present with the pain. There is such a lack of control over one's body with a migraine that it is as if a large part of you ceases to exist for a while and the migraine or the person with the migraine seems to be a stranger to me. This is why I found it fascinating when Claire kept referring to herself as "that woman".

> "Now you've mentioned a couple of times, um, 'that woman', I said. "That Woman?" she asked. "That woman", I repeated. "Oh, so that's what I think when I call myself…", laughing. "Well I, 'cause I did…", she started to say. "Do you, do you see yourself um, as, as sort of separate when you have the migraine and, and you're going for help?", I asked. "Um hmm. Well I just, I, I, there's so little control over my body when that happens, right? There's, well, there's none. And I do, I don't, I don't feel like, like I said earlier, like a freak because like, I, and not in a bad way, I mean freak is such a bad connotation but, I remember when I went, started and being in the Medi-centre and finally asking, 'Could I have a dark room to lie down in?' Because I could see people looking at me out of the corner of my eyes, crawling into my own skin and thinking, 'Oh God, what are they thinking about me?' Because I can't, I can't cope with this right now?" she explained. "Yeah", I acknowledged. "And uh…", she started. "It's hard to have people watch you when you're like that". "It is,"she said, "it is hard and I'm not, like in my, in my own life I, I mean, I'm not concerned with what people think, but in that case, I think they're thinking, "Well what's, there's something horribly wrong with you." Because you, you are squirming and you are curling up

into a ball and yeah. So I think, and I always felt, when I had to go to a Medicentre too, that, that there was a sense of judgment, like it was never, “Oh, I’m so sorry this happened to you” and it was always like, “Oh, okay. You need some pain medication”. And I’d say, you know, look at my file, I’ve been here before. And I think too, like there’s, there is a stigma because of, because of addiction and because of people who, who are self medicating or whatever they’re doing that there is that sort of stigma with people who come in and are, you know, crawling in their own skin”. “Um hmm”, I confirmed. “And there are definitely people who take advantage of that and I think that’s always in the back of my mind, I don’t want them to think that I’m here just because I need the medication. I’m here because I’m dying. You know, I’m dying and I can’t function. And there’s nothing that’s gonna take this away. You know? ‘Cause I have, I mean there’s times where I’ve, I’ve been in pain for two hours, like to me that’s excruciating and I think, “Oh please God, it’s gonna go away, it’s gonna go away.” And it’s just getting worse and then I’m throwing up and, and, and I think, “Okay, now I’ve got to go. I’ve got to deal with this.” So you know, I call my husband, I call my best friend, I say, “You need to take me again.” Right, like it’s just that phone call. And they realize but…”, she said. “Is it hard to make that phone call?” I asked. “Um, sometimes, like, and I find like, there’s times that I’ve driven myself ‘cause I, it’s coming on and I’m driving, I’m pulling over. Well, the other night, I was casting a show. I was auditioning people for a production and it was coming on and I, we finally finished and I was like, “Guys I can’t even talk about this, I need to go right now.” Uh, and I, I mean I threw up on myself in my car. Right, like that’s so horrible to have to deal with that and I thought, “I’m gonna be okay, I’m gonna make it, I’m gonna make it.” ‘Cause I, you do, there are times when you just want to deal with it yourself, right? And so when I say “that lady”, it’s like it doesn’t feel like me. You know, I’ve, I’m very much in control of my life and my, you know, my destiny is all of these things, but when, when this comes on, it’s horrible and I do, I feel like there’s no control”, Claire explained. “A creature”, I suggested. “Yeah. This creature who needs so much help, like a wounded animal, you know? Like please put me out of my misery", she agreed.

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Claire had not realized that she was referring to herself in the third person as "that woman" until I mentioned it. She had called herself a freak at one point earlier in our talks and then rescinded it as the term is very negative and she really meant that she just felt so different when she had a migraine, different perhaps as in not understood as much as anything. Here she talks about different as lacking control over her body and feeling that she is somehow making a spectacle of herself "squirming", "curling up into a ball", "crawling into my own skin". She feels the eyes of those around her are judging eyes and she is unable to cope with this added stressor. I could relate to those feelings. There usually is no place to lie down in a waiting room, nothing to lean your head against and so you lean forward, put your head in your lap, perhaps cry silently as you wait for a bed in the Emergency room.

Claire brings up another issue related to judgment and that is the fear of being labeled as an addict. I wonder how many women with migraines experience this. Claire notes that some people self medicate inappropriately and take advantage of the Emergency room to obtain drugs for the wrong reason. She is not one of them and she tells us how important it is for people to know she is not here for the drugs, she is here because, "I'm dying and I can't function. And there's nothing that's gonna take this away". It may not be easy to imagine the extent of the dilemma that women face when they are in so much pain that nothing they try at home is helping and the only alternative is the Emergency room, yet the Emergency room represents a place where their motives may be questioned and judged despite their obvious illness.

Claire gives us an example of her trying to put off going to the Emergency room, in part so her colleagues will not know she is sick and her work will be completed, and in part because "there are times when you just want to deal with it yourself". She is a woman used to being in control and to have that control gradually slip away must be a frightening experience for her. Like Claire I have driven myself to the Emergency room and her words "I'm gonna be okay, I'm gonna make it, I'm gonna make it" brought tears to my eyes as I remembered the effort it took to stay focused long enough to get to the hospital on several occasions. I knew how she felt, like a helpless little creature and I
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suggested this. She grasped the idea immediately and talked about a wounded animal that needed to be put out of its misery. These were powerful words to end a story that had started with “that woman”.

Please Don’t Judge Me

> “So would you say it’s, it’s both a control issue and a vulnerability issue?” I asked. “Absolutely. Absolutely, yup, yup. And you know, and with the vulnerability is uh, when, when you’re in that waiting room and you feel like everybody’s judging you, you don’t even want to have that ounce of thought in there because it’s just compounding everything that’s going on. I mean, yeah”, Claire said. “You want to bring the blank”. I said. “Yeah, yeah. Just, again, I know there’s times when I just prayed the world to swallow me, you know, just swallow me up, because it’s too much to bear. Yeah. Yeah. It’s a bizarre thing that the body goes through. It’s a bizarre, bizarre thing. Yeah. It really is”, she finished.
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> “Yeah. And is that, when you were at that casting meeting, that uh, you had such, you held yourself in there until the end…”, I wondered. “Well yeah, yeah, I had to. I had to”, Claire responded. “And you probably needed to go in the middle of it”, I suggested. “Yup, oh yeah. There was like a good hour that I should have gone before. At least. But I hide, you know, I just, I knew I had to and these were also, with this whole vulnerability is, these were people I had not worked with before? And they’re looking at me, and, and you know, like I mean, I have a piercing and braided hair and I think, I don’t want them to think that I, that there’s something else going on with me? You know… Right. …there’s that other judgment that creeps in? Right, right. And uh, because I, I don’t use drugs and I, you know, except for my medication… Right. …and uh, you know, they’re, they’re looking at me and I’m like, “You guys, I’m not feeling well, I’m not good” and, and uh, you know, just them looking at me and thinking, “This is really important, why are you leaving”, and I’m like, “You don’t understand”, like when this comes on, it’s, it’s ugly. It’s ugly, you don’t want to be witnessing this. So, yeah, yeah”, she concluded.

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Claire talked about the feelings of vulnerability and lack of control she experienced in the waiting room as more than enough without the feeling of being judged compounding her misery. Sometimes she said she prayed the world would swallow her up because it was too much to bear. As in the previous story, where she talks of feeling she is dying, her words are strong. This is an extreme experience for her. As she says, "it's a bizarre thing that the body goes through". I wonder how many women with migraines also experience such feelings of being at their wits end.

Claire gives us further insight into the story of the night she was casting a show and had to leave early. Here was another situation where she was afraid of being judged. She was working with people she had not worked with before, people who did not know of her problem, who might not understand migraines and so she hid her problem as long as she could. She did not want a lack of understanding of a medical problem being misinterpreted as something else because of something as minor as her piercing and braided hair. This need to hide an illness can be very isolating for an individual and I know from my own experience can lead to a very real sense of loneliness at times. I think this was one reason why Claire and I took comfort in sharing our stories with one another for we felt a little less lonely in the experience of our migraines.

I felt for her as she talked about the experience being ugly, saying "you don't want to be witnessing this". These sounded like very lonely words to me. I think this is a different kind of loneliness than I refer to in the paragraph above. This is not a case of choosing to hide our experience, this is a case of feeling our experience will repel others because it is ugly and therefore we are ugly and perhaps not worthy of care. This can also contribute to fear of seeking help. I think such feelings may come about because of others reactions to us or because of our own fear of how others may react. I wondered if that was how Claire was feeling in those moments.

I'm Home, Please Help Me

> "Not really. No, I have to ask. He doesn't anticipate like, you know, he'll say, 'What can I get for you?' But as you know, like it's, you, just the sound, there are times when you can't talk. You know, and it's like, I have to get these words out, I have to ask him for it. You know, like two tablets and a glass of water", Claire said. "Right", I nodded. "And you know, cause he's just standing

> there going, ‘What, what can I do?’ You know?” she said. “Right”, I agreed. “And I think it’s hard for him…”, Claire suggested. “Like does the brain work enough to get the words out?” I asked. “Yeah, yeah”, Claire agreed. “And I, I just find that it, it’s hard, you’re afraid to open your mouth that you’re gonna throw up”, I said. “Well that’s it. Exactly”, said Claire. “You know, and that’s what, I was stuck, that’s it and I was, you know, and I would come in through the door and I was, I mean I was covered in puke because I’d thrown up in my car and, you know, just, and there, he’s, ‘Okay, what? What?’ You know, and I go through all the things, ‘Okay, contact case’, you know, ‘Medication, and turn off all the lights’. And that’s, you know, and that, ‘and get me a blanket, ‘cause I’m not moving from this spot’”, she finished. “Right”, I affirmed. “You know, ‘cause that’s, I can’t, you know, I’ve expended enough energy to get to the back door that, I’m gonna stay there until, well, I’ll sleep there. I mean that’s horrible, but I, if I have to, that’s where I’m gonna sleep because I, I can’t make it up the stairs”, she said. “Yeah”, I nodded. “Cause I’ve used everything I have to get to the door”.

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Claire paints a vivid picture of a woman at the end of her rope. She has made it home, but is covered in her own vomit, her head is splitting, she desperately needs help, she really cannot talk easily and yet she has to give instructions for the help she requires. She is frustrated and we see that frustration in her decision to stay where she is for the night. To go upstairs is more than she can face. Help is readily at hand but her husband has not learned to anticipate her needs and as Claire admitted to me later she had not addressed that problem with him. One of the issues that arises with hiding one’s pain is that it can interfere with setting up a system of help. I told Claire about a code from one to ten, I developed to help my family understand my level of pain and disability and the level of help I needed from them. This saved a lot of discussion at a time when I was not able to communicate well and was a very valuable tool for me. Claire thought this was a great idea and said she would think about trying something like this. She said she kept meaning to talk to her husband about her needs but she always realized the need for the discussion when he was in the midst of helping her. How could she criticize his approach
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at a time when he was being so good to her? She seemed to feel guilty even thinking about having a talk with him about further needs. It does sound a bit picky to say things like, "I need you to help me upstairs but first take off your shoes because the sound of them is bothering me", or "I need you to take me to the hospital as fast as you can but you must not hit any bumps or pot holes, and be sure you drive smoothly and do not swerve because it makes me sick and hurts my head". These are important helping issues when you have a migraine but being this specific does feel a bit like biting the hand that feeds you. I wonder how many other women are faced with this dilemma.

It's Like a Fire Drill

> "…and she knew that I needed a couple pillows in the car because I couldn't sit up, I would lie down in the back", I said. "Yeah, yeah", Claire nodded in understanding. "You know, and she'd get me the garbage bags and uh, you know, my heating pad and all the sort of things that you need in the Emergency room", I finished. "Yeah. Exactly, exactly. Well that's good. But I, I also think that, um, that's a relationship that women have though? Like they, they have, like when you say your daughter, my sister, if my sister knows that I'm going through this, I mean, it's, it's not even a question, she would be there", Claire stated. "Yes", I said. "Right?" she queried. "Yes", I agreed. "She'd be there and, you know, she would, 'I'll sit with you in the Medi-centre'. She's like, 'Just call me'. You know, and then like you said, there are times when you just can't pick up that phone", she said. "Yeah", I nodded. "You know, you are, you're just looking at it or it's too far away. It's just too far away! Yeah, and that's when you feel like, wherever you are, you feel like you need to have a phone taped. You know? Why is there a phone taped to the toilet? I don't understand." (Both laughing) "Yeah", I agreed. "Yeah. So, but um, yeah. I think sometimes men just don't have that, that little switch that says, okay, I've got everything, I understand", Claire said. (Laughs) "Yeah", I chuckled. "Yeah. It's like practicing a fire drill, right?" she asked. "Yeah. Yeah, it is kind of. You almost need a list for them, you know?" I agreed. "Well I think that's, I mean, I work in a school, I think, we practice fire drills for those people that need to reinforce the skills set all the time. Really, once you've done it, I think you know

> it. Soo yeah, I think those are, those are made for men. (Laughs) But anyway, you can even quote me on that", she finished.

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We both laughed a lot during this bit of the conversation but there were some serious concerns underneath the hilarity. We had both found that in our experience women seemed to understand and anticipate needs more readily than men and yet it was our husbands to whom we had to turn initially for help. It was a bit frustrating to have to provide the extra information they seemed to need. Not to say that this is the case with all men but men and women in our experience communicated differently and we both felt there was an element of truth in her story about the fire drill. Another interesting part of this particular story that might go unnoticed was the part about wanting a phone taped to the toilet. While we laughed about this as well, we were also very serious for each of us had been in the situation of clinging to the toilet with uncontrollable vomiting, needing help and not being able to get to a phone. We both felt that this is an experience you have to live through to fully appreciate. All of these issues are about three things. The first is how important it is to have open clear lines of communication so help can be brought to bear quickly and efficiently. The second is that communication has to be accessible. The third is about dealing with illness and the use of humour and how valuable it is to be able to laugh at some of the unpredictable situations in which you can find yourself. As we talked and laughed, I realized that there was also a sense of comfort that day in being able to share these experiences with each other and laugh about them together. Sometimes I have felt that the feeling of isolation in a chronic illness is one of the hardest things to bear.

So Afraid

> "'cause they're further apart now, you know, like, okay, it's never going to happen again. I think. And I think part of me is, is hoping, okay, it's never going to happen. It hasn't happened. It hasn't happened in two weeks, right. And then, it'll happen", Claire started. "Right," I said. "Um, so a part of me always hopes that it's, like my body has you know, has been cured or is repaired or whatever, you know, whatever gets this going um, I think there's that. But there's always that fear that it can come on. So it's never a, it's never a, this is my, it's done, I
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> don't have this, whatever. There's always the fear that a migraine will come. You know, like I, I like to run three or four times a week..." she explained. "Um hmm", I murmured. "And there are times when my run will trigger it. Right? So, I'm running and in the back of my mind, I'm thinking, okay, I can't go that extra ten blocks because if I do" ..., she said. "Right", I encouraged. "I'm done for today. Like that's it", she finished. "Cause you can feel it coming?" I asked. "Yeah, can totally feel it coming. So, that is, it's present there and when I'm sitting at my computer, and I've rehearsed for five hours and I'm still not at home, and I'm thinking, okay there's a pain here, okay, careful, 'cause it could come. Right? And so there's always a sort of precautionary voice in my head that okay, it's present, it's present, it's present. So as much as there's time between where I feel like, okay, I'm okay, I'm okay, I'm okay. There's always that, that sense that they're there ... like it's okay, when is it coming next? And I think, you know, and I just, 'cause it's, those are the days that I fear the most. You know, I, I would rather have someone yell at me and, you know, I'd rather be crying and you know, whatever, like, anything else, than have to go through that. 'Cause it's so horrible, you know..." she stated. "Cause you've really, you've reached the stage where you're afraid of it", I said. "Yes. Absolutely. Oh, I'm so, I'm so afraid of it. Yeah. 'Cause they're so severe. It's like, even though they, they're not as frequent, they're more severe than they used to be", Claire replied. "Yeah", I encouraged. "You know, when I, I would get them and I would be in pain and uh, a little bit nauseous. But ... now, like, it's full blown vomiting and um, and chills and, like everything. It's ... it's full blown. So it has, like they've progressed to something else from what I initially had", she explained. "Right", I agreed. "So yeah, there's a huge fear of, of getting them, yeah. Yeah, absolutely", she said.

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Claire provides us with a wonderful description not only of the uncertainty in living with migraines, but also of the constant evaluation of one's body and the decision making that goes on, on a daily basis in managing this disease. I can almost feel the broad appraisal as she counts off the weeks she has been headache free. Part of her even hopes for a cure. At a deeper more physical level she tells us how she feels "it's present,
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it's present, it's present", like a warning bell singing out a need for caution, for it's coming. At other times her body signals, "I'm okay, I'm okay, I'm okay. But, despite the 'okay' message we see that she lives with this constant assessment and constant uncertainty of when will it strike, when will I have to face this thing I fear so much.

These signals, so beautifully captured in Claire's narrative, paint a picture of a life lived on the edge. She never knows when everything will come to a halt, when her work will have to stop, when she will need help, when she will have to experience severe pain and other noxious symptoms. Her words resonate with me. I understand what it feels like to have a headache almost there; to feel like one must walk on eggshells for fear that the headache will break into the open, to wonder if one can keep it a bay. I also know the feeling of I'm okay, I'm okay and the accompanying wonder, but for how long will I be okay. If I do this, will I still be okay. It is a balancing act that is ongoing and underneath it all is the fear. Like Claire I am so so afraid of migraines, afraid of the migraine itself and afraid of the process of seeking help.

Just a Few More Minutes

> "If I just wait a little longer it'll go away. But it never does. It never does. I've never had a migraine go away on its own. I've always had to seek help. Right, so there's that, I think there's that, it's funny how we still hope that though, just wait a few more minutes, it'll be okay. 'Cause you don't, it's true, you don't want to, one: you don't want to drive, or two: I don't want to make that call. You know, I've, I don't want to be throwing up in somebody else's vehicle. Right, like all of those things and yeah, it's, it's every time, you're thinking, okay, it'll go away, it'll be okay. It'll be okay, and then, and then to the point where you just can't cope. You cannot cope", Claire stated. "Yeah. Yeah. So a lot of it is an identity issue, I think", I suggested. "Um hmm", she considered. "I think" I said. "Yeah, absolutely. Well it makes sense, makes perfect sense too", she agreed.
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> "Like I'm always so embarrassed because I will have had a heating pad and, and a gel pack..." I started. "Um hmm, she nodded. "...and everything else plastered all over my head..." I finished. "Yeah", she said. "...maybe for twenty four hours, you know, before I go into the hospital. So my hair is just out to here..." I said. "Yeah, yeah", she agreed. "...you know, and I look like, like

death, and I'm off balance, and you know…" I add. "Can't stand up straight", Claire added. "You're clinging to, to your husband and you just feel the whole world is looking at you and I'm thinking, 'Oh you must be so embarrassed to have me here, here I am coming in, along with my bag' and…" I said. "Yeah, yeah. Exactly. Well I know, I, I mean I can think of like how many times I've apologized to my husband, "I'm so sorry to put you through this", Claire said. "Yeah." I agreed. "Right and, and I think wow, like afterwards, I think "I'm not putting you through anything. But I, you know, you are, you're like, 'I'm sorry and I'm sorry that you have to deal with this'. You know, like and that's, that's interesting too. That says something. Yeah. And it is, it's, it is embarrassing to be there and to be, to be that, you know, that freak show for other people" she explained. "And why is it that we say we're sorry?" I asked. "Yeah. You know, 'cause as you say, we're the ones that are, are suffering…" Claire responded. "Really out of it, I mean…" I said. "…yeah", she nodded. "…they may be bored and their work's been upset and things like that and it's no fun to sit by somebody's bed for a couple hours. Cause those are, those are pretty minor when you put it next to what you're going through", I added. "Yeah, yeah. Exactly", she agreed. "And yet, you know, I find myself, you know, I would come home when there was the minimum better, I'm cooking or cleaning the house or, or…", I mused. "Yeah, yeah", she said. "…and I'm needing to get my hair washed. Try and get some makeup on and, and kind of make up for it?" I continued. "Yeah, yeah. Yeah, isn't that funny, it's the truth", Claire agreed. "It's really a, a weird sort of thing that we put ourselves through", I suggested. "Um hmm. Yeah. It's very true", Claire said.

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This story delves into some of the other barriers to seeking help. If we think back to the uncertainty discussed in the previous story, we can understand some of the hesitation talked of at the beginning of this story. It may be the element of hope for a reprieve that drives the waiting to seek help or something more elemental like the fear of the full force of the migraine or the treatment itself. Claire has always needed help with her migraines but I can manage some of mine on my own. There is a different quality to
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the pain of a migraine that will end up sending me to hospital and I can recognize that quality almost from the minute the headache starts but you can't go into an Emergency room with a story like that. You have to wait until it is out of your control to ask for help, until the full force of the migraine is upon you. What a conundrum. Treatment poses another barrier for me for I have been treated with medications by intravenous solution for the last 20 years. IV's are very painful and hard to insert when I have a migraine and for a period of time I remember the fear of an IV posed a significant barrier for me.

When Claire mentioned not wanting to throw up in someone else's car it made me think of all the other embarrassing things that can happen and how I always attempted to compensate for them after a headache. When I suggested these as identity issues, she agreed and shared her own story of saying to her husband "I'm so sorry to put you through this." Guilt seemed to be an issue for both of us and we wondered why as we continued to discuss what we went through. As I ponder these things, I wonder if some of it is because of our identity as part of a couple. As such, we may have felt that what went on with us reflected badly on our partner. I wonder how our partners would have described these situations.

When I think about the identity issue here, I think the question that comes to mind is that of worth and how it affects identity. If my behavior as a result of illness reflects badly on my partner, does that make me less worthy than he? If I take on feelings of guilt am I buying into this assumption? If this is the case, is worth a component of identity that comes not from just within but also from another? Do I believe an illness is something that should ever be a criterion for evaluation of one's worth. These are important questions with more than a few ethical implications. I do not think Claire or I had really given thought to what we were saying about ourselves when we gave in to feelings about guilt because of the way we looked, while ill, with our husbands.

Assessment

> "When you've gone into um, hospital, how, how much of an assessment uh, have they done with you?" I asked. "Well, they've always checked my eyes, which is extremely painful, I'll always remember that. Um, they check my eyes, they've checked um, pulse, um, sometimes they'll do breathing. They don't

always check that. Pulse, eyes, um, and pressure", she answered. "Yea", I encouraged. "Like yeah, the blood pressure. Um, that's, that's really kind of as far as it goes. Ask a few questions", she added. "Umm", I murmured. "Yup. Yeah. So, and no more than that. And probably because I'm having trouble getting the words out too that..." she began. "Right", I said. "...you know, I think they reach a point where they, 'Okay, this woman is really in pain'. We, you know, we understand now, okay. Yeah. Like that's, I always remember that light in my eyes and I, yeah, and the band around my arm. Yeah. I think there was one time when someone checked my reflexes, which was weird, I mean ...should they do that?" she asked. "Yeah", I started. "So they had done that um..., she said. "That's part of a neurological assessment", I continued. "Okay", she said. "Migraines are a neurological disorder", I finished. "Right. So that one person, out of a hundred, yeah. Yeah. I think I just remember thinking, I'm curled up in a ball, how can you check this? Um, yeah, so my reflexes were checked and yeah, that's, that's pretty much the extent of it though. Yeah. That's not too thorough. So", she stated. "Yeah, it's difficult to assess people when they are that sick", I added. "Yeah, oh yeah. I think, you know, it's a tough job. I think it's a tough job", Claire emphasized.

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It was interesting to ask Claire about the kinds of things done in assessing her condition whenever she went into hospital with a migraine. I suspect that she does not remember having her temperature taken and that she would have been unaware that temperature, pulse, respirations, and blood pressure are routine measurements taken on all patients on admission to Emergency rooms. I was not surprised that only one person had checked her reflexes as in the many years of treatment for migraines I have only had a neurological assessment done a few times. Given the potential for other serious causes of headaches, however this is a matter of some concern and I wondered why nurses and physicians did not do more in this area. Perhaps the most interesting part of our conversation about assessment was that the topic of pain assessment did not even come up. There was no mention of use of a pain measurement tool or measurement of pain relief after treatment. Given that pain was her main reason for being in hospital it is
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interesting to wonder why Claire did not mention this as part of the initial and ongoing assessment. Claire did recognize that assessment is difficult when someone is as ill as she is with a migraine.

Being assessed during a migraine is never easy. I've talked to doctors and nurses with my face covered by a towel, a blanket, a hot pad, a magic bag, and my hands. There is always that awful moment when they have to check your eyes with a light, unpleasant because photophobia is one of the major symptoms of migraine. However talking is probably the most difficult part because your brain just is not functioning very well and finding the words is difficult. Add to this the fear that if you open your mouth too much, you may get sick again and you start to appreciate the obstacles to good communication. That being said, I wonder, when Claire mentions the nurses concluding that "Okay, this woman is really in pain, we, you know, we understand now, okay", if this is not something that needs to be considered. Are assessments cut too short because they are difficult? Women often know a great deal about their own illness and their own bodies. I wonder if healthcare providers miss valuable information that could lead to better care. I wonder how women would feel about more extensive assessments if it led to more effective care.

I'm Here for the Treatment, Not the Medication

> "Yeah. Well and, almost every time I've had to deal with a Medi-centre or Emergency situation where they're coming round, it's, "Okay, can you leave the room now?" So and, the one time where I had been medicated through the nose, a tablet and then finally given a shot because nothing was working, they'd come in and they're like, "Anything? Anything?" And I'm like, still getting sick and then because I'd had all this medication in my body, the nurse came in again and I, I was getting sick again and it's always like, it's so severe how sick...", Claire said. "Projectile?" I asked. "...it's projectile. I've, I mean, it's not like that any other time", she answered. But when I'm, when I have a migraine, and she, the nurse had come in and she's like, 'Oh, okay, you can stay a little longer'." Where is the help in this scenario I wonder? Does she offer any or does she leave Claire to manage on her own? Claire goes on to tell us that it never seems to reach the point where there are enquiries related to ongoing help.

"You know, because I was still so sick. And, but they were trying to get me out of the room. You know, so it's not to the point where they're like, 'Okay now, now you've been treated now, so what can we do for you?' It's like, 'You've been treated, now go'. So, yeah", she explained. "Yeah and, and how do you find that affects you, your thoughts about going?" I asked. "Oh it's, well it's a pain to go, right, like you, again it goes back to that, I feel like they, they feel like I'm just there for the medication ...", Claire answered. "Right", I acknowledged. "...and not for the treatment. Right, and I'm there because there's nothing else that's going to work. And I, you know, so I do, I feel like this person who, I think they deal with so many people who go for the smallest reasons, you know, and maybe it's the Medi-centre people can't tell you apart, and so whatever is close and I think that's scary. It's to the point where, you know, I, I'm here because I need help. Please just, just help me. You know, I'm not here because I'm hooked on Demerol. I'd rather not be here. I'd rather not, I mean, I have a huge fear of needles too. My phobia, I can't even look at the needle. I mean, I'm not looking anyway, 'cause it's getting, you know..." she continued. "Right", I agreed.

"...um, so but I mean, I have a horrible phobia of that. I mean, I all, I don't ever want to have to get a needle if I don't need it. You know, to give blood, the, the place where my doctor sends me for my, my lab tests?" she started. "Um hmm", I murmured. "I mean, they know enough to, 'Okay Claire, start slow, sit before you stand up' and 'let's talk of what are you doing right now' and they talk me through the whole thing because I'm passing out", she explained. "Right", I nodded. "You know? It's a horrible experience, so you know, like yeah, I, I'd love for them to know that I'm there because there's nothing else that I can do. But it's, it doesn't feel like it when I'm, when I go. Yeah. So, yeah. It's just an overall bad time", she concluded. "Yeah", I agreed. "Yeah, real, really, really is", she emphasized.

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There is a lot of frustration in this story and bewilderment over the attitude of healthcare workers who do not seem to understand that Claire is really sick and requires
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their assistance. I feel for Claire as she describes being sick to her stomach and the nurse coming in and saying, "Oh, okay, you can say a little longer". Where is the help in this scenario I wonder? Does she offer any or does she leave Claire to manage on her own. Claire goes on to tell us that it never seems to reach the point where there are enquires as to what can be done next for her. The help given seems to remain at the level of "you've been treated, now go". This seems an approach based more on a concern for moving patients efficiently through the system than on ensuring their needs have been met.

Claire raises a concern about being compared with individuals who may abuse the system and her fear that staff are unable to differentiate her from these individuals. I was impressed with her statement that she is there for the treatment, not the medication. I think this is a good way to put it for treatment takes more forms than just medication and removes the issue of drug abuse from the equation. Drug abuse tends to centre on narcotic analgesic medications and migraines are often treated with medications from other classes of drugs that are non-addictive (Aukerman, Knutson, & Miser, 2002). In my own experience, I have not had a narcotic analgesic for a migraine in an Emergency room for over 20 years. There are other more effective non-narcotic medications given by IV that have been used to control my pain.

As Claire states, the thought of being rushed to leave when you are not yet well, the thought that you may be labeled a drug abuser, and the worry about the treatment itself (in her case overcoming a phobia of needles) makes seeking help in a clinic or Emergency room difficult. It is as she says something you do because there is no other choice. You are unable to manage the pain and you have to have help. I wonder how many healthcare providers are aware how difficult it is to face coming in for help under these circumstances. As Claire says, "It's a horrible experience, so you know, like yeah, I, I'd love for them to know that I'm there because there's nothing else that I can do".

It's a Detour

Migraines can cause significant disability in terms of time lost from work, decreased ability to function at work and in activities of daily living, and days lost through illness and recovery (Aukerman, Knutson, & Miser, 2002; Dueland, Leira, Burke, Hillyer, & Bolge, 2005). Claire gives us some idea of the extent of her disability and how it impacts other things in her life in the following story.

"So how much of a, a, how much disability would you say you have in your life because of it?" I inquired. "Um…" thinking. "When you think about work and daily activities…" I prompted. "Oh yeah." she said. "…and everything." I added. "Well, it's, I mean it does, it, it's a detour. Right, it's a detour every time it happens. Best way I can describe it. Like, it's like a road block goes up. I've now lost, you know, like, the other day is a perfect example, I'm casting a show, so rather than be able to say, cast it that night, I had to go and rearrange my schedule yesterday so I could meet, to get approval from the artistic director of the S…, because I couldn't get it that night", she explained. "Right", I said. "So I had to rearrange my schedule so I could meet with him, um, so my whole day got switched around, um and then there was another day where I couldn't contact my women that I want to put in my show, so I had to contact them later last night. So that put our rehearsal schedule off. By a day", Claire explained. "Right", I agreed. "Um, like there's a good example of when this happens, how everything gets dropped", she added. "Right', I said. "Um, and I think of too, there's times where, like I got a really severe migraine after just a basic five kilometre road race, and was entered in one for the next weekend um, and my body could not do the next one. Like I, I had been so sick for two days and then third day starting, starting to recover was too close to the next race", she explained. "Yeah.", I said. "So I thought okay, well, I can't, I can't do that. So, you know, that, just knowing that I had to readjust that schedule is, yeah, like it's, like it does, it affects me and, and…" she finished. "Does it affect your social life?" I asked. "Oh absolutely. I mean, like it has because you know we, we try to be fairly sociable people, we had people over last night. I can remember even a couple of times this year where we had dinner parties planned, people were at our house, Ned had to leave, my husband, and come get me from the hospital or the Medi-centre. Right, and he was bringing me back, putting me in bed and I'm walking past people who are in our living room. Right, and they're like, "Oh", you know, and they know…" Claire explained. "Yeah", I nodded. "…my friends know, so that's fine but they're like, oh, you know, "I'm really sorry" and I'm trying to say to him, "Just go and visit with them and I'll be fine" and he's

> like, "No that's alright, I'll go down in like…" there I am, "Sorry, I'm sorry" and uh…" she said. "There it is again", I stated. "…yeah, and there's the apology again", she agreed. "Guilt", I repeated. "…and, and the guilt that, okay, I've ruined this party", she said.

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Claire describes a migraine as a detour. When we think of the word detour, we usually picture an alternative route that takes us out of our way, lengthens our trip, and often takes us into unknown areas. I think that is a good description for a migraine does result in lost days which lengthen many of the activities we have ongoing. They require us to be creative in many cases as we try to makeup for lost time and sometimes lost access to the help of others. This is one way of looking at going out of our way and moving into unknown areas. Claire's description of how her casting of a show was interrupted and rescheduled and how this affected rehearsals is a perfect example of the ripple effect that occurs so often when a migraine happens. It also shows the social nature of this illness for the impact is on more than one person. As the impact spreads, so does the sense of obligation and with it feelings of guilt. Claire has even experienced being unable to attend her own dinner parties due to a migraine. While her friends know of her illness, she still feels the need to apologize, an understandable response given the level of achievement this young woman sets for herself in all areas. It does put extra pressure on her. I wonder if her guests would react negatively if an apology were not forthcoming. What is the level of understanding for most people even when we "know" about an existing chronic illness?

The Invisible/Visible Safety Net

> "And we have um, on our staff, one of our science teachers uh; his wife is a massage therapist? So he has quite a bit of skill, and I'll feel like its coming and I'll think, 'Okay, if he just rubs my neck for like ten minutes, it'll go away, it'll go away.' And I'll, I'll go down to his classroom, and I'm like, 'Can you just work on my neck?' He's like, 'Oh it's coming on, hey?'", Claire began. "Um hmm", I encouraged. "Like he's quite understanding, it's interesting", she pondered. "Um hmm", I agreed. "Um, but he's very aware of the body, I think because of who he lives with", she concluded. "Yes", I agreed. "So he's very aware of that and um,
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> you know, and then the, the secretary in our office, who, when she went to the States, she bought um, Advil migraine medication to keep at her desk for me", Claire said. "Um hmm", I encouraged. "It's so funny. She's like, 'Just take one of these'. And I said, 'Well, its probably is not gonna touch it', 'cause it doesn't really", she said. Um, she's like, 'Just take it right now, and you know, in case you need to drive' and um, or you know, if one of us needs to take you and but like I've been fairly lucky where if it is coming on, it's coming on later in the day and then I, I've had to cancel rehearsals, after school, because I do a lot of productions in school", she explained. "Right", I said. "So it's, you know, but not too many times, thank God for that. But, yeah", she finished.
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> "It's really interesting how people plan around it and we don't even know it, I suggested. "Yup. Well and that's, I think where I'm very blessed at work because they, you know, they're a little more aware, but I spend a lot of time there, too", Claire added. "Yeah", I agreed. "I think that, you know, they kind of, they understand a bit more. So, and there's two of us on staff that get severe, severe migraines, so they..." she started. "Ohh", I said. "...so they kind of..., she continued. "That probably helps, I inserted. "I think it does, you know, when there's more than one of you...whose going through something ... yeah, so it adds, it is an interpretive process. For sure, but I always question why. Why am I going through this again? Why am I going through this again?

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I think this story addresses an interesting phenomenon in society. In my experience, people will often pick up extra work or do things for an individual who is ill, pregnant, or handicapped in some way. How much people are willing to do can depend on how well they understand the inability to fulfill a socially prescribed role and how well thought of the individual is. From her stories, we know that Claire spends a lot of time at school and as she says "I do a lot of productions in school". This makes her a valued staff member. She is not the only one with migraines and this makes her problems less easy to dismiss. Because she has had migraines at school, there is some level of understanding of the severity of her affliction and I think this helps others empathize with her.
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I found her discussion of the science teacher's awareness of the body interesting. Claire has already told us of the significant over-sensitivity of the body that occurs with a migraine. It seems reasonable to assume that this must manifest itself in some kind of outward form that can be recognized. Claire and others have talked about the "look" of a migraine. Is this an awareness of the body? Is this something that can be learned, that can be taught? Does the secretary in the school have this same awareness?

I think the kind of support Claire talks of can be overt or covert. Sometimes individuals plan around us, like the secretary who bought the Advil just in case and then presented it. At other times, the support is an outright offer of help.

My Memory Box

Claire's memory items were ones I might have picked but the bag she brought them in was quite unique and had a story all its own. What amazed me the most though was how long we would talk starting with a simple pencil.

Figure 5 Claire's Memory Box Items

Musical theatre bag.

"Well I'll tell you first, it's in um, a musical theatre bag, um, for two reasons. One um, music is something that helps relieve stress for me. Um, when I, when I'm feeling like I'm, I'm … stress is probably one of the main forces that brings a migraine on, um, and I find music uh, is a big, big factor, but also on the other end of the spectrum is when I'm in my car taking myself to get treated uh, everything shuts off and the radio is always on in my car, like it's, it's on constantly, it's on in the background, it's there, so I'm in my car a lot…", Claire explained. "Right", I affirmed. "And so it's my company and it's the first thing that goes when I, when, so it's interesting, so that's like two ends of the spectrum", nodding. "Yeah", I agree. "And I also dance, and dance is a big stress relief for me. So um, that's why it's Billy Elliot, my bag, so 'cause I looked, I've got to find a bag for this, there's, there's some meaning there. Um, so…", she hesitated. "Does dance go, the same way music would go?" I asked. "Oh yeah, any movement goes. And movement is a language for me. Like I, I've been dancing almost as long as I can walk and it's a language for me and it goes. Like it, you know, you're just in a ball and that's it. There's no movement. Movement equates to sound in the air and all the things you need to stop", she said. "Right", I agreed. "So yeah, so the, it was symbolic that it was in that bag", Claire concluded.

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Putting her memory items in a musical theatre bag was a way of capturing the essence of Claire for she is music and dance, sound and movement, and these are two things affected by migraines. In fact, phonophobia is one of the diagnostic criteria for migraines (Aukerman, Knutson, & Miser, 2002). Surprisingly enough, the need to be still is not. My experience is similar to Claire's in that I also want movement to stop when I have a migraine. Her statement, "Movement equates to sound in the air and all the things you need to stop", is really profound for you do want everything to stop and even sound has the power to hurt one's over sensitized body physically. It is interesting that there seems to be no middle ground. Claire does not want these stimuli reduced, she wants them gone.
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I am reminded of a chat with a childhood friend the other day in church. She was telling my husband that my mother used to say, "Sharon used to sing from the time she woke up until she went to bed". I still love to sing and I used to have music in my home all the time, but after a lifetime with migraines I no longer play music during the day and rarely have it on in the car. I came to value the quiet because of years of daily migraines. But I am on a new medication now and no longer have migraines on a daily basis and as I sit here writing this I realize that I could try reintroducing music back into my life. What a revelation.

Hot and cold.

> "So a facecloth um, for uh, for the times when I'm at home uh, and either it will have ice in it or it'll be uh, super cold. The facecloth is always cold", Claire explained. "Always cold", I asked. "Always cold. Um and usually it'll go on my uh, my sinus area first", she answered. "Um hmm", I prompted. "Uh, and then, I'll get another one for the back of my neck. Um, and that's, it has to be cold to start. Um, so that, that's part of, okay, something's coming on here. And it just, the cold water, cold compress and um, usually if it, if the, the headache will start in the back, it's, it'll be warm, but if it starts in the front, it has to be cold. And I don't know if that's like I've had a history of sinus problems or something but yeah", she specified. "Hmm", I pondered.
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> "Just it, uh, and I have my grain bag that goes around my neck", she added. "Right", I said. "So that's for warm, that's warm and that, especially if it starts in the back. And yeah, that just, it has, it has to be warm for that. Um, but this too will move around my face so it'll be here, and then it'll be here and then it'll be across my eyes and um, if I can handle the weight. Sometimes the weight of it on my face, when I've got a really bad, bad migraine, I can't handle the weight of it. So it just, it's something that again, I was thinking about these, these two ends of the spectrum that you're always fighting with, like I need the warmth, but I can't handle the weight of this.

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Claire showed her intimate knowledge of her physical suffering in this story and how best to bring herself some relief through the use of heat and cold. The use of these
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extremes in therapy depends on the location of the migraine which indicates an ability to differentiate between different types of migraines and what works best for which type of headache. Her problem with the weight of her grain bag led us into a discussion of the use of gel packs which can be used hot or cold and are much lighter. I have also found that weight can be an issue at times and so I suggested she try a gel pack for this had proven useful for me. This was not the first sharing of potentially useful information between us and it makes me wonder if migraine support groups or self-help books would not be very valuable tools for women with migraines.

Hair clips.

> "Oh, I also put some hair clips in here. Um...and this is uh, this is interesting because the um, there are certain points, and I think that, I don't know if it goes back to like, like acupuncture, pressure points or something but there are certain times when I've had to have my hair up for different things or I've had a different hairstyle, probably for shows and things, but where the hair clips have triggered a migraine. And I really had to think about this and it was..." Claire started. "Ohhh", I queried. "...just like, because there was a pin probably digging somewhere or I don't know if it was like the weight of where my hair was at, but I remember there was at least three times where, because of having my hair in a really, really tight bun, with a bobby pin or a clip, in a certain place...", she continued. "Right", I said. "...that it triggered, it triggered the migraine. So um, yeah, just thinking back on like all the triggers for me, what those were, um, so I put hair clips in here. And just, I mean, always having to, like for dance exams and things like that? You, you have to have this severe, like ends, there can't be a hair sticking out and just...", she explained. "Right", I said. "...just pulled back but it, it's not even like the tension of the hair back, but it's where the clips are, right, it's where the, there's a like, especially back in here, if there's a pin digging into my medulla oblongata or whatever it is...", she concluded. "Yeah.", I agreed. "...then, yeah, then by, you know, by the, the end of the session, I'm like, "Oh this is not good." Like, having to take, taking the hair down, but it's already too late", she said. "Too late, yeah, right", I agreed. "Yeah. Because it's already triggered something", she finished.

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What an everyday thing, pinning your hair up with hair clips. Who would think that such innocuous objects could trigger the horror of a severe migraine as Claire has described it. Yet this is one of the things she must consider and as a dancer in particular it has been a required part of her life on occasion. She reminded me that it is not the tension in a hairdo, that causes a problem, it is the placement of the clips. We had already discussed her braids and she had said that the tension in them the first day they were done was noticeable but did not trigger a migraine and the braids were easy maintenance. It would be interesting to know if women with migraines are more sensitive in particular areas of their scalp or their scalp in general, or if hair maintenance is an issue. I wonder how many consider their headaches when they choose a hairstyle.

Medications: Trial and error.

