

UNTOLD STORIES:
WOMEN, IN THE HELPING PROFESSIONS,
AS SUFFERERS OF CHRONIC PAIN
(RE)STORYING (DIS)ABILITY

JUDY E. MacDONALD



**Untold Stories: Women, in the Helping Professions, as Sufferers of
Chronic Pain (Re)Storying (dis)Ability**

By

© Judy E. MacDonald

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Abstract

Chronic pain and (dis)Ability leaves one struggling for normalcy, trying to make sense out of the fundamental operations of one's body, the meaning of suffering and the social construction of wellness. Within this research the "untold" was brought into the realm of the "told," for most of the women had never before storied their own experiences of living with chronic pain, dealing with the medical system, or connecting their personal pain and (dis)Ability with their helping roles.

Set within a postmodern anti-oppressive theoretical framework, the guiding research question was, how can the stories of women in the helping professions, who are sufferers of chronic pain and (dis)Ability, inform an anti-oppressive approach to social work practice in working with sufferers? Six sufferers participated, two physicians, two nurses and two social workers, providing a cross-disciplinary lens to their experiences. A narrative testimonial methodology was employed, whereby the person who testified had struggled for survival and the reader, through witnessing their strife, was called to act.

The women's stories of life with pain were a testament to their struggles and experiences of oppression, told from locations of vulnerability, strength, and resilience. Personal findings called for a reconceptualization of psychological pain theories, redefining sick-role behaviors as strategic coping mechanisms. Professional findings identified the need for structural transformation in meeting the needs of sufferers, such as believe the sufferer's account of her pain, work from a sufferer-centered approach, challenge dominant discourses that pathologize or blame the sufferer and bring forward systemic changes. Systemic changes included more immediate and inclusive access to services, classification of pain as disabling and compensatory, and extensive education on

pain for service providers and families. Ultimately, social work and other helping professions need to find ways to learn from sufferers, to listen to their stories, deriving insight from their knowledges, in order to more effectively attend to their health care needs.

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Being a woman with a (dis)Ability, specifically a chronic pain sufferer, this research process took longer than the average time allotted a doctoral dissertation. Health crisis, pacing needs and managing pain all affected the schedule of work. Without the supports of my supervisor, family, friends, and committee this vision would not be fulfilled. I wish to extend my gratitude and appreciation to the following people:

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Chapter One: Situating the Research

1.0 Introduction

“The vulnerability of our work, our identities, and our voices also need to be heard if we are to create the conditions of decolonization.” (Tierney, 2000, p. 549)

Within this research, the vulnerabilities of the sufferers have been brought to the surface as they have passionately told their stories of living with chronic pain and stifling health care services. The relationship between participants and myself, as researcher, is based upon a shared identity, as I have lived with chronic pain for twenty years and have continually negotiated life within the social construction of (dis)Ability. In sharing elements of my own vulnerability, connections with participants have been solidified. Tierney (2000) identifies a reciprocal process whereby participants’ vulnerable voices come forward to meet the researcher’s own vulnerability, and through writing from this position the researcher calls for the reader to respond with sensitivity. Testimonio, the methodology applied in this research, calls for an engagement with the text, whereby the reader cannot remain passive but is compelled to act “to change the more oppressive aspects of life that silence and marginalize some and privilege others” (p. 549).

Understanding the interconnectedness of those who testify, the researcher and the reader, is important for setting the context of this research. A testimonio methodology, set within a narrative inquiry, was purposefully selected to reach beyond the stories of illness and connect with a socio-political discourse that unsettles the meta-narratives currently shaping chronic pain assessment and intervention (Beverley, 2000; Clandinin & Connelly, 2000; Tierney, 2000). This political direction and action component is an appropriate fit for a rights-based disability lens (Hanes, 2002; Oliver, 1996; C. Thomas,

1999), coupled with an anti-oppressive social work perspective (Carniol, 2000; Dominelli, 2002).

Linguistically, disability is written as (dis)Ability when referencing my own experiences and knowledges and in relation to the sufferers' storied experiences of living with chronic pain. This politically shifts the emphasis onto an alternative reading of ability, hence challenging society's construction of the term as impairment, incapacity, or handicap (as depicted in *The Canadian Oxford Dictionary*, 1998), while not denying the social and physical connection with disability. People with disabilities continually navigate an ablist world, searching for modes of accommodation, often left to their own devices in framing an alternative route, so that they will not be excluded and isolated from the social world (Oliver, 1990, 1996; C. Thomas, 1999; Wendell, 1997). I recognize others have terms (such as disability or impairment) that represent their own frameworks and these will be respected throughout this research.

To begin the journey I situate myself as a chronic pain sufferer, a woman with a (dis)Ability, and as the researcher. The research guiding question will then be identified, followed by an exploration of how the research evolved, including the need for the study, identification of key terms, theoretical influences and methodological processes. The chapter will conclude with a layout of the dissertation, highlighting the content of each chapter.

1.1 Locating the Researcher

In the edited collection by Rioux and Bach (1994) on research in disability, numerous authors attend to the identity of the researcher and the involvement of the

participants in interpreting their own text. While the participants in this research did not engage in the actual narrative analysis, it was from their testimonies and knowledges that insights were derived. Historically, people with disabilities have been excluded from the decision-making components of the research process, often leading to their exploitation; likewise, chronic pain research has been dominated by the medical profession, and devoid of sufferers' interpretations. "Illness stories require an interplay of mutual presences: the listener must be present as a potentially suffering body to receive the testimony that is the suffering body of the teller" (Frank, 1995, p. 144). Challenging the expert status of researcher, I clearly identify and situate myself within the discourse of chronic pain and (dis)Ability. Informed by my experiences and self-knowledges, I enter this journey as a former medical social worker who worked with chronic pain, both malignant and non-malignant, in an acute care hospital; as a university educator who has taught courses in (dis)Ability and anti-oppressive social work practice; as a scholar who has researched the topics, written articles and conducted workshops on chronic pain and (dis)Ability; and most fundamentally, as a woman sufferer of chronic pain who lives with (dis)Ability. I have known chronic pain for as long as I have known the profession of social work. I have been challenged, pushed beyond my original theoretical constructs, and have grown to respect the valuable lessons learned through suffering. Social work is a fundamental component of my identity; it has shaped who I am, how I think and most importantly, how I act. Likewise, being a woman sufferer has greatly impacted my life; it has taught me about internalized oppression, societal barriers to accommodation, the struggles of being heard within the medical system, the power of self-determination, the will of my spirit and the vital role of friends and family in surviving.

I have first-hand knowledge of the emotional and physical complexity involved in testifying to one's life in pain. Within this research, participants' stories are not taken for granted or trivialized; they are respected, appreciated and honoured. Personally, I have storied my own experiences as a pain sufferer within health care (MacDonald, 2004a). From that experience I learned about the struggles and rewards in telling one's story and the importance of utilizing the knowledge derived from the story to promote systemic change.

From storying my own experiences of life with pain, I know the emotional vulnerability associated with publicly claiming a voice. The most significant part of my pain story was when I had Reflex Sympathetic Dystrophy, a short-circuiting of the sympathetic nervous system that relayed intense pain signals to my entire left leg. Living with the pain was horrific, but the oppressive experiences I encountered while seeking treatment were overwhelming (MacDonald, 2004a). The most emotionally debilitating and oppressive experience I encountered was in a chronic pain treatment center in the United States. As a means to regain power and critically challenge the delivery mode, I wrote and had accepted for publication my illness story.

Through my own experiences I learned that a deep seated trust in the listener is required for the sharing of intimate personal details (Tierney, 2000). The sufferer is exposing herself through the sharing of her feelings and physical experiences. Trusting that this information will not be misused or abused, the sufferer relays her story for the purpose of some greater good. Honouring this process, I was guided towards a theoretical framework and methodology that was respectful of participants' voices.

As much as my personal experiences have influenced this research, my professional lens has helped formulate the guiding research question and informed my way of working with participants. As indicated above, I began my social work career as a medical social worker in an acute care hospital, over time covering burns, oncology, general hospital rotation, rheumatoid arthritis, chronic pain and palliative care. The common denominator crossing all areas of intervention was pain. The last couple of years employed at the hospital I focused exclusively on palliative care in which I helped create a palliative care unit, developed bereavement services and crafted my participation in a hospice field study in England. Like the participants in this research, I was intimately familiar with medical services from both sides of the desk, as I was a chronic pain consumer of health services within the institution where I was employed. From this location, I was privy to insights and understandings of health politics, while appreciative of the vulnerable position of the consumer. Personally and professionally, I witnessed the oppression of health consumers as they tried to get their needs met within the medical system.

1.2 Locating the Question

Feminist, (dis)Ability and anti-oppressive theories framed my practice intervention. Levine (1982), in her definition of feminist social work stated, “The focus is on women helping women in a non-hierarchical, reciprocal and supportive way [and on] a critical analysis of the sexism embedded in the theory and practice of the helping professions” (p. 199). In my research, from a feminist perspective, it was important to hear women’s voices of living with chronic pain and to challenge the patriarchal structures within health care. Men have been the invisibly gendered norm of medical

investigation (Gill, 1997; Greenhalgh, 2001; Thomas, 2001). Women have been marginalized by the attitudes and assumptions of physicians; for example, the dismissive manner in which women's health complaints are handled (Thomas, 2001; Wendell, 1996). Further, the selection, access and funding of health services is dominated by male defined illnesses and subsequently lacking women-specific services such as in heart disease (Doyal, 1995; Sherwin & The Feminist Health Care Ethics Research Network, 1998; Thomas, 2001).

Thomas (2001) identifies disablism, along with patriarchy, as systemic structures embedded within medicine and health services. Women with disabilities have been “dehumanized and objectified in medical settings – viewed exclusively in terms of their disabilities, not as total persons or women” (Gill, 1997, p. 8). Within traditional medical settings expert knowledge belonging to the ‘truth’ holder is sanctioned by medical authority (Bury, 1998; Greenhalgh, 2001; Oliver, 1996; Wendell, 1996), while the sufferer's knowledge is dismissed, even disregarded. Western medicine endorses the myth of bodily control, whereby it is believed that physicians armed with the tools of modern medicine can control disease and illness (Wendell, 1997). “The pernicious myth that it is possible to avoid almost all pain by controlling the body gives the fear of pain greater power than it should have and blames the victims of unavoidable pain” (Wendell, 1997, p. 270).

Through my experiences and knowledge formation it became clear that the medical discourse facing women living with chronic pain needed to be disrupted, for only then would their voices emerge from underneath the patriarchal, hierarchal and ablist medical structure. Dismantling the notion of ‘truth’ within a modernist assumption led to

a post-modern appreciation of multiple perspectives that are evolving and fluid; the aim is to get the stories out into the open where their values, conflicts, power dynamics and influence can be explored (Morris, 2002).

Extending beyond medicine, social work and other helping professions need to be conscious of the oppressive elements within their practice structures. Gilson, Bricout and Baskind (1998) found that social work does not always embrace inclusive practices when working with people with disabilities. “Study participants noted that by failing to listen, social workers lose out on the opportunity to allow consumer needs and aspirations to guide social work services and advocacy” (p. 192). Dunn, Hanes, Hardie and MacDonald (2006) conducted a study examining disability inclusion within Schools of Social Work in Canada. Their findings indicated that, although there had been significant changes over the last ten years, substantive barriers to disability inclusion remained. Social workers have a responsibility within their social justice mandate to champion diversity and work towards the eradication of oppression with marginalized groups (Canadian Association of Social Workers, 2005). Through collaborative work with (dis)Able persons who are sufferers of chronic pain they can “effectively shake the foundation of the medical establishment” (MacDonald, 2004a, p. 32), shifting the power base towards the empowerment of sufferers. Dominelli (2002) identifies oppression as being “socially constructed through people’s actions with and behaviours towards others” (p. 9). Furthermore, “oppressors attack identity – its formation and reformation – at its core, by depicting a socially constructed status as natural and immutable and, crucial to an oppressive framing of it, as inferior to that held by them” (pp. 9 – 10). The power-over dynamic embedded in medicine and the helping professions needs to be challenged,

offsetting the identity displacement of women with (dis)Abilities. From a feminist, (dis)Ability, anti-oppressive lens the following question emerged as the guide to this research: *'How can the stories of women in the helping professions, who are sufferers of chronic pain and (dis)Ability, inform an anti-oppressive approach to social work practice in working with sufferers?'*

Linguistically, 'sufferer' was consciously chosen to represent participants. Jovey (2002) defines suffering as "the global impairment of quality of life due to a combination of pain, decreased function and various psychosocial factors" (p. 8). One of the dominant discourses in chronic pain is the psychologizing of pain, whereby the authenticity of the person's physical experiences of pain is brought into question (Dworkin & Caligor, 1988; Fordyce, 1990). For this very reason, I wanted to validate the participants' struggle and witness the physical pain they endured.

Dominelli (2002) identifies the processes of emerging from an oppressive location:

The survival strategies of oppressed peoples in responses that run from various forms of accommodation, or coming to terms with a subjugated status, to resistance to oppression and moving on to create egalitarian relations that celebrate and accept 'difference' within an ethical framework that validates equality and social justice. (p. 8)

The research process extends beyond the personal into the political through envisioning an anti-oppressive way of working with chronic pain sufferers. Specific terms such as testify and witness have been consciously chosen to respectively describe the process of telling one's story of living with pain and the process of listening and acting on what one has heard. In the act of testifying, a person from a marginalized group shares an aspect of her life history with the intention of prompting societal changes

to oppressive structures (Tierney, 2000). Witness moves beyond the standard definition of observing or being present at an event (*The Canadian Oxford Dictionary*, 1998), to include an emotional connection with the sufferer's story and an obligation to respond. According to Tierney (2000), the writer, speaker and reader are all vulnerable: "Vulnerability is not a position of weakness, but one from which to attempt change and social fellowship" (p. 551). Bringing together chronic pain intervention with anti-oppressive ways of working, framed within a narrative context, can bring forth sufferers' stories, testifying to the oppressive encounters within medicine and the helping professions while pushing towards an egalitarian, social justice vision.

1.3 Methodological Tenets

"Narrative and identity are so intimately linked" (Eakin, 1999, p. 100). As identified earlier, my own location as a chronic pain sufferer, woman with a (dis)Ability and helping professional provided insights and ways of knowing that helped formulate this research study. However, my role here was one of researcher, taking responsibility for the processes, ethics, analysis and distribution. Noting the patriarchal, ablist and oppressive discourses influencing (dis)Ability and chronic pain, simply a telling of the sufferers' stories was insufficient. A socio-political lens to narrative was critical to the unsettling of the meta-narratives so that empowering principles of intervention could emerge. Given the marginalization of women with disabilities (Thomas, 2001; Wendell, 1996, 1997) and chronic pain sufferers (MacDonald, 2000, 2004a; Rose, 1994; Seers & Friedli, 1996) and the torment of chronic persistent pain, it was appropriate to select a testimonio strategy of inquiry (Beverley, 2000; Tierney, 2000).

“The testimonio is developed by the one who testifies in the hope that his or her life’s story will move the reader to action in concert with the group with which the testifier identifies” (Tierney, 2000, p. 540). The sufferers testifying in this research knew the urgency of disrupting the dominant discourses in pain treatment. Without fail, each woman’s conceptualization of pain consisted of the political and social dynamics. Anti-oppressive social work consists of applying the three ‘A’s: awareness, analysis and action (Bernard & Hamilton-Hinch, 2005). Without the last step of action, the status quo will prevail, with those traditionally in power remaining in power. This action component also attends to the reconceptualized validity of the research process; for narrative research does not seek to locate the ultimate ‘truth’, but rather identifies a process of trustworthiness where the research is moved into the social world (Lather, 1991; Riessman, 2002). The decisive representation of action is found in the practice principles outlining an anti-oppressive way of working with chronic pain sufferers.

1.4 Overview of Dissertation

Within this chapter, I situated myself as the researcher, framed the question to guide the research process and introduced the methodology. Wendell (1996) suggests that “much of the experience of disability and illness goes underground” (p. 40). Through this research, sufferers’ stories that have previously remained untold, surface into the realm of the told, thus calling conscientious social workers and helping professionals into action.

From this introductory chapter the reader will progress to the literature review in Chapter Two, where the juncture between chronic pain and disability is formulated. Chronic pain is situated, first by its economic costs, followed by an exploration of the

Supreme Court of Canada decision on whether chronic pain is to be compensated, and then the history of pain is explored, leading into contemporary theories of pain, such as catastrophizing and the pathologizing of pain. This is then followed by the identification of progressive writings on pain, including Greenhalgh's (2001) critique of the medicalization of pain and Howell's (1994) four categories of experiencing life with pain. Disability is then explored beginning with its historical lens, followed by its economic costs and Enns and Neufeldt's (2003) five dominant models of disability – medical, charity, sociological, economic and socio-political, with the addition of spiritual. The dominant discourses in disability are highlighted, including the medicalization of illness, the social model and the post-modern/feminist lens.

Chapter Three presents the research processes, identifying the narrative methodology within a testimonio frame. The introduction underlines the guiding research question, followed by locating the importance of illness stories. The specific methodological applications of testimonio and autoethnography are then highlighted. From there are investigated the applications of research processes, such as the sampling procedures using criterion sampling, and the data collection methods/processes, such as pre-participation interview, primary interviews, debriefing, and focus group teleconference. Once the collection processes have been identified, the narrative analysis is described. In the narrative fashion, trustworthiness is examined, along with the limitations of the research. The chapter concludes with the application of ethical considerations to the research process.

Chapter Four, the longest chapter, is the first of three chapters on findings, in which the stories of the sufferers are constructed. Each woman's story is told

individually, using personal contribution(s) to depict her life with chronic pain. The richness and depth of their stories sets the stage for understanding both the personal testimonies in Chapter Five and the professional testimonies in Chapter Six. At the beginning of each sufferer's story, I reflect upon the impact of listening from the location of researcher.

Chapter Five features findings associated with the personal testimonies of the sufferers. Four discrete areas are identified through this process: spirit, emotion, treatment and coping. Each area is explored in detail, identifying sub-categories, (for example, spirit has four sub-categories; relating to a higher power, finding purpose and meaning, understanding life and death options, and conceptualizing the will). The spirit category is then concluded with identification of a spiritual discourse, including the meta-narratives challenged by the findings. Each area is explored in the same fashion.

Chapter Six is the final chapter on findings, and focuses on professional testimonies of the sufferers. The chapter begins with the exploration of case stories, extrapolated from the sufferers' storied lives as helping professionals working with chronic pain sufferers. Nine cases are explored in total; each with the researcher's identified learning following the presentation of the case. Leading off from the case stories, practice principles are highlighted for working with sufferers from an anti-oppressive location, each being associated with either Carniol's (2000, 2003) or Dominelli's (1997, 2002) anti-oppressive skills. Each principle is then associated with a meta-narrative that needs to be unsettled to achieve the principle in full. From a postmodern framework unsettled is intended to interrupt the meta-narratives, disturbing

the dominant discourses that have shaped chronic pain knowledges and treatments (Ristock & Pennell, 1996).

The final and seventh chapter concludes with a reflection on the impact of participating on sufferers, a short reflection on my experiences both from the position of researcher and chronic pain sufferer, identification of the major challenges put forth by the research, applied use of the research findings and future research directions.

“People in pain and knowledge of pain could be fully integrated into our culture, to everyone’s benefit” (Wendell, 1997, p. 270). The ultimate goal of this research and respect of sufferers’ testimonies would be to enact this statement.

Chapter Two: Locating the Literature

2.0 Introduction: Chronic Pain and Disability

Chronic pain and disability are interwoven at the most intimate level, for both entities leave one struggling for normalcy, trying to make sense out of the fundamental operations of one's body, the meaning of suffering and the social construction of wellness (Jackson, 2002; MacDonald, 2000; Oliver, 1996; C. Thomas, 1999; Wendell, 1996). Yet, the disciplines of chronic pain and disability have limited interaction, whether in theory, intervention or social organization. Some disability advocates clearly identify chronic pain as a component of persons with disabilities' struggles but believe that the medical domination in the field of chronic pain has kept them from seeking treatment (Cummings, personal interview, in MacDonald, 2001). The Disability Movement has worked diligently towards redefining the experience of disability, understanding disability as a social construct rather than a medical entity (Oliver, 1990, 1996; Wendell, 1996; Zola, 1982). It appears as though "the disability community strategically divorced chronic pain, not wanting their socially constructed movement to be infiltrated by the medical establishment" (MacDonald, 2001, p. 13), further distancing disability from ill-health, pain and suffering.

At the same time, chronic pain sufferers and medical personnel who work in the field of pain would not deny that chronic pain is disabling in and of itself. Although much of the attention and focused intervention is about minimizing the disabling effects of living with chronic pain (Bonica, 1990; Fordyce, 1990; Howell, 1994; Jackson, 2002; Loeser, Seres, & Newman, 1990), the sufferers' interpretations of their own experiences are not given due consideration. Both academic and practice entities in the discipline of

chronic pain downplay the relationship with disability, pushing the sufferer consistently towards socially defined concepts of normal behaviour. And, if disability becomes a component of the chronic pain sufferer's identity, it is often considered a cognitive deficit with "significant psychological dysfunction . . . and physical performance decrements" (Sullivan, Tripp, & French, 2001, p. 16). Whether aligned with physical or psychological causation, chronic pain intervention has a significant focus on healing the sufferer of disability, which could be defined in terms of returning the sufferer to gainful employment, reducing the sufferer's reliance on the health care system, or re-establishing the sufferer as a contributing member of her family and society (Fordyce, 1990; Linton, 1998; Main, Keefe, & Rollman, 2002).

Given that chronic pain and disability can be intimately connected, a question arises as to why there does not appear to be a connection between their disciplines, in theory or practice. One explanation might be that some aspects of the Disability Movement has centered its efforts on redefining what society views as 'normal', integrating disability into that vision, believing that you are only as disabled as society makes you, hence, disability is socially constructed (Oliver, 1990, 1996; Wendell, 1996); whereas, chronic pain has remained within a medical forum, focused on diagnosis, intervention and cure. Initially, the objective of medical intervention is to find the cause of the pain, intervene through surgery, pharmacology or other medical procedures. If chronic pain persists, a shift occurs whereby the objective becomes defined as the return of function, activity and ability. To be disabled (for example, unable to work or function "normally") is to be avoided at all costs (Bonica, 1990; Sullivan, Stanish, Waite, Sullivan, & Tripp, 1998; Sullivan et al., 2001).

Within this literature review chapter, three main areas are explored: chronic pain, disability and anti-oppressive social work. First, chronic pain is situated economically, historically and theoretically. Theoretically, I identified dominant areas of thought and intervention by exploring journals of pain, such as *Pain* and the *Journal of Pain and Symptom Management*. Key word searches were conducted on chronic pain and non-malignant pain, both on-line and at health sciences libraries. Books circulating in the popular media were reviewed, for example, Jackson's (2002) book *Pain: The Fifth Vital Sign*. Pain texts were identified and reviewed, such as *The Management of Pain* edited by John Bonica (1990) and *Progress in Pain Research and Management* edited by Cohen and Campbell (1996). Pain conferences were attended and interviews were sought with leading theorists in the field, for instance Dr. Sullivan and Dr. Jovey. Articles or literature focusing on a progressive lens (re: sufferer centered) were highlighted. Second, disability is historically located, followed by economic costs and then an exploration of disability models. In seeking out information on disability I went to known authors in the field, such as Oliver and Wendell. Drawing on my own knowledge of having written and taught in the area of (dis)Ability was an asset. Finally, anti-oppressive social work theory is explored, highlighting the work of Carniol (2000, 2003) and Dominelli (1998, 2002) who have been referenced consistently throughout the findings chapters. The areas highlighted are not meant to be an exhaustive exploration of the field, but rather a glimpse into some of the existing discourses currently impacting upon practice.

2.1 Chronic Pain

“Pain always arrives with a hidden narrative.” (Jackson, 2002, p. 9)

Chronic pain is a growing concern for health professionals, for it is a complex multidimensional problem that affects the sufferer’s personal, social, spiritual, physical and economic wellbeing. Sufferers can struggle with physical complaints such as insomnia, high blood pressure, weight gain, deconditioning, immune deficiency, and irritable bowel; mentally they can experience confusion, memory loss, and difficulties concentrating; emotionally, depression, anxiety and stress are commonly associated with chronic pain; and spiritually, it is not uncommon for sufferers to question the meaning of their lives, face faith crises and ultimately struggle with suicidal options (Arnstein, 2003; MacDonald, 2000; Seers & Friedli, 1996). Feelings of desperation, helplessness and hopelessness are common emotive responses associated with chronic pain (St. Marie, 2003). “Pain is simultaneously physical and emotional, biological and phenomenologically embodied” (Bendelow & Williams, 1995, p. 147). The nature and degree of this embodiment is not denied; however, where the emphasis is placed and how it gets conceptualized and operationalized can have tremendous impact upon the sufferer.

Economic Costs

Research has found that 20 to 40% of the population suffers from chronic pain, resulting in economic costs of over \$100 billion per year and 700 million lost workdays in the United States alone (Blackwell, 1989; MacDonald, 2000; Moulin, Clark, Speechley, & Morley-Foster, 2002; Sieppert, 1996; St. Marie, 2003; Turk, 1996). Migraines alone have an annual cost to employers of \$4,000 per working female migraine

sufferer compared to \$7,000 per working male migraine sufferer (Saper, 1996); with women being three times more likely to experience migraines (Jackson, 2002). The rationale for women migraine sufferers' annual cost to employers being less than men's relates to gendered pay discrepancies, and potentially to gendered pain behaviours where women continue to work while experiencing migraines. Estimates project that twenty-five million people in the United States are migraine sufferers (Jackson, 2002). Three billion dollars a year is spent on over-the-counter pain medications such as Advil or Tylenol; and four tons of aspirin are consumed (Jackson, 2002). The politics of pain medication play out in many ways. For example, prescription pain medication, such as morphine, has been associated with addiction (Campbell, 1996; Jackson, 2002), while the serious side-effects of gastrointestinal bleeding caused by aspirin or liver damage created by acetaminophen (Tylenol) go unnoticed.

Chronic pain sufferers often have a lengthy history of hospitalization, medical procedures and tests, having sought the opinion of a myriad of specialists, undergone numerous surgeries, and been prescribed a multitude of medications; all in an attempt to gain some sense of control over their pain. Health care costs in Canada have been on a continual, sometimes drastic, incline over the past decade; for example, on average Canadians spent \$409.46 in 1998 on prescription medications, which is a 106% increase from the \$198.50 spent in 1985 (inflation controlled) (Armstrong & Armstrong, 2003). Health spending overall has increased between 20 and 25% over that same time period (Armstrong & Armstrong, 2003). In 1994, Canadian insurance companies paid out \$103 million in long-term disability when combining fibromyalgia, repetitive strain injury and chronic fatigue syndrome claims (Mailis-Gagnon & Israelson, 2003). In Canada,

mobility is the most common disability, affecting 2.5 million adults (Keung, 2004), whereas chronic pain is “the most prevalent form of disability among the working population” (Keung, 2004, p. A19). Given the magnitude of the economic strain that chronic pain places upon the health care system and society as a whole, it is feasible to speculate that cost influences, if not dictates, intervention choices. Influences from big businesses, insurance and pharmaceutical companies and government need to be viewed with caution (Campbell, 1996; Saper, 1996). “Pain hurts, it hurts patients and families; it hurts the economy and the public . . . effective pain control is . . . an unavoidable responsibility of health professionals” (Saper, 1996, p. 282).

Supreme Court of Canada Decision

Sufferers of chronic pain have met many levels of discrimination; the following case examples are a vivid depiction of the judgment and disregard extended to pain sufferers. Up until the fall of 2003, a person with chronic pain was not deemed eligible for compensation under the Workers’ Compensation Act of Nova Scotia. The following court challenges brought about a change.

Claimant Laseur, Ruth:

In 1987, Ruth Laseur was injured while working as a bus driver. She fell off the bumper of the bus while cleaning the windshield. Ruth attempted to return to work several times after her injury, but her pain was exacerbated by each attempt. Workers’ Compensation paid Ruth temporary benefits during these periods of absence until they terminated her benefits in the fall of 1989. A report from the Board noted that Ruth had “fallen into the usual chronic pain picture” (Supreme

Court of Canada, 2003, p. 8), and the Board could find no obvious etiology to justify her claim. In 1991 when she realized that she could not continue with this line of work, after trying numerous times to return to the job, she applied for benefits under the classification of permanent medical impairment. The Administrator replied with compassion and an undertone of judgment. “This is basically a chronic pain problem, perhaps even a chronic pain syndrome although she seems to be a very pleasant individual with not the usual features of this type of problem” (p. 9). Ruth Laseur’s claim was denied.

Claimant Martin, Donald:

In February 1996, Donald Martin while working as a foreman at a car company, lifted a tow dolly and towed it backwards for about fifteen feet. Suddenly sharp shooting pain in his lumbar spine took his breath away; later he was diagnosed with a lumbar sprain. Over the course of weeks stretching into months, he attempted to return to work several times; however, each attempt was met with defeat as his job activities escalated his pain. Donald agreed to attend a work conditioning and hardening program sponsored by Workers’ Compensation. He received temporary benefits while in the rehabilitation program but as it became evident that a permanent return to work was not likely, his benefits were discontinued. Donald sought a review of this decision, which was subsequently denied. The review officer noted that there was “no demonstrated pathology to support Mr. Martin’s complaint of pain” (p. 9). Chronic pain had become an evident feature of Mr. Martin’s injury and in so doing, provided the Compensation Board with a viable out option under their guidelines.

The Supreme Court of Canada ruled (in *Nova Scotia Workers' Compensation Board versus Martin*; *Nova Scotia Workers' Compensation Board versus Laseur*) that the exclusion of chronic pain from compensation was in violation of the Charter of Rights and Freedoms in that it was discrimination on the basis of disability (CBC, 2004; Supreme Court of Canada, 2003). Prior to this ruling, the Workers' Compensation Board commented in a public presentation that chronic pain was not deemed a disability because there was no tissue damage or impairment, concluding that people should therefore be able to return to work (Graham, 2002). The Workers' Compensation Appeals Tribunal wrote in judgment of Laseur's appeal, "She probably has a full blown chronic pain syndrome, which is a non-compensable condition and is well known to be virtually totally related to psychosocial factors" (Supreme Court of Canada, 2003). The Board has spent thousands of dollars in consultation and training with psychologists to develop a ten-week program for workers with soft tissue injuries. This program was designed primarily on functionality, with activity at the center of its intervention (Sullivan, Adams, Rhodenizer, & Shaw, 2002). If the participant was still suffering from pain after completing the ten-week program the case status shifted to chronic and they were no longer eligible for services under the umbrella of Workers' Compensation. They would not service workers who were sufferers of chronic pain. The Supreme Court of Canada (2003) ruled:

The denial of the reality of the pain suffered by the affected workers reinforces widespread negative assumptions held by employers, compensation officials and some members of the medical profession, and demeans the essential human dignity of chronic pain sufferers, violating s.15(1) of the Charter. (p. 8)

The practice implications resulting from this decision have yet to be fully realized; however, unmistakably chronic pain can no longer be disregarded or compensation so blatantly denied.

History of Pain Science

The science of pain has grown exponentially since World War II, when a need for specialized intervention was recognized (Bonica, 1990). Soldiers were returning from battle with war injuries, amputated limbs, and various pain complications including pain associated traumas. They had served their country, and now the scientific community needed to find a way to serve them. However, pain presented a unique challenge to science, for science is logical, predictable, able to be duplicated given the same conditions and variables; on the other hand, “pain is subjective, invisible, multifaceted, and individual” (Jackson, 2002, p. 9). Jackson (2002) refers to pain and science as ‘uneasy bedfellows’. With advancements in medicine came an increased prevalence of pain; people were living longer, which meant an increased susceptibility to degenerative painful conditions like arthritis. For example, almost 70% of nursing home residents experience chronic pain associated with arthritis (St. Marie, 2003). Eventually, transplants were successfully performed with a number of organs but the surgical procedure sometimes resulted in nerve or tissue damage causing unrelenting pain. Cancers that would have had a 95% fatality rate ten years ago now have an increased probability of being cured or put in remission; however, the side effects of treatment can leave patients in pain. Subsequently, medical advances have inadvertently contributed to the growing number of chronic pain sufferers (Jackson, 2002). In addition, the

perception of modern medicine is based on curative regimes, concluding that pain should be able to be eliminated, and, if not eliminated, then certainly controlled (Craig, 1999).

A historical lens into modern medicine's exploration into pain, including theory, research and intervention, begins with the notable landmark of Melzack and Wall's (1988) gate control theory in 1965. The gate control theory views pain as a message system traveling along the spinal column to the brain. Pain is received through two different types of nerve fibres: A fibres, which travel to the brain quickly for an immediate response and sensation of pain, and C fibres, which travel slowly to the dorsal horn region of the spinal cord. The dorsal horn has gating mechanisms that can transmit or block information, thus, alternating the pain messages received by the brain (Jackson, 2002; Koestler & Doleys, 2002; Wall in Rosenfeld, 2003). The gate control theory shifted the focus away from the pain site and moved it towards an exploration of the interactions between the brain and spinal cord and how perceptions could influence the gates' mobility. As illustrated in an example recently given by Ron Melzack (in Rosenfeld, 2003) a football player could be kicked in the shin, resulting in a cracked bone and not realize it until the game is over because he is ultimately focused on the game causing the gates to close, thus blocking the nerve transmission of pain to his brain. Following this theory, new research initiatives were developed focused upon stimulating the nervous system in an attempt to modify pain perception (Long, 1996). In the 1970s, under the premise of the gate-control theory, bio-medical companies such as Medtronic, developed nervous system stimulator implants and later the transcutaneous nerve stimulator (commonly known as TENS).

At the same time that “the anatomy and physiology of pain perception” (Long, 1996, p. 4) was at the forefront of scientific exploration, others like Bonica (1990), Fordyce (1976, 1990, 1996) and Long (1996) were interested in the clinical treatment of pain. The psychological implications and presentations of pain became the organizing feature of the multidisciplinary pain clinic, which focused on three specific concerns about chronic pain sufferers: one, substance abuse; two, deconditioning; and three, psychiatric comorbidities such as depression. Long (1996), in relating experience derived from The Hopkins Pain Treatment Center, reflects:

We postulated that a subgroup of chronic pain patients were disabled from chronic pain, with primarily behavioral versus structural pathology. Pain had become the focus of their lives. We believed the majority were seriously depressed, suffered from chronic anxiety, and had lifelong histories of psychological vulnerability, many having medication misuse histories. (p. 9)

Alongside the development of the multidisciplinary pain clinic emerged the palliative/hospice movement. Dame Cicely Saunders, a social worker who went back to school to become a physician, opened in 1967 the first freestanding hospice in the modern-world, St. Christopher’s Hospice in Sydenham, England. The creation of this hospice, and ultimately the hospice movement, began with a compassionate understanding that dying people needed better pain relief and symptom management. Saunders coined the term ‘total pain’ where the social, spiritual and emotional needs of patients were as vital a component of treatment as were their biological needs (DuBoulay, 1984). Cicely Saunders was a young medical social worker who often comforted dying patients with her kind demeanour. David, a forty-year-old man with inoperative cancer, found comfort and peace in dialoguing with Cicely. They spent hours conversing about the struggles of the dying and Cicely’s vision of a hospital dedicated solely to the care of

patients in the death and dying process. When David died, he willed Cicely 500 pounds, stating “I’ll be the window in your home” (DuBoulay, 1984, p. 58). Twenty years later St. Christopher’s Hospice opened its doors, built with a brilliant array of windows; one of them dedicated to the memory of David Tasma. The modern day hospice movement brought an understanding of pain as all encompassing - mind, body and spirit. Pain management became a multidisciplinary exploration leading to research and case conferencing on the dynamics of pain and potential treatment options. Today the ideal intervention for chronic pain is to have the sufferer seen by a skilled multidisciplinary team who focuses specifically on the treatment of persistent pain (Jovey, 2002).

Research and pain initiatives that have emerged since the beginning of the hospice movement, include: 1975 - the development of the McGill pain questionnaire by Ron Melzack, the first measurement of pain intensity, was utilized in pain clinics and hospitals throughout the world; 1986 – the World Health Organization established guidelines for administration of analgesics in the treatment of malignant pain; 1995 – the Joint Committee on Accreditation of Healthcare Organizations identified pain as the ‘fifth vital sign’, whereby hospitals in the U.S. must chart pain in the same context as blood pressure, pulse, temperature, and breathing; and 2000 – the United States government under Clinton’s administration declared a ‘Decade of Pain Awareness and Research’ (Jackson, 2002; Mailis-Gagnon & Israelson, 2003). Much has been accomplished with the advancement of pharmaceuticals for the treatment of pain; the World Health Organization developed an analgesic ladder which consists of four steps in the administration of pain medications to treat mild to severe pain (Jovey, 2002). For someone experiencing mild pain, treatment would begin with over-the-counter

medications such as acetaminophen / ibuprofen / or stronger anti-inflammatory medications, the second step would be codeine, the third step oxycodone, and the final step, for severe pain, fentanyl, hydromorphone, methadone or morphine (Jovey, 2002). Polypharmacy techniques, which combine medications that affect different pain pathways, have been successful in the treatment of resistant pain problems, problems that did not respond well to single medication trials (Jovey, 2002). Treatment modalities that consist of blocking nerve pathways have been performed; these have included trigger point injections where a local anaesthetic is injected into specific trigger points, epidural or spinal blocks where analgesia and possible steroids are injected at a specific point along the spine (epidural catheters have been implanted to administer opioids or local anaesthetics), sympathetic blocks where medication is injected into the sympathetic ganglion to shut down sympathetically mediated pain responses, and intravenous regional blocks that specifically attend to pain in the extremities (Jovey, 2002; Mailis-Gagnon & Israelson, 2003). Neurosurgeons can even implant spinal cord stimulators (SCS) where wires and electrodes are surgically implanted on the surface of the spinal cord producing electrical pulses that then reduce pain. Estimates suggest that “14,000 stimulators are implanted worldwide each year” (Mailis-Gagnon & Israelson, 2003, p. 129). Modern medicine has made considerable contributions to advance the treatment of chronic pain.

Behaviourists and capitalists might claim that pain has evolved as a cultural trait of the 21st century; pain that was ignored, put-up with and suffered through fifty years ago is now the motivating influence behind insurance claims and sick-role behaviour. Those devoted to the research and treatment of sufferers might believe that the stories of

pain are finally being listened to, that pain “now has a face – it is a recognized discipline” (Mailis-Gagnon & Israelson, 2003, p. 225).

Behavioural Approach to Chronic Pain

Critics of the behavioural approach to chronic pain contend that pain behaviours are initiated because medicine has not been helpful in responding to sufferers’ needs; pain intensity and severity dictate sufferers’ responses. For example, if a sufferer’s pain is severe, measuring 9 on a 10-point scale, there will be a heightened probability that they will seek medical attention, risk surgeries or invasive procedures that have questionable success rates, and actively seek medication to lessen the pain (Campbell, 1996; Crombez, Morley, McCracken, Sensky, & Pincus, 2003). These markers, which Campbell (1996) believes are rational actions given the sufferer’s situation, are used to label their behaviour through diagnoses such as malingering, somatization disorder, or other psychologically mediated forms of chronic pain, predominantly when obvious, identifiable pathology cannot be found by the medical establishment (MacDonald, 2000; Staats, 1996). Jovey (2002) cautions against the use of these labels and that true psychogenic pathology is both rare and stigmatizing; often this classification of pain is redefined as neuropathic pain once its true etiology is discovered and the knowledge of pain mechanisms becomes clearer.

Medicine has not been able to scientifically identify all the presenting etiology involved in chronic pain and has broadened the assessment lens, whereby the sufferer’s psychological profile has become a contributing, if not, primary focus. A psychological-behavioural approach to chronic pain is the intervention choice in a great number of

chronic pain programs throughout North America (Bendelow & Williams, 1995; Bonica, 1990). Within this approach, Parson's (1951) sick role theory clearly articulates the sufferer's responsibility to get well: If the sufferer is not responsive to this role (for example, if she does not get better under medical treatment) it is deemed that she has become fixated in her sick role. Fixation, according to this theory, is often facilitated by environmental gains the sufferer is receiving through identification with this sick role: gains such as attention from colleagues, family and friends; medical personnel's care; decreased role responsibility, as for example, household chores are picked up by other family members; financial compensation through litigation, disability benefits or sick pay; and access to pain medication or mood altering drugs (Finn, 1988; Fordyce, 1990; Loeser & Egan, 1989).

The sufferer's experience of loss is overlooked in this model: loss of lifestyle through the sufferer's inability to maintain full-time employment; loss of intimate relationships due to the sufferer's lack of energy to navigate social environments; loss of control experienced through ill health and subjection to the medical hierarchy; and a diminished voice (MacDonald, 2000, 2004a). Often chronic pain patients are put through a battery of psychological tests, which could include intelligence testing (IQ tests), Minnesota Multiphasic Personality Inventory (MMPI), California Personality Inventory (CPI), Sickness Impact Profile (SIP), Pain and Impairment Relationship Scale (PAIRS), Multidimensional Pain Inventory (MPI), and Coping Strategies Questionnaire (CSQ), to name a few. The interventions supported by the clinic would include a combination of the following: detoxification (of narcotics and sedative-hypnotics), drug therapy for depression/anxiety (predominately with tricyclic antidepressants), physical

rehabilitation (exercise program, leisure), behavioural modifications (pain is not responded to except in specific situations/locations/times), somatic therapies (deep muscle relaxation, biofeedback, self-hypnosis), and cognitive therapies (psychotherapy, attention/diversion, reinterpretation of pain sensations, problem-solving strategies, assertiveness training) (Ahern, 2002; Long, 1996). The focus is specifically on eliminating the sick role behavior and re-establishing well behaviour regardless of the sufferer's ongoing pain (Bonica, 1990; Fordyce, 1990).

According to Howell (1994), behavioural theory directs nurses to punish any sick role behaviour depicting pain or suffering. Once this has been successfully achieved, functionality would be restored, health care utilization reduced, and employability re-established. This complicates the relationship of the physical (body) to the mental (emotions); if the cause of the pain cannot be medically located within the body, causation becomes aligned with the sufferer's emotions and mental processes. The sufferer's pain is real but deemed to be originating from psychological pathology (Fordyce, 1990). Decreasing the sufferer's experience of pain is not the primary focus, rather, improving functionality and reducing the costs of chronic pain becomes the measure of success (Campbell, 1996; Graham, 2002).

Catastrophizing

Catastrophizing is another psychological pain theory, whereby the sufferer is assessed for "an exaggerated negative orientation toward noxious stimuli" (Sullivan, Bishop, & Pivik, 1995). The belief is that sufferers who respond to their pain in a catastrophizing manner experience more pain and disability (Sullivan, Tripp, Rodgers, &

Stanish, 2000). Catastrophizing is classified as rumination, in that the sufferer cannot stop thinking about the pain; magnification, where the sufferer worries that something serious may happen; and helplessness, the sufferer believes nothing can be done to reduce the intensity of the pain. Chronic pain sufferers who are identified as catastrophizers are believed to have impaired coping strategies and hold pessimistic outlooks towards dealing with their pain. They are identified with exhibiting more sick role behaviours, illustrated through lengthened hospital stays, more frequent use of health care resources, excessive use of both prescribed and over-the-counter medications, and exacerbated stress and emotional distress in relation to their pain (Sullivan et al., 1998; Sullivan & Neish, 1999; Sullivan, Thorn, Haythornthwaite, Keefe, Martin, Bradley, & Lefebvre, 2001).

A gender difference was noted in one catastrophizing study, with women who were sufferers of osteoarthritis, as they were found to exhibit more pain behaviour than men with the same condition (Keefe, Lefebvre, Egert, Affleck, Sullivan, & Caldwell, 2000). Furthermore, the women reported significantly higher levels of pain and demonstrated more disability in relation to their medical condition. In another study by Sullivan, Tripp and Santor (2000), gender differences were noted with women reporting higher pain intensity and displaying more pain behaviours. The authors, however, caution the readers, suggesting that the results might be affiliated with gender specific aspects of social learning; women might be conditioned to express their emotions, sense of identity or ability in a distinctly different way than their male counterparts. Within this study, it was women's sense of helplessness and rumination that impacted the results; gender differences were not evident in respect to coping strategies (Sullivan et al., 2000).

In the catastrophizing research studies the intensity of pain experienced by a sufferer has not been a controlled variable. Likewise, a number of the studies have been conducted in laboratory settings, thus creating both a temporary and contrived pain experience, which has the potential to differ substantively from living with chronic pain (Turner & Aaron, 2001). Depression has been studied in direct relation to catastrophizing, whereby catastrophizing has been a predictor of future depression (Sullivan et al., 2001). However, re-interpreting this theoretical position, the sufferer's mental and emotional vulnerability would be directly related to her physical pain intensity.

Pathologizing Pain

A modernist medical approach to chronic pain has been critiqued for relying too heavily on psychological variables, especially when physical etiology is not clearly defined (Greenhalgh, 2001; MacDonald, 2000). This approach has been claimed as an exact science, based upon empirical findings, conclusive evidence and a clear 'cause and effect' correlation (Couvalis, 1997; Sherwin, 1998). A specific example of this reliance is evident in the 1999 edition of the *Journal of Pain and Symptom Management*, in an article on the use of sodium pentothal, commonly known as 'truth serum', in the treatment of complex regional pain syndrome. The patient is injected with this drug and instructed to perform physical activities utilizing the affected bodily part to assess range of motion and prior guarded behaviours, leaving the practitioner to judge the 'true' essence of the patient's pain experience (Simon & Dahl, 1999). The ethics of this approach must be questioned. The sufferer's reports of pain are not believed. Ultimately, through the colonization of sufferers' experiences, their identity and voices are lost.

Dr. Angela Mailis-Gagnon, Director of the Comprehensive Pain Program in an urban hospital, uses a similar drug, sodium amytal, with complex pain problems with a distinctly different intent behind the procedure. She believes that the brain actually receives, re-routes and blocks pain messages in ways not clearly understood by science. Mailis-Gagnon's work resituates the causation associated with pain experiences that defy modern medicine's explanations, even pain coined psychogenic in nature she believes is a complex interaction of the brain pathways influenced by thoughts, feelings and emotions. She clearly recognizes that her medical training on anatomy and physiology are not sufficient in diagnosing and treating chronic pain: Chronic pain forces her to "think differently, outside the conventional realm of traditional medicine" (Mailis-Gagnon & Israelson, 2003, pp. 182-183). Traditional medicine's response has been to quantify the sufferer's experience into distinct classifications, categorizing and diagnosing illness in search of a cure or treatment regime. The "diversity of suffering [is] reduced by a unifying general view . . . that of clinical medicine" (Frank, 1995, p. 11). Research is being conducted in the areas of pharmacology, neurological and biological causation and treatments, and clinical trials with particular pain syndromes. Yet, in the words of Dr. Helen Haynes (2002), "We are only beginning to understand some of the reasons for chronic pain" (p. 7).

Progressive Lens to Chronic Pain Treatment

Greenhalgh (2001) in reflecting on Foucault's reference to the medical gaze, believes the sufferer is transformed into "an object of science and then reduced to a disease, [a process that is both] . . . jarring and violent" (p. 19). Four specific processes are identified in this patient-making process: objectification, quantification,

pathologization and amelioration. First, medicine objectifies the sufferer by creating a dualism between the body and the mind and emotions; second, once the body has become the focus of attention, bodily signs and symptoms are measured against a standardized norm, information that cannot be quantified is discarded; third, following a disease orientation, contrasted against a health focus, the patient is labelled and diagnosed, highlighting the pathology of illness; and fourth, through amelioration the ultimate vision is on treatment, restoring the body to its former way of functioning, with little to no attention paid to causation. This model does not fit with chronic pain sufferers' experiences, for to be a good patient, clear identifiable etiology needs to be present and responsive to medical intervention. Chronic pain in its definition alone suggests an alternate reading: The sufferer has had an acute situation that has not responded to medical intervention. An alternative reading of the sufferer's story is not welcomed within this framework. This process is "detrimental to women, specifically because it places them within a masculinist biomedical order in which the patient's knowledge of her body and life is silenced in discourses of objectification that make the doctor the expert on the patient's body" (Greenhalgh, 2001, p. 320). Multiple ways of knowing in a complex web of bodily and psychic expressions are totally negated by this narrowly defined discourse, ultimately silencing the sufferer's own knowledge.

Wendell (1996) further articulates the struggle, "Not only does modern medicine take little interest in treating suffering that it cannot eliminate, but its conceptual schemes deprive suffering of meaning and context in a patient's life, when meaning and context are often essential to living" (p. 137). Identifying herself as a sufferer, Wendell knows all too personally the blight of chronic pain within the power ridden medical system. She

suffers from myalgic encephalomyelitis, more commonly known as chronic fatigue syndrome: a chronic painful condition more frequently experienced by women, cast in the medical stereotypes as being a mysterious illness, difficult to treat, unable to fix, heading straight towards a pathologizing rationale. Modern medicine is more concerned with controlling the human body, technological advances, life-saving heroics than dealing with the chronicity of medical flare-ups, emotional exhaustion and overall fatigue imposed upon sufferers as they struggle to redefine their existence in a life with pain. “Knowledge of how to live with the suffering and limitation it cannot cure remains on the margins of medicine” (Wendell, 1996, p. 137).

A limited amount of research and writing reflects an anti-oppressive/feminist lens to chronic pain, a lens that is respectful of sufferer’s voice, knowledge and diversified experiences and that provides a critique of modernist medicine. A post-modern or post-colonial shift is required, whereby the sufferers denounce being the silent, obedient patients following modernist medical rules, thus “refusing to be reduced to ‘clinical material’ in the construction of the medical text” (Frank, 1995, p. 12). In Brown and Williams’ (1995) exploration of women’s experiences of living with rheumatoid arthritis, they invite illness sufferers, researchers and medical personnel to visualize how “people who experience illness can . . . make an active contribution to shaping how their problems are both conceived and resolved” (p. 700). There is not one answer to the pain problem but multiple ways to listen to and engage with the sufferer in understanding her pain. Nurses and others in the helping professions need to be patient-centered, inviting sufferers to share their experiences of living with chronic illness. How one poses

questions, expresses interest and actively listens to the sufferer will influence the depth and degree of experiences the sufferer is willing to share.

Howell's (1994) research with women living with chronic non-malignant pain found that women who had their experience of pain validated tended to progress through the experiences of living with chronic pain in a healthier manner. A caring relationship with a health professional meant that the sufferer was less likely to succumb to isolation or despair. A significant component of validation included believing that the woman's experience of pain was originating from an organic source, as opposed to psychologically manifested pain. Most of the women had been diagnosed with psychogenic pain at some point in their pursuit for medical assistance and experienced a blaming response from health care professionals. Howell identifies four categories that women can experience in living with pain: The categories are identified as healthy phase one – 'the pain takes over', two – 'filling my life with new hope', and three – 'fulfilling my life with pain', shadowed by the possibility to divert to an illness phase – 'filling my life with pain and despair' at any point during phase one or two. The first healthy phase, 'the pain takes over', usually coincides with the early days of living with chronic pain, when one's energy is consumed with obtaining a diagnosis, finding a cure and resuming life as it previously was. Leaving this initial location, the sufferer tends to go one of two ways, either remaining on a healthy path to 'filling my life with new hope' or diverting to the illness category, 'filling my life with pain and despair'. 'Filling my life with pain and despair' is primarily characterized as a negative response to the chronic state, most often reinforced by professionals' and family's disbelief concerning the sufferer's pain,

displayed in blaming and doubting attitudes. The sufferer is overwhelmed by the pain and views life from a dark, hopeless location, isolating oneself socially and emotionally.

‘Filling my life with new hope’, phase two, is a positive response to living with pain, and it begins with the sufferer recognizing the losses her chronic pain and disability have created, actively grieving those losses and adjusting to a new way of being. This adjustment includes recognizing barriers and limitations, creatively adapting through appropriate accommodations, seeking assistance from self and others and actively managing her pain. The final category, ‘fulfilling my life with pain’, phase three, is building on the positive aspects achieved in the last category. Typically there are both ‘good days’ and ‘not so good days’; as one sufferer puts it, “Some days a diamond; some days a stone” (p. 112). The sufferer has learned to live with her chronic pain through self awareness, community support and a connectedness with her mind/body/spirit. Progression through the phases is not always distinct or in a linear fashion; similar to Kubler-Ross’s stages of death and dying, the sufferer can regress or stagnate at any given phase. There may be times when depression and despair present themselves, yet the sufferer appears to be coping.

Seers and Friedli (1996), in examining non-malignant chronic pain sufferers’ experiences with health care, identified five specific themes: sufferers felt their pain was not believed; chronic pain was treated like acute pain; physicians often relayed feelings of desperation/frustration when treating sufferers; sufferers felt blame was shifted onto them personally; and communication barriers existed between sufferers and physicians. On the basis of their research findings they conclude that talking to people with chronic pain is an invaluable intervention to clinical practice. Talking involves listening,

something often dismissed as simplistic, devoid of expert knowledge and irrelevant to medical discovery, yet obviously fundamental to the healing spirit of sufferers.

The majority of progressive research on chronic pain has come from the nursing profession, even though social workers are members of interdisciplinary teams in chronic pain clinics. Three Canadian social workers have written on chronic pain. Ranjan Roy (1988, 1992, 1999, 2001) at the University of Manitoba (cross-appointed with psychiatry), has written books focused primarily upon the family, including the relationship of childhood abuse and chronic pain, theoretically locating his work within a systems approach to pain. In Roy's early writings he tended to use language and theoretical positioning similar to a cognitive-behavioural approach to chronic pain; however, in his more recent writings he has shifted to a more critical examination of 'traditional pain theories' moving towards a sufferer-centered application. Jackie Sieppert (1996) at the University of Calgary, wrote an article on attitude and knowledge of medical social workers in relation to chronic pain and utilized a historical lens to examine professional practice. His research found that social work was becoming more involved with chronic pain, but social workers' knowledge base for chronic pain and the depth of their involvement needed further development. On an encouraging note, social workers were more likely to consider alternative interventions, extending beyond the traditional medical model of treatment.

I have written an article on deconstructing current medical practices with chronic pain, in that I challenge the sick-role behaviourist assumptions of sufferers' existence and conceptualize an alternative reading to understanding their experiences, giving respect to their knowledges and encouraging their voices as central components of any intervention

(MacDonald, 2000). Another article that I have written is an autoethnographic piece on personally experiencing modernist medicines treatment of chronic pain; here I weave other sufferers' experiences into the text of my own illness narrative to illustrate multiple voices in our struggles with pain and the system imposed to treat that pain (MacDonald, 2004a). Using the criteria of validating sufferers' experience and advocating the inclusion of their voices, I postulate that I am the only social worker above who writes from a post-modern lens, whereby the sufferer's voice is central to the discourse.

Anita Unruh (1996), an occupational therapist with a masters degree in social work, conducted one of the most comprehensive reviews of medical literature's inclusion of gender in chronic pain studies/articles. Her findings suggest that women have heightened pain sensations compared to men, in areas of frequency, duration and severity of pain experienced. To understand such findings, further research is needed, including: perception and response to pain from a gendered lens; biological, environmental and social learning factors that might influence gender variation in pain experience and communication; and an examination of how the medical system itself responds to men and women in pain. She cautions, "Women may be more vulnerable than men to unwarranted psychogenic attributions by health care providers for pain" (p. 123). Given this possibility, my own location as a woman sufferer, and my feminist underpinnings, I have specifically chosen to focus upon women sufferers within this study. This gender distinction is an alternative reading to the male dominant medical system that monopolizes the chronic pain field.

2.2 Disability

“Shame will no longer structure our wardrobe or our discourse.”

(Linton, 1998, p.4)

Historical lens

People with disabilities have been beaten, sexually abused, ostracized, socially segregated, politically silenced, sterilized, institutionalized, hidden, tormented, tortured and killed (Chadwick & Dias, 2000; Linton, 1998; MacDonald, 2005a; Oliver, 1990, 1996; Wendell, 1996). People with disabilities were considered not quite human, certainly not normal (Goffman, 1963). They were used as a source of entertainment in circus-like ‘Freak Shows’ in the United States up until the 1940s. Sterilization was a common practice in Canada, disguised as a legitimate practice under the ‘mental hygiene movement’ (Stienstra & Wight-Felske, 2003), deviating little from the mandatory procedure in Germany under Hitler’s regime. The most blatant oppression of disabled persons was in Germany, as Hitler’s power intensified, his goals altered from preventing procreation to extinction. Estimates indicate that 250,000 people with disabilities were eliminated through the T-4 program of eugenics, originally applying gassing until protests from clergy sent the program underground resulting in death by starvation or poisoning (Chadwick & Dias, 2000). African and Chinese practices were to leave disabled infants to die. In European or North American culture, people with disabilities were hidden from society, either by being institutionalized or locked in family attics or basements, by attending ‘special’ schools and using segregated transportation (Linton, 1998; MacDonald, 2005a; Oliver, 1999).

The eugenic practices of excluding disabled people is not only historically located, some disability rights activists believe that the modern day extinction of people with disabilities is found in our current medical practices, such as “eliminating disability prenatally by genetic screening and termination” (Stienstra & Wight-Felske, 2003, p. 4); ‘do not resuscitate’ orders placed on charts often without patient consultation; and refusal of transplants, citing compliance as the rationale (Stienstra & Wight-Felske, 2003). On the other hand, the economic costs of keeping someone with severe disabilities and gravely compromised quality of life alive, against their expressed wishes, can be astronomical. Nineteen percent of acute care hospital bed-utilization is occupied by long-term stay patients due to a shortage of nursing home beds, putting a strain on the health care system by clogging acute care admissions and building lengthy waitlists (Nova Scotia Department of Health, 2001-a). A long-term care facility charges \$137.00 per day or \$50,000.00 per year (Nova Scotia Department of Health, 2001-b), with an occupancy rate exceeding 98%, thus creating lengthy waitlists for placement (Nova Scotia Department of Health, 1999). The cost per in-patient stay in a general ward of an acute care hospital is \$1,173 per day (personal communication with L. Parker at the Queen Elizabeth II Hospital, Finance Department), approximately 8.5 times the cost of a nursing home bed. To maintain the life of persons with severe disabilities against their will puts additional economic strain on an already depleted health care system.

Economic Costs

Over four million people in Canada, 16% of the population reported some level of disability in 1991 (Hanes, 2002, p. 219): one in eight (13.2%) were considered to be disabled (Enns & Neufeldt, 2003). Projected estimates relate that close to 40% of ever-

married women with disabilities will be assaulted by their partners (Nova Scotia Department of Community Services, 2002), compared to eight percent of women in the general population (Statistics Canada, 1999). Eighty-three percent of women with disabilities will be sexually assaulted within their lifetime (Nova Scotia Department of Community Services, 2002; Ranjan, 2004), placing the risk of sexual abuse for women with disabilities at least 150% greater than non-disabled women (Ranjan, 2004). Forty-seven percent of Nova Scotian women with disabilities are living well below the poverty line, with an annual income under \$5,000 (NEEDS Project, 1996). The poverty rate for women in Canada is 19% (Hicks, 2002). Fifty-six percent of adults (aged 15 – 64) with disabilities were considered poor in 1991 (Enns & Neufeldt, 2003), compared to 14 – 17% of the general Canadian population aged 15 – 64 (Hicks, 2004).

Medical costs for people with chronic disease consume 60% of the health care budget, with projections of increases in expenditures as the population ages (Nova Scotia Department of Health, 2004) surfacing concerns about demand for care exceeding supply and resource. Disability touches us all, either through knowing someone with a disability, personally identifying as a person with a disability or being ‘temporarily able-bodied’ as the likelihood of spending at least some portion of our lives with a disability is statistically close to 100% (Zola, 1982). The oppression and silencing of people with disabilities has formed a meta-narrative within our cultural storyline, as reflected in historical narratives and modern day reflections.

Disability Models

Enns and Neufeldt (2003) identify five dominant models in disability: medical, charity or philanthropic, sociological, economic and the socio-political. Extending the parameters of disability, spiritual and post-modern models will also be explored. The medical model is centrally associated with health services, where the person with the disability can receive services in the form of diagnosis, treatment and ultimately cure. This lens will be expanded upon in the next section titled 'medicalization of illness'. The charity or philanthropic model evokes sympathy from the general populace, where disabled people are seen as unproductive, welfare recipients of society. They are to be pitied; their disability viewed as a tragic misfortune. People with disabilities can respond to these stereotypes with "shame, embarrassment and sometimes, hatred" (p. 7). The charity lens is believed to be the most dominant view of disability throughout the world. The sociological model views people with disabilities as deviants, defying or failing to meet societal norms. Societal roles and functions are examined, with specific emphasis on the stereotypes and stigmas associated with having a disability. What is the role of people with disabilities within a community, what is their status, purpose and function? In turn, what is the community's response to their presence? The economic model examines the costs and benefits to having people with disabilities within the community, in relation to job placements, schooling, housing and services. The socio-political model is a disability rights model, which refuses to view disability from an individual problem base. Disability is seen within its social and political context; for example, the stairs only entry to the bank is not viewed as the person's in a wheelchair problem but seen rather as a community access problem. Personal ownership of societal barriers is refuted.

A spiritual lens to disability exists in the literature to a lesser extent, primarily associated with L'Arche communities, created by Jean Vanier, for persons with developmental disabilities (Favaro, 2002). What began as a house in France, where Jean Vanier invited two men with developmental disabilities to live with him, now has extended to over one hundred L'Arche communities throughout the world (Vanier, 1998). The spiritual lens is associated with meaning, growth and communion, extending "an invitation to respond to another's pain and suffering, and to be faithful in . . . relationships" (Fararo, 2002, p. 216). Belonging seeks "to include the weak, the needy, and the different, for they have a secret power that opens up people's hearts and leads them to compassion and mutual trust" (Vanier, 1998, p. 163). The spiritual quest of finding meaning in one's struggle can bring a new level of insight about the human condition. Similar to the palliative care philosophy, journeying alongside a sufferer, in palliative terms 'the dying', can be an enlightening and spirit raising quest (Saunders, 1988). "People with disabilities have a capacity of the heart that is contagious" (Favaro, 2002, p. 218). In applying the spiritual lens individuals, helping professionals and communities will need to rediscover people with disabilities (Vash, 1981).

The post-modern model of disability critiques the universalization of the body, the normative context from which all disabled bodies are judged (Wendell, 1997). To be disabled is to be outside the norm. "Disabilities are covered over, and made invisible, by the structures and assumptions of normalcy" (Titchkosky, 2001, p. 3) or "bodies deemed inferior become spectacles of otherness while the unmasked are sheltered in the neutral space of normalcy" (Thomson, 1997, p. 8). Either way, what limits, restricts and isolates persons with disabilities, the notion of normalcy needs to be deconstructed, taken apart

and exposed. Disabilities are multiple, fluid and evolving and therefore cannot be categorized into a single defining entity for the purpose of medicine or social organization.

Engaging with this rediscovery process, the medical model encapsulated within ‘the medicalization of illness’ will be explored, examining its relationship to other ways of understanding disability. Further, aligning with the theoretical tenets of anti-oppressive perspectives of disability, the socio-political/social model and the post-modern/feminist model of disability will be examined (Dominelli, 1997; Mullaly, 2002).

Medicalization of Illness

The dominant discourse pertaining to disability has been enfolded within the medicalization of illness, deformity and impairment. The medical model, in which the personal tragedy model of disability is framed, is an individualistic, reductionist approach that relies upon the knowledge and expertise of medical personnel (Oliver, 1990, 1996; Wendell, 1996). Emanating from the Enlightenment period, the medical model was born out of a secularly driven enterprise based on technology, advancement and the ultimate pursuit of truth, located within the scientific acquisition of knowledge (Lather, 1991). Action is based upon an evaluative ranking, aimed at identifying (classifying) illnesses, diagnosing their presence and prescribing appropriate treatment (Bickenbach, 1993). Within a disability application, the problem lies with the individual’s impairment, and causal significance is associated with functional or psychological deficits (Oliver, 1996). Intervention is geared towards ‘return of function’, to restore one’s previous way of being if at all possible, and, if this is unachievable, to limit the impact of the impairment.

Examples of medical research and intervention from this perspective would include research efforts to repair spinal cord injuries and the advancements in reconstructive surgeries, and, to a lesser extent, the development of prosthetics and rehabilitation programs. “The personal tragedy theory of disability . . . is some terrible chance event which occurs at random to unfortunate individuals” (Oliver, 1996, p. 32).

Kuppers (2003) starts with the experiences of the person with a disability and then situates the construct of personal tragedy within a societal context.

The disruption of disability to an individual’s life can be (but not need to be) physically and psychologically painful, but is most likely painful in its encounter with the social. The social narrative of disability sees it as negativity, and the social world excludes disabled people through environmental and attitudinal barriers. Language and narrative re-present disability as pain and tragedy. (pp. 90 – 91)

Feminist scholars, disability activists and post-modern thinkers have critiqued the personal tragedy model of disability for its objectification of individuals, whereby people are made into a body part, devoid of personality, story and purpose, and turned into medical cases (Bury, 1998; Oliver, 1996; Wendell, 1996). “Only the doctor can know the truth about illness through the language of disease, the patient becomes a passive agent . . . a docile body caught in the web of medical knowledge and medical power” (Bury, 1998, p. 7). Expert status belongs to the medical personnel, not with the person who is surviving the illness or living with the disability. As physicians gain power, the layperson’s autonomy is diminished. As physicians enhance their position to exclusively define illness and its treatment, the knowledge of ‘patients’ becomes irrelevant. The ‘patient’ is oppressed by the authoritative structure of medicine, by her diminished voice and denied self-knowledge of her body and abilities, environment and social relations.

“The person with a disability is invited within this discourse to think of themselves as a deficient human being” (Mitchell & Winslade, 1997, p. 167). Thompson (1997) suggests the medical discourse confuses essence with existence, by defining what is healthy and ‘normal’ and subsequently, what is sick and ‘abnormal’. He further suggests that oppressed groups are seen as being ill, whether they are disabled, gay or lesbian, or old and therefore in need of healing. Normalcy becomes socially sanctioned, defined within the ideal body type (Bickenbach, 1993; Bury, 1998; Wendell, 1996). An illustration of this perspective is found in Lorde’s (1980) journal writings reflecting on her experience with breast cancer. During a follow-up appointment after a mastectomy, Lorde was instructed by her surgeon’s nurse to wear a prosthesis into the office so as not to lower the morale of others. Her identity as a woman with one breast was denied, conformity became the defining objective of the medical establishment. Rimmom-Kenan (2002) critiques Western society for its unbalanced emphasis on wellness, seeing the first order of illness to ‘get well’; disability by its very existence, challenges this meta-narrative.

Social Model of Disability

The social model of disability emerged out of the Disability Rights Movement as a theoretical and policy response to the medical model of disability. This model is based on social oppression theory, whereby societal isolation, prejudice, institutional discrimination and stigmatization define illness (Linton, 1998; Oliver, 1990, 1996; Wendell, 1996). Disability is understood as a social construction, for “many of the struggles of people with disabilities and much of what is disabling, are the consequences of having those physical conditions under social arrangements” (Wendell, 1996, p. 42). Oliver (1990) critiques industrialization and the growth of capitalism as major

contributors to the social oppression of people with disabilities, where the mode of production was redefined, calling for a reorganization of the family system. Wage labour became the norm, and people's abilities were evaluated in a substantively different manner, based upon an individualistic assessment. People with disabilities, who had once contributed to a collective expression of family and work, were no longer deemed useful. Extended families were reduced to single family units, now unequipped to care for their family members who had impairments. Institutions became the mechanism of control over people with disabilities; for "under capitalism . . . disability became individual pathology" (Oliver, 1990, p. 47). The social organization of people with disabilities has had far reaching implications, including disadvantages with respect to housing, employment, education, transportation, physical access to communities and ultimately segregation from full participation in society (Oliver, 1990, 1996).

Post-modern/Feminist Lens

Post-modern/feminist scholars in disability studies have critiqued the social model of disability from two main perspectives. First, the model's extensive focus on the material conditions of people with disabilities negates the impact of suffering emanating from one's physical and/or mental experiences of body (Morris, 1991; Oliver, 1996; Wendell, 1996). Second, are its problematic dualisms, "wherein the body is separated from the 'mind', socio-economic structure is separated from culture, social structure is separated from human agency and 'the social' is separated from the individual and her/his experiences" (C. Thomas, 1999 reflecting on Corker, 1993, 1996, 1998). Scholars in disability studies, such as Peters (1996), C. Thomas (1999) and Wendell (1996) are calling for women with disabilities to come forward to tell their stories, to

proclaim their voices, and through the interpretation of experiences alternative ways of knowing, new visions will contribute to the understanding of disability. Illness narratives, reflective of post-modern times, are stories by people living with chronic illness or having had a life altering illness experience, who are purposefully and intently restorying their lives, creating new meaning, insight and reflection, and in so doing, challenging the dominant medical discourse (Frank, 1991, 1995, 2000). It was in the light of these challenges that this research project was envisioned.

2.3 Anti-Oppressive Social Work

Anti-oppressive social work promotes equality and inclusion, understanding that society is not based upon equal distribution of power and privilege (Campbell, 2003; Carniol, 2000; Dominelli, 2002). Knowledge is recognized as being multiple, complex and developing. First voice experiences of those who have been marginalized (as in people with disabilities, Aboriginal people, and people living in poverty) are invited forward in anticipation of deconstructing dominant knowledge claims (Campbell, 2003). Dalrymple and Burke (1995) declare:

No one group or individual possesses the theory . . . that allows it to discover the absolute truth about other people's experiences. What is required is an organizing framework that allows different perspectives on the truth to be held. (p. 11)

Experiences/stories of people with disabilities and sufferers of chronic pain need to be welcomed into the discourse on chronic pain, a discourse that has been predominately occupied by biomedicine.

Two of the leading contributors to anti-oppressive social work are Ben Carniol (2000, 2003) and Lena Dominelli (1998, 2002). I have specifically chosen these authors

because of the explicit integration of anti-oppressive theory and practice that is evident in their work, thereby promoting both theoretical and practice links to sufferers' voices.

Carniol's (2000) work has championed the rights of marginalized groups, from Aboriginal peoples, women, immigrants, gay, lesbian, bisexual, transgendered peoples, the unemployed, to people with disabilities, to name a few. He understands oppression from very personal experience, as his parents were killed by Nazis; his mother at the Auschwitz concentration camp and his father en route to the camp. Similar to the women sufferers in this research, Carniol derives his practice from personal experience. One of the first tenets of his theory is the personal-political connection of "reframing private problems as public issues" (p. 115). Within this reframing process, power needs to be repositioned. Instead of having power over clients, helpers need to encourage clients to claim their own power. The coming together of clients with like interests is one way to break down client isolation, find mutual support and define action steps in addressing social inequalities. Social workers need to "apply a critical consciousness" so that "we can reframe the problem" (p. 118); diverting away from personal pathology and blame toward a liberation practice based on democratizing the system.

Dominelli (1998, 2002) aligns anti-oppressive social work practice with social justice, historically predated by radical social work in the 1970s and feminist and anti-racist social work in the 1980s. Social work's focus is on eradicating the social injustices experienced by marginalized groups and through this process social change is both envisioned and secured. The personal-political connection becomes central to the understanding and operative aspects of practice. For, according to Dominelli (1998), "Anti-oppressive practice, insofar as it is preoccupied with the implementation of social

justice, is intimately bound up with notions of improving the quality of life or well-being of individuals, groups and communities” (p. 5). Theoretically, Dominelli (2002) conceptualizes oppression along a continuum from oppression (the realization of marginalized status), to anti-oppression (multiple forms of resistance), to non-oppression (action to create egalitarian space that embraces diversity within a framework of equality and social justice). Social workers need to be involved in a process coined by Dominelli (2002) as ‘conscientisation’, “becoming aware of how oppression works and is reproduced in and through daily interactions” (p. 13).

In an anti-oppressive practice location social work’s practice cuts across all disciplines, in advocating for the rights of sufferers, in working towards empowerment practices and in striving for equitable treatment, built on the foundation of social justice and eradication of oppression (Mullaly, 2002).

2.4 Summary

Disability and chronic pain historically have been encroached upon and dominated by the medical system. The Disability Rights Movement challenged the hierarchical approach controlled by medicine; re-defined what living with a disability meant; and presented an alternative conceptualization of disability within a societal context. Ultimately they shifted the dominant paradigm away from a professionally led curative and functional lens, towards a rights-based consumer-controlled lens, respectful of voices and multiple understandings of life with a disability, echoing the sentiments, “no more about us, without us” (Stienstra & Wight-Felske, 2003, p. 7). By the 1970s the Disability Rights Movement was pushing for full inclusion of persons with disabilities within society, calling for the range of civil and legal rights afforded the

general populace. Chronic pain, compared to disability activism, is at an early stage of disestablishing the medical model's hold on intervention; be it theory, policy or treatment associations. Vulnerability is often interrelated with need; most chronic pain sufferers need medicine as a component of their treatment regime. Physicians, along with helping professionals, need to find ways to deliver services in empowering ways. This research will direct an exploration into an anti-oppressive approach to working with sufferers, beginning with locating the sufferer at the centre of the discourse; followed by an inclusive, respectful, rights-based alternative to the biomedical model of intervention.

Chapter Three: Testimonio – A Narrative Methodology

3.0 Introduction

Given the critique in Chapter Two of the medical model's location within modernity as a positivist, reductionist approach, and the call for interpreted, reflective voices of chronic pain sufferers living with (dis)Ability, a qualitative approach was appropriate for this research. Qualitative research has found a particular location within the humanities and social sciences (Denzin & Lincoln, 2000), a location respectful of an interactive, egalitarian approach with an emphasis on process, flexibility and mutual learning (Westhues, Cadell, Karabanow, Maxwell, & Sanchez, 1999). Some defining features of qualitative research include that the research occurs within its natural setting, fieldwork is time consuming, data analysis is complex, usually involving a detailed examination of the topic, research protocols lack set guidelines or maps and write-ups are usually an expression of numerous, multi-layered perspectives (Creswell, 1998).