> "And then I brought, because I've been on so many medications that actually…", Claire started. "Oh, I recognize that box!", I said laughing. "…yeah, this one, this one, this is what I take now. This is the Zomeg I take now", Claire stated. "Zomeg", I said. "And uh, this, this was…", Claire pondered. "Maxalt", I said. "Yeah", she agreed. "That's what I take", I said. "And this, this actually didn't work for me", she said. "Oh okay", I nodded. "And then the Rel-pass or whatever it's called. Yeah. We tried one of those. It didn't work. So I've got, it's funny, I thought I'd sort of take them all back to the doctor's but I had a few cases of, 'Oh yeah, here's all the stuff that we tried.' (Laughs)", she explained. "Right." I agreed in understanding. "So uh, yeah, yeah. Interesting", Claire said. "Yeah and it is a trial and error", I said. Yup, yeah. Exactly. "And people are, are very different because um, like I think the Zomeg is, I think it's a Triptin…yup. The, this one and this one, I don't know about this one…are derivatives from Imitrex", I said. "Oh, which I've also taken", Claire responded. "Yeah. 'Cause Imitrex was the first triptin to come out, and now there's a whole family of Triptins", I explained. "Okay, okay", she said. "And I used to take the Imitrex and the Imitrex caused heart problems for some people", I said. "Yeah", nodding. "And I was taking so much of it…", I started. "Right", Claire encouraged. "…that the neurologist said, 'Look, you're gonna have a heart attack'", I
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concluded. “Right. Yeah”, Claire said. “You know, we’ve got to do anything you can to get the amount down you know”, I said. “Holy Cow!”, Claire exclaimed. “And I quit my job”, I said. “Really, just a, to save yourself, basically”, she said. “Yeah. That scared me”, I replied. “No kidding”, she said. “He really scared me”, I responded. “Holy Cow”, Claire said again. “And they switched me to Maxalt, which is still a Triptin…but um, it doesn’t work quite as well as the Imitrex did”, I explained. “Um hmm”, Claire murmured. “Imitrex was the best one that worked for me”, I said. “Right”, she agreed. “Um, with Maxalt, I have to take it a little bit sooner…but it doesn’t have, you know, it’s just modified enough that it, it doesn’t have quite the same uh, heart problems”, I said “So when you, when you take your medication, like do, are you able to, to like function? Like can you be sitting up and functioning, or are you in bed when you take the medication?”, Claire asked. “Oh no, I take it when I’m still up”, I answered. “Okay. But are you, like after you take it, are you able to carry on or are you…” she pursued. “Yeah if I haven’t waited too long”, I said. “Okay. Okay. Yeah, ‘cause like, when I take this, it knocks me out. Like I cannot…”, she started. “Oh, you are…”, I said. “…comprehend rhyme or reason” she finished. “…you’re really sensitive to medication”, I concluded. “Yeah”, she agreed.

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Claire has only had migraines for 6 years and already she has a long list of medications that did not work. This means time spent suffering while trying to find something to control her pain. The symptoms of migraine vary considerably from person to person and within an individual over time (Holmes, MacGregor, & Dodick, 2001). What works for one person may not work for another and so as Claire stated, the approach is often one of trial of error. This can be less than satisfactory. What I think of when I read this story is the importance of diagnosis for today there are some very effective migraine specific medications available for treatment. This relief however can come at a very dear price in terms of money, for medications like the triptins are very expensive, and risk for serious side effects. For Claire and I, side effects of the medications were a primary concern. She finds the medications very sedating and this
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can have a major impact on her being able to take them in a timely fashion, something that is crucial to their efficacy. For me, the sheer number of headaches meant that the amount of medication put me at risk for serious health problems. Prophylactic medications would have benefited both of us but I had been unable to find an effective one up until that time and Claire had not tried one. I wondered when her physician would consider her problems severe enough to look at prevention as a primary part of her treatment regime.

Women endure.

I had been telling Claire about the first time I remember having a headache. It was in school and I was 5. I was curled up on my teacher's lap, head burrowed into her chest trying desperately to block out the faces of all the other 5 year olds who were staring at me. Even then I was acutely uncomfortable with someone else seeing me in pain. We started to talk about how women hide their pain, how they learn to do this, and the consequences this could have for seeking help.

> "Yeah but when you think about it, it kind of makes sense because what, what do we tell little kids, you know, we tell little boys they have to be brave...", I said. "Yeah, strong", Claire agreed. "...strong and everything and, and we've, we tell little girls uh, in a different way that, that they have to um, suck it up and keep going", I proposed. "Um hmm". Claire said. "You know", I said. "Yeah, yeah. Don't say anything about it, just carry on", she suggested. "Just carry on", I agreed. "Yeah.", Claire confirmed. "It's quite different with men and women, really", I suggested. "Yeah", she agreed. "Very overt, I think with men", I proposed. "Yeah, I, you think it would be because I think everything else is overt with men too", she said. "Yeah, yeah", I agreed, "We tell them right out, you've got to be strong. You've got to be brave, you've got to be tough, you know, all these things. With little girls, um, we model a lot of it. You know, because our, our, I was, my mother had a lot of chronic health problems and she always kept going", I said. "That's exactly the same with my mother", Claire said. "It took so much before she had to go to bed...", I said. "Yeah, yeah", Claire agreed. "...and if she had to go to bed, she was really sick", I said. "Yeah. My mother actually, this uh, she just finished in May uh, her rounds of Chemo, 'cause she,

she has Lymphoma in her…", Claire started. "Ohh, I said. "…and uh, and she, I mean she is the epitome of, of life goes on, keep going. I mean here's a woman who has, she'll have chemo and this thing, I mean you're ill, you're sick and you know, you're throwing up and but, you know, she's at the Church setting up for you know, whatever altar guild and… she's you know, driving in to help somebody with a luncheon here and, and uh, you know, it's like, 'My God, why don't you just stay home?' And she's like, 'Why?' You know, she's like, 'There's all these things that have to get done, they just have to get done', that's her thing. Like, 'I have to do these things'. Like well, maybe ask somebody else. And she's like, 'I've always done this.' You know, gotta get it done", Claire explained. "Yeah", I agreed. "You know, it's just like, wow. And then same thing like with uh, when my Mother, if she went to bed or had a nap or something, like, 'What's wrong with you?'", Claire added. "Yeah", I acknowledged. "What's going on? You know. Are you, you must be really, really sick", she said. "Yeah", I agreed ....

"…But yeah, like, it's so true that this, this behaviour is modeled. Like a lot of people say to me, 'You never stop' and I'm like, 'Have you met my Mother?' (Laughs) That's all I have to say and they're like, 'Oh yeah, okay. I understand. I understand completely.'" "Yeah", I acknowledged. "Yeah so, but it is, it's, I think for, for women is that sort of unspoken, modeled behaviour, I mean you…" Claire started. "Women endure…", I said. "…yeah, they, yeah, that's a great way to say it", Claire agreed.

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This story provides "food for thought" about how some women learn to address health issues. As a young child, I remembered wanting to hide my illness, and in the same vein I think we teach young children to be strong and to tough it out when they are sick or injured. Claire and I both felt that as women this idea was modeled as we grew up through our mothers. We learned to keep going, to suffer in silence, and to control our response to pain. Instead of being out there where it is easy to get help, we had learned to be out there enduring. Claire captured her experience well as she compared herself to her mother. She tells us that people are always saying to her, "'You never stop' and I'm like,
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'Have you met my Mother?' That's all I have to say and they're like, 'Oh yeah, okay. I understand. I understand completely'". What message is in these words? Perhaps it is that we do not understand ourselves. If we understood that our way of handling our illness was keeping us from timely help we might change our behavior. If we understood that enduring is not necessary we might seek help. If we understood we might redefine health for ourselves. And then we can wonder does understanding make it okay?

A pencil.

> "I brought a pencil, oh, it's broken now, uh because I'm a teacher and I, actually everything I write is in pencil. I love pencils. I love them, I have a big collection of them. Uh, and I was…", Claire said. "I do too you know, I don't usually say…", I started. "…do you really? I love a pencil. I love it. Yeah, and I think part of it is because I direct a lot of plays and everything has to go in pencil, so I've carried it over to my whole life. Like, don't give me a pen! I want a really nice pencil", Claire said. "Well I have to be able to make changes…", I said. "Exactly!" Claire agreed. "…and you don't have to push as hard…" I started. "For it to show up", she finished. "with, with a pencil as you do with a pen, I concluded. "Exactly. Exactly." Claire agreed. "And that puts less tension on my wrist, my arm, and ultimately my head", I said. "So it's, that's so true!" she said, "That's so true!" "I just started using pencils a couple of years ago", I explained. "Yeah", she nodded.
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> "… A pencil, I hope it never, I hope it never goes away, 'cause I love it. Especially …but um, I was thinking of uh, the first time that I got a migraine at the high school that I'm teaching at, and we used to have this uh, in the end of our office, our offices, main office is very narrow, and down at the counseling end was a curtained area with one of those mangy, horrible cots in it…", Claire explained. "Oh yeah", I nodded in understanding. "…and I remember uh, 'cause I'm always at work early, but by five to eight, having to be on that mangy, horrible cot. Um, behind the curtain and just lying there in this, in excruciating pain and, and people walking by and thinking, oh please don't look through the little, the little…", she hesitated. "The crack", I said. "…the sort of a crack, yeah, I just don't want anyone to see me uh, because too, like I, in my job I

always try to be um, very strong…", she said. "Yes", I agree. "…you know, and, and uh, the epitome of organization and um, as someone that people can come to if there's something going on. I love students who come to me with their issues and things like that…", she explained. "Right", I agreed. " …but that area, because it was right next to the counseling area too, kids are coming and going all the time, she told me. "Right", I acknowledge. "Um, and you know, and missing the, the you know, first part of my class because I'm down there and can't, like I can't move, I'm in a ball and the counselor coming in, at that time was a female counselor um, she's not with our school anymore but she came in and she was massaging my hand, she was massaging the back of my neck and um, so she's sitting in there with me but, but also just, just that image of the crack in the curtain…and how that became so important, like just, I just hoped that nobody sees me. You know, I don't want anyone to see me in here like this. And um, you know, just the, questions I would have to answer afterwards about why were you there, what's wrong with you, you know…", she said. "Is it, do you think it's, it's the um, I don't want you to see me with out my complete control face … in place?" I asked. "Yeah", she said. "It's, it's not really about the, well I look really pale and…", I suggested. "Oh no, it's not about that, it wasn't about, oh I, you know, I look sick and, and pale. It was like, I don't want them to see me, I think, in the simplest terms, looking weak, too, was part of it", she suggested. "Right", I said. "You know, and I, I think too, it was fairly early on when I had been out of school and was trying to build this program so there were all those pressures and I just felt like, I, I don't want them to pass judgment on me, I don't want them to think that either there's something really, I mean, it is horrible, there's something really horrible wrong with me or does Claire have a hangover? (Laughs) Like, all those things, right?", she said. "Um hmm. Right", I agreed. "And, I was never, like in my life I would never show up to work with a hangover" she asserted. "Right", I stated. "I would never do that to myself, I'm, you know, I would never put myself in that position. But being a young teacher on staff and what are all these judgment calls that are being made and, and um, you know, and I, I guess, you know, my style is a little more alternative than some

> of the people I work with who wear suits… and don't have piercings, um, and so, you know, you, I was, I was worried about that too … I can remember all of these things going, you know like, it's as simple as that little crack in the curtain and, and what are all the things I'm going to have to answer about that. You know, so that was thinking back to that situation, 'cause that was the first time I'd had a migraine at school. You know, and to be taken to the X.Y. and got a shot and my husband had to pick me up and bring me home…", she continued. "Umm", I murmured. "…then he had to drive me to work the next day because my car was still at work. And, you know, like that whole…", she said. "Right." I acknowledged. "…that whole incident was, yeah", she stopped. "It gets very big doesn't it?", I suggested. "It does. It gets really big, really quickly", she agreed.

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We started this part of our conversation with a pencil and from that came a long discussion of memories of Claire's first migraine at school, as a teacher. She takes us to a narrow curtained off space at the end of a long office, where we imagine her curled up in pain on a "mangy, horrible cot". She is near the counseling centre and there is a lot of traffic as students and others pass by this small retreat. Claire is in excruciating pain but a large part of her focus centres on a small crack between the curtains and the fear that people can see her. It is not the face of illness that she is afraid to show but rather the face of vulnerability and weakness. As I look back at our conversation, I find it interesting how Claire lists her strengths at work as she talks about this experience. She is "always at work early", is "the epitome of organization", and is "someone that people can come to if there's something going on". She was working hard at building a program at the school and did not want people passing judgment on her. The idea of judgment carries over into her personal life choices as well as she mentions her style of dress and piercings and the fact that she would never come to school with a hangover and would not want anyone to think that this was the problem. This is a lot of extraneous worry for an individual to experience when they are legitimately ill. I wonder now if Claire was justifying the vulnerability that is part of having a migraine.

Claire goes on to talk about the implications of someone seeing her through the crack. There are questions she will have to answer. What does this tell us about her own
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perception of a migraine? Does she see it as a personal weakness or something she should be able to control or prevent? What are the consequences in the classroom or the staffroom when your students and colleagues know you have a weakness? Then, there is her car. Her husband has to take her to the hospital and so her car is in the schoolyard overnight. There seems to be no way to keep this migraine a secret. We agree that this story "gets really big, really quickly". Migraine would seem to be a social illness with social consequences.

My Students Know

> "It's kind of the minute you, now I hadn't, I hadn't really thought about that myself, but the minute you involve one person in it, then all of a sudden, boom, there's a whole lot of people", I said. "Yeah. Yeah, so true. And I, and I think of that, that microcosm of a school, right, and how this incident happens and then, that, especially, 'cause it's like a small town, a school…", Claire agreed. "Oh yes!" I added. "…absolutely and just how, you know, the next day, it's like, 'Oh what happened to you, what was going on?'", she said. "Oh yeah…", I said. "…you know, and you're like…", she started. "…I bet all the kids would know", I suggested. "Yeah, yeah, absolutely", she agreed. "I mean, it goes through schools like wild fire", I said. "Why weren't you here? It does, like, 'Your car was here, what…?' 'I had a migraine'. Ohh.", she said. "Yeah." I agreed. "You know, and it's like, you had a headache so you left? You know, like…", nodding. "Yeah", I said. "…no, you don't understand, like this, yeah. And having to explain to students, 'Here's what my body goes through when, when this happens to me'. It's not just um, a headache, when you feel like, oh I have a headache, I didn't eat very much today or whatever. No, you know, throwing up and the light and if, you know, if you had talked to me, that would be like my skull splitting in two. Like, try to, try to imagine that", she explained. "Um hmm", I encouraged. "And of course, I'm fortunate enough that I teach theatre kids, right, so I'm like, 'Okay, use your imagination here and imagine that, okay…'", Claire suggested. "Yeah, I can see that theatre kids would…", I said. "You know, they would get that a little bit more", Claire added.

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In this short story Claire provides a glimpse of her migraines from the perspective of her students. I think the most telling line in this story is the one, "you had a headache so you left?". It demonstrates the general understanding of a headache. Headaches are considered a minor ailment and for many they are. Some migraines are not overly severe but many result in significant disability and for some are a major handicap. It is difficult for anyone who looks healthy at the time to explain the extent of incapacitation that is possible because of a serious migraine. Most young people are relatively healthy and so explaining disability to this group is even harder due to their limited life experience in general. Unfortunately the questions are still there for Claire and she felt she needed to address what happened for it affected her ability to interact effectively with her students in the classroom. As evident above, if we do not explain, people make assumptions based on their current level of understanding.

My Co-workers Know

> "And my co-workers know now. Yeah. Yeah. And I mean they're, the varied reactions of, oh, you know, 'Are you okay, how, how's today?' To people going, 'You were sick yesterday'. You know, and that's all they say, and then they walk away?" Claire explained. "Yeah!" I exclaimed. "And it's like, 'What does that mean?' (laughing) What was that about, you know?" she asked. "Yeah", I agreed. "Or you, 'I saw you lying on the cot' and you know, it's like, 'Yeah, okay', like you know, just that and, and they do, because I say, it's a small town and everybody comments on it. Or if they're not commenting, they're physically commenting on it, right?" she said. "Yeah, yeah", I said, "Yeah, that's very true". "Yeah", Claire said. "You get the look", I said. "The look or something, right? Yeah.", Claire suggested. "Yeah.", I agreed. "Yeah, so it is, and you, and it's very true, you know, if you, if you do have to build it up and I think part of me is like, and again my, because my students are so honest, I'll be honest with them and I'll say, 'Okay, here's what I went through', you know, 'it happens to me'. Um, but it did take a while to get to that point", Claire voiced, "right because it, initially you just want it to go away and forget about it". "Umm", I agreed. "Um, but then it's, now it's like, okay, here's what happens to me, know this. Um, and maybe you might see it as a weakness in me but, you

> know what, I am back and I'm back in full force. Life will continue on. It's that carry on, again, right?", she explained. "Right", I said. "The voice of my mother", Claire said. "Right", I agreed. "Carry on, you know, and but, but that's something that, that I have progressed to, for sure. Because initially it would just be like, go away, don't talk, let's not talk about it. Like, let's ignore it", she said.

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This story resonates so with me. It is embarrassing to be brought down by a headache, for that is the impression that is out there and while I could substitute migraine for headache, it really does not make any difference for this term is so misunderstood. I can relate with Claire's experience of the enquiries about your health that seem more part enquiry and part commentary and the "look" that is all commentary. There is a genuine stigma attached to migraines and it is something that almost pushes one to excel just to overcome the feared impression of weakness. Perhaps one of the more difficult issues, and I think this is evident in Claire's story, is that individual's beliefs about migraines are rarely stated outright. Instead, there is innuendo and there are strange looks that do far more harm to the person who is already living a difficult life. I wonder too how many of us who have migraines buy into the stereotyping that is out there and judge ourselves before anyone else.

Frail Lady

> "When I first started teaching, it was interesting, and that this, at this point, it, my migraines were very rare, but I worked for a woman, 'cause I used, I was subbing when first started and I remember this woman, and I would, when I first met her, um, she, she had called me, and the conversation, this is when, when you got booked for supply teaching, the, the phone would ring, but also the teacher could call you direct...", Claire started. "Right", I said. "...and now it's just a recording, right? So she would call and was very abrupt and my plans are duh-duh-duh-duh-duh, and just click. And I was like, 'That's really weird, that's really weird'. But then this woman had called me back uh, couple days later and had apologized and had said she'd been, she'd had a migraine and she was in a horrible state", she continued. "Ohhh", I said. "And I had, I had worked for her and subbed for her for three days. And then she had called me and she just said,
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you know, um, 'Just, I'm just going to put you as my, as my main sub and just know that this can happen'. It's so frequent with her, it was scary. Um, and she, and she explained to me, she went through the whole process of how she had her blackout curtains in her room um, how her, her son would take her to the hospital and just the whole process. And it was interesting 'cause I hadn't thought about this in years, but how she had taken the time to phone me and explain this to me um, because she had wanted me to go in and be her supply teacher any time it happened, and, if I was available", she said. "Right", I encouraged. "And I was like, 'Oh of course I'll do this' and, and then I met her, I ended up meeting her uh, 'cause I took a long term supply position at the school she was at…" she explained. "Um hmm" I murmured. "…and not for her, for another teacher, and meeting her, and just like, in my head, I'd had this image of this very frail woman and how, like I saw her and she wasn't frail and she wasn't, like she was very lively and very, you know, just like this amazing person that I'd had this image from that, that voice on the phone and you know, this like, very frail, you know, and I had made that judgment…you know, and…", she continued. "She probably found it hard, hard to talk to you, I suggested. "…oh yeah! Exactly", Claire agreed. "It was probably a huge effort for her to call you", I added. "Yeah, and I thought, you know, like then, when, going through the same thing as that, God, like the fact that she picked up the phone, you know and, and how that, but also that system hadn't been set up for you to get the recording of what your job was", she finished. "Right", I said. "And here was someone who, the, the instructions were important enough that, here's what you need to know, click", she said. "Um hmm", I murmured. "Um, but now, I mean, you just make a recording of that", Claire explained. "Right", I nodded. "And just the, yeah, just that, I always remember that whole experience with this woman and, and thinking, 'Oh what does she look like? She's got to be so fragile'. And then meeting her and complete opposite of that. Yeah. But it was, but here was someone who was really suffering."

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Here is an example of someone making a judgment based on limited information and this was Claire who had already had several migraines. What a surprise when she met this woman who she had thought would be so fragile and found her to be so strong. If she had thought about it someone could have had the same experience in meeting her. Claire is a vibrant powerhouse of a woman and I can imagine the vitality she brings to her teaching and to the theatre work she does. It is not hard to picture the high standards she sets for herself and her students. Based on my experience it is not hard to imagine her with a severe migraine but I can also imagine how shocked people, who have never seen someone with a really severe migraine before, would be to see Claire in the throes of a bad one. I remember the face of my husband when he saw me the first time with a bad one. He tells people, 'she wasn't quite unconscious but she wasn't far from it, she couldn't move'. The only word to describe his reaction to seeing me was shock. I wonder how we convey the reality of a severe migraine to healthcare professionals such as family physicians who treat well women between migraines and may never see what goes on with those women in Emergency rooms on other days.

Surrender

> "Yeah, exactly. And that, that is so true, like the, there's so many times where I've thought, 'Okay, I've just, I've got to get through this day. I've got to finish this'. And you are, and it's, it is torture and then sometimes it's like everything, it just overrides. Like it's over ride because now I'm throwing up and I can't do anything", Claire explained. "Right", I said. "But there's moments where I'm like, 'Okay, just give me five more minutes because this class will be done.' Or this rehearsal will be done and I, I've got to get through this, like, Please God, Please God. And I'm not a religious person but at that moment I am", she adds. "Like, God, you know, I'll be a better person! You know, and yeah, and you do and it, I think that is a huge statement about the human body too, like how far we'll push it, how far you will, you know, allow yourself to, to go through torture, you know… and then you finally, either it just says, 'No' you know, big red flashing sign, or you know, you just surrender... You just surrender to it, you have to", she added. "Yeah, and it is, it is, that's a good word. I hadn't even thought about that word but, but that is it, yeah. You, you get to the place of

help…and you, yeah, you surrender", I agreed. "Yeah", Claire said. "And then the whole world, really, falls apart", I suggested. "Um hmm", she agreed. "Um yeah, cause that's different from, it's like this battle that you have going on…to um, you know, maintain it, and I mentioned a couple of times about, you know, um, driving yourself to, to a place of help. I mean I've driven myself to Emergency when I shouldn't have been driving", I stated. "Yeah, oh yeah.", understanding. "I know I shouldn't have been driving. But that process to get somebody else…" I stopped. "Yeah", she said. "…to get me there, would have been huge and my car would have been left and…and I can just picture this whole, and is it, it gets large…you know? I asked. "Yeah, exactly", she agreed. "It would have been this whole process of how do I get my car back?", I said. "It's true, it's so true", she agreed. "You know, who's gonna do that? It's gonna involve at least two people to do it", I continued. "Yeah, exactly. Exactly", Claire added. "And uh, you uh, you want to involve, avoid that so much", I concluded. "Yeah. It's true, well I think it is like that, that step to surrender all of that is hard. It is hard. Like to go to, to go okay, now it's, it's to the point where I need this help, I can't drive myself, um, I'm not trying to suppress everything my body's going through right now. I've just, it's happening and just, I think, and I think that's why surrender is such a good word because it's, you, everything else explodes at that moment um, and, and then you just, the steps have to start coming into place. Like alright, who, who's driving me?" she explained. "Right", I said. "Where, yeah, what's gonna happen to my car? Who's taking my class if that's part of the factor…um, how am I gonna make up this time tomorrow? Right, like all of that, you know, but you, there comes a point where you just go, 'Okay, this has to happen.' But it's hard, that's a hard step", she said. "Yeah, and I, and I think sometimes there is a conscious surrender…um, you know that you hit the wall … and other times, um, the wall hits you", I suggested. "Oh yeah. Yeah. I think more often, the wall hits you", laughing.

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This story is about a point of transition from a state of managing with great difficulty to a state of not being able to manage the pain and other symptoms of a
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migraine. For Claire this point of transition often comes after minutes or hours of pushing herself to hold on despite the pain until class is finished, rehearsal is completed, or the day is done. She tries hard not to let her migraines impact negatively on her work and her personal life and this means pushing her body to the limits of endurance. At the point of transition there is a conscious or unconscious surrender and an opening of herself to the idea of help. My own experience has always been the same and I wonder why it is that we wait so long to seek help. Is it the consequences of lost time at work and things to make up that prevents us from sharing our need? Do we fear being seen in a weakened state? Or is our fear related to the reception we may receive at a clinic or Emergency room and the treatment we will undergo. Perhaps all of these are the problem. Perhaps the combination is too much to deal with and this is what pushes us to try manage on our own. Whatever the reason it is a lonely and difficult path we follow and I wonder if it has to be this way.

The Pain

> "Um, and then like you say, that switch happens and yeah, I think it is and that's why, I mean, you never, you never want to re-experience that horrible pain again and um, but it, it is, it's always looming, what's going to trigger this?", Claire said. "Yeah", I agreed. "Please don't make me have to go through that this week. Right? And yeah, it's a huge, huge level of fear, 'cause it is, like it's the worst thing my body goes through. You know, and I, I mean, as a dancer, I've had so many injuries, you know? She said. "Um hmm" I encouraged. "Broken bones and sprained things and but you know, like I think about those moments, even, you know, getting casts and things, that's horrible. It is horrible, and then I think about how many times I've gone through this, this process of having, being in such excruciating pain that someone's injecting a needle into my backside, you know?" she asked. "Umm hmm" I acknowledged. "Like that is the most excruciating pain I've ever been through. You know and I live with, I have arthritis and I live with that pain and, you know, like no, nothing is as horrible as this", she stated. "Yeah", I agreed. "It just, it just isn't, you know, like it, yeah. Like I have some level of pain in my body every day. Like I do, it's just,

> everything that's happened to me. But that's, that level of pain and I just, the whole wrenching that your body goes through, you know?" she finished.

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Claire compares the pain of her migraines to that she has experienced as a dancer. She mentions having injuries and broken bones and next to these a migraine is much worse. I think it is helpful to have some reference points so others can comprehend the level of pain that is possible with a severe migraine. I would compare some of my migraines to the pain of a very difficult childbirth, only the pain is continuous. The pain of a migraine does not always respond well to pain medications, even narcotic analgesics like morphine. Migraine specific medications are often the only drugs that bring relief.

The other issue with the pain is the fear. Many people have more than one trigger for their migraines and some have unknown triggers. This creates a high level of uncertainty in one's life as you are constantly wondering when the next headache will strike. It also means you have to be prepared for a headache at all times. You have to have medications with you and you have to include the possibility of a migraine into the planning of every part of your day. I remember telling a psychologist once that I could only plan for 4 days a week as I had to plan for being sick the other 3 days. He told me that was absurd. Perhaps it was, but it was my reality at that time. I wondered how he would have handled the situation in my shoes.

A Social Condition

> "And uh, so it's really kind of a social…", I started. "Yeah, yeah it's true", she agreed. "…a social condition", I finished. "Yeah, yeah. It's so, that's so true. And it's interesting like, probably prior to this conversation, I, I've probably always knew that, but just, you know, to actually voice that it is, is also interesting. You know", Claire added. "Yeah it is, cause I hadn't said it either" I added. "Yeah, yeah", she said. "I've gone all the way around it but it's the first time that I've actually thought…there are social diseases and there are ones that don't have to be…", I began. "That's right", she interjected. "…social diseases", I finished. "But this one…", I said …"they have to be interactive". "Yeah", Claire agreed. "They can be just experienced by the individual but it's very difficult to have a migraine and not have somebody to know about it", I
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concluded. "Yeah. Yeah, yeah. Exactly. Exactly. Yeah. And, and as you say, I had help every, every time", Claire suggested. And I've needed help every time". "Right", I agreed. "Yeah. Yeah and even, like even carrying into the next day, because I'm having to re-adjust because I, and this is a horrible thing, but I've lost a day of my life, you know, like and I…", she realized. "Right! Absolutely", I said. "You lose a day of your life and, and when we do live by a clock, a lot of the time, you know, you live by these expectations that happen um, that help carry it into the next day, 'cause you're like, oh can you, could you do this because of this and you know, and you're juggling these things and…", she explained. "Right, right", I agreed. "…so it doesn't always stop, you know, once the treatment's happened and you're home in bed. You know, the, the help kind of carries into the next day because you have lost a day, or two", she said. "So in effect it, it spreads the obligation doesn't it?" I suggested. "Absolutely. Absolutely, yeah", Claire agreed. "And, and that's probably one of the things that feeds our guilt", I said. "Oh yeah. Yeah. My family is Irish, guilt is in the middle of our name", Claire said. "Yeah. It's just more apologies the second day and…'I'm sorry but can we move that meeting?'", I added. "Yeah, but it's true, it's so true", she said. "You know, and 'Gee thanks, it was so nice of you to do…'", I finished.

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Claire and I came to a new way of looking at migraine in this discussion. We realized that severe migraines force the individual into a social interaction in order to obtain help and so they are really social diseases. In our experience we agreed that it is difficult to manage a really severe migraine without the assistance of someone. A migraine brings with it a strong sense of vulnerability and uncertainty surrounding the need for help and how this will manifest itself. For the woman with chronic migraine this feeling of vulnerability and uncertainty also becomes chronic as does a feeling of obligation to those who provide help. Claire told me about keeping a stack of thank you cards on her desk to give to people who help her when she has a migraine. While the thanks is genuine, so is the sense of guilt for bothering people. The timing of the headache determines the level of interruption in one's life and the amount of help that is
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required to keep things going until she can take over again. One must sometimes allow for several days with the headache and then a lowered level of function for a day or two after. I think the latter is seldom evident as the individual often looks fine by that time. This creates a problem for if you look well, how do you justify the need to work carefully for fear the headache will return?

Figure 6 “Snaps” – Claire’s Representation of a Migraine

“So, so what have you brought me?” I asked. “I painted this. Uh, I thought, I’m a visual learner and I, I don’t have time to create you a piece of theatre”, laughing. So uh, so I created this and I call it um, “Synapses” but it’s

> supposed to be snaps, right? Cause that little trigger in your brain?", Claire explained. "Um hmm", I acknowledged. "Um, so I put in the centre of it, an eye. Um, to represent two things, one is uh, that's where a big source of the pain is when it starts, but also um, the thought of people watching when you're going through this process", she said. "Um hmm", I murmured. "And all the discussion we had about that. Um, and so the, the purple of the eye continues throughout because that sort of, it sort of spreads, that feeling of being watched and then the pain", she added. "Right", I said. "And the red is almost like a, it's a brain synapses in my head…", Claire suggested. "Um hmm", I thought. "they're almost like this, this creature that just sort of takes over. And there's nothing you can do about it so, there, it's even coming from the other side, it's coming from the inside…", she said, "so no escape". "Um hmm, um hmm", I pondered. "And then the green vine is um, the life that you hope continues on, um, in spite of all of this…", she proposed. "Right", I said. "…it's still present, but it's…", she began. "Right. It's at the edges", I suggested. "Exactly. It's at the edges because this is the only thing that's happening…", she agreed.

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I find Claire's painting compelling and disturbing. Perhaps it resonates too well with me. The eye is so powerful in it and I almost feel the pulsing pain in my own eye when I look at it. She captures the double meaning of the centre of pain and the fear of being watched so well with that large purple eye that dominates the picture just as a migraine dominates us. Perhaps that is what disturbs me so much about this picture is that the eye dominates just as a migraine does. It gradually shuts down our systems until there seems to be nothing left but the pain. We can focus on nothing but the pain. We care about nothing but the pain and getting it stopped.

Then there are the bright red lines of pain. Claire refers to them as a creature that comes at the eye from both sides and is inescapable. This seems to hint at the feelings of otherness that have arisen in our discussions before, that sense that the migraine is somehow not us. The vine is our life as it was before the migraine, pushed to the periphery and as Claire says we hope still going on without us. This is a wonder for us but a small one for the pain is all consuming at this time.
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The Pattern of Life

> "the life…", I started, "…continuing, even though it's, it's off to the side and overshadowed". "Yeah", she answered. "It's um, it's in the back of your mind…", I suggested. "Yeah", she said. "…all the time…" I pointed out. "Exactly", Claire acknowledged. "…how am I gonna deal with this. I'm missing this and, you know…", I suggested. "Yeah, yeah", she agreed. "…when you can get your brain to work for a minute…", I continued. "Exactly", she confirmed. "…well I mean…", laughing. "Exactly. And that's what I thought, it had to, initially it was just on the one side, I thought no, it has to come in somewhere else too", she said. "Um hmm", I agreed. "Because it, like it's, you're always thinking about, well not always, but when, like you said, when you can, how am I gonna deal with this the next day, what's, how's my life been affected by this?" she explained. And then trying to get back to that track. And that's why I thought like a vine was kind of, 'cause a vine kinda follows a pattern…", she explained. "Um hmm, um hmm", I acknowledged. "…that you do have to try to get back into that pattern of…of your life", she said. "And the, and a vine is really a, a good metaphor too because um, it's not just one straight line…", I suggested. "Exactly", she said. "…you know, there are many parts of our lives…so they branch off and, and there's a whole lot of stuff that, and that goes back to our talk about how it spreads", I concluded

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Claire and I had talked at length about how easily the knowledge that one has a bad migraine spreads. For her it was as simple as having to leave her car at work or missing the start of a class while she rested on a cot and the word was through the school like wild fire. The vine she chose to represent her life gives an apt representation of the many pathways in her life. During a severe migraine there are many times when you are unable to think about anything but the pain, but at times it dulls enough that you focus on how do I pull things together again. You picture all the branches of your life and the things that have stopped or slowed because you were not there and slowly start making a plan for how you will repair the damage. I do not think this is a time of feeling guilty but rather a time of problem solving. Guilt comes later when you must interact with
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colleagues and ask for favours and changes. I wonder how many other women would agree that the first help with the aftermath of a migraine comes from within.

The Colours of Experience

> "So it was uh, it was fun. (laughs) Fun to do that and, and it was good, it was good to think about, sort of the process that we had been through and to, to really think about what, what does this represent to me? You know, what it, what it's, you know the fact, and the colours, like the colours were very, I did, I looked at the palate for a long time, I thought, "Okay, can mix these…" and I did, I mean, the purples are all different colours but the red stayed the strong, strong red", Claire explained. "Um hmm", I answered. "Because it overpowers everything, right?" she questioned. "Right", I answered. "So it just had to. And I mean, of course, green being on the other spectrum of red, was really important but the fact that it does represent this vibrancy…and so when, when you're going through this, you curl up into this little ball. And so…" she explained. "Right", I agreed. "…and that's what, like these are, these are curves too. Like they're strong but they're also forcing this inward movement to happen so…" she continued. "Um hmm, yeah, because it does look like everything is focused around the eye", I suggested.
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> "Yeah", she agreed. "And, and that's the way it is", I said. "Yeah", Claire said. "And certainly we, we think of, of life force as, as green", I observed. "Um hmm. Yeah", she said. "You know, and actually um, a lot of people, if you give them colours, um, to represent their pain…like if you give them an outline of a person, say okay, draw in your pain where it is and pick a colour to, to represent how strong the pain is in various areas …red is invariably… it's the one that best describes it", I explained. "Yeah, I imagine" Claire agreed. "You know?" I questioned. "Such a passionate colour", she responded. "Yeah, yeah. It is. Yeah and purple gets used a lot too", I said. "Does it? Yeah", she wondered. "Yeah.", I said. "I, I went to a, not a psychic uh, just gonna put this over here, but a, a spiritual path reader once, 'cause it was a friend of my, uh, it was my friend's mother…", Claire explained. "Um hmm", I encouraged. "And she said, "Purple is a very important colour for you, Claire." It's funny because I never wore purple

> or anything, so I thought, the eye has to be purple from that, because of that conversation I had", laughing.

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This was an interesting part of Claire's discussion of her painting for we focused on her use of colour. Her choice of red for pain was not surprising for this is quite common in the work done on colour in pain assessment tools. The colour stayed a strong red, "Because it (the pain) overpowers everything, right?" I liked how she curved the red lines and compared them to the bowing of the body that takes place. Claire had made many references in her stories to being curled up in a ball with a migraine. In my experience as well there is something about a migraine that makes you want to bow your head and curl into a fetal position as if this will help or perhaps because holding the head up is simply too difficult. The choice of purple is also common in indicating pain. Claire is a very spiritual and imaginative person and so the link between her choice of purple and the reading by her mother's friend was very much in character. Claire refers to green for the vine as being opposite in the spectrum of red. Claire has talked of opposites before and I feel this reflects the passionate part of her character. She seems to feel things very deeply and she opinions are strong. Given the difficulty women have communicating when they have a migraine, I wonder if a colour pain assessment tool would be useful?

Migraines: Part of the Process

> "I was listening to the tape again this morning when I woke up, as I was sitting in bed … I just went through it again and, just to see, what all we had talked about, you know? And uh, it was interesting, one of the things that came to me um, uh about this research process, was the fact that um, as, as I've been doing interviews, I've often had migraines", I explained. "Wow" Claire exclaimed. "Like the first, the first interview that I did with you…", I started. "Um hmm", she said. "…I had a mild migraine", I continued. "Um hmm", she acknowledged. "And it wasn't bothering me too much, but it made me have to concentrate…a little bit more, I said. "Yeah", she said. "Our last interview, I was fine until about the last twenty minutes…", I said. "Oh wow", she said. "…and then I started getting really, a really bad migraine and I was finding it was really
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difficult…, I continued…and this morning, I woke up at 2:15, with a terrible migraine", laughing. "Yeah", Claire acknowledged. "And like, you know, I lie there thinking, 'Okay, you've got to get up and do something about this.' So I came downstairs, got my gel pack heated and I took Tylenol #3's, I took a Maxalt and I took Clonazapam and went back to bed and did my relaxation exercises and I thought, 'You've got to do everything you can because you've got this interview tomorrow', I explained. "Ohh. Yeah", she agreed. "'You've got to get it stopped', you know? And I'm fine now. But that, that's one of the realities of doing the research", I said. "Absolutely, yeah", she agreed. "And there, there have been other interviews that I have done with some people where it's all I could do to pay attention…to what they were saying", I said.

"And I'm trying to think, "Okay, so where does that take us" and you know…try to stay…", I started. "Oh my gosh, yeah. Yeah." Claire added. "It's uh, I hadn't really thought about that before research, but I did as I went, was going through this again", I continued. "Yeah. That creates a very interesting dynamic case, yeah", she suggested. "Yeah, it does. It does because you can't even research it without it being part of it", I said. "Without it being present. Well it, I think it, it's probably on the tape from the first session, I was recovering from a migraine", Claire remembered. "That's right", I acknowledged. "When I came to see you. And I mean that, that day I was dragging myself around. You know, like it was, that was like a recovery day for me and so it's interesting too, 'cause that was very present. It was very, very present. And I had um, I had like a bout this weekend and the same thing, like the headache woke me up on Sunday, it was probably about four o'clock, 'cause the sun was coming up. I remember that, it was really bright. And but it, the pain woke me up", she explained. "Hmm", I affirmed. "Yeah. And the same thing, like I got, I was well enough to get my own medication…", she said. "Um hmm", I acknowledged. "…but I made my husband go get the face cloth and you know…waking him up at four o'clock in the morning was not…not good, I mean he gets up at six, so that four o'clock is like when your alarm goes off before you really want it to…yeah. So, yeah, that's, it is, it's interesting that it is so present. So, so present Yeah", she

> explained. “Yeah, yeah. Yeah, it made me wonder, ‘cause it was something that I hadn’t, I hadn’t asked uh, the other women… whether or not they had a migraine at the time”, I said. “You know, I, I wasn’t aware that they did”, I continued. “Um hmm”, she murmured. “Um, but they might have”, I said. “Yeah. Yeah, in that heightened concentration. ‘Cause you’re trying so hard to just get through that moment, yeah, because you have to. You know, like it’s, like with this too, there’s more pressure because you have to get this done and in a certain amount of time. You’re leaving next week. You know, so time is of the essence and so that heightens the pressure of, ‘Okay, I’ve got this to deal with, but I also have to really focus on this interview’”, she suggested. “Um hmm”, I agreed. “You know, it’s like when I had that migraine during the auditions for Steel Magnolias, and I was fighting so hard but I can’t, I can’t leave. This is the only time I meet these women. This is it. So you know, as the walls are caving in, you’re like, ‘Okay, try to remember what this woman looks like because she could be the perfect woman in your cast.’ But you’re fighting with all these other elements and yeah. Yeah, so I, I parallel that action, in a big way, yeah”, she said.

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In this story I shared with Claire how migraines had affected the actual process of our conversations each time we had met. She reminded me that migraines had been a part of the process several times for her as well. We marveled at the fact that we could not even research the topic without it having an impact on the process. I think it was a tribute to our interest and as Claire said to time running out that kept us on our schedule of meetings. It is difficult to gauge the impact of having a migraine while doing research. I certainly think it added to our insight but at the same time it may have led us to miss something said in the conversation. One can only hope the former outweighs the latter.

More Than Just a Timeout

> “You know, how, I think you made me very aware, and you were probably very aware as you were uh, doing that casting, of everything that people were doing…but it’s the inability sometimes to put together…”, I proposed. “Yeah, yeah”, she encouraged. “…and sometimes, you know, uh, that comes later”. I continued. “Um hmm. Yeah, oh definitely’, she agreed. “But the, the
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impressions were there", I finished. "Yeah", she said. "Um, but you don't always have that ability to, to pull it all together and, and to make a decision", I said. """Yeah", Claire said. "That's really hard", I stated. "Absolutely. And I, and I did get affected by that because there were, and I, I started to write down uh, and I have a very good memory, I started to write down what the women were wearing...how their hair was styled and if they had glasses and things like this, but near the end of the night, I had met this woman, and for the life of me, when I went back to my notes, I could not remember who she was. I tried so hard, and I, I had written down the monologue she had done, everything, but I just, I had tried, my brain had sort of worked so hard ...to make it through ... that this woman who was right near the end, you know, poor soul, and it was good I had someone else there with me, who said, 'Okay this is what she did.' And I was like, 'Okay, I kind of remember it', but initially looking at her information on the paper, nothing. Like nothing would trigger and it was so frustrating", she said. "Yeah.", I agreed. "Because I thought, Oh, not only am I doing her a disservice, I'm doing myself a disservice because I'm trying to put together this production that is stellar, right? Like you just always want to do your best". "Right. Right", I agreed. "And then, then I also thought...", she started. "Maybe she was the best. You're not sure...", I suggested. "I'm not sure, like you know, I had tried so hard to just function. You know, and I was just, I, and you do, you feel like, wow, like, there maybe is an opportunity that's going. Yeah, so that was hard, that was really hard to deal with. Yeah", Claire explained. "Yeah. So a lot of the disability is, is a lowering in the level of your function" I proposed. "Um hmm, yeah", she agreed. "You know, it's not just being taken out of a situation...", I said.