The voice of both the researcher and the participants can be heard, for meanings are constructed from the interaction of voices and the exchanges of interpretations, confirming a respect for difference without negating the potential for commonality. Janesick (2000) characterizes qualitative design as holistic, with a wide-angle lens, attentive to relationships, from researcher to participants, and to culture and society. The research is personal and intimate, woven out of understanding and descriptions, rather than predictions; it is attentive to ethical concerns; and it requires a narration of both the research process and the participants' stories of themselves. Narrative inquiry was the specific tradition applied within a qualitative research frame with respect to this study.

In narrative research, the researcher has a general question in mind that directs the selection of participants and informs procedural methods, but without a specific hypothesis identified prior to the commencement of the research project (Lieblich, Zilber, & Tuval-Mashiach, 1998; Riessman, 1993, 2002). The following question served as a guide:

How can the stories of women in the helping professions, who are sufferers of chronic pain and (dis)Ability, inform an anti-oppressive approach to social work practice in working with sufferers?

3.1 Locating Illness Stories

Telling stories is age old, historically situated with the birth of language, and culturally embedded as one of the first ways of relating what we learn as children (Riessman, 2002). Yet, according to Frank (1995) illness stories are sculpted in unique forms of telling. He identifies three forms of narrative in relating the story of one's illness: restitution stories, which are shaped by society's need to know that people survive illness episodes and return to health (comparable to Parson's sick-role and the medical model's emphasis on cure); chaos stories, which are anxiety ridden, where the ill person never envisions returning to health, is in a disorganized, chaotic state where suffering overshadows her very existence (comparable to Sullivan's (1995, 1998, 2000, 2001) pain catastrophizing); and quest stories, where the ill person accepts illness and uses it to elicit a journey, to turn suffering into a gain, narrating a social action event.

According to Frank (1995), "the quest narrative affords the ill person a voice as teller of her own story, because only in quest stories does the *teller* have a story to tell"

(p. 115). In restitution stories, the active teller is the 'remedy', the cure or those who delivered it, and in chaos stories, the voice of the sufferer is too entangled in the pain and suffering to be heard above the chaos. Participants able to tell quest stories would potentially contribute rich texts and be more present in the telling and reflective in the analysis. As a researcher, I was concerned about the potential vulnerability of those who would be inclined to tell chaos stories. Further exploration of this concern will be addressed under ethical considerations. Frank (1995) also indicated that chaos stories are usually found with newly diagnosed people and that distance from the immediacy of illness is usually needed to be able to give order to the story. As a point of caution, I had identified one of the criteria of participation as living with chronic pain for at least two years. Personal stories serve as opportunities to not only tell one's story, but to create meaning and identity for oneself and for others in relation to oneself. The telling of one's story can be empowering, giving voice to the often silenced worlds of sufferers of chronic pain; more specifically, women sufferers of chronic pain who live with (dis)Ability.

3.2 Testimonio

The narrative tradition that was followed in this research process was that of life history, utilizing the format of a 'testimonio' as described by Tierney (2000) and Beverley (1992, 2000). The testimonio was formed from the participant testifying to components of her life story. In this incidence, the story was specifically related to illness, chronic pain and (dis)Ability. This form was purposefully selected, for a testimonio is about finding voice for those who have been silenced, oppressed and marginalized within a dominant social structure, bringing change to an oppressive

structure or practice, putting a political, social justice location onto a narrative form of inquiry (Beverley, 2000; Tierney, 2000). According to Beverley (2000), “testimonio could be said to coincide with the feminist slogan “The personal is the political” (p. 556). The tensions between difference and solidarity are explicit within this format, for the voice of the participant stands for something greater than her own individual narrative or illness story; the representation and extension of her voice is located within a socially marginalized group. This is a distinguishing feature of testimonio, for if it ceases to make the connection to a greater whole, it reverts to being an autobiographical or autoethnographical piece (Beverley, 2000; Tierney, 2000).

From my own location as researcher and chronic pain sufferer, it was important to not only give voice to women sufferers but to have those voices inform the public, the profession of social work and other health care providers who are working with sufferers of chronic pain. Moving beyond the personal biographical location of storytelling is important in making political connections to narrative inquiry, reaching in an exploratory form to ‘how the stories of women sufferers can inform an anti-oppressive approach to social work practice in working with sufferers’. The life history narrative format of testimonio validates the knowledges of participants, respecting the phenomenological presentation derived from their stories, while recognizing their illness stories as true quest stories that can be translated into action. From a location of sufferer to reflections on helping, connections can be derived to inform understanding, meaning and potential change.

Participants in this research were primarily from a middle-class economic location; they were well educated, highly literate and articulate in relating their own

stories; characteristics not usually found with participants of a testimonio, for they are often impoverished, illiterate and culturally segregated (Tierney, 2000). Testimonio participants have usually suffered “torture, imprisonment, social upheaval, and the struggle for survival” (Tierney, 2000, p. 541). How does this relate to chronic pain sufferers? Sufferers of chronic pain lack voice for several reasons. Their suffering alone may utilize all their emotional and physical strength, where the simplest of tasks become insurmountable. Likewise, they are ‘struggling for survival’ in a torturous world, as pain can be all consuming (MacDonald, 2000, 2001, 2004a). To find the energy necessary to write their own stories is often beyond their grasp. The researcher then becomes the vehicle for relaying their stories, for guiding the process of analysis, as the testimonio researcher becomes “the instrument of the individual who testifies” (Tierney, 2000, p. 540).

3.3 Autoethnography

A testimonio is usually a novel length narrative on the life history of a person; however, a segment of life history or a significant life experience can become the focal point. In this research, the illness narrative and related experiences in working with sufferers of chronic pain was defined as the event (Beverley, 2000). Given the interconnectedness between testimonio and autoethnography, it was methodologically sound to present an option of self expression, traditionally defined as autoethnographical, to the participants of this research. This facilitated an additional element to the study, as depicted by Ellis and Bochner (2000):

Autoethnography is an autobiographical genre of writing and research that displays multiple layers of consciousness, connecting the personal to the cultural.

Back and forth autoethnographers gaze, first through an ethnographic wide-angle lens, focusing outward on social and cultural aspects of their personal experience; then, look inward, exposing a vulnerable self that is moved by and may move through, refract, and resist cultural interpretations. (p. 739)

As the researcher, I also used this method as the first order of data collection, narrating my own illness story in the attempt to locate my own identity and to familiarize myself with the process of storying one's illness experience (MacDonald, 2004a). As a researcher I did not want to ask my participants to do anything that I was not prepared to do myself; furthermore, I believed journeying along this path would provide personal learnings not available through other means. Segments of my story were shared with the women on a participant-by-participant base, depending on each woman's expression of her own story and whether she asked specific questions of my experience, or if I determined she would benefit from my sharing (following a similar guide to that of self-disclosure in the counselling process) (Dominelli, 1997; Mattaini, 1998). I was cognizant of sharing only that which was appropriate for the moment, being cautious not to influence the story being expressed by the participant. Ellis and Bochner (2000) support the flexible use of self in the research process, indicating that it is epistemologically representative of both feminist and post-modern lens. Using oneself in the research process helps address power relations, minimizing the distance between the researcher and those being researched, and contributes to understandings/interpretations of locating knowledge through dialogue (Becker, 1999). Given the professional location of participants and their wealth of knowledge in living and working with chronic pain, the research process very much resembled a coming together of that experience couched in dialogue, sharing and an unrelenting dedication to the cause. Mutual concern, respect for each others' story and location and an innate desire to bring about change in the system

were defining components that wove the participants, their stories and the researcher together.

3.4 Sampling Procedures

Criterion sampling was the strategy utilized in this research. Although more commonly used in phenomenological or grounded theory studies (Creswell, 1998), it was fitting for this narrative study given the untold stories this research wanted to share with the reader. Narrative is more reflective upon the nature of the relationship between participant(s) and researcher than the selection process (Atkinson, 1998; Bruner, 2002; Clandinin & Connelly, 2000; Hyden & Overlien, 2004), thus leaving the researcher to draw upon qualitative sampling methods in general.

The purpose of criterion sampling is to have all participants meet selected criterion within specific classifications, providing consistency and thus heightening quality assurance (Miles & Huberman, 1994 in Creswell, 1998). For selection as participants in this study, five criteria had to be met: Participants had to be women because women experience suffering in different ways than men (Howell, 1994) and they have not been the gendered norm of chronic pain research (Howell, 1994; Unruh, 1996); be a member of a helping profession, currently working, retired or on disability pension; have worked with sufferers of chronic pain within their helping roles; be a Canadian citizen having received the majority of their medical intervention within their own country (given the public health care system in Canada where accessibility is not dependent upon financial means); and have lived with chronic non-malignant pain for at least two years. Chronic pain is usually defined as pain that persists beyond expected

healing time and has occurred for at least six months (Bonica, 1990; Howell, 1994, Melzack & Wall, 1988). The two-year-minimum criterion was used because duration was expected to add to the sufferers' depth of experience, interpretations and ability to tell their story and safeguard against the stories being chaos stories (Frank, 1995).

The sampling size was reflective of the 'polyphonic testimonio' wherein more than one participant have experienced the same event (Beverley, 2000). In this research, the event was living with chronic pain and the identified sample size was six participants: two physicians (one family physician and one psychiatrist), two social workers (one in health policy and one in mental health practice), and two nurses (one in psychiatric/mental health and one in general practice, with extensive volunteer experience in chronic pain). Geographically, two participants were from Nova Scotia, three from New Brunswick and one from Ontario. All participants were from a middle-class background (one currently in the lower-middle class due to her level of pension benefits); all were professional white women, with ages ranging from 45 to 62 years. All women, except for one, had originally been trained in nursing or as a nursing assistant, although I did not know this until data collection began. Length of time experiencing chronic pain varied from seven to twenty-five years, with the combined experience of 92 years, averaging 15 years per participant. Primary diagnoses ranged from rheumatoid arthritis (with anaemia/asthma/fibromyalgia), ankylosis spondylitis (with degenerative disc disease/fibromyalgia), failed back surgery (with arachnoiditis/fibromyalgia), breast cancer and broken patella (with ruptured implants/bone chips on spine), trigeminal neuralgia and neurological sleep disorder (with fibromyalgia and borderline lupus), and neuropathic pain, left knee, following radical surgery (with previous history of

endometriosis). Two participants were working full-time, two were working part-time and two were on disability pensions. Five out of the six participants had some identified struggle with insurers concerning their disability; this will be discussed further in Chapter Five.

Participants found out about the research through a networking process, I knew some of the women through working in the field of chronic pain, others I came in contact with through chronic pain workshops, conferences and support groups. The selection of the number of participants was within the expected range for narrative studies, where the numbers range from one to ten participants (Creswell, 1998; Ellis & Bochner, 2000; Lieblich et al., 1998). The number is appropriate given the volume of data collected through interviews, the meticulous attending involved in listening, transcribing, working and reworking the texts, and active engagement of participants in verifying transcripts and providing their interpretations to the analysis (Lieblich et al., 1998; Riessman, 1993, 2002; Tierney, 2000). All participants were informed of the research study and aware of the guiding question and were invited to share their stories, interpretations and reflections. Given my connections with the chronic pain and disability communities and my professional link to the helping professions, a heightened probability existed that participants would have been known to me prior to being invited to participate. In anticipation of this possibility, I formulated an ethical standard prior to extending invitations: that no current professional relationship (being defined as within the past four years, since the fall of 1999, as research commenced fall of 2003) existed with participants. For example, a former colleague was invited to participate (a colleague I knew through work prior to 1999), but no current colleagues were included. Likewise,

one participant I had seen in my professional role and another had seen me in her professional role; however, termination of those roles occurred prior to the fall of 1999. Participants were not pressured into participating, and the risks and benefits of participating were discussed in detail. All the women invited to participate accepted expressing a keen interest in both telling their stories and informing an anti-oppressive way of working with sufferers.

My approach was one of working with participants, dialoguing, using voice, storytelling and reflection as elements of healing and testifying to injustices experienced within health care, in the hopes that the women would feel empowered through this process. In the words of one participant, “I think you have done a fabulous job and thank you for what you have done. I sincerely hope you get a good response and that, aside from getting passed, people are really interested in what you have done” (Helen, May 2, 2004).

3.5 Data Collection Methods and Processes

In a narrative analysis, the story itself becomes the unit of analysis (Riessman, 1993, 2002) and as such, the eliciting of stories through the use of interviews becomes the preferred method of data collection (Lieblich et al., 1998; Riessman, 1993, 2002; Tierney, 2000). The interviewing structure for this research consisted of three distinct phases; first, the pre-participation interview; second, the primary interviews (consisting of two, and in one case three interviews); and third, the focus group teleconference. The pre-participation interview and the debriefing process were not collection methods but rather integral components of the collection process and therefore have been included

under this section. Table 3.1 below lists the interview steps and their length of time.

Another method of data collection consisted of the optional autoethnographic contribution, intended to provide a forum for participants to express their pain story in a unique and personally creative way.

Table 3.1: Data Collection Processes

Pre-Participation Interviews: 30 – 60 minutes (note: debriefing was additional time)

Fall 2003:

First Interview	Second Interview	Third Interview	Total Time
B – 2 Nov 136.81 m	B – 4 Nov 72.93 m		B – 209.74 minutes
b- 10 Sep 76.03 m	b – 29 Oct 51.52 m		b- 127.55 minutes
D – 11 Sep 67.53 m	D – 3 Oct 48.37 m	D – 14 Nov 29.59 m	D – 145.49 minutes
E – 6 Oct 85.14 m	E– 29 Oct 101.77 m		E- 186.91 minutes
H – 18 Nov 55.22 m	H – 27 Nov 64.94 m		H – 120.16 minutes
M – 19 Dec 68.30 m	M – 19 Dec 34.86		M – 103.16 minutes

Combined Total of Primary Interviews - 890.55 minutes

Mean time for Primary Interviews - 148.25 minutes

Range for Primary Interviews - 106.58 minutes

Focus Group Teleconference – April 8 72.58 minutes

***five of the six participants were involved in the teleconference.**

Autoethnographic Contribution:

[D]awn – conference paper presentation [b]endy - cartoon character/dream

[E]velyn – poems/ drawings [H]elen – paintings [M]arg – vision

[B]arbara – did not make an autoethnographic contribution

Note: Sep = September; Oct = October; Nov = November; Dec = December; m = minute

Pre-Participation Interview

The interview process began with a pre-participation interview, where I shared aspects of myself as researcher and sufferer, followed by an explanation of the research process. I specifically identified what would be required of the participants and consciously explored potential areas of emotional intensity that might arise out of their participation. The individual interviews were identified as the only required components of this research, leaving the focus group teleconference and the autoethnographic contribution as optional. The pre-participation interviews lasted between 30 and 60 minutes and were conducted either in person or over the phone, depending on the participants' availability, geographic location and preference. Participants were given a week to decide on participation, to weigh their personal risks versus benefits of being involved in this research project. Furthermore, they were given a detailed consent form that outlined the research process, what would be required of them, and potential risks and benefits associated with their involvement (see Appendix A). Even if they immediately agreed to involvement, I stayed with the established protocol, allowing time for reflection.

Primary Interviews

All interviews were conducted in the fall of 2003. Before individual interviews were scheduled, I received all consent forms signed and dated. All women invited to participate agreed, with only one woman asking for clarification on the ownership of her story. I explained to her the research process, how data would be used, that elements of her story would be written in a dissertation and potentially used in a publication; but that

she owned her story and would have editing rights to all transcribed data relating to her story. Due to geographical distance and preference of participants, some interviews were performed consecutively, for example, Marg had interviews one and two on the same day. The longest time between interviews for a participant was a month and a half, again this being due to the participant's schedule. A storyboard (see Appendix B) was provided to participants as a way of beginning their narrative, whereby three specific interviews were outlined with broad questions (see Appendix C); however the number of interviews slightly varied depending upon the needs of the participants (including pain levels) and how they articulated their story. All participants had two interviews, except for one woman, who had three. The participant who had three interviews was just under the mean total interview time, with a total time of 145.49 minutes compared to the mean of 148.25 minutes. The overall focus of the interviews remained constant irrespective of the number of interviews conducted.

Cognizant of participants' potential need for accommodations, I traveled to their communities and gave them the option to be interviewed in their homes or an alternate location. Four participants were interviewed in the comfort of their own homes, with two choosing other facilities. During the interview process, I was attentive to both their physical and emotional needs. For example, if a participant started to shift in her chair, I would ask if she was in pain and therefore needed to stretch, or, if an emotionally intense telling occurred, I would check in with her on an affect level and clarify if a break was needed. This, of course, varied per participant and interview.

The first interview focused upon the sufferer's personal story, including the onset of chronic pain, acquiring a diagnosis and subsequent treatment, and ultimately

journeying through life with pain. Although participants used the storyboard and interview guide to begin and follow the storying process, distinct differences were noted in how participants chose to relay their stories; some began with the onset of their chronic pain – the event that initiated that journey; others had more of a global presentation of their pain experience, weaving in specific pain events; one participant related her ill health and struggles back to her childhood. I respected their chosen starting point and listened attentively to their defined journey. The second interview had more of a professional focus, where sufferers were asked to relay their experiences in working with chronic pain sufferers, concluding with their practice wish list.

Total interview time for the individual interviews ranged from the lengthiest at 209.74 minutes, to the shortest, at 103.16 minutes, with a difference of 106.58 between the maximum and minimum times. The total interview time of all six participants was 890.55 minutes. The interviews translated into 159 single typed, 12 pt font pages of transcript. The length of the interviews raised concern for me, aware of the increased potential for chronic pain sufferers to fatigue; however, respect for their choice of expression in telling, including determining the flow and length of their story, took precedence.

Debriefing

Debriefing was central, clarifying with participants their responses following the interview process. A detailed debriefing protocol was followed; including structured termination of the interview, exploration of the emotional and physical impact of the interview, and dispersed written debriefing protocol that highlighted on-line and

community resources, and the contact names and numbers for myself, my supervisor and an independent counsellor secured purposively for debriefing (see Appendix D).

Debriefing, immediately following the interview, was a non-recorded, non-transcribed conversation facilitated by a check-in with the participant as to how she was feeling, including any thoughts or concerns she might have following the sharing of her story. The length of time spent debriefing varied, for some participants required very little support following the interviews, while others required twenty to thirty minutes of dialogue, as well as check-ins via phone or e-mail up to a week later. Howell's (1994) Four Categories of Processes in determining pain response and impact acted as an informative guide to the debriefing process (see Appendix E), along with exploring participants' support structures that could be called upon if the need arose.

The participants could contact me directly for further debriefing or they could call the counsellor, at no cost to them. The need for extended debriefing only took place once following an initial interview, when emotional pain was stirred to the surface. I spent approximately 45 minutes with this participant on the phone; listening, validating and paying witness to her vulnerabilities and strengths. She needed to process the interview in greater detail and free from the recorder. Contact with participants happened at each stage of the research, either through e-mail correspondence, postal mail or telephone. Further, the participants were contacted by e-mail or telephone in the spring of 2005, a full year after the last data collection process (teleconference), to explore the impact of the research upon them and to see how they were doing.

Autoethnographic Contribution

The women were invited to not only tell their stories (through a series of interviews), but also identify/express their pain in a medium of their choosing. They related their stories in different forms; including poetry, academic paper presentation, paintings, doodles, dreams, visions and written narratives. This element of expression enriched their testimonies, as participants dared to expose their most intimate fears and struggles. With admiration and gratitude, I include these valuable contributions to their stories; illustrated as an extension to their personal stories, they add description, emotionality, and colour to one's understanding of living in pain. The contributions were not subject to analysis, for they were invited as an extension to the sufferer's personal story in Chapter Four; however, the participants were asked to include a brief description of their piece. Five of the six participants made a contribution, four adding an aspect of their pain journey from previously depicted works. Creating a new expression of their life in pain proved challenging. The one participant who chose not to add this feature to her story had originally tried to create a pain collage. Before she could finish her expression, she had a flare-up of her pain and decided to forgo this aspect of the journey. In the following chapter, each sufferer's testimonio is shared, along with their autoethnographic contributions.

Focus Group Teleconference

Following completion of the interviews, and once all reviewed transcripts were returned, an invitation was extended to the participants to connect with each other by way of a focus group teleconference. This was an opportunity for them to share their

experiences, insights and reflections on living with chronic pain, working with sufferers of pain and being involved in this interview process. At least three months had passed since their last interview, providing time for individual reflection on the process. In keeping with the testimonio methodology;

Focus groups can be an important element in the advancement of an agenda of social justice for women, because they can serve to expose and validate women's everyday experiences of subjugation and their individual and collective survival and resistance strategies. (Madriz, 2000, p. 836)

The women's everyday experiences were housed in living as a sufferer and working with sufferers of chronic pain.

A 30-page report on preliminary findings was drafted, specifically attending to the common themes identified from the interviews. The report was scaled down to an eight page agenda that was used as a discussion guide for the teleconference (see Appendix F). Each sub-section was highlighted, comments were elicited and a subsequent discussion evolved. Some sections prompted more discussion than others (for example, spirituality). All sections appeared to be of interest. The teleconference served as a group validity check for the categorical-content analysis, as sufferers' comments and reflections were noted by the chair with both manual and electronic recording. The overall discussion could have carried on well beyond the allotted time, but unfortunately, we were on a time scheduled teleconference.

A face-to-face focus group format was originally planned, but in order to respond to pain needs and geographical distances, a teleconference was organized. This format was more accommodating for participants; for example, one participant was in bed due to pain; a local participant opted for a phone line in an effort to avoid pain created from

traveling; and, another participant was in Ontario and had family visiting. In total, there were five phone lines, with myself and one participant in the same room and the other four participants in their own homes. Initially, the plan was to have myself and three participants together linking to two other participants via phone lines. However, this plan needed to be altered due to unpredicted pain situations. This serves as a demonstration of the need for flexibility in sufferers' lives. Reflecting back, I wonder if sharing physical space with one participant had any impact on her level of involvement. Speculating, I believe that it might have limited her contributions in that I was consuming vocal space to chair the meeting. She certainly made major contributions but I was aware of her occupying less air time than other participants. The intent of the group meeting was two fold, one, to initiate lively discussion on the formation of an anti-oppressive approach in working with chronic pain sufferers, and two, to empower the participants through the sharing of struggle and survival. Madriz (2000) refers to focus groups as collective testimony whereby levels of consciousness are raised through viewing problems from their structural roots, and in so doing, calling for social change. The teleconference was 72.58 minutes of recorded transcript time, equating 23 single spaced typed pages once transcribed and transcript verification was sought from all participants.

The face-to-face focus group format would have allowed participants to share their autoethnographical expressions of living with chronic pain; for example, Helen could have shown her art pieces depicting a body in pain, and Evelyn could have read some of her poetry on struggling with chronic pain. Given the richness of this participant group and in keeping with the interpretative nature of narrative inquiry, the physical coming together of this group would have facilitated participants' phenomenological

associations to the autoethnographical components. Chronic pain is not stagnant, sufferers continually struggle to negotiate their environments, and therefore extending beyond the hour-and-a-half time frame might have exceeded their tolerance levels. Bringing them physically together proved impossible; however, this did not detract from the strength derived from their verbal connection. Extending this connection, each participant received a copy of Chapter Four, where their individual stories were presented to the reader, accented by their autoethnographic contributions. Prior to the dissemination of this chapter, consent was sought from the participants; as they were specifically asked if they wanted to have their story shared with other participants and if, in turn, they wanted to read others' stories. This particular initiative was born out of an appreciation of participants' willingness to share themselves, and thus furthering the connections made during the teleconference and as a group building strategy to strengthen collegial relations in anticipation of future work together.

3.6 Narrative Analysis

I struggled somewhat with the concept of data analysis, recognizing my responsibility as a researcher, using a testimonio methodology to extract from participants' experiences the political and social justice challenges, yet not wanting to impose my interpretations of the participants' stories onto them or to suggest by the analysis process that their stories would be reshaped, if you will, restoried. Becker (1999) struggles with the conventions of narrative analysis, suggesting that they are representative of the dominant discourse embedded in the modernist tradition and, thus, she calls for an alternative reading of narratives that would listen to unconventional ways of storying. She further postulates that they are deemed 'good stories', worthy of telling

if they follow a logical sequence, are coherent, and represent a moral endpoint (as suggested by Labov, 1972; Polkinghorne, 1988). Becker (1999) states, “For chronic pain sufferers that seems to be a challenging task, for if pain continuously destroys or threatens the self and the world, then every narrative of the self in pain remains fragile” (p. 75). Remaining cognizant of participants’ potential vulnerability and how it might get relayed in their storying is important to the narrating process. And, if the researcher espouses a more equalitarian interactive relationship with the participants then attention to the interview process is imperative (Clandinin & Connelly, 2000).

In response to the analytical tension noted above and wanting to be inclusive of peoples’ various methods of telling, I identified three collection methods: one, the interviews with women sufferers; two, the option to express living with chronic pain in a distinct form, such as art, poetry, or journaling; and three, the group interview via teleconference with participants. Recognizing that I was a vehicle through which the sufferers’ stories could be told (Tierney, 2000) and keeping with my anti-oppressive theoretical positioning, participants’ reflections and input were a defining feature of the analysis. Participants’ reflections were integrated into the research process beginning with an interview guide that elicited their personal-professional knowledge, asking “Given your knowledge in working with sufferers of chronic pain and in suffering from chronic pain yourself, how would you define or re-define working with sufferers in a way that is empowering?” and “How does practice need to be structured in order to give sufferers a clear voice in their treatment?” This was then followed by a dialogue with participants on the preliminary findings (specifically the categorical-content analysis)

through the teleconference with five of the six participants and by private e-mail for the participant who was not available for the teleconference.

Transcript verification and editing rights were other ways of respecting participant voice, along with the option to read/edit their individual stories found in Chapter Four. Participant analysis was formally built into the research process to help combat potential distortions that could have arisen from the researcher's interpretations of participants' stories and to honour the empowerment discourse embedded within testimonio methodology (Beverly, 2000; Tierney, 2000). Academic research calls for a degree of rigor whereby data should be subjected to a consistent, transparent process; first and foremost, it was important for honouring participant reflection that transparency had to be evident to the sufferers and then to the readership. In attending to this requirement, consistency was applied to the process from initial contact with potential participants to completion of the data gathering. Participants were kept informed of the process as it evolved and their thoughts and reflections were specifically solicited on the preliminary findings, an anti-oppressive lens to working with sufferers and their participation in the research process.

Different methodologists have distinct ways of reading the data, and although testimonio has a distinctive quality in reaching beyond the spoken word into a political milieu, the researcher is still required to attend to basic methods of reading. For example, Riessman (2002) calls for "close and repeated listenings, coupled with methodical transcribing" (p. 253) whereby the subtlest vocal expressions, be it sighs or pauses, are captured. She attentively listens to the speaker, identifying changes in tone and pitch and drawing breaks in the transcription according to those changes rather than strictly

following the spoken words. While transcribing the interviews, I noted any obvious affective expressions, as in laughter or crying; typed vocal expressions, such as ‘ah’ or ‘umm’; and noted substantive pauses in dialogue; however, reflections on tone or vocal variations were not noted as the research focus was primarily on content, not form. I typed verbatim what I heard. Following Riessman’s guidelines, close and repeated readings were conducted, re-reading the transcripts when emerging themes, plots or discourses arose; for example, when the second, third and fourth story contained a similar experience around seeking disability insurance, I went back to each transcript carefully reading for this plot line. The intent of the mode of analysis was systematic, rigorous, and reflective: although qualitative data analysis software could have been used, testimonio has its own processes which were applied (Beverley, 2000; Tierney, 2000).

Clandinin and Connelly (2000) focus on four directions in narrative inquiry: inward and outward, backward and forward. Inward attends to the internal conditions, such as emotive expressions, values, hopes and aspirations: outward is existentially situated, looking to the external environment, the social context: backward and forward are temporal, looking to the past, present and future aspects of the story. In applying Clandinin and Connelly’s directions to this research, transcripts were read highlighting emotional expressions of sufferers, their fears and losses and ultimately, their hopes and strengths. This was attended to for the purpose of situating the reader into the lives of the women living with chronic pain, so that the reader’s understanding would be expanded into an empathic positioning for the sufferer. The outward external dimension is represented by the testimonio methodology, where individual readings of the texts were linked to the socio-political context, calling for health professionals to move towards an

anti-oppressive model of working with sufferers. And finally, temporality was invoked through the sufferers telling of their stories; re-calling past experiences, locating present struggles, and envisioning future directions for working with chronic pain sufferers.

Leiblich and colleagues (1998) have designed a model of classification and organization of types of narrative whereby two primary classifications are identified, holistic versus categorical approaches and content versus form. From these two classifications, they identify a matrix of four cells, those being holistic-content, holistic-form, categorical-content, and categorical-form. The holistic-content mode of analysis considers the entire life story and reflects any content therein against the meanings derived from its entirety. The holistic-form once again considers the entire life story but is attentive to the plots, climax and structures exhibited within the narrative. The categorical-content mode specifically identifies and defines categories in the area of investigation; then text components “are extracted, classified and gathered into these categories/groups” (Leiblich et al., 1998, p. 13). The final cell, categorical-form, “focuses on discrete stylistic or linguistic characteristics of defined units of the narrative” (p. 13), such as considering the use of metaphors or active versus passive voice. For the purpose of this research, attention was more formally paid to content emphasizing its connection to testimonio’s focus on social change, wherein an obligation is placed upon the reader to act (Beverley, 2000); and categorical given its appropriateness to problem or group analysis (Leiblich et al., 1998). The socio-political juncture of testimonio differentiates it from other forms of narrative, for “the narrator bears witness to a social urgency”, as testimonio is rooted in “resistance” with a call for “social change” (Tierney, 2000, p. 540).

Using a holistic-content reading for analysis of the data from this research, I encapsulated the similarities and dissimilarities of the women's lives in suffering from chronic pain and in relating to their work from that specific location. The foci of the stories were identified and weighed against the meta-narratives presented in the dominant discourses of chronic pain and disability. The other cell that contributed to the analysis was the categorical-content reading of the text. This style of reading "focuses on the content of narratives as manifested in separate parts of the story" (Leiblich et al., p. 16) and could consist of a narrow categorization of words or a broader schema of events or explanations. Both content readings offered a substantive contribution to data analysis, aligning with the purpose of the research in opening the reader to the lives, experiences and knowledges of women sufferers of chronic pain living with (dis)Ability. Form was utilized in the analysis but to a lesser degree, where linguistic style, presentation and delivery were reflected upon in an effort to enhance the understanding of content. In Chapter Four, holistic-form was examined in the researcher's reflection sections as an added dimension to understanding the emotive experiences of the sufferer and cueing myself, as researcher, in debriefing explorations. For example, if a sufferer painstakingly told of an oppressive experience during an interview, the form analysis might indicate areas of vulnerability needing debriefing. While individual differences were noted, through every reading and analysis I remained cognizant of the need to address the larger socio-political context from which the stories were told.

Testimonio's political orientation, wherein the narrator is testifying to a social injustice, pushed me beyond the original reading models that have emanated from the linguistic or humanities sectors of the academy; turning towards the disciplines of

sociology and social work that have presented some unique approaches to understanding narratives texts. Randall and Clews (2001) have conceptualized a reading that is developed from four main angles: the poetical, the hermeneutic, the therapeutic and the political. The poetical angle examines the text internally, locating plot, character, meaning, genre, exploring the literary elements to understand the life story, hence, “the result is a unique analysis of psychosocial development that appreciates the aesthetic subtleties and “novelty” of individuals’ lives” (p. 11). The hermeneutical angle built upon the process of interpretation, turns the text ‘upside down’ and ‘inside out’ to derive meanings from the texts outside of the dominant discourses. These first two angles present interpretations that can be found in other methods of reading; the next two angles consist of unique interpretative lenses that were useful in understanding both the different knowledges presented in the narratives of this research and in relation to envisioning an anti-oppressive approach to working with sufferers.

The therapeutic angle is essentially the narratives that helping professionals bring to their practice, the narratives reflective of a profession at any given time. For example, “anti-oppressive narratives will encourage helping discourses that make reference to issues of power, domination, and empowerment” (Randell & Clews, 2001, p. 13). Professional discourses are located within disciplines, respective of time and place, for example, what governs psychiatry in Canada in the year 2003 would be substantially different from what governs social work in Israel in the 1970s. Understanding the professional-based narratives of the women participants in this research lead to a greater depth of analysis. Finally, the fourth angle, the political angle, is referring to the internal and external “dynamics of power and decision making” (p. 15). Reading the texts for an

understanding of power relations revealed untold stories. Stories that came from the exploration of questions, such as ‘who has power within the story and why?’; ‘what are the external expectations of power and the professional allegiance to power?’, and ‘how have power relations impacted upon the sufferers’ experiences of living with chronic pain?’

Women in the helping professions, who are sufferers of chronic pain and have worked with sufferers, told their stories for the first time and in this way, the stories themselves were deemed previously untold. Professionally, the women had been commanded to listen to others’ stories, not to be tellers. Untold stories were also derived from the quieter voices within their narratives; the voices the women themselves brought to the surface but did not elaborate upon. Active listening on the part of the researcher means attending to the unspoken, what stories are not being told and why? I meticulously went through the transcripts identifying any partial story, incomplete sentences, thoughts or mini stories. In uncovering the untold stories, I utilized an analytical process to enhance the identification of discrete nuances, by listening to the taped interview while reading the written transcript, hearing the story on two channels, auditory and visual text. Aspects of the story that might be missed with one mode of reading can potentially be picked-up with dual reading (Riessman, 1993, 2002). Likewise, I identified the narratives emerging from the participants’ stories and compared them to the meta-narratives presented by the dominant discourses within the literature on chronic pain and disability. Leiblich and colleagues (1998) assert that “narrative studies are flourishing as a means of understanding the personal identity, lifestyle, culture, and historical world of the narrator” (p. 3). Emerging beyond Leiblich’s individual

psychological and historical emphasis and in keeping with the testimonio tradition, I would add Randall and Clews' (2001) social-political world to my analysis.

In the process of analyzing data, I continually recognized that narrative interpretations are co-produced (Riessman, 2002) between the researcher and participants. When paying honest adherence to the state of interaction, no systematic, logical format can be specified for ordering the processes of analysis, for they were dependent upon participant selection, degree of involvement from participants and the signifiers exhibited within the processes themselves. What I can identify is the rigor with which I examined the texts; in that, I transcribed the data personally and applied multiple readings to the transcripts. The multiple readings began with reading all the stories together as a complete text, followed by individual readings which consisted of highlighting distinct nuances with different coloured markers and noting specific categories within the margins; and finally, creating categories supported by identified quotes from participants' stories.

The value of personally transcribing the data was not anticipated, nor fully realized until the task was complete. It was tedious, time consuming and labour intensive; however, as the researcher, I became intimately familiar with the texts and can literally recall the emotionality, clarity and tone presented by the participant, through simply reading the text. I remained cognizant of Silverman's (2000) suggestions of common errors in text analysis, such as analyzing a line of the text outside the context of the entire text, thus extracting an element of the story out of its global meaning. Or not recognizing that your reading is one understanding and hence making "grandiose claims about originality, scope or applicability to social problems" (p. 825).

In summary, “narrative inquiry is stories lived and told” (Clandinin & Connelly, 2000, p. 20). Narrative inquiry based upon a testimonio methodology embraces a socio-political dimension of witnessing and uncovering the previously untold stories of oppressed peoples, specifically in this instance, the untold stories of women, who are helping professionals and sufferers of chronic pain. To capture those untold stories, a number of reading methods were utilized, from the more traditional readings focused on form and content, to the more progressive readings extending the texts to political discourses; those highlighted were Riessman (1993, 2002); Clandinin and Connelly (2000); Leiblich, Tuval-Mashiach and Zilber (1998); and Randell and Clews (2001).

3.7 Trustworthiness and Limitations

Many qualitative researchers have addressed the need for a different view of validity from that in the positivist research paradigm. Lincoln and Guba (1985) specify five axioms where they locate a positivist paradigm in contrast to what they describe as a naturalist paradigm of inquiry. The five axioms are the nature of reality, the relationship of the knower to the known, the possibility of generalization, the possibility of causal linkages and the role of values. In the naturalist paradigm,

Realities are multiple, constructed and holistic, the knower and known are interactive, inseparable, only time and context bound working hypotheses are possible, all entities are in a state of mutual simultaneous shaping, so that it is impossible to distinguish causes from effects and inquiry is value-bound. (p. 37)

A narrative methodology fits within Lincoln and Guba’s naturalist paradigm in that perceptions are based upon fluid evolving understandings between the teller, the listener and the reader (Bruner, 2002; Clandinin & Connelly, 2000). The participants and the researcher are in relationship, “making the knower and the known inseparable”

(Bruner, 2002, p. 27). The researcher brings herself into the storying process, being aware of her own narratives and conscious of the tension that exists between her story and the story of the participants (Clandinin & Connelly, 2000). Clandinin and Connelly assert, "Moving into close relationships with participants is necessary work in narrative inquiry" (p. 82). Narrative inquiry is in sharp contrast to a positivist paradigm of inquiry and has its own parameters of trustworthiness.

For the purpose of this research, I attended to Riessman's measure of validity for she specifically speaks to narrative methodology, the tradition in which testimonio is framed. Narratives are not meant to be a representative worldview, nor an exact science that would be replicated given the same circumstances. "Narratives are laced with social discourses and power relations, which do not remain constant over time (e.g., the category of sexual harassment)" (Riessman, 2002, p. 257). Given the interpretative location of narrative, it is fitting to examine trustworthiness rather than focus on defining truth; for truth "assumes an objective reality" whereas trustworthiness "moves the process into the social world" (Riessman, 2002, p. 258), making public the experiences of women sufferers and an alternative way of working with chronic pain. Riessman (1993, 2002) identifies four areas of exploration within narrative research for consideration in the area of validation: persuasiveness, correspondence, coherence, and pragmatic use.

"Persuasiveness", simply, is how reasonable and make-sensible are the interpretations. According to Riessman (2002), "persuasiveness is greatest when theoretical claims are supported with evidence from informants' accounts and when alternative interpretations of the data are considered" (p. 258). Throughout Chapters

Five and Six, findings are set in the context of both the progressive literature on chronic pain and the dominant meta-narratives in pain assessment and treatment. Alternative interpretations of the data were considered; for example, a discrepancy existed between sufferers with respect to the role of opioids in pain treatment. Where most of the sufferers believed opioids to be a fundamental coping strategy, one cautioned to their potential harm, harm she witnessed through her mental health practice with sufferers. The strength of narrative lies with the multiple understandings that can emerge. Another example of an alternative reading existed with my own understanding of access to health services for physicians. Emanating from the hierarchal structure of medicine, I assumed that physicians would receive preferential treatment within health care. Yet, the sufferers' stories told of oppressive experiences.

“Correspondence” means bringing the data and analysis back to the participants, as a way to verify representation; this respect has been outlined in this research in a number of ways; for example, through participant verification of transcripts, invitation to contribute to the interpretation of data, the researcher sharing findings with every participant, giving them Chapter Four, ‘the stories’, and offering access to the full dissertation. Transcript verification was an essential component of this research, for if I was entrusted to relay the sufferers’ stories, my understanding of those stories had to be reflective of the sufferers’. Participant review of transcripts verified accurate representation of their stories and allowed participants to check the content before public dissemination. Furthermore, if segments of an interview were missing from the transcript due to auditory quality in recording, participants filled in content from memory. As soon as each interview was transcribed, it was forwarded to the participant, either by e-mail

attachment or public mail, depending on their preference. Participants either mailed them back in a self-addressed stamped envelope provided or I made arrangements to pick them up. Their editorial comments pertained more to sentence format and grammar than to content, with most exercising this right to a limited degree.

Atkinson (1998) clearly identifies transcript review and verification by participants as one of the essential steps in the interview process. One participant expressed a concern about representation of her critical lens into health care, fearing the implications of having to work in a system that she critiqued. In response to this concern, I wove participants' critique of the system into a collective analysis, refrained from using participants' names in the medical treatment section and agreed to be cautious about using identifiable information or quotations pertaining to this topic. Editorial options were critical to ensuring that their voices were not misrepresented; I envisioned this research process as a mutual engagement, whereby participant involvement was welcomed and encouraged at all stages.

"Coherence" is located within Agar and Hobbs' (1982) identification of three types; global, local and themal coherence. Global relates to the narrator's goals, what they are to achieve through storying; local is specific to the telling of the story itself, stylistic representation within the narrative; and finally, themal coherence utilizes segments of the story itself to identify thematic sequencing within the narrative meaning. Chapter Five attends to the similarities and differences between the stories and highlights all three sub-categories of coherence, while Chapter Six takes this application specifically to professional understandings and challenges.

The final area is “pragmatic use”, which is the applicability of this work to further research and the contribution of the participants’ stories to social work practice in working with sufferers of chronic pain. This is the most difficult of the four to realize until the research has been fully disseminated. More immediately, participants will probably incorporate their learnings from the study into their own work with sufferers. From a practice location, recommendations to inform an anti-oppressive way of working with sufferers need to be conveyed to social workers and allied health professionals to both realize the goal of this research, as identified through the research question, and to give respectability to participants so that telling their stories will have served a greater purpose. Testimonio is to testify, to challenge the status quo, to bring forth change, to move the agenda forward (Beverley, 2000; Tierney, 2000). The majority of efforts at disseminating the findings to date have concentrated on conference presentations reaching a limited number of persons, primarily from the academic community (MacDonald, 2004b, 2005b, 2005c, 2005d, 2006a, 2006b, 2006c).

In narrative research, we must make the research process evident to both the readers and participants, detailing specific steps. Through our transparent process, trustworthiness is established. Riessman (2002) facilitated the transparency by: “(a) describing how the interpretations were produced, (b) making visible what we did, (c) specifying how we accomplished successive transformations, and (d) making primary data available to other researchers” (p.261). As a researcher operating from an anti-oppressive lens, Riessman’s fourth point pertaining to the sharing of data with other researchers presents an ethical tension. I do not believe that I own the data, but rather, have been entrusted with its safe keeping by the participants for the purpose of this

research study. I have been conscientious throughout this research to be respectful of participants' voices. As a compromise, requests for usage of the primary data will be considered through a collective decision-making process based upon shared rights and responsibilities for its dissemination with research participants. If individual requests were forthcoming, each participant would have to decide if she wanted to share her story in another context; for the participants own their personal stories.

A narrative research approach is time consuming, requires detailed and attentive readings of the texts, and therefore is not an appropriate method for large numbers of participants. In listening to this small participant group, diversity of sufferers was limited. I regret that I was not able to represent more racial diversity and other aspects of diversity within the sample. Coming from an anti-oppressive theoretical position, I recognize the multiple layers of oppression (MacDonald, Bernard, Campbell, Fay, MacDonald, & Richard, 2003; Mullaly, 2002) that exist within society, and believe sufferers from racial or sexual orientation diverse locations would have added unique lenses to the research. However, I was also conscious of tokenism, and did not want to have a participant misunderstood as representing their entire race or sexual orientation. Further research opportunities are envisioned, for example, collaborating with Aboriginal people or African Canadians to explore the experiences of sufferers of chronic pain within their communities.

The limited number of participants in narrative research also challenges the traditional scientific application of generalizability to a population, although theoretical inferences, (for example, generalizations to causality), have been derived through this method. Interpretations being central to the process, no set formula, guidelines or receipt

can be constructed to outline the research process (Beverley, 2000; Leiblich et al., 1998; Riessman, 1993, 2002; Tierney, 2000). However, testimonio narrative analysis follows a process of reaching out to the frameworks of participants and integrating those findings into a socio-political context. Narrative research can give voice to those often silenced and bring personal experiences, meanings and interpretations into the realm of social scientific exploration.

3.8 Ethical Considerations

Frank's (1995) categorizations of illness stories, that of restitution, chaos and quest narratives, were used as a safeguard in assessing participants' readiness to tell their own illness stories. If preliminary findings, derived from the pre-participation interview, had indicated that the participant might be in the chaos story category, the researcher was prepared to share this perception with the woman, and if confirmed by the participant, an honest and direct discussion would have explored the participant's willingness and ability to continue in the research given the magnitude of her suffering. Thankfully, all women were situated within the quest narrative, with some overlay with restitution given their professional helping roles. As noted previously, I did need to pay additional attention to one participant, as her recall stirred memories that elicited emotional pain. In the end, this participant told me that the research process was a healing journey, a journey that was long overdue. It was all the more prudent that due care was exercised in the debriefing process with this participant. More time was taken at the conclusion of each interview to check in with her and contact between interviews extended the debriefing and allowed me to ascertain her emotional availability for the second interview.

Although I firmly believe in participants' rights to choice, I also recognized my responsibility as a researcher and social worker to assess the level of risk to participants. The depth of involvement might have been altered if I determined a participant to be at high risk for elevated pain levels due to participation. I was cognizant that a situation could have arisen whereby I professionally believed it would not be in the best interest of a woman to be involved in this research. In such a circumstance, my judgment would have prevailed and I would have dialogued with the woman about alternative ways of staying involved in the research. The ultimate decision to participate would have remained with the participant under most circumstances.

From both my personal and professional knowledges, I realized the potential for vulnerability associated with testifying. In an ethically responsible manner, I built in research processes to attend to this aspect, such as the pre-interview, the debriefing protocol, access to a counsellor at no cost to participants, and phone and e-mail access to myself as researcher. I had anticipated the collaborative aspects of this design (such as the expression of voice, transcript verification and reflection on preliminary findings) would strengthen their connection to the research process and guard against exploitation, ultimately leading to an empowering experience. Coming from an anti-oppressive position, it was very important for me to attend to the power dynamics within the research process, to make sure that I did not contribute to their oppressive experiences of being a chronic pain sufferer. Likewise, attention to power relations is in keeping with my selected methodology, for "testimonio is a fundamentally democratic and egalitarian narrative form" (Beverley, 2000, p. 557).

Confidentiality was also a concern, for I worried the participants would be easily identified given the small population from which they are drawn and the demographic information shared with the readership. The Interdisciplinary Committee on Ethics in Human Research at Memorial University approved the ethics proposal, yet stated that the limits to confidentiality needed to be “explicitly stated” to participants (see Appendix G). This concern was expressed to each participant and a discussion then followed on how they wanted to be identified within the research. Each and every woman decided to use her own first name, it was important for their stories to be told; for not only a voice to be heard, but an identity to be acclaimed. The only request, initiated out of concern of having to work within that system, was for the medical critique given by one participant to not be directly associated with her name. This was addressed by collectively reporting on the medical system, so that participants could not be singled out for their comments.

Ethical considerations previously identified included a four-year protective window (September 1999) from professional relationships with participants and the involvement of participants in the research process through review of their transcripts, access to an editing option and an opportunity to interpret the data. Other ethical considerations included respect of participants’ voices by structuring an opportunity for participants to share their stories with one another through a teleconference and inviting them to contribute to an anti-oppressive model of practice in working with sufferers. Finally, respect for the struggle of living with chronic pain was recognized through the detailed debriefing protocol discussed above, the identified support systems available to participants and the offer to give a mini workshop on survival techniques in living with chronic pain. Participants did not express a need for the mini workshop or for the

counselling services; however, access was available. The collection, transcription and storage of data are other ethical considerations whereby I maintained security of the data from time of collection to locked storage, including transcribing all texts personally.

3.9 Summary

This chapter has attended to the research process, methodologically located within a narrative testimonio framework, with a post-modern leaning in alternative readings and interpretations stemming from the narrative tradition (Tierney, 2000), and an anti-oppressive association emanating from testimonio's call to social action and change (Beverley, 2000). The methods of inquiry were highlighted, beginning with sampling procedures, followed by data collection and narrative analysis. Trustworthiness was explored from a qualitative research perspective with special consideration of narrative inquiry. Limitations of the research were discussed, including the time commitment involved with narrative research and difficulty with traditional scientific applications of generalizability. Further, I noted the lack of racial and other diversity within the sample population, identifying future research possibilities, for example, with chronic pain and (dis)Ability in Aboriginal and African Canadian communities. Finally, ethical considerations were discussed, attending specifically to participant involvement in the research process, respecting their voice at all levels of engagement, including their request to be referred to by their first names.

The next chapter tells the participants' stories. This tells the reader about the experiences of the sufferers before collective findings are explored and an anti-oppressive framework in working with sufferers is detailed. For, according to Atkinson (1998),

“telling our stories enables us to be heard, recognized, and acknowledged by others.

Story makes the implicit explicit, the hidden seen, the unformed formed, and the confusing clear” (p. 7).

Chapter Four – the Stories

4.0 Introduction:

The descriptor of ‘untold stories’ inscribed in the title of this research is multifaceted: in the first instance, the storying brings the untold into the realm of the told; secondly, close and repeated collective readings and applied methods of analysis elicit new learnings and insights; and finally, through the act of testifying, the personal story becomes political and social-political dimensions of the sufferers’ struggles are revealed. Throughout this research, primary attention has been focused upon Lieblich and colleagues (1998) content cells; specifically in this chapter, holistic content was used to construct the sufferers’ stories, thus inviting the reader into an understanding of life with chronic pain. Further, through the process of testifying sufferers claim their own voice. This research could not be ethically presented without this chapter, for the sufferers’ stories place the research in context. Reading the stories is witnessing the pain journeys; testifying and witnessing need to be synonymous.

The categorical-content findings are presented in Chapter Five and Chapter Six, deriving personal and professional insights and learnings from the sufferers’ interviews and teleconference. This analysis specifically relates to the guiding research question, ‘how can the stories of women in the helping professions, who are sufferers of chronic pain and (dis)Ability, inform an anti-oppressive approach to social work practice in working with sufferers?’, whereby practice guidelines informed by the sufferers’ stories are identified. Storying began with interviewing each sufferer, asking them about their illness narrative, and then deriving the story from the interview transcripts. Each sufferer’s transcripts were read and re-read, in an attempt to capture the unique

experiences and nuances of her story. Colour markers and numerical sequencing were used to identify the timeline and flow of the story. Although dates, times of the year, age of people in storied components, along with other demographical and historical clues were used in developing the storyline, time was primarily associated with the narrative tradition of the “unfolding of crucial events” (Bruner, 1996, p. 133). Some stories were told in an event focused manner, while others required closer readings to capture the details and flow. Given that the stories were listened to at one particular moment in time, they are conveyed in past tense. This also recognizes that the women’s stories continue to unfold and that this depiction is but one relay of their experienced lives.

All sufferers were asked if they wanted to verify their stories, and all six sufferers stated that the transcript verification process was sufficient. However, one sufferer was interested in hearing her story, so it was read to her over the telephone. No changes were requested. According to Frank (1997),

In social scientific considerations of illness, the “story” usually denotes a narrative elicited by a third-person interviewer. The story may emerge with very little prompting, or it may be pieced together out of responses to a variety of questions. (p. 38)

As described in Chapter Three, the storyboard and interview-guide were used as prompts; however, the sufferers relayed their stories in a free-flowing manner. The sufferers were also invited to contribute an autoethnographic piece, along with a short descriptor, depicting their life with pain. These autoethnographic contributions are linked into the sufferers’ stories, in the form of poetry, paintings, drawings, dreams/visions and professional paper presentation. Four of the six sufferers contributed a piece or pieces they had created previous to this research, during times when pain gripped their lives. The two sufferers who tried to create something after the research interviews, struggled

with the emotional aspect created by this journey. In the throes of creating a representation of life with pain, one sufferer described the item in an e-mail. The e-mail graphically captured the autoethnographic expression, so permission was sought to include it in her story. She then sent a more developed analysis, which added depth to her original description. The second sufferer began with a pain collage, not anticipating the emotional memories that would surface during this activity. Respectful of self-care, she took her time with the activity, but before she could finish she had a flare-up of her condition and had to abandon the collage. She thought about including it, titled 'unfinished pain'. Both sufferers were offered a chance to dialogue about their experiences and e-mail contact was utilized as a check-in on their well-being.

As women, in the helping professions, all participating sufferers were keen to challenge the meta-narratives circulating in medicine and the helping professions, as well as the assumptions about pain within the general populace. They were also eager to reach out to other sufferers through the sharing of their own experiences.

Illness (chronic pain), reshapes our story, impacting upon every aspect of our lives (Brody, 2003). The storyline of the illness itself is not enough, for the sufferer's experiences in living and relating to that illness need to be told: "a voice of one's own" (Frank, 1997) needs to be proclaimed. Through the proclamation of voice, the process of storying, the intent is to validate the sufferer's experiences and build a sense of community (Atkinson, 1998; MacDonald, 2004a). Paying witness to the sufferers' torment, so that they felt heard, was one goal of the research; obliging the reader to thought and action, was the other. Morris (2002) coined the concept 'thinking with narrative', whereby as the reader one "takes the radical step back . . . of allowing

narrative to work on us” (p. 196). Bruner (1987, 2002) deems that tellers and listeners must develop a relationship with one another for the message in the story to be understood. I hope that the readers gifted by the stories of the women in this chapter, will be called to that thought process, to re-think the myths and stereotypes surrounding those suffering in chronic pain, to open their minds so that they might understand the sufferers’ experiences. Within this chapter the reader will find shared experiences and commonalities, and unique occurrences and differences, for each story is self-contained, yet connections are evident (see Appendix H -- Sufferers Profiles).

Each story will begin with a researcher’s reflection, whereby I comment on the process of storying, relating to Lieblich and colleagues (1998) cells of analysis, specifically the form category, touching on both holistic-form and categorical-form (see Appendix I). Reaching beyond analysis, I have commented in this fashion to respect the impact of storying upon the sufferer and upon me as listener and to highlight the lessons I have learned through the process. As a sufferer of chronic pain myself, I know all too well the vulnerability felt through storying, but I also know the empowerment derived through finding one’s voice. I want to thank the sufferers for sharing their rich and meaningful explorations.

4.1 Barbara ~ (no autoethnographic contribution)

Researcher’s reflection: Barbara relayed her story from an emotive location, following her feelings and thoughts as they related to her past experiences in living and sorting out a life in pain. Expressively told, she related to relationships of a personal and professional nature, paying specific attention to the power differentials between consumers and health care providers. Barbara’s critique of the hierarchal ordering of

medicine, coupled with her ability to address her own vulnerabilities, speaks to the sufferer's marginalized location within this power dynamic. A power dynamic, that can be shifted to better serve the sufferer if the physician were to believe the sufferers' story, and work alongside the sufferer towards pain reduction.

Barbara's Story:

Barbara finished her bachelor's degree in social work in the spring of 1990, at the age of thirty-two, and was accepted into a Master's program to commence in the fall of the same year. Moving provinces with two children and a partner from her second marriage, Barbara had limited time to get settled before classes would begin. To complicate the situation, her son, the eldest of her two children (ages 12 and 11), was a child with physical and mental (dis)Abilities. He developed serious medical complications and had to undergo brain surgery just as school was to begin. Her son was very ill and almost died.

Understandably, this was a very trying and stressful time for Barbara. She was exhausted and feeling this general malaise. When she got out of bed in the morning she was tired. The fatigue followed her throughout the day, and she returned to bed as tired as she awoke. Barbara herself thought it was her body reacting to all the changes, stress and complications in her life, until one morning she literally could not get out of bed. She awoke in excruciating pain, her skin hurt, and she felt like one gigantic bruise covering her entire body. Recalling her experience, "it felt like actually I had been hit with a Mack truck." Then a wave of emotions struck, as she lay there trying to differentiate between the physical and emotional pain – concluding the primary pain was

definitely physical with emotional association. Emotionally, Barbara felt a deep penetrating sense of loneliness; although loved ones were close by, she was alone in this new pain experience. In a panic stricken voice, she called for her daughter and together they were able to get Barbara out of bed. Initial movement resembled Rusty the Tin Man from Wizard of Oz, stiff legged joints creaked with every forced step. When she could not manoeuvre sufficiently enough to get out of her bedclothes, she knew that something was definitely wrong.

Being new to the area, Barbara did not have a family physician, so her only option was to seek the services of the local emergency department. During the examination, the physician moved her joints and pressed on various parts of her body, hitting on trigger points that brought beads of cold sweat to her forehead. Specific questions were asked of her, such as, had she been drinking or taking drugs, did she have a history of mental illness, was she ever institutionalized. To these she answered “no”. Barbara recounted, “When they asked where does it hurt and I said all over, they did not like to hear that.” To Barbara it felt like the physician was trying to stereotype her. The triage nurse had written stress in big letters and encircled it on the front of Barbara’s chart. She then quizzed Barbara about the possibility of traumatic events in her life. Barbara related her son’s medical crisis. The suspicious questioning by medical personal and the lack of help forthcoming left Barbara feeling like a ‘second rate citizen’. They suggested that she might have inflamed joints and recommended Ibuprofen. The attending physician then invited Barbara as a patient into his family practice for follow-up. Feeling vulnerable and isolated and in need of medical assistance, Barbara accepted his offer.

Barbara was trapped within her body. Pain invaded every aspect of her life. She had to wear silky cloths so that the fabric would not rub against her skin and cause pain. She was not sleeping. Eating did not interest her for she had lost her appetite. Emotionally, she was frightened that nothing would ease the pain and that her life would be altered forever. Worst of all was the uncertainty, not having a firm diagnosis. Barbara's natural tendency is to relate to the world as an emotional being, relying more upon her psyche than her physical being or even her intellectual self. This lead to her own questioning about the etiology of her pain, but she knew in her heart her pain was real, not imagined, superimposed or created out of hysteria. A label of 'not yet diagnosed' or non-malignant chronic pain leaves the sufferer vulnerable to being pathologized, and subsequently classified as experiencing psychologically induced pain (MacDonald, 2000, 2004a). She was beginning to feel the eyes of the medical profession looking towards the classification of psychologically induced pain. Further evidence emerged when her family physician sent her to the mental health hospital to be tested for depression. The psychiatrist told Barbara she was no more depressed than the psychiatrist, identifying Barbara's good days and bad days as a normal life pattern, while at the same time validating her excellent coping skills. Barbara believed her family physician was convinced she was depressed, with the depression being manifested through physical anomalies.

Barbara's family physician did a number of blood tests, looking specifically at thyroid and hormone levels. When no obvious answers presented themselves, he became a broker, referring Barbara to a number of specialists including: a dermatologist to explore why her skin hurt, an eye specialist due to her blurred vision, an internist who

diagnosed her with irritable bowel syndrome, and a rheumatologist where she got placed on a lengthy waiting list. No one could explain her pain or why a once healthy, energetic, physically active dancer, mother and student woke up one day and could not move. The internist, through his questioning and demeanour, left Barbara thinking her genuineness was being doubted. Barbara articulated her thoughts and feelings upon leaving his office: “When I left here I had no answers, I was still in chronic pain, but what was happening was I was now in more emotional pain because things were being inferred, there was this undercurrent; things weren’t out there.” Barbara left feeling the internist was questioning the authenticity of her pain, ultimately disbelieving her pain story. The internist’s pain management advice reinforced Barbara’s belief, for he began with suggesting Ibuprofen and when Barbara revealed that it irritated her stomach he then recommended extra strength Tylenol. When she indicated that Tylenol did not touch her pain, she was advised to take Advil (which is ibuprofen). None of these changed her perception of pain or reduced her pain level.

A year and a half after the family physician’s referral Barbara received her appointment time for the rheumatologist. She suspects she missed the initial appointment due to oversight created by illness. A few days prior to her appointment, Barbara had an episode that left her scared and confused. She was in the kitchen preparing dinner, while her daughter was in the dining room doing homework. Barbara remembered not feeling well and voicing to her daughter that she was going to move into the living-room, to a softer chair. For a period of time after that, Barbara remembered nothing. When her daughter asked her a question and received no reply, she went over to her mother and started tapping her on the shoulder. Barbara eventually responded but with an

inappropriate answer. After some time, she got up, went back to the kitchen, saw the pots sitting on the counter and a can of green beans unopened. Using deductive reasoning, she speculated she must have been making dinner, but she could not remember her prior actions or what to do next. Literally, she did not know the steps involved in opening the can of beans. Barbara started to uncontrollably shake, shivering as if cold water was running over her veins, and weeping from the depths of her soul. Her daughter assisted her to bed.

The next morning Barbara stiffly got out of bed, cautiously got ready for work, and somehow made her way to the office, including a ride on the city metro bus. She still was very unwell, exhibiting signs of confusion, disorientation and shakiness. Barbara's boss immediately picked up on her condition and drove her home, making arrangements for Barbara's partner to meet them at the house. He placed a call to the family physician. Arrangements were made to meet at Emergency, whereupon examination he initiated an urgent consultation with neurology. The neurologist did not know the exact nature of the ischemic attack, other than defining it as a seizure. Numerous tests were performed, with inconclusive results. He followed Barbara for seven years, never really knowing what exactly transpired that day, or why an intelligent young woman who was professionally trained in problem solving could not figure out how to open a can of beans. From this incident Barbara was left with trigeminal neuralgia – severe nerve pain involving the cranial nerves.

The rheumatologist diagnosed Barbara with fibromyalgia. She had a positive response to all eighteen diagnostic indicators. He asked her appropriate questions. It was like he was telling her story by the questions he asked. Immediately, Barbara felt heard.

A medical professional finally knew and believed what she was going through. He gave her a cortisone injection in her inflamed hip, which provided immediate relief, if only temporarily. Barbara had never heard of fibromyalgia but was relieved to have a diagnosis, to have a label put to her experience. The rheumatologist took the time to explain the illness to Barbara, even elaborating on different schools of thought. This was the first time she felt a physician connected with her on a personal level, for he was attentive, engaging and empathic. Maybe now things would turn around and she could regain control over her life. This was the first glimmer of hope Barbara had seen in a very long time. He prescribed Tylenol #3 to help with her pain. With the help of the medication, Barbara could now get out of bed in the morning more easily; she did not need her partner's help to put on her socks, she could get dressed on her own. Pain was still her reality, but it was more controllable with the assistance of a mild narcotic.

When Barbara returned a month later to her rheumatologist requesting another prescription for Tylenol #3, he became alarmed for he believed that a prescription for 60 tablets would last her three to four months, even though he prescribed 'one to two tablets every three to four hours as needed'. Barbara later became aware her neurologist had written her rheumatologist a letter expressing concern that she was on Tylenol #3 for pain associated with fibromyalgia. The neurologist firmly believed that you do not treat non-malignant chronic pain with narcotic medication, instead promoting as the treatment of choice a low dose anti-depressant, such as Amitriptyline, to influence the sufferer's pain perception. He had started Barbara on 50 to 75 mg of the drug. Just as Barbara was getting some relief with the Tylenol #3, her use of that drug came under suspicion by her specialists. Her life started to spiral downwards – quickly. Her family physician

increased the Amitriptyline to a therapeutic dose for depression, even though he was not the original prescriber. Barbara did not respond well to this dosage, she ballooned up, going from 155 lbs to 237 lbs, feeling blotted and extreme fatigued, with swollen and stiff joints.

Barbara had to push through horrific pain on a daily basis in order to just live. Juggling between self-care and care of her children, she shared this story about caring for her (dis)Abled son:

He required fairly hands-on care like with his grooming, meal preparation, clothing and all those things. There were times when I should have been in bed, when my pain level was so high that I was just ill, vomiting, headache, and so on. I would be bathing him in the tub, scrubbing his back or just being there spending time with him to talk, because he did have difficulty moving around in the tub. And, I would have to go from being bent over the tub, to the toilet to throw-up, mop my brow and return to him. He would say, "Are you okay Mommy?" and I would say, "Oh yes, I am fine, I just have some sort of flu bug."

Being a very conscientious mother, Barbara struggled with guilt and self-disappointment for the times she was not available to her two children. Fondly, she remembered times when she could not get out of bed due to the degree of pain and stiffness, and her children would come to her with homework, tales of the day's activities or just about anything. They would cuddle, her son on one side, her daughter on the other, and they would reminisce about happy times. Barbara worried about her daughter, for she was growing up too quickly, having caring responsibilities for her (dis)Abled brother, on an all too frequent basis, and occasionally, having to come to the aid of her mother.

Barbara's second marriage was emotionally abusive and did not survive her health crisis. When she had put on the weight from the Amitriptyline, he referred to her

as a 'fat cow'. When his supper was not ready because she was having a difficult day and needed to lie down after a long day at the office, he would scoff at her. If they were out at a party, or at dinner with friends and Barbara fatigued, she went home on her own. Being a determined spirit and not a quitter, she convinced her partner to go with her to counselling. On one occasion, Barbara ended up going on her own. The counsellor was very frank with Barbara, stating it was her professional opinion that he was making her sicker, and that he would eventually kill her either through physical violence or by exacerbating the disease process. In an attempt to regain control over her life, Barbara asked her partner to leave, negotiated coming off the Amitriptyline with her rheumatologist and neurologist as it had caused serious complications including toxicity, and turned to alternative therapies. Conducting research on appropriate therapies for fibromyalgia and trigeminal neuralgia, she then sought out a homeopathic doctor. Barbara was very skilled at seeking out alternative routes to complicated problems. She finally mustered the physical strength and cognitive fortitude to apply her abilities to her own situation. Some of the alternative therapies she found included acupressure, acupuncture, massage therapy, self-hypnosis and meditation. As part of regaining control, Barbara decided to discontinue taking the limited number of Tylenol #3 she had been allowed since her rheumatologist began closely monitoring her intake. This was more emotionally freeing, for she felt like she was constantly under the microscope and labelled a 'druggie' by her physicians.

Life was moving along. If Barbara paced herself, took time for self-care and spiritual renewal, she could cope with her daily pain. Barbara became attuned to her body, being able to identify when she was becoming overly fatigued and using that as a

clue to slow down. She had established some new friendships, was able to work from home on really bad days and her children were both becoming young adults. Not looking for another partner relationship, Barbara met this most gentle, understanding and kind man at her dance class. Before she knew it, they were in a love relationship. Adjustments took place and things went well for a while. Then management at work changed and Barbara was no longer allowed to work from home due to pain. Her new partner came from an abusive relationship and he had a teenaged daughter who had been abused and emotionally tormented by her mother. She came to live with her father and Barbara, bringing numerous stressors into the household.

Barbara's health started to spiral downwards again. She applied for disability benefits through her employer. This turned out to be a gruelling process, embedded with its own prejudices and oppressive structures. In Barbara's words:

Because the diagnosis was fibromyalgia, it was too questionable, it's not pointable. The question is 'why are you off work?' Well, I am sick, I am in pain. 'Where is your pain?' Well, it's all over! So I wasn't able to get short term disability, which put real financial strain on our family.

She was told she could reapply, but she was too discouraged from the initial process to subject herself to it again. Time had elapsed, as it took the insurers forever to get back to Barbara with their initial decision, and by the time she received their letter she was actually back to work. To reapply she would need a full chronology of every medical appointment over the past five years, lists of treatments, diagnoses, medications and so forth. Barbara recalled:

As you can imagine, all of this was compounding my situation. And even though I have a very loving relationship with J that doesn't help with the fact that I am

now in extreme pain, I am depressed because of the financial situation, I have a step-daughter who is acting out . . . and I am tired, absolutely exhausted.

To cope with the situation she went back to work on a part-time basis; working Monday and Tuesday, sleeping Wednesday, so that she could go back to work for Thursday and Friday. The weekend was totally dedicated to energy and sleep restoration, yet her body never seemed to recharge. She was emotionally, physically and spiritually exhausted. Barbara realized she was reaching the bottom and carefully contemplated how she could bring hope back into her situation. She recalled all the specialists she had consulted with, looking for an avenue not yet explored. Although she was tested for depression at the mental health hospital, she had not officially seen a psychiatrist. Maybe, she thought, the pain was all in her head, as she questioned the possibility of her experience being related to mental illness. All she knew was that she had to do something, her coping abilities were quickly dwindling and more than once she found herself thinking about suicide as a viable option. It took her days, but she finally finished a letter that she sent out to all the physicians she had seen: family physician, rheumatologist, neurologist, internist, and urologist. The letter was clearly a cry for help, where she articulated her current situation and asked for their help in referring her to a psychiatrist. As Barbara recalled, "It took me days to write the letter. I was at the bottom and I was dipping even lower. At the same time I was holding onto hope that maybe this was it, this was really it."

The specialist Barbara had originally trusted, the rheumatologist, was the only one who responded to her letter. Her faith was restored in him, for upon receipt of her letter he immediately contacted a colleague and made arrangements for Barbara to be seen as an urgent consultation. The next day Barbara received a phone call from the

psychiatrist's office and within days she had an appointment. Instantly, Barbara knew this experience was going to be different, for she felt heard by this physician. Upon reflection, Barbara commented, "He did not pass judgment, in fact he did not even diagnose. I just felt like I had an opportunity to tell my story." He asked Barbara questions about her sleep patterns and history, as he began to make connections between her chronic pain, edema and sleep deprivation. As a young child, Barbara would put herself to bed for a nap. Upon returning from school, she would have a snack and then lay down for a nap until her mother woke her for dinner. After dinner, she would do her homework, watch a little television and go to bed. In the more recent past, her sleep had been erratic and no matter how much sleep she got, she would remain fatigued and energy deprived.

Within a week, Barbara was at the sleep clinic on the referral of her psychiatrist. Numerous tests were run, concluding that Barbara was getting virtually no restorative sleep; the sleep that is needed for healing, general health and mental focus. She was diagnosed with a neurological sleep disorder involving restless leg syndrome, which most definitely impacted upon her fibromyalgia. With this new information she was referred back to the psychiatrist, who immediately started her on a medication regime to deal with the sleep disorder. He was amazed at Barbara's ability to cope and function given her physical struggle; she raised two children (one with a (dis)Ability), advanced a professional career, and nurtured a partner relationship and a relationship with a stepdaughter, all the while living in chronic pain, devoid of energy and deprived of sleep. This validation meant a great deal to Barbara, for not only was she being believed, her struggle was being acknowledged. Reflecting on her experience, Barbara recalled:

I can tell you, that after I started, after I was on the right pill choice, my pain level started to reduce significantly, I was feeling human again, I started to laugh, I had a social life, I was feeling focused, still had a bit of difficulty with memory on occasion but I couldn't get over it!

Pain was still Barbara's daily reality, but it was for the most part manageable.

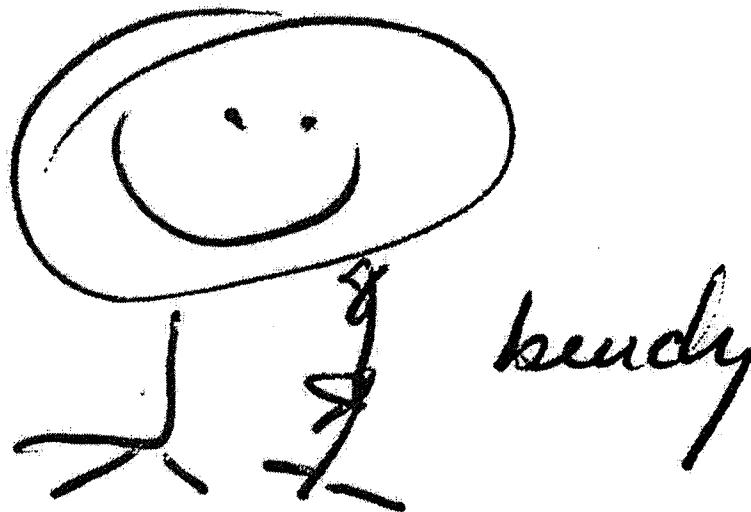
Through diet, supplements, medication, exercise, meditation and follow-up with her psychiatrist, according to Barbara, "Life had turned around." The genuine care of her psychiatrist had played a significant role in this change. She related one incident where her (dis)Able son was critically ill and hospitalized. Barbara was spending the nights in the hospital with him to attend to his physical and emotional needs. She gave her psychiatrist a call to inform him of the situation, as she was to notify him of any significant changes in her sleep pattern. He asked her to stop by the office. Simply, he wanted to make sure she was okay for he knew hospitals and sleep were not compatible. Barbara shared with him that she was continuing to take her medication, for the sheer adrenalin of knowing her child needed her was enough to wake her out of a deep sleep. Control is back in Barbara's hands. Through pacing her activities and being conscious of her own needs she is managing her pain. Barbara proclaimed the turning point in her life's struggle with pain was having someone truly listen to her story.

4.2 bendy ~ (autoethnographic contribution -- drawing of a happy face with a (dis)Able leg (insignia used on memos, letters, and other correspondence) & running dream)

Researcher's reflections: bendy told her story with directed flow, detailing each sequence with chronological accuracy, and humour intermingled throughout the text. I believe humour was used to lighten serious moments in both storying and living the pain experience; for bendy, possibly a coping mechanism. As the researcher, I came across an

important finding – physicians suffer within the medical system as patients, in the same way as lay persons. I had assumed doctors of medicine would be given special privileges within the system, such as: attentive care, immediate access to specialists, basically the five-star approach to health care. bendy's story challenged my stereotypes and assumptions and taught me a valuable lesson: to listen, truly listen to people's experiences, for within their stories lie many variations of truths. bendy's professionalism and 'belief' in the sufferer locate her as an ally to all who genuinely face the daily strife of life in pain.

Fig. 4.1 Happy Face with (dis)Abled Leg



bendy's Story:

bendy's autoethnographic contribution comes in two forms, one, the above insignia of a happy face, and two, a dream focused upon her most significant loss resulting from her injury, the loss of her ability to mid-distance run. Acceptance of her (dis)Ability is

depicted in her autoethnographic piece, the above insignia of a happy face with a (dis)Able leg. Prior to having her accident bendy used the traditional happy face insignia of a circle with two dots for eyes and a smile. After her accident, she started to use this insignia. When asked why she switched to this design, she was not sure, but believed it was related to her identity as a woman with a (dis)Able leg, for the previous happy face no longer represented who she was. While relating this connection, bendy realized she had not used her correspondence seal of a little red hen for some time. Reflecting back, she realized the time line was directly correlated with her accident. And, upon closer examination the happy face legs resemble chicken or hens' feet.