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I think this is a really good example of how migraines can result in a lowering of function without actually taking you out of the situation. Claire was struggling to stay this evening to finish casting a show. She really needed help but felt obligated to stay as long as she could. Unfortunately, her brain was not functioning as well as usual. As she says "like nothing would trigger and it was so frustrating". She had taken measures to help herself, such as making notes, but nothing was helping. Her migraine was beyond
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her self-help measures. The indirect cost of migraine in the workplace due to absenteeism and performing below par is a serious problem (Berry, 2007). Performing at less than our best, called presenteeism (Levin-Epstein, 2005) can be a hidden disability. It can be covered up by excuses such as I did not sleep well or I was up with the children last night. I have done this and then worked extra hard to not only catch up but to excel to make up for what I was unable to do, out of feelings of guilt. I wonder how prevalent this need to cover up and then to make up is.

Looking Inward

> "And then when this, this curveball gets thrown at you and it's out of your control, if you, I think there's more, and this is what I've been thinking about too, is that, there's more that you deal with because now you, your routine has been jogged, for sure. But you're also dealing with, okay well, I've been in the process of rehearsing this and now my rehearsal is compromised or my, this next step in the creation is compromised because I've gone through this. This bout, and you know, there's so many other factors that come into play. You know, and then you start thinking about yeah, this level that I want to reach has been compromised because I've had these like, three bad days of, of migraine and now everything has to get restructured. Like how do I fix that, right? So…", Claire explained. "Um hmm", I responded. "…it's a whole other, a whole other dynamic to deal with. Yeah.", she said. "And I got thinking about it, um, think about this last night, does this, does this have implications um, when we talk about help? Not only in terms of um, well I guess when we say we need help, um, is it that we're needing, always needing help from someone else or are we looking for help from ourselves? Which may be a weird thought", I wondered. "Um hmm. It's not a weird thought, it's a, makes sense but…", she paused. "Um…do we, do we have to find new ways to help ourselves to get back to that level?" I asked. "To bring the project back to that level?" "Um hmm. Oh yeah, I, I think you're, you're getting on there, 'cause I think that, each time we're faced with this, you, you're coming up with a new way of coping because you're, you're dealing with a, a set of things that have changed yet again. And so you are going, "Okay now…" and I think it's always within yourself initially, that you go, 'Where, what do I need to

> do first?' How can I, how can I make this better? So how are you helping yourself?", Claire suggested. "Um hmm", I said. "And I think that every time that this happens and you're having to look at the restructuring or the, the getting back into your routine, you, you do have to come up with that creative solution or um, uh, the next logical step to get back on track. And I, and I think it all, well with me, it, it always comes from me first. And then … but there have been times when I'd think, 'Okay, I do need help, so I've got to ask outside myself for this'", she added. "Um hmm", I responded. "Um, but I think when you say, 'Do we ask ourselves?' I think we do, 'cause I think that's where it starts. You know, especially with, with migraines because there are so many people who just don't understand. They don't understand the level of what you're going through. They don't understand the level of pain, or the level of shutdown that you're going through", she stated. "Um hmm", I agreed. "And so, like I, I think I'm still dealing with that. My family knows, I've a few good friends and a few people that I work with, but if it's a new situation with people that I have to explain things to, um, I don't, I don't then expand the realm of help. It stays like this, or it stays with the people who are very knowledgeable of what I've gone through", she said. "Right", I confirmed. "Yeah. But I, it always starts with, with what am I gonna do first. Yeah", she said.

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I believe the majority of help is initiated from within and begins with a recognition that there is a lowering of function significant enough that it leads to a state of need. We have already reviewed stories of Claire's experiences leading up to a migraine and going through a migraine and the need for help in these stages. In the aftermath of a migraine, she now provides us with some sense of how she assesses what things have not been done, what projects may have gone astray, and what new tasks may have arisen. Priorities are reset and decisions are made as to rescheduling events and what help is needed to get back on track. As we discuss this process we agree that it comes back to her in that she is the one who must initiate the process of help. She must decide what help she needs and where to turn for it. Claire notes she has a small circle of people from whom she draws on for help as these individuals understand what she goes
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through and this is a key criteria in their being able to help her. I think this goes back to the fact that only the individual who needs help can define what is helpful. I wonder how many of us reach out with good intentions to help someone without first asking, how can I help.

You Need a Safety Net

> "Yeah. And I think it, I said this in our first meeting, that, that some people think because they have a bad headache that they have a migraine and so they kind of equate that with, well, you know, can't be that bad. And so you're having to explain to them, "No", like 'I'm not present. I'm not gonna be present because my body's slowly shutting down in front of you'", Claire stated. "Um hmm", I agreed. "And, and then I won't be able to communicate this anymore to you. So just know that, if there's time, we'll talk about this later. But right now, it's, you know, it's starting to happen", she continued. "Yeah", I said. "Yeah. And I think that, the, you know, the new situations with new people, that that gets harder, um, and you do have to get a little more creative with how you fix that the next day. You know, and it forces you to, to rethink and redo and, yeah, interesting, interesting dynamic. I think, if that makes sense", laughing. "Yeah, yeah it does. Like I found that over the years, you know um, I learned that in order to, to function, uh, like when I was a professor, in order to um, get everything done that I wanted, and, and get it done at the level that I wanted, that I had to hire help", I said. "So I hired students to work for me", I added. "Um hmm. Yeah", Claire responded. "And they would, they would come in and they, they would file and they would organize my office and, and go through things and, and they'd go photocopy stuff or they'd go look for articles for me or they'd...you know?" I explained. "Um hmm. Yeah.", she confirmed. "Uh, they'd type something up for me or just, you know, every day types of things...", I said. "Yeah", Claire nodded. "...that, but things that I just didn't have the time or the energy for... because part of the time I was working at this, this lower level of function", I added. "Um hmm. Yeah. And those are also things that, if something does go wrong, they don't get lost, they keep, they're maintained", Claire suggested. "They're maintained", I repeated. "Exactly", she said. "Yeah

> and it, it allowed me to keep my standard", I said, so I didn't compromise my standard. "Um hmm. That's interesting too, 'cause I, when I work at school and I'm working on all my theatre elements that are outside of classes, I actually have in place, uh, a group of students, and it's alumni and current students…", Claire explained. "Um hmm", I murmured. " … that um, I always have an assistant director whose graduated from my program, um, and a stage manager whose within the program and those, those two students, if something does go on, could probably pick up the pieces…so that we don't fully lose and that's interesting that that, yeah, that they're kind of in place. 'Cause that's not very common, right, to have, you know, students in those roles. But that's interesting 'cause that resonates with me, that you're said, you're saying that, 'cause I do, I, you know, they're there to have the safety net, I think. Yeah", she mused.

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Claire was talking about the difference between a regular headache and a migraine and how she tries to explain to some people that she will not be present, that her body is shutting down in front of them. It is so true but I wonder as I think about it if people can really follow that analogy unless they see it to the end. The point she was leading to was that with new people she has to be more creative in how she restructures things after the migraine has passed because they do not have that understanding of what she has been through. This led to an interesting discussion of how we had both set up what was in effect a safety net in our separate work places. In order to manage my workload and maintain a particular standard of work as a professor of nursing I had routinely hired students to help with office work. Claire, in her theatre work had two students in positions of responsibility who could probably take over in an emergency. In her words, "that's not very common, right, to have, you know, students in those roles". Neither of us had taken these steps consciously because of our migraines and yet when we thought about it, this was the actual motivation. I wonder if other women with migraines have created safety nets for themselves and what these look like.

Help Me, Then Go Away

> "Yeah. But it's really, when I think about, you know, how do we help women with migraines…", I wondered. "Um hmm.", Claire murmured. "When
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you've got this hypersensitivity, um, I want somebody with me", I thought out loud, "I do, I don't know, how do you feel about it?" "When I've, when I'm hypersensitive like that?", she asked. "When, when you really need help. "Um when I really need help, I want someone to help me but I want them to leave. I want them to leave me alone. Like I, I want the, the help and, I guess kind of, knowing that they're somewhere, but I don't want them in the immediate space, 'cause I'm so, what's the word, I'm gonna use tortured. That's the word I'm gonna use. I'm so tortured that I just need to be in my own space… it's so, Yeah", she explained. "So, so let me clarify this then, is it interaction that you need to be free of?" I asked. "Yes", she answered. "Or is it the presence", I continued. "Um, I think, well, I'm gonna say both, because I, it's the, it is that proximity and that, and I think it goes to that other energy that you're talking about, when you can feel that, like, like that person's presence, their, their breathing, the sound of just, and this, even sometimes just the smell of their body…", she concluded. "Um hmm", I mused. "…like all of that. I just want every thing that is bombarding me to go away. And then I also like, once, once I know that help's in place, I don't want someone asking me what else I need. I just want to start to recover. Does that make sense?", she asked. "Yes", I said. "Yeah. I just, and I just need to be in my own space and do that. Like, as a matter of fact, my body right now is telling that actually, my, I'm like, I, just like, go away, I can feel it. Like it's, it's very much, I need to be in my own space. Like I will, if I'm at home, and I'm not sleeping in the bathroom…I'm in, we have a spare bedroom that's um, it's, is quite dark. And that's, I'll get a garbage bag and I'll be in there. I cannot be in the same room as my husband. And especially because he breathes loudly", Claire explained. "Right", I acknowledged. "But uh, yeah, I mean I just, like I can't be around anyone else. I just can't", she said. "Yeah. Don't sit on my bed or…", I suggested. "Exactly", she agreed. "…or", I started. "All of that, or all of that. It's just too, it's too much. Just too much for my body to handle. And I, it is, it's that heightened sensitivity to everything and I think if, if the medical profession can be aware of that, like it is, it's everything from the air moving past your body, the smells, the sounds, the light, every sense in your body goes to its

> extreme peak. And, and until someone can dull that with medication or…", she continued. "Right.", I said. "…whatever it is they're going to do to help you, that it is, it's torture. It's, you know, it's a form of torture", she said. "Yeah, yeah' I agreed. "Yeah. And that's where I think too, when people, like when I ask you, do people really understand? I don't, like when people are trying to help you, I think that's, that's also part of the, the concern is that they don't understand that when they're running and pounding up the staircase to help you or, you know, around the house, that is compounding what you're going through", Claire explained. "Um hmm", I murmured. "And so to understand that it's, you know, for sure they have to hurry because you want that immediate help, but also, you know, how, how do they go about that? And you never have time, and you never want to also say, look, I haven't had this conversation with my husband to say, okay, here's the steps you have to go through…I mean, he knows he has to get my medication, he knows that but to say to him, can you not, could you walk in socks? And could you put, put things close to me, but then go away. You know, like, we actually haven't had that conversation. But when it's happening, it's like, ugh, why is he wearing his shoes in the house?", she said. "Right.", I agreed. "You know, like all those things", she sighed.

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How do we help women when they are in a hypersensitive state with a migraine? Claire's answer to this question was filled with seemingly mixed feelings. "I want someone to help me, but I want them to leave. I want them to leave me alone". She said she wanted to know they were somewhere close at hand but "I don't want them in the immediate space". Her reason for this was that she was so "tortured". When I pressed her for clarification, it seemed that it was both interaction and the presence of others that she wanted to avoid. I understood her feelings. When I have a migraine it takes too much energy to interact with people and this is why communicating with others is so difficult. The presence of others is difficult simply because every sense is amplified. Every sight, sound, smell, touch and taste is too intense to the point of being painful and so it is easier if others are not present. At the same time there is great fear of being alone
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and so it is important that the migraine patient know that someone is nearby, that help is nearby and that there is a way to summon that help, for example using a call bell.

I found it interesting when Claire talked of the need to just be in her own space and start to recover. It reminded me of all the times when I was just starting to recover in hospital and a nurse would come in and ask if I was better and if so I should go home as the hospital was a poor place to recover, too noisy and bright. While these latter points may have been true, I had usually blocked these out by then and was into my own space and would have easily slept for some time if left alone. Being forced to go home when I was not sure the headache was really gone created great fear and stress in me and interrupted the process of recovery. On several cases it resulted in my having to come back to the Emergency room for further treatment. Finding the right time to send someone home is not easy with migraines because there is that aftermath that takes time to go away. Also everyone is different in their sensitivities and their needs. There are no easy answers.

Prove It

> "That our, that this whole system is set up on, 'You have to prove it to me and I, as a professional, with specialized knowledge, have to agree'...", I said. "Um hmm. Yeah.", Claire replied. "...with what you say. And that's, that's why we need this empirical proof that, you know, I, I need to be able to...I need to be able to measure something" I concluded. "Um hmm", Claire murmured. "Your pulse has to be higher or blood pressure has to be up or, or you have to be throwing up or something", I said. "Yeah, something measurable. Cause everything else, if you go in and you have, you know, a sinus infection, I mean, they can look at the colour of your mucous and they know, or something, right?" she stated". "Right. Right", I agreed. "Yeah, exactly. But I think that, this is where I think it's harder too because besides the two things that, the sound sensitivity and the photosensitivity as you talked about um, you very, you sometimes are, I mean, how measurable are those? So you're curled up in a ball, or you're throwing up, you know, do all of the medical professionals that you come across go, 'Oh', instantly, 'You must be having a migraine'. Or you say you're having a migraine but they still put you through twenty five questions to

> figure out how they're going to treat you in that moment", Claire said. "Um hmm", I said. "Right, if they don't know you. Because okay, you're curled up in a ball, you're throwing up, well, do you have food poisoning, did you eat something funny? All of those things and you're like, okay, no, I've, look at my chart, I've gone through this before, you know?" she said. "Yeah", I acknowledged. "Yeah, but instead, they're checking off their list everything else that could potentially cause this. And that's why I think that the symptoms are, they're, like you said, they're not defined enough. And, but also, that they vary per individual, right?" she asked. "Um hmm", I answered. "Yeah. Yeah. It's a struggle. But it's so true, like you absolutely, beyond a shadow of a doubt, you have to prove all of these things before they go, 'Alright, here's your treatment.' Until you have that, that doctor, like I have now, my doctor who is, you know, the first question is, 'How are the migraines?'", she said. "Right", I agreed. "You know, like, I see her on Friday and that's the first conversation we're gonna have. And that, I mean, there's comfort in that. There's huge comfort in that", she said. "Because you've reached that trust with her", I suggested. "Exactly", she responded. "She trusts you", I said. "Exactly", she agreed.

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This story is about diagnosis, but underlying this is the issue of trust and how we earn a physician's trust for without that trust there is no treatment, no help. You cannot see a migraine. You only see the symptoms that are manifestations of this neurological disorder. You cannot see the pain, but you can see the individual grimacing, crying, curled up in a ball, holding their head. You cannot see nausea but you can see vomiting. You cannot see vertigo but you can see a person stumble as they try and walk. Diagnosis has to be made in part on empirical evidence and in part on what the individual tells the physician and in part on the person's history. Claire bemoans the fact that often no one looks at her history and she has to go through many questions while a multitude of potential conditions are ruled out. Given the difficulty with communication in the midst of a severe migraine this is a valid concern. She feels she has to prove that she has a migraine. With her own doctor she has already passed that point and enjoys the comfort of starting each visit past that point.
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I understand how Claire feels. It is very nice to work with a healthcare provider who knows you have migraines and starts from that point of knowledge. I was thinking recently that it would be very valuable to have the diagnosis of migraines on a medic alert bracelet to eliminate a lot of the diagnostic process that goes on in Emergency rooms. When you feel that you have to prove you are ill it places you in a difficult position. If you have had migraines for some time and are knowledgeable about them you may say too much and physicians may jump to the conclusion that you are there for the drugs not the treatment. I remember once making a real effort to focus and speak carefully to a physician on one occasion and he said after we had talked, 'well you don't seem too bad'. He had no idea of the effort that conversation had taken. I have not made that mistake since. It makes one wonder after a while what kind of face to put forward. Should I be knowledgeable or pretend I know little about migraines? Should I tell them how I am usually treated or suffer through what they think will work first? How do we earn the trust of complete strangers when we present with a disease tainted by stigma because a very small number of people abuse medication?

Chapter VII Gloria's Story

In the course of this study I was fortunate to interview Gloria, a nurse working at a pain clinic in a large tertiary care hospital. As we chat in her office during our first meeting, Gloria tells me she has 18 years experience in acute and palliative care and a little over a year's experience working in this pain clinic where the focus is chronic pain. Her soft short brown curls move slightly with her head as she talks. She has a light, high voice and maintains eye contact as she speaks earnestly about a pain project in which she was involved in acute care. Her interest in pain management is readily apparent as she talks and I am eager to hear of her experiences.

We Don't Understand

> "I think they had, for a lot of people, they had a huge gap between the nurse's understanding of pain and the patient's understanding of pain… ah because they felt … a lot of people that I worked with were not able to communicate that they had pain. They were explained, they would be explained in preadmission that they needed to be asking for their pain medication …", Gloria began. "Um hmm", I responded. "They were given handouts on this process", she said. "Right", I said. "But in actual fact when it came to doing the process, and even if the nurse working with the patient was very competent in explaining how to do it, there was a huge gap between the communication where the patient either would understand the process and would ask for pain medication appropriately … that would happen in a lot of cases …and they would manage not too badly with their pain experience … but the other problem with that even if they had a competent nurse explaining it, then they might have a nurse on the other end that wasn't, that didn't really understand the pain process so that they tended to really under-medicate the patient even if the patient is asking for the pain medication …they (the nurses) would still not deliver it appropriately, like they would be very lax in giving it to them" she explained. "Right", I said. "The other hurdle was that the patient was in pain and had had surgery and was lacking the judgment perhaps or just the ability to ask for the pain medication … just didn't understand the process

and their expectation seemed to be that the nurse would bring them the medication … like they would be dependent, they would be often quite dependent on the nurse … they would regress was how the literature went and that was my understanding in actual practice that that was happening … they would actually regress even if they understood the whole process, they would still go back because of the pain … the pain situation was more than they could cope with like logically", she stated. "So can you explain what you mean by regress specifically?" I asked. "They would, they would actually say like, like an adult level of communication understanding, but they would almost go back to their childhood, like their dependence on their mother, like that level of development they would really regress … like people that were in ICU would you know because they're not able to communicate properly their needs … that's pretty common I think that would be pretty common knowledge ... but even on orthopedics even after major surgery where they're in extreme … sometimes their bodies are so shocked by the experience they cannot seem to cope properly with it … they don't seem to have the tools to ask like somehow and they would go back to like a lesser level of psychological development where they couldn't really cope so they were way more dependent on the nurse to provide them with proper pain medication", Gloria explained. "So if the nurse came in and asked, you know, 'Are you having pain?', 'Do you need something?', would they then be able to say 'Yes I do' or did they need even more, as you say, the nurse just bringing it?" I asked. (The issue here was did the patient just need the nurse to bring the medication without having to ask for it) "Yes I think they actually did just need the nurse to bring it in because then you get into some cultural problems too where it's like they, and there's a huge problem with addiction .. like not addiction with acute pain people because that isn't really an issue as far as I'm concerned, it's addiction because if they're in acute pain, they're in acute pain so addiction really isn't an issue, but they hear it. Their family members come and tell them it kind of like don't take anything unless you absolutely have to because you might get addicted", she said. "Right", I agreed. "So they have that running through their minds in the background plus their idea … still I think a lot of

> people still feel like the nurse and the doctor know the best for them", she suggested. "Right. Do you think, did you find that many nurses were worried about addiction in even acute pain?" I asked. "Very much ... they have, and maybe some of their feelings were rubbing off on the patient ... I'm sure they were, cause a lot of nurses really are stuck in the old way of thinking about pain control, that if you give a narcotic to a patient they'll become addicted to it", she answered.

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Gloria had my attention with her first statement. How many times I thought have I read of this same problem. There always seems to be a gap between the understanding of pain on the part of health professionals and that of patients. I remember that from my own days of nursing practice and I remember hearing this from student nurses. It seems that we as nurses continue to experience difficulties in communicating with patients. Gloria went on to explain a program trial on an acute care unit, where she had worked, where they used pamphlets to educate patients about the need to ask for pain medication after surgery. Gloria continued to wonder about the different reasons for the "gap" around adequate medication of patients for pain. Everyone in this particular trial had the pain medication process explained in preadmission according to Gloria and they received handouts on the process at this time. She said that, "when it came to doing the process, and even if the nurse working with the patient was very competent in explaining how to do it, there was a huge gap between the communication where the patient either would understand the process and would ask for pain medication appropriately ... that would happen in a lot of cases ...and they would manage not too badly with their pain experience ... but the other problem with that even if they had a competent nurse explaining it, then they might have a nurse on the other end that wasn't, that didn't really understand the pain process so that they tended to really under-medicate the patient even if the patient is asking for the pain medication ...they (the nurses) would still not deliver it appropriately, like they would be very lax in giving it to them". In other words Gloria saw areas of potential problems on both the part of nurses and patient even if the patients understood the process and asked for medication.
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The problems were not limited to nurses. Gloria went on to discuss the issue of role as she described the level of dependency on nurses that patients often develop following surgery. Citing the literature, she described this dependency as regression, "they would, they would actually say like an adult level of communication understanding, but they would almost go back to their childhood, like their dependence on their mother, like that level of development they would really regress…". She talked about patients' bodies being "so shocked by the experience they cannot seem to cope properly with it … they don't seem to have the tools to ask like somehow and they would go back to like a lesser level of psychological development where they couldn't really cope so they were way more dependent on the nurse to provide them with proper pain medication". As I listened I realized I felt disturbed for I wondered if viewing the need for help in this way placed dependence in a negative frame rather than as a normal response to stressors that exceeded a patient's resources. I thought of Orem's work on self-help (Orem, 2004) where she proposed that the need for nursing intervention naturally increased as an individual's ability to maintain self-help decreased. As an individual got well and was able to take over self-help once again, the need for nursing intervention decreased. I wondered if Gloria's words about the body experiencing a shock suggested that she saw a physical cause for dependency rather than a psychological regression. As I thought about this issue, I pondered my own experience. When I am in the midst of a severe migraine, my focus shrinks from a broader focus on the world around me to the pain and other noxious symptoms that are so intense they drown out other stimuli, even other thoughts. My one need at that time is to have these stimuli stop. I wondered if that could be seen as becoming childlike. Was that what Gloria might have seen if she had been a nurse who treated me, I wondered. I resisted that view as I continued to imagine how I would be seen. I may be curled up in a ball and be quite unresponsive for the most part but that is a way I lived out my experience and tried to sustain myself. I could not do anything else and still deal with these noxious stimuli. However, I know that if the doctor comes in and has to talk to me I could usually rouse myself with great effort and talk to him or her about treatment. That takes a great effort and much concentration. The effort required for such consultation usually left me in a further weakened state and often in greater pain. However, it is not something that I could sustain with the nurses. It was all I could do for the short period of time that the physician was with me. As a nurse, I know that the body will shut down some functions, such as interaction with the environment, while it deals with extreme stimuli from within. This suggests that at these times nurses' roles will increase. Gloria's words helped me move between my experiences as a nurse and my experiences as a migraine sufferer. I realized as a migraine sufferer that I saw myself as dependent for a time and experiencing what I saw as a normal need for help at other times.

Gloria also raised the issue of fear of addiction. She noted it is not an actual problem in acute care but rather it is the fear of addiction that families introduce to patients that is of concern. Some family members say, "don't take anything unless you absolutely have to because you might get addicted". Gloria's experiences resonated with my own experiences in both acute, chronic, and palliative care. I asked Gloria if nurses worried about addiction in her experience in acute care. She said, "Very much ... they have, and maybe some of their feelings were rubbing off on the patient ... I'm sure they were, cause a lot of nurses really are stuck in the old way of thinking about pain control, that if you give a narcotic to a patient they'll become addicted to it". I could see Gloria understood that many people are uncomfortable with drugs in general today and it was important not to overmedicate people. She positioned herself as understanding that addiction was not a serious concern. I wonder if the pamphlets used in the project Gloria described, addressed the fears of addiction. Fear of patients becoming addicted is something I have come across many times in my own practice as a nurse.

Can I Have Something for My Pain?

> "It was interesting because all the patients come through preadmission. They're given pamphlets for their care and I saw none of those pamphlets at the bedside. I did not see a single patient, maybe one patient in my pretty well my 20 years or I guess 18 years of experience working in acute pain settings, none of them were using them ... so they were really relying on what was happening to them...", Gloria proposed. "Right", I said. "at the present time", she continued. "Right", I agreed. "So yeah I think this whole thing between the prn (as needed) teaching that the nurses really held, their whole view was that the patient should be asking for the pain medication ... they didn't need it unless they asked ... and the

patient's view that that umm the doctor or the nurse should be delivering it to them", she started. "Right", I encouraged. "There's a huge, huge problem there", she concluded. "Do you think that there's, that we have a problem in terms of the actual language that we use? I know in my experience, I said, sometimes if you ask somebody well are you having, having pain ... 'well I'm just a bit sore' and I you know, soreness is pain and people really they just don't equate the two together ... they have a very distinct, in my experience, a very distinct idea of what is pain and a whole lot of other words that are something else", I suggested. "We get into a huge cultural thing with patients ... that's where the cultural part comes in cause the nurse could be asking the patient if they have pain. But there again it's surprising how many nurses actually ask the patient ... cause if they ask the patient then they'll have to give the patient pain medication so it's more work on the nurse's part ... young and old .. like the young ones will probably be asking, but the older ones like if they're really worked off their feet anyways, they might not be asking even. So like recently this was written on the care map for the orthopaedic patients was you would have morphine on a prn (as needed) basis ... it would be IM (intramuscular) or, or usually IM or SC (subcutaneous) one of the two, but usually IM at that point, and it was a prn basis and they also had Tylenol #3's (a combination of acetaminophen, codeine, and caffeine). Originally the understanding was that they would be able, they would take their morphine when they were having, like at first initially for pain control, and then they would go to Tylenol 3's. But after I did my work with working the literature on palliative care (literature research on pain management) and I talked with our clinical educators we sort of came to the conclusion that the patient could have the Tylenol 3's for breakthrough pain (pain that develops despite the fact that the patient is having regular pain medication) because they (the medications) were working on a different pain pathway", she explained. "Right, right", I agreed. "They're quite different, those two different medications different treatments, they don't work on the same pathway so it would be ok and we started doing that and we had better we had much, much better results with the pain control once the nurses that I worked with ... they were having better results, the

> patients were happier, less problems. But now I understand, like I haven't seen the recent care mapping, but I understand Dr. R. has worked with nurses here at the P. hospital and he's implemented regular oral morphine on a regular basis", she said. "Ohh", I commented. "So to me that is, and they're reporting much better much better pain control with that type of thing because it overcomes a lot of the problems we discussed", Gloria said. "Right like the communication", I suggested. "Yeah. That's right. And then when you move that into the chronic pain setting, because the patient has had a bad experience with their acute pain, having had surgery whatever, they've got pathways set up already for chronic pain, like they've got the pathway, they've had a bad experience … they've got it set up … then it makes dealing with chronic pain way more difficult too … just even having that knowledge. So it's my understanding that the whole, to have better pain control in the acute phase is very beneficial", she concluded.

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In Gloria's experience working in acute care, patients seemed to rely on what was happening to them at the time with regard to pain and did not use the strategies outlined in pamphlets supplied at preadmission to the hospital. The pamphlets would have informed the patient that they needed to ask for pain medication. Gloria said, "Nurses really held, their whole view was that the patient should be asking for the pain medications … they didn't need it unless they asked" and unfortunately the patients view was "that that umm the doctor or the nurse should be delivering it to them". She concluded that this created a huge problem for nurses and patients were working at cross purposes. This created a significant tension for Gloria and I think was one of the motivators for her to get involved in studies on pain management. One of the things I wondered about as I went back over Gloria's words was the possible assumption that patients are not in pain unless they say they are in pain. There can be many reasons for patients not to voice their discomfort and I wonder now what Gloria would say about this section of the transcript.

I wondered if language was an issue in communicating pain and asked Gloria what she thought. I noted that there is a world of difference between medical language and the language of every day. Medical language is filled with highly specialized terms
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or jargon and many abbreviations that can place a barrier between the healthcare provider and the patient. There are also differences in how individuals report pain. While I was thinking of all the different words we use for pain Gloria was thinking of a slightly different issue, that of culture. She stated, "We get into a huge cultural thing with patients … that's where the cultural part comes in cause the nurse could be asking for the patient if they have pain". As I thought about this I thought of issues around different languages as well as acceptability of expressing pain behaviors in different cultures. These could be things that would make it difficult for the patient in a system that relies on the patient asking for pain medication. When Gloria said that some nurses saw pain and treatment of pain connected to work load, I knew in my heart that this is also sometimes true. While I saw this as an ethical issue, I am not sure if Gloria would have framed her knowing in that way. Gloria told me about some of the work being done to move beyond the current system of giving medication on a prn or as needed basis (as requested) basis. She noted that, "Originally the understanding was that they (patients) would be able, they would take their morphine when they were having like at first initially for pain control and then they would go to Tylenol 3's". This worked well as long as a patient did not suffer breakthrough pain, unexpected pain not controlled by the regular pain medication that had been ordered. Gloria had been doing a literature search on pain management for palliative care and in the course of this work realized that pain medications work on different pain pathways. Because of this work and consultation with nurse educators on her unit, they started using Tylenol #3's as breakthrough medication when needed. The result was, "we had better we had much, much better results with the pain control once the nurses that I worked with … they were having better results, the patients were happier, less problems". It was evident throughout our conversations that Gloria kept up with the latest research on pain management and was able to positively impact clinical practice by sharing it with her colleagues. Evidence based practice was important to Gloria and seemed to take priority over making decisions based on experience. Gloria noted that one of the doctors at the P. hospital was now ordering medication on a regular basis versus a prn or as needed basis and the results were "much better much better pain control with that type of thing because it overcomes a lot of the problems we discussed". She noted that communication difficulties were fewer and there were fewer problems with patients being set up for chronic pain because of a bad experience with poorly controlled acute pain. This was another example of changing practice based on new information.

Whose Responsibility Is It?

> "Now what do you find, like the group that I'm studying, women with migraines, ah they're dealing with when they come into say an acute care setting … they're coming in with acute pain but it's on top of a chronic pain problem", I said. "Right", Gloria responded. "So have you had experience with that and how that works because you've got two different philosophies of care", I elaborated. "Right. Exactly. They're actually presenting in Emergency right? I've had a little experience with that, not a great deal. Um, but I know there's again a lot of cultural problems for them … There's a lot of problems for the nurses dealing with that in Emergency departments because of the pressures. The patients present themselves with an acute episode of a migraine and um it it goes into the drug addiction thing again I think. The nurses think this patient is probably abusing the system, maybe because they're coming into the Emergency department repetitively and nothing is happening with the problem, and so the patient gets their dose of medication, goes home and comes back again, and it's a real little vicious circle … and it creates more work for the nurses too when the patient comes in so it's a whole round about circle", Gloria explained. "It really is and there's a lot of labeling and it doesn't mean just because somebody comes back it doesn't mean it's because they want the medication …in most cases they want relief .. so ultimately the chronic pain is not being dealt with", I added. "That's correct", Gloria said. "And it's escalating and then they're getting the acute pain on top of it", I said. "Um hmm that's right. And every time they come in they're greeted with the same, you know, may be the same staff are working, they're not coming into a very good circumstance because of the way emergencies are set up in to begin with. They're waiting maybe 8 hours", she suggested. "Um hmm", I murmured. "So it's not, it's certainly not a good way to spend 8 hours to begin with", Gloria said. "Well I know a lot of people and certainly from my own experience, I'd do anything to avoid going into

Emergency", I stated. "Oh I do too", Gloria agreed.

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In this short conversation, I brought up the issue of two different philosophies of care, one for acute illness and another for chronic illness, for I was interested in how Gloria saw these playing out in emergency situations for migraine patients. For clarity, in acute care, the emphasis is on fixing the problem while in chronic care the emphasis is on long term management of the problem. Since migraine is a chronic illness, diagnosis and treatment of the immediate acute symptoms would be the approach taken under the acute care model. Looking at potential causes of the migraine, prevention, and long-term symptom management would be the approach under a chronic care model. In my experience women with migraines who come into Emergency are treated under the acute care model with minimal attention to the chronic nature of the illness. The stigma that tends to go with the treatment of chronic pain, being the risk of addiction if narcotics are used, is always a factor.

While Gloria said she had "a little experience with that", she noted that many nurses just assume that patients are abusing the system because the same patients continue to come back and it seems that nothing is being done about the chronic nature of their problem, "The nurses think this patient is probably abusing the system, maybe because they're coming into the Emergency department repetitively and nothing is happening with the problem, and so the patient gets their dose of medication, goes home and comes back again, and it's a real little vicious circle … and it creates more work for the nurses too when the patient comes in so it's a whole round about circle". It is not hard to see really that nurses working in an acute care setting would find it frustrating to see women coming in over and over with no apparent attention being paid to the cause of the problem. As I think about how Gloria is experiencing this I realize that I am wondering about who is responsible for starting the process of seeking the cause of a woman's migraines. Gloria does not see the milieu of the Emergency room as an ideal place for women with migraines to come, noting that , "Every time they come in they're greeted with the same, you know, may be the same staff are working, they're not coming into a very good circumstance because of the way emergencies are set up in to begin with. They're waiting maybe 8 hours, she suggested". As I think about Gloria's choice
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of words I cannot help but wonder why an acute care facility would be considered as the place to delve into the why of the headaches. I think Gloria would see it as a place for referrals to be made back to family physicians or on to specialists for there is neither the time nor the resources in Emergency rooms for investigating the cause of migraines.

The Foundation

> "Yeah that works in well with the little work I'm trying to do with the family doctors, like trying to get them to work on some kind of plan of care…yeah and as you said a lot of them don't know what to do. I think they don't know what to do and often times they, they think that a referral to the pain clinic is going to solve the problem but I mean it's a one stop thing … it sort of they're not doing their full role then if they're doing that. Like they're not doing their role as a family doctor. . I mean because we see a lot of people that come here that have not had their pain researched. Not really", Gloria stated. "Right", I said. "To me that's like the baseline … and to give a person some kind of pain control. I guess they go together, like they would go together but any of my work with palliative care is that before you start anywhere, the bottom of like you have the pyramid, you have the needs … I can't remember the name of the pyramid I forget … I haven't worked with that for a while … but anyways it's at the bottom of the pyramid and at the bottom is pain control before you do almost anything, before you do anything else you have to have some pain control", she explained. "Right it's like, well I've worked in palliative care too and I've done a lot of different things in acute care … used relaxation tapes and things like that for pain control and taught that to um children in particular because kids are just wonderful at it cause they have such great imaginations they can get right into it", I said. "That's right yeah they can", she agreed. "And you know everybody else looking at me like I had three heads like what are you doing but I mean you just you try anything … but the one thing that ah I learned very early on was you can't teach people these things if they're in pain", I stated. "That would be correct, yup", she agreed. "You know you have to teach these when they're comfortable and then gradually help them to learn to use these other techniques when they are in pain", I explained. "Yeah, that's right. When you get into the chronic, if you

> have a chronic pain sufferer, someone who's had pain for more than 6 months, that's classed as a chronic pain sufferer", Gloria said. "Yeah", I agreed. "But um they definitely need to have some kind of pain control that's for sure", she concluded.

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Gloria and I were in total agreement as she described the foundation for pain management in chronic pain. She talked about working with family physicians, "trying to get them to work on some kind of plan of care". Gloria felt that physicians saw the pain clinic as a solution to chronic pain problems, "they think that a referral to the pain clinic is going to solve the problem but I mean it's a one stop thing … it sort of they're not doing their full role then if they're doing that". Gloria noted that patients often came to the clinic with their pain poorly researched, "Because we see a lot of people that come here that have not had their pain researched. Not really", Gloria stated. "Right", I said. "To me that's like the baseline … and to give a person some kind of pain control". She emphasized the need for basic pain control as a starting point. It was obvious that Gloria saw an expanded role for family physicians in the areas of researching pain and establishing pain control. Having both worked in palliative care Gloria and I were familiar with the approach to pain management taken in this field and pain control is a priority in this area. I could understand Gloria's concern about pain control for I knew the goal of the pain clinic was to help patients shift their focus to other things besides their pain and this can only be done if there is reasonable pain management to start. I wondered if Gloria went to work in the pain clinic because she saw that it would be a place where something positive could be done with patients and their pain. Maybe a sense that she is searching for ways to be more effective in the system.

A Change of Focus

> "Um do you find are there many discussions around the pain clinic with other staff and what not around the ethics of leaving someone in pain versus using something a little stronger?" I asked. "Well here what they do is everybody that comes into the clinic is considered in pain. They, no, to rephrase it, what the person's perception of their pain is is taken for face value, like there is no argument. If the patient says their pain is 12 out of 10, that's what's recorded so
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that is definitely, it doesn't matter if they're repetitively coming to the clinic, ah they're still considered to be having pain and the problem is discussed with the patient and um I don't think there's any withholding of narcotics at any time. I don't feel that. I don't really take part in the actual ordering of the narcotics myself because that is the role of the physician and they're always present in the pain centre when I'm here so it's a little bit different role for me than what I'm used to in the acute pain setting where the nurse kind of does it all … you know the doctor does the orders and then you just carry out with the delivery … but in this case the doctors do the ordering, the patients take the prescriptions … but I do a lot of work with the patients on the phone doing a lot of counseling and it's very interesting … like speaking of, if you're talking about migraine patients which they seem to be .. there really isn't a lot of differentiating between migraine sufferers and patients with back pain and patients with herpes zoster … you know there really isn't a lot of differentiation … they all come in and the diagnosis isn't in the front of the discussion usually", Gloria answered. "Um hmm", I responded. "It's usually, what we discuss, well what I discuss as my role as the nurse what I discuss is their pain level of course and then I like to go through a pain assessment with them … I discuss their symptoms, I also like to discuss depression, anxiety, their well being and I'm working with a new concept of their percentage of pain relief that they're getting… so that it's sort of rephrasing their whole pain treatment, maybe their whole perception of pain control because what you were discussing you do get a real background of chronic pain sufferers really have a problem with their perception, their pain perception because they have been not been treated properly in the past right?" she explained. "Um", I murmured. "You know they've had a lot of bad experiences with their pain control going into Emergency and being really fearful that they're not going to get enough and that really plays a factor in their pain control. But it's interesting that if you ask a patient what their pain level is they will tell you whatever their perception is … and a lot of times they will really paint a black picture of their pain and they will also have a lot of pain acting, um there's a word for it, I forget what they use for it, pain um they'll be wincing, pulling their head", she wondered. "Right pain

> behaviours", I suggested. "pain behaviours, that's the word for it, there's a lot of that attached to the pain … their spoken pain level, I'll ask them what their pain level is and along with that then there's a lot of this acting pain behaviours is it? But I'm also asking, I'm thinking about adding to our pain assessment um asking them the percentage of relief that they're getting from their pain treatment, treatment some …. But anyways I notice when they come in after they've been treated that often times they'll still rate their pain at extremely high levels, they'll still have the pain behaviours, they'll often state that their percentage of relief is pretty good like maybe fairly good, at least over 50 %, but on the other ratings like their energy levels, their fatigue levels, their well being, their depression, their anxiety levels, like all 5 of these levels will often be improved a lot and even looking at the person, like they'll be dressed nicely, have the focus, have another focus outside of their chronic pain", she added. "Right", I agreed. "Which is the goal, I think that's the major goal for the clinic is to try and relieve their pain, with fewer symptoms, and have them move their focus from their chronic pain to something else", she said.

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Gloria works at an out-patient pain clinic. I wondered about their philosophy of looking at pain and asked her directly about the ethics of pain management at the clinic. Her response, "If the patient says their pain is 12 out of 10, that's what's recorded so that is definitely, it doesn't matter if they're repetitively coming to the clinic ah they're still considered to be having pain and the problem is discussed with the patient and um I don't think there's any withholding of narcotics at any time" resonated with what I felt was right. I say that because it brings back memories of my time at an in-patient pain clinic. I remember arriving and having to turn over all my medication to the staff at the clinic. I was so afraid they might not give me enough medication for my migraines. It took a great leap of faith to embark on the six-week program that would ultimately help me. I can see why individuals in the program Gloria works in might paint their pain very black even if there was improvement in some areas. Their medication depended on their pain report and even if their pain was improving it could be very frightening not to have a certain amount of medication on hand. The new term Gloria was using, percentage of
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pain relief, seemed a safer term for her patients to report. I wondered whether Gloria knew that migraine sufferers might have the fear that I did as I turned over my medications.

Gloria explained that her role is really in the areas of assessment and counseling. As she talked about the multidisciplinary assessment, she noted that "there really isn't a lot of differentiating between migraine sufferers and patients with back pain and patients with herpes zoster ... you know there really isn't a lot of differentiation ... they all come in and the diagnosis isn't in the front of the discussion usually". I wondered if the type and location of pain would not impact the quality of life of individuals in different ways. If so, here was something that opened the door to nursing care. Gloria went on to describe the assessment she does on pain and I felt that she probably got at these issues more in her work at the clinic. "I like to go through a pain assessment with them ... I discuss their symptoms, I also like to discuss depression, anxiety, their well being and I'm working with a new concept of their percentage of pain relief that they're getting... so that it's sort of rephrasing their whole pain treatment, maybe their whole perception of pain control because what you were discussing you do get a real background of chronic pain sufferers really have a problem with their perception, their pain perception because they have been not been treated properly in the past right?" As Gloria described how she saw her role, it was one of listening to people's stories of pain and how it is affecting their lives. She saw herself as teasing out the multiple impacts pain has, making referrals when necessary, and counseling patients herself. Through her work she has discovered that patients' perception of pain may be skewed because they have not had proper treatment in the past. Gloria spoke of how she sees the pain behaviors she observes in her work. These are actions that reflect the presence of pain in her patients "they'll be wincing, pulling their head". In the course of trying to change a patient's focus in his or her lifestyle to introduce something besides pain she works with them to try and reduce the use of pain behaviors. Careful observation is another way in which Gloria listens to her patients and gradually develops a picture of the changing landscape of her patient's lives with chronic pain. In her experience, she sees herself as trying to attend to the patients' experiences and trying to understand from inside each patient's story.