Dream: A runner for thirty-five years, running between ten and fifteen kilometres a day; after a run with two friends, slips on ice, has nowhere to turn as one small friend is in front of her and another behind her. Results, left knee ripped apart, tearing the anterior cruciate ligament, the medial co-lateral ligament, the posterior oblique and the medial cartilage. Never to be a runner again! In thirty-five years of running, bendy never dreamed of running. Following the accident, her dreams became a window to understanding her (dis)Ability.

Initially the dream envisioned bendy running along the beach, with her family watching in the skyline. She called out to them, "Look at me, I can run, I'm not crippled." Her running form carried the grace of a gazelle, an amazing style, one that she could never master in real time. Over the last couple of years the dream changed: bendy was still running, but painstakingly as the once graceful presentation had vanished. She called out to her family, "Look, I can kind of run." bendy believed this was a more

realistic picture of her life. It was her way of dealing with the initial denial of her injury; admitting she sustained a permanent injury that would alter her life.

bendy is a fifty-two year old woman who has experienced chronic pain almost half her life; between the ages of fifteen and thirty-two she had endometriosis and since the age of forty-six she has lived with neuropathic pain in her left knee. bendy's passion has been to be active, to move, whether it be running or swimming or hiking through the woods. She has been dedicated to the medical profession her entire life; first as a nurse, then a nursing instructor and finally as a family physician. Work consumed a great deal of her time; she took shifts in the emergency department of the local hospital, assisted surgeons in the operating room, and maintained an active family practice. Stress created by her work was channelled through physical outlets of exercise, such as, mid-distance running, masters swimming, and nature hiking. On February 12, 1998 bendy's life changed when she sustained a major injury to her left knee. Her running friends took her to the emergency department where she waited for what seemed like a lifetime for the surgeon to examine her knee. Upon initial examination the orthopaedic surgeon did not believe her injury to be of a traumatic nature. However, due to the extreme tenderness of the knee he wanted to fully examine it under anaesthetic. bendy knew that her knee was 'wrecked' for she heard the ligaments tear as she fell. When she awoke from surgery, her leg was in a forty-five pound cast, bent at a ninety degree angle. The surgeon said, "You knew it, didn't you? We'll talk about your future tomorrow."

The surgery was extensive. The procedure performed was a surgical advancement of the vastus medialis, whereby, according to bendy, "He cut down the medial part of my quad muscle and swung it down through my knee to act as an anterior

cruciate ligament.” A surgical technique that was performed in the sixties was the only option given the extensive damage done to the knee. bendy firmly believed that if she had not had a surgeon with extensive experience and knowledge of older techniques that she would not be walking today. The rehabilitation regime to follow would consist of seven days in the hospital, three weeks with the forty-five pound cast, four months in a wheelchair, twelve weeks with no weight bearing and an extended period of rigorous physiotherapy.

To begin her story, bendy told of her frightful days in the hospital as a patient, where her mobility was extremely restricted leaving her more dependent than any experience she had previously. Mobility, to stay active, was how bendy existed. To be deprived of that coping strategy all of a sudden, to have that taken away from her, to be restricted in a hospital bed, dependent on the nurses for her basic needs, left her feeling trapped. bendy recalled, “I have had half a dozen major abdominal surgeries, wrist surgery, ear surgeries . . . to move was my life and this was the first time I could not move!” bendy was a strong woman, she swam an entire lake using the butterfly stroke, she had a great deal of upper body strength; yet she could not lift her leg in that iron-clad cast. A screw was placed in the cast connecting to the sling swung around her neck; still she could not lift her leg. On the third day in hospital, a physiotherapist came into her room and wanted her to walk a set of stairs, claiming that bendy’s discharge was dependent upon this task. bendy laughed through her frustration, stating “I’m not doing that.” The physiotherapist replied, “You have to, I’m not letting you go until you do these stairs.” bendy retorted, “Obviously, I’m not very good on my feet, I don’t think we are doing that today.” To be immobile and dependent increased her potential

vulnerability; vulnerability shaped by helplessness in the face of professional authoritarianism.

Pain management following surgery was another area that presented some concern. The anaesthetist who was involved with bendy's surgery put in a drug delivery system so that bendy could self-administer morphine, 2mg at any given time. bendy under-medicated herself only using approximately 100 mg of morphine during her seven day hospital stay. An assumption is made – if patients have a self-delivery system they will manage their pain – with heightened expectations for patients with medical knowledge, such as nurses, or physicians. Professional status aside, at that moment they are patients, and, like any other patient, it is vitally important that medical personnel check on their pain level; whether they are on a delivery system or not.

Pain has been recognized as the fifth vital sign in the United States, meaning nursing has to check pain just as they would check blood pressure, pulse, temperature and respiration (Jackson, 2002). No one asked bendy about her pain during her entire hospital stay. bendy knew that she under-medicated herself, with the message 'don't take pills' echoing in the back of her mind. bendy knows there is a professional culture among physicians whereby they believe that they are not allowed to get sick; illness does not befall them and if by strange happenings it does, then the code of conduct is one of stoicism. bendy commented:

Sometimes when I am in extreme pain . . . I just look at it and say this can't really be me. It doesn't really exist, I'm just making it up, if I can just park it someplace else, I can carry on. I don't know, I think it is because I have kind of a cavalier attitude to my own self, to my own pain; it doesn't matter if I have pain or not – it really doesn't matter if I have pain or not. If I have pain, then so what; it's kind of a blasé attitude. No, physicians aren't allowed to have pain. I know of a physician who has had both knees replaced, and both hips replaced . . . he still works. And you can see him limp from one end of the parking lot to the other; in

the middle of winter and if you ask him, ‘how are you today?’– ‘the very best’. Amazing!

bendy placed great personal value on facing pain with a stoic demeanour. The belief that physicians do not express hurt, that their own personal physical needs are denied, must influence their access to effective treatment. If physicians are unable to self-advocate for appropriate treatment, then the chances of their pain being ill-managed increases greatly. Furthermore, bendy believed she did not think clearly on medication, her mind turned into “brain mud”. Someone needed to be there checking on the amount of medication she was taking and the result it was producing.

bendy was from a large extended family, the ninth child out of ten. She had been administering care to others her entire life, whether looking after older siblings’ children as a youngster, bed-side nursing, nursing instruction to student nurses, or attending to patients as a family physician. Conditioning began at a young age, for “when you are number nine, you slip and slide, and you do all sorts, you can get along with anyone, do anything, go anywhere, you do what others want, your drive is to keep the peace; to avoid problems.” This moral belief is illustrated clearly in her story ‘The Afghan’ (see Appendix J), which she told as a side-bar in her interview. bendy sincerely believed that all people deserve to be treated with ‘care’ and that the human element is vital to healing in medicine. Yet when it came to her own personal situation she did not want to bother people, especially those she loved. “If other people see that I am in pain, it drags them down a bit. I just don’t want to bother them. I don’t want to insert into their day unpleasant moments.” She had an overwhelming tendency to want to protect others, displacing any attention that might be directed towards her.

A challenge was upon her, for she knew that she could not go home. She lived in the middle of the woods in an inaccessible house, with stairs at the entry and no space for a wheelchair to manoeuvre. "I laid in that bed thinking 'where will I go?' 'What will I do?' I can't go home." Then bendy's older sister came in for a visit. This was the same sister bendy spent summers with as a youth, helping her care for her children. bendy asked her, "Can I come home with you?" and without hesitation, her sister replied, "Yes!" bendy was to spend the following five months in a converted living-room transformed into a bedroom, at the centre of their home. bendy recalled, "I thought - I will be able to get up and around, I'll be able to do this and that! I couldn't do anything. The request was simple, the consequence and the burden on her and her family was phenomenal." bendy's sister and family provided emotional, physical and spiritual care to her as she healed. In bendy's words, "I received the best care I have ever received in my life: from my family!" To prepare for her visit her brother-in-law built a bathroom on the main level ten feet from the hospital bed they brought in. They found a wheelchair, a walker, a bedpan and other necessities, to transform a family home into a rehabilitation centre.

The months ahead proved challenging testing bendy's emotional and physical strength like it had never been tested before. The pain was overwhelming; sleep was a concept from the past. bendy's way of dealing with her pain was to withdraw, to hide, to forget about its presence; but, when the pain became so overwhelming that it took over her central core those coping mechanisms failed to produce their desired effects and the pain became a nightmare. A colleague prescribed something to help with the pain at night: sometimes the pain was so intense bendy would throw up. Lack of sleep, being in

someone else's home, pain-induced migraines, nausea and immobility combined to leave bendy in a fog, where her thinking was not clear; described in her own words as "a lot of brain mud". bendy needed someone to take over her pain management; to prescribe and manage her care like she had done for so many patients in the past. She was unable to recognize this need as those closest to her failed to see it as well. The laughter, care and community that was created within her sister's home was what facilitated bendy's healing; first on a spiritual and emotional level, then onto physical healing. bendy recalled, "Laugh, I haven't laughed so hard in my entire life."

Not all moments were ones of laughter, however. bendy related this memorable situation which happened at about three or four weeks after the operation. Her partner came to visit this particular day. He came faithfully, bringing her gifts, taking her out for drives, trying to stay connected in a meaningful way. This one particular day they were out for a drive. bendy was in the back with her leg at a ninety degree angle over the seat. They were driving by a friend's shop, where before the accident bendy had left a cross-stitch for framing. She suggested that they stop in to see if the framing was complete. Her partner said in a firm rough voice, devoid of consideration or empathy, "Nobody wants a cripple in their establishment!" All bendy heard was "nobody wants a cripple!" She vividly recalled, "I sat back, bit back the tears, I said nothing else." Instantly he tried to re-track his statement, but the damage had been done. In her own reflection:

The message I got was nobody wants a cripple. And to this day, it still is very true, society doesn't want a cripple, your family doesn't want a cripple, the one you love doesn't want a cripple. That really altered my thinking from then on, accepting the fact that I have an impairment was much easier from that blunt harsh attitude. I didn't appreciate it at the time, I think it is an incorrect attitude, but it is very true, "Nobody wants a cripple."

As difficult as it was to hear those words from someone you love, it gave bendy ammunition to tackle her own struggle. Determination to regain mobility was seeded in those words. To be mobile, to be active, was to live: to be immobile, to be physically restricted, challenged her at the very core of her being.

bendy was to face many challenges. She regained degrees of mobility through tears, frustration and raw determination. Hours were spent at physiotherapy. In the fall of that year she returned to work. Knowing that she could no longer work in the emergency department or assist surgeons in the operating room, she tried to maintain her family practice. As time went on, her pain escalated. She was not able to sleep due to the pain; she gained weight through restricted activity. Work was becoming impossible; pain was defining her existence. Her medical partner and nurse knew that she could not continue to function in this manner. Eventually she came to this realization too. bendy's entire life had centered on care-giving, putting the needs of others ahead of her own. Her (dis)Ability would no longer tolerate her altruism, as her body screamed through pain and exhaustion for her attention.

In January 2001 bendy applied for part-time disability insurance through her private insurer, the same insurer that treated her with respect and professionalism with her short-term disability claim at the time of the accident. This time things were different. A physician was requesting part-time permanent disability requiring ongoing compensation from the insurer. bendy assembled the initial application in haste, not elaborating on the extent of her medical condition and the resultant limitations it necessitated. Personality wise, bendy was not a complainer. Her optimistic outlook to find positives in all experiences resulted in an application that did not depict a

substantively (dis)abled individual. She did not adequately describe her suffering and plight, and therefore her application was denied. Her life partner, a lawyer, convinced her to appeal and coached her in that process to make sure all the necessary documentation was enclosed. She was turned down flat, with prejudices. Over twenty years of paying high insurance rates only to be denied benefits. bendy was penalized because she did not whine and complain. She did not burden the medical system when she knew that there was nothing further they could offer her, and she worked, and worked hard. bendy expressed frustration, "Knowing I was at medical finality, there was no reason to whine and complain to any doctors . . . I worked, I worked as hard as I could for as long as I could. I didn't whine and complain, I knew there was nothing else that could be done."

Faced with no other choice, bendy gave up her practice in April, 2001. She now fills in for other physicians, doing locums as a temporary substitute in doctors' offices when they are away; as she noted, "I'm like a Hollywood doctor." bendy still lives with chronic pain, however her coping techniques are more effective now that her pain has been reduced to a manageable level through pacing her work schedule. bendy's sense of humour and light-heartedness has seen her through some of the darker days.

One story she told was the persistence of people to point out her impairment – as if she did not know that she had a leg that did not function 'normally'. bendy wore shorts all year long; her injury resulted in a hyper-sensitive area on the lateral compartment of her knee, where the slightest touch, even of the lightest material, results in excruciating pain. Total strangers, colleagues and patients would come up to her in the winter and tell her how cold it was out and ask 'do you know that you are wearing shorts?' The most

frustrating component of this experience was when people who knew of her situation still comment in a similar fashion. She equated this experience with going up to a blind person and saying to them, 'Excuse me, do you know that you can't see?' So one day, she was visiting her mother and her mother had bought some stick-on bumble bee tattoos for her grandchildren. bendy asked for a couple of the bumble bees. She placed one on each leg. That day, not one person commented on her shorts, not strangers, not colleagues, not patients, no one! A creative solution to her problem had been found – who would have thought it would be bumble bee tattoos!

Other ways that bendy coped with her pain was through physical activity. She swam on two masters' teams, in the pool six days a week and went on the treadmill three to four times a week depending on her work schedule. The treadmill activity became entangled in a vicious circle: "the more I can treadmill the more I can work, the more I can work the less I can treadmill, the less I can treadmill the less I can work! So it is a hard place to find a balance." Living with pain is like that – always trying to pace yourself, to find balance in your activities, in your life. bendy admits that if she swims really hard for two hours she gets significant endorphin release but it still does not equate to the runner's high she used to experience when running ten to fifteen kilometres. With humility and gratitude she is thankful that she can walk and swim, but being human she would also love to run again someday.

"My whole life has been to be physical, I was always extremely grateful to be able to do that, always. Thank you God for these ugly legs that work, every morning, that was my mantra - Thank you God, thank you, thank you, thank you. And now it's thank you God for these ugly legs that walk."

4.3 Dawn ~ (autoethnographic contribution – paper presented at Psychiatric conference – ‘The Therapist in Pain’ see Appendix K)

“The struggle to be compassionate in the face of one’s own suffering is paramount.”

“The warmth of my beloved Lab, Colton, lying against my spine has reinforced in me the human need for touch and unconditional love. This connects me with my humanity as a therapist and helps me better understand the needs of those in my care.”

Exerts from: “The Therapist in Pain: A Personal Perspective” presented at a National Psychiatric Conference, 2002.

Researcher’s Reflection: Dawn’s passion for addressing the injustices faced by sufferers of chronic pain and her critique of health care services, wove professional and personal threads of her story together, as she laid an intricate rug of knowledge before the reader. Dawn, similar to bendy, tells her story in a sequential, event focused order. Emotive and spiritual expressions highlight her learnings and provide an opportunity for insight. She speaks eloquently about her coping strategies in negotiating a life in pain; yet, she is not hesitant to name her fears and inhibitions created out of her struggle. As the researcher, on a personal level, I admire Dawn’s location as a psychiatrist who not only believes the stories and struggles of sufferers, but, intimately knows the fight often necessary in communicating one’s pain.

Dawn’s Story:

Dawn’s first pain incident occurred three years into her psychiatric practice, at the age of thirty-five, with an episode of sacroiliitis. Inflammation in the sacro iliac joint was the presenting physical finding; however, physicians were uncertain as to the underlying

cause of this inflammation. Dawn was placed on anti-inflammatory drugs and went for physiotherapy. Three months later she was feeling much better and never gave the pain another thought. Five years following, in 1996, she was helping her then partner dig post holes when a disc herniated. She recalled, “That was quite excruciatingly painful but it healed quickly and I came through it.” Chronicity associated with her back problem began the following June, as Dawn was moving into a new house. After the movers had left, she realized something was awfully wrong; another disc had herniated. She was bedridden, in excruciating pain, with neurological symptoms. Due to prior back problems her private disability insurer had written a disclaimer against her coverage, meaning she could not disclose back problems for ten years or her coverage would be cancelled. Fearing this implication, she did not seek medical assistance with respect to an orthopaedic consultation or pain management. Hence, she suffered horribly, with only mild pain medication her pain was totally out of control. “Tylenol #3 for the pain – Smarties! So that was the beginning”, Dawn recounted.

The next two years, Dawn suffered from back pain including radiating neurological pain down her leg. Flare-ups would leave her in horrific pain, then they would subside and she would be left with mild to moderate pain. However, with each flare-up the subsequent aftermath of pain worsened. Until one day in August while getting dressed for work, she felt something let go in her lower back as she was bent over pulling up her socks. Throughout the morning, as she was counselling clients in her home office, the spasms were increasing. At the conclusion of her last morning session, she went to get out of her chair, she could not stand, she was completely unable to walk, and the pain was horrifyingly intense. In Dawn’s own words, “I was in the worst pain

that I was ever, ever in, in my life! I am not prone to screaming in pain, but that was a screaming-in-pain event. I was beside myself.” Fortunately, someone was there to call for help. A friend came to assist, a physician friend who was able to get Dawn some medication for the pain; and, with the medication and the friend’s help, Dawn manoeuvred into her bed. She was completely bedridden, literally unable to move her body; she could not turn over, lift her head, feed herself, get up to go to the bathroom – the only part of her body that she could move were her eyes and mouth. Dawn remembered, “There wasn’t a part of me I could move without severe, severe spasm, severe pain.”

Dawn’s elderly Aunt came to care for her and Colton, Dawn’s trusted loyal black Labrador Retriever. In the worst of the pain an emotional struggle emerged, a struggle encapsulated in fear of dependency. One particular situation prompted this fear to surface with such intensity that it emotionally preoccupied Dawn in a way that she had not previously experienced. Immobilized and crippled with pain, Dawn had to urinate. With no bedpan available and the unlikelihood of being able to manoeuvre onto one anyway, an alternative had to be quickly crafted. The Aunt managed to place garbage bags under Dawn, covering them with wads of towels, and the signal for ‘all clear’ was given. Somehow she was able to get Dawn cleaned up without increasing her pain substantively. For Dawn the shame, embarrassment and distress created by this helpless situation haunted her, for her primary fear was that of total dependency; that someday she will be immobilized for an extended period, rendered dependent upon another for her basic care.

Frustrated and scared, in absolute terror that the situation would never improve,

she was entrapped within her body: unable to care for herself or her dog Colton. She could not tend to Colton's care – brushing, feeding, letting him in or out; she could not tend to her own care – personal hygiene, going to the bathroom, lifting her leg into the shower, making her own meals. As an independent professional woman used to caring for herself, living alone with her trusted pet, she relied on her own skills and abilities; however, when those were challenged, the very core of her being was challenged. In Dawn's reflection:

Just the frustration of every simple task being magnified a hundred times, everything from opening a milk carton to getting dressed, figuring out how to put on underwear when you can't bend. Everything just becomes so difficult, that is when the frustration really sets in.

This episode was Dawn's first experience of plus ten pain (on a pain scale of one being little to no pain and ten being excruciating pain); subsequently, this developed into her reference point for rating other pain experiences, for example, 'how is my current pain in relation to the summer 1999 event?' This incredibly painful, immobilizing experience made Dawn realize that something serious was happening with her recurring back problems, and despite potential insurance implications, she consulted her family physician. Her family physician referred her to physiotherapy and a rheumatologist. The rheumatologist diagnosed Dawn with various kinds of arthritis and degenerative disc disease; prescribed high doses of Celebrex, recommended continuation of physiotherapy, and moderate activity levels. The Celebrex did provide some relief. However, Dawn was in chronic pain and was seeking more permanent solutions. Her third visit to the rheumatologist proved to be emotionally charged, as Dawn recalled, "I was basically told ... I had arthritis ... I had to learn to live with it, and I was wasting her time. I informed her that was quite fine, I didn't want to waste her time or mine, and subsequently fired

her.” Dawn further informed the rheumatologist that if all she did was go home and pray she was doing something about her pain. She felt devastated, even demoralized, to be basically told that there was not anything wrong with her, yet her experiences and her body told her differently.

Dawn’s back spasms would be so severe that they would take her breath away and literally drop her to the ground. “I accordion down, my paravertebral muscles just collapse, go to the ground, which is really bad because of course I can’t get up from the ground.” Dawn had more than one experience of this nature. She found this horribly embarrassing and frightening, not knowing what to do, trapped in her own body. One time Dawn was gardening, sitting on a bucket pulling out a few weeds, when her back went into spasm, dropping her to the ground. Dawn had nothing with her to pull herself up, no sharp tool she could dig into the ground, no cell phone to call for help, basically she was stranded. She ended up rolling across her lawn and driveway to her front steps. There, she reached for the railing and with sheer determination and will, managed to pull herself to an upward position. Embarrassed, Dawn had no indication whether she was seen in this position. If she was, she notes that the horrifying event was viewed as a spectator sport, for no one came forward to offer assistance. Dawn’s self knowledge about her body contradicted the rheumatologist’s findings. She left the rheumatologist’s office in tears, not from an expression of sadness but out of total frustration, tears fuelled by anger.

Dawn remained on Celebrex for three years until she developed serious side-effects from the medication, including borderline renal failure and high blood pressure. Coming off Celebrex created a crisis for Dawn, her pain became completely

uncontrolled; and to further complicate the situation, her family physician was not comfortable about progressing up the pain ladder of treatment, typically prescribing Tylenol #3 rather than stronger opioids such as hydromorphone or morphine. Dawn tried to control her pain using a variety of modalities, including physiotherapy, acupuncture, hydrotherapy, aquacise, stretching exercises, massage therapy and reflexology. She did whatever she could to keep mobile, for mobility was the key to independence, expressed in words of determination, “You kept going along, and going along.”

In October 2002, Dawn herniated another disc. This was the third disc to blow. As Dawn recalled, it was not as painful as the previous time. However, her mobility was restricted for a longer period and the rehabilitation process was substantively slower. “It was quite long lasting; I was twelve weeks of really severe disability with that one.” Dawn’s discs were herniating at a rate of about one every three years due to her spine being arthritic and curved. Basically, her spine was disintegrating and the curvature mechanically pushed them out. Feeling frustrated, worn-down, and in constant pain, she requested to see a neurosurgeon. In Dawn’s words, “I was quite willing to let them do anything, anything, absolutely anything, they could have amputated me at the waist I would have been happy.”

Frustration built for Dawn, as the neurosurgeon refused to operate considering her too high of a risk. Her spinal stenosis (narrowing of the spinal canal) meant that there was a 50/50 chance of permanent paralysis resulting from the surgery, a risk Dawn was willing to take, but the surgeon was not. The famous dismissive words echoed through her head once again, ‘you are going to have to learn to live with it.’ For Dawn this meant

she was a medical finality. Feeling rejected, she commented, “No one would ever touch me – so that is what it has been, that is it.”

Knowing that a cure was unrealistic, the next battle Dawn had to tackle was getting her family physician to diagnose her medical condition as chronic pain. Dawn commented:

Although she is wonderful, it took time for her to get her courage up to accept that this was in fact a chronic pain situation that had to be managed, not something that was going to go away with minor management.

Her physician eventually became comfortable with prescribing hydromorphone in a long acting, slow release formula but the journey up the pain ladder of medications was slow and painful for the sufferer. “It took a long time to actually get pain control, from being in severe pain in 1997 to having some pain management in 2003.” Dawn’s pain was called everything but chronic; it was called stress, burnout, even depression. For six years she lived with uncontrolled pain. She began to doubt herself, applying her professional lens of psychiatry in questioning emotional or psychological pain factors. For example, ‘Is my pain worse because I am grieving or because I am stressed?’ “And, of course, all these things are true, but it’s not the source of it. And my greatest stress was getting someone to treat me for my pain.”

Dawn believed that the myth ‘doctors never get sick’ worked against her. She was embarrassed by her own profession, at how physicians treated their own; for she firmly believed that she would have received better treatment had she not been a doctor. Trapped within her own professional identity, Dawn struggled to have her voice heard, to have her concerns taken seriously, to receive appropriate treatment for her pain.

Through sheer persistence Dawn returned to her physician repeating her story over and over again. She was willing to keep a pain diary, invited her doctor to monitor her narcotic usage, including the counting of her pills, and she offered to sign a contract. “I did anything that someone asked of me to the best of my ability . . . because I wanted to feel better, I wanted to cooperate, I wanted them to see me not as someone who was being difficult but as someone who was cooperating for treatment.” Desperate, Dawn was willing to do just about anything to get treatment for her pain. “I have done all kinds of wacky things to prove that they did nor didn’t work.” Dawn recalled one time being prescribed Capsaicin cream to rub on her arthritic joints. She wondered if it was a good idea given that she was highly sensitive to hot peppers, but listening to the doctor, she rubbed it all over her joints. Subsequently, Dawn developed a severe total body rash.

The “stupidest” thing she recalled doing was going, on the recommendation of her physiotherapist, to a traditional acupuncturist. The procedure was called a transverse technique, where they pinched up folds of the skin and shot a needle through hitting trigger points with a driver gun. One needle hit a vein in Dawn’s chest wall, creating a huge haematoma. In her neck, Dawn’s occipital nerve ended up entrapped and developed into occipital neuralgia. This experience landed Dawn in a total body flare, a traumatic event that elevated her pain to the height of the pain scale. She now had new head pain along with a total body rash. For her, “It was unbelievable.” Dawn’s entire body was in one uncontrollable rage. Saving measures were taken by Dawn’s reflexologist, her ‘angel on earth’; she gave Dawn a treatment, gently soothing her wounded body and nurturing her soul. The reflexologist contemplated taking Dawn to the hospital due to her condition. Instead, she applied her hands, ice, and so forth, taking her time with care,

eventually calming the raging tissues and nerves in Dawn's body. Dawn unequivocally believes that without reflexology and massage therapy her mobility would be so restricted that she would need walking aids to manoeuvre.

Eventually Dawn was heard; her physician finally diagnosed her with chronic pain and began to treat it appropriately. In her own words:

It just took going back, saying you have to do something, I can't work, I can't function, I can't do this anymore, unless you help me and eventually, she has. It's been excellent since then, in terms of her care.

Through all the pain and immobility, Dawn continued to work. She would grab her walker and head to her office, hobbling along, one painful step at a time. With her heating pad, reclining chair and footstool she was able to see patients that needed psychiatric counselling. Most patients understood Dawn's condition; those that did not were referred elsewhere. As soon as Dawn was able to get herself out of bed, she was back in her counselling role. Dawn was in private practice and if she wanted to keep her house, she had to work. Medicare fees are only paid out for services rendered; therefore if Dawn did not see patients she did not have an income. Initially, she fell into the myth of physicians not getting ill, as it played on her own denial of the situation. "When you are a doctor you work; patients get sick we don't, and you are somehow indispensable." Eventually, Dawn's beliefs shifted as she realized work was consuming all her energy. She would work, rest, and return to work. Her personal life was severely compromised. She could not drive in a car for more than two hours; sitting through an entire movie was impossible. If she took a trip, involving air flight, she had to calculate recovery time into her visit. Simply getting groceries was a tremendous chore. She realized that life was becoming extremely limiting. She had no energy to take a course. Her passion of

gardening had to be done from a standing position (most difficult when it came to weeding) and Colton, her trusted companion, could no longer be taken for walks (luckily he preferred lounging).

Through consultation with her physician, Dawn finally realized that to work part-time would be in her and her clients' best interests. She contacted her private insurer to apply for partial disability, under the premise that it would reduce her pain levels, increase the quality of her work and facilitate a lengthier career. Dawn had to fill out a 27 page application form, including essays on how her condition affected her daily life, an hourly account of her daily activities, every doctor's appointment (including date, time and address), details-upon-details of her life and condition. On top of her application, she had to have her physician fill out forms on her medical condition. Luckily, her physician was supportive of her application. Once everything was filed, the deliberation was painstakingly slow. Finally, a case manager phoned her. The attitude she encountered from the case manager was unexpected, for he was condescending, rude and sarcastic.

Dawn recalled:

When I told him I worked at home, he scoffed and said, 'Oh you work at home, you can do whatever you want, it's not like you have to commute to work . . . you expect to take time off and have us pay for it.'

He was totally dismissive of Dawn's work, claiming that psychiatry was a low stress, sedentary job. The insurance company wanted Dawn to show that she had a loss of income, but she was looking to reduce her hours so that the quality of her service could be maintained and her pain more controllable. Basically, as long as she could sit in a chair and see people, the quality of her work was insignificant. Dawn's dedication to her

work, the fact that she returned to work after every episode as soon as she was literally out of bed, in the end, did her a disservice.

Months later, the same disrespectful man called, informing Dawn that her application was denied as there was no indication that she had a disabling condition. Dawn felt prejudiced against due to her specialization – as long as she could still see clients, the insurers did not consider the ‘quality’ of care being administered. For example, if Dawn was forced to sit past her pain threshold the intensity of her pain might distract her from total engagement with the client, yet this was of no concern to the insurer; for as long as she could be a body in a chair, able to hear and respond, they were satisfied. Dawn commented:

As long as we can hear people and we are not demented, we are not disabled. Now, if I were a surgeon with my back problems, I would be permanently disabled because I couldn’t stand and operate. But, you know, because all I do is sit in my comfy chair and talk nice to people, so there isn’t really a problem! I felt very much that I was prejudiced against because of my specialty, as well as, my chronic pain! You lose, you lose!

Exhausted, frustrated and defeated Dawn did not appeal their decision. The conditions for appeal seemed totally unreachable. Obviously the company was not seeing chronic pain as a disabling condition. Dawn wrote the company a lengthy letter, outlining what a demoralizing, dehumanizing experience the whole process had been. Three months later she received a response, thanking her for the letter and repeating that her claim had been denied. In Dawn’s reflection:

I am still very angry with how the insurance company handled things and the fact that they have such a totally narrow definition of what disables someone or impacts on someone’s ability to function. They completely misunderstood not only my illness but my profession. I am very resentful every month when I continue to pay huge premiums for my disability insurance that I can’t access.

Dawn admitted that this gruelling experience has made her more conscious of what her patients have to go through. She does not complain when she has to fill out forms on their behalf and takes time to explain to her clients her documented medical report in lay terms. The experiences of her clients with insurers has been cumbersome, some have had to submit medical reports as often as monthly. Others have been followed, photographed or placed under surveillance, all in an attempt to catch the clients in a lie. A client of Dawn's was videoed carrying his terminally ill child into the children's hospital and subsequently had his disability claim cancelled. The insurance company tried to claim his back was not disabling if he could carry his child. The client threatened to go to the media and the insurance company conceded. In Dawn's summation, "you are automatically assumed to be lying, cheating, out for an easy grab, and you are treated like that."

Dawn was so disheartened by the way she was treated in her dealings with the insurance company that she did not appeal their decision. She already felt defeated. However, she did not allow that sense of defeat to transfer into her personal life, as she continues to cope with her chronic pain and related (dis)Ability by the restructuring of hope exhibited through her unrelenting spirit. Hope for Dawn was defined, in what some might call, 'realistic' terms; hope that she could continue to find the strength to deal with her pain. In her own words:

Hope is very familiar to me, it is always there. One of my favourite quotations about hope is by Elizabeth Kubler-Ross, "hope means at the end, I will never be forsaken." For me I guess, hope for chronic pain on a personal level has been a reinforcement, that somewhere in there, believing that someday it may be better. . it's just hope that I can handle it. That I will continue to receive the strength, or find the strength to just handle it. One thing that has been good about going to plus 10 pain is that I know that I can survive that because I did.

Professionally, Dawn believed:

Psychiatrists are brokers of hope. That's what we do, we meet people in places of desperation, quiet or otherwise, and somehow help them define a reason, which is hope, to keep going: to recover from illness, to survive grief, to get out of abuse, to whatever.

Translating her professional standard into a personal goal, Dawn had been able to redefine her life with chronic pain, making numerous adjustments, be it in gardening, sleeping strategies, alternative therapies or adapting work schedules. Reflectively, Dawn commented, "Mostly the hope is about me being able to cope. To be able to work, to be able to keep my house, to be able, you know, to stay independent."

Colton, Dawn's Labrador Retriever, is her main source of strength, her defined 'soul mate'. He pulls her out of bed on bad days. He licks away her tears of pain quietly dripping down her cheek. He acts like a warm furry water bottle snuggled up against her aching spine – in totality, he is her comfort. Redefining hope and ability on a daily basis, sometimes in a moment, is what living with chronic pain is all about. To survive is to learn this skill well.

4.4 Evelyn ~ (autoethnographic contribution – poems, doodle drawings)

Researcher's reflections: Evelyn told her story in a soft, self-reflective voice. I often had to listen to the tape several times to pickup what she was saying. With emotionally raw components, her voice would soften further. For Evelyn, telling her childhood story very much fit with her pain journey: the emotional, mental, physical and spiritual pain merged into one, for it could not be separated. It was vital that I honour this connection and that I respect where her story would lead; knowing that she alone knew the road upon which it traveled. Tears were shared and hugs were exchanged. This was not an easy

process for her, but I believe in the end it was a component of her healing, as Evelyn herself had expressed this sentiment. Evelyn is a gracious, giving and caring woman; I know this through the way she treats others, her clients, her family and her friends. She is an extremely brave woman, as well. A spiritual link was formed in talking with the other sufferers, as they shared common stories. Healing tears were shed as she journeyed through her own painful memories and power emanated from helping others through the telling of her own struggles and triumphs.

Evelyn's Story:

During long periods of flare-up of Evelyn's rheumatoid arthritis she would write as a method of expression, as a coping mechanism, to vent her emotions created by the physical pain. As her story indicates, Evelyn loved to garden, so her writings often touch on elements of nature. The closer to the earth she could get, the more connected with her spirit she became, deriving strength through a connection to God through nature.

Falling Leaves

**The falling leaves,
Faded to decay,
Lay over my feet - - -
A freshly laid grave. Evelyn 1984**

When Evelyn wrote this poem her feet and legs were very painful. She could hardly walk due to the pain created by her rheumatoid arthritis. The poem was a written testament to her suffering.

In her 63rd year Evelyn continued to touch the hearts and souls of those around her, rising above her bodily reality of pain. Her primary diagnoses included rheumatoid

arthritis, pernicious anaemia, leukopenia, thrombocytopenia, asthma, hypothyroidism, sinusitis and fibromyalgia. Evelyn had lived a life full of sorrow and hardship, no more evident than in the pain-stricken features of her face and a body ensnared in torment. Yet in describing Evelyn's character one would not begin with pain, anguish, torment or sorrow, for somehow in some way, this woman had been able to transcend beyond her agony, to gently touch the hearts and souls of those she had worked with and those who had befriended her. She had been a nurse her entire life, dedicated to healing, to the power of touch, to the connection of the mind, body and spirit. In reaching out to help others, her pain and suffering had existed quietly in the background; noticeable to those who understand pain, shadowed from those who were indifferent.

Evelyn's journey with illness dated back to her childhood, woven in a pattern of physical vulnerability with emotional uncertainty and mental displacement. She was adopted by older parents. Her father was seventy-three when she came into their home as a one-year-old child. Her adoptive parents had grown children, grandchildren, and great-grandchildren who were unwilling to accept their parents adopting a child in their golden years. This was blatantly and punitively exhibited. One such experience was when Evelyn was not identified as a family member in her parents' obituaries. Evelyn only found out she was adopted when she began school. In grade one, school children scoffed, "You know they are not your real parents!" Upon confronting her parents, she was told, "You are our child!" Evelyn believed that this was the moment she stopped asking questions, for her questions never seemed to receive an accurate, detailed response.

Evelyn was close to her father. Her mother was legally blind and partly deaf. Her parents, "Ma" and "Da", tried to shelter her from the mean spirited antics of her adult

siblings. In fact, Evelyn referred to them as her parents' children, stating adamantly, "I can't call them siblings because they are not." She fondly recalled her father's belief in her. One Christmas Evelyn was upset because she received a doctor's kit instead of a much anticipated nurse's kit. Her father looked her in the eyes and said, "You can be a doctor too". In the early forties women were not physicians, at least not in the rural Maritimes. They were secretaries, teachers or nurses until they became mothers and then they were stay-at-home moms. 'Da' believed in her, protected her and helped her navigate around the extended family. In the spring of 1953, Evelyn's world changed. Her father had not been well. He got up to go to the bathroom, returned to his chair and died. He was eighty-four years old. Evelyn was twelve. She remembered neighbours and relatives putting 'Da' on her bed. She sat beside him holding his hand, talking to him. The person whom Evelyn had entrusted with her emotional wellbeing, the person who had believed in her, was gone. Life would never be as it was. Evelyn recalled, "I watched as they put him on the stretcher, into the hearse and drove him down the road."

Her father's funeral was huge. He was a respected member of the community, a World War One Veteran, and well known within the political circles. In a soft, shaky and mournful voice Evelyn reflected upon the event, "I wasn't allowed to cry. . . I was in the back of the church and nobody touched me, nobody hugged me, nobody talked to me. Ma was in the front with the family." That raw rejection was never forgotten, embedded within her psyche, presenting itself at her most vulnerable moments.

After her father's death the extended family took over. Her mother's son wanted her mother to move to Toronto to live with him and his family. Evelyn was trotted along as extra "baggage", in her belief. They left with the clothes they had on their backs and a

small shopping bag carrying a change of clothes. Evelyn's possessions – her dolls, books, awards, and piano, everything that she treasured and could call her own – were left behind. Once in Toronto, Evelyn enrolled in school. Her mother would sit in their bedroom all day. No one interacted with her and she was ignored. Evelyn would return from school and go to their bedroom to spend the remainder of the day with her mother. Actions and demeanour sent the clear message that they were not wanted.

Evelyn would listen to the song 'oh my papa'. The tears would start and flow like they were never going to run dry. She was told to stop crying. The son and possibly other siblings sold the family home with 'Ma' receiving little or no money from the transaction. "I never saw anything again . . . nothing, nothing, everything was sold, or given away or thrown away. My mother never talked about it, but how sad it must have been for her." In the middle of February, 'Ma' and Evelyn had had enough of staring at the four walls of their bedroom and decided to return to their home community. They boarded a train heading east. "It was cold. My mother who was grieving, sad, old . . . and had osteoporosis . . . was freezing."

Evelyn and her mother moved in with a granddaughter who lived next door to the old homestead. Instantly, Evelyn became the "scullery maid" looking after the kids, changing diapers, doing dishes. Whatever had to be done she was left to attend to. And once again Evelyn and her mother shared a bedroom. She remembered the ceiling sweating. Water was literally dripping from the ceiling. Evelyn became exhausted, she collapsed; the diagnosis - tuberculosis. She was only in grade nine, but she ended up being institutionalized in the TB Sanatorium.

Through Evelyn's young years she had many trips to the hospital, and spent many nights occupying a hospital bed, dealing with TB, pneumonia or pleurisy. Each trip she took on her own. From these experiences she grew to know the hospital environment well, and became quite comfortable with the role and function of nursing. Her mother had little money, was blind, partly deaf and an elder, but one gift she gave Evelyn was the determination and insight to follow a profession. 'Ma' instilled in Evelyn the importance of independence, knowing her life expectancy and health status could not be predicted and the extended family could not be counted on for support. To fulfill this mission, she encouraged Evelyn to follow her dream of becoming a nurse. From a very young age, Evelyn had been looking after herself, helping her elderly parents with care. She was all too familiar with the caring role. Her blind mother was a solid role model, an independent capable woman who did not let the lack of sight limit her abilities. Evelyn learned independence and self-direction that assisted her over many hurdles in life. However, this also restricted her ability to reach out to others for help, for independence taken to extremes spilled into isolation, both physically and emotionally created.

Evelyn and her mother eventually moved into a little apartment, until it was time for Evelyn to attend nursing school in a neighbouring community. The bond between Evelyn and her mother remained strong. Out of dedication to her mother, Evelyn would hitchhike home every weekend. One day she received a phone call from a neighbour, her mother had fallen and broken her hip. Evelyn rushed home to be by her mother's side, but her mother insisted that she return to school. She desperately wanted Evelyn to get an education that would lead to a 'good' job. Once discharged from hospital, Ma's son-in-law, grandson and his wife moved in to provide home-care. Evelyn's sense of

home was displaced. “Again, I felt like I did not belong anywhere.” She witnessed, again, her mother being used for monetary gain. The carers received free rent yet anytime they took ‘Ma’ to the doctor’s, to get groceries and so forth, they charged her. Evelyn dreamed of the day she could provide for ‘Ma’, but that day was never realized. ‘Ma’ eventually died of bone cancer, thankfully not before she saw Evelyn receive her nurse’s cap in 1962.

Upon reflecting on this time, Evelyn recounted that “it was years of continual hell . . . cruelty . . . how I rose above it, again, it’s my faith. It was always God.” Evelyn’s childhood was filled with sorrow, strife and struggle: the loss of her father, chronic illnesses, multiple trips to the hospital, months in the TB Sanatorium, displacement from home, multiple moves, chastisement by extended family members, and eventually the death of her (dis)Abled mother. Through it all she maintained her faith, learned to take care of herself and received an education.

The year that Evelyn received her nurse’s cap, she also buried her mother, moved to another province, got married and was expecting her own child. Evelyn remembered working continually both within her professional role and as a mother and wife. She worked shift work as a nurse and cared for her children (she soon had two children), while also supporting her husband through graduate school. Evelyn negated her own needs, always pushing them to the sidelines, while she attended to others, be it patients, children or husband. She was becoming exhausted, trying to juggle all the demands upon her.

The year 1974 would prove to be climatic, calling upon Evelyn’s faith for stability. Her third child was born by caesarean section. Evelyn was quite ill at the time.

Five months later her husband walked out, leaving her with three children, aged five months, five years and eleven years. The marriage had been tumultuous at best, plagued with emotional abuse. In the months following the separation, Evelyn's health spiralled downward. Approximately five months after the separation she had an emergency hysterectomy in an attempt to stop profuse bleeding that had been troubling since her last delivery. Within that year, she had a bowel obstruction that required a segment dissection of the bowel; was diagnosed with hypo-thyroidism; experienced extreme exhaustion; then began her pain journey. Evelyn originally attributed her exhaustion and pain to her anaemia caused by the bleeding, her recent surgeries, and the emotional upheaval of the separation.

The surgical scars healed, the hypo-thyroidism was under medical management, and the haemoglobin was rising gradually. However, the pain, stiffness and exhaustion were worsening. Eventually, a close friend of Evelyn's noticed her exhaustion, her restricted mobility and the expressions of pain mirrored on her face. She believed these were symptoms of arthritis. There was no rheumatologist in the city, so Evelyn was referred to a larger urban centre for a consultation. In 1978, she was diagnosed with systemic rheumatoid arthritis. Evelyn's condition was so grave that she was instructed to stop work and to refrain from housework - basically, to completely rest. Evelyn remembered being told her diagnosis. There was a fly on the window in the doctor's office. The fly was trapped between the window panes, ensnared and frantically trying to find an escape route. She stared at the fly and immediately felt the fly's entrapment, as she recalled, "The fly was trapped in the window panes, trapped, it was trying to get out

but it couldn't – I remember thinking I was trapped, feeling trapped." Trapped within her own body, she was unable to escape, feeling exhausted and in pain.

Evelyn wrote this poem reflecting that experience, switching the location of the fly from the window to a spider's web:

Without Wings

**Like you Mr. Fly
I am Trapped
You in the spider web
So intrinsically woven
Me in my body
So riddled in pain**

**You feel it too
Your body
Screams
Throbs
Cries**

**You hang on
I do too
You are almost dead
I am too**

**I try
I climb
I live**

**Unlike you Mr. Fly
You were caught
By your enemy
I am my enemy
I am the web**

Afraid, Evelyn worried if she took the doctor's advice she would end up in a wheelchair. She feared if she did not keep moving, no matter how painful and difficult that was, she would seize up, as she related, "I didn't listen to him, I was afraid if I didn't move that I would end up in a wheelchair." Besides, she had three children who

depended on her financially and emotionally. Thankfully, she was not working on a surgical floor but in psychiatry, where she did not have to do much lifting or heavy physical work. At noon hour, she would go over to the physiotherapy department and get into their hyper tank (circulating water) or have hot packs applied to her inflamed joints. It took approximately two years for her medication to provide any relief. It was not substantial relief, but when you are in chronic pain, any relief is accepted with gratitude. Evelyn recalled those days, “I never dreamed the pain would be so bad. I couldn’t do anything . . . getting up in the morning to go to work, it took me hours to get ready, the children would have to help me, pull me up, open the car door . . . the pain was exhausting.” Her comforts were the tub, hot water and bed. Her solace through gardening was denied. Evelyn noted, “I didn’t give into the pain. I got on my feet. I always got on my feet. I don’t know how. It was sheer will, and three children, I couldn’t give up.”

Quoting from Evelyn’s journal:

All my life I have known pain – physical, emotional & mental. I am so tired of it all. My energy is drained, I’m exhausted but I can’t rest – I must work. I can’t give up everything – I want to. Jesus, you’ve got to help me hang on. Some days, like today, I feel as if I am drowning. When I am in pain all the time, it wears me down. I feel worn out – worn down. I don’t have the strength to move, but I keep pushing & pushing & pushing & pushing my body – mind – SOUL!
Evelyn 1991

Evelyn’s work experiences, in psychiatry and then mental health, were substantially different when it came to dealing with her and her pain. In Psychiatry, they understood. They saw the compassion and insight Evelyn had for the people she worked with (her patients). Evelyn did not hide her pain nor suffering. Neither did she dwell on it. She lived with it. She used it as a tool to relate to others in pain, be it emotional or

physical, using her own experience for teachable moments – taught through example. Evelyn was respected by her colleagues, viewed as a highly ethical practitioner, devoted to the patients, and giving of herself and her location as a woman with a chronic illness. In the mid eighties, when she switched jobs to work in mental health, she went from casual work to a full-time position, leaving behind shift work for Monday to Friday days.

She was still in pain and she was still tired, but she was struggling along.

Evelyn's primary job focused on seniors. In time, the provincial government would change the service delivery to this population, expanding the role of community services without adequately staffing positions to meet the demand. The fallout landed squarely on the shoulders of nurses like Evelyn, for her workload quadrupled. As a sufferer of chronic pain, balance was essential. Evelyn had to pace herself at work by taking the necessary breaks and juggling her physical needs against practical implications, such as workload. This balance was quickly slipping away. Evelyn recalled, "The caseload was tremendous . . . There was no time for anything. I'd come home stiff, go to bed, get a bath, you know it carried on. I was getting weaker, more tired, more exhausted, more pain." Even Evelyn's rheumatologist sent a letter to her director, requesting extra help and a reduced workload. If this was not forthcoming, he feared she would pay the consequences physically. Quoting from his letter:

Unless there is some decrease in her stress level at the work place (more regular working hours with less overtime and less tasks to perform) then we are headed for a flare up of her rheumatoid arthritis and a likely medical leave of absence in the not too distant future.

The director did not respond to this letter. Evelyn felt abandoned by her co-workers, by her employer and ultimately by the director. She had been there so many times for others, supporting their crises. She helped them negotiate the system. Yet, when she

needed help, no one was forthcoming. “I was falling apart and no one saw it, whether or not they wanted to, didn’t care?” Evelyn ended-up in a full-blown flare-up of her arthritis, complicated by serious drug side-effects which depleted her immune system. She was emotionally and physically exhausted. “I left the . . . job completely void [sic] of energy, completely filled with pain and went out on disability. They had to hire two nurses to replace me.”

In horrific shape some days, Evelyn could hardly lift her head from her pillow. Lying in bed, unable to move more than her arms, she would reach for her color pencils by the bedside and doodle her expressions of pain on the book cover of a novel. This was an outlet of expression often utilized when the written words would not come forth; when the pain was so severe that her being was screaming for a method of expression, which she exhibited through descriptive colourful designs.

Fig. 4.2 Raging Pain



The first piece Evelyn named 'Raging Pain', providing the following description:

The pain at that time was beyond description; it lasted for almost a year. I look at the drawing and remember the state I was in at that time, wondering when it would end, and praying for relief. It was excruciating! The will is strong; I pray that it will never pain like that again, I do not think I could handle it today. I still have pain in my feet, et cetera, but not like that. I thank God He got me through it and that He is with me all the way. My physiotherapist worked with me three days a week. She wondered how I even got to the hospital. She told me later, a year and a half into physio, "When I first met you and assessed you and started working with you I said to God, 'what am I supposed to do with this lady?'" Two years of Physio helped. It was a painful journey, but it was worth it.

The second drawing which Evelyn titled 'Tangled in Pain', captured the same pain experience.

Fig. 4.3 Tangled in Pain



The following is her description of the drawing.

I felt trapped; fear, depression, shame, guilt. I felt like a tight web held me so tight I would never be released. I look at it now and shudder. It was a dark time, the pain was unbearable, but I had to go on. The days and nights ran into one. It was difficult to move, to think, to eat, to sleep. It was always pain; systemic pain.

I had to crawl at times to get to the bathroom. I pray it will never be like that again. I wonder how I did it.

When asked to describe her drawings, Evelyn shared her emotional and cognitive response to the process. In Evelyn's words:

I feel like crying as I look at it, think about it, write about it. I feel nauseated. It was a dreadful period in my life. Words cannot really describe how I felt, what I experienced, what it was like to keep trying to survive.

With Evelyn's degree of (dis)Ability, one thing was clear, she could not return to work, ever. At the age of fifty-seven, with thirty-six years as a nurse, she applied for Canada Pension Disability, after long-term disability from her employer (the provincial government) ran out. This process in and of itself was gruelling, the forms overwhelming. Evelyn's immune system was compromised. She was exhausted and in continual pain. Her ability to concentrate and her memory were severely taxed; a cognitive side-effect from chronic illness. On first application, Evelyn was denied. She had nowhere to turn. The window entrapping the fly was getting smaller and smaller. Evelyn's condition was so grave that she could not navigate which foot to put in which shoe. Physiotherapy was a life-line for Evelyn. Eventually mobility was increased and clarity of thought returned. But, it was a long, tedious process over a three-year span that required commitment, work ethic and diligence. Evelyn's blood levels were depleted, a serious side-effect from her potent arthritic drugs. Immobilized by the pain and stiffness, and shadowed with depression and hopelessness, she could do little. Yet she was denied Canada Pension Disability, for the decision makers believed that Evelyn's condition was not sufficiently disabling. The struggle was heard in Evelyn's desperation:

I was beginning to think I was making this up, I'm not in pain, of course I can do this, I can do that, and I was collapsing. I was crawling to the bathtub, thinking I

would walk, and I got up to walk and I was so weak I couldn't do it. And still having to write these stupid forms. You know, I keep thinking there has to be something done along the way to help people who are in chronic pain, you can't do it alone. In writing these letters, even though I answered all these questions, which took me three or four months, and trying to describe where I was, and the rheumatologist writing letters.

Feeling isolated, alone and rejected, Evelyn reached out to a social worker she knew in her hospital days, a woman who lived with pain and understood its realities. This worker could not believe Evelyn was denied benefits, for, in her opinion, Evelyn exceeded the minimum qualification necessary for disability pension. To put her through an appeal tribunal was unnecessary. Furthermore, it could exacerbate her symptoms. So, the social worker wrote a detailed letter, with Evelyn's assistance, documenting Evelyn's suffering and the impact it had upon her daily life. As well, Evelyn asked her rheumatologist to write another letter. The pension board granted Evelyn her disability benefits without demanding she appear in front of the tribunal.

Evelyn's story was one of struggle, loneliness and pain, but it was also one of hope, faith and determination. She never gave up on herself or others. Through gardening, friendships, writing, children and faith, Evelyn navigated through her illness. She wrote poetry to express her pain, often using elements of nature symbolically, as illustrated in the poem, November, below.

November

It is fall

**I look through the back porch window
The wet wrinkled leaves cling to the earth
The garden rests and waits.**

**The cold winds blow
A damp chill creeps through the house
Through my bones
My body aches.**

**The dark grey sky
Covers the day
Night comes quickly
In November
In my body.**

Evelyn 2003

When Evelyn wrote this poem, winter was settling in and with winter came increased pain to her arthritic body. She recalled the cold winter piercing her body with flaring joint pain, stiffness and general fatigue. Evelyn, being an avid gardener, was frustrated that her garden care for the winter could not be completed due to her physical condition.

Over the years, Evelyn has drawn on many coping mechanisms, including her gardening, for gardening invoked a spiritual journey.

That doing something physical does help, that digging a hole, watching a flower grow does help . . . you sure notice the little things when you are coming out of great pain. That is why gardening is so important to me.

To nurture and stroke elements of nature brought great relief and joy to Evelyn's tired and depleted system. As Evelyn voiced in a documentary on women with invisible (dis)Abilities, called 'Almost Normal: Stories from the Well Within':

Just planting the seeds and watching the flowers grow, it always amazes me. Putting a seed in the garden and watching it grow gives me great joy. It's not just the flowers; it's everything in the garden, the whole landscape. Very meaningful, beautiful, intriguing, healing. (Kozar, 2004)

Symbolically, the garden had given Evelyn's depleted system renewed energy.

Evelyn expressed her location in the garden, "When I am in my garden, I believe any gardener, when they are in their garden they forget, everything else ceases to exist; your mind is nowhere but in your garden" (Kozar, 2004). A friend attending Evelyn's garden party as part of the documentary commented, "she assumes, rightly or wrongly, that we are all going to be happier in a garden" (Kozar, 2004). For Evelyn, the garden has

become her solace, a place where her pain and (dis)Ability could be forgotten for a few moments, a place where she could become connected with nature, not fighting against it, as one so often does with bodies in pain. Other coping mechanisms like feminist healing circles have been formed by Evelyn's female friends. Through prayer, expressions of emotional support and healing touch, hope and rekindled energy has been found. In Evelyn's words, "I feel if we can give some comforting words to each other as we pass each other on our life path, then we have done something good. Validation is the one thing that is needed for the human condition."

4.5 Helen ~ (autoethnographic contribution - four pain paintings)

Researcher's reflection: For Helen, telling her story about living with chronic pain was not a new adventure, as in her volunteer capacity she had related her struggles and triumphs numerous times to other chronic pain sufferers, to the media and medical professionals. I admire her fortitude in being able to challenge the myths and stereotypes about chronic pain. She is both a historian and a visionary, weaving through her story reflections on nursing practices with chronic pain sufferers in years past (highlighted under professional findings, Chapter Six), while envisioning empowerment based ways of working to challenge the present. Helen's nursing career might have been halted eighteen months into practice due to a horrific life altering accident, but her current work on a local and national level is practice reincarnated. I appreciate her telling her story once more, for with each telling brings new opportunities and insights.

Helen's Story:

In the 1960s, women became school teachers, secretaries, nurses or stay-at-home mothers. Helen had selected nursing as her career path, but was quickly short changed of the opportunities her career might have provided when, a year and a half into practice she sustained what would prove to be a life altering injury. On this particular shift, a patient had fallen out of bed, Helen and an orderly went to lift him back into bed. Helen took his head and shoulders, while the orderly took his hips and legs. Helen recounted:

I said, 'on the count of three, we will lift him to our legs and the next count of three we will stand him up; do you understand? Do you really understand what I am saying? We haven't worked together before'.

The orderly assured Helen he understood, dismissing her questions as worrisome over caution. Helen counted, one, two, and three and then lifted. The next thing she knew, she was under the patient. In a defensive tone, the orderly proclaimed he was waiting for Helen to say 'go'. As a result, of this incident Helen was on strict bed rest for two weeks, for a myelogram had detected a slipped disc. The pain did not recede, so surgery was performed, a laminectomy, to remove the disc that was pushing into her nerve end. Helen thought she was recovered quite well, but the surgeon recommended a disability pension with Worker's Compensation, believing rehabilitation from back surgery was often complicated. The wisdom of this surgeon later came to the forefront, as Helen's problems were far from over.

Being newly married and wanting to begin a family, Helen consulted her physician about the potential complications pregnancy might bring to her health. She was reassured she would be fine. At about seven months into her pregnancy, her back became bothersome and by the time Helen delivered, the pain in her back was out of

control. The baby was in a breach position, complicating delivery further. This resulted in permanent sciatica for Helen, with persistent pain shooting down her right leg. Due to these complications, Helen and her husband decided to adopt their second child.

The next few years went along fairly smoothly, as long as Helen adequately compensated for her back problems. She always was aware of her vulnerability, especially trying to get the children in and out of snowsuits, boots and other attire. Help was needed with the children at times and housework was beyond her capacity. Her friends teased her about the luxury of having house cleaning services. Little did they know about the pain and struggle that created this need. Then in 1973, Helen was in a car accident, a head-on collision with a dump truck on a single-lane bridge. Fortunately, no one was seriously injured, but Helen (snapped into her seat belt) dislocated her collarbone and sustained whiplash. The collarbone flexed back into place on its own. The whiplash would prove to be more troublesome. At the time, she was told the whiplash was a soft tissue injury, but nothing to worry about.

Within a couple of years, her pain had etched a particular complex pathway, spreading from her neck into her shoulders, then traveled down her legs, sending stabbing sensations to her hip, then returned to her neck to begin the cycle once again. In Helen's words, "There was no rhyme or reason to it." She had x-rays and blood work. Nothing pointed to a diagnosis. The pain became so intense that she was hospitalized for seven weeks. This proved to be one of Helen's most trying times, as she recalled:

That was the period in my life that was perhaps the hardest time I ever went through; and that is because of the way I was treated as a patient. It was awful. The nurses decided that there was nothing wrong with me and that I was malingering.

For example, the nurses would not respond to Helen's requests. She would ask for the hot packs the physiotherapist had instructed her to use and the nurses would produce half the requested amount. Helen heard the nurses mocking her, saying things like, 'oh that's just Helen – there's nothing wrong with her' or 'she puts on the light because she thinks she's in pain, but she isn't' or 'she's just making it up'. When Helen heard this commentary, she became angered and disheartened to think that women in her own profession could treat a patient this way, and furthermore, could treat one of their own this way. Attending to the ethics of care, Helen spoke to the head nurse about this incident. The head nurse responded in a judgmental manner, telling her to get out of bed, get dressed, go home and grow up. Helen was demoralized. Reflecting back, Helen believed the nurses intentionally spoke loud enough for her to hear, as they wanted Helen to know they had caught onto her little scheme. Helen could not understand how they could misinterpret her anguish as a plotted scheme, adding emotional pain to her pain repertoire.

When Helen's family physician saw her during nightly rounds, she informed him about the nurses' antics. He was at a loss with respect to Helen's diagnosis. Having no where to turn, he suggested they consult a psychiatrist. Helen was baffled. It felt like everyone was labelling her as the creator of her own pain. Boldly, Helen asked her physician, "Do you think it is all in my head too?" He replied that he was uncertain, but eliminating that possibility would be in Helen's favour. Feeling her options were limited, Helen agreed to the consultation. The psychiatrist diagnosed Helen with depression and wanted to prescribe anti-depressant medication. Helen firmly retorted, "I know that I am depressed, it's because of the pain, get rid of the pain and I won't be depressed." The

psychiatrist's position was that Helen's depression was of clinical etiology and she needed to be medically treated. Helen stood her ground, her depression was created by living with pain; treat the pain, not the depression. She refused to take the anti-depressants and requested a consultation out of province.

Helen was referred to a specialist in a large metropolitan center. He spent two hours examining her and concluded she had fibrocitis syndrome (now referred to as fibromyalgia). This was 1976. Fibrocitis syndrome was new to the medical community. Helen suspects she was the first to receive this diagnosis in her province. The diagnosis brought relief. She had a bona fide medical condition, not something she imagined or created. Helen spoke to her experience, "I can't tell you how happy I was to have a diagnosis, to come home and say, 'look at this folks, I was not making this up, this is for real!'" Helen's family physician was relieved as well, and he ended up collaborating with the specialist on a journal article pertaining to fibrocitis syndrome. Unfortunately, Helen's elation wore off as she continued to face pain on a daily basis. A referral was made to the local pain clinic, where the consulting physician was a proponent of acupuncture. For six weeks, she had rounds of acupuncture, the results lasting four to five hours, with no long term effects. She continued like this for years, with her life revolving around appointment after appointment, ranging from physiotherapy to acupuncture and aquacise. It was like a fine balancing act, trying to keep her pain at a liveable level.

Then, in 1983, Helen had further back surgery, a double fusion. Again, she did well post-operatively, achieving her rehabilitation mark of walking four miles a day at the three month intervals, two miles in the morning and another two in the evening. Her

energy and stamina returned. Helen went back to her painting, as well as teaching classes to interested students. Gradually, the pain in the back of her legs reappeared, growing with intensity as the days passed.

Then, one day in the late 80s, Helen was visiting a friend in the country, sitting and relaxing in her friend's yard, enjoying the sunshine and company, when suddenly she plummeted to the ground. Helen felt like she had been shot in the back, with this burning, stabbing pain crippling her every sensation. The lawn chair she had been sitting on collapsed. The explosion of burning pain was so intense Helen thought she was going to lose consciousness. Somehow, she maintained her composure. Her friends got her into the house and called the local doctor. For days, she lay completely still, unable to move. Routinely, the doctor came to the house, checking on Helen's status and giving her injections of pain medication. Finally, her husband got her home and contacted her physician, who immediately arranged for admission into hospital. Within a couple of days, she was referred to the pain clinic, this time to receive a series of nerve blocks.

Helen recalled the attitude at the clinic;

You go in, they meet you and they say 'okay you have pain, how can I help you?' and there is no indication that anyone in there thinks you are a malingerer. You are believed and they want to help you. And that is why I think the doctors in there 'walk on water'.

The nerve blocks would help for a while, maybe a couple to three months and then she would need another series. The blocks relieved a degree of the pain, but Helen was never pain free.

On a relationship level, due to her pain Helen lost some friends who were not willing to accommodate her needs. One friend, with whom Helen used to go on painting excursions, found it difficult to see Helen in so much pain and suggested that Helen call

her on a 'good' day. In Helen's words, "If you can't take me on the bad days, you can't have me on the good days. That is all there is to it, this is me." Another group of friends that were shopping mates were able to accommodate Helen's needs. Helen could no longer do the marathon shopping day, so she would arrange to meet them at a designated location for lunch. This way she could maintain contact and still feel that collegial support.

Sometimes Helen would push her boundaries and end-up paying the consequences. One weekend she and her husband wanted to have friends over for supper. Helen knew from past experiences Friday evenings were not a good time for dinner guests, for scheduling dinner on Saturday or Sunday evening meant Helen had her husband to help with the preparation. Because this couple was only available on Friday evening, Helen overlooked her own needs to accommodate their schedule. Helen tried to pace herself throughout the day, but by 9:30 pm her pain lines and fatigue were evident, even to the guests. The rest of the weekend was lost, as Helen needed it for recuperation time.

A great part of Helen's coping ability she attributed to having supportive family and friends. Her parents were very understanding and helpful. Her mother worried tremendously about Helen's health. Her husband's mother was more pragmatic and would stop by to do the laundry or bring supper over when Helen was bedridden. Helen's husband was an engineer and as a mark of his trade, he thought in terms of graphs, with logic and mathematics as his center. Emotional expression did not come easily to him. Helen knew he coped with her pain by burying himself in his work, which had benefited his business financially, but had stifled communication between them.

When Helen would be bedridden, he would make sure she had everything she needed and then retreat to his office. Fortunately, his downstairs office was connected to the bedroom through an intercom system. Helen respected his need to cope in this manner and was cautious not to misunderstand his actions as non-caring. However, total appreciation of the impact of her illness upon her husband was not realized until her son verbalized his father's struggle. Helen commented:

It bothers him, it bothers him when I am laid up. My son . . . told me how bothered his Dad gets when I am having a rough patch, because he hides it from me, he doesn't let on that he's being affected in anyway.

In an attempt to open up communication, Helen spoke to him, "I understand that when I am laid up this really bothers you." His reply was short, but admitting, "yeah, I guess it does."

There were times when her husband's emotional location had surfaced. Helen had been interviewed by a radio reporter about living with chronic pain, and subsequently received a copy of the interview. When her husband heard the interview, he commented that it was a very moving piece. A couple of weeks later, a friend was visiting and they were listening to music on the disc player. Suddenly, the music was interrupted by the interview. Helen went to shut it off, when her friend protested that she wanted to hear it. Helen's husband sat down to listen to it again. In the quiet of the moment, Helen looked over at him to see tears trickling down his cheeks. This was the first time she had ever seen him cry in relation to her illness. Commenting on the event, Helen said, "I would not have realized that that impacted him the way it did."

In the following years, she tried numerous alternative therapies, reaching for any pain relief possible. At a cost of \$6,000 per year, she spent a total of \$18,000 in a three-

year span on eastern acupuncture, cranial-sacro massage, and other therapies in a desperate search for pain control. Helen even went to art therapy, where she painted her pain as she was experiencing it, hoping that the emotional release expressed through creativity would decrease her pain levels. For three months, Helen followed a creative process, which began with sketching images that reflected her pain.

The first image she found to represent her pain was a maple seedling, as it visually resembled her legs and sacrum. The next step was for her to capture her dreams, to sketch out images that would come to her during the night in her sleep. The intent was to see if aspects of pain were filtering through her dreams. Another exploration was to creatively capture how others saw her. Helen dressed impeccably. Everything was in its proper place, make-up specifically applied, and clothes neat, color coordinated and fashionable, presenting a controlled and organized exterior, in contrast to her inner unrevealing pain-filled self. The paintings below depict an extension of her inner and outer self, the controlled versus the unravelling dimensions of living with pain. Every time Helen participated in art therapy she became absolutely “wiped”. Instead of enjoying her painting time, it became an onerous task. What she experienced was the loss of a coping mechanism, for previously, the joy of painting had acted as a pain distraction.



Fig. 4.4 Everything Under Control Helen is holding everything together in order to present a controlled picture to the outer world. In her words, "Even though I am in pain and uncomfortable, I am able to hold it in and pretend it is not there to the public."



Fig. 4.5 Losing Control In this painting, Helen was trying to keep control but she could no longer maintain composure, everything was coming apart. In her mind she thought, "Got to get home, out of the public."



Fig. 4.6 Muscle Spasm

Helen painted this picture when she was experiencing a muscle spasm.



Fig. 4.7 Raging Inferno Taking the advice of the art therapist to capture acute trauma (either emotional or physical) on canvas, Helen painted this picture the

day after an excruciating and exhausting five hour round trip to a family reunion. Her leg was on fire, in total spasm.

Getting nowhere with the alternative approaches, Helen asked for another consultation at a larger center. She remembered the experience with a degree of clarity not often afforded pain sufferers. First, the resident came into the examining room to take Helen's case history. He inadvertently suggested that Helen might have arachnoiditis; a condition caused by dye used in myelograms in the 60s and 70s, where the dura of the spinal column literally ulcerates, exposing nerves. The specialist entered and examined Helen, he suggested she have a stimulator surgically placed along her spinal column, basically, an implanted TENS unit. He went on to speculate, if that failed to produce substantive relief they could always cut the sciatic nerve. Helen, having been a nurse, wondered about the implications of such a radical procedure and questioned him in this regard, asking, "Will I be able to walk?" His response was basically, "Do you want to walk or do you want pain relief?" Helen then asked him if there was any chance she had arachnoiditis. "Oh, I don't think so" was his response. The resident looked at Helen, Helen looked at the resident and both said nothing, for it was obvious the resident had spoken beyond his authority.

Leaving the appointment, Helen recalled, "I came out feeling like not only was my bucket empty, but it had a hole in the bottom. There was no hope left. He was my last hope and it was gone." As she went out to lunch with her husband and cousin, she strove to hide her emotional upset. They attempted to distract her and bring her into the conversation. She knew what they were doing and tried to play along, but all she could

think about was her intense disappointment. Returning home empty handed, Helen began to research this puzzling condition, arachnoiditis. She found out that eventually the ulceration will hit the nerves that control the bowel and bladder, and function in those areas will be impaired. Consulting with her orthopaedic surgeon, he indicated that the shadowy patches on her scan could very likely be arachnoiditis. However, it was difficult to conclusively prove and there was no known treatment. Helen had been desperately hoping that the consultation would result in some resolution for her pain. As she recalled, “I guess I was still in the hopeful phase of hoping that chronic pain wasn’t something I had, hoping to disprove it.”

Having exhausted all treatment modalities known to her and her physician, and finally accepting that she had chronic pain, she agreed to try opioids. Helen’s initial injury occurred in 1967, she was diagnosed with fibromyalgia in 1976 and she did not begin taking opioids for her chronic pain until early in the 1990s. As Helen recalled:

I didn’t want to take them because I didn’t like the thought of having to take something for the rest of my life; however, it was the best decision I have ever made because I got the quality of life back and I am able to do the volunteer work that I am now doing. And it is absolutely giving me a quality of life that I didn’t have before.

With the use of opioids, a treadmill and a very supportive husband, Helen manages to live her life with chronic pain. She continues to paint and devote a great deal of her time to advocating for chronic pain services, while supporting other sufferers in their struggles to find treatment options. Helen is a champion in promoting awareness of chronic pain to the general public, sufferers and medical personnel.

4.6 Marg ~ (autoethnographic contribution – description of ‘going into the pain’)

Researcher’s reflection: Unlike the other participants, Marg’s journey with pain began with malignant pain associated with her mastectomy, and then traveled into back pain where the etiology was questionable, and concluded with non-malignant pain in relation to her broken knee. In telling her story, she spoke of harrowing times, depicting emotional strife and physical anguish. Yet, throughout her telling, emotional expression was defined within the parameters of calm, reflective and humorous expression. This might equate with her ability to compartmentalize her pain experiences, keeping them emotionally confined through the utilization of cognitive will. Her ability to use the power of her brain to literally block pain transmission, and certainly alter pain perception, was phenomenal. This spoke to her survival character, in that she would not be defeated. I admired the strength of her call to service, for throughout all of the adversity, she continued to care for others, be it professionally or personally. She did not let the pain engulf her. Neither pain, nor cancer, was going to be her defining character.

Marg’s Story:

Marg’s story began when she was a young nurse, at the age of twenty-eight, and had to have a biopsy on lumps found in her breasts. She recalled the experience vividly, defining it as an oppressive episode. As a young nurse, she was trained to be a ‘handmaiden’ to physicians and to never question their opinions or practices. The surgeon was middle aged and accustomed to nurses treating him in this manner. This set the tone for the encounter that was about to happen. Marg had to go to the local emergency department to have a biopsy preformed. As she remembered, it was more like

a lumpectomy then a biopsy, done under a topical anaesthetic. She came in, stripped off and lay down. The worst of the situation was the way the surgeon had the light adjusted, for the reflection on the silver light transformed it into a mirror. Marg could see everything he was doing, how he was mutilating her body. As Marg attested, "It was the grossest thing, I was a nurse and I worked in the OR, but it was the grossest thing to see this being done to your own breast." Gaining the courage to speak up, Marg told him she could see everything. He did not respond. Her voice was ignored. She wanted to scream at him to move the light but, being a nurse, she knew she could not relate to a doctor in this manner, so, in silence, she put up with the procedure. Ten days later, she went to his office to receive the results. He was seated behind a cluttered desk, peering up from his glasses, and in a matter-of-fact voice, told her it was not a question of if she was going to get cancer, it was a question of when. So, the biopsy was negative but pre-cancerous tissue must have been evident, for he then instructed her to go for a breast exam every year, and after the age of thirty, to have a yearly mammogram. Marg related:

That was so fatalistic. And so, at twenty-eight, you have this hanging over you. So picture it, every breast exam thinking 'well okay, what's this?' I was so relieved when I finally had my mastectomy because that wasn't hanging over me anymore. Oh yeah, it was a huge relief.

At the age of thirty, Marg had cancer in both breasts and was going in to have a bi-lateral mastectomy. The surgeon might have been correct with his prognosis, but he could have delivered his message in a more caring and compassionate manner.

The surgery was performed in August, 1987, by a different surgeon, in a separate hospital, in another city. What was scheduled to be an hour and a half surgery, turned into an eight hour marathon; where Marg almost lost her life. Her heart stopped during the procedure and she had to be resuscitated. Marg was in a coma for the first ten days

following surgery. Memory loss was sustained due to brain damage, which now affects her ability to recall the event in detail. Marg remembered waking up from the coma and not knowing that her arm was her arm. “I remember saying ‘what’s that?’ and it was my hand. I remember looking at it, it was a very intriguing thing and I wasn’t the least bit disturbed, but it was fascinating.” Unfortunately, her memory loss did not affect her pain recall, as she remembers with incredible detail the intense pain in the area of her sternum. Like it was yesterday, when really it was seventeen years prior, the intensity of the pain, in going from a lying to a sitting position, can still come flooding back with a vengeance. For months after the surgery, in order to sit up, she would have to mentally psyche herself up, sometimes taking thirty or more minutes to muster the courage. The situation was made worse as Marg had always slept on her stomach. Now she was being forced to sleep on her back. She would be violently woken from her sleep with the slightest movement. Tylenol #3 was prescribed as a pain killer, but for Marg, instead of easing the pain, it just complicated the situation. Marg would have, in her words, ‘wacko’ hallucinations, while her pain perception was altered little. As a matter of fact, it interfered with her mental and emotional ability to deal with the pain. Thinking of the pain as acute post-op pain, she was convinced that it would subside. In her previous surgery experiences, the pain eventually went away, but this time was different. For Marg, this mapped the blueprint for her entire pain experience, originating with acute pain that would last seven years.