Disability

"So you're really starting to look at the um the level of disability the pain is causing", I said. "Oh absolutely, yeah that's definitely a goal", Gloria answered. "and making a change in that", I added. "And I think that's one of the goals of the chronic pain clinic because we are a multidisciplinary clinic versus just doing the medical model where the patient would come in, like it's similar to acute care because the patient comes in and says they have pain well then the physician comes in and says well then we can do surgery on you to fix you", she continued. "Um hmm", I encouraged. "Which is fine in an initial setting, but, if you do that repetitively, it's not, that's not going to help right?" she said. "Right", I agreed. "... it's like putting a band aid over and pretty soon the hole gets bigger and bigger and it's not a, not a permanent fix for the patient", she added. "No", I said. "So yeah that's the focus that we try to do in chronic pain rather than like having them come in and have a treatment like a local block, a nerve block ... it's more beneficial I think for them to take that, that's good for acute pain you know for the first few initial times, but you don't want to do that to your body repetitively either", she explained. "No", I said. "come back in repetitively, repetitively for that treatment, so it's better if they take their focus from those treatments and try and give themselves some goals and things to accomplish outside of, you know, on a different level other than treating it just strictly medical", she said. "Right, so you're looking at lifestyle changes and that sort of thing", I suggested. "Um hmm, trying to enhance them, their psychological and social aspects of their life. I mean some of them will still have their chronic pain ... there's not going to be (break while talking to staff member). So yeah no that's what, that's what sort of the outlook is for the chronic pain but doing some literature research for the family doctors, I'm thinking that maybe that model can be moved in or started, it's started at the family doctor's level", Gloria proposed. "Um hmm. Why I know some of the reading I've done recently, they're now working with assessment tools that actually assess the disability that chronic pain is causing within a person's life", I said. "Right", she agreed. "And this is something that hasn't been done, I mean this is relatively new in general practice and it just blows me away that it's not been done before", I stated. "Right, cause we do, we did the multidisciplinary approach and our psychologist is so busy … we could have several of him … there could actually be a group to begin with to start people out and then they could come … they could start with that, start at a point and still work with their family doctor and then be on that, do that first and if they don't see an improvement in their pain, or else liaise with the chronic pain, with our centre and see what can be done, see what can be suggested before they even get here", she said. "Right, right. So how often do you see people to the program, say women with migraines that come in , are they really open to the different approach?" I asked. "There is a lot of psychological teaching that needs to be done there because some people, for some people they can't seem to part from their pain behaviours … like that seems to become, that focus is very important to them. They become very, the word I could use is attached, but it's just what they've become accustomed to, it's like, it's their life, like their pain is running their life, like that migraine is running their life and for them to see life despite the migraine … it's a difficult process for people", Gloria explained. "It's almost like a habit", I suggested. "yeah, it's a habit, it's probably it's like, it's probably not unsimilar to people that smoke, because that's a way of life for them to run their life around the cigarettes, even if it's crippling them, in many ways, I mean they can't see anything different from that so that maybe women with migraines, speaking about migraines specifically, but yeah I think I think they have a lot of trouble with that seeing that there is something other than the migraines … I mean it would for some people it would certainly take a long time to introduce that cause the literature says that the longer they are in chronic pain, the longer it is for them to change their lifestyle. They've really arranged their life around that, the treatment of their migraines", she said. "Plus you'd have to have a fair improvement in the pain level", I suggested. "I think so but it's funny because you've got to have the pain treatment right but purely treating the pain doesn't help either if they're totally focused into the pain, so that's where the difficult area starts is to even try to have them do a bit of work around that. So I think a lot of patients that we see in the pain centre, they probably take years of work in the psychological area", she finished.

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Gloria used a very powerful metaphor of her knowing to help me understand the problem of treating chronic pain from purely an acute perspective when she said, "it's like putting a band aid over and pretty soon the hole gets bigger and bigger and it's not a not a permanent fix for the patient" or "So yeah that's the focus that we try to do in chronic pain rather than like having them come in and have a treatment like a local block, a nerve block … it's more beneficial I think for them to take that, that's good for acute pain you know for the first few initial times, but you don't want to do that to your body repetitively either". Gloria said "so it's better if they take their focus from those treatments and try and give themselves some goals and things to accomplish outside of, you know, on a different level other than treating it just strictly medical". The emphasis was then "on trying to enhance them, their psychological and social aspects of their life" Gloria said. She has a strong sense that this is what is needed. Having gone through a program such as the one in which Gloria works I can attest to the value of it for I know from personal experience that migraines can cause a person to withdraw from many activities and it is very helpful to be pushed back into life again.

Gloria talked about moving the multidisciplinary approach into the primary care level with family physicians. This seems like a promising idea since most women with migraines are treated by family physicians. As Gloria noted, pain clinics are few in number and usually located in large centres so access to them is not universal and waiting times are long. She talked about the psychosocial model they were using in the pain clinic saying, "I'm thinking that maybe that model can be moved in or started, it's started at the family doctor's level". I agreed and noted that the introduction of new tools for assessing disability would be one way to help family physicians move into a broader way of looking at the impact of migraines on people's lives. As we talked about these possibilities our conversation came back to pain behaviours and I realized that Gloria saw this term in a broader context than I had first thought. For her pain behaviors included how people planned around their migraines and the treatment of them. Gloria said, "They've really arranged their life around that, the treatment of their migraines". As Gloria noted this, I realized that she and I shared this knowledge even though she did not
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have experience as a migraine sufferer. I thought yes, that is true. When I get up in the morning, my first thought is 'how is my head'. I plan my day around the answer and the treatment I may have to take during the day. So her experience was that it was not easy to get women to change their focus. As I reflected on that, I realized that what she said would hold for me. Chronic pain is very draining both physically and emotionally. I went to a pain clinic because my doctor did not know what else to do. I tried very hard at the clinic because I was afraid when he said it was the last thing he knew to try. I suppose it had taken many years to become so focused on the pain and perhaps it takes many years to learn to focus on other things again. I needed nurses like Gloria who could journey with me through those years and understand their impact. This kind of intervention was very late for me in my illness experience. Gloria was proposing an early intervention at the primary care level of family physicians, a really exciting idea.

Getting Your Life Back

> "I can think of one woman in particular um, I've seen her, when I first started working here for the first year I would see her really quite frequently, she would be coming in to see her pain physician, and then she had a referral to our psychologist so then she would come in to see him and I could tell when I was talking to her, you know, I would be talking to her about her lifestyle, some lifestyle questions, and um she didn't really have a lot of lifestyle it seemed … there really wasn't much there from what she told me", Gloria explained. "Um hmm", I said. "And then she started working with the psychologist and she came in to see him fairly often but actually I've haven't seen her in 3 months now which is very, I'm wondering what she's up to", she said. "Um hmm", I murmured. "But maybe she has some life besides coming here. But I haven't seen her for I think 3 months now. And she was one that was very handicapped by her migraine, her migraines. And there's a few other ones too that are, the older ones when I first started here that were really new and they're also showing some, like maybe when they come in state that their migraines are very severe and everything but I mean it's interesting that they have that big long spread between visits now", she said. "Um hmm. So they're managing better", I stated. "Yes I think just and that's what the literature was telling me too was that um even the

> family doctors could do this too, just take some time and talk to the patients on a regular basis, get them on regular pain medication, like not prn (as needed) but regular … so then the focus wasn't quite as much on oh am I having pain or not having pain", she explained.

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Gloria tells this story of hope and caring to show me that what she and others are doing at the pain clinic does lead to better quality of life for patients. She tells a story of a woman who "didn't really have a lot of lifestyle it seemed … there really wasn't much there from what she told me". Gloria seemed to imply that for this woman so handicapped by migraines, even the visits to the clinic added to her lifestyle, "But maybe she has some life besides coming here". This comment resonated with me for I know what it is like when your social life consists of doctor's visits and trips to the Emergency room. I almost take this for granted and pass over it too quickly and have to stop and tell myself how abnormal this is and that this should not be what women are forced to live through.

The multidisciplinary nature of the pain clinic is obviously helpful as Gloria mentions that the psychologist is very busy seeing patients in addition to herself and the physicians. She brings up the role of the family physician once more noting that one of the things patients need is someone to listen to them on a regular basis. I think again Gloria has a sense that listening to the patient's experience is so important. Gloria sees this as a role for the family physician outside of the pain clinic. She also mentions that patients must be on regular pain medications, not prn (as needed) medications so that the issues of "am I having pain or not having pain" is removed from the equation. I could see that one thing Gloria did was identify patterns in the treatment process for she was aware of changes in the pattern of appointment of her regular patients and realized this was potentially an indication of improvement in their health, "I've haven't seen her in 3 months now which is very, I'm wondering what she's up to". Because of how Gloria was positioned at the clinic she was able to coordinate care and see the broader picture. In this way, she came to know more of the story of these women's lives and this allowed her to compose a better narrative understanding of the impact of migraines.
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Money, Money, Money

"So um do you think that, you said the waiting list here is over a year. Umm your results though I assume are positive enough, positive enough to keep the clinic going, why aren't they looking at expanding?" I asked. "I understand from one of the doctors that it takes a lot of work to train a new doctor for one thing. I think it's financial, they probably have finances for what is here, well actually there has been, oh there's been four doctors based out of here plus they usually have one that's working on his sabbatical for chronic pain so that we've had two of those coming through the clinic ... and one doctor's leaving so I really do feel that it's financial", Gloria answered. "And yet the cost of chronic pain is tremendous, I ventured. "That's right, that's for sure", she agreed. "And it's becoming ... one of the biggest problems now in community health is chronic pain", I added. "Oh yeah, even to have even to have referral ... which they quite often do, some of the doctors are really good at that, they'll do a referral, bring people in, figure out what they're doing and then they'll refer them directly back to their family doctor", she said. "Um hmm", I encouraged. "Which I think that's a really good process, although some of the other doctors will take over the care of the patient, which I'm not, I'm not sure if that's a good plan. I mean I can see them bringing them in, treating their chronic pain problem, getting them stabilized, and then referring them to their family doctor ... which is a good, that's what I think the ideal is .. but some of the doctors tend to want to keep them", she explained. "Um hmm, right", I said. "But I would say yeah just the biggest problem is financial, just not having the funding for a certain number of patients. But I can certainly see that , like this hospital has a chronic pain division, the A. has one but it's smaller. But from my understanding, the X.Y. has not had the division, which would be helpful if they would establish theirs too, like even if they could do the same number, have four, that would probably half our wait list. It should. Theoretically", she finished.

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Gloria and I talked about the long waits to be seen at the pain clinic. She told me that from her perspective it was a funding issue primarily for it takes a long time to educate a physician to work in the clinic and in chronic pain, “I understand from one of the doctors that it takes a lot of work to train a new doctor for one thing. I think it’s financial, they probably have finances for what is here, well actually there has been, oh there’s been four doctors based out of here plus they usually have one that’s working on his sabbatical for chronic pain so that we’ve had two of those coming through the clinic … and one doctor’s leaving so I really do feel that it’s financial”. The other issue she raised was style of working with patients. She noted that some patients are referred to the clinic, are seen, diagnosed, and stabilized and then sent back to their own physicians for ongoing care, “Oh yeah, even to have even to have referral … which they quite often do, some of the doctors are really good at that, they’ll do a referral, bring people in, figure out what they’re doing and then they’ll refer them directly back to their family doctor”. Others have their care taken over by the clinic physicians. Gloria felt the referral process was the most effective, “Which I think that’s a really good process”. This seemed congruent with her previous comments in other stories about the importance of family physicians being prepared to play a key role in the care of chronic pain patients. I wondered how the physicians in the clinic felt about these issues.

Gloria and I talked about the importance of expanding services both in terms of more staff and in terms of more clinics. This was different from the issues of how patients are seen and handled. I wondered if a narrative understanding of the patient experiences, from studies like this one, would not have a strong impact when planning was being done and decisions were being made for the future allocation of resources to chronic pain.

Family Doctor’s Role

> “I think so but I think the family doctor’s role is one that maybe could be worked on too. Just reading what the literature that I’ve been reading … because they’re the ones that see the patients … and they have a specialty, like they took over they established the general practitioner specialty … it’s been there since the 60’s probably and um they’re the ones that see the patients like maybe once a month and they have they have they see the patient as a person right, I mean they should

> see the whole dynamics but for some reason when it's a chronic pain person, they get very … there's a lot of um prejudice I guess against them", Gloria explained. "Um hmm", I encouraged. "Some doctors, some doctors are good I think you know cause there's a few doctors that we get that we seem to see a lot of referrals from and there's other doctors, like I could go through … I have a database of which doctors have referred patients to the clinic so I could probably go through and tell you which ones have done a lot of referring and which ones don't do any referring", she added. "Right", I agreed. "So that's also very interesting", Gloria said. "Right", I agreed. "So I really do feel there's some family doctors out there, like you were mentioning that you have a really good one … that are doing the job …. They're not getting credit for it even … they're actually looking after their patients, seeing that their needs are being met. But I do feel like they should there should be more um availability to triplicates (program for ordering and tracking narcotics) cause then the family doctors if they knew they were out they could be monitoring these patients just as well as the doctors here in the clinic. Cause that's the goal of the clinic, is to have the patient sent back to their family doctors", she explained. "Right", I said. "And then the doctors can write the triplicates. So and in fact you know a new referral letter, I think that's written on the new referral letter .. I'm not positive of that, I'd have to sit and read that or the referral form but I think that's one of the understandings that when they refer patients to the clinic here that they would be willing to take back the care once they're stabilized", she concluded.

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As I listened to Gloria tell this story, I was surprised that she was noting the diversity among physicians in referral practices. I realized that I thought all physicians would be part of the program for ordering and monitoring the use of narcotics (triplicates). Gloria mentioned that general practice was established as a specialty back in the 60's and as such, "they're the ones that see the patients like maybe once a month and they have, they have, they see the patient as a person right, I mean they should see the whole dynamics" but she for some reason she stated, "when it's a chronic pain person, they get very … there's a lot of um prejudice I guess against them". From Gloria's
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perspective it seemed that hospitals were not the only place where women with migraines might encounter stigma. Gloria went on to talk about the referral practices of physicians. She obviously felt that this was an important part of good care, “Some doctors, some doctors are good I think you know cause there’s a few doctors that we get that we seem to see a lot of referrals from and there’s other doctors, like I could go through … I have a database of which doctors have referred patients to the clinic so I could probably go through and tell you which ones have done a lot of referring and which ones don’t do any referring”. She had obviously identified a definite pattern in the referral practice of some physicians and saw this as a strength for those who referred a lot and a weakness for those who did not refer patients to the clinic. Women with severe migraines are routinely seen by neurologists and other specialists so I could understand Gloria’s concern about the referral practices of physicians.

Gloria and I discussed the triplicate program for prescribing narcotics. She stated, “But I do feel like they (physicians) should there should be more um availability to triplicates cause then the family doctors if they knew they were out they could be monitoring these patients just as well as the doctors here in the clinic. Cause that’s the goal of the clinic, is to have the patient sent back to their family doctors”. Gloria recognized that with the end goal of the clinic being to have the patient back under the care of the family physician and with long term narcotics a potential part of the treatment regime, being part of the triplicate program was necessary for the family physician. After listening to Gloria’s comments I wondered how physicians managed their caseloads without being a part of the triplicate program.

The Look

> “Have you ever had a … do you think it makes a difference where the pain is in a person’s body … like I’ve always thought in reading about migraines and thinking about them and of course I have a personal interest in it, that because your head is the part of you that thinks, that runs the rest of your body … that pain in the head a is particularly problematic when it comes to explaining to people what’s wrong and asking for help and that sort of thing”, I suggested. “It probably would be because there is some preconceived ideas in general I think that people with people with migraines versus other types of pain problems …

like back pain … I'm not sure but I think 50% of our patients would fall under that pain … it's a very big amount … but back pain you can see on the x-ray right, you know you can see a bulging disk and you can see the nerves … when the doctors do the exam they can see that there's a nerve impingement in a lot of cases … but when it comes to migraines, sometimes there's no real sign and like a lot of the patients can't come in here when they're in an acute migraine because they can't stand up", she answered. "Right", I agreed. "So it's", she started. "I know my own my own doctor has never seen me with a really bad migraine", I said. "Um hmm, that's right, so, when they talk about people … so the doctors can't really see the fact that you're having a migraine other than the fact I can usually tell when people seem to be in you know having the pain … their reactions are a little bit different, the way they talk, their eyes", Gloria noted. "Um hmm", I murmured. "There are some signs there but they're not, not like a back, even the doctors themselves, like I sit back and listen when they have their discussions and how they talk about patients with back pain like they'll say well this patient has such and such a symptom, I mean they'll really … that means something to them I guess when they see that that that's quite out there in front and they'll report on the impingement of the nerve … you know how far down it goes", she explained. "Right", I agreed. "That sort of thing, but migraines no there's really not a lot of visual signs", she stated. "No, and yet you can get to read them", I said. "By reports? Or just by signs and symptoms?" she asked. "Just by signs and symptoms", I answered. "Yeah and you actually have to look at … but I guess x-rays and CT scans often don't show anything though do they?" she said. "No they don't", I stated. "Not a thing. I mean it only shows what you don't have .. which is good that you don't have that", she said. "Right", I agreed. "But you still have that learned response to that you know that pain pathway sets up … and once it's there you don't unlearn it", she suggested. "No, no you don't", I said. "You know one of the interesting pain theories I found I ran across was matrix pathways", she said. "Yes that's brand new", I said. "Have you read about, that's a really interesting", she started. "Yes, very, very interesting" I added. "They're relating pain pathways to learning to ride a bike, which makes perfect sense to me", she suggested. You don't unlearn to ride the bike, once you've learned it it's there … I mean you might be shaky, may have trouble getting on the bike but you've learned it and they're equating pain pathways with that", she explained. "yeah, plus it's much more holistic, it accounts for a lot of the things they couldn't account for before and they're able to account for things like phantom pain", I added. "Right", she agreed. "Which I found was just fascinating", I said. "It is and it actually makes total sense when you stop to think about it and it's actually not a hard concept", Gloria said. "Yeah and when I think of how many parts of my body are affected by migraines, you know a headache is just one thing, you know I have cold hands, there are just all kinds of things that contribute to the, the aura that you get and things like that and this idea of this matrix helps explain all that", I said. "Yeah it certainly does, it really does", she agreed. "It makes it, you sort of understand it as a whole body experience", I pointed out.

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When I asked Gloria about her thoughts, on the effects of pain in the head versus pain in other areas of the body, on the process of asking for help for her she thought in terms of the diagnosis initially. She discussed in particular the ease of diagnosing back pain using x-rays to reveal pinched nerves and bulging disks and the problem of not being able to visualize a migraine. Gloria presented a picture of doctors discussing back pain and migraine patients, "back pain you can see on the x-ray right, you know you can see a bulging disk and you can see the nerves … when the doctors do the exam they can see that there's a nerve impingement in a lot of cases … but when it comes to migraines, sometimes there's no real sign and like a lot of the patients can't come in here when they're in an acute migraine because they can't stand up". Then Gloria proceeded to talk about the "look" of migraines, "so the doctors can't really see the fact that you're having a migraine other than the fact I can usually tell when people seem to be in you know having the pain … their reactions are a little bit different, the way they talk, their eyes", Gloria noted. "Um hmm", I murmured. Here Gloria shows her attending to the signs and symptoms of the women with migraines. This is storied knowledge that is not found in the literature but comes from her experience. She makes a comparison, "There are some
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signs there but they're not, not like a back". Perhaps these storied symptoms need to be included in how we describe a migraine and incorporated into an assessment of the patient. As Gloria says it is a learned response to the pain that can be seen. Perhaps the response is not always seen because there is a story that needs to be told to accompany the response. The response is more than just physical, it involves all areas of an individual's life and it needs to be personalized for there to be real understanding. I think Gloria understood the "look" of migraines because she heard the stories and I do not know if physicians always have that same opportunity for a narrative understanding.

The other interesting part of this story was our discussion of the neuromatrix theory of pain (Melzack, 2005) for it brought up the question of the impact of psychological or physical stress that can be associated with chronic pain. Melzack proposes that, "the neuromatrix theory of pain provides a new conceptual framework to examine these problems. It proposes that the output patterns of the body-self neuromatrix activate perceptual, homeostatic, and behavioral programs after injury, pathology, or chronic stress. Pain, then is produced by the output of a widely distributed neural network in the brain rather than directly by sensory input evoked by injury, inflammation, or other pathology" (p. 85). This means that experience of pain originates in the brain rather than at the site of injury and that injury is not necessary for pain to occur. "the neuromatrix, which is genetically determined and modified by sensory experience, is the primary mechanism that generates the neural pattern that produces pain. Its output pattern is determined by multiple influences, of which the somatic sensory input is only a part, that converge on the Neuromatrix" (Melzack, 2005, p. 85). Melzack is suggesting that stress over time can be one of the causes of chronic pain as can a genetic predisposition. I wonder about the implications for acute care facilities in terms of how acute pain is treated as chronic pain becomes more and more part of the daily regime of care. Is it possible for us to prevent some of the chronic pain by treating acute pain more aggressively? Melzack suggests the need for an interdisciplinary approach to pain management and the incorporation of specialists in endocrinology and immunology in pain clinics. It will be interesting to see if a broader range of pain management therapies will in time appear at the bedside. Gloria and I both found the implications of this new theory very interesting.

Phone Contact

> "But it's interesting, this telephone, just to keep in contact with our patients, just to talk with them, find out how they're doing …and often I sort of think of that now with our migraine patients usually the encounters, telephone encounters are very brief. They're quite important, they tend to say what they need to say. I'm particularly, often they're just looking for appointments … they want another appointment … it seems to be quite important to keep contact with the doctors in the clinic and with the process of being just an update on how they're doing with their pain situation", Gloria explained.

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This was a short section but it seemed very meaningful to me because Gloria and I had discussed communication issues before and in this section she made specific reference to her phone contacts with migraine patients. Gloria pointed out that for her, "migraine patients usually the encounters, telephone encounters are very brief. They're quite important, they tend to say what they need to say". She went on to note that this was usually about making appointments to see the physician. It seemed that the phone was not a medium for long discussions, it was for most however an important mode for keeping in touch with the clinic. As I thought about the brevity Gloria mentioned and then about the complexity of a migraine story, I wondered if a phone would be a useful tool for anything but brief contacts in most cases. Migraine stories are stories of vulnerability and it may be easier to trust enough to share this in a person-to-person encounter. I wondered if Gloria shared my wonder here.

Memory Box

Gloria undertook the memory box project just as the women with migraines had. I was not sure what to expect and was delighted when she had three different pieces of literature to show me during our second meeting.
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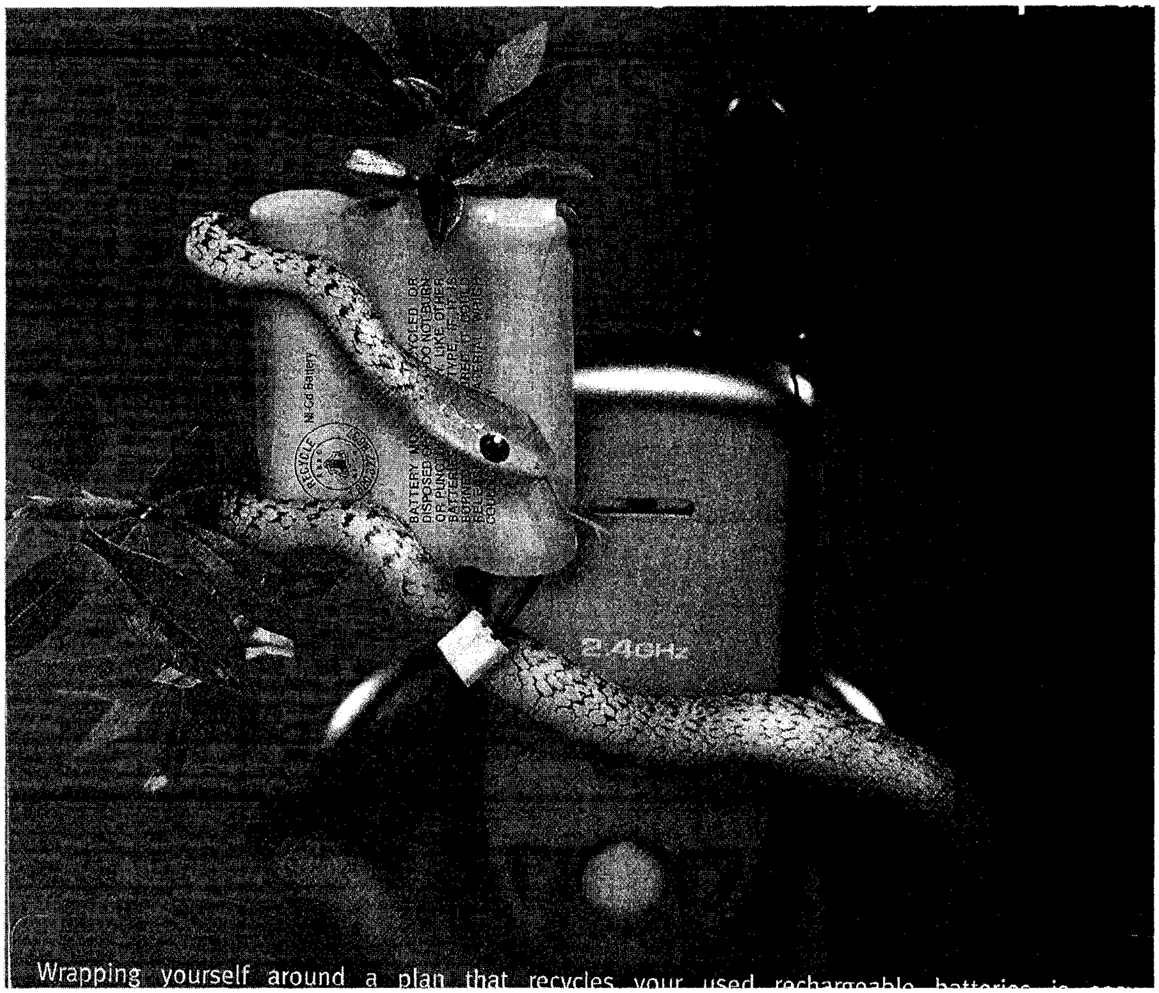

Figure 7 Barriers to Communication

"Yeah … it's kind of interesting your first picture now you've got a cell phone", I remarked. "Yes", she responded. "And it's got a snake around it … it sort of I'm looking at that and thinking is there some symbolism there?" I asked. "I think there is actually … it's interesting that I would pick out that picture too, but um I think with using the telephone maybe there are things that we don't see as versus the face to face and maybe I've never, maybe that comes out for me cause I'm not, I like, I mean I have no problem making the telephone because it's part of my work, it's a tool ... you use for all the patients … but there's so much hidden there that you can't see when you're using the telephone and maybe that came kind of came out with the snake and hidden elements", Gloria explained. "Yeah … a little bit of a barrier there too", I suggested. "Yup, I think so", she agreed. "And some people are not telephone people … you know some people just will not

> share on the phone, they're not comfortable with the phone at all", I added. "No, no … and that might not be their way of communicating … it's probably not their their vehicle of saying what they need to say like the face to face", she said. "That's quite an appropriate picture actually", I suggested. "Very interesting now … and there's also a little bit of symbolism because, I, because I find it very disturbing when you're dealing with people and they interrupt what they're doing to talk on their cell phones. I find that a little bit bothersome at times", she started. "Um hmm", I encouraged. "Or even when people come in for interviews and they're not necessarily talking on the phone but they may as well be because they'll pull out a magazine like we're in here you know like the face to face kind of little interview … and it only lasts a few minutes … and they know you know they've been in so they kind of know the process but they still pull out the magazine and they're reading the magazine and I", she continued. "You're trying to communicate with them", I added. "Yeah, trying to understand a little bit of their pain process", she concluded. "That's interesting", I said. "That they do that …I find it very interesting that they do that … like it's like another kind of mask", Gloria posed. "Yeah, yeah", I thought. "that people wear sometimes" she continued. "and I wouldn't have thought of that at all", I said.

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The first item Gloria had chosen was a page from a journal with a picture of a cell phone with a small snake around it. Since Gloria uses the phone extensively in keeping in touch with clinic patients I immediately asked her about possible symbolism in the picture. She said she thought, "with using the telephone maybe there are things that we don't see as versus the face to face and maybe I've never, maybe that comes out for me cause I'm not, I like, I mean I have no problem making the telephone because it's part of my work, it's a tool ... you use for all the patients … but there's so much hidden there that you can't see when you're using the telephone and maybe that came kind of came out with the snake and hidden elements". As Gloria noted in this story for some people the phone is simply not a communication mode through which they are comfortable sharing. They need a face to face encounter. Almost on the flip side of this, Gloria shared how uncomfortable she was when people use things like a cell phone to
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interrupt face to face communication, "Very interesting now … and there's also a little bit of symbolism because, I, because I find it very disturbing when you're dealing with people and they interrupt what they're doing to talk on their cell phones. "She went on to say, "Or even when people come in for interviews and they're not necessarily talking on the phone but they may as well be because they'll pull out a magazine like we're in here you know like the face to face kind of little interview … and it only lasts a few minutes … and they know you know they've been in so they kind of know the process but they still pull out the magazine and they're reading the magazine". This was obviously something that Gloria found hard to deal with but her next comment was very revealing, "I find it very interesting that they do that … like it's like another kind of mask", Gloria posed, " …that people wear sometimes". This was very interesting for Gloria and I had talked about the idea of "mask", a kind of false face that people with migraines often use to keep others from knowing they are in pain. Here was another kind of mask in Gloria's opinion, a behavior that shut down communication perhaps? I wondered if Gloria felt she was being personally shut out when this happened, was this a personal threat to her role as helper.

The Mask.

> "Well it's interesting with your migraine sufferers because I know a lot of even one of my friends that I used to work with a lot and she used to be a very severe migraine sufferer but you could tell as soon as she had a migraine you could see that mask … it was like she wasn't communicating she was just sort of pulled down, she was just there and that was it … she really wasn't open to anything … and I think it was because of the pain", Gloria suggested. "Oh sure", I agreed. "I'm sure it is because of the pain … it's her coping mechanism that she had tried ... it was exactly the same as K, the lady that I have as a patient, she was very interesting cause as soon as you could get her to put her mask down then she could talk … and there is a lot of research, at least when I did my chronic pain course there is a chapter on how people have channels you know for processing in their brain, how your brain works .. and if your pain is on if your brain is on channel .. like even if you do have severe pain and it's on that channel then if you for a minute can move your brain to a different channel, watching TV is a

favourite one for people, music for other people, but your brain has trouble processing both of them fully at the same time so that in effect will tone down the pain channel so it won't be so severe. So I ..", she explained. "Right, the whole issue of distraction", I said. "I really watch for that for patients and also I feel that it's um for a lot of people with chronic pain they're denying themselves sometimes any enjoyment in life … tangible? … not all of them but there is a fair number that and we can talk about that in a minute when we because I do discuss that with them, I discuss their enjoyment in life", Gloria stated. "Um", I listened. "For some people they will deny any enjoyment in life, whether they're allowing themselves the enjoyment … but I feel that they are not allowing themselves to have that enjoyment … for whatever reason I don't know", she wondered. "It takes a lot of energy though", I suggested. "Yeah I think it depends on how you process too. Like what you feel is important to you and how you process enjoyment in life .. will have different views of what is enjoyment in life is too", she said. "Yeah I find certain there are certain pain levels that when I get to that level I can't switch off to something else … the distraction just doesn't work … the pain signal is just so overwhelming… I just don't have the energy or whatever it is to be able to participate in something else … but it can be very effective up until then", I said. "I think so, I think it is … and it would be interesting to know about other cultures too … how what is the difference between different cultures and migraine as well", Gloria proposed. "Um hmm um hmm", I agreed. "cause a lot of what we do is learned … it's cultural but it's a definite set of cultural values and what, what is dictated as important and not important", she suggested. "Yeah and what's acceptable and what's not acceptable", I added. "Um hmm that's right", she said.

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In this story, Gloria shows us several ways she imagines examining the "mask". She explains the mask with a story of a person, "but you could tell as soon as she had a migraine you could see that mask … it was like she wasn't communicating she was just sort of pulled down, she was just there and that was it … she really wasn't open to anything … and I think it was because of the pain". In this sense the mask is a coping
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mechanism, a retreat when pain is too overwhelming. Then Gloria suggests that if the patient can lower the mask and focus on something else, pain can be decreased through the use of distraction, "when I did my chronic pain course there is a chapter on how people have channels you know for processing in their brain, how your brain works .. and if your pain is on if your brain is on channel .. like even if you do have severe pain and it's on that channel then if you for a minute can move your brain to a different channel, watching TV is a favourite one for people, music for other people, but your brain has trouble processing both of them fully at the same time so that in effect will tone down the pain channel so it won't be so severe". I wondered about this and as I think more on it I am not sure the mask has to come down for the patient to engage in the use of distraction. For example, I am an avid reader, and even with a significant headache it is easier for me to distract myself with a good book than with a conversation with someone. The mask is down while I am reading. I did tell Gloria that for me there is a level of pain at which distraction no longer works and in my experience I reached that level all too often. I was always beyond that level when I asked for help in an Emergency room. The final point that Gloria raised in this discussion was that the mask might be a function of culture, "it would be interesting to know about other cultures too … how what is the difference between different cultures and migraine as well", Gloria proposed. "Um hmm um hmm", I agreed. "cause a lot of what we do is learned … it's cultural but it's a definite set of cultural values and what, what is dictated as important and not important". It is interesting to think of how culture might affect the mask. I could see that a culture that values stoicism for instance might be one where the mask would be less acceptable at an early stage of a headache. The mask might not be seen much in a culture where behaviors associated with pain and anguish are openly accepted. Gloria did not talk about her practice in this area but I wonder now if she has found a difference is required in her practice because of cultural differences in the mask.

Face to Face.

"But I do notice particularly, I've been in the clinic for a year and a half now and I've noticed with one of our major patients whose a major migraine sufferer … at one point when I first started she used to be coming into the clinic like maybe once a month I believe", Gloria said. "Um hmm", I acknowledged. "And now the doctor has her physician has actually referred her to the psychiatrist and she hasn't been in the clinic very, I haven't seen her probably for about three months", she added. "Okay", I said. "So I think she's, you know, she's stabilized, she's seeing a psychiatrist and I think she is um she's doing ok but interesting enough um she just to give on her is the fact that we would get some connection because she and I shared a hobby together and we'd talk about the hobby when she came in. She likes to sew."

The second item in Gloria's memory box was another page from a journal showing a picture of a woman with a smiling face. Unlike the first item which showed barriers to communication, this one depicted open face to face communication.

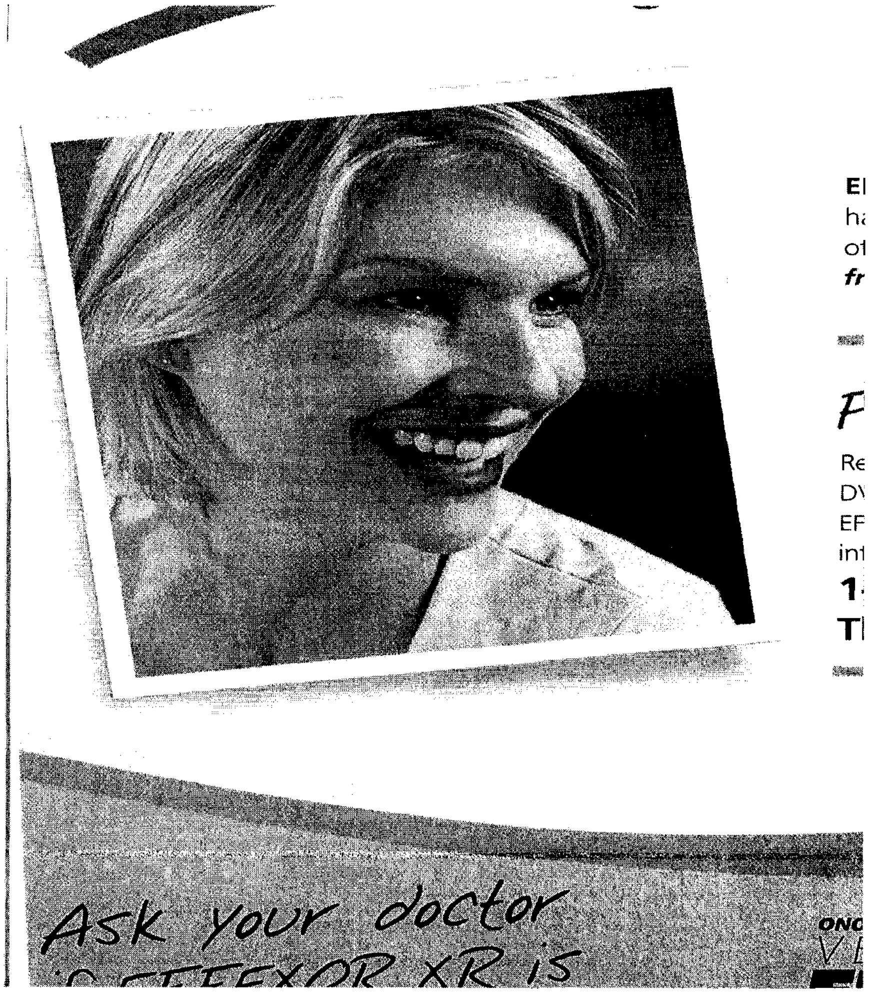

Figure 8 Face to Face Communication

"Oh, okay", I said. "So she would come in and be chatting, umm not ever over the telephone, like she wouldn't do the telephone thing too much, like she her brief encounters, very brief over the telephone but actually in person her encounters were much longer …so that's what the second picture is about, just talking to somebody face to face", she explained. "Right", I agreed. "Not to worry about the medication, that's sort of a side light … I think it's the encounter part that's very important with all our patients but particularly with this lady and in particular that I'm thinking about because she would come in and sometimes you could see the migraine … I don't think she was ever really free of it", she said, "it seemed to be there present for her". "Do you think that's, is that like a trust issue? Do you think that it's easier to put your faith into someone if you are actually seeing them and seeing their facial reaction to you and that sort of thing?" I asked. "I think so, I think that there's a different kind of communication that this lady I'm talking about .. her first name is K … I can use her first name … umm with her particularly it seemed to be um she yeah I think she did like to come in and have the contact … ah speaking person to person and the faith issue perhaps … oh and I think it also made her feel better too, I think she enjoyed that face-to-face contact. Being able to talk about her situation …", she explained. "Right", I said. "It seemed to actually we would go through a little interview, which I'll talk about for my third item, I'll talk about that in a few minutes, but she would, she would come in and we would go over her pain and how it was affecting her and then I always asked her about what she would like to do for wellbeing … there were some things that she could do that she could enjoy to do and she always brought up the sewing …so when she started talking about the sewing then we seemed to have kind of a mutual kind of contact and I think she enjoyed that encounter … I think there was a level of enjoyment there because she could talk about her latest projects", she suggested. "I wonder if there is an element of feeling normal", I said. "I think, I think you're right, and I think for her it was that was that it made her feel worthwhile … that it was something that she liked to do …", Gloria agreed.

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In order to help me see her knowing, Gloria gave an example of the difference between telephone and face-to-face encounters with one patient in particular. "She and I shared a hobby together and we'd talk about the hobby when she came in. She likes to
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sew", Gloria said. "Oh, okay", I said. "So she would come in and be chatting, umm not ever over the telephone, like she wouldn't do the telephone thing too much, like she her brief encounters, very brief over the telephone but actually in person her encounters were much longer ...so that's what the second picture is about, just talking to somebody face to face". It was as if this woman needed an actual place for the contact, not just a way of contact. It reminds me of the difference between learning in a classroom and learning online. Some individuals can create a classroom in their minds, imagining the other students at their computers around the country hooked up together, while others seem unable to make that leap and need the face to face contact, the physical structure of an actual encounter, and the non-verbal interplay that is possible when two people interact in person. Gloria describes how the interaction helps her and a patient lift the "mask", "Initially when she first started the interview she was pretty low key and pretty hidden behind that mask, there's a mask there, but as soon as we got onto the sewing she kind of brightened, they then she kind of dropped the mask for a little while ... when she talked about how much she just loved the fabric, where to buy it ... she was full of ideas actually so throughout the summer whenever she came in she asked me how the suit came to be and how the wedding was ... she quite enjoyed that", Gloria explained. "Um hmm", I nodded. "So I found that to be very interesting, it was the face-to-face encounter", she said. "Right", I agreed. "That um I would not have gotten over the telephone with her", she added. "Right, right", I confirmed. "So there's quite a contrast", she suggested". In addition to revealing herself and being able to have a deeper level of interaction, the face-to-face encounter also allowed for a more in depth assessment of her state of health. "Not to worry about the medication, that's sort of a side light ... I think it's the encounter part that's very important with all our patients but particularly with this lady and in particular that I'm thinking about because she would come in and sometimes you could see the migraine ... I don't think she was ever really free of it", she said, "it seemed to be there present for her". Gloria again reveals her perception of the presence of a migraine by the "look" of it. I wondered how much credence she placed in her own ability to identify a migraine, in her clinical experience. I wondered if it was easier for someone to place their faith and trust in someone in person. "I think she did like to come in and have the contact ... ah speaking person-to-person and the faith issue perhaps … oh and I think it also made her feel better too, I think she enjoyed that face-to-face contact. Being able to talk about her situation …", she explained. "Right", I said. "It seemed to actually we would go through a little interview, which I'll talk about for my third item, I'll talk about that in a few minutes, but she would she would come in and we would go over her pain and how it was affecting her and then I always asked her about what she would like to do for wellbeing … there were some things that she could do that she could enjoy to do and she always brought up the sewing". This was interesting to hear Gloria talking about the importance of her face to face impressions of the patient for in our earlier conversations she was very focused on evidence based practice and seemed to place her own experience second. Here she is integrating her own observations and instincts with the formal assessments to gain a more holistic storied understanding of how this woman is really doing. In thinking about the goal of the clinic's program, that of moving the individual's focus away from their pain, I can see where the topic of her sewing would be something that this woman would see not only as something to build a conversation around but also as something to show she was meeting the goal of the clinic program. I wonder if Gloria had seen it that way. I also wondered if for this woman this activity of sewing brought a sense of normalcy into her life. Gloria felt it brought a sense of worth and while I do not disagree with her, I wonder if she underestimates the extent of feelings of abnormality that can accompany a disease like severe migraines. From my own experience, I think a sense of worth comes with a feeling of normalcy.

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Total Pain.

The third set of documents in Gloria's memory box consisted of the assessment documents she uses with her patients in the clinic. To maintain anonymity I have not included these documents and will include only our general discussion of them.