By April of the following year, Marg was hospitalized for her thirteenth surgery since her mastectomy. In less than a year, she had undergone repeated surgeries to attend to damaged tissue, skin breakdown and implant complications associated with her

traumatized chest. As one can imagine, she was fragile, worn-down, weary and totally overwhelmed by the entire ordeal. The pain, loss of both breasts, disfigurement, coupled with repeated hospitalizations, uncertainty, and dealing with the big 'C' (cancer), at such a young age, would leave anyone struggling emotionally. Complicating matters, she was a nurse, and therefore, expectations were that she should be able to handle this. One evening, the emotional impact of her experience finally hit her. Late at night, standing dressed in a housecoat, in the bathroom of her private hospital room, she began to cry. This was the first time since her initial surgery where her emotions rose to the surface. She rang for the nurse, requesting pain medication. Deep down she knew she needed someone to be with her, to comfort and console her, as much, if not more, than she needed pain medication. Marg recalled the experience:

So I am leaning in the doorway of the bathroom and I am crying and I remember her berating me for crying. And really chiding me, like 'what's the matter?' and 'grow up', and 'what do you have to cry about?' and all this and it just went on and on and on. I remember her saying, 'it's not that bad' – the comment being about the pain, but also the whole experience. And I remember thinking, 'It's not that bad, how much worse would you like to make it?' And I remember, relating it to the pain, and holding my chest and saying, "oh but it really, really hurts". . . . That message had such an impact, it was 'grow up', 'stop crying' and 'it's not that bad'! So that was it then, I would not cry and it was not that bad.

Knowing it emanates from a perverse twist, Marg believed she had a lot to thank the nurse for, because at that moment, Marg began to deal with her pain and the entire situation mentally, from an internalized cognitive location. Unconsciously, she taught herself mental control methods that would serve her well throughout her struggle. However, another complication was associated with that evening, for in that experience, Marg learned to keep her emotions hidden, often tucked away even from her own consciousness. As a psychic release to the bottled-up emotions, Marg developed

nightmares where she would vividly relive the pain experience. They were so real, entailing the physical, emotional and mental components of her pain struggle, taking her a while to differentiate between nightmare pain and real pain. She would bolt awake, be experiencing intense pain and have to scan her body to see if the pain was real or imagined. Even today, years later, she will still occasionally have such a nightmare. And if she moves slightly during her sleep, she will be awakened. A good night's sleep has occurred when she awakes in the morning, in the exact same position she went to sleep in, laying on her back, holding the book she had been reading. An artifact of her pain journey has been insomnia associated with movement.

Marg's pain journey and cancer threat were far from being over, for in 1989 she was diagnosed with metastasis to her spine, during which time she experienced unrelenting pain in her lower back. Amazingly, on one bone scan, a tumour and hot spots would show, and then on the next scan, there would be nothing. This was at a time when Marg was diligently trying to reshape her life. She had returned to school to take social work. In an attempt to deal with the pain, Marg engaged with the entire assortment of in vogue alternative therapies, including meditation, relaxation, and exercises. Nothing seemed to ease her pain, so she retreated to what she knew best, mental control. A part of the control process was to become totally engaged with her studies, completing her undergraduate degree and continuing with her masters, receiving awards and scholarships.

Marg stalwartly resisted the concept of 'fighting' cancer, believing that it automatically set-up oppositional ends, winners versus losers. Likewise, she resisted the concept of living with pain, in her own words:

Going with the pain . . . making it a thing, I made pain an object that was outside of me, pain was not a part of me. And actually, one of the things I sort of struggled with was the whole concept of living with chronic pain, because it was more for me living beside or having chronic pain as a next door neighbour, I didn't live with it, I did not choose to co-habit with chronic pain. I kept it separate, it wasn't a part of me, you know it wasn't me, it wasn't part of my definition at all, at all!

Creatively, Marg developed a method of going with the pain, of entering into it instead of fighting against it or accepting it as a part of her identity. She made pain 'a thing' as a way of controlling it; an unbelievable method of mental control. In Marg's words, "if you accept the pain, you accept the cancer, if you accept the cancer, you accept death, and if you accept death, you accept finality, and more simplistically, its limitations." So, pain was an entity outside herself, and the going with process was literally envisioning sinking into the pain. She described the process:

If you can picture pain as sort of a cloud or a really cushy pillow, so you sink into it and so then, you are no longer fighting it and you are more one with it and you are moving through it, through that process.

You become one with the pain, so the pain does not consume you, but rather, you consume the pain. A mind over matter control process. But in order for this mental process to be effective for Marg, it had to be exactly the same process for each and every application. In exploring an autoethnographic contribution to add an extra dimension to her storying, Marg envisioned:

A box, lined with cotton batting, containing miniature marshmallows, in the middle of which is a little, dried out burdock. A burdock can be quite innocuous looking in a garden or field but as soon as you even get close to it, almost like a leech, it reaches out its tentacles and sticks to you. It scratches your bare skin and is stubbornly resistant to all efforts to get rid of it. You need only touch one of its thousands of little sticky spikes for it to firmly and resolutely adhere to you and suddenly that brown burr becomes almost a part of you. And, if you have the misfortune of encountering one burdock, most likely you become attached to its whole multigenerational family.

Rarely does one escape with one stuck to one's pant leg, rather, there is a whole clump that takes on a life of its own.

So too with pain, you put it in a box and build as much protection around yourself as possible; medications, breathing, distraction, sinking into the cushy softness that you make surround it, but always right there in the middle is its harsh spiny tentacles. And, if any one of them makes contact with you, it becomes the centre of your universe and the more you tug at it trying to rid yourself of it, the more it adheres. So, instead, you sink back into the white marshmellowy softness, with it stuck to you and focus on the softness around you, taking control back and reminding yourself that it is only a burdock.

Mornings were the most difficult times, as getting out of bed proved a unique challenge. To compensate, Marg would set her alarm clock an hour earlier, so if she normally got up at seven, she would set it for six, to be up for seven and to work by eight. The mental work necessary to get out of bed took an hour and it had to be the exact same mental process every time. Even once she was up, she followed the exact same process, Monday to Friday, putting on her make-up in the exact same way, getting her coffee at the exact same time, in the exact same manner. It was a control process and if something was altered, it did not work; for example, if the phone happened to ring, the mental control would be broken and the pain would return. Even today, Marg follows this routine during the working week, a conditioned process that she is aware of and in complete control of.

In 1993, Marg had just moved to begin work as a mental health social worker, when her uncle became ill. Being single and a former nurse, Marg was entrusted with the family care giving role. Moving her uncle into bed, Marg's back gave out. She was off work for six months, almost completely incapacitated. The diagnosis was vague. She had degenerative discs in her lower back, where the vertebrae was eroding and bone scans again would indicate cancerous hot spots one time and not the next. Her family

doctor was very understanding and supportive, but lacked knowledge in this area. The pain cocktails were overpowering Marg, as she stated, “Oh my God, my poor little head.” The mental fog interfered with her ability to control the pain. The acute pain of this new injury, on-top of her chronic back pain, derailed her previous coping strategies. Her prior morning routine was not enough. Each morning, it was as if she were facing a brand new battle. Having achieved the task the day before gave her no leverage to tackle the task before her at that moment.

In the dead of winter, she was mentally and physically tired, weary of the months struggling with pain. Depression might have been lurking around the corner. No matter, what was previously working was no longer enough. Determined as she was, Marg took an idea out of ‘The Woman’s Comfort Book’ (Louden, 1992) and applied it to her situation. This section of the book was on the use of humour and specifically, an exercise on acting like an ape. So that is what Marg did - she acted like an ape.

So for that winter, I hopped out of bed and went around like an ape, I exaggerated moving like an ape and it worked, and worked so well. As soon as I woke up, I would jump out of bed and I would go around and if you think about it bio-chemically, I got a punch of endorphins going and all the rest of it, but what got me out of bed again was that mental, that complete denial of reality, so hop out of bed and go. . . .A real conscious denial. There is nothing wrong with me, I do not have pain, I do not have any health problems, there is nothing wrong.

This conscious denial worked wonders when Marg was counselling, for as soon as she shut the door of her office and sat down with a client, she had no pain. It was literally gone during the fifty-five minute session. Marg’s colleagues thought of her as a workaholic, but it was sheer pain control. Work was her escape, her release. Once she realized the absence of pain during a session, she scheduled back-to-back sessions throughout the day and sometimes into the evening. As soon as the secretary called to

tell Marg another client was there and she stood up to walk the current client out, her pain returned full force. While she was walking the client out, going to the bathroom and returning with another client to her office, pain accompanied her. As soon as she began the session, the pain vanished, again for fifty-five minutes. This repeated itself, with one hundred percent accuracy.

However, outside work, Marg's back was becoming extremely problematic. Physiotherapy was literally crippling her. She would walk into the appointment and her leg would give out underneath her on the way out. Finally, after having to resort to using a cane, Marg fired the physiotherapist. An out-of-town consultation was made to an orthopedist in a larger health center. Immediately, he diagnosed Marg as having bone chips that were pushing on her nerves along her spine. With minor surgery, he cleaned up the loose fragments and determined no tumors were present at that time. It was miraculous, for within a very short time, Marg was recovered and back to work. And, as long as she did her back exercises and did not over stress her back, it was fine.

The first time in a very long time, Marg was doing well. For a few years she had hounded local business owners to rent her the vacant apartment on the first floor of this beautiful old home that housed their company. Finally, they relented and agreed to a rental arrangement. She moved in on Saturday and bright and early Sunday morning she was heading back to her old apartment to give it a final cleaning. Just outside her new apartment door she slipped on a piece of ice; down she went, with a shattering thud. Something was definitely wrong, as she could not get up. Her leg throbbed. People across the street came immediately to her assistance. Instinctively, Marg knew something was seriously wrong. Immediately, she went into a shut down mode. They

helped her into her apartment, and offered to take her to the hospital. Marg thanked them for their assistance but turned down their offer to drive her to the hospital. She then hobbled down the hall to her bathroom and proceeded to search for her razor and shave her leg. As she recalled:

Honest to God, honest to God, I shaved my leg. Here I am, my knee is all . . . bleeding and all that, and I didn't clean it I just shaved it. I knew that I was going to the hospital, I knew that I was going to have a cast on and . . . and so I needed to shave my leg.

After her leg was neatly shaved, Marg called a friend to take her to the hospital.

The emergency room was packed, it had been a very icy weekend and she was the twenty-third ice victim. The doctor who saw Marg presented with an attitude, like 'why are you bothering me, can't you see I'm busy, you only fell and scraped your knee, stop whining.' He told her he did not think anything serious was wrong, but to weigh on the side of caution, he put her leg in an immobilizer, gave her a prescription for Tylenol #3 and told her to return to the orthopaedic clinic the next day to be checked by the surgeon. Her friend was a nurse with emergency room experience and was convinced Marg had sustained damage. And, sure enough, as soon as the orthopaedic surgeon put the x-ray on the viewing screen, he saw the break, a clean break right through the distal post. Marg had broken her patella, plus she had ligament damage. But, it was when the surgeon handed her a slip saying that she was to be off work for six to eight weeks, that things really hit her. Plus, she was to return to the clinic in three days for a re-check. The surgeon was convinced that he was going to have to perform surgery to attend to the break. All Marg could think was, 'here I go again'.

By the time family started arriving, Marg was experiencing sheer terror, thinking 'oh my God, it's happening again.' She was lying on the couch, as that was the only

place she could get somewhat settled, crying uncontrollably. Marg recalled, “family came and I just did the crying, the crying, it was absolute utter panic.” She knew her emotions were out of control, but nothing could calm her down. The first few days, the pain was unbelievable. As Marg recounted, “the pain was different from my other experience of pain . . . I had no sense of control over it. I was totally overwhelmed by it, totally.” And having been originally trained as a nurse, Marg would not deviate from the physician’s prescription, for if he prescribed one to two Tylenol #3 every three to four hours for pain, there was no way she would increase the number of pills or decrease the time interval. Instead, she suffered, for the effects of the narcotic only lasted a maximum of two hours. None of her former coping mechanisms were at her disposal. In her words, “I totally lost it in terms of any sense of control over the pain. The pain was the center of my universe. I was just consumed.” And, then the fear would come flooding in, fearing that the pain would never subside, that it would remain forever. After all, her post-op acute pain from her bi-lateral mastectomy lasted seven years.

Fortunately, by the second week, things started to improve a little. Unlike her experience with cancer, as soon as she saw the slightest improvement, the fight was on. She even used militaristic words to describe her situation; for example, defining her recovery process as a mission. In the beginning, she saw the doctor every other day, until he was convinced that she was not going to need surgery. Physiotherapy became a central part of Marg’s regime, beginning in the second week. This time, physiotherapy was through the hospital and it was an appropriate intervention, given her diagnosis. They worked hand in hand with Marg to return her mobility. In her opinion, they were wonderful. Marg approached her rehabilitation like a full time job, diligently attending to

every order she received. If she was told to do twenty repetitions of a particular exercise, she did twenty reps, not nineteen, nor twenty-one, but twenty. She did everything to the exact letter. The best prognosis the surgeon would give Marg was a seventy-five percent return in terms of mobility, but that she would always have some pain associated with her knee. Fear followed Marg's every step, believing that this experience with pain was going to mimic her past experiences with pain, acute pain that never went away.

Early on, however, Marg felt a difference. As soon as she noticed the first bit of improvement, hope began to grow. And, with every segment of improvement thereafter, successful completion of the mission drew closer. This time, Marg was going to do everything right, implying she had done something wrong during her cancer experience. Reflecting back, Marg had the impression that she was not a 'good enough patient' when she was ill with her malignancy. Somewhere in her cancer treatment, she received the message she was to blame. Maybe the message came from the surgeon who did her initial biopsy or the nurse that berated her crying after having a bi-lateral mastectomy and thirteen repair surgeries in less than a year. However, the message was delivered, this time she purposely was disciplined, self-motivated, even driven, towards regaining mobility and range of motion in that knee. And she did it. She exceeded the surgeon's upper prognostic limit, achieving almost complete range of motion, and for a long time she was pain free. Unfortunately, Marg's knee is more susceptible to injury and she has experienced falls that have reactivated periods of pain in her leg.

Through all of Marg's physical struggles and emotional upsets, she has remained a genuine caregiver to family and friends in times of need. She continued to make

substantive contributions to her community, both as a therapist and as an advocate for those less fortunate.

4.7 Summary:

I was both humbled and inspired as I respectfully listened to these women's stories: They have so much to tell. Their stories are a testament to their struggles, experienced oppressions and marginalized status as chronic pain sufferers. However, their stories are also a testament to their fortitude, strength and will. Six white, middle-aged women, all professionally located within the helping professions, their age range spans eighteen years, life-in-pain stretches from seven to twenty-five years, four of the six have fibromyalgia as a primary or secondary diagnosis, five of the six have applied for disability pensions (two successful), five of the six have nursing as an initial career (two – remained in nursing, two went into social work and one became a family physician), three are mothers to grown children (one would attest to being the mother of a black lab), and three are gardeners. All are women of conviction, compassion, intellectual insight and spiritual strength. As a chronic pain sufferer myself, I listened, transcribed, re-read and formulated their personal stories, all the while remaining cognizant of the privilege bestowed upon me. With each telling, I learned more about myself and my struggle. With each telling, I respected the woman with greater depth. With each telling, anger and anguish were expressed for the past injustices, and with each telling, hope and empowerment were envisioned for the future.

The next chapter will focus on narrative analysis, where the stories will be explored for their similarities and discrete nuances. Personal storytelling will be translated

into political understandings, shifting and unsettling the dominant discourses currently embedded in chronic pain assessment and treatment.

Chapter Five - Personal Testimonies

5.0 Introduction

“Many ill people find they cannot live the story, or just the story, that biomedicine tells of their illnesses; the need for a voice of one’s own is a particularity of our times” (Frank, 1997, p. 31). The sufferers in this research have used their own voice to testify to the struggles, inequities and disservice to which they have paid witness in living with chronic pain and in working with sufferers in their professional capacities. The previous chapter captured the sufferers’ personal stories of living with pain. Storytelling was used to inform the reader’s personal understanding of the sufferer’s position by inviting the reader into the sufferer’s place (Ellis & Bochner, 2000). In this chapter, their stories become more than their own stories. Through narrative analysis and critical examination, their stories become vehicles for political and social change, the distinguishing characteristics of testimonio (Beverley, 2000; Tierney, 2000).

Risoberta Menchu, an Indian woman from Guatemala, uses her story as a testimonio of her people. She states, “It’s not only my life, it’s the testimony of my people . . . My story is the story of all poor Guatemalans. My personal experience is the reality of a whole people” (Tierney, 2000, p. 540). Similarly, common experiences have been extrapolated from the sufferers’ testimonies in this research, experiences that demonstrate the marginalization of this group. Differences exist as well, demonstrating the complexities within and amongst testimonies, thus bringing to surface the multiple discourses of chronic pain.

The final analysis chapter, Chapter Six, will focus upon professional testimonies by the sufferers, highlighting case examples and related practice principles from the sufferers' knowledges and experiences in working with chronic pain sufferers within their helping roles. Testimonials in Chapter Six will be used as a form of resistance to challenge the meta-narratives in chronic pain treatment, pushing for socio-political change in service delivery.

5.1 Personal Testimonies

Each participant had a unique story to tell. Yet, commonalities rose to the forefront between each testimony, commonalities that distinguished their identity as sufferers. Lieblich, Zilber, and Tuval-Mashiach's (1998) four-cell approach has been used in this research as the model of analysis. Primary emphasis has been placed upon the two content cells, with minimal reflection upon the form cells. The focus is on the content within sufferers' stories; how the women lived and coped with chronic pain and how that knowledge translated into anti-oppressive ways of working with sufferers. In Chapter Four, the holistic-content was the main method utilized, with the holistic-form analysis appearing in the researcher's reflection on each story. Within this chapter and the next, categorical-content is the mode of analysis. The categorical-form is briefly reflected upon in Chapter Seven, surfacing ideas for future research initiatives. Details of the method of application can be found in Chapter Three: Testimonio – A Narrative Methodology.

The process followed for identifying the categorical-content segments consisted of compiling each sufferer's transcripts into one distinct file. For example, if a sufferer had participated in three interviews, all three transcripts would be put into one file

marked with her name. The transcripts were read and re-read across the files, looking for similarities in plot lines. If themes emerged, they were noted and color-coded. I then returned to the previously read files, specifically reading for the identified theme. This process was repeated each time a potential theme emerged. As well, the teleconference was used as an opportunity for the sufferers to look across their experiences and discern or validate content categories (see Agenda in Appendix F). The transcript of the teleconference was closely read and theme color-coded. Through the teleconference, sufferers were given an opportunity to reflect upon the narrative analysis, furthering the involvement of their voices in the research process. For the one sufferer who was unable to participate in the teleconference, e-mail was utilized as the means of communication, whereby she was provided a summary of the categorical themes and invited to comment. This process attended to trustworthiness, specifically defined as correspondence, according to Riessman's (2002) verification schema, where data and analysis are brought back to participants. The next step involved returning to the individual transcripts for added depth and identification of discrete nuances. Finally, the emerging themes were weighed against the dominant discourses presented in the literature, either affirming or unsettling the established ethos.

Applying Lieblich and colleagues' (1998) categorical-content analysis, four discrete areas were identified: spirit, emotion, treatment and coping. Testimonio requires the reader to respond to the text and to take action against the injustices and inequities witnessed (Beverley, 2000, Tierney, 2000). This methodology is anchored in morals, ethics and the human connection, "provoking the reader . . . to enter empathically into worlds of experience different from their own" (Ellis & Bochner, 2000, p. 748).

However, if the reader is a chronic pain sufferer or identifies as a person with a (dis)Ability, she is then challenged to reconceptualize her experiences, viewing her own story through the political nuances highlighted in the analysis.

Through inclusion of spirit and emotion categories, the readers' sensitivity, and ultimately, understanding are extended, while highlighting treatment and coping experiences exposed injustices that might not otherwise have surfaced. Each of the four categories stemming from the categorical-content analysis is explored in detail, with the addition of sub-categories where appropriate. A chart has been collated to display each participant's experience of testifying through the four-cell approach (see Appendix I).

A criticism of this approach is that it resembles victim art, whereby the narratives play on the readers' sympathies, thereby manipulating their emotional response to the text (Ellis & Bochner, 2000). The women's dedication to improving the lives of those suffering from chronic pain was most evident. They had a story to tell, a message to transcend the medical discourse. They wanted to be heard and their fear was that people would not listen. This fear originated from not having their pain experiences heard within the medical community. Marg was told her pain was "not that bad". Dawn was informed she "shouldn't be in that much pain". Helen recalled the message, "there was nothing wrong with me; I was malingering". And, Barbara felt an "undercurrent of disbelief" when she related her perception of pain. Transcending the sufferers' experiences of not being heard, the women's knowledges and perspectives on living with chronic pain were welcomed and encouraged.

5.2 Spirit

<i>Faith</i>	<i>God</i>	<i>Higher Power</i>	<i>Hope</i>
<i>Journey</i>	<i>Life and Death</i>	<i>Life Force</i>	
<i>Meaning</i>	<i>Meditation</i>	<i>Mysticism</i>	
<i>Prayer</i>	<i>Purpose</i>	<i>Will</i>	

Ideas about the human spirit filtered through the storylines; expressed in different forms, delivered in distinct fashions, but ever present as it shaped the essence of their tales. Through the repeated readings involved in the analysis, the sufferers' spirit jumped off the pages of the transcripts, the sense of the sufferers being able to somehow carry on given all their adversity. Four distinct themes emerged; one, relating to a higher spirit (sometimes referred to as 'God'); two, finding purpose and meaning; three, understanding life and death options; and four, conceptualizing the 'will'. The themes were presented to the sufferers during a teleconference. Their response is captured in the dialogue below, as they articulated both the meaning and concept of spirit as it relates to their suffering experiences.

In conversation:

Judy: The concept of spirit was related to differently by different people. Often there was a *strong work ethic* that people continued to work in various ways . . . to contribute to a greater good. I think it is partly from being women, partly from being in the helping professions, that there is an ability to not get swallowed up in our own pain, in our own story.

Barbara: It is amazing. I am in awe of myself to be honest with you, that despite all the things that I faced, that the *spirit of survival*, although there were times I wish that in fact I wouldn't, that I am and continue to [sic] survive. And even in my darkest and deepest days, I am able to somehow go out of that and I get to be happy again, to feel joy tomorrow. And that's my spirit. I don't know where it comes from; I just know that it's there. And I can see that in the story from others as well, it's pretty amazing.

Evelyn: It's a gift, it really is. I really do believe it is a gift. I call it *faith*, spirit, faith. It's something that I have always had and I thank God I have it because it has gotten me through my life, in every aspect. And I think it *makes us stronger, to go through pain, you certainly understand another's pain.*

bendy: I think it is a *mystical part* of our personality we are blessed with, and so many people that she sees and that I see and that we all see, just don't have it. And you cannot teach it or give it to other people, they just don't have it and they need more help than we do. I think there is more to this world than what we can sense or see; some people call it *faith*, some people *call it spirit, mysticism*, whatever, but it's *part of our collective being* and we are just lucky to have it.

Barbara: I call it *my purpose*.

Helen: And *we help others*. That is why I got involved with chronic pain work. It puts purpose into all of this!

Judy: We help others; it is the *reaching out beyond ourselves* that is an important piece.

Evelyn: We are definitely all in the helping professions, and we all give, and *by giving, we learn more and we get more.*

Dawn: I think there is something bigger – bigger than whether we are in the helping professions, or whether we are women, or whether we are caregivers, or whether we reach out, and even bigger than the faith piece or spirit piece that is huge, there is that, just that, *unquenchable life force in people*, in all living creatures, in my daffodils out there that have just emerged from ninety-five centimeters of snow, that no matter what, there is basically a will to survive and to strive and to somehow make it. You know, you can tap into that. When I am working with people, I call it their *healthy part*, their *strong part*, their whatever, no matter what, if you can reach that part, even if it is one percent of them on that given day, it's that part that gives you the strength to say 'I can breathe for another minute.' It's such an important piece of all of this that underpins all the other things we are labelling as faith, or giving or altruism, or whatever. There is something that keeps us going, otherwise, why would any of us stick around?

Evelyn: *The will.*

Dawn: Absolutely.

Evelyn: Victor Franklin's book 'Man's Search for Meaning'. *The will to live, the will to go on* and having that will is a big part. I have a deep faith, so I believe it is *the will from God*.

Dawn: Even people who do not describe themselves as people of faith necessarily, whether it is people of a certain religious faith or a spiritual faith, even people who don't self-identify as having that will have this inner strength that they survive and find their way through. I think it is perhaps more *highly developed in people who face adversity* of whatever kind, and survive it and maybe it is *a requirement* if you are going to be *a) a woman* and *b) a woman in the helping professions* and *c) a woman in the helping*

professions in pain. I think you have to have *a really strong survival instinct and life force* to do that.

In conversation with the women sufferers, I was able to witness the conceptualization process involved in transforming their pain into meaningful survival. The words highlighted help frame the varied discourses in association with living and surviving life with chronic pain. Finding purpose and meaning in one's life was explicitly associated with sufferers' helping roles. For example, Helen identified assisting others ("we help others . . . it puts purpose in all of this") as the motivation associated with surviving life with pain, while Evelyn reflected upon both the altruistic ("to go through pain, you certainly understand another's pain") and reciprocal ("by giving we learn more and get more") nature of the helping relationship. Life and death considerations were portrayed within two contexts, the will ("the will to live", "the will to go on"), and survival ("spirit of survival", "survival instinct"). The most detailed exploration came from Dawn, who defined survival as an "unquenchable life force" instinctively expressed by all living things. She associated the life force with an inner strength, recognizing the potential of the sufferer to tap into this resource. For Dawn, this inner strength is not based upon an external being, as in a higher power, but rather exists as a part of the sufferer. The same way one has a personality, one has a core inner strength. The skill consists of being able to tap into this strength when the pain and suffering is overwhelming. The more adversity one faces, the more crafted one becomes in navigating this skill. Overall, the sufferers' combined reflection reinforced the four categories expressed in the analysis, and included in the agenda for the teleconference (see Appendix F), were derived from their personal interviews.

Relating to a Higher Power

All sufferers except one, referred to 'God' in their testimonies. Sometimes it was a language qualifier, as in 'Thank God there is a name', or 'Oh my God, it's happening again', or 'God forbid'. Other times, as with Evelyn, it was a direct reference to praying or faith in God. For example:

I was so exhausted, the more I did, the more exhausted I became. I cried, I cried a great deal. My life was pretty much work, bathtub and bed. That's how I kept going, and a lot of prayer, a lot of prayer.

Evelyn continued to relate to her connection with God:

For me, my grasp has always been God. The church was certainly my center place to go, all my life; I have been going to mass all my life. I remember when I was four I was going, even before that I was going, because my parents always went and the high school and nursing school were Catholic and when I went to work in Quebec, it was with the nuns and then I worked at the Halifax Infirmary and it was still with nuns; I had mass every morning of my life. So I talk to God. You have to have faith, faith that it will end, that something better will happen and it does. It's still a struggle, but no, I have never asked 'why me', I never did.

Evelyn has relied on her faith in God to carry her through emotionally and physically tough times. Her story, depicted in the previous chapter, gives further examples of her connection with God, a relationship originally defined within the teachings of Catholicism, which had evolved into a personally meaningful and strength-based anchor of support. Another sufferer, Helen, commented, "I have a pretty strong faith", but did not elaborate. bendy spoke about handing one's pain off to a higher power as a source of coping:

A sense of something else other than ourselves; because that, in and of itself, may not lend meaning to chronic pain, but it may allow a person to accept or to pass off your chronic pain to some other power. We all have a spiritual being inside ourselves.

For the sufferers who defined their spirituality as a belief in 'God', prayer was an important part of their pain management (Arnstein, 2003; Jackson, 2002), for they derived strength to continue their journey, comfort in dealing with their pain and companionship in knowing they were not traveling this rough terrain alone. Arriving at a point of comfort through faith often involved a meandering process, one that began with questioning why a caring God would allow such suffering and concluded with the belief that God suffers with the sufferers (Jackson, 2002).

On the other hand, some religious beliefs suggest: a) pain is a punishment for wrong-doings, either on the part of the sufferer or the sufferer's deceased relatives (Wendell, 1996); b) pain is glorified, blessing those who suffer (Frank, 1995); or c) pain is overcome in performing religious rituals as a demonstration of faith, rituals such as hook-hanging or fire-walking, which are performed in the Middle East and Sri Lanka (Mailis-Gagnon & Israelson, 2003). bendy identified an existential purpose to her pain experiences, "I think everything happens for a reason, and the reason I buggered my knee is that I needed a come-uppance for something – I don't know. Come-uppance! Maybe life was too easy, I don't know." For the most part, the sufferers in this research explored more the concepts of 'why me' or 'why now'. Dawn demonstrated this thought process in the following statement:

You have more time to think, to work through 'why me, what is this about and why is it in my life right now? Did I bring it to me, and why, and if I didn't bring it to me, where did it come from?' All those big unanswerables you still explore. But, mostly, it's just finding ways you can find to cope.

Other connections to the religiosity of pain were not evident. Overall, the sufferers drew upon their belief systems for emotional and spiritual support as they negotiated a life with pain.

Finding Purpose and Meaning

Reid, Ewan, and Lowy (1991) identify chronic pain sufferers' pilgrimage as "a search for relief, belief and understanding" (p. 609). Exploring the meaning of one's pain is identified as the first soul searching reflection of the sufferer, with the evolution of thought towards understanding the meaning of one's life as a chronic pain sufferer. While Morris (1991) describes the relationship between meaning and pain as the "neglected encounter" (p. 3), most sufferers in this research shared aspects of their quest towards purpose and meaning in their pain journeys. The six sufferers were not new to pain experiences, for their average length of time living with pain was fifteen years. How they approached this understanding differed, four of the six associated aspects of their helping work as components of their own coping. Through experiencing chronic pain, their professional understanding and awareness grew, and thus enabled them to be more effective in helping other sufferers. Helen considered the meaning associated with her pain:

If there is a reason, I don't know, perhaps it is so I can help others who have pain. And that is what I am trying to do through NACPAC (North American Chronic Pain Association of Canada) work, through the support group work; because it really helps people with chronic pain to talk to others who have it. Our doctors are wonderful but if they don't have it, it is really hard for them to get it.

By 'get it' she means to understand what it is like living with chronic pain, the pacing, the juggling of coping mechanisms, the need for medications and so forth. bendy related a similar directive for her pain experiences:

I think every experience you have should be used to help you help others in some way. And this helps me with my patients with chronic pain, brings back memories, I don't know, but there is something good that comes out of everything. This was something unpleasant, will always be unpleasant, but it's just another thing that you deal with in life.

In bendy's statement, she links meaning to her struggles by understanding her role in helping others cope with their pain. Chronic pain is viewed simply as another journey in life's path, calling upon the sufferer to adapt. In the following quote, Dawn explored her struggle to make sense out of suffering:

Spiritual growth for me, is trying to make some sense out of suffering, in the bigger context of things, trying to figure out where your strength comes from that gives you some meaning, when most days you would rather chuck it. Those kinds of things that really you didn't have to think about a lot, you think about more when you can't get out of bed.

A cause and effect correlation was not specified, however, as they did not articulate that they believed their pain was created so that they would be empathic and knowledgeable practitioners, but rather that some helpful purpose can come out of their suffering, which in turn brings meaning to their pain experience. Rose (1994) states, "If people are to adjust to a life which includes chronic pain, they have to be able to see it as having a meaningful component; it has to become a part of life, but not the whole of life" (p. 27). Within each exploration above you can read the uncertainty, the questioning that is taking place, and searching for understanding the complexity of their pain. One might ask why they have not fixated on blaming themselves for their pain experience or turned bitter, possibly because they allow themselves to actively explore these questions, bringing the unmentionables to the surface, which then directs them to a different place. Frank (1995) would identify these explorations as quest stories, where the illness experience is met head-on and the sufferer derives something meaningful and good from her experiences of suffering. Wendell (1996) expresses this in relation to her illness:

Illness has forced me to change in ways that I am grateful for, and so, although I would joyfully accept a cure if it were offered me, I do not regret having become ill. Yet, I do not believe that I became ill because I needed to learn what illness

has taught me, nor that I will get well when I have learned everything I need to know from it. (p. 175)

In the quest to find purpose and meaning in her life with pain, Barbara ventured deeper into a personal searching process, reading and exercising self-hypnosis, meditation and intense inner spiritual work. On the other hand, Marg dealt with her experiences of pain by denying the pain's very existence and subsequently, any meaning the pain would hold. This coping mechanism will be explored in more detail under the sections on emotions and coping.

Understanding Life and Death Options

At moments when the pain is unrelenting, all encasing and pervasive, the sufferer searches for relief, only to realize that it is outside her grasp. In that moment, in that space, death feels comforting and could easily be called close and welcomed if it was to appear in the distance. Chronic pain sufferers walk that edge between wanting to live, in the fullest sense of the word, and openly welcoming death as a friend who could relieve their torment and suffering. Dawn expressed being in that location:

When you are at the most desperate state and thinking that death is a friend, of course you get to that point. I'm not sure that it is suicidal thinking in that 'I want to kill myself', I'm sure it is not that, but it is very common amongst pain people and certainly I have experienced it many times. Where it would just be so easy to float off in a haze of something and just say, 'okay, this life was a painful one, let's try another one'. Umm, I think that that is extremely common. And when I've been at my worst, I certainly can remember lying in my bed, with tears running down my face and saying, 'please take me now, this is unbearable'. And sometimes when it isn't acute, when you are really tired and really sore, life has just been too heavy that week and you say, 'what the hell'. And, it is just thinking, if life was over that would be fine. I don't think that it's depressive and I don't think that it's suicidal, although it can be, I just think it is a state of mind, where people think that things are just bad enough, that if it ended, that wouldn't be a tragedy.

Miles (1992), in her research on women and chronic pain, identifies suicidal thoughts as a subsection to negative self-worth, associated with not trusting one's self, viewing pain as punishment and experiences of depression. MacDonald (2004a), on the other hand, believes that thoughts of ending life in chronic pain are a natural cognitive expression when the pain is unrelenting and all encompassing. As depicted in the quotes by Dawn (on the adjacent page) and Barbara (below), the intent is not active engagement in taking one's own life, but rather the thoughts of passive submission to death, changing the norm of viewing death as an enemy to welcoming death as a friend. Hitchcock, Ferrell and McCaffery (1994) found that fifty percent of their research participants considered suicide because of chronic pain. Rosenfeld (2003) writes, "severe chronic pain is a state of bondage so total and so hard for non-sufferers to imagine that they simply cannot understand why those in pain would sometimes rather die than continue living without relief" (p. 1).

Sufferers were unconstrained in their intimate portrayal of life and death thought processes, as they willingly shared their personal experiences. Barbara commented on the relation of pain to death:

You say, 'I'm not doing this anymore'. And it is not, it is not necessarily thoughts of suicide, but you get pretty damn close, you know, like how many times do you have to wish that if you fell asleep, that you would wake up and it would all be a bad nightmare, or that you wouldn't wake up. And then you start feeling guilty because what about the children, what about this and what about that? They all suffer too when you are suffering.

Similar to Barbara, Helen identified her children, and husband, as being the motive that kept her from giving up:

There were times in my life that it was so bad that I thought, 'I can't live with this, somebody had to do something.' Yet, I have lived with it, I am still here. It is amazing. Well, I guess I thought I wasn't going to stop. It wasn't going to take

me out. [But] there were times that I thought, 'if this doesn't stop, I wish it would take me out'. I have a pretty strong faith, and I guess it wasn't my time. What kept me going? Well, I had children and a husband and meaning. That is probably what kept me going.

Helen cited family support, meaning in her life and having a strong faith as reasons why she kept trying to deal with her pain, instead of giving up on herself and her life.

Conceptualizing the 'Will'

Sufferers express their spiritual selves in different ways, but what was common among all the women who participated in this research was their ability to re-conceptualize hope, to turn a grave situation – living with chronic pain – into something meaningful and hopeful. And to have gratitude for those who helped them along their journey. bendy is a prime example of someone being able to look at the positive things that came out of an accident that destroyed over two-thirds of her knee. She could have become stuck in despair, grieving the mid-distance running which she truly loved, but instead, she reflected upon her blessings, the opportunities presented to her through her pain and suffering. bendy shared the following:

I feel extremely fortunate that I can walk. I have said to my surgeon, 'I don't know how you thank someone who has returned the gift of walking. I don't know how you do that'. Many good things have come out of this; I got to know my sister again, I'm not working full-time, I got to reconnect with my mother, because prior to this knee, working, working, working, that's all I did.

bendy had stayed with her sister and her family during her recovery and now recounts every moment as a gift of friendship, family, laughter and memories. She also had the opportunity to spend every Saturday morning with her mother, who has since died.

Dawn believed that spirit differentiates between those who survive and those who succumb.