> "And then this first part is a bit of pain history … what they've tried in the past and then this bottom scale is how they're managing at home and", Gloria started. "Oh that's good so you've got activities of daily living and you're getting at the disability". I said. "That's right and also it's got a double scale there where we ask um if um they want to use it … they don't have to …but um good days, bad
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days and every day in conjunction with the scale", she continued, "so they can read that into it too so it becomes quite a little bit of a creation". "Right, right", I agreed. "It becomes quite interesting", Gloria added. "Wouldn't that be wonderful for a family physician to use", I suggested. "I'm writing a paper on that … I'm writing a paper on the family physician's role in chronic pain", she said. "cause they just don't ask about anything like that", I said. "No, and I'm gonna do a little research to see how much, how the pay scale is, if they will tell me … I'm not sure if the college will tell me but I want to find out what the pay scale is versus like a ten minute visit … which seems to be standard", she said. "Right", I encouraged. "This would be probably take about a 20 minute visit", she continued. "Right", I agreed. "But if they could bill for the full 20 minutes per person … that's some information I need for the paper I'm writing", she finished. "Right", I said. "Because the primary physician has contact with the patient and their family", Gloria said. "Yeah and all the new literature is talking about getting at the disability", I noted. "And monitoring ", Gloria added. "And they say that's the aspect that's not, not assessed generally speaking" I added. "That's right and ah to have some structure and what is suggested too is that people could be on pain medication you know for their pain control … and then you have to you don't give people prn (as needed) pain medication on the whole … this is in the chronic area … you need to have structured visits and you need to be able to discuss activities of daily living … how that works for them um and you need to do it in conjunction with their chronic pain but you have to have a tool outside of just discussing the pain because just talking about the pain isn't always very beneficial for the patient cause they'll just focus on their pain and there isn't really any …. they can't see they're making any progress if they just talk about their pain", she explained. "just talk about it", I echoed. ".. I'm just coming to … the last page is it's borrowed from, it's the X symptom assessment system graph … um some of the doctors object to this a little bit because they say it's just used for, it actually was brought in for use in the palliative patient", she said. "I was just going to say I think I've seen that, something like that with palliative", I said. "But it's adapted … this one's adapted a little bit … so this is actually the tool that I use a great deal because we get to talk about the pain … the first question is about their pain and it's just a basic how is your pain, like rating it from 0 to 10 …so I limit it to the last 24 hours and all the rest of the symptoms I basically limit to the last 24 … but these are symptoms like general symptoms and I go through each one. Like we talk about their tiredness which in the chronic pain circumstance is usually very high … it will be the same type as the pain ... The nausea is, some of these are just straight symptoms, the nausea is we'll ask about that … and then depression anxiety … I find that if you ask the question people appreciate your interest … doesn't seem to be causing any labeling or anything like that. I think people just think that if you're interested you'll ask and they'll give you a fairly factual, fairly descriptive answer. And especially once they've been coming to the clinic a few times versus the first time they're a little bit ah removed from it, they're a little bit guarded. They don't understand the process, they think that I might be asking them questions and I might be snooping a bit too much", she explained. "Um hmm", I murmured. "And that was initially some of the doctor's concern about using this type of graph. But I find that as time has gone by they become more relaxed and they actually ask me to ask them the questions … which is interesting to me", Gloria said. "Um hmm", I agreed. "In most cases they will be quite prepared … no problem. So the depression and anxiety … I kind of like to personalize these ones for them a little bit for them so um so underneath the depression I'll say well maybe they're feeling angry is one word that comes up …so it allows them some individual expression, so I'll write it in there … and the same with anxiety .. I'll kind of try to individualize it if they want it individualized. Energy levels is an interesting one cause sometimes it varies a great deal from these two the top two … they will have some energy and the wellbeing I find to be very interesting … and I find with chronic pain people it gives me an idea of their life at home … their social life …some people will say that they have great wellbeing despite the fact that they have they're rating their pain very high .. and a lot of people will give me an idea of what they like to do and I think that's very important", she explained. "Well and it's quite possible because it's similar to um what we would have talked about in palliative care that you can you can be dying but you can still be well", I said. "That's right. You can still have", she started. "You can still have quality of life each day", I said. "and there can be something that you like to enjoy", she added. "Um hmm", I agreed. "Like I class this one as enjoyment in life", she said. "Um hmm", I said. "When I describe it to them I say well what are you able to find some enjoyment into your life? And ah try and individualize it to the individual… like some people, I mean if you had injured your foot in a sports related injury and you have a regional ah chronic regional sympathetic dystrophy where you get um change in that limb … you can't expect them to be going on enjoying sports anymore but for them to adapt to the chronic pain situation … I would say a lot of people .. I think the majority have some degree of enjoyment in their life. Some people a lot", she said. "Yeah", I agreed. "And then the other side of this is that when you get somebody that is black (describing himself or herself in very dark or negative terms) .. like if they are, if they have been fairly ah scoring fairly low on the scale, the lower the better, the higher the more severe their pain is … that's how I've been grading it", she explained. "Oh okay", I said. "If they are scoring very high on this sometimes they will do an intervention … they'll bring in a psychologist immediately … like he's available for people in the clinic so it is I think it's very useful", she pointed out, "And it's also useful for people to see that they are moving a little bit … there's some benefit". "Um hmm, right". "And the drowsiness is fairly descriptive like that's just there when taking pain medications usually", she said. "Right", I said. "And the constipation is also a symptom that needs to be treated .. and then under other I will ask them if there's any pain on that day that they're having consistently or actually I'm thinking about revising my graph a little bit and adding percentage of pain relief they're getting from their pain treatment", she finished. "Yeah now I'm thinking about that um … why percentage of pain relief … why did you choose that? Um over um I don't know I kind of wondered why you would look at that over the change in the disability? Or is it over it or is it in addition to it?" I asked. "In addition to it, cause I'm getting like on these questions I'm getting an idea of how the chronic pain situation is affecting their life. Like I am actually getting a picture when I'm talking to them about all of these different things. But the percentage of pain relief is an interesting question and the more I work with it the more interesting it becomes because when I ask people what their pain is, a lot of people, I would say a good percentage will say my pain is a 10 or my pain is an 11 or a 12 and I know underneath like ok you're already taking all these pain medications and you're telling that you're able to get out and go for walks and doing all this, so what's happening here?, she said. "Right", I said. "But, when I ask them their percentage of pain relief they're getting from their pain treatment, they will come up with a high rating, sometimes 60, 70, 80%. A few people will be at zero but that will be a rarity", she said. "Right", I agreed. "And I was talking with our clinical educator, she spent some time here, doing a paper too … she came every day for a few days and we were talking about that but I think what happens is that people, when they come to the .. you have to remember they're coming to the pain centre to have their prescriptions renewed and if they say that their pain is really low then they feel that they won't be, continue to be seen here in the clinic", she said. "Oh, okay", I said. "And if you ask about the percentage of pain relief, then they rate that as quite high, because that's a safe question", she explained, "But their degree of pain they are having is not a safe question, so they rate that very high. They rate tiredness very high, almost consistently". "Right. Well that's interesting", I said. "Yeah it is very interesting, I find that very interesting" Gloria said. "Yeah", I agreed. "So I quite like that question actually", she said. "Yeah cause that that tells me a lot about coming for help and some of the things that are involved in it … that there are safe things to talk about and non-safe things to talk about", I said. "That's right, yeah", she agreed. "So it gets at their vulnerability", I suggested. "Definitely because they are afraid of losing their pain identity or not necessarily their pain identity, I think that they're just afraid they're gonna lose that treatment. Somebody that wants to care for them", she said. "Oh yeah, yeah and especially if it's improved", I said. "Right", she said. "You know if they are getting relief", she started, "And they don't want to admit it, that it is better". "Yeah", I said. "To some degree … and for a lot of people, they will come in and they will try to reduce their pain medication … see they're given some options like when they get to a high level like when they're being treated with methadone … and they get to a very high level of methadone and they're still saying oh my pain is 12 out of 10, I think at some point they will be offered a choice of rotating to a different narcotic, for a short while or whatever and then if they're still coming back here or the other choice is to cut back, to start cutting back or to have a vacation to have a vacation from the narcotic … just so they know that they are getting pain relief", she explained. "Right, right", I said. "Cause if they've been taking the same narcotic for years and years they sort of feel that it's not helping any more" she started. "You don't really know", I added. "Right cause you've been taking the same drug and that's kind of some of the motivation too for the long acting narcotics", she continued. "Um hmm", I said. "That's kind of one of the principles of chronic pain is to have people on the long acting narcotics, not the short acting. Something to work toward", she explained. "Very, very hard to deal with your pain relief going up and down like this (showing up and down movement with hands) for a long time", I said. "So anyways I work a lot with this this um rating scale", Gloria said. "Oh I like that, I can see you've sort of pulled pieces from from different things like the McGill pain assessment tool and from the others that you see around. So it's a nice ah …and it's not too long", I said. "No it it actually takes me 5 minutes to go through it all … and I think it gives all our patients a feeling that somebody cares to ask", she said. "Um hmm and they're being seen as a whole person", I suggested. "That's right, yup", she agreed. "You know even the the picture, you're giving them the opportunity to put in pain that may not be their primary pain but pain that they're still having", I suggested. "Yeah it gives you more of an idea of the total pain", she said. "Of the total pain picture", I agreed. "That is affecting their lives and there can be interventions too if things are seemingly very black ... and sometimes people will do that very rapidly …they'll have a very rapid decline …and so some interventions need to be taken.

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The assessment document Gloria had put together and was using was quite comprehensive and provided some interesting opportunities for gathering data of
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potential areas of need. "A bit of pain history ...what they've tried in the past" and "how they're managing at home" help provide a baseline for where to start. To make it more comprehensive Gloria even had a double scale for capturing data on good and bad days if the patient chose to differentiate between them. I mentioned that this would be a great tool for family physicians and Gloria said she was writing a paper, as part of her work, on the family physician role in chronic pain and this kind of assessment tool was something she had in mind. She was researching the time allotted for physician visits. We discussed the difficulty of doing a holistic assessment in only 10 minutes (the usual time allotment) and Gloria proposed the need for a more structured approach with the use of an assessment tool, "That's right and ah to have some structure and what is suggested too is that people could be on pain medication you know for their pain control ... and then you have to you don't give people prn (as needed) pain medication on the whole ... this is in the chronic area ... you need to have structured visits and you need to be able to discuss activities of daily living ... how that works for them um and you need to do it in conjunction with their chronic pain but you have to have a tool outside of just discussing the pain because just talking about the pain isn't always very beneficial for the patient cause they'll just focus on their pain and there isn't really any .... they can't see they're making any progress if they just talk about their pain". The symptom assessment tool Gloria uses is an adaptation of one from palliative care and is therefore very comprehensive. More important from Gloria's and my perspective is the fact that this tool is holistic and focuses on quality of life. Quality of life is a major goal in both palliative care and in the area of chronic pain care. Gloria noted that while some patients might think, "I might be snooping a bit too much", at first, they soon get used to it and "as time has gone by they become more relaxed and they actually ask me to ask them the questions". Gloria noted that many of the questions need to be personalized to the individual, for example depression may be hiding an underlying feeling of anger and she has to find ways to bring this out as she uses the tool. She noted that other indicators such as wellbeing and energy help her see that her patients do have some quality of life despite reports of continued chronic pain.

Gloria noted that sometimes people rated their pain and other symptoms very severe and, "if they are scoring very high on this sometimes they will do an intervention

… they'll bring in a psychologist immediately". Gloria went on to say that her assessment graph really paints a picture of the life her patients are leading but in the area of pain itself she uses additional scores to get the full picture. Many patients continue to say, "my pain is a 10 or my pain is an 11 or a 12 and I know underneath like okay you're already taking all these pain medications and you're telling that you're able to get out and go for walks and doing all this, so what's happening here?" To try and find out she asks patients what is their percentage of pain relief and often finds this is rated quite high. Her conclusion is that "that's a safe question" but "their degree of pain they are having is not a safe question, so they rate that very high". The latter is tied to their medications and the former is not; the latter is tied to their vulnerability and the former is not. This raises many questions about what happens to the self as one gets better. Gloria wonders first if they are afraid of losing their pain identity and then revises this idea to fear of losing their treatment. I can see where this is a valid concern for one can have remissions in chronic pain and the patients would always have that fear of what do I do if the pain comes back. Chronic pain creates such an intense vulnerability in a person and I wonder if that ever goes away.

Some individuals will have to take a vacation from their medications to help them see that they are still benefiting from them or they may have to switch medications Gloria says when they continue to report high pain levels. In her experience however getting people onto long acting narcotics is very helpful in gaining better control over chronic pain. She noted it is, "Very, very hard to deal with your pain relief going up and down like this (showing up and down movement with hands) for a long time". The assessment tool she was using even included a picture of an adult human being on which the individual could mark areas where pain was being experienced. As she noted the assessment, which only takes about 5 minutes, "gives you more of an idea of the total pain". Gloria is very committed to evidence based practice and has adapted a variety of assessment tools to meet the needs of the situation in which she practices. She is also quite intuitive in assessing her patients and I wonder where in the tool is the place for these equally valuable impressions.

Suicidal Thoughts

"Do you find have you run across many people that were suicidal?" I asked.

"There's a few people that are just coming into the clinic, like initially, um hmm … yeah there are some people that are truly suicidal that have", Gloria started. "Or even suicidal ideation?" I added. "Yeah", she said. "You know not necessarily ready to do it but thinking sort of I'm not sure how I can make it through another day", I suggested. "Yup there's people like that. There is the .. doctors are very used to dealing with that kind of thought process and they'll often bring in a new kind of medication like Zyprexa on occasions or just something to give them a bit more quality of life. For some people they have very poor quality of life, they're very, they would they've kind of had their pain problems for many years … some are in wheelchairs … I think they actually look forward to their visit to the clinic", Gloria explained. "Um hmm", I encouraged. "Because somebody listens to them", she said. "Um hmm", I said. "So it gives them a chance to voice their problems and", she started. "Right, have their pain experience validated", I said. "Right cause I did learn that aspect from working in palliative care too cause so many people would skirt around the issue …. They wouldn't actually ask them how they felt and they just felt really a, just a relief to be able to discuss some of their major issues", she explained. "Oh sure, sure … like in palliative care being able to talk about maybe you're dying you know, to have it just an open topic", I agreed. "Right", she said. "That you could talk about any time and people aren't going to freak out or freeze up on you or skirt out the door as fast as they can and you know it makes it such a different place. It makes it a very positive place instead of the you know a dark pall over everything", I explained. "Where nobody will talk to them", Gloria added. "Yeah, yeah cause it's very isolating and I think pain is very isolating in the same way", I said. "A pain is, pain is cause that is one of the problems … like you were mentioning that the doctor told you that husbands don't like, well that's something that a chronic pain person has to live with and that's definitely one of the issues that's brought up in our life despite pain sessions is the fact that your family support people can get kind of worn down but on the other side that they need to be given recognition too that there is support for them as well. Like they need to seek out support. They need to understand sometimes … they need to seek out support", she stated. "Um hmm yeah, yeah and they need to understand this whole process as much ...like I find with my new husband I'm trying to talk to him about you know the inner details of my pain experience so he has a better understanding than my first husband ever did", I explained. "That's right", Gloria commented. "And fortunately Gordon is very sensitive and he just understands better ...but it is important that they know that you don't necessarily have a lot of control over", I said. "No, no ... it's just part of your being like you have green eyes or whatever", she added. "Yeah or one leg, or whatever. Well that's really interesting", I concluded.

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When asked, Gloria agreed that some people with chronic pain had suicidal ideas in that they wondered how they would ever go on with their pain while a few were actually suicidal. She said the doctors were familiar with dealing with this kind of thinking and would treat them with medications such as the antipsychotic drug Zyprexa. It did not seem from what she said that Gloria saw dealing with these kinds of thoughts to be a specific part of her counseling role. She did show her understanding of the poor quality of life that many people with chronic pain have and the importance of having someone to talk to, "For some people they have very poor quality of life, they're very, they would they've kind of had their pain problems for many years ... some are in wheelchairs ... I think they actually look forward to their visit to the clinic", Gloria explained. "Um hmm", I encouraged. "Because somebody listens to them", she said. "Um hmm", I said. "So it gives them a chance to voice their problems and", she started. "Right, have their pain experience validated", I said. "Right cause I did learn that aspect from working in palliative care too cause so many people would skirt around the issue". As we continued to talk about the importance of having someone listen, Gloria elaborated on the needs of support for caregivers as well. We agreed that one of the key issues in facilitating support for both patients and families was open communication and understanding of the chronic pain that, "you don't necessarily have a lot of control over" I said. "No, no ... it's just part of your being like you have green eyes or whatever", she added, "yeah or one leg or whatever". I wondered if we would ever reach a stage of such acceptance.
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Not Enough Time

"So I have a few things to bring up to what we talked about last time. Umm we had talked about severe migraines, the issue of suffering, and pain behaviours. I was wondering do you think that there's a medical acceptance of these in general?" I posed. "Um well I know in the workplace I know coworkers that do suffer from migraines and they do have the migraines ... there isn't always a lot of acceptance there because that person goes home and then everybody else has to work short handed so that is a problem, can be a problem ... and I think you were mentioning too that a bit of that dark mask does come over that person...and things aren't quite as much fun. The person's definitely not as much fun", she mused. "Not as much fun", I repeated. "Yeah, yeah. And I think too how our healthcare is set up, it's a bit disturbing too where we've gone to limiting doctor's visits to 10 minutes per person", she said. "Right, you're in and out pretty fast", I said. "That's right and if you have a chronic pain problem ... unless it's really planned properly the person can use up the whole 10 minutes just talking about their pain and then feel nobody's heard me because they've spent the whole 10 minutes describing how the pain is", she explained. "Yeah, I know I've, I've even booked extra time you know I'm going to need extra time and they've booked extra time for me and I've gone in and said ok I really need to talk about a number of things today and the doctor has said no not today ... I'm too busy", I said. "Ohh!" Gloria exclaimed. "And it's like well how do I get you for that time that I need ...you know he'll look at my list, cause I always bring a list, and he'll say ok we'll address this one and this one and this one. And it's like yeah but I'm not part of a person, I'm a whole person", I said. "I know", she agreed. "And all of these things are connected", I said. "Um hmm. This is some of the research I've been doing on family physicians, although there is some thought about maybe doing things on the internet ... like a little bit of internet liaison between the doctor and the patient where you can email the doctor and then you've got a list of questions and maybe you can take some of those off the list ... some of them can be answered on the internet, not everything, and then when you come to your chat with the doctor you could just focus on maybe two of the things that are outstanding" she suggested. "Right", I said. "But even doing this work doing the assessment scale too, I think if the doctors would take a bit more responsibility and actually drive the program … like there's a difference between putting band-aids on like your coming in … put a band-aid on …you're fixed, go home type of idea …. Instead of having that approach, if you could just have it the problems dealt with and what the literature was recommending was to have once a month visits for the patient to check in and say this is how I'm doing today", she explained. "Right because I find it's often the cumulative symptoms and what not that get to you that you know I can handle the headache with only so many things … and we have so many people that have comorbidity (more than one illness) today", I noted. "Yes", Gloria agreed. "And I have three chronic conditions and so if they're all acting up I can't handle the headaches …", I said. "Right", she agreed. "It's just way too much and so I, I need to be able to talk about the interaction of all the other things that are going on", I said. "Right, but if the doctor had some kind of plan, like some kind of symptom assessment scale he could take a look at that and show you", she started. "Right", I said, "and see you as a whole". "Yeah so you're more comfortable to put a little bit more comfort more boundaries on your visit", Gloria concluded. "You'd probably still have to pay for the time they'd go on the internet though", I suggested. "I'm not sure like it was something that in the States they've been doing and I don't know about here …but that would be interesting to find out. No you could pay … the average person would not mind paying I mean I don't think payment is an issue like in our country like in the States it is … they probably bill. Although I think the time here too maybe that would be more beneficial than the doctor going in and giving you a bottle of pills", she suggested. "Yeah", I agreed. "It is if you just paid for some for a chat with the doctor", she said. "Yeah cause sometimes you just need to have them say ok you're doing alright … I know you're going through a rough spot but you've had them before and you'll get through them … it's that sort of thing that you know … no you don't have a tumor, you're not suddenly dying or you know you worry about things getting missed", I said. "Yeah and utilizing the doctor's knowledge, just utilizing it … I mean maybe he could give you a paper

> from off of the internet or something that or some literature that he has access to and email it back to you and say read this. The other thing that they had mentioned is support groups and a referral to a psychologist that is specific to pain to dealing with pain. I know here our psychologist has a support group of people that he sees over and above his individual sessions … that he has a group that he sees on Mondays", Gloria explained. "Oh does he", I said. "and he cycles people through there which is a great idea", she said. "Now are they people that come to the clinic or are they just anybody?" I asked. "No they're referrals that he's received and sometimes what he'll do before he sees them … he won't have time to see them on an individual basis, but he'll have them come to the group history sessions and he goes over all the different ways of treating different situations and gives them sort of a format to use …and then if they still need his individual counseling, for some people they'll find …they just need to come and have their pain assessed ... but this is a specific program dealing with chronic pain", she explained. "Right", I said. "So I want to, before I finish this paper I want talk to him about how it could be implemented maybe in the community", she stated. "Yeah. Yeah there's definitely a need for a lot of that", I said.

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It is very difficult at times to separate my own feelings from what I write and this section in particular is very disturbing for it deals with disability and personal worth and entitlement within society despite disability. As I read Gloria's words about coworkers, "there isn't always a lot of acceptance there because that person goes home and then everybody else has to work short handed so that is a problem, can be a problem", I think well why would you not replace that person the way you would replace someone else who is ill? But, today there are fewer casual workers to fill in and in many workplaces no one is replaced for any reason. Does that mean an individual with a disability should not be hired. Then Gloria talks about working with someone with a migraine, "… and I think you were mentioning too that a bit of that dark mask does come over that person…and things aren't quite as much fun. The person's definitely not as much fun". Gloria was simply stating a fact but it made me wonder how many women with migraines like myself have asked themselves if they deserve to be allowed to work
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because they might miss work or they might have days when they are not quite up to par. I wonder how many like myself try harder to make up for what they perceive as a failure every time they miss a day or cannot keep the mask off.

Gloria sees an important role for family physicians in helping women with migraines in the community by having regular visits to monitor their conditions and help prevent migraines, not just treat them. She noted that , "it's a bit disturbing too where we've gone to limiting doctor's visits to 10 minutes per person", she said. "Right, you're in and out pretty fast", I said. "That's right and if you have a chronic pain problem ... unless it's really planned properly the person can use up the whole 10 minutes just talking about their pain and then feel nobody's heard me because they've spent the whole 10 minutes describing how the pain is". As we discussed the problem of not enough time, she mentioned possible solutions such as using the internet for some questions for one's physician. She also stated that, "if the doctor had some kind of plan, like some kind of symptom assessment scale he could take a look at that and show you", she started. "Right", I said, "and see you as a whole". "Yeah so you're more comfortable to put a little bit more comfort more boundaries on your visit". In other words, she felt the use of an assessment tool would help the doctor work more efficiently in a less time and the patient would be comfortable with that. Gloria also suggested the use of support groups run by psychologists in the community as another way of providing services to migraine patients. This service is currently available to clinic patients at the pain clinic in which Gloria works. I imagine all of these suggestions would help make the care of migraine patients more efficient and effective. I wonder though how the holistic nature of migraines is addressed if intervention comes from multiple programs. I wonder what Gloria would think of that. Is there a need for an overall integration of programs and a recognition that migraines are indeed a disability, albeit one that is virtually invisible most of the time.

A Walk Through the Clinic

Gloria had planned to do a collage for her creative representation project but ran out of time and so I suggested we take a walk through the clinic and she outline a typical day for me, "what your day is like and how you interact with patients and what you'd be thinking you know, just picture yourself perhaps taking a patient through". Gloria's day starts with gathering information on the patients for that day and this involves "spending a fair amount of time on the telephone". She writes up messages patients want brought to the attention of the doctors and add notes to the care plan map. She noted that many of these notes have to do with medications. Gloria then sets out the schedule of patients for the day on the computer. Approximately 20 patients are seen in a day. That sounded like a lot to me but she said that is based on 20 minutes per return patients and 40 minutes for new patients.

Gloria walked me through the clinic so I could see the physical layout. There is a small plain waiting room with 6 to 8 chairs on the left as you come in. Gloria's office is to the right of this area. She shares her office space with another staff member. The office is long and very narrow with 2 computers on a long desk plus several filing cabinets. There is little room to move about and I wondered how she managed in such a small space. Patients are greeted in the waiting room and Gloria finds out which doctor they are seeing. They then proceed to an examination room down the hall. These rooms are typical of examination rooms in doctor's offices with an examination table and several chairs. She noted that this is where she would do her assessment. Given the psychosocial focus of the clinic I expected a less medical look to the rooms.

We named our imaginary patient Frank. Gloria said, "I'd have Frank sit down and um, we'd have a little update about what's happened to him since his last visit". She noted that there "would be discussion of Frank's um, pain um, situation and what I do is I have a list of assessment questions um, I try to have him rate his pain on a scale of 1 to 10". She stressed that she liked to have "a fresh assessment every single time they come in". We talked about the fact that some people have pain in more than one area and it is hard to know which one to rate. Gloria said she usually asks, "Well, um, what is your worst pain in your body in the last 24 hours?" I wondered how she was capturing the effect of pain over time for this is one of the big issues in chronic pain. She went back to the assessment forms we had looked at earlier. Gloria said, "because I understand that pain is way more complex than just the patient telling me what their pain was in the last 24 hours, so I go through a bit of a, whole body assessment". She noted that by measuring other symptoms such as tiredness level, nausea, and depression she is able to get some depth to the measure of total pain experience. Gloria stated that, "people are a little bit daunted by the scale of 1 to 10, they don't seem to like that, particularly the older people seem to get boggled down by that. So I will have them go small, medium or large and then I kind of work it into the 10 points". The way all of the symptoms are recorded using a 1 to 10 point scale allows Gloria to create a graph of each patient's progress in each area. In this way she can see the change in symptoms over time.

One of the interesting points Gloria made was "I've noticed now that I've been here for a while, it's the fact that I actually teach the patients about talking about their pain, it is a good way to teach them to be able to talk about it. To look at it more than just what, how much pain you're having". She said that after patients have been coming for a while they start asking her to ask the questions. I noted that people with chronic pain get used to thinking that their pain is their little secret and Gloria agreed. It is a barrier that has to be breached before they can be helped. One thing Gloria said that was interesting is that, "I get a lot of additional information about um, say Frank, his life, what he's been doing, 'cause sometimes they'll volunteer information on you know, just random information that's very helpful. So then I'll quickly … put that on the patient's records".

Gloria talked about how, in her experience, wellbeing can be present despite the presence of pain and other noxious symptoms. "I try to um, steer away from um challenging them or anything, it's just a peer uh, question, like can you find something you like to do? And I make a few suggestions and, and often times, people that maybe will rate their pain at a ten, appear, and their target's at a ten, and their depression midrange, and their anxiety kind of maybe not that high, they'll be rating their wellbeing as actually quite a high level. They are actually able to find something they like to do". She noted she differentiates between tiredness and drowsiness because the latter can be medication related as can constipation. The final category of percentage of pain relief is quite useful, Gloria noted, especially with new patients when treatments are being started or altered.

"So", she said, "I've got Frank here and I've chatted with him and I've um, written down the information, anything that he tells me that I might pass on to the physician. Gloria tells me that no physical assessment is done other than general appearance, for example grooming, "'cause it's not really meeting the philosophy of the clinic … the clinic is, is more based on more of the psychological level … the more holistic , like how is this patient physically presenting". She said, "we're trying to stay away from us curing the patient, we want them the patient to be looking after themselves". Gloria did say that assessments such as vital signs would be done if a specific treatment was being done.

In looking at the assessment graph Gloria has noticed "a real pattern built up on the page, like I'll have um, for a patient that is very um, negative, for how they rate their scores in a very high range. And I mean, that's the patient's prerogative to say what they want, but I will notice even the high rangers will, an improvement for some people is bring their pain down from a ten to an eight". She also finds that while their pain may stay constant, other improvements in tiredness, depression, anxiety, energy levels, and wellbeing indicate an improvement in their overall condition and ability to function. Another thing Gloria has noticed is that patients that are on exercise programs for instance try harder to maintain a regular schedule of exercise when they are coming in to the clinic on a regular basis. Having to report seems to make a difference.

When it comes to assessing quality of life and disability Gloria noted "that my assessment after the patient can be way different than their assessment. Like some of the people that I would think that would be very, have a hard time having a fairly normal life, quality of life would not be good? They rate their quality as actually quite high". I wondered if as disability sets in individuals gradually realize they cannot set their goals at the same levels as before and they lower their expectations. Gloria suggested that "maybe taking a look at their pain is very valuable to the person, like, having had a chance to actually discuss it with someone". She said that "it's really good to, to get away from um, how they like to describe their pain and some people will go in um and talk about um, how sharp it was and the tingling and all that, like they really focus on that but looking at it this way is more holistic, how it's affecting their whole life like I find it's a little bit more um, productive for the patient". Gloria was quick to point out here that if there is a sudden worsening of the patient's condition, that immediate intervention is available. A change in condition might come in the form of depression and Gloria stated it was important to be open in her questions such as, "well, what is it (the pain) like for you?" Not only does this open the door for the patient to share but it helps to "build up the relationship between the nurse and the patient too".

New patients go through a very in-depth assessment process, first with Gloria and then with one of the physicians. A medical history and holistic health and social history provide a baseline database. Patients are given a physical and doctors review data that has come in with the referral. Gloria said that patients fill in their history as much as possible on their own in the waiting room initially and then she sits down with them for the rest. She gives them a card with a phone number and then they see the physician. Once the physician has processed the data, he or she devises a plan of treatment and presents it to the patient. Sometimes additional testing is scheduled if required. The patient is then followed either by the family physician or by the clinic physician. Occasionally there is some kind of treatment that can be offered to the patient but this is rare. Although the clinic takes a multidisciplinary approach in that a nurse, a psychologist, physiotherapist, and a psychiatrist can be involved, the physician draws up the care plan. The plan is very detailed and is sent out to the family physician. Gloria acts as the liaison person between the patient and the doctor at the clinic. If she feels a patient needs to be seen she can schedule an appointment for the patient to come into the clinic. She also noted that a fair number of patients just drop into the clinic and she will chat with them on these occasions. I thought this latter comment was quite telling. Although I did not find the esthetics of the clinic particularly appealing, it was a medical clinic like any other medical clinic, Gloria and the other staff create a milieu that must seem welcoming and safe for individuals feel they can drop in at any time. I do wonder why those running a clinic with a psychosocial focus would not see that removing the "medical look" of the place might help patients in changing their way of thinking about their chronic pain.

Live Despite Pain

Gloria told me about another program that she, the psychologist and one of the pain doctors have been running since 2005, called Live Despite Pain. It is an open ended support program for patients with chronic pain. Patients attend 3 one hour educational sessions over a 3 week period and then come in for assessment and goal setting. Following this they are seen roughly every 6 weeks for as long as they need. They are required to set goals for themselves for things they need to change and to work on these goals while in the program. The staff is there to provide support for them. Gloria said people could be in the program for years if it was of benefit to them. I really liked this idea and mentioned again how hard it had been for me when I had finished the in-patient pain clinic program I had attended. I was afraid to leave for there was nothing else to try at that time. Gloria said, "but going back to what you had said about being discharged from a program and our patients that leave here, there is some, yes, they probably would have some apprehension and I try, that's why I give them my card, the phone number, and encourage them to call. And if they call and they need an update or if they need to see the doctor again, they haven't had full cooperation from their family doctor, then, I will get them an appointment". She stated "it is open ended". I commented that I thought this was important and Gloria said, "Well I think that's the nice part about having a nurse involved in the program because the patient isn't just having a secretary. Nothing against them, you know, but sometimes they don't have the authority to say to the doctor, 'This person needs to come in and see you'... They don't have the training to do that. Uh, they might miss some little, you know, intricacies ... also I find what happens often too with our girls is that um, the patient will call in and all they need to do is talk. They just need to talk". Gloria noted that as a nurse she can address what's bothering them, do immediate counseling on the phone and they'll often say, "Oh, okay, I'm fine now. Bye, you know?" So Gloria saw this as a very positive element of the program. She noted it is very hard to do that with a physician. They just don't have time for you to come in and "Well I just need to share this with you". Gloria noted that it is this kind of service that she would like to see available in the community. "Often you just need to, somebody that will listen just, you just get it out there in the air and when you get it out there, it's not as scary. This brought our discussion back once more to the need for regular and longer appointments with family physicians, the use of long term narcotics if necessary for better pain control, and another part Gloria noted would be better liaison between family doctors and home care. Gloria stated that the literature supported regular visits every month or six weeks for patients with chronic pain. She noted that the College of Physicians listed physicians as responsible for front line psychological care so the mandate is there. I could not help but wonder how many problems could be eliminated or minimized if patients were seen on a regular basis and physicians and patients were more proactive with pain management.

Some Final Wonders

I asked Gloria with her years of experience what she thought about the acceptability of seeking help with pain and she said that she felt there was "no problem, on a physical level for pain, or for any problem that they have because they have something wrong with their bodies that is physically noticeable" but "when it becomes a chronic problem and that's one of the things we discussed was chronic pain to, um in our Live to, Live Despite Pain program is the fact that there is, seems to be a social stigma in our culture that um, its um does not encourage" the seeking of help. Gloria also mentioned the issue of addiction that is tied to the use of narcotics and the importance of independence in our society as other barriers to help. She wondered about the lack of acceptance of alternative therapies for treating chronic pain and noted that people "don't take time out of their lives to do any kind of spiritual care". These are things that can provide other ways of helping people with chronic pain. Another of our wonders was the whole issue of the ethics of leaving people in pain because of the fear of addiction and who should get to make this decision. These issues made me think of the role that patients need to play in doing everything they can to help themselves. Sometimes I know I just shut down, get very quiet and it is that mask that Gloria and I had talked about that creeps over me. I am not even aware of it. My husband is really good at reading me now and he has learned to come up and ask, "Do you have a headache dear, do you need a cup of coffee?" or you know, "Can I get you your magic bag for you?" and it makes me stop and realize that I have been talking in one word sentences and that I need to take some action before the headache gets too bad. This brings me back to the idea that migraine is a social disease and sometimes patients need help in identifying what is happening to them. I am not always aware when I have stopped being terribly social and have that "look" in my eyes that Gordon can see. I do wonder if we can teach these things to nurses and doctors for early intervention and diagnosis are such key issues in the treatment of migraines. Gloria noted that the big thing with migraines is the difficulty in communication and she agreed that learning to identify subtle changes in behavior and appearance would be helpful. I wonder how open nurses and doctors in Emergency rooms would be to this kind of assessment.

Gloria asked me if the reception would be the same if I went to my doctor's office with a migraine. I told her I would not go there because I need parenteral (injection) medication, due to the nausea and vomiting, and you can only get that at an Emergency room or out patient clinic. There is also the problem that pain medications do not work as well on a migraine, due to the very nature of the illness, and so other types of drugs are often given by an intravenous route. I told Gloria that one of the reasons for my interviewing nurses and women with severe migraines is that I want to get a more accurate picture out there of what a severe migraine is really like. I was telling her that my husband saw me with a bad migraine for the first time about a month ago and he was so shocked he kept telling people about it for the next couple of weeks. "Sharon had this migraine the other day, he said, "I couldn't believe it. She was practically unconscious!" That description even surprised me and yet I realized that it was a very good description of how shut down I was. It is not surprising that a person in this non-communicative state is difficult and not pleasant to deal with in an Emergency room. Gloria noted that the Emergency room was a difficult place for migraine patients. I agreed and I feel for the nurses who have to try and triage those of us who come for help but I wonder if they know how much many of us fear how they will treat us.

Chapter VIII Ellen's Stories

Ellen is the wife of a psychologist friend. I had not met her before and when my friend said that she was interested in participating in the study I was thrilled for I was having great difficulty finding nurses for the study. I knew this woman had considerable experience in Emergency room and critical care nursing although she now works in the area of diagnostic nursing. She told me she used to work mainly nights in Emergency so she could sleep while her children were at school. While there is no prime time for people to come in with migraines, Ellen did say that many women came in with migraines at night so this meant she had had a lot of experience in caring for women with migraines.

The first thing that struck me was Ellen's genuine smile and dark eyes that seemed to miss nothing. Petite in stature with short dark hair and long bangs, she is of Chinese heritage. We decided to meet at her house for our conversations. Her home was warm and inviting. At our first meeting, Ellen moved swiftly around the room getting us settled with a cold drink, then settled on the end of the sofa. She was relaxed and focused on our conversation as quickly as she had been physically active. It was a change I would see her make often over the course of our talks. I thought what a great quality that was to have as a nurse, to be able to go so rapidly from activity to instant focus and active listening. As we reviewed the purpose of the study before I turned the tape recorder on, Ellen immediately appeared to agree that there was a need for the study and indicated that there could be problems in seeking help with migraines.

There's a Woman with a Migraine

> "Until last year, um, I was in Emergency um, I have looked after a lot of women, and men, um, but a lot of women, surprisingly, that have mig, severe migraines", Ellen stated. "Um hmm, okay. Um, so that's really the area where you come into contact with them", I inquired. "Yeah", she responded. "So, tell me what, just in general, tell me what that experience was like for you", I suggested. "Well, there's no, no time of the day that you would see someone coming with a migraine. Um, if they come in with a migraine, I have not, as I say I have not seen men with migraines very much at all but I have been with lots of women that have migraines, that's, to me there's more women than men that have trouble with

migraines", Ellen explained. "Oh, a lot more", I agreed. "I've had a lot more and so um, you could, you could tell when they come into the Emergency Department uh, they're very distressed, um, some that wear big black sunglasses um, they, they can't walk very well, they're uh, some of them will have, they wear hooded, uh hoodies, they call it, just to cover up most of the head", she described. "Right", I encouraged. "Because of sunlight, um, because they couldn't really walk straight and they would be like hunching over and, or putting their whole, like, both hands covering their face, they, they can't handle the light. Because Emergency is very bright, you walk in and it's bright…they need dark glasses", she said. "That's very true", I agreed. "And so you see those and you know. Immediately you know there's a migraine woman or there's a woman with severe migraine headache coming in. And, and so you don't let them walk any further, you offer a wheelchair, just as they're walking in, and you don't have them just dragging their feet and putting their head down and um, in both hands and that tells you that, you know, that person has, is having a severe headache. So we get, we usually like, what I did is I usually put them in a wheelchair, if they can not walk very far, and then I quickly, I quickly triage them, cause they couldn't talk a lot but they might be bringing up, if they talk too much and that comes with the nausea and vomiting", she explained. "Right", I said. "So there's that photophobia there, nausea and vomiting and they couldn't see you very well because they can't see, you know, with the light and all that. And you often ask the person next to them, their information, and if they could tell you some, then you put that down too. Then you wanted to take them as quick out of the light as possible um, if we have a room", she said. "Right", I encouraged. "If we don't and you want to put them in a corner where, you know, you want to put a whole sheet, you know bed sheet on them, that way they don't see the brightness of the Emerg department", she started. "I know I've had a towel thrown over my face, anything, you know, to block it out", I added. "Yeah, yeah. And if you do have a room that's great but you take them in there, turn off all the lights, pull the curtains, shut the door. And, and then you go in there now, do an assessment um, they, they would rather to not lay flat. They might, well, bring up, so you sort of put them on a little, you know, sitting up position and then you pick up a little "k" basin and put it right beside them because they might just bring up on you, you know?" She continued. "Um hmm", I murmured. "It's one of those things; you anticipate things like that when you look after a severe migraine patient. So you, write in the dark", she concluded. And they would tell you, if you don't turn off the light, they'll tell you to turn off the light. And then you start to assess their symptoms. Make sure, you know, um, uncover all the, you know, the blood pressure and the symptoms and you know, how long have you had it um, how severe it is and you give them a scale of zero to ten to describe their, the pain scale. Then what, when you give the meds, you can assess the scale again, if, you know, is it five or six or is it two now? You know, before you discharge them", she explained. "Yeah", I said. "So you're not, you know, you ask them how long they had migraine, whether, you know, had they had this before, um, if so, how long they had the migraine for. I mean our Emergency department; we keep cards for migraine patients. You go and if they've had migraine before, they have, have you been to the department before? They'll tell us that yes, I have been here before and this is how long I had migraine before. You go in and find the little name in the migraine card box…" she said. "Really!" I said, surprised. "You take it out and you look at when was the last time they came in and what medications that helped them. Yeah, like that helped lots", Ellen explained. "Now I had never heard of that being done", I said. "Yeah, that is a, that is a wonderful thing to have" she said. "And I've been in to the K. with a migraine, so perhaps I'm in there, I suggested. "And I'm sure you were and then so you pick up the card and stick it with the assessment and the form and you hand that the pat, uh, to the doctor. And then the doctor will say, well the patient's been here before, the last time we treated her, this is what we gave her, so now lets do the same thing, see what happens. So then, you speed up your, your pain relief…" she explained. "Oh yeah", I agreed. "…pain relief, like if they've gone back and did it work? So this card will have the name on it, and all the time they came, and who saw them, like which doctor saw them…and, and what medication they had. Not, not a lot about the symptom and all that, but just what medication helped

> them. Yeah, and if you've been in to me more than once, your name is in there. You would have a migraine card, yes. And then, you know", she concluded. "That's a really good idea, great idea", I said, so you can track them". "Well it, it sounds to me like it shows that um, the staff accept the fact that women will be in again", I suggested. "Oh yes", Ellen agreed. "And that there's nothing wrong with that", I proposed. "Um hmm, no", she said. "That's an expectation of the disease, you know, that people understand that this happens and it's not that you're coming in for the drugs or for the attention or…" I stopped.

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As I listened to Ellen talk, I thought, here is a woman who really recognizes a person with a migraine when she sees one. She described women coming into the hospital, "some that wear big black sunglasses um, they, they can't walk very well, they're uh, some of them will have, they wear hooded, uh hoodies, they call it, just to cover up most of the head", she described. "Right", I encouraged. "Because of sunlight, um, because they couldn't really walk straight and they would be like hunching over and, or putting their whole, like, both hands covering their face, they, they can't handle the light". From my own experience, it is incredibly difficult to tolerate light and this makes it very hard to see so sunglasses are a must. Ellen's description of women being hunched over captures the way the pain bows a migraine sufferer down. In bed, the individual can curl up in a ball but while walking the best he/she can do is put his/her head down to accommodate the tremendous weight of the pain that presses the head down. I was impressed when Ellen talked of noticing the difficulty women with migraines have walking. "And, and so you don't let them walk any further, you offer a wheelchair, just as they're walking in, and you don't have them just dragging their feet and putting their head down and um, in both hands and that tells you that, you know, that person has, is having a severe headache". Ellen understood how difficult it is to navigate alone in the throes of a severe migraine. That simple gesture would have been so welcoming to me as a woman coming in with a migraine. Ellen continued to describe the assessment process. "I quickly triage them, cause they couldn't talk a lot but they might bring up, if they talk too much and that comes with the nausea and vomiting", she explained. "Right", I said. "So there's that photophobia there, of nausea and vomiting and they couldn't see you
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very well because they can't see, you know, with the light and all that. And you often ask the person next to them, their information, and if they could tell you some, then you put that down too". I could certainly relate to this. I always came into Emergency with two grocery bags put together just in case I would be sick and I tried not to talk for fear of being sick again. My husband always gave the triage nurse my information and signed the consent form for me for I could hardly think or move at these times. Ellen continued to tell me how she would settle her patients in a slightly upright position and provide a "k" basin to handle the nausea and vomiting that are a constant problem, turn down the lights, and then take a history of the migraine and assess the pain. She used a pain scale of zero to ten to help patients relate the severity of their pain. This scale allowed her to assess improvement after treatment as well. "You give them a scale of zero to ten to describe their, the pain scale. Then what, when you give the meds, you can assess the scale again, if, you know, is it five or six or is it two now? You know, before you discharge them", she explained" I was impressed with the approach Ellen took in caring for migraine patients for not only did she recognize them before they identified their problem, she anticipated their needs and provided for their comfort without being asked. The account she gave me was a very storied one and I could picture that woman coming in with big sunglasses and a hood over her head, hunched over and having difficulty walking. In my mind, I watched Ellen quickly meet her with a wheelchair, help her through the triage process, and then settle her in a stretcher in a section of the Emergency room. I felt the gentleness of the assessment process and the anticipation of needs as lights were dimmed, a basin was supplied, and the stretcher was raised. As I listened to Ellen talk, I found that I was that woman and for once, I felt safe in that small partitioned area.

We continued to talk about how the particular hospital where Ellen worked, handled migraine patients. Ellen explained that a card was kept in a book on all regular migraine patients, containing information on past treatment. "So this card will have the name on it, and all the time they came, and who saw them, like which doctor saw them...and, and what medication they had. Not, not a lot about the symptom and all that, but just what medication helped them". What struck me as particularly remarkable, aside from the practicality of this, was the fact that this practice was based on the understanding that migraines are chronic and it was normal to see women coming in from time to time for help. This may indicate a milieu where fewer stigmas are attached to seeking help. Ellen also mentioned that several other hospitals used the card system and this allowed staff to identify the odd person who misused the system to obtain drugs for purposes other than pain relief. "We have to call the department or call the P. Hospital, the Emerg department, um, and ask if they've (some individual) been running around the whole evening finding drugs to do something other than migraines, they can fake it. And if they fake it too much, we'll find them out too". This was the first time I had heard of a card system for helping migraine patients and I was left wondering how common it is today in other areas.

Faking It for the Drugs

> "So how do you, what sorts of things make you suspect that somebody is after the drugs?" I asked. "Um, well they fake it really well, uh, the one thing we look at is, is um, how, how frequent they, they come. Like if they, they've been there last night, they were there tonight and the night after, then, then, they could be having really severe headaches and migraines and they're coming back. The other thing is then you start to think, now, this is the third time you've come in, and I would like to check the other hospital and see if they have you at the other hospital. That is totally experience like, you're an experienced nurse, you have a lot of migraines come in the door and you have, you kind of have this little thing in the back of your head and you just wanted to check. So you can call the P. Hospital, you call the A, you might even call the X.Y., if this person has gone there, or two, and sometimes it, it is true that they'd be looking for drugs and they have been going through the hospitals. They might have three times, gone that night through the A. to the P and now to here", she explained. "Really", I said. "And then they have gone through again three times and this is the third night. Or this would be like the first round they have been doing and they come in and they say, yeah my migraine came back and they'll say, you know, and they give you the, they do it so well, they can fake it so well, and it's the first night...", Ellen explained. "Do they even look the same?" I asked. " Well, they look the same from night to night but um, they, they could fake really well, some of them", she answered. "I know

that when I have a migraine, and I can usually, ‘cause I know my own so well, I can see it before anybody else. It’s, your eyes get a different look”, I said. “Um hmm, she murmured. “You know, they’re either glassy or they’re very flat or you just, I, I know, I’m trying to hide it from my Mum and she always knew. You know she would take one look at me and say, ‘You’ve got a headache’. You know, I would be plastering a smile on my face, but my eyes never lied”, I explained. “That’s why they wear dark sunglasses. And they won’t take them off because they will die. And you see them like, when they are genuinely having a headache, having a migraine, like you were, but some of them, like the one, one time we caught this one lady, she wore big black glasses like covered an entire front, like one third of her face was covered with glasses, I caught her ‘cause she was there for like third time and, and we, like once you have a migraine card then you know, we can do that”, Ellen stated. “Right”, I agreed. “And she must be desperate or something that night, but she came around third time, and we go, “You know what, we know this is, you know, this is a patient that we have, because she came before but, third night now” and we don’t see too many returns third night in a row, we might, but on the whole, we have seen, like maybe the second night before, then the afternoon perhaps, but that’s it, we don’t see them anymore. But, third night now and, and we thought, do you think she’s faking this? You think she’s at the other hospitals and we start talking amongst each other, and to the doctors to check. And sure enough she had gone to the other hospital, she’d gone yesterday, this was her third round to get the meds, to get the drugs”, she said. “So I wonder if these people actually have migraines”, I stated. “Yeah, so do I, at all”, she agreed, “or they might, you know, be hooked on like, Demerol or Morphine, that, that they’re doing the rounds? And, and really you cannot go and confront them either, but you cannot go on, and you just talk to the doctor and the doctor will say that um, we have, I know you have gone to more than one hospital too much now, giving you too much medication. And it’s not even safe for you to have that much and we know that you have a headache and we know that you need that, you know, I’m really sorry, this is like too much medication. And you know, even, even though they have lied, to go home. They,

> they, a person coming with migraine, if they came in by taxi or by whatever, we have to make sure that after we give them the medication, that they have a ride home. Not a taxi ride home, but a ride home with a friend or a relative or whoever that they would, you know, get someone to come pick them up and take them home", she explained. "So that's a policy that you would try and, and get someone", I said.

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One of the issues that migraine patients face when coming into an Emergency room is an inflated concern about addiction on the part of families and staff. While narcotics continue to be used to treat migraines, many other non-addictive medications are now given intravenously to treat migraines. Despite these alternative treatments and the fact that the literature shows that the risk of addiction is very low, the worry about addiction persists. The fear of addiction is an old storyline and older nurses will tell you about learning about the significant risks of addiction many many years ago in nursing school. It is so much a part of the landscape of healthcare amenities that its validity is not questioned. It is also embedded in the stories passed down by generations of people who use the healthcare system and their fears feed into the established norms of healthcare. The result is that migraine patients are seen as potentially there for the drugs rather than for treatment. The stigma of addiction readily attaches to migraine patients and presents as a potential barrier that may keep patients from seeking help at Emergency rooms. Migraine patients know that this storyline lives on the landscape and they worry that they will be seen as characters in that story.

Ellen told me a bit about patients who faked migraines to obtain drugs. I asked her how they identified them. "Um, well they fake it really well, uh, the one thing we look at is, is um, how, how frequent they, they come. Like if they, they've been there last night, they were there tonight and the night after, then, then, they could be having really severe headaches and migraines and they're coming back. The other thing is then you start to think, now, this is the third time you've come in, and I would like to check the other hospital and see if they have you at the other hospital. I mean total experience like, you're an experienced nurse, you have a lot of migraines come in the door and you have, you kind of have this little thing in the back of your head and you just wanted to check".

I found it interesting to think about people coming back so many times for migraines. In thinking about my own experiences, I have only had to come back two or three times in the 50 plus years I have had them because I do not go home until I am sure my headache is under control. The trip to the hospital is so draining that the thought of facing another one is too much and so I make sure I am better before I go home. I simply insist they keep me until my headache is well in hand. Individuals so in need of drugs that they have to resort to faking an illness to get them have a different story to tell and unfortunately, there seems to be no place in the storied landscape of healthcare for them. If migraine patients are painted with the same brush strokes, they too may find the landscape harsh and unwelcoming. Ellen said only a small percent of individuals fake migraines to get drugs. I wonder how many nurses are aware of the storied tragedy that plays out in Emergency rooms like the one where Ellen worked when known statistics are skewed and applied incorrectly on a population that is seeking treatment, not drugs.

Designated Driver

> "Cause I know I've, I've been in at times when I, I, my husband was out of town or something and I've had to come in by taxi. "Yeah", Ellen said. "And dragging two little children with me", I added. "I often ask a volunteer to come and, and entertain children that, that came with migraine women, 'cause you know they have to go to town, they got migraine, kids home, they have nobody to help them. Uh, family's not around, so they came in and like, after the medication, you have to call someone to come take you home. That is one of the policies, for us to give you the medication, you need a ride home", Ellen explained. "That's really a good idea. I know I got sent home once at about three o'clock in the morning in a taxi… without my husband knowing that I was coming. You know, I said to them all, don't wake him up, you know, I'll just go home. And I, I think back now, as, as a nurse, and think, I would no more let a woman that, who was medicated, to go home in a, to go home in the middle of the night…with nobody knowing she's coming. It's scary to think of that and I mean, anything could happen", I said. "Yeah, because the, the cab driver is not supposed to be responsible for any of your, your medical care, like, any of your physical care", Ellen stated. "Well sure, yeah", I said. "If you collapse in his car and he wouldn't be charged for not

> taking care of you. And he could dump you anywhere and nobody would know, you know?" she continued. "That's right", I agreed. "And so it's the hospital policy if you give any sedation, any medication like Morphine, Demerol, things like that to anybody, we have to have a ride home, with like, a relative. So if they don't have anybody to take them home, they can spend the night in the hospital", she said. "That's really sensible", I said. "Right", she concurred. "Yeah", I agreed. "We'll put them in a hallway if we don't have a bed, then they can sleep and, or maybe not, until the morning and the medication wears off", Ellen explained. "Like six to eight hours, then they can take the bus, take the cab, whatever they like, but they are, they're ready to look after themselves".

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This was an interesting part of our conversation for it addressed an area of vulnerability easily overlooked. Help is readily available to women with migraines if they can get to a hospital but getting there often involves finding someone to care for children, getting a relative or neighbour to drive, or a taxi. This is a lot of planning and organization for someone who is very disabled by symptoms such as nausea, vomiting, and extreme pain. Ellen spoke of asking "a volunteer to come and, and entertain children that, that came with migraine women". Just as important is the question of how one gets home. We talked about the policy at her hospital that anyone medicated with a narcotic must have a family member take them home. I told her about being sent home by taxi one night at three in the morning with my family not knowing I was coming. I had told the staff not to bother my husband but on the other hand, I had a lot of medication in my system and it would have been quite understandable to question my judgment. I certainly questioned it when I arrived home. We lived in a new subdivision and our house was well away from other homes and there were no streetlights and no lights on outside our house. It was a dark, cold night and I shivered as I stumbled up our long driveway. My head was fuzzy and I fumbled as I tried to find the right key and unlock the door. I felt more than a little fear until I was inside and the door locked again. I was very unsteady on my feet from the medication and really needed help getting ready for bed but tried to move quietly so as not to disturb my sleeping husband. The next day with my head clear of medications, I recognized how vulnerable I had been.
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It was obvious from the policy Ellen had outlined that the hospital had given thought to just such situations and recognized that family members are not always available to take patients home. It is when policies are developed from the storied experiences of patients that family centered care really becomes a reality.

Assessment and Treatment

"Now, uh, I haven't had, well other than after surgery, I, 'cause anesthetics give me a migraine, but I haven't had a narcotic for migraines for years", I explained. "Wow", Ellen exclaimed. "Because they, they treat them with other medications", I added. "Um hmm. The preventive ones", she acknowledged. "So um, what's your experience in, in the last while, when you were working in Emergency, were you still giving a lot of narcotics?" I asked. "Um, we try the fluids, um, we try fluids first, because some women are dehydrated. And, and there was actually a study, if you give them 500 cc's of saline over say half an hour, um, you give it to them and see if they get better. And then, and I remember when there was a study on that oh, I can't remember how long ago now, and everybody that comes in, we started an intravenous", Ellen explained. "Oh yes, I always got an intravenous", I agreed. "Yeah. So then you're, you hydrate yourself and see if that will get better and, and if they do, then you can go home and take the migraine medication, she said. "Um hmm", I murmured. "Instead of, you know, zapping them with narcotics", she added. "Right. Did you use oxygen therapy?" I asked. "Um, no, not a lot. Now, it could be different now, just, you know, they…" she started. "No, that's something that they used to use a lot on me", I said. "Oh, and it worked?" she asked. "It helped", I answered. "Um hmm!" she said. "Yeah, just one more thing that helped", I added. "No I never thought of that ... that would be a good idea, so you do that with chest pain patients. When, when they come in, use oxygen would help", she said. "Yeah, I find if I go in with a migraine, I'm usually hyperventilating, you know what I mean?" I asked. "Yeah, yeah. Or they don't breathe, they hold it up", she said. "Yeah, you don't tend to breathe right", I agreed. "Yeah, yeah", she said. "Now would you do a neurological assessment or do you leave that to the doctor?" I asked. "Well we, we do, we do the checking, checking of the, well, it depends on how much time we have, how busy it is. If uh, the area, how familiar we are with the patient", she answered. "Right", I said. "Uh, we could assess by their symptoms. Like um, are you photophobia, are you uh nausea, vomiting, uh, where is your pain, like front or back, um, are you able to walk a straight line or are you able to walk with proper balancing. You could uh, um, usually we don't, we don't do their pupil check uh, we often ask them if they have any numbness. Um, sometimes they're really, like, you can sort of feel out the patient when you talk with them and if it's necessary, you ask them if they, they could squeeze a hand. They should be equal. But if they're walking in, you know they could walk. Um, if they're sitting in a wheelchair, or they cannot walk uh, you would assess if they got strength in their legs. Then they, then it would be the doctor's turn to do all the other stuff", she finished. "Right" I said. "But we don't, we don't do the entire, neuro, check", she explained. "You find the doctors do it very much?" I asked. "Um, if the doctor knew the patient well, they'd, they'd pick up on it. Like if the patient has been in and is known, and he's looking at the card and there's many, many dates on it, like they don't bother", she said. "Right", I agreed. "But if this is a new patient, like I've never had this patient before, like it's the first time they had severe headache with all the symptoms of a migraine, he would do a check", she asserted. "Okay", I said. "And then it depends how, how cooperative the patient is when doing the check. Like they couldn't sit up very well, they couldn't see very well, they couldn't, you know, ... Yeah, it's very hard. I mean, they're so involved with their pain um, like uh, they're struggling with pain, and they couldn't really follow what you're saying. "Yeah... you really can't think straight", I suggested. "...they really can't get the right words out" she continued. "Yeah, and some of them are bringing up too, and you know, you don't, you just, you know, you get some Gravol, you get them some Morphine or Demerol and settle them down first and see what happens", she stated. "Um hmm", I murmured. "And, and with the first migraine, a lot of doctors will do a CT scan of the head", she said. "Oh would they?" I questioned. "Just to get, like there's a lot more now than before", Ellen stated. "Right", I said. "Because you're, you've never had it before, you came in with all the symptoms, just to

> slow things a little bit…they would do a CT scan. There's a lot more head CT scans now with headaches", she said.

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I was interested in Ellen's experience of how migraine patients were assessed and treated on a usual basis. I asked Ellen if her experience included giving narcotics and she said one of the things they tried first was fluids, "Um, we try the fluids, um, we try fluids first, because some women are dehydrated. And, and there was actually a study, if you give them 500 cc's of saline over say half an hour, um, you give it to them and see if they get better". This hospital was obviously using both experience and research in the development of treatment policies. Dehydration is a huge problem because of the nausea and vomiting and I could relate to the need for fluids. Ellen continued about the benefits of hydration, "So then you're, you hydrate yourself and see if that will get better and, and if they do, then you can go home and take the migraine medication, she said". It seemed the goal was to be able to avoid taking really potentially addictive medications such as strong narcotics and to help patients use their regular medications. I mentioned that I had been given non-narcotic medications intravenously for many years and had not had narcotics except following surgery. She seemed surprised at this so I assumed narcotics were still used where she worked. It may be that narcotics are still used for moderate migraines. I have a history of very severe migraines and for me narcotics are not very effective and in my experience in hospitals in a number of different cities around the country, other kinds of medications have been the norm for me. We also talked about the use of oxygen therapy. Ellen said this was not common. I had found this helpful in the past because, "I find if I go in with a migraine, I'm usually hyperventilating, you know what I mean?" I asked. "Yeah, yeah. Or they don't breathe, they hold it up", she said. "Yeah, you don't tend to breathe right", I agreed. "Yeah, yeah", she said". I have always found the use of oxygen therapy helpful but it is not routinely offered in many hospitals and I often have to ask for it. I have not seen it mentioned much in the literature either so perhaps there has not been much research done on the usefulness of oxygen therapy with migraines. It was not offered to me when I was in the hospital where Ellen works so I was not surprised that she did not find this common.

We then went on to discuss assessment, in particular neurological assessment
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since migraine is a neurological disorder. Ellen described some of the basic things they assessed. “Uh, we could assess by their symptoms. Like um, are you photophobia, are you uh nausea, vomiting, uh, where is your pain, like front or back, um, are you able to walk a straight line or are you able to walk with proper balancing. You could uh, um, usually we don’t, we don’t do their pupil check uh, we often ask them if they have any numbness”. These same symptoms however make it difficult to do more in depth assessments, “And then it depends how, how cooperative the patient is when doing the check. Like they couldn’t sit up very well, they couldn’t see very well, they couldn’t, you know, ... Yeah, it’s very hard. I mean, they’re so involved with their pain um, like uh, they’re struggling with pain, and they couldn’t really follow what you’re saying”. She said that some, “...are bringing up too, and you know, you don’t, you just, you know, you get some Gravol, you get them some Morphine or Demerol and settle them down first and see what happens”. Ellen noted that for first time migraine patients more doctors are doing CT scans. It seemed that assessments were done with a team approach, with nurses doing part and physicians doing part and all of it depending on the patient’s condition and ability to cooperate.

Why Can’t You Walk?

> Ellen provided some insight into a common problem seen with migraine patients. “Um hmm. Yeah. I find it really interesting that you, you have noticed uh, the difficulty walking”, I said to Ellen. “Um hmm. Oh yeah”, laughing. “Because I know from my own experience, I’ve had a lot of nurses who just didn’t seem to get that. They would traipse off down the hall and say, ‘Follow me’ and I’m going along, hanging on and I...” I said. “I know!” Ellen agreed. “...can’t figure out how she got so far so fast. It’s like, I really need you to hold me up or I’m gonna fall down. And you know, I can remember, one migraine I had where, my husband and my son, actually had to both, you know, hold me up”, I added. “Oh yeah.” Ellen agreed. “And practically carried me out. I just couldn’t walk and I remember my son saying, “Mum, why can’t you walk, you’ve got a headache”, you know. And I said, ‘Yeah, I don’t know, I just can’t walk’”. “That’s right. It affects your balance, and when you’re nauseated, you just, and you’ve got this pounding thing, your vision is affected and you feel nauseated. You can’t walk

> very well" Ellen explained. "No, no. Now that's, that's something that I don't think in any of the literature, uh, I have ever seen that. As a sign or symptom", I noted. "But when you talk, when you think about the balance gone, like they can't balance very well, they're off...I've, I mean, I'll often ask them, 'Can you walk, can you balance?' And some of them would say, 'Not very well' and then because when you're balance is off, you can't walk, you can't walk very well", she finished. "Yeah, um hmm. But I think it's something that we, I think there are areas of assessment that in really, many institutions we don't do a good job of", I suggested. "Um hmm", Ellen murmured. "And that's one thing, because it's not in the textbooks", I said. No, it's all to describe the head, like the visual part, the nausea part, the aura, and all the vision and all that, but when you think about all these disturbances, do you think the person can walk?" Ellen asked. "Yeah", I agreed. "They can't walk. They can't walk very well", she said. "You're being, in your assessment, you're taking a separate, you're thinking through", I started. "Yeah. Cause when you see them coming in, they wear dark sunglasses, and they've got this thing over their head, should they be able to walk very well? I don't even want to walk if I get a headache, let alone a migraine!" she concluded.

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Migraine is a total body experience and symptoms affect many body systems. In this story Ellen and I were talking about walking, something we take for granted and something most of us would not think of when it comes to a headache. Difficulty with balance and trouble walking are not diagnostic criteria for migraine but they can add to the difficulty of obtaining help. As Ellen noted, "No, it's all to describe the head, like the visual part, the nausea part, the aura, and all the vision and all that, but when you think about all these disturbances, do you think the person can walk?" While cases where a woman cannot walk at all are probably rare, even being a bit off balance can affect the process of preparing to seek help as women see to children or finish up work and arrange for transportation. Thinking about the ability to walk was a normal part of assessment for Ellen, "Cause when you see them coming in, they wear dark sunglasses, and they've got this thing over their head, should they be able to walk very well? I don't even want to
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walk if I get a headache, let alone a migraine!"

Why Aren't You Going to the Hospital?

"So, what percentage would you think, did you run across where drugs are the issue?" I asked. "Very little", Ellen replied. "Very little", I repeated. "Very, very little, like I would say once in a blue moon. That little, that we would discover that it's a drug thing", Ellen responded. "Because of, it's something that comes up in the literature a lot, a tremendous fear of addiction, amongst nurses. And of physicians as well. And you would think it would, you know, like half of the people coming in were coming for drugs", I suggested". "Um hmm", she agreed. "Because it's talked about so much. And because there's so much stigma attached to coming in, I mean I've been accused of being addicted to drugs that I didn't even normally take, that the doctor gave me. Um, when I've asked for a second shot", I said. "Um hmm, she encouraged. "Now I had one doctor say to me once, he said 'You're addicted to Demerol'. And he had talked me into having Demerol, 'cause I never took that. It didn't, it didn't work well for me, it got me sick, you know, but it was what he was used to giving, so he wanted to give it", I explained. "Oh!" Ellen exclaimed. "And so, after three hours ... Demerol only lasts three hours, I still had the headache. And he looked at me and he said, "You're addicted!" And he said, "You know, better people than you have been addicted to Demerol", I recounted. "Oh, I wouldn't come to see him any more!" Ellen said. "I mean he didn't know me, he had never seen me before. I was just horrified, you know...You know, how dare you do that to me? How dare you judge me like that? You know, what do you base it on? And then, he said, and then he went ahead and said, 'Okay, we'll admit you' and wrote orders not to give me any drugs", I explained. "Oh hoh! Well now, that's not a good assessment at all! Ellen exclaimed. "And it took me half the night to another nurse, to get the nurse to get another doctor in. So...and he immediately medicated me", I continued. The next morning, seven o'clock in the morning, my own doctor was there, apologizing up and down for what had happened", I finished. "Yeah, yeah", she said. "I mean, that was just a horrible experience and I felt that, that was years ago and it stayed with me", I said. "Um hmm. Oh yes", she agreed. "Those are serious, it really affects whether or not you will go to the hospital. I will do anything to avoid going to the hospital. Now what you're telling me about the A and how you handle things there, and I, I was treated very well there, when I was there. Um, if I knew that was how things were handled, it would make it much easier for me to go in. I would go in sooner", I concluded. "Um hmm, um hmm", she said. Instead of going in when I'm at death's door", I said. "Well yeah, yeah", she said. "Practically crawling in", I said. "You all crawl when you come in, you know", Ellen said. "And then it's that's harder to get it stopped", I added. "Lot harder to, you always end up coming in the next day again, you know, it might, you know, keep for the night or the morning, it will come back. Or if it's not a full day, and it comes back", Ellen stated. "Yeah, yeah. So what kind of attitudes have you found among nurses that, like where you did a lot of work, like did you work the whole time at the A? "I um, well I worked the longest in the Emergency department. I worked in Intensive Care for five years, and then they, they shut down the Intensive Care in the building in 1995, when cuts came along. So then I, I got dropped there. Got a call back there, you know, they often call back, they hadn't called us all there yet. Emergency shut down and then we become the west end Emergency centre", she explained. "Okay.", I said. "So they expanded the Emergency actually. They called me back because I was a critical care nurse, so I was called back because of that. And I worked there for almost ten years. And I worked mostly nights because my children were younger and I liked to work when they were in school, I mean, I work when they were sleeping and then sleep when they were in school. That was my reason. So I worked a lot of nights then. Interesting enough, that's when they come in, nights. Horrible for them, severe migraine, they can't sleep, and you've got this huge headache and you can't get rid of it", Ellen said. "And I think a lot of women have spent the whole day trying to get it to go…", I started. "…and night time, coming in. So when night comes, when everybody's asleep in bed, everybody's quiet, and here you are with this gigantic headache, not able to go away, not, can't sleep, next day you have to work, come in crying … Um, nurses are, depends on, well the group that I worked with, that I worked nights with, this group of nurses, a lot, and we always worked nights together. Most of them I would say, um, would not look at them as coming in for drugs, Oh look at that one, she's, why didn't you come in earlier? Kind of thing, like, you're in a mess now, kind of, you're, you're like why didn't you manage this earlier. That would, you know, what we might, sort of tell them, or not tell them, when they'd get better, we'd be, 'Next time don't come in when you're like going to die, you know, manage this earlier'. You know?" she explained. "Right", I agreed. "And they would tell you, well I have kids, and I tried this or that, I'll try not to be long, and I'll ask, how long have you had it? 'All day'. Well what did you do, you know? I'm trying everything, do this, do that, didn't go away. And then they're flat here. You know?" she continued. "Right", I agreed. "And that was, that was when it was getting really bad, they come in. You know, they don't, of course, their stay is longer too. Like you have to watch them so they get better and they can get up and walk and they got someone to give them a ride home and all that. Then, it's when they cannot, you know, take care of their headache anymore, they're, that they're at wits end, end of their rope. I'm coming now! We find it's a lot of nights when they come, yeah", she concluded. "Their symptoms are more overwhelming, I think, at night", I suggested. "And they turn into yourself more too…where in the daytime you're quite distracted, yeah, with family and work and all that, by the time you pop your pill in, you know, see if it works, and then continue to work and have kids to pick up, and the supper to do, all that stuff, what you do in the evening, till everybody's in bed…I still have this headache… it's not going away … it's worse, then she's turning into herself more and flopping and flopping… goes, 'Would you take me to Emerg?' and they come in, and it's like, you know, really bad", she said. "My daughter would say to me, 'Mum why aren't you going to the Emergency Room?' 'Well, um, maybe it'll go away in another half hour'…I suggested. "Exactly!" laughing. "…or an hour" I laughed too. "And it was really because I, I was terrified of going into the Emergency room. Because I had some bad experiences. That was, you know, just being ignored and not being treated well", I said. "And there are nights like that when um, when the Emergency is, is like, I think it's a better now, um, when

> they, when they look at you and, as not just come for those kind of things, how to deal with whatever you have. Like what is the degree of your pain and all that, when you have a pain scale to go by and all that. So everyone can, whoever will attend to, you know, your migraine, you can't wait very long because the brightness can be, it's hard for people to wait, you know" Ellen suggested.

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Ellen and I started out talking about the incidence of women coming in for drugs rather than treatment and she said "Very, very little, like I would say once in a blue moon. That little, that they're there for the drug thing". Her answer was what I expected and yet I noted that the literature on this topic continued to show that nurses and physicians are overly concerned with addiction and those requiring narcotics are highly stigmatized. She readily agreed. I went on to tell her a story from my own experience of being falsely accused of being addicted to a medication and then denied treatment. This incident has had a significant impact on me over the years in terms of the fear I feel when going to a hospital for help. This led us into a discussion of why women wait so long to come to Emergency. Ellen said, "You all crawl when you come in, you know". I remarked that it made it harder to get it stopped and she said, "Lot harder to, you always end up coming in the next day again, you know, it might, you know, keep for the night or the morning, it will come back". In other words, Ellen felt women waited until they could hardly walk before seeking help. In her experience by not coming in earlier it was not only harder to treat the migraine, it often resulted in a second visit to Emergency. I was interested in how Ellen thought other nurses felt about women coming in with migraines. She thought, "Most of them I would say, um, would not look at them as coming in for drugs, Oh look at that one, she's, why didn't you come in earlier? Kind of thing, like, you're in a mess now, kind of, you're, you're like why didn't you manage this earlier. That would, you know, what we might, sort of tell them, or not tell them, when they'd get better, we'd be, 'Next time don't come in when you're like going to die, you know, manage this earlier'. You know?" she explained". This was a very caring attitude and I wondered how we could get this message out to women instead of the negative message about addiction that might be keeping them home. Ellen had thought a lot about the dynamics of women getting migraines and needing to come to hospital for help. "So
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I worked a lot of nights then. Interesting enough, that's when they come in, nights. Horrible for them, severe migraine, they can't sleep, and you've got this huge headache and you can't get rid of it", Ellen said. "And I think a lot of women have spent the whole day trying to get it to go…", I started. "…and night time, coming in. So when night comes, when everybody's asleep in bed, everybody's quiet, and here you are with this gigantic headache, not able to go away, not, can't sleep, next day you have to work, come in crying". I could relate to this description so well. It was usually evenings or nights when headaches overwhelmed me. In the quiet hours when there is nothing to distract you, a migraine headache can take on monstrous proportions. Ellen talked about this as well, "We find it's a lot of nights when they come, yeah", she concluded. "Their symptoms are more overwhelming, I think, at night", I suggested. "And they turn into yourself more too…where in the daytime you're quite distracted, yeah, with family and work and all that, by the time you pop your pill in, you know, see if it works, and then continue to work and have kids to pick up, and supper to do, all that stuff, what you do in the evening, till everybody's in bed …I still have this headache …it's not going away, it's worse, then she's turning into herself more and flopping and flopping… goes, "Would you take me to Emerg?" and they come in, and it's like, you know, really bad", she said". I liked how Ellen described the way a woman would be "turning into herself more", for it captures the way a migraine shuts her down bit by bit until there is only one major focus, the pain. In her description of the many things that have to be taken care of, one can see the social aspect of the disease, for so many women have multiple roles and must find substitutes before they can seek help.

Emergency Room

> "…when a severe migraine patient comes to the Emergency, it's a horrible place to come to, 'cause they can't see very well, they can't hear very well, they can't stand very well, even put them in a hall, cover them up, you know? Put them in a dull room", she said. "Yeah", I agreed. "And you're looking at when it's really busy, then, then you triage them and you assess them and then you have to wait forever for the doctor to come in to assess them, give them medication. That part is agonizing and then you can't get at them, it's so simple, you know, why don't we see this one first, it's a migraine and gonna be fast. So sometimes what we did

is we fast-track them", Ellen explained. "Oh really?", I said. "Yeah. There's, there's two laws in the hospital. First law is you put them in the order of severity, like chest pain is first...you know, like that. Um, you got abdominal pain, got constipated, what not, you know, last", she said. "Right", I said. "And then go on like that. And then we have a fast-track part where somebody that does not need a lot of assessing, like doesn't need lab work, doesn't need x-ray and all that stuff, they just need doctor to go in there, say this is what you have and you're having pain, okay, lets give you a shot", she continued. "Right", I encouraged. "No big deal. So those are our fast-track, go there, and do our thing, and come back out", she said. "Right", I agreed. "And so we'll do that, and sometimes migraines we'll put on the fast-track. We'll see, you know, um, how, how busy the department is, that's what we usually do, you know, with migraines, is put them in the fast-track. "That's a really good idea. I've never thought of that", I said. "It really helps them, yeah. And I think that's a trick that we do to move patients, because sometimes that's what they need is just a shot. And then, in fifteen minutes, they're feeling better already, and if somebody came with them that they knew how to monitor migraine patients, some people could take them home already. So you free up the space already", she concluded. "Yeah", I said. "But your, if you're a triage nurse, a charge nurse that's worked in Emerg for a long time, like you know how to, how to handle patients, how to move them faster, 'cause that's one of our tricks, the fast track...", she paused. "Now if it was me coming in, one shot, well, when they used to give me a shot of narcotics or something, one shot would just rarely do it", I said. "Um hmm", Ellen nodded. "Because it, at the end of three or four hours, it'd be back", I added. "Yeah. So then we'd have, we have to treat you as, like I could usually, like you are, then we would have, we would have everything on the migraine card. Okay, Sharon has been in here before, Sharon had this and this is what happened and we need to do this and then, and then we've got to go, 'Oh well, this patient has to stay in here for a little bit longer. She needs more than one shot. So let's put her somewhere that she can stay here for a little bit'", she concluded. "Right", I agreed. "We have these fast-track rooms too. Where you can put a patient in there, shut the door, they don't need, you know, um, any monitoring, they don't need any uh, constant care and all that. We leave the room all by itself", Ellen explained. "So you're not in the main drag", she said. "In the main drag you have curtains there, you have no door", she said. "Right", I said. "So you just…", she started. "Yeah shut the lights off", I said. "Right, you turn the light off, shut the door. Because you know I'm not going to look at you for another hour, till you get better. I'll come back and check you and usually, you know, we'll do it, an hourly check on somebody who's staying there a longer time", she explained. "Right", I said. "But we look at it as, you have somebody there with you there, you're going to be there for a longer time, give you a k basin, give you a call bell, to call us if you need us, and we shut all the doors and stuff, doors and then we walk out. And then, if you put like, it's the main, the lights are on and all the sound and all the goings on, that's no good, can't get better. Usually we put headache people on the corner, like the corner, the last one here or one over there or whatever", she said. "Like, better for them, we don't put them in the centre of this". "Right", I said. "But that is not when you're not just new here, that's when you're there for a while maybe, and you have experience, you've seen it and you know what help the best", Ellen stated. "Right", I said. "Um, they do need the quiet …Um, they do need the quiet, the darkness and to the, to get better, she said. "Right", I agreed. "…make sure they can get to us if they need us. Shut the door and go. And go back and see what happened to you later on.

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I found this a really interesting story for while I was certainly aware that triage was based on severity of illness taking priority "like chest pain is first…you know, like that. Um, you got abdominal pain, got constipated, what not, you know, last", I had not heard of fast tracking "we have a fast-track part where somebody that does not need a lot of assessing, like doesn't need lab work, doesn't need x-ray and all that stuff, they just need doctor to go in there, say this is what you have and you're having pain, okay, let's give you a shot" as the second law in the Emergency room. Both of these policies from Ellen's perspective allow the nurse to help patients in need sooner and free up beds faster. These policies have developed to meet the increasing need for Emergency services but I
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noticed Ellen mentioned freeing up beds several times and as a person with severe migraines this triggers one of my main worries, that of being sent home too soon. Ellen said in her discussion of fast tracking, "And then, in fifteen minutes, they're feeling better already, and if somebody came with them that they knew how to monitor migraine patients, some people could take them home already. So you free up the space already". I could not help but wonder for how many women that initial feeling better time is sufficient time to know if the migraine is indeed under control. For me, I never knew until the medication wore off three or four hours later whether the headache was gone or whether I required further treatment and given how difficult it was to come in in the first place, I never wanted to be sent home early. Ellen reassured me that in her hospital that information would be on my "card" but based on my experience I have not been to hospitals that had cards before. I have certainly experienced what Ellen referred to as fast-track rooms, "We have these fast-track rooms too. Where you can put a patient in there, shut the door, they don't need, you know, um, any monitoring, they don't need any uh, constant care and all that. We leave the room all by itself", Ellen explained. "So you're not in the main drag". They are indeed much better than being in the noisy, bright areas of the Emergency room. For the migraine patient they are like little islands of sanity in a world gone crazy because one's body is so over sensitive to stimuli. On the other hand if no one is with you and if the nurse forgets to give you the call bell you can be easily forgotten and left in need. Ellen presented a much rosier picture than had been my experience. Again I wondered what was the norm for Ellen presented a more ideal world of nursing in the Emergency room than I had seen. I could hear the experience in Ellen's voice and storied lines about the Emergency room. For her it would be a given that you would draw on your tacit knowledge in making judgments about how to apply policies as you move patients effectively and safely through this busy landscape. Ellen made me feel safe in this space she described but my voice of experience kept saying yes but not every nurse is like Ellen.

Keeping It Simple

> "Yeah, yeah. It's good to hear that uh, you use a pain scale", I said. "Yes we do use a pain scale...", Ellen responded. "...but there's a lot of them haven't over the years", I commented. "...um hmm, well it's nice to use the pain scale for

every kind of pain that we have. We have, we have kind the sort of patient that have, we have a pain scale for chest pain, we have a pain scale for migraine, anything we give narcotic to, the pain scale. Then you know if it's worked or not…like when you have an even number on the head, but you know what to give them, that's one thing, but you know the pain is getting better", Ellen explained. "Right", I agreed. "You know, it doesn't matter if you experience it this much, or given five or that much given two, that you know if it's five, four, three, two, one, it's going to full…", she started. "That's right", I said. "So you assess them, you think, like now the patient is, this is the number, so you know the pain is starting to drop off", she continued. "Right", I agreed. "So it's a good tool for that", she concluded. "Yeah. I even had a, um, John, my ex-husband, and I used a scale for when I needed to come, to go to the hospital", I said. "Is that a good idea? Yeah?" Ellen asked. "You know, I, I knew that, you know, if it got to uh, you know, was a five, I could still function. You know, and if I got distracted enough, or I was forgetful about it, I had it, if it got to be a six, I could no longer uh, distraction didn't work any longer, I was struggling, I would keep going but I was struggling", I explained. "Um hmm", she said. "When it was a seven, I had to go to bed", I continued. "Yeah", she said. "And if it was an eight, I had to go to the hospital", I finished. "That's right", she agreed. "And I, I, and, we developed that because they would, you know, everybody'd be asking me, well, do you want to go to the hospital? Do you need, you know…", I said. "That's right", she said understanding. "…and I'm trying to process in a head that's just not processing, you know, and uh, to try and make that, I couldn't even make that decision", I continued. "Um hmm", she murmured. "To be able to just say, it's an eight", I started. "Yeah, and you will let go", she responded. "…and they would, they knew they had to help me get dressed…", I continued. "That's right", Ellen agreed. "…and all, I can't walk any more!" I concluded. "That's what you do when it's an eight", she reiterated. "Yeah, don't ask me to do anything myself, I can't do it. "Yeah, yeah. I have a sister that has it, uh, has migraines", Ellen said. "Oh do you", I responded. "So yeah, I do understand more, when she tells me her symptoms and…", she continued. "Right", I said. "…she needs to go to the hospital and what helps, what not and all that", she continued. "Right" I agreed. "Yeah", she said.

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This story is about communication and the value of simplifying how we communicate when under stress. Ellen used a pain scale in assessing both the level of pain before and after treatment, "We have, we have kind the sort of patient that have, we have a pain scale for chest pain, we have a pain scale for migraine, anything we give narcotic to, the pain scale. Then you know if it's worked or not". The simplest pain scale is usually having the patient rate his or her pain on a scale of zero to ten with zero being no pain and ten being the worst pain imaginable. Many people find this easier than trying to describe the kind of pain, the location, the intensity and so forth. Women with migraines have great difficulty communicating because of the pain itself and how it shuts down their ability to think and make decisions and so a pain scale can be very helpful because of its simplicity. I described a similar use of a scale, to Ellen, for deciding when to go to the hospital, a scale my family and I developed to help me with that decision when I was in great pain. "You know, I, I knew that, you know, if it got to uh, you know, was a five, I could still function. You know, and if I got distracted enough, or I was forgetful about it, I had it, if it got to be a six, I could no longer uh, distraction didn't work any longer, I was struggling, I would keep going but I was struggling", I explained. "Um hmm", she said. "When it was a seven, I had to go to bed", I continued. "Yeah", she said. "And if it was an eight, I had to go to the hospital". Again the simplicity of it was very helpful. I share this with other women with migraines whenever the opportunity arises because it has been so helpful for me. While there is a wealth of research on the use of pain scales such as Ellen described, there are still many Emergency rooms where they are not used. I have found nothing in the literature on the very real difficulty of thinking and making decisions when one has a migraine and needs help and I wonder why. When our heads are consumed with pain and nausea, when we cannot see well, are off balance, over sensitive to smells and sounds, it seems obvious that we might have trouble making decisions. I wonder why this is not one of the issues considered around seeking help because for me it has been a significant barrier to getting help.
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I Don't Want to Bother You

"Right. So um, how do you think the, how do you think women view it when they're coming in?", I asked. "Like the patient themselves?" she asked. "The patients themselves, yeah. What's your, what's your impression of, of um, do you think people are afraid to come in to the, or um, do you get any sense of, of what it, you know, aside from the extreme pain and the symptoms, do you get any sense of uh, they're feeling vulnerable or um, being, being afraid to come in?" I clarified. "Well one thing they, they often tell us that, that, 'You guys are busy and I don't want to bother you'", she said. "Okay", I responded. "So like a, um, almost like I can hear that other, other kind of comments. But they, 'you guys are busy, I didn't really want to bother you' that was what come out of it, their, their mouth, like soon as you assess them, that, like, sometimes you hear that. But like…" Ellen continued. "…one of the reasons they didn't come in?" I asked. "Because, because they didn't think migraine is a thing of emergency. You know? Until they're out there, couldn't help themselves. So, so they were like, once we put them in the place, turn off the lights, check back with them, and we would ask them, "So how long have you had that?" And they will say, "Well, all day." And then they'll come out of it, 'I didn't really want to bother you, I know that you're so busy'. And it's almost like, you know, I didn't really want to come in. I didn't want to bother anybody. I just wanted help", Ellen explained. "But perhaps they don't view it as a legitimate emergency", I suggested. "Um hmm, yeah. Yup. They think that's like, compared to the dead and dying um, that's, that, you know, this is not, the world is not going to end with my migraine, kind of thing. But…" she started. "That could be the last, like some people do die of migraine", I said. "Oh, yeah, yeah. It has happened, and also if you had gotten the blood pressure so high, um, you know, the body", she continued. "…can't handle it", I interjected. "Yeah, and they will have a stroke", she said. "Yeah, yeah", I agreed. "And that goes with the pain, the pressure shoots up really high and, when they come in. And the first thing, like you would hear more of a, a mum that gives care a lot, those are the women who you can, you kind of know that um, they have family and they don't really want to bother anybody. Especially at night, you know", she said. “Right”, I agreed. “They’re coming and bothering somebody. It’s not that urgent but I can’t help myself. So they come in, “I’m really sorry to bother you, I know you’re busy” and you hear that, and you, and then you would say, ‘No, you should come in’. And you would say that, you don’t bother us, this is not bothering us. You assure them that, that they’re not bothersome. That they have this much pain, they should come in and get relief. Because they’ll get in trouble if not, like the worst trouble, they’ll get dehydrated and all that, and …or your blood pressure’s untreated and it won’t help your poor migraine”, Ellen explained. “Right”, I agreed. “And plus you might bring up …Your body clears out from one end to the other”, she said. “That’s right”, I agreed. “And it’s awful. It’s so bad, you know? Nothing helps, get help before you get there”, she said. “Yeah. But that’s interesting because that, that gives a little bit of insight into what people are thinking, you know, because um, it is very difficult to seek help. For one thing, you’re so sick, um, I used to find that even the trip to the hospital…was a major barrier. You know? And every pothole, and John would drive so carefully and, you know, and still just, just being moved at all was like, “Don’t touch me, don’t move, don’t move the bed” You know…”, I said. “Right”, Ellen agreed. “…and if you have to drive any distance at all, and uh, things like getting dressed”, I started. “…you were one of those women, like if I touch you and you sort of like, you know, if you go away like this, that would be fine!”, she said. “Yeah, yeah. It’s very incapacitating”, I agreed. “Um hmm”, she murmured. “I think all those things really influence our ability to get help”, I said. “Um hmm. Um hmm, yeah”, she agreed.

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What is an emergency? This is an important question for many women when it comes to seeking help with a migraine for many women seem to question whether there is a fit between a migraine and the Emergency department. Ellen noted that women frequently say, “you guys are busy, I didn’t really want to bother you’ that was what come out of it, their, their mouth, like soon as you assess them, that, like, sometimes you hear that” as if they are asking for the nurse to validate their presence in the Emergency department. When I asked Ellen if she thought people were afraid or feeling vulnerable
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and this kept them from coming in she replied that patients don't come in, "Because, because they didn't think migraine is a thing of emergency". I wonder if the media has portrayed the Emergency room as a place where people come who are bleeding and at death's door. Do we no longer consider extreme suffering a criteria for emergency care. Ellen noted that one group that has great difficulty coming in are mums " that gives care a lot, those are the women who you can, you kind of know that um, they have family and they don't really want to bother anybody. Especially at night, you know", she said. "Right", I agreed. "They're coming and bothering somebody. It's not that urgent but I can't help myself. So they come in, "I'm really sorry to bother you, I know you're busy" and you hear that, and you, and then you would say, 'No, you should come in'. And you would say that, you don't bother us, this is not bothering us. You assure them that, that they're not bothersome. That they have this much pain, they should come in and get relief. Because they'll get in trouble if not, like the worst trouble, they'll get dehydrated and all that". Many women do not know the dangers of high blood pressure during a severe migraine or the potential for a stroke. If they did they might take seeking help more seriously. As Ellen noted women wait until they cannot help themselves and at that point the trip to the hospital is itself a barrier. With an over-sensitized body, every movement, sight, and sound is an assault on the senses. I wonder how we can get women to not see themselves as a bother but to view migraine as a legitimate illness that requires significant intervention in a timely fashion from trained health care professionals.

Educating Ourselves

> "Any thoughts on, on how we can, how we can help women more?" I asked. "I think what's being, really important is to, to tell them that um, it's not, like we won't, we won't judge you, like we won't see you as somebody who, who um, like don't put a name on them, like don't put, don't put a stigma on them 'cause they have, you know, "Oh there she goes again..." You know, kind of thing?", Ellen said. "Um hmm", I responded. "I mean, each time you come in, assure them that, you're not bothering us, you need to get help and you if you think you should come in, you should come in. Not until uh, you wait till the, you know, you couldn't handle it anymore. It's just like, you know, you couldn't even get control of yourself anymore? Then come in? That's the worst time to come in. It

takes such a long time to get rid of the pain. And I mean, each time is longer. Um, so you, you have to um, probably educate them to, to know themselves. To know that at what point, I'm not going to wait to this point to come in, I'm going to come in when it's at this point, when I can still talk, I can still, you know, see and walk and I know I would get there. So if I, I caught it a little bit earlier, then I could manage it better. Um, but I would seek help faster" Ellen explained. "Um hmm", I murmured. "Of course now that the Emergency waiting room is always like totally packed, always a long wait there, for four hours, whatever hours, you know? But that would, that would really, someone who really wanted to get help right away would prohibit them from coming because what's the point of coming in if I have to wait for four hours before a doctor sees me", she said. "Yeah, yeah. Especially, if you can't lie down", I said. "That's right. If I have to go to the waiting room, all that time, the noise and the lights, why bother go there?", she wondered. "Yeah.", I agreed. "Because our Emergency is always really busy now, it's kind of unfortunate. Um, and I knew, in the A. Hospital, they have pain, kind of if you have pain, you go to a different section of the Emergency", she stated. "Oh yeah?" I said. "And, and it could be, I'm not sure if it's chest pain or any kind of pain. Um, or just a headache or a certain pain, you go to a different section of the Emergency. So you don't have to file in with the rest. It seems to me, they have, they have something different there. I'm not sure, 'cause I haven't spent time there, and I haven't worked there", she said. "Um hmm", I responded. "But I, I heard about this pain part of the Emergency", she noted. "Right", I said. "That's, so you don't just go with everybody else because you have pain, so then you just go in here to get assessed …have to go get, you know, get help there a little faster…you know, get help there…a little faster…'cause there are people that just needed to get …fast track them… want a more detailed, you have to like, the other thing that we have to do, they need to have all these things in place, then do a diagnosis… Whereas migraine's so easily, you know, assessed, that it, you could assess a migraine person a lot more easily", Ellen explained. "Most of them know…whether the migraine is different. Or whether they even have a migraine", I said. "Um hmm, yeah. And whereas you just have this pain, or this, whatever

> you have, you don't even know what it is, then you have to go into a lot of other testing and you know, waiting for the x-ray to come back, waiting for the lab report to come back, before you can diagnose, give them any medication. But migraine is so, like different from it, the women know once they have it once or twice, they will tell you exactly what it is, like you know, this is what I have, this is what I used to do", she said.

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Ellen seemed to feel there were several things we could do to facilitate the process of helping women seeking help with migraines. "I think what's being, really important is to, to tell them that um, it's not, like we won't, we won't judge you, like we won't see you as somebody who, who um, like don't put a name on them, like don't put, don't put a stigma on them 'cause they have, you know, 'Oh there she goes again…' You know, kind of thing?" The next is to make it clear to women that they are not bothering the nurses. Another point of education for women with migraines is when to come in. Most women wait "till the, you know, you couldn't handle it anymore. It's just like, you know, you couldn't even get control of yourself anymore? Then come in? That's the worst time to come in. It takes such a long time to get rid of the pain. And I mean, each time is longer. Um, so you, you have to um, probably educate them to, to know themselves. To know that at what point, I'm not going to wait to this point to come in, I'm going to come in when it's at this point, when I can still talk, I can still, you know, see and walk and I know I would get there. So if I, I caught it a little bit earlier, then I could manage it better. Um, but I would seek help faster". I think Ellen's words about still being able to communicate are particularly important for this is where many misunderstandings come in. On the nurses' side, nurses need to realize that a woman who is still able to talk can still be in severe pain. I was in Emergency recently and was explaining my headache to the triage nurse and I was at the stage where I could still talk with an effort. Suddenly I lost my control and burst into tears and that was it for my communication. The nurse who had been fairly non-responsive to me up to that time was suddenly all over me with understanding and kindness saying that until that point she did not think I was really that badly off. This was one example of where an assessment using a pain scale would have been very beneficial. As Ellen would have said, I was fast tracked from then on. Our
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final discussion in this story was on the long waits in Emergency rooms and the difficulties this creates for migraines patients for whom the harsh milieu is the worst place for them to be. These are broader issues and ones that need to be addressed at an institutional and societal level. Ellen did note that one hospital had a section for pain patients that helped speed relief for that sector of the emergency population. I wonder if this is common or something relatively new. It certainly sounds promising and shows a recognition that there is a need for multiple paths to help on the landscape of healthcare.

Tread Softly

> "So you have, how do you have, what's your experience as far as um, nurses dealing with patient expertise?" I asked. "Like nurses that, that deal with patients that knew exactly what they were going through, what they need? Is that what you mean?" she responded. "Um hmm", I said. "I think nurses need to be careful too. That um, yes you have to listen to the patient but you also need to listen to, to yourself and how you, well once you interact with the patient, and the patient knew what they have, you have to listen to them and you also have to listen to yourself. And what you're finding, is it um, is it consistent, like do you have these symptoms, well that's what migraine is, so let me see if you really have what you think", she explained. "Um hmm", I responded. "And they have to be very consistent with each other. Then you know the patient is really telling you something that's not true or true", she said. "Right because I, you know, a lot of people are very knowledgeable about a chronic illness in here. And getting more so because of the internet", I suggested. "Yes, yes", she replied. "And in some cases they know more about it than", I started. "It's true", she said. "the nurses", I continued. "It's true, she said. "the physicians do", I finished. "Sure", Ellen agreed. "You know the latest things and um, do you think that, that's threatening?" I asked. "I personally don't think it's threatening to me. I think it's good for them to know all these, but it's one thing to know all that and the other thing is to demand it all up to them, like they might tell us how to treat them", she said. "Um hmm", I said. "And when they start to tell us how to treat them, that's a threat. Like a threat to, not, not quite the nurse, the doctor. Cause the nurse does not prescribe treatment but they have to carry them out", she responded.

"Right", I said. "The doctor prescribes the treatment. Like the, "You know what, it worked with Demerol 75", you know, kind of thing", she said. "Right", I said. "You know, um, 'So if you give me 50, forget it'. You know, and that's what you, that's what the doctor prescribed like, it's okay, uh, we just give. We, we put down how much Dr. A will give, some of them will go right to the doctor, if you ask him, he will give you seventy five. And then it's written on that migraine card he said seventy five", she explained. "Right", I said. "If it's written on it fifty, he is not gonna give you seventy five. It's when they start to prescribe their treatment, like if, if they start to tell us what works, like it would work with this, or it's almost like, I do this, but do you agree with me? Those kind of attitude now, people take that much better than when they demand what they need to be done", she suggested. "Right", I agreed. "That's what's helpful to the doctor, and also to the nurses um, too, sometimes", she said. "Yeah, I, I have found that sometimes it's, you don't know whether to come in and be knowledgeable or come in and act dumb. Uh, just sometimes, you know, one works and the other doesn't and sometimes it's the other way and, and that's one thing that I used to find was, I didn't know what was safe to say", I suggested. "Um hmm", Ellen thought. "You know? When someone would over-react because like if, I knew exactly, you know, I knew that if he gave me 50 of Demerol, what, ridiculous, like it wouldn't touch me", I said. "Yeah", she said. "You know? Um, but on the other hand, I've been having migraines since I was five years old and I've had so much medication over the years and I, I'm very resistant to, to a lot of things", I continued. "Yeah, yeah", she said understanding. "You know, I mean I, I've had them give me just huge quantities of drugs and it hasn't touched it", I said. "Um hmm, um hmm", she murmured. "You know?" I said. "And that is one thing, when we start to think about, you know, part of that picture, it's because we've been given this much, and not have it touch it. And you have to take good history, yeah, like if you take good history, and you say, you know what, it's not going to cut it, you know, then you know it's not going to cut it. But if you don't take good history, you don't have time to take good history, then, you know, you would go and do such mental things about how, you know, well it's it's not going to help her, it can't touch her, you know, we'll give her something else maybe", she explained. "So it was nice when they stopped, when they started treating with um, things like um, Largactil intravenously (IV) or uh, Corticosteroid (IV), Decadron (IV), you know, um, there were a lot of drugs, experiment with a lot of things. You know, and um, you know, eventually I got them like where um, they would have to give Dehydroxyergotamine (DHE) intravenously ... You know, that was really the only thing uh, that would work after a while. You know, but then, then when we had Imitrex come out and whatnot, why, they tell you okay, if you take an Imitrex within twenty four hours, uh, you don't want to go get the DHE. Because it can, you can really cause severe dangerous side effects and uh, but you come in and it's like, 'I don't care, give it to me'", I explained. " I know. Anything but this!" Ellen agreed. "My head's gonna blow apart, you know?" I said. "No!", she said. "So it, it's very tricky and it's interesting that um, there's some literature out there on asthma patients that they face the same problem. That they come in, in severe stress, often waiting uh, because sometimes they'll come in and somebody'll say, 'Well you're not that bad, why are you here?' And then, other times, they'll come in and say, 'Well, why did you wait too long?'", I said. "Yup", Ellen agreed. "And it's like, how do I know when to come in, you know? And um, they're very afraid uh, some of them, that they will die uh, because the assessments aren't good enough and because, you know, that they're not listening to what they're saying. And yet, they know their body so well, and it is true, that you listen to their chest and it doesn't sound that bad and that person is more aware of how bad it really is", I explained. "'Cause they could go down real fast", Ellen said. "They, they go very, very fast, 'cause they know. They know. And the thing about the migraines, if I wake up in the morning with a migraine, I can tell you then, whether that migraine's gonna get better", I said. "That's right", she said. "I would know, you know, almost a hundred percent of the time, whether that migraine was gonna land me in hospital", I said. "Um hmm", she murmured. "And yet I would fight that darn thing all day before I would give in. "Very stubborn", Ellen says smiling at me. I grinned back. "There's a different quality to it and I could no more describe that quality to you than anything, I just, I just know. It's different", I explained. "Yup. And you're the only one who knows", she suggested. "You're the only one that knows that it's a little bit different, that it's gonna get you in trouble", I agreed. "Yup", she said. "And yet, if I went in early, and said well, this one's a little different, this one's gonna, you know, I would have ended up here, you know, like you have to wait till you're, till your outward symptoms are a certain level of severity", I said. "Um hmm. And in the back of your head go, I just don't really want to go in to bother them, because I could still live yet", Ellen said. "Yeah", I said laughing. "You know, it's true. I could still pull through!" she said. "Yeah, yeah. It's bright spots. Once in a while, I can manage it on my own because we do have a lot of drugs", I agreed. "And you do, if you do, you yourself know how to manage it. You know how to manage it, how to make it go away sometimes", she said. "Yes", I replied. "Sometimes not", she said. "Yeah, yeah", I agreed. "Nobody can treat you better than yourself. That's what it means, you have to know, know yourself. How, how it could turn out, how this migraine that I get up in the morning, and I see how it's gonna turn out. And a lot of times you know, how should it turn out, like what I should do. And sometimes we don't do what our heart tells us, it tells us, you know, you should do this now, but no, not yet...(laughs). It gets us into trouble...", she suggested.

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In this story we got into one of the sensitive issues for health care professionals, that of patient expertise regarding their own illness. With so many new sources of information readily available to patients, it is common for them to be very well informed and in many cases trying self-help and alternative therapies in addition to traditional therapies. Ellen said she was okay with patient expertise and believed you need to, "listen to the patient but you also need to listen to, to yourself and how you, well once you interact with the patient, and the patient knew what they have, you have to listen to them and you also have to listen to yourself". It sounded as if she felt it was important not to give up her professional role to the patient but she was certainly willing to collaborate with them. She explained that nurses need to compare their assessment with the patient's to see "if is it consistent, like do you have these symptoms, well that's what
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migraine is, so let me see if you really have what you think". Ellen seemed to be saying that it was alright for the patient to recognize her symptoms but the nurse needed to verify them. Ellen went on to say that this was not personally threatening to her. "I think it's good for them to know all these, but it's one thing to know all that and the other thing to is demand it all up to them, like they might tell us how to treat them", she said. "Um hmm", I said. "And when they start to tell us how to treat them, that's a threat. Like a threat to, not, not quite the nurse, the doctor. Cause the nurse does not prescribe treatment but they have to carry them out". I wondered what Ellen meant by demand treatment of a particular kind for I have often made suggestions about treatment and I thought at the time oh dear we are going to have a parting of the ways here. She went on to give me an example of what individuals say, "You know what, it worked with Demerol 75", you know, kind of thing", she said. "Right", I said. "You know, um, 'So if you give me 50, forget it'". I could understand that this might be worded in a less demanding manner but at the same time I realized that the content was important for I have been in that same situation where I knew that a particular dosage would not touch the pain and to suffer through a lower dose before the doctor realized I needed a larger dose was to put myself through needless suffering. The difficult part is how to word this personal insight in a way that does not challenge the physician's knowledge and authority. Unfortunately in many cases the physician or nurse are not endeavouring to meet you half way in such conversations by asking what has worked before and what has not and so there may be no safe statements. Ellen then proposed a better way for patients to present their ideas, "It's when they start to prescribe their treatment, like if, if they start to tell us what works, like it would work with this, or it's almost like, I do this, but do you agree with me? Those kind of attitudes now, people take that much better than when they demand what they need to be done". I could see this working but I could also see that this approach does maintain the power differential between the nurse and the patient and I wonder if this is true to the underlying assumption of a collaborative relationship. Ellen mentioned that patients with special needs like myself would have these recorded on the migraine cards and all patients would have the dose that worked the previous time recorded. I wondered if too much reliance on this past information superseded a thorough assessment of the presenting condition when the Emergency room was busy.

We had a discussion about similar problems faced by asthma patients who are not sure when to come in for sometimes they are accused of coming too soon if the nurse determines they are not that bad compared with the patient's assessment or are asked why they waited so long if their condition is deemed serious. I explained to Ellen that this difficulty in knowing when to come in was similar with migraines because of the differential between how patients and nurses assess the situation and the wonder of what is a safe question to ask. Ellen seemed to understand the asthma situation very well. "And yet, they know their body so well, and it is true, that you listen to their chest and it doesn't sound that bad and that person is more aware of how bad it really is", I explained. "'Cause they could go down real fast", Ellen said. "They, they go very, very fast, 'cause they know. They know". I went on to explain about migraines, "And the thing about the migraines, if I wake up in the morning with a migraine, I can tell you then, whether that migraine's gonna get better", I said. "That's right", she said. "I would know, you know, almost a hundred percent of the time, whether that migraine was gonna land me in hospital", I said. This is something that is not in the literature and I wonder how common it is. I suspect many women could tell you the same thing and yet we have to wait until our symptoms reach a level where nurses and physicians can validate their seriousness in order to get help. Ellen came back with an interesting comment, "You know how to manage it, how to make it go away sometimes", she said. "Yes", I replied. "Sometimes not", she said. "Yeah, yeah", I agreed. "Nobody can treat you better than yourself. That's what it means, you have to know, know yourself. How, how it could turn out, how this migraine that I get up in the morning, and I see how it's gonna turn out. And a lot of times you know, how should it turn out, like what I should do. And sometimes we don't do what our heart tells us, it tells us, you know, you should do this now, but no, not yet...(laughs). It gets us into trouble...", she suggested". Her words resonated with me in that they brought up the ever present questions in my life about do I have the right to have what others have. Is it fair for me and other like me to set out the same goals as others if it means we need a little extra time or a little extra help. Do we need to work twice as hard to make up for the times when we cannot work as hard. I wonder about these questions all the time and they are a constant source of angst for me for they strike at the heart of my identity and my sense of self worth. I wondered if Ellen realized the depth of the issues we were talking about that day.

Chronicity

> "And I feel really bad for them, I mean, when it gets not like, oh I mean, I can get rid of it today, it'll never come back. It would be so easy, but it's not. It's going to live with me forever, like for a long time, it's going to be all my life, migraine does follow you everywhere", Ellen said. "Umm", I agreed. "And, and you know, it does not go away, it's not like some other pain, you do this and it goes away and will never come back. You know, and if you can avoid this food, your stomach will not come again, you know, this kind of thing? Whereas you cannot avoid things, migraine's there all the time. There's some things maybe you can help to lessen it, you know. I know my sister had migraine all her life and she knows how to, she kind of knows how to, how to manage it now, like as it, as she gets older, she knows how to manage it. She knows she shouldn't take, she'll take a day off, she doesn't go to work, things like that. Like go to work and only have to come back you know, or got to go to the hospital, you know", she explained. "Right", I said. "She kind of knows that, so she won't go down that road", Ellen said. "But society doesn't accept that very well", I said. "No, no. Because they think, probably just all in their head or she's just looking for drugs...oh, you know, um, if she does this, then it will go away. Or why isn't it going away, what aren't you, not doing right? You know, kind of thing", she said. "Yeah. Because there can be a lot of things", I said, "And um, I know I was asked to change my job uh...". "...is it stress, or why are you doing this? Can't you stop, you know, kind of thing", Ellen mentioned. "Oh yeah! Yeah. I had one nurse tell me I was a bad mother because...", I started. "Oh!", she exclaimed. "...I was putting um, my kids through so much because I was going to school, working part time and...", I continued. "...and having migraines!", Ellen added. "and migraines, and why was I doing this, why didn't I just stop and stay home?" I finished. "And the migraine will stop too? I don't know", Ellen said. "Uh, you know, I mean, I tried staying home and doing, not doing anything. And I still had

the migraines so it was like, I'm going to have the best life I can in this. You know, manage it. So society doesn't really accept that too well", I said.

Ellen was very cognizant of the impact of temporality in illness, "And I feel really bad for them, I mean, when it gets not like, oh I mean, I can get rid of it today, it'll never come back. It would be so easy, but it's not. It's going to live with me forever, like for a long time, it's going to be all my life, migraine does follow you everywhere". One has to question what chronicity does to the notion of hope in illness. When there is no hope for cure, is hope redirected to hope for less pain, a good day? How is quality of life defined and redefined and how does this impact how we help individuals set realistic goals for the future? Ellen talked about her sister's challenges with migraine, "I know my sister had migraine all her life and she knows how to, she kind of knows how to, how to manage it now, like as it, as she gets older, she knows how to manage it. She knows she shouldn't take, she'll take a day off, she doesn't go to work, things like that. Like go to work and only have to come back you know, or got to go to the hospital, you know", she explained. "Right", I said. She kind of knows that, so she won't go down that road", Ellen said. "But society doesn't accept that very well", I said. "No, no. Because they think, probably just all in their head or she's just looking for drugs...oh, you know, um, if she does this, then it will go away. Or why isn't it going away, what aren't you, not doing right? You know, kind of thing", she said. "Yeah. Because there can be a lot of things", I said, "And um, I know I was asked to change my job uh...". "...is it stress, or why are you doing this? Can't you stop, you know, kind of thing", Ellen mentioned. The mixed messages society presents to migraine patients make it difficult to know how to respond to the illness. Stigma attached to the illness can present a significant barrier to taking proper care of oneself and yet the consequences of illness and missed work are just as dire. Ellen's understanding of her sister's experience helped her a great deal in working with other patients for she was able to anticipate and understand their needs without their asking and for patients who cannot communicate well this is a valuable skill.

Memory Box

The day we met to talk about Ellen's memory box was both wonderful and a disaster for me. The tape recorder did not work and I forgot my camera. We had a wonderful discussion though and I immediately sat down and taped everything I could remember of what we had talked about as soon as I arrived home and realized the tape had failed. The following are my memories of that day.

The first item Ellen shared was a small candle which she used to represent the need for soft lighting in the room where a migraine patient is resting. We both agreed that while a candle would be unsafe, the idea of something like a soft nightlight was good for a migraine can be disorienting and although the patient is photophobic a soft light to orient the patient and help the nurse navigate around the room would serve two purposes. Her second item also dealt with light. It was a small flashlight that she carries with her when working nights so she can check on patients without disturbing them. It was similar to the one I had used in my practice. It serves the dual purpose of helping you navigate around the room and being able to check pupil response and other vital responses in your patient.

One of the items that Ellen had forgotten to bring home was a syringe. This had great significance for her for the syringe represented relief from pain for her. She told me that long before the doctor would see the patient she would be picturing filling the syringe with medication and preparing it for use. She could not wait to be able to provide that relief to her patient and her mind was already busy thinking of other things she could do to bring some comfort to her patient before she could give the medication. Ellen saw the Emergency room environment as bright, noisy, busy, and cold and so she thought of measures to counteract this. She made sure the patient had a comfortable pillow and that the bed was raised a bit as this often helped especially if the patient was nauseated. Several warm blankets were usually welcome additions and I told her how much I appreciated it when nurses offered these without my asking. Ellen noted that many younger women bring in their own blankets, a sign of people feeling freer to advocate for their own care today. We talked about having a facecloth to wash one's face if one had been vomiting and having a k basin for that purpose handy. She always had a box of Kleenex nearby as well. Ellen also talked about the use of a cold cloth for comfort or a magic bag to provide heat if the patient had one and that was preferred. These many comfort measures she saw as in tune with real nursing roles as opposed to the physician assistant role and something that could bring immediate relief without waiting for the physician to see the patient. She also related these interventions to care more often provided by older more experienced nurses than younger nurses who are sometimes more caught up in the technical role of the Emergency room.

One of the things that occurred to me as Ellen talked was that women with migraines are very turned into themselves when their pain is very intense and their communication is minimal. As a result nurses providing comfort measures may not get a lot of positive feedback from them and may not realize how much that care is appreciated and how much it helps get them across that time gap until the physician can see them. This is probably something patients need to be aware of and respond to after the pain has subsided. One of the other important things that goes on when comfort measures are being given is the establishment of a relationship between nurse and patient and with this sense of caring comes a sense of trust. Ellen noted that if she picked up a migraine patient after she had already been treated, she did not have that same connection for she had not gone through the initial assessment, history gathering, and comfort measures and this is when that connection is established. It changed the dynamics entirely for when talking is limited the physical acts of nursing are an important part of establishing that connection with an individual and is a way of showing you care. From my perspective as a woman with a history of severe migraines I would describe this relationship as feeling safe in the hands of that nurse. It is a relationship established more by physical acts than by words and it is something that plays a key role in healing for I feel I do not have to attend to everything that is going on around me, I can leave it to the nurse to keep me safe.

I brought up the issue of how often patients are checked for this was something we had discussed in our first meeting. I shared with Ellen my feelings that only being checked once an hour can seem like you have been forgotten if you are in a closed room away from the main area of the Emergency room. With the heightened sensitivity one experienced, even having a nurse look in the door would probably be noted and appreciated. Family do not always stay and nurses sometimes forget to put call bells on the beds and ready access to help is a critical component of feeling secure. In my experience the need for comfort care continues even when a patient has been treated with medication.

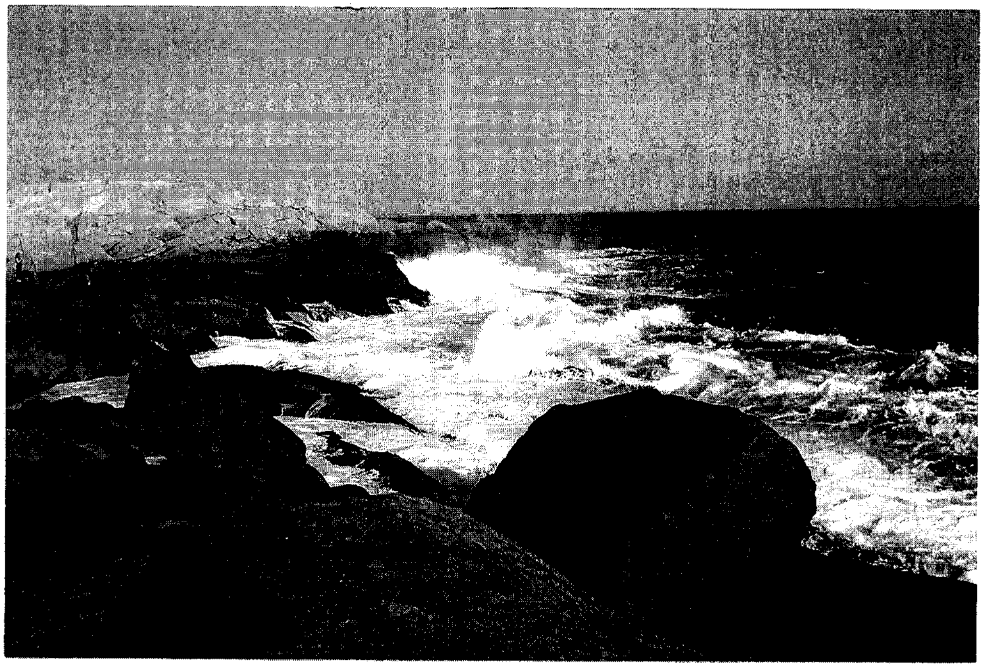

Figure 9 The Wave

Ellen had been thinking of a way to represent the unpredictability of migraines and consequently of the need for help. On a trip to Nova Scotia and while at Peggy's Cove the answer came to her while watching the ocean and she took this picture for me. She shared some of her thoughts, "Coming in and going out. And that's why I thought that, I thought of like the, the image. I go, like, 'That would be compared to it'. I thought, 'It's like those waves'". (laughs) "Yeah", I agreed. "A big, you think it's going to be a big one but it didn't. Some days you didn't feel it would be a big one, it hits you. It hits you and it just poof! You know, and in one way...", she said. "Once in a while", I remarked. "Yeah, yeah. And you couldn't help it", she noted. "It is, the image also captures the uncertainty of the disease", I suggested. "Yeah. You never know when it's gonna hit hard", she said. "Yeah. Like every wave that comes in and it swells up and...", she continued. "The waves never stop", I said. "No. It keeps coming every day, you know, and I can tell that you, and every day you get up and you said, I have a headache every day when I get up, it hurts. It depends on how it goes, sometime is goes away and sometimes it hits, you know", she said. "Yes", I agreed. "I thought that was, that was like a wave", she concluded. (laughs) "Yeah. That's a, that's a really good image", I said.

Chapter IX Peeking Through the Crack

Lessons To Be Learned

At the end of a story, there are often lessons to be learned, and as I reflect back on the narrative accounts in the 5 results chapters I am aware of an overlapping and intertwining of ideas and experiences that brings forth a narrative understanding of the issues around women's experiences of seeking help with migraines and of nurses' experiences with women who are experiencing migraines. Perhaps those narrative understandings are the wisdom Bateson (2000) spoke of that "is born of the overlapping of lives, the resonance between stories" (p, 243). Bateson also stated that to become wise, "one must have cared deeply about someone or something that could not be controlled or predicted, like a child or a lover or the fate of one's own body" (p. 242). If this is the case then the wisdom we have gained is surely born of wisdom from the women in the study: both women who have suffered migraines and nurses who have cared for them and who participated in this study of a condition of the body that is characterized by its uncertainty. In Bateson's words, "Wisdom follows the realization that all commitments, even commitments to oneself or to God, involve moving targets. Wisdom comes not by accumulation of more and more experiences but through discerning pattern in the deeper mystery of what is already there" (p. 243). In this study the participants and I looked at their experiences in different ways through conversations, memory boxes, and creative representations to tease out new insights into what they had lived. Through reflection on those narratives and representations of the experiences of participants in this study, I can begin to capture the depth and multiplicity of meaning in their storied accounts. By overlapping the experiences of women in the study, it is possible to discern patterns that help move toward a narrative understanding of what it means to experience seeking help with a severe migraine.

To reflect on the wisdom born of overlapping stories, I believe it is necessary to continue to work within the metaphorical three-dimensional narrative inquiry space (Clandinin and Connelly, 2000) used in the study. Perhaps I can think of the wisdom born of overlapping stories as threads that resonate across stories. The threads that weave through and across the stories told by the participants can only be understood by moving inward and outward to tap into personal and social dimensions and forward and backward to explore the meaning of memories and experiences from the past to the present and into a projected future. The insights must be grounded within the boundaries of inquiry context and the landscapes of the participants' and researcher's storied lives.

Resonating Threads Across Stories

For the women with migraines, the stories in this study reveal the private, personal side of migraines, the existential moments seldom shared and never seen. These are the times when women in the study have experienced the loneliness of suffering, the alienation of stigma and labeling, the fear of uncertainty, and the burden of chronicity. Side by side has been the hope that this headache will not need outside intervention, that there will never be another headache, that people will not notice they are in pain, that people will notice they are in pain and will offer help. My understanding of the experience of seeking help with migraines grows as I trace the pattern of social interaction of each woman from family to work to broader social context. Migraines are a social illness, an illness difficult to undergo without involving others because they so often affect socially prescribed roles. The wider the circle of contacts and responsibilities, the more potential there is for impact when a migraine occurs. Looking in the broader context, the social narratives of culture, institutions, and families that surround the individual often dictate how illness in general is viewed and how migraine in particular is understood and treated. For the nurses in the study their own family experience with migraines had an impact on how they worked with women with migraines and helped them to process the larger social issues that come into play in the form of formal policies and procedures. Experience generates tactful care.

In the process of writing the research texts I identified narrative threads that resonated across the transcripts of the participants. These narrative threads are described below with links to the participants stories as well as links to other research findings.

Resonating narrative thread one: Severity of migraines and need for help.

One of the narrative threads running through and across all of the conversations was the severity of migraines and the need for help. Inherent in the stories I heard was the fact that migraines can be so severe that the illness itself creates a barrier for the person in seeking help. Strong descriptive words resonated throughout and across the conversations with all the participants as we talked about the experience of having a migraine. Grace had sought help with her migraines over the years from a variety of sources but was not used to describing her headaches in detail. Her early words included “awful”, “pretty severe”, and “throbbing”. Over time, her descriptions intensified to “terrible” and “just unbearable”. In our final visit she talked about a headache so wicked that she had to pack her head in ice, it felt like a war zone she said. She also compared her headache pain to when, “as a young girl growing up on a farm she had become entangled in a barbed wire fence and still had scars on her back from that painful experience”. Although Grace’s migraines were severe, the thought of a long wait in a hospital waiting room was always too much for her and this had held her back from availing herself of this source of help. She did say that, “I have sought very much help … as much as I could find … but ah and some has helped and some has not”. Grace’s search for help has been self-driven and she has sought help through both traditional and alternative therapies.

Nina’s migraines were very severe from the time she was a young child and her family was very involved in helping her with them. Later, as an adult, she would spend many hours in Emergency rooms getting help but her key support system …was always her family. Her family was there for her at home and there to take her to hospital whenever necessary. Her stories of her migraines were open to her family but when it came to outsiders she found it was often safer to keep her stories silent. Because I had similar experiences with her accounts of seeking help with migraines perhaps she felt comfortable sharing with me how bad her headaches had been. Nina said, “it’s hard to understand how bad the headache is” … “your eyes hurt”, “you feel like you’re going to throw up”. She talked about “getting pale and your blood pressure went down and I don’t know, you got cold, you got hot”. When I asked Nina about her fears she said, “because the throbbing pain, you know, you think your head is gonna explode and then you’re gonna die of uh, I don’t know. Yeah I did get scared many, many times”. After a migraine she wondered, “how my stomach, how my body my muscles can take so much?” You know, it’s like you dehydrated and you feel so sick that then it’s like a new life after you, when you’ve felt so bad … like you’ve been in a coma or something”. She stated, “I’m so glad that I don’t have it anymore!”

Claire has never been able to manage a migraine without assistance and usually has to go to a Medi-centre or an Emergency room for professional help. I found as we talked she was like a sponge open and ready to soak up anything new I could tell her about migraines. Her theatre background seemed to help her in storying her experience with words rich in meaning and metaphors that resonated for me. I could picture what a wonderful teacher she would be. Claire wondered if she had some kind of horrible flu when she had her first migraine for she thought her "head was going to split open". She told me she is one of those migraine sufferers who are, "throwing up until I can't throw up anymore". She described herself as, "my face is caving in", "I can't open my eyes", "and the sound of your breathing is affecting me". She frequently referred to herself as curled up in a ball when she has a migraine and said she felt like, "kind of like a freak" the first year. She referred to her extreme sensitivity, "when you're curled up on that table and there's footsteps and that is like making your bones rattle you know?" Claire referred to the pain as pure torture and said, "there's time when I just prayed for the world to swallow me, you know, just swallow me up, because it's too much to bear".

I found nothing in the professional health literature that reflected these three descriptions of severe migraine headaches. These narratives fill a void in the understanding of what it is like to actually have a severe migraine. From her experience in caring for women with severe migraines in an Emergency room, Ellen translated these storied ideas into medical signs and symptoms that women experience: severe pain, nausea and vomiting, difficulty seeing due to photophobia, sensitivity to sound and touch, loss of balance, difficulty walking, and difficulty making decisions. She noted that the level of illness of women coming into an Emergency room with a migraine is often severe enough to interfere with their ability to explain their need for help and someone may have to do this for them. Making a connection here between the severity of the illness and the ability to seek help is also a new idea that is not talked of in the professional literature. Gloria stated that the doctors at the pain clinic where she worked would often not have seen the women they treated when they actually had a severe migraine for these women would not have been able to even stand up and come in to see them at those times. Nowhere in the literature have I seen mention of this dilemma of treating severe chronic migraines when you have not actually seen your patient in the throes of one. Ellen has family with migraines and Gloria has had migraines herself and they both stated that this was a great advantage in recognizing and understanding the needs of women with severe migraines.

The International Association for the Study of Pain (IASP) has a definition of pain that can be briefly summarized as, "an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage" (as cited in Carter, 2004, p. 211: American Pain Foundation website). But the narratives these women have used take us well beyond signs and symptoms and allow us to see and almost feel the embodied experiences. In Carter's words relating to the generic quality of the IASP definition, "Pain dramatically shifts and forever changes the landscape of a person's world and their positioning in it" (p. 211). The intensity of the language the participants have chosen to story their experiences is similar. The stories in this study take us into the realm of suffering and help us appreciate how difficult it would be for women to get to a place of help let alone converse with a nurse or a physician about their needs. All of the women with migraines in the study felt that there was a general lack of appreciation for the severity of their migraines by healthcare professionals and others outside of their families and, as a result, they kept their circle of helpers to a small group of close friends and family who had a better understanding of their experience. They did not feel that their suffering was fully understood or that it mattered in Emergency rooms and Medi-centres. If, as Loeser (2005) believed, pain and disease are experiences of the body, then those working with individuals suffering from pain, such as that produced by migraine, must understand the implications of an embodied holistic phenomenon like pain. One of the underlying theoretical perspectives of this study is the basic premise that all nursing care and every nursing decision is an ethical one (Bergum, 1994; 1999). Bergum (1994) proposed that to understand how the individual is living through the moment in question, what she termed the "living 'I' (p. 75), both parties must work collaboratively to discover inherent knowledge within a nurse/person relationship. Nurses assist individuals to make self-determined decisions and do so by helping them unify the abstract "body as object" with the subjective experience of the living "I" (p.76). Such collaboration brings about mutual respect and reciprocity and provides a sound ontological and epistemological perspective from which to examine the world of the chronically ill. In the formation of inherent knowledge it is essential to not just pull together descriptions and measurable facts; we must also incorporate the meaning and effect of signs and symptoms and the actual experience of living through not just with the challenges of change and transitions that make up past life experiences (Bergum 1994). This is not an easy task when women are very ill and nurses must tune into the experiential narratives that are seen and unseen and those which are unheard as well as heard to try and come to a deeper, more grounded story of the experience.

Resonating narrative thread two: Perception of the self with a migraine.

When I first started thinking about doing this study I had just finished writing a paper entitled “Migraine, the Stranger Within”, for, from my own experience with migraines, I have often felt that when I had a migraine I was at odds with some entity within that was not I. I wondered how this conceptualization affected my ability to seek and accept help. All of the women in the study, who experienced migraines, referred to fighting an entity, the migraine, that was not part of the self and that threatened the self and their loved ones. There seemed to be a lot of uncertainty around whether a migraine is separate or part of the self. At the same time there is this implied sense of needing to protect others from the look of pain. I wonder why it is necessary and what the cost is for the woman who is ill. This palpable tension is felt with each migraine as seen in this study, the tension between oneself and the migraine (as other taking over one’s existence and one not being able to protect oneself from this process) and the tension between oneself and other people (the need to protect others who witness the otherness of the migraine). This shows the response of the women to the notion of the stranger within or the otherness of the migraine taking over, the idea that one cannot protect oneself from this, but one must still try at all costs and be vigilant about protecting others from the migraine. Migraine sufferers constantly mediate between these tensions that may be brought on by this thought of otherness, and work hard at this at a time when they are least able to do so. I wonder why this is necessary. The topic of feeling guilty about asking for help or letting others down when help was needed was one of the narrative threads in this research. What does this say about society’s outlook on those who require help and others’ willingness to provide help? How do these attitudes or beliefs impact women’s decisions to seek help and ultimately their quality of life?

Melzack(2005) reminded us that "our brains are built to produce" qualities of experience (p. 87). In other words experience is not something exterior to us, waiting for us to encounter or feel. Experience is an internal construction of the interaction of mind, body, and environment. Melzack also noted that the complex stress response initiated by pain vastly expands the puzzle of pain (p. 89). There seemed to be a lot of uncertainty around whether a migraine is separate or part of the self. His work helps explain some of the elements of chronic pain often attributed to psychological cause, resulting in negative labeling of individuals and stereotypical expectations of behavior and motivation.

Grace pointed to the page, "I think that maybe that's me down there at the bottom, that ugly vulture" a picture that accompanied her poem. This seemed to capture the otherness of the moment she was describing. This comment went with our conversation about feeling embarrassed and guilty over how we look with a migraine. Grace vacillated a bit around owning the headaches for she saw the headache, as being very cruel and she was not sure if it was separate or not. Nina captured the sense of otherness when she said, "I look at the person in the mirror and it, it was like it wasn't me". Claire had said to colleagues who were new to the experience, "You don't understand, like when this comes on, it's it's ugly. It's ugly; you don't want to be witnessing this". Here again is the sense of something outside of the self, taking over and again the idea of wanting to protect others from the sight of it. In describing part of her painting Claire had noted that the red streaks represented "this creature that just sort of takes over"... there is "no escape". Again, there is the idea of otherness and that it comes from the inside. If we take this idea to a broader social perspective, we find social narratives that touch on the notion that women have some control over their illness and can shield others from their migraines. This may have contributed to the fact that the women in the study waited until they were very ill before seeking help.

To gaze into the face of one with chronic illness is to behold the face of suffering. These women saw that face as ugly, other than, and not of the self. They had learned to cover up suffering in an effort to appear normal and avoid stigma (Joachim & Acorn, 2000). Younger (1995) referred to the root meaning of suffering as, "submitting or being forced to submit to some particular set of circumstances, forced to admit to an existence that is not under our control or to the intrusion of an activity operating under another law than ours. Thus, it makes us not ourselves, and it is a threat to our integrity" (p. 3). This seems to fit with what the women were saying for they were experiencing one of life's great paradoxes, the alienation of the sufferer. With this alienation comes a second type of suffering, the loss of community or connectedness and as John Donne (1987) stated, "the greatest misery of sickness is solitude" (p. 106). Younger (1995) also suggested that suffering is, "what we choose to do with pain" (p. 4). Pain then becomes experience and contributes to the perception of self and ultimately over time must have an impact on identity.

bell hooks (1997) introduces us to the idea of social narratives, beliefs widely held that act like funnels moving individuals along into predetermined lifestyles or actions with matching moral sets. She wanted to be a writer and her parents, unable to dissuade her, saw teaching and remaining single the only option for her. In a way it was a means for protecting her and providing for her in the future and if it meant she had to live within certain bounds, so be it. There were few choices for women then and to go against the grain was to bring upon oneself and one's family significant stigma and uncertainty. Nina found herself up against a social narrative of a different kind. She told me her mother said she should, "try to take care of yourself and not getting, not being sick too much because men get tired of it. They don't like women who get sick a lot". Here was one example of a social narrative that protected men from the reality of acknowledging women's migraine illness and set up a barrier for women to getting help, for to seek help she would have to reveal her need. The frightening implication for Nina was that it created a constant element of fear that her husband might leave her because of her illness and this fear stayed with her over the years. Nina's mother no doubt had the best interests of her daughter in mind and was trying to keep the uncertainty factor low. When Nina's migraines were gone the fear left, only to return when she developed severe heart disease.

Claire shared a story of her first migraine as a new teacher at her school and the fear of being recognized through the crack between the curtains as she lay curled up in agony on a small cot at the end of a hallway. At a personal level, Claire did not want people to see her in a weakened state, looking and feeling so unwell. At a more social level her professional identity was at stake, that image of a strong woman, "the epitome of organization", "someone that people can come to if there is something going on". This would be the start of a new public identity, as a teacher who has severe disabling migraines. There would be many questions to answer and parts of her reputation to reestablish. Here was another social narrative, one that prescribed acceptable behavior for a teacher. Living with the deviation from the expected norm influenced her self-image.

Ellen described women coming for help, hidden behind sunglasses and covered by hoodies, bodies bowed by pain. This resonated with me as I thought of the humiliation I usually felt coming into Emergency rooms similarly overwhelmed by pain and light. As varied as these stories are they share the same idea of self-image when one has a migraine and the sense of decreased worth one has at the time. This is something both culturally and socially defined and that varies over time. For example, the younger, new teacher, Claire, was more susceptible to challenges to her self-image that day behind the curtain, than the older more experienced woman who recently shared her story with me. Today it is easier for her to accept migraines as part of herself. Grace is probably the most accepting of her illness. She manages a busy social life despite her headaches by knowing her own limitations. When she was working she tells me she turned down a higher paying, higher stress job to avoid the risk of missing work with migraines. Her self-image seems to include acceptance of a level of control over her migraines that incorporates a significant amount of suffering. I think Nina's ability to accept her illness was largely due to the strong support she received from her family. They looked at it as a family illness and that went a long way toward lessening the isolation and alienation of her illness experience.

Another factor that contributes to how women think about themselves with migraines is the stigma that is attached to it. Stigma is one of those issues that comes with the diagnosis of migraine. It primarily arises from the fact that narcotics are sometimes used to treat migraines and a small percentage of people misuse narcotics and misrepresent themselves in Emergency rooms with migraines and in need of drugs. The fear of addiction among patients by healthcare professionals has been highly exaggerated for years and this has led to the potential for stigma being attached to all migraine patients (Joachim & Acorn, 2000). Evidence of disability can also lead to labeling of individuals that results in isolation, lack of support, and ridicule. Nina told of colleagues at work thinking that headaches were an excuse to get out of work, "because of this, people may think you're making it up", "so it's not fair" she said. This spoke to the very social nature of the illness. She said when it came to work, that, despite her migraines, "I'd hang in there, hang in there until I could come, it was time to come home". Even social relationships were tested by her migraines, she noted, when friends would acknowledge "the look" of her headache and say, "oh your headache" with an implied and sometimes frustrated "again" left unspoken. Nina even found that her self-help efforts, like staying on a special diet, made her subject to pressure to conform to social norms and this added to the stress of her illness.

Grace did not talk about stigma directly but she certainly kept the reality of her migraines to herself as much as possible and she did deal with some drug related issues that she felt labeled her. She was never treated with narcotics so these drugs were not an issue but one doctor told her she was addicted to Tylenol and her husband does not like her taking it. Nina was treated in hospital many times but did not speak of drugs and addiction as an issue. Claire, however, found this was an issue, especially in the Medi-centres she attended. It was in talking about these experiences that she referred to herself as "that woman", "there's that one we don't know what's wrong with her but um, we have to give her a shot". Claire always felt a sense of judgment because some people abused the drugs she needed and said when she went for help it was never, "Oh I'm so sorry this happened to you", rather it was, "Oh okay you need some pain medication". She did not want the staff thinking she was there just for the medication; she was there because she needed treatment.

Resonating narrative thread three: Feeling guilty.

The topic of feeling guilty also resonated throughout the narratives and first arose in talking with Grace about whether her migraines had ever interfered with her social life. She mentioned one occasion when she was unable to make dinner for her brother and sister-in-law following an afternoon out because of a migraine. She seemed to feel guilty about this for she stressed that she was "feeling quite sick that time". This kind of interruption of social roles was a common theme for Nina and Claire as well, who both talked about the social events they missed due to their migraines. Nina told me how many times she had to, “drop everything and you have to go and lay down”. She noted that she missed socializing with family and friends so many times and she used to cry in frustration wondering why and where the migraines came from. This was a new idea for while the literature is full of common triggers for migraines, many just come for no discernable reason leaving the individual wondering what they did to cause this. Claire talked about more than once returning from the hospital and walking by guests in her own livingroom on her way to bed and saying, “Sorry, I’m sorry”. She noted, “and there’s the apology again” … “and, and the guilt that, okay, I’ve ruined this party”.

Feelings of guilt were common around the immediate issue of treatment of migraines. Claire mentioned the many times she apologized to her husband on the way to or from the hospital, “I’m sorry to put you through this”. When we compared what he was going through with her experience at the time, we once again saw an example of trying to shield men from the reality of women’s experiences with migraines. Feeling guilty came up several times in discussions of medications Grace was taking at one time or another. Grace had always relied on Tylenol as her main medication for migraines and at one particular time her doctor had told her she must be addicted to it and that she would need to go off it for three weeks. Tylenol is not considered an addictive medication and telling her she was addicted was very upsetting. She managed to go with nothing for the three weeks and then started taking Tylenol again for she had nothing else to take for her migraines. Grace’s husband does not like her taking a lot of Tylenol and this experience only adds to her feelings of guilt every time she takes this medication. Grace also had to go off a medication called Imitrex as it was thought it caused her to have a stroke and seizure shortly after her 65th birthday. She was told she had “OD ed” on Imitrex. She was taking a lot of Imitrex but she was not exceeding the prescribed amount, she simply had too many migraines and nothing else to take. The fact that she was following her doctor’s orders does not help the feelings of guilt that her actions caused the stroke. It was obvious to me that how we even talk to women about medications and other factors related to their illness can have a significant impact on their guilt load.

Nina told of showing up at events to be sociable and having to leave early but making the effort anyway. She went, knowing that she would have to leave early but also knowing that the effort must be made to keep her friendships alive and well. Claire provided an example of staying the course one day when she was casting a play. She worked until she was ready to drop and was sick in her car as she finally left for home. She noted that the people she was working with that night were new to her and she did not want to give the wrong impression by leaving early. Claire understood the social consequences of chronic illness when that illness may not be well understood by others.

These images brought up the basic issue of identity and the impact that feelings of guilt about having migraines can have on who we are, who we become, and the choices we make. Some of these choices impact our openness to seeking help. Younger (1995) introduced an interesting take on suffering and pain that suffering is, "what we choose to do with pain" (p. 4). As such, suffering becomes a source of experience, one in which we may, "endure, hold out, resist, or sustain" (p. 4). Is it possible, that in moving through an experience of suffering, we seek to find meaning in why we are being hurt (Weil as cited in Younger, 1995, p. 4), and through this, find our very selves modified? Even though two of the women had had migraines most of their lives and one had had them for six years, all three showed the same propensity to hide their pain from others, to manage their pain on their own as long as possible, and to seek help only when they were too ill to help themselves anymore. This practice had to have a significant effect on their quality of life. How a person thinks about himself or herself is tied to how others react to them and to evidence of disability or illness. Without acceptance or when there is lack of belief in one's experience, individuals are at risk for ridicule, isolation, lack of support and inappropriate treatment. Because things like disability are tied to culture, location, gender, sociopolitical factors and history (Wendell, 1996), identity may also be influenced by these factors.

The issues of blame, guilt, and stigma are closely intertwined as we listen to the storied lives of these women. Ellen spoke directly to the question of seeking help when she talked of women frequently saying they did not come in to Emergency earlier because they did not want to bother the nurses. They felt guilty for coming in with a migraine, something they saw as less than an emergency, as something they should have been able to handle themselves. When asked why they did not come sooner when it would have been easier to manage, they listed all the responsibilities they had to fulfill before they could come. I know that Grace worries about the amount of Tylenol she takes and feels guilty about it. While she could benefit from Emergency room intervention she takes Tylenol and goes to bed with her ice pack and endures. She seeks alternative therapies and I wonder if that is in part because they are seen as a safer or more acceptable choice. Nina grew tired of the guilt and decided to try and rid herself of the headaches. She sought out the help of an alternative practitioner who put her on a special diet. She was successful. Claire is still being treated in Emergency rooms and is only just being started on prophylactic medications at this stage. She is just starting to explore alternative therapies.

The issue of guilt does not stop at the treatment stage for there is a ripple effect when these women have a migraine and lose a day or more in their lives. The migraine impacts more than themselves because they are all part of a social network and with this comes a sense of obligation and feelings of guilt. Claire described her migraines as “it’s a detour every time it happens”. After the migraine on the day when she was casting a show, “My entire day got switched around and then there was another day when I couldn’t contact my women that I want to put in my show, so I had to contact them later last night. So that put our rehearsal schedule off by a day”. The ripple effect is obvious as is the number of people that are affected. Claire told me she keeps a stack of thank you notes on her desk to send to people who help her with her migraines and with the aftermath of her migraines. Nina also mentioned keeping thank you notes on her desk at work for this same purpose. Whenever Nina talked about her migraines, she talked about the impact it had on her family or at work. For her, migraines were always relational and came with a sense of obligation and feelings of guilt.

Resonating narrative thread four: Burden of chronicity.

Two things that contribute to the burden of chronic illness are the uncertainty of it and the disability it creates. These factors can play out in a variety of ways. Bleeker and Muylderij (1992) noted that in the experience of chronic illness the body is no longer silent but calls attention to itself. Claire described how her ability to remember people’s auditions was affected at a casting session at work and that she had to rely on a colleague to help her make decisions. She remarked about one woman that she could not remember well, “not only am I doing her a disservice, I’m doing myself a disservice because I’m trying to put together this production that is stellar, right? Like you just always want to do your best". To deal with the uncertainty of her illness Claire had taken the somewhat unprecedented step of having students who had been through her theatre program in positions of stage manager and assistant director. She noted they could probably take over if necessary. In fact, Claire had not realized that she had indeed created a safety net for herself until we talked about the issue. This resonated with me for in my work as a professor of nursing I had hired students to help me with clerical work that I would have been behind in otherwise because of my migraines. Grace on the other hand had elected to not push herself into a work situation where the workload of the job could leave her at risk if her migraines became too much. Here was a thread of meaning that provided insight into the disability that migraines can cause but it is a disability that is hidden from most people.

Uncertainty often appeared in the lives of these women. Claire noted that part of her always hopes that her body has been cured or repaired between migraines and that she will not have one again, but along side the hope is the fear that a migraine will come. When a migraine strikes she is faced with the uncertainty associated with "that woman", the term she used for herself with a migraine for, "there's so little control over my body when that happens right? There's, well, there's none, she said." Claire, storied uncertainty in her life another way as we looked at the picture she had painted for the study. In the picture, the vine represented the many branches of her life and she said that after a migraine she often wondered, "how am I gonna deal with this the next day, what's, how's my life been affected by this?" She said, "you have to get back into that pattern of your life and a vine is really a, a good metaphor too because, it's not one straight line you know, there are many parts of our lives … so they branch off". At these times, she has to look to herself first to see what kind of help she needs to get her life back on track and with each migraine that self help can be different.

Part of the uncertainty of living with migraines is the constant need to weigh the risk of potential suffering and need for treatment against the benefits of activity, be it physical, psychosocial or spiritual, as a part of daily living. All three women with migraines in the study were aware of this balancing act. Price (1996) reminded us that quality of life measures reflect social norms of the healthy and may not be appropriate or meaningful for the chronically ill given the uncertainty in their lives. Chronic illness needs to be defined in a much broader way, taking into consideration the "socially constructed world" in which it is embedded (Thorne, 2000, p. 6).

Resonating narrative thread five: Tacit knowing in migraines.

There was evidence of tacit knowing of the migraine experience among the women with migraines and the nurses who treated these women. Grace showed how her migraines were part of, and yet separate from, herself in the way she described them in purely physical terms that required observation for validation, leaving out much of the evidence of suffering from her rhetoric. Her memory box had items related to treatment and frequency with no reference to her suffering. In her poem, she referred to waging a war and she included caricatures of what could be the headache or she with the headache. Nina also spoke of being at war with her migraines and as she looked at herself in the mirror she felt an almost out of body experience for the "look" of a migraine was so foreign to her. She talked about her eyes going inward, looking less shiny and being different. Grace also recognized elements of the "look" and was surprised when others did not see her pain. Claire took the "look" to another level as she talked about "that woman" who had the migraine. Polanyi proposed that we reconsider human knowledge "by starting from the fact that 'we can know more than we can tell' (author's italics)" (as cited in Taggart, 2002). He was referring to tacit knowledge, knowing that is subsidiary to what is the focal object in the environment (Taggart, 2002). I would suggest that the "look" is tacit knowledge that the women in the study gradually learned.

The two nurses in the study also told stories of women with the "look" and how they were able to recognize it in their practice. Ellen in particular connected elements of the "look" with problems such as photophobia and problems with balance and connected these to the need for interventions such as securing a darkened room and a wheelchair. This was an example of Ellen using her tacit knowledge, putting herself in the sufferer's place and finding understanding. This is storied experiential knowledge and we can learn from how she attends to her patients. Gloria made a connection between "the look" and the narrative that she was privy to as she interviewed patients. She concluded that she was able to recognize and interpret the look better than physicians because she understood the story that accompanied it. "The look" then as tacit knowledge takes on a multiplicity of meanings from very individual self-assessment to social narrative but in each case, it can be connected to identity, to perception of worth, to relationships, and to social action. The question this raises as to tacit knowledge, knowing more than we can tell, is that while in professional practice, one demonstrates tacit knowledge working all the time, as we see from Gloria here, tacit knowledge in the migraine sufferer more often remains inside. It is difficult to demonstrate except via these few recognizable signs. Self-care tacit knowledge of migraine sufferers is not always valued by healthcare professionals and so it too remains hidden.

Another way of looking at how Ellen works with women with migraines is to consider what Lugones called "World-Traveling" (1987). Lugones speaks to the many experiential worlds we inhabit, some where we are comfortable and some not, some where we can be playful and some not, some where we are accepted and some not. I think Ellen has learned to recognize the boundaries of the world of migraines. She understands the norms, the beliefs, the values and is able to enter that world because of this knowledge and is accepted there. The women she cares for accept her and feel safe in her care because of her knowledge of the experience of that world. More nurses need to learn to be World Travelers like Ellen.

Resonating narrative thread six: Seeking help.

When the issue of seeking help is examined, the women with migraines in the study all advocated for themselves when they were well and sought out help for their migraines, but when they were ill they waited until they could not handle the migraine anymore before seeking outside assistance. Nina says she did not want to be a burden and say she did not feel well every time and so she, "put up with it until I couldn't handle it anymore". Then she would say, "Please take me to the hospital". Nina and I talked about the importance in society of, "being willing and able all the time", and how this social narrative contributed to our staying home with a migraine until the last minute. By this, we meant that as women we felt we had many family obligations that were culturally and socially prescribed and these had to be handled before we could tend to our own needs. Nina also said that going to the hospital was not something she took lightly for while they knew her by name she felt she was known better by the category "just a headache". In her mind, her migraines were anything but just a headache. Treatments tended to consist of a shot and being told to go home to "sleep it out". Since one of her aunts had died of a migraine, there was little comfort in the quick dismissal she usually had from the hospital. She literally feared that she might suffer something serious like an aneurysm on her way home. Nina would eventually be rid of her migraines completely but she then developed serious cardiac problems also requiring visits to the Emergency room. It is interesting that in terms of suffering, she equated the visits with migraines and cardiac events the same, and yet the treatment for her migraines was far less supportive. It begs the question, does suffering count anymore or do we have to be in a life-threatening situation to warrant real support.

Suffering is a source of experience in which we may "endure, hold out, resist, or sustain" (Younger, 1995, p. 4). Sometimes I think we can choose how to react to illness and other times I think illness grasps us in a hold that barely allows us to find a breath. When this happens I think we are one with the illness and there is no sense of "it" and "I" nor is there a separate "I" that can go for help. While it is nice to think of the illness being separate from us in the resonating thread earlier of the stranger that takes over, in reality, the migraine is lived through each painful moment. This kind of vulnerability is life changing and impacts how we face the next crisis.

Claire also talked about the quick dismissal from the Emergency room. "Okay, I've got a migraine. All right, we'll give you a shot. Are you okay to go home? Go home. Like that was always how it was, she said". There seemed to be something missing for her in this approach to care. For one thing, she said there was never any follow-up on the fact that she was making frequent visits to the Emergency room. She had to bring this up with her own family physician. Grace and Nina had similar experiences in that they had to seek out sources of help from their family physicians and alternative therapists. The one thing really lacking was someone to coordinate their search for help with their migraines.

Ellen brought a different perspective on providing help in a timely fashion as she explained the process of fast tracking migraine patients. This process helps patients to be seen sooner and to leave sooner. We also saw Ellen and Gloria working in relationship with patients to develop experiential inherent knowledge, a combination of descriptive and objective knowledge that led them to a narrative understanding of the situation.

Understanding the meaning of illness to a patient allowed them to work at an intuitive level of practice, not just relying on best practice guidelines as the key to ethical practice.

Nursing Implications

As I peeked through the "crack in the curtain" during this study I was caught by the evocative stories that lay beyond. Even though it is a small study there is considerable depth to the content and the experiences of the women participants raise many questions. I believe the study does provide a beginning narrative understanding of the experiences of the women in the study seeking help with severe migraines. I know their stories will resonate with the experiences of other women with migraines and other nurses who care for women with migraines. The professional health literature is missing storied accounts of the experiences of women seeking professional help with severe migraines. It is my hope that this study will begin to fill that gap. Based on the literature, this study, and my own experience I believe that many health care professionals do not fully appreciate the severity of the migraine experience, the impact that it has on women's ability to communicate effectively about their needs, and the effect this problem has on women's ability to seek and find appropriate help in a timely fashion. Having discussed these issues in the resonating narrative threads I would now like to address how these and a few other issues relevant to seeking help with migraines, that arose in the course of the study, have direct implications for nursing.

Looking at how we assess patients.

What is strongly apparent, is that the Emergency department and its current triage system does not work for variable illnesses. This must must be reassessed as there is no other place for people with migraine to access care. For staff nurses and for patients, it is a process of learning how to communicate, how to respond, how to match the signs and symptoms with practice guidelines and how to emote caring and concern at the same time. The key to providing help is to understand the patient's situation as well as her needs and this means a thorough assessment. Nurses need to understand that women with severe migraines often stay at home until their symptoms reach a point at which they can no longer manage them on their own. It is only then that they make the trip to clinics and Emergency rooms for help. To come earlier is to risk presenting with a complaint that is not legitimate in the eyes of health care professionals. This problem of legitimacy has not been directly addressed in the migraine literature. Some of the literature on stigma and labeling (Joachim & Acorn, 2000) captures some of the issue of legitimacy of illness and it is nicely presented in the case of asthma patients who face a similar problem (Becker, 1993). It takes courage to wait to be an "emergency", to be thinking all the time, is it legitimate enough this time, something most of us never have to think about, especially when this event happens over and over again, and when women know they may be facing a long wait before receiving help. Women with migraines are at an increased risk for stroke and longer waits do pose some additional risk and as in Nina's case, where a relative had died from a migraine, a long wait brings a lot of fear.

All of the women in the study spoke of a recognizable "look" of a migraine. The nurses and the women with the migraines were able to speak to this look in terms that involved more than just clinical signs and symptoms. They also involved behavior, posture, and movement. It may be that nurses could benefit from learning about a group of elements we might call a migraine matrix that make up this look. Some research has been done in the field of recognizing suffering and pain (Deyo, Prkachin, & Mercer, 2004), but I found no mention of particular signs in the migraine literature that might help nurses recognize a migraine. Difficulty talking and thinking were mentioned several times in this study and this should readily translate into the need to take a history slowly and give the patient time to form an answer. Several other signs and symptoms not mentioned in the literature as specific to migraines but identified in this study as causing difficulty in seeking help and contributing to suffering are difficulty walking and extreme sensitivity to touch and movement. These resonated with me and I believe these need to be considered for inclusion into signs and symptoms common to migraine. Balance interferes with more than just walking, it affects the normal rhythms of life activities, including those that may be part of seeking help. Balance and difficulty walking are also safety issues. Ellen noted that women often came into Emergency with sunglasses, their heads covered, and bowed over from the pain. These also resonated with me. The sunglasses in particular should be readily associated with photophobia.

Often there is a search for the presence or absence of a sign or symptom on route to a diagnosis but there is not consideration of all the implications for the patient if the signs or symptoms are present. Ellen presented the ideal scenario of a nurse who is able to recognize the look of a migraine and then anticipate the needs of the woman and act immediately to meet some of those needs before the patient is seen by a physician. With better recognition of migraines, the distressing burden of proving one has a migraine will be lessened for women seeking help. Anticipating some of the basic physical needs of a woman with a migraine is one way to decrease suffering and to establish trust with a minimum of time and effort. From the patient's perspective, it also shows if a nurse appreciates the level of physical suffering that is associated with a severe migraine. Ellen showed us that it is in that one-on-one relationship where trust and a feeling of safety are established. Nurses need to understand how vulnerable these women are at this time, when the effects of the migraine have virtually shut down their ability to interact with another person other than at a very basic level. Women are not well enough to think to ask for a wheelchair even though they need one, or any other basic physical comfort interventions.

Ellen's stories bring us back to Bergum's (1994) work on knowledge for ethical care. To care for someone nurses need several kinds of knowledge in deciding what is the right thing to do. They need knowledge of the subjective experience, "where a person describes immediate personal symptoms to the professional" (Bergum, 1994, p. 72). This is value based, emotion laden knowledge, unique to the individual. Nurses also need to step back from the patient and collect abstract knowledge "to theorize and categorize in order to identify the underlying causes of symptoms" (Bergum, 1994, p. 73). To fully appreciate both kinds of knowledge they must be brought together as inherent knowledge, that is constructed within the relationship between the patient and the healthcare professional. Inherent knowledge of the living 'I', according to Bergum, is "not knowledge that is interchangeable or universal, but rather knowledge that is irreplaceable and unique to this relationship, this patient and this professional. It is complex, dynamic, comprehensive, and ethical" (1994, p. 74).

Bergum takes us further as she helps us see how to apply the concept of inherent knowledge for ethical practice. Because we are inherently in the world she states that collaboration is the path we must take to understand inherent knowledge. Ethical knowledge is not available to us before it is needed, it is contingent on the moment and so the first step we must take is to move from a place of domination to one of collaboration.

A second consideration is that we are all culturally bound and shaped and so our consideration of a situation must always take us from the abstract to the contextual. The third step in applying inherent knowledge is to move from beneficence to nurturance. Nurturance occurs when nurses effort "is to strengthen and support each person's ability to choose what is best 'for his or her own good'" (Bergum, 1994, p. 77). Unlike beneficence it occurs in reciprocation through interaction and so is always relational. It is in relationship and through nurturance that vulnerability is recognized and can be reduced, healing is made possible, and hope can be found (Bergum, 1994).

Bearing witness.

Nurses are present with patients through many times of great emotion, vulnerability, change, and unfolding of new life stories. Naef (2006) proposed that bearing witness is a moral way of engaging in the nurse-person relationship at these times. Based on Levinas's ethics of the face, Naef claimed that bearing witness is "enacting one's moral responsibility which arises from the encounter with the other" (p. 146). Levinas (1985) proposed that all persons are responsible for each other and that that responsibility arises at the moment of seeing the face of another. This experience is prereflective, pretheoretical and therefore outside intentionality (Levinas as cited in Naef, 2006). It seems to me that in a profession where caring is a seminal element of practice, bearing witness for populations who are vulnerable and often marginalized is an ethical imperative. When applied to the situation of chronic illness and in particular migraine headaches, I can see that bearing witness is one way nurses can help to testify to the authenticity of the experience of suffering in a migraine. I think bearing witness is both a conceptual way to teach moral care as well as a practice that can be identified, different than other concepts such as advocacy because it entails an immediacy on which one can not turn one's back.

Consider the fact that the issue of stigma and labeling is still with us despite the evidence that few people with chronic pain become addicted to narcotics. Part of the stigma that accompanies migraine is a belief that women should somehow be able to control their illness, that they are the cause of their illness and if they only adjusted their lifestyle, they would not have to come to an Emergency room. There is no evidence to support this supposition. All of the women in the study made adjustments in their lives to try to lower their stress and they still had migraines. It was clear in our discussions that feeling labeled was a factor that kept women from coming to the Emergency room early in their attacks, at a time when it would have been easier to manage their migraine. Stigma also contributed negatively to an altered self-image over time. Nurses and physicians need to address this issue realistically and recognize the damage that is being done to a large population of women because a few people misuse drugs. These same attitudes exist in the larger population and healthcare professionals can play a role in dispelling unwarranted concerns among families and patients themselves.

One of the difficulties faced by women with migraines who must seek help in Emergency rooms is the wait time, for women are generally coming in when they can no longer handle the pain by themselves and they need to lie down not sit in a waiting room. The system of fast tracking and the Emergency room pain route described by Ellen are excellent ways to help reduce wait times. These policies while positive on one end do raise a concern in that they can lead to too speedy a discharge. I wonder, in light of the feelings about being dismissed too soon expressed by Claire and Nina, if sending women home quickly is really a good idea. This practice is based on the belief that the treatment will have a lasting effect and that the woman will be able to rest at home. This is not always the case and perhaps more consideration needs to be given to the usual course of a woman's migraines and the resources available to her at home. Gloria's storied accounts showed us the importance of face-to-face encounters and taking a holistic approach to care. If the goal of an Emergency room is to move people through as quickly as possible, is there any room for psychosocial care? That care may help to prevent a return trip to the Emergency room. This may not be the ideal time to help women plan the first step to better health, but every opportunity must be seized to refer women to primary health care sources for follow-up investigation of their problem. This is especially important for women without a family physician. These are important issues and nurses need to bear witness on behalf of women with migraines so that policies and procedures can reflect the reality of the experience of women moving through Emergency rooms.

Seeking help.

One thing that was evident in this study was that experiences about seeking help with migraines can be accessed in a number of ways. Story telling was the primary method used but some of the most telling stories came out in discussions of articles in the memory boxes and items made for the artistic representation of the experience of seeking help with migraines or the migraine experience. The use of such tools in clinics such as the one where Gloria works could be invaluable in helping both healthcare professionals and patients understand their true feelings about their migraines and the experiences they have had with seeking help. Memory boxes in this study, served to assist the women to access their experiential knowledge, how they live the dis-ease from the inside, how they thought of the dis-ease as a patient from the totality of their experience with it. The uncertainty of this illness and the nature of it, coming and going seemingly at will, the stigma and embarrassment of it, shows itself clearly in the memory boxes here.

It would seem that there are several types of help available to women with migraines and the consequences of each facilitate or act as barriers to women taking advantage of that help. Some help comes from sources that are known to the women, that are intuitive and are readily offered without having to ask. These are easy to accept. Some help is available but instructions are needed as to how the help should be given. With the difficulties women have in communicating during a severe migraine, this kind of help is welcome but not as easily accessed. There is help that is asked for and readily given by knowledgeable people but again communication limits access to this. Then there is help that is asked for and grudgingly given or refused for it is tied to stigma and labeling not always based on valid facts. This results in feelings of low self esteem, embarrassment, and anger and inhibits patients from seeking help the next time they are in need.

The lived experience of being comforted by a nurse.

Bottorff (2002) has written a beautiful article on the experience of being comforted by a nurse, in which she looks at what it means to be comforted and what it is about nursing that brings comfort. She explores how comfort, like health, is more often described by what noxious symptoms are missing than by what positive experiences are present. As Bottorff examined the experience of a nurse being present with a patient, she drew on the doctoral dissertation of Olsen (1986). A nurse who is truly present with a patient responds to the losses that accompany disease and patients are aware of this response for it in turn generates a kind of hopefulness (Olsen, 1986). Being present then becomes a moment of being with and this is the source of comfort.

I cannot stress enough how important it is that nurses establish a caring relationship with these women and their families when they seek professional help. If the person is not affirmed at this basic level of interaction between themselves and the professional they will not improve much. Both patients and healthcare professionals have to be taught this. If we are serious about the quality of care we provide then we need to stop looking at why we cannot implement findings coming out of research studies like this one and find ways to change our practice. Most of the findings from this study relate to attitudes, knowledge, and basic nursing care. The implications for women seeking help with severe migraines are huge in terms of reduction of suffering, feeling free to seek help sooner and thus shortening hospital stays, removing stigma from their illness, and removing barriers to seeking help.

Implications for Research

There is a dearth of research on the actual experience of living through a severe migraine and seeking professional help with one. More studies like this one will help to further story the experience in a way that captures the impact of past experiences and projections about the future on help seeking decisions being made in the here and now. Narrative inquiry allows us to highlight both the positive and negative influences of the particular and the broader social narratives that tend to shape individuals in one direction or another. Much of the research on migraines is directed at diagnosis and treatment from a medical perspective and I was unable to find any nursing studies that address the suffering in a migraine and the nursing interventions that can do so much to ameliorate that pain. While there are many studies on the use of assessment tools, some significant factors may be lacking in those tools that have a direct bearing on nursing interventions. I believe the issue of stigma and labeling must be addressed in collaborative research studies with both health care professionals and patients involved. Most importantly I think nursing must take the lead in studying how to establish better patient professional relationships at a basic level for this seems to be a forgotten art or one overshadowed by the new technologically oriented nurse. No matter what health promotion programs or skills we teach, health will not improve until we are able to engage with people at a level that is meaningful to them.

In the field of chronic illness we need to ask ourselves if we are dissociating from those with chronic illness and disability? As Bergum (1994) suggested, our answer may be to become disembodied from the experience, seeing the other as object and in that process, ourselves becoming object. To understand the lived "I", Bergum (1994) said, "nurses must be re-embodied, must experience their bodies as part of their own subjectivity rather than as unfeeling instruments" (p. 76). I believe this holds true in nursing research as well and that studies in relational methodologies such as narrative inquiry are one way to help overcome this problem. I believe that relational methodologies also bring a personal investment in the research that helps motivate the researcher to address the urgency that exists when it comes to finding a way to translate findings into nursing practice and interprofessional practice as often takes place in Emergency Departments.

Narrative inquiry is a relational research methodology, which is its strength for studying medical conditions that are variable, episodic, as we are able to more sincerely understand illness as experience. Listening to someone else's experience, and having it resonate with your own experience, raises the question of who's perspective is this, the one who is telling or the one who is listening. But it is here that the relational part of narrative inquiry comes into play; we each own our experience, we each give an account of our own experience in a certain way, and we show a process of coming to understand our own headaches and our interactions with others to secure treatment as we move through the conversation together. Unlike more traditional research methodologies, where shared experiences are not considered part of the data, in narrative inquiry the conversations in total as field texts and the interactive process are the basis for the final research texts. Stories unfold anew each time they are told and there is potential for new insight given the context of the conversation. The rigor then of narrative inquiry, is how we then represent these conversations to others in a research text because we must make the relational conversation between the researcher and participant as transparent as possible. As the conversation moves on in the field text, there is a co-construction of meaning taking place, a co-composition among the participants. As the final research text takes shape, it then becomes an acknowledgement that the readers who read this work, will also co-construct their own understanding and meaning. Quantitative research can provide us with some of the objective elements of a migraine. Narrative inquiry can show a process of living through, and the meaning of what happens when one experiences acute episodes of migraine headaches and seeks help with them.

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Appendix A

ADVERTISEMENT FOR PARTICIPANT RECRUITMENT

A Narrative Inquiry into the Experience of Women Seeking Professional Help with Severe Chronic Migraines

Researcher – Sharon D. Dublin B. Sc BN MN (pc) PhD RN

I am looking for women, with a history of severe migraine headaches, and for registered nurses, who have experience caring for women with severe migraine headaches to volunteer to share their experiences with me, in a research study running from January, 2005 to September, 2006.

Women with migraines, must be at least 35 years old, understand and speak English fluently, have been diagnosed with migraine headaches by a doctor, have suffered from migraine for at least 10 years, and have sought help with migraine headaches in both hospital and community settings in Canada. Registered nurses, must be at least 35 years old, understand and speak English fluently. They must have practiced nursing at least 10 years in the Canadian Healthcare System, and have provided nursing care to women with severe migraines in either a hospital or community setting.

If you are interested in participating in the study or wish more information about the study, please contact Sharon Dublin by phone 780-633-1641 or by email sdublin@ualberta.ca. By contacting me, you are under no obligation to take part in this study. Individuals can also contact my supervisors: Dr. Brenda Cameron at the Faculty of Nursing 780-492-2699 or Dr. Jean Clandinin at the Faculty of Education 780-492-7770 for further information or verification of the study.

Appendix B
(U of A Letterhead)
Information Letter for Women with Migraines

Study Title: A Narrative Inquiry into the Experience of Women Seeking Professional Help with Severe Chronic Migraines

Investigator:
Sharon Dublin, RN PhD Candidate
Faculty of Nursing, University of Alberta
Phone: 780-633-1641 Email: sdublin@ualberta.ca

Co-Supervisors:
Dr. Brenda Cameron 780-492-6417
Faculty of Nursing, University of Alberta
Phone: 780-492-6217 Email: brenda.cameron@ualberta.ca

Dr. Jean Clandinin
Faculty of Education, University of Alberta
Phone: 780-492-7770 Email: jean.clandinin@ualberta.ca

Purpose of this study:

The purpose of this study is to understand the experiences of women seeking help with severe chronic migraines and the experiences of nurses who have worked with women who suffer from migraines.

What will happen in this study:

In this study, you will be asked to talk about your experiences of seeking help with severe chronic migraine headaches. There will be three tape-recorded conversations, at a time and place that is best for you. Conversations will last 60-90 minutes.

Each conversation with the investigator will be different. The **first conversation** will be a time for you to tell your story of having migraines. For the **second conversation,** you will be asked to tell more of your experiences using items collected for what we call a memory box, to help you remember things that have happened to you over the years. The items you choose will have meaning for you and will connect to your experience of migraines. You will be shown a memory box during the first meeting with the researcher. For the **third conversation**, you will be asked to show your experiences in a different way. You may take photos of places, people, or things that tell something about your experience. You may also draw or paint pictures, make a collage, or keep a diary of your daily life for a short time. Supplies, such as a disposable camera or paint, will be given to you. During the third conversation, you will be asked to show and talk about your creative projects and how can help us understand your experience of seeking help with migraines.

The goal for the investigator is to write your story of the experience of seeking help with migraines, and she will need your help to see that she understands your experience clearly. She will contact you from time to time to discuss what she has written and obtain suggestions from you to improve the work. **Any questions that you have about taking part in this study will be answered at any time.**

Staying in or Leaving the Study:

You do not have to be in this study if you do not want to be. If you want to leave the study, you can do so at any time. You just have to tell the investigator. This will have no effect on any healthcare you receive in the future.

What can happen if you are in this study:

There is no anticipated risk or direct benefit to you if you are in this study. However, you or the investigator may stop the interview at any time if talking about your experiences becomes too upsetting. If you do not feel able to or do not wish to continue, the issue will be discussed and if necessary a plan of action will be developed. If needed, you will be directed to the appropriate professional support system.

The results of this study may help caregivers, for example, nurses, to give better care to women seeking help with severe migraines. What is learned about the experience of participants in the study may contribute to developing standards of nursing care for individuals with migraines.

Making sure of your privacy:

All information will be held private, except when professional codes of ethics or legislation require reporting. Your real name will not be used in this study. Instead a code name and number will be used to identify all documents, computer files, audiotapes, and computer storage devices (DVD's, CD's, and Floppy Disks). Your real name and your code name and number will be kept in a locked filing cabinet and the investigator will be the only one with a key. The typist transcribing the audiotapes will sign a form to say that no one else will hear about anything that is on the tapes. The data will be held for a minimum of five years.

The results of the study may be published or presented at meetings. Your real name or anything that links you to the study will never be used.

If you want to be part of this study, you will be asked to sign a consent form. You will also be asked to think of a fake (code) name that will be used for anything to do with the study. Your real name will not be used at all. The investigator may want to use the data from this study for more research. If you agree, approval from an ethics committee will be obtained before the start of that study.

If you have any concerns about any aspect of this research project, you may contact the Faculty of Nursing Research Office and speak with Dr. Kathy Kovacs-Burns at 780-492-3769. You can also contact my supervisors: Dr. Brenda Cameron at the Faculty of Nursing 780-492-2699 and Dr. Jean Clandinin at the Faculty of Education 780-492-7770 for further information or verification of the study.

Appendix C
(U of A Letterhead)
Information Letter for Registered Nurses

Study Title:	A Narrative Inquiry into the Experience of Women Seeking Professional Help with Severe Chronic Migraines
Investigator:	Sharon Dublin, RN PhD Candidate Faculty of Nursing, University of Alberta Phone: 780-633-1641 Email: sdublin@ualberta.ca
Co-Supervisors:	Dr. Brenda Cameron 780-492-6417 Faculty of Nursing, University of Alberta Phone: 780-492-6217 Email: brenda.cameron@ualberta.ca
	Dr. Jean Clandinin Faculty of Education, University of Alberta Phone: 780-492-7770 Email: jean.clandinin@ualberta.ca

Purpose of this study:

The purpose of this study is to understand the experiences of women seeking help with severe chronic migraines and the experiences of nurses who have worked with women who suffer from migraines.

What will happen in this study:

In this study, you will be asked to talk about your experiences providing nursing care to women seeking help with severe chronic migraine headaches. There will be three tape-recorded conversations, at a time and place that is best for you. Conversations will last 60-90 minutes.

Each conversation with the investigator will be different. The **first conversation** will be a time for you to tell your story of providing nursing care to women with severe migraines. For the **second conversation,** you will be asked to tell more of your experiences using items collected for what we call a memory box, to help you remember things that have happened to you over the years. The items you choose will have meaning for you and will connect to your experience of nursing practice. You will be shown a memory box during the first meeting with the researcher. For the **third conversation**, you will be asked to show your experiences in a different way. You may take photos of places, people, or things that tell something about your experience. You may also draw or paint pictures, make a collage, or keep a diary of your daily life for a short time. Supplies, such as a disposable camera or paint, will be given to you. During the third conversation, you will be asked to show and talk about your creative projects and how can help us understand your experience of providing nursing care to women seeking help with migraines.

The goal for the investigator is to write your story of the experience of providing nursing care to women seeking help with severe migraines, and she will need your help to ensure that she understands your experience clearly. She will contact you from time to time to discuss what she has written and obtain suggestions from you to improve the work. **Any questions that you have about taking part in this study will be answered at any time.**

Staying in or Leaving the Study:

You do not have to be in this study if you do not want to be. If you want to leave the study, you can do so at any time. You just have to tell the investigator. This will have no effect on your career as a registered nurse.

What can happen if you are in this study:

There is no anticipated risk or direct benefit to you if you are in this study. However, you or the investigator may stop the interview at any time if talking about your experiences becomes too upsetting. If you do not feel able to or do not wish to continue, the issue will be discussed and if necessary a plan of action will be developed. If needed, you will be directed to the appropriate professional support system.

The results of this study may help caregivers, for example, nurses like yourself, to give better care to women seeking help with severe migraines. What is learned about the experience of participants in the study may contribute to developing standards of nursing care for individuals with migraines.

Making sure of your privacy:

All information will be held private, except when professional codes of ethics or legislation require reporting. Your real name will not be used in this study. Instead a code name and number will be used to identify all documents, computer files, audiotapes, and computer storage devices (DVD's, CD's, and Floppy Disks). Your real name and your code name and number will be kept in a locked filing cabinet and the investigator will be the only one with a key. The typist transcribing the audiotapes will sign a form to say that no one else will hear about anything that is on the tapes. The data will be held for a minimum of five years. The results of the study may be published or presented at meetings. Your real name or anything that links you to the study will never be used.

If you want to be part of this study, you will be asked to sign a consent form. You will also be asked to think of a fake (code) name that will be used for anything to do with the study. Your real name will not be used at all. The investigator may want to use the data from this study for more research. If you agree, approval from an ethics committee will be obtained before the start of that study.

If you have any concerns about any aspect of this research project, you may contact the Faculty of Nursing Research Office and speak with Dr. Kathy Kovacs-Burns at 780-492-3769.

You can also contact my supervisors: Dr. Brenda Cameron at the Faculty of Nursing 780-492-2699 and Dr. Jean Clandinin at the Faculty of Education 780-492-7770 for further information or verification of the study.

(U of A Letterhead)

Appendix D Patient Informed Consent

A Narrative Inquiry into the Experience of Women Seeking Professional Help with Severe Chronic Migraines		
Principal Investigator: Sharon Dublin RN MN PhD Candidate, Faculty of Nursing, University of Alberta, Edmonton, Alberta 780-633-1641 sdublin@ualberta.ca Co-Supervisors: Dr. Brenda Cameron Faculty of Nursing, University of Alberta 780-492-6217 brenda.cameron@ualberta.ca	Dr. Jean Clandinin Faculty of Education, University of Alberta 780-492-7770 jean.clandinin@ualberta.ca	
	Yes	**No**
Do you understand that you have been asked to be in a research study?		
Have you read and received a copy of the attached information sheet?		
Do you understand the benefits and risks involved in taking part in this research study?		
Have you had an opportunity to ask questions and discuss the study?		
Do you understand that you are free to refuse to participate or withdraw from the study at any time? You do not have to give a reason and it will not affect your care or your work.		
Has the issue of confidentiality been explained to you? Do you understand who will have access to your records/information?		

This study was explained to me by:

____

Date:

____

I agree to take part in this study.

Signature of Research Participant:

____

Printed Name:

____

Witness (if available): ____ Printed Name: ____
I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate. Researcher: ____ Printed Name: ____
* A copy of this consent form must be given to the subject.

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Appendix E

Biographical Data Form for Participants

Date: ____________ Participant Number ________

Interviewer: ____

DEMOGRAPHICS

Name:____

Address:

____

City: ____ Postal Code: __________________

Phone: _______________ Ext.: ____ Cell: ______________ Pager: _______________

DOB (dd/mo/yr):___________________ Age ____________

☐0. Male ☐1. Female

C-1 What is your marital status?

☐1. Single (never married) ☐3. Widowed ☐5. Separated
☐2. Married ☐4. Divorced ☐6. Common law

C-2 What is your first language?

☐1. English ☐2. French
☐3. Other ______________________________________

C-3 What is your highest level of education?

☐1. Grade 8 or less
☐2. Partial high school
☐3. Completed high school
☐4. Partial technical school or university
☐5. Completed technical school
☐6. Completed university

C-4 Where do you live?

☐1. House
☐2. Apartment or condominium
☐3. Seniors complex
☐4. Seniors lodge
☐5. Nursing home/Auxiliary
☐6. Other (specify) ____________________________

C-5 Other than yourself, how many people permanently live in this residence?

____

C-6 What is your current employment status (mark all that apply)
☐1. Working full-time
☐2. Working part-time
☐3. Student
☐4. Homemaker
☐5. On sick leave
☐6. On worker's compensation
☐7. On unemployment insurance
☐8. On disability plan
☐9. Retired from work
☐10. Unemployed

C-7 What is your approximate combined family's income before deductions from all sources?
☐1. $0 to $499
☐2. $500 to $999
☐3. $1,000 to $1,999
☐4. $2,000 to $2,999
☐5. $3,000 to $3,999
☐6. $4,000 to $4,999
☐7. $5,000 to $5,999
☐8. $6,000 or over

C-8 All together, how many people live on this income?

____

C-9 Women with Migraines

☐ Migraine Approximate Year of Diagnosis

______

☐ Other Chronic Conditions (please list below)

____

____

C-10 Nurses – Please list your experience in providing nursing care to women with severe migraines. Include setting.