Certainly spirit has so much to do with surviving versus succumbing. I think knowledge has a lot to do with it. Having the temperament to do something, as opposed to being a complete victim, having enough courage to keep fighting for help. Having support of someone around you from somewhere that says this is not your fault, isn't this terrible, but you can do the best you can. You still make a difference somehow. You look for those little moments of joy, and if you don't have the capacity to find those little moments of joy, because of your temperament, because of your life experiences, because of your intellect, because of whatever, if you don't have that capacity, I think you would succumb.

Evelyn recounted her experiences with pain and the ultimate will that would not let her give up on herself.

But I did get up and get going. I didn't give into the pain. But at the time I didn't know if I was going to be able to. The exhaustion too, it was all of that and more. I got on my feet; I always got on my feet. I don't know how, the reason why I have, but I did. I think it is sheer will, and three children, I couldn't give up. Not that I didn't think about it, where am I going, what am I doing? But then you think about the children. I didn't think much about myself, but more about the children.

Barbara, Helen and Evelyn all shared experiences of their children motivating them to keep going when their pain would present as overwhelming. But all six women were able to look beyond their own situations to see themselves as members of a larger group and therefore, had responsibility to that group to keep going. The concept of the will may, in part, refer to meaningful relationships, where the bond to others overshadows the sufferer's individualistic needs. Arnstein (2003) and Brown and Williams (1995) both identify meaningful, purposeful relations as an important coping factor for chronic pain sufferers.

Spiritual Discourse

All sufferers in this research displayed strength of spirit, some deriving more support for traditional religious practices, as in praying to God, while others were journeying with their pain towards greater understanding, defining meaning and purpose

within the context of their lives. Arnstein (2003) equates the disease process with destroying the body, while the pain itself erodes the soul, suggesting that pain is so potentially powerful that it can not only shake the base of a sufferer's beliefs, values and purpose, but literally crumble the spiritual foundation. The sufferers in this research did not crumble under their experiences of pain. They struggled. They questioned the meaning of their lives in pain; they even contemplated life and death options. Anderson (2000) shares her story of living with the chronic illness of scleroderma, where for years she had to be fed by a feeding tube and therefore, was highly susceptible to infections. On one occasion, the infection raged, sending her temperature to one hundred and seven degrees. The medical team rushed her to CAT-scan, in an attempt to locate the abscess through magnetic imaging. Anderson (2000) recalls:

At that moment, I knew with absolute clarity that all I had to do was to relax and let go and I would be at peace. But I knew with equal clarity that I did not want to die then, and I fought against that feeling that was so attractive. (p. 38)

This near death experience actually alleviated her fear of death.

MacDonald (2004a) viewed death as “a comfort and friend” (p. 30) when trying to cope with chronic pain within the oppressive structure of a chronic pain program. Upon reflection, she identified this cognitive manoeuvre as a method to gain control in an uncontrollable environment. Dawn framed the debate between life and death as a personal negotiation, as she stated, “If I am not feeling better tomorrow or next week, or next month, then it's an option.” When chronic pain leaves one feeling hopeless and out of control, contemplating life and death options poses as a creative solution to re-establishing a sense of personal power. Interestingly, when the opportunity has arisen, sufferers recounted fighting for their lives, as in Anderson's experience. Sufferers did

not testify to suicidal attempts. The possibility exists that the sufferers might have been guarded with their comments pertaining to suicidal ideation, as my consent protocol (see Appendix A) identifies my duty to report self-harm. However, given the depth of sharing between sufferers and myself and my use of self-disclosure as a chronic pain sufferer, I believe they were genuine and forthcoming in telling their stories.

When Barbara thought, “I’m not doing this anymore” or Dawn reflected, “the pills are there and God knows the need to escape is there” or Helen recapped, “it was so bad that I thought I can’t live with this”, were times when the sufferers’ pain was raging out of control and they were fraught with exhaustion. Thoughts of ultimate relief through death need to be explored as potential cognitive coping strategies for sufferers when their day- to-day coping mechanisms fail under the duress of severe persistent pain.

Understanding suicidal thought from this particular lens challenges the pathologizing of pain within psychogenic classifications. For example, Dworkin and Caligor’s (1988) finding that sixteen to fifty-three per cent of the chronic pain population suffer from somatoform disorders; or, Katon, Egan, and Miller’s (1985) report that nearly one-third of their chronic pain sample merited a diagnosis of psychogenic pain disorder. Sufferers’ physical pain has been so intense that they have contemplated the relief they would receive through death, yet none testified to suicidal attempts, demonstrating their psychological and spiritual strength. Simply asking if a chronic pain sufferer has ever considered suicide is insufficient wording to understand risk potential, for, within the context of their experiences, thoughts of relief through death can be expected.

Spiritual strength is derived from “making peace with the past, being spiritually aware in the present, and making a commitment to go forward with life despite the pain”

(Arnstein, 2003, p. 412). Yet, getting to this location and expressing this commitment has various pathways and could be dependent upon the sufferer's severity of pain within any given moment.

5.3 Emotions

*Abandoned Alone Afraid Anguish Angry Appreciative Dehumanized
Demoralized Denial Depressed Desperate Devastated Distressed Driven
Doubtful Embarrassed Exhausted Empty Fearful Fortunate Frustrated
Grateful Grief Stricken Guilty Happy Helpless Hopeful Hopeless Humoured
Meaningful Overcome Overwhelmed Panicked Relieved Resentful Resigned
Saddened Scared Self-pitied Shamed Spirited Spiteful Stoic
Stressed Terrorized Thankful Tired Trapped Unhappy Upheaval
Vulnerable Wearied Withdrawn Worn Worried*

Pain is an emotional journey as much as it is a physical entity (Craig, 1999; Loeser, Seres, & Newman, 1990; Mailis-Gagnon & Israelson, 2003; S. Murray, 1997). This list of emotions was compiled from the interviews with the sufferers and presented to them during the teleconference for verification and discussion. Relating to the emotional descriptors above, Evelyn noted, "I can identify with each one". The emotions are intimately connected to the sufferers' struggles in living with pain and their appreciation for the supports and pain controlling mechanisms that greatly add to the quality of their lives. Emotions connected to strife and struggles are depicted above, along with emotions associated with hope and gratitude. Contrary to Fordyce (1990) and Roy's (1988, 1992, 2001) position that sufferers overstate their pain to family, sufferers in this research tried to protect loved ones from their pain by shielding their emotional responses. Barbara tried to protect her daughter from her pain invoked emotions, as she stated, "She was taking care of Mom and putting her young life on hold . . . I do find

myself hiding things from her . . . putting on my front.” bendy confided, “I had a lot of pain, but I’m not one that will . . . talk about it.” And Helen identified similar experiences related to her husband, “There were times when I think I should protect him from it and I have tried to do that, but he sees through me.”

Other times, sufferers evade the emotional side of pain as a defence against the medical system’s classification of chronic pain into psychological categories. Loeser, Seres and Newman (1990) state, “Most chronic pain patients reject the notion that there is anything psychologically wrong with them and fear that their problems will be defined as psychological in origin” (p. 2116). Barbara commented on her general practitioner’s view, “he was thinking that everything was psychological”, but she entrusted her rheumatologist with her emotional experiences, only to be left with the impression that he thought she was feeling sorry for herself. Nonetheless, all sufferers recognized the emotional struggle living with pain creates, as depicted in their descriptions below. Evelyn described her struggle with pain, both from a physical and an emotional viewpoint:

There were times when I went to get groceries and I would come home without them because I couldn’t get out of the car. I would go to bed with my clothes on, because I didn’t have the energy to take them off. So going for groceries was pure hell. I couldn’t do anything, couldn’t do the dishes, I couldn’t do anything. I felt desperate.

This was at a particularly difficult time when Evelyn was in a flare-up with her rheumatoid arthritis. Her medication was causing her blood levels to drop, resulting in low haemoglobin and platelet counts, which created a drain on her energy. Evelyn went on to describe the physical and emotional interconnection:

Pain comes, then stress, it affects the whole immune system; it affects everything that is connected within us. With chronic stress and chronic pain and never knowing if I would be able to get out of bed and walk again, was overload on my system. But I kept pushing myself to do more anyway. It never seemed as if it would end and depression sets in. It brings you down, the depression sets in again.

Evelyn's shared experience challenges the behavioural approach to chronic pain, where the primary focus is upon eliminating sick-role behaviour (Bonica, 1990; Fordyce, 1990). In Evelyn's experience, the pain and immobility came first, thus creating reactions of depression and anxiety, particularly when relief was not in sight. Specialists confuse the issue when exaggerated emphasis is placed upon treating the emotional effects without addressing the pain (Campbell, 1996; Long, 1996). Mailis-Gagnon and Israelson (2003) state, "There is no linear relationship between chronic pain and a particular personality. Chronic pain may provoke personality changes, create negative emotions and alter behaviour" (p. 10).

Barbara struggled for years without a full diagnosis. She had a partial diagnosis of fibromyalgia but was receiving little help with pain management. Desperately, she tried to find out what was happening to her. During our first interview, she shared the following:

I was wondering if there was any way possible that what I was experiencing was related to any kind of mental illness. I was at the bottom and I was dipping even lower. At the same time, I was holding onto hope that maybe this was it and again I would be diagnosed. I didn't have a diagnosis and I was at the end.

Difficulty arises when medicine and other helping professions doubt the physical origins of the sufferer's pain (MacDonald, 2000). Evelyn questioned the authenticity of her own experience, as she noted, "I was beginning to think I was making this up, I'm not in pain,

of course I can do this, I can do that, and I was collapsing.” Rosenfeld (2003) believes, “as the science and technology of medicine evolve, conditions that were previously dismissed are suddenly revealed to be genuine, and the organic basis for seemingly undocumentable pain is often discovered” (p. 287).

The above exploration primarily deals with the relationship between pain and emotions, as the sufferers in this research have identified various emotional consequences of living with chronic pain. The next section delves into aspects of emotional expression. Through the narrative analysis, two main emotions emerged as being significant in the sufferers’ testimonies, those being sense of loss and fears.

Sense of Loss

One of the most profound statements about the impact of chronic pain is found in Seers and Friedli’s (1996) research, where one of their participants commented, “pain takes your personality away” (p. 1164). Other participants in their study commented along similar lines, “I’m not me anymore” and “I am a much reduced person because of the pain” (p. 1164). Sufferers also make specific comments about aspects of their lives they have lost due to their chronic pain. “One woman indicated her frustration at being physically unable to pick up her grandchildren” and others “missed what could be seen by many to be very mundane activities, such as cooking, cleaning” (Brown & Williams, 1995, p. 699). Dawn articulated with clarity the association between chronic pain and loss, “you lose so much, there is so much you grieve with chronic pain.”

The following table (Table 5.1) compiles the sufferers’ losses. Specifics associated with these losses can be found through the finding chapters, Chapters Four

through Six. All sufferers testified to numerous losses within their lives attributed to chronic pain. For example, they had to make work adjustments to accommodate their pain, or had to retire, or had to switch from full-time work to part-time hours, and all had periods where they were physically unable to work. Given the work adaptations, sufferers experienced financial consequences. The cumulative effect of the listed losses could be overwhelming. Adaptation, coping and re-adjustment are skills needed to navigate these emotional experiences. As illustrated through Evelyn's testimony, for if she had received adequate accommodations for her (dis)Ability at work, she might have been able to continue working until her natural retirement at age sixty-five. Likewise, if alternative therapies were part of our health care system, sufferers would not have to pay the inordinate costs and their financial losses would be reduced.

Table 5.1: Losses: As a component of their emotional selves, sufferers expressed numerous losses that chronic pain has produced. They included:

Loss:	Specifics:
Financial	Treatment costs (one sufferer spent \$6,000 per year for three years on alternative interventions – with no long term results); reduced work hours; disability pensions
Avocational Activities/ Recreational	Running, hiking, walking through the woods Gardening – can't bend or kneel Painting – on-location changed to areas near home; can only paint for short periods Traveling – unable to sit for long periods, jarring of car increases pain
Relationships	Some friends withdraw because they find it difficult to be around someone in pain, or lack understanding when plans need to be changed because the sufferer is having a painful day

Parenting Style	Parentified child – older children have to help care for younger siblings when the parent is having a pain-filled day; parenting happens from a bedside; limited ability to participate in children's activities
Spontaneity	With travel, recreational activities, socializing, parenting and intimate relations: have to plan ahead, yet be flexible within those plans for changing physical condition
Work	Former ways of working often have to be modified: cut back hours, work part-time, redefine types of work, retire or go on disability pension. Secondary loss – loss of work relationships and loss of faith in own profession
Identity	One's identity is often redefined: formerly a runner – now a walker; been a helper – now helped

Two subcategories emerged from the sufferers' portrayal of their sense of loss, loss of relationships (counterbalanced by close supports) and loss of control (counterbalanced by re-balancing). The counterbalanced elements are indicators of the sufferers' abilities to adjust, whereby they have been able to acknowledge the loss, work through the related grief and reinvest in coping strategies. This process aligns with the stages of grief work (Worden, 2002). Each subcategory will be explored within the context of the sufferers' experiences.

i) Loss of Relationships: Counterbalanced by Close Supports

Four of the six sufferers specifically identified relationship losses. Seers and Friedli (1996) classify relationships with family and friends as one of the main themes emerging from their interviews with seventy-five non-malignant chronic pain patients. Specifically, Seers and Friedli's participants acknowledged that their friends stopped

calling, families were unwilling to discuss their pain, and overall, they were left with feelings of isolation. Rose (1994) identifies the overwhelming nature of the pain building isolation and creating relationship loss. "One woman stated that 'even talking to my husband sometimes seems, well, too big an effort'" (p. 26). Both researchers extended the connection from relationship losses to fractured social lives (Rose, 1994; Seers & Friedli, 1996).

Similar trends of relationship losses were identified by sufferers in this research. Barbara shared her experience with trying to juggle friendship commitments and health needs:

What social life? You don't have anything left, you don't have anything left in the evenings and you don't have anything left on the weekends for your friends. So, out of ten friends you might have eight left . . . let's say of the now eight friendships, there are five who will now call you or include you . . . and say 'how would you like to go for coffee'. And you say, 'yes I'd love to', because you have every intention. So what do you do? You do as little as possible all day so that you will be rested up for the evening and about four o'clock you are exhausted, not able to move around. So you make that dreaded call.

Barbara's partner at the time would often stay at parties after she had to leave. Barbara felt this heightened her isolation and disconnect from her partner and social group, in her own words, "he was only getting started". He was emotionally abusive to Barbara, making fun of her medication-induced weight gain. As she recalled, "he would say things like, 'you are either like a grandma, because you can't even move or you are a fat cow'. He called me a fat cow a number of times." Barbara eventually asked this partner to leave their home, as she came to realize that his self-involved and abusive demeanour was not supportive of her health and emotional needs.

Barbara had responsibilities as a parent and primarily as a single parent, given the lack of support from her partner at the time. Barbara's oldest child has developmental and physical (dis)Abilities, which require additional parental involvement in his care. At times, when Barbara's pain would be exacerbated, she would need to rely upon her daughter to assist with her son's care. In her opinion, her daughter's childhood was cut short because of Barbara's health situation. Barbara expressed her frustration, "I am angry that our relationship, our mother-daughter relationship, although very close, is defined in part by chronic pain." She grieved her daughter's loss of a carefree childhood and in part, struggled with her own guilt in perpetuating this situation.

Dawn explored her own frustration with having to convince friends that her pain is genuinely (dis)Abling and that she cannot always be available when they are free:

Chronic pain definitely affects your relationships, it affects your friendships, people don't get it, and they expect you to be available when they are available. Most of my friends are professional people as well, as their time is limited, so when they manage to find some free time, because I am not married and don't have children, they think that I should be free. And whether or not I am free is irregardless, who cares. If I can't move that day, I can't move. So, friends really have a hard time with it and you whittle down to the people you really look forward to, the people who would come at four o'clock in the morning if you can't get out of bed or if you are trapped in the bathtub.

The sufferers in this research knew or learned how to identify genuinely supportive friends and partnerships, and each had their own solid support system that helped them navigate through their life with pain. Helen, in telling her pain story in four different contexts (in this research, on the radio, in a public presentation and during a national conference), each time pointedly mentioned how supportive and caring her husband had been. Evelyn had a network of women friends who offered emotional and spiritual support to each other, sometimes in the structure of healing circles. Marg had a

close-knit extended family and wonderfully supportive colleagues, whose friendships extended outside the office. bendy had longstanding connections with her swim mates and former running group, a large extended family, along with an unbreakable bond with her office nurse, who she referred to as 'boss'. For the most part, they were able to differentiate between healthy and supportive relationships and non-supportive, potentially destructive ones. The sufferers experienced relationship losses; some lost friends, others lost intimate partners, but through renegotiating their relationships (letting go of those who were not accepting of their chronic pain status and the impact it had upon their lives), they were able to care and be cared for by people who were able to accept their (dis)Abilities. Fundamentally, it was important for the sufferers to recognize their unhealthy relationships and if positive change was not possible to grieve their loss. Through actively grieving their losses, room was made for new healthy relationships (Worden, 2002).

ii) Loss of Control: Counterbalanced by Re-balancing

The loss of control, or the misperceptions associated with being in control of one's pain, often haunts sufferers. Loss of control can result from uncontrolled pain and the sufferer's inability to be in charge of their body, or it can be associated with the effects of chronic pain, for example, the loss of employment. The misperception of being in control relates to messages received from helping professionals that sufferers should be able to control their pain. According to Wendell (1996), "as long as the goal is to control the body, there is great potential in all healing practices for blaming the victims and for discarding or ignoring all those whose bodies are out of control" (p. 98). Dawn related the message she received from a specialist, "The message was clear, that you are

defective and if you would just smarten up, you could control it.” Evelyn’s been able to use her own experiences with the emotional side of pain to help people she has worked with as a psychiatric nurse. “It’s knowing the fear, the doubt, the depression, the sadness, the despair, the pain, the disability, and the emptiness and having no control of a situation. Control, the loss of control was a big issue”. Sufferers have shared many points where they have felt a loss of control. Not being able to control the pain or emotional responses at times of greatest vulnerability have certainly weighed heavy.

Loss of control can also be associated with loss of hope. Throughout the sufferers’ stories, despair was felt; times when an intervention was supposed to relieve their suffering and it failed, or times when hints of relief did not materialize into sustained relief, or through the compounded effects of chronic pain (such as unemployment, relationship losses, et cetera). Through these experiences, the sufferers felt control slipping through their fingers. Helen shared how she felt when she came out of a specialist appointment: “I came out feeling like not only was my bucket empty, but it had a hole in the bottom. There was no hope left; he was my last hope and it was gone”. Dawn spoke to her frustration of not being able to control her time or activities: “it’s just that limitation of not being able to do the things you want to do, when you want to do it. It’s huge!” Chronic pain takes one’s energy away, it takes longer to do the routine activities of daily living and managing the pain itself takes time, all of which deplete the sufferer of energy and consume what would have been defined as spare time. Marg related to the energy drain, “the biggest impact was that whole energy thing, not being able to do what I wanted to do, not being able to function the way I wanted to function.”

Living with chronic pain involves a process of redefining hope and staying hopeful gives one an essence of control. The sufferers in this research continually sought alternative interventions, looking for a glimmer of hope in pain relief. Some interventions proved to be problematic, as in Dawn's transverse technique of acupuncture that put her in a total body flare. But for the most part, problem solving through envisioning alternate paths provided a spark of hope and reason for sufferers to continue their journey towards pain control. The sufferers were involved in a re-balancing process, where they reflected upon elements of their lives that had to be altered to accommodate their pain. Their coping abilities helped them redefine aspects of their lives. For example, bendy could no longer run, so she swam and walked. Helen could no longer work in the profession she trained for and loved, but she dedicated a tremendous amount of time to advocating for chronic pain sufferers and bringing chronic pain awareness to society. Evelyn had to leave her job, a job in which she was highly respected, but she filled her time with promoting chronic pain awareness, involvement in women's healing networks and spiritually anchoring herself in her gardening. All the sufferers recognized their losses, grieved them for a short time and moved on to reinvest in alternate ways of doing things. At moments of great vulnerability, those losses most likely resurfaced, reactivating the cycle of loss, grieving and reinvestment (Worden, 2002). Being able to re-balance one's life might signify the difference between succumbing and surviving life with chronic pain.

In a mode of survival, the sufferers found ways to work through their losses. Through active grief work, they engaged with the process of letting go and adjusted their lives to accommodate their pain experiences. An ongoing progression, the act of

modifying is continual, drawing on creativity, support, determination and will. This process calls for societal recognition of the rights of sufferers to receive accommodations (Hanes, 2002; Leslie, Leslie, & Murphy, 2003). Accommodations such as physical alterations to a work environment or access to flexible working hours; or financial accommodation through expedited application to disability pensions; or mobility associated physically accessible public buildings and public transit; or community based recreational and leisure programs designed for chronic pain sufferers. Numerous forms of accommodations exist. The beginning step is an attitudinal shift in recognizing the rights of the sufferers to receive accommodations, for sufferers living with chronic pain can experience multiple (dis)Abilities.

Fears

Along with a sense of loss, fear was a prevalent emotion for the participants. Fear is defined as “an unpleasant emotion caused by exposure to danger, expectation of pain,” (Barber, 1998, p. 506) whereas chronic pain is defined as persistent pain that extends beyond the expected duration of an illness or injury, usually exceeding three to six months (Jovey, 2002). The relationship between chronic pain and fear is both understandable and predictable. Craig (1999) identifies anger, fear and sadness as common emotional responses from chronic pain sufferers. Yet, Ahern (2002) focuses prominently on anxiety and fear as creating psychological and behavioural disturbances in sufferers, whereby pain related fear is believed to emerge from a catastrophizing pain sufferer. Craig normalizes emotional reactions to chronic pain, while Ahern classifies emotional components of chronic pain as psychological pathology. Caution must be

exercised not to over emphasize sufferers' fears or anxieties, for the sufferers' fears depicted below seem proportionate to their pain experiences.

Two sub-categories of fear (see Table 5.2, p. 207) emerged within the analysis, the fear of immobility and dependency (counterbalanced by determination to keep going) and the fear of uncontrollable pain (counterbalanced by coping mechanisms).

i) Immobility & Dependency: Counterbalanced by Determination to Keep Going

Dawn has chronic back pain, which has on a few occasions, left her totally immobilized, unable to move, confined to bed and subsequently, relying on a relative to attend to her physical needs. She described her worst fear:

That totally, totally scary place, which for me is my greatest fear, is being unable to look after myself, getting to the point of physical dependence, umm, on anybody or anything. Having been there, those few places, when you can't get up to go to the bathroom or you couldn't turn over in bed, that just, that to me is desperation, that is worse than the pain, that immobility is worse than the pain, that total, complete fear that someday, someone will have to be getting me out of bed to go to the bathroom, that's a big scare.

Dawn described this as a 'desperate feeling', as it fills her mind with numerous questions. She asked, "who would look after me, what would I ever do, how could I cope, how could I function?" Evelyn, when diagnosed with systemic rheumatoid arthritis, was instructed by the specialist to stop paid work and housework, to literally do nothing until the flare-up settled. She did not comply, partly because she was a single parent and the sole person responsible for her children, and partly because she was afraid if she stopped moving she would never get moving again and ultimately end up in a wheelchair. Evelyn shared her determination and rationale:

Fear, I never wanted to end up in a wheelchair. I knew, I kept moving no matter how much pain, yes, I was doing damage to the joints, so I was told, but on the other hand, I was moving and I knew movement was good for the joints, was good for the body. I was so exhausted, the more I did, the more exhausted I became. I cried, I cried a great deal but I couldn't give up, I had to keep going.

bendy's greatest fear was associated with her loss. She was a mid-distance runner, who received a euphoric high from endorphin release. Life was to run. Due to her accident, she could no longer run; in fact, she was fortunate to be able to walk.

bendy expressed her losses and subsequent fear as follows:

My specific losses are all the avocational losses. I don't expect to be free of chronic pain, and that doesn't bother me, and I don't know why. I don't know what it would take for me to despair. Humm, I should back that up a bit, for me, to despair would be for me to be immobile. I would be in such severe mental pain that I would despair.

bendy spent four months of her recovery in a wheelchair, every moment determined that she was going to walk again, for to not be able to walk would truly be an emotional and spiritual challenge for her. bendy herself commented on her reaction to people who utilize wheelchairs:

I also know myself to know that I don't think, I don't truly think I could live my life in a wheelchair. I truly don't think I could do that! And, people who do . . . always have my admiration, they have far more than my admiration, I don't know what to call it, the respect, the fortitude, the courage of those people is phenomenal.

When one considers the sufferer's fear within the context of their holistic-content testimony, their fear is rationally based. For example, Dawn's fear was dependency, worrying how she would make out if she became immobile for an extended period of time. Given that Dawn lives alone, except for her beloved dog Colton, has no immediate family (a cousin being her closest relative), coupled with the fact that she has experienced

times when she literally could not get up from her sitting or lying position, her fear appears situational and historically rational.

ii) Uncontrollable Pain: Counterbalanced by Coping Mechanisms

Other sufferers identified fear, even terror, associated with the return of their pain or prior health condition. Marg, who had suffered through cancer pain with multiple surgeries and hot spots (the beginnings of cancer that had moved to other locations) pressing on nerves, relates her reaction when she received a note from the doctor indicating that she would need to be off work for six to eight weeks due to a broken patella: “that struck terror in me. I thought ‘oh my God, it’s happening again’. That is when . . . family came and I just did the crying, the crying, it was absolute utter panic.” Marg explained that this pain was different from her cancer pain, for with her cancer she was able to cognitively control the pain. She elaborated on her pain experience:

I can remember lying on my pillow, just going out of my skin because of the pain. And that pain, different from my other experience of pain, I had no, I had no sense of control over. I was totally overwhelmed by it, totally! I totally lost it, in terms of any sense of control over the pain. The pain was the center of my universe; I was just consumed. And then the fear, the fear that it was going to be like this forever. Fortunately, it wasn’t, and fortunately, like after that first week, it improved. This was another acute pain experience and my previous experience with acute pain lasted for seven or eight years.

Marg, who had so effectively used mind control to block her cancer pain, was not able to muster up any sense of control over this non-malignant pain. Thankfully, the intensity of her experience was not long lasting, but for the week while it was so acute, the emotional panic she endured was as great a stress as the physical pain.

Dawn has a different perception of plus ten pain (pain scale: one being least pain, ten being worst pain), for her having survived an experience of extreme pain dissipates the fear of her pain escalating to that point and imagining her inability to cope. Dawn articulated her thoughts on this issue:

One thing that has been good about going to plus 10 is that I know that I can survive that because I did. If I was in plus 10 everyday I don't know how you would survive that. I don't fear so much going back to that because I know that I can handle it.

Sufferers' experiences could greatly impact upon their view of returning to uncontrolled pain. MacDonald (2004a) wrote about living with extreme pain caused by Reflex Sympathetic Dystrophy (RSD) over a period of eight years. At the end of her narrative she wrote, "Still, tucked away in the corner of my soul is the fear that the RSD might someday come out of remission, returning to the horror of this crippling pain" (p. 31). Pain is etched in sufferers' memories. What becomes of those memories determines the success of one's ability to cope, for if the sufferer is absorbed with their pain memories, they could become hyper vigilant to every pain sensation or indicator (for example, Dawn's dependency or bendy's immobility) associated with their memory (Frank, 1995; Wendell, 1996).

The sufferers in this research shared numerous fears associated with living with chronic pain. The table below describes some of those fears in more detail, thus helping the reader understand the intensity of the pain experiences.

Table 5.2: Fears: Sufferers spoke about their inner fears as they struggled to deal with a life in pain. Fears such as:

Fears:	Description:
Immobility	Not being able to get out of bed, or move around independently. Having to rely on walking aids, canes, walkers, wheelchair
Dependency	Needing to rely upon another for basic needs, such as personal care, meals, finances, and so forth
Uncontrollable Pain	Pain would reach ten out of ten on pain scale and not rescind; pain medications would no longer be effective
Loneliness	In two ways; alone in pain experience – others don't understand what sufferer is going through; and, literally alone, people withdraw their support because it's too difficult being around someone in pain
Overall sense of being frightened	Fearful of pain, pain treatments, lack of treatment options, sufferer's own reactions to pain
Disability	Feared inabilities – not being able to participate in life as one once did; be it work, recreation, relationships
Medical mismanagement	Getting the label 'nyd' not-yet-diagnosed or worse 'psychogenic pain'; or having their pain discredited, not believed, displaced

A great number of their fears were based upon the extremes of their situations. For example, a sufferer coped with pain rated at a six out of ten. However, her fear was that the pain would escalate to ten and remain at that level. Another sufferer's fear was dependency, as she was a very independent person and had to totally rely on another in times of acute flare-ups. Her fear was that the situational dependency would someday turn into permanent dependency. For yet another sufferer, being physically active was her solace. After her injury, she had to redefine this important aspect of herself into realistic endeavours. Her deep-seated fear was to become immobile.

Sufferers need to identify the fears associated with their chronic pain. Once fears have been discovered, they can work towards dispelling the fears by sketching out potential solutions. Ultimately, having a contingency plan to address their worst fear will dissipate the intensity of the fear.

Emotional Discourse

The binary split between the emotional and physical experiences of chronic pain is a false divide; sufferers are holistic, they are not compartmentalized into their diseased entities (Mailis-Gagnon & Israelson, 2003; T.J. Murray, 1997; Wendell, 1996).

MacDonald (2000) postulates, "Difficulty surfaces . . . when physical cause cannot be located in a medical diagnosis, and there is a subsequent reversion to . . . the psychological explanation of chronic pain" (p. 53). Medical intervention needs to shift away from this divisive approach towards a more integrated understanding of pain.

Because sufferers have not been believed (Bendelow & Williams, 1996; Reid, Ewan, & Lowy, 1991; Seers & Friedli, 1996), and because there has been an over emphasis on

psychological variables at the exclusion of physical experiences, especially for those with undefined etiology (MacDonald, 2000, 2004a; Seers & Friedli, 1996), sufferers have responded by denying or downplaying the emotional impact chronic pain has upon their lives (Loeser, Seres, & Newman, 1990).

The sufferers in this research believed that pain is both a physical and an emotional experience, with their testimonies serving as witness to the emotional struggles embedded in navigating a life in pain. The debate is whether emotional experiences are the “causes or consequences of pain” (Craig, 1999, p. 335). Gamsa and Vikis-Freibergs’s (1991) research supports the premise that pain causes emotional reactions in sufferers. In a tone of frustration, Helen explained to a psychiatrist: “I wasn’t depressed before I had that pain, and if you get rid of it, I won’t be depressed anymore.” He had diagnosed her pain as secondary to her depression, as she struggled to explain that the pain was the primary source of ailment. Barbara related her physician’s position: “My GP was convinced, is convinced that, in fact, I suffer from depression and it is the depression that causes the fibromyalgia.” This was after she had gone for psychiatric testing for depression at the request of her physician, only to be told by the testing psychiatrist, “You are no more depressed than I am. You have good days and you have bad days just like everyone else and, besides that, you have excellent coping skills and coping strategies.”

The continual association of emotions to pain causation by physicians and pain specialists heightens the chance that sufferers’ pain stories will not be believed. Dr. John Sarno (interviewed in Rosenfeld, 2003), a professor of clinical rehabilitation medicine at New York University School of Medicine, adamantly states that fibromyalgia is an

epidemic of the 21st century due to doctors missing its psychosomatic origins. Four of the six sufferers in this research had fibromyalgia as a primary or secondary diagnosis. While they acknowledged the emotional effect pain had on their being, they clearly denounced the emotions as the cause of pain. Rose (1994) admits:

Gaining a first-hand account of what it was like to suffer from chronic pain made me realize how cruel it was to label chronic pain patients as having a particular personality, or to ascribe their symptoms to a psychological cause, as if the pain was their fault. (p. 27)

This linear association of emotional stress creating pain responses dates back to ancient times under the classification of hysteria (Jackson, 2002; Mailis-Gagnon & Israelson, 2003). Mailis-Gagnon and Israelson (2003) explore this historical relevance, while placing the debate within a current context.

Sigmund Freud was the first to establish a psychological language for describing how body symptoms, including pain, may be the result of unresolved conflicts and troubled emotions, which, in turn, are converted and expressed in somatic complaints. Such a notion has been frequently employed to explain chronic pain symptoms when the doctors cannot find much wrong with a person's body. However, as science progresses and as our horizons widen, some symptoms and signs previously attributed to thoughts and emotions are found to have their roots in biology. (p. 11)

Sufferers, through their testimonies, not only challenged this notion of emotional causation of physical pain, but also dealt with their emotional experiences in a problem solving fashion, for each sense of loss or fear experienced was counterbalanced with a coping strategy. For example, the loss of a relationship was counterbalanced by strengthening their supportive relationships. Likewise, their fear of immobility and dependency was counterbalanced by their determination to keep going, resulting in the recalibrating of pacing strategies. If anything, emotional strength was exhibited repeatedly throughout their stories. The debate whether emotions are the cause or

consequence of pain needs to be abandoned, while attention is drawn to the emotional impact of living with chronic pain. Wendell (1996) writes:

Why are they telling their patients that their symptoms have psychological causes, instead of telling them that they do not yet know what is wrong and they must wait and see? Psychosomatic illness was not being diagnosed on the basis of positive evidence of psychological problems; it was a *default* diagnosis for physical symptoms. Why do physicians burden their patients with self-doubt? (p. 99)

5.4 Treatment

“Go home and live with it!”

“Grin and bear it!”

“Grow up!”

“There is nothing wrong with her!”

“What do you have to cry about?”

“What you need is a sugar daddy!”

“Don’t worry, she doesn’t need anything, she just puts her light on because she thinks she is in pain, but she isn’t, she is just making it up!”

The above quotations were relayed by the sufferers as specific examples of statements they received by helping professionals (specifically physicians and nurses) while seeking treatment for chronic pain.

Brown and Williams (1995) identify medical impotence as a common theme in the stories they heard from women seeking treatment for rheumatoid arthritis. Bendelow and Williams (1996) refer to medicine as potentially both a “fountain of hope and a font of despair” (p. 1129) for the chronically ill. Rose (1994) wrote that the participants in her study felt they were not believed in respect to their pain stories, especially if the etiology was unclear. Seers and Friedli (1996) interviewed seventy-five chronic non-malignant

pain sufferers, noting that it was a common theme for sufferers to feel their pain was not believed by health professionals, specifically by general practitioners.

Sufferers in this research related similar experiences, either from their personal experience in seeking treatment for chronic pain or through observation in working with helping professionals. One sufferer recalled: "Medical doctors would come in and examine the patients, sometimes there was little communication. There really wasn't too much connection with the emotional, the spiritual or whatever." Most believed chronic pain was not understood by the majority of helping professionals. Another reflected upon pain and evidence-based practice, as she proclaimed: "There are obvious biases in medicine that, if you can't document it scientifically, it doesn't exist. Pain obviously cannot be evidence based because you cannot measure it, and that is a problem." Helping professionals can have a tremendous impact upon the sufferer. As one sufferer noted, they are brokers of hope, while another affirmed the importance of demonstrating trust and belief in the sufferer. The importance of believing the sufferer surfaced numerous times within documented research studies (Bendelow & Williams, 1995, 1996; Rose, 1994; Seers & Friedli, 1996).

Note that, within this section, the names of individual sufferers will not be identified. A collective presentation is being compiled to help safeguard the identities of participants. This section is critiquing medical and health care treatment and relaying the attitudes of helping professionals. Some of the sufferers work within these professions and have working relationships that they wish to preserve.

Impact of Professional Identity on Pain Treatment

The judgment, stigma and prejudices that chronic pain sufferers faced within the medical system were evident through the stories they told. Being in the helping professions did not fashion special privileges. As a matter of fact, it created additional barriers to empathic treatment by nurses, physicians and allied health professionals. As one sufferer expressed:

I don't doubt that my pain has been a benefit to my patients; that my patients have benefited from my pain experience, that I have been a better physician for them. However, my treatment as a pain patient has been compromised because of that. So, it has been great for my patients and lousy for me.

During the teleconference, the impact of professional identity on pain treatment was raised with the sufferers. The assumption that helping professionals, particularly physicians, would receive preferential treatment within health care was challenged by the sufferers, as they clearly stated that their professional identity was a "hindrance" to their care. One can speculate whether those providing care could not see beyond the sufferers' professional identity to regard them as sufferers needing care, or assumptions were made about the sufferers' ability to care for themselves. More research is needed in this area to explore the interconnections between professional and personal identities.

Treatment of chronic pain sufferers has, at times, lacked empathic understanding (Clements & Cummings, 1991; Seers & Friedli, 1996). Clements and Cummings (1991) identify nurses' responses to pain patients as often characterized by avoidance, with frustration stemming from helplessness and ultimately apathy. One sufferer in my study firmly believed that her own identity as a nurse made the nursing staff doubt her even more. She could hear them talking about her outside her hospital room, mocking her

requests for pain medications. MacDonald (2004a) related a similar experience with a nurse in a chronic pain program: “Her tone was one of sarcasm, over laden authority, and outright disrespect. My anger heightened when I overheard her mocking me to the head nurse. I felt totally belittled” (p. 29). Relating to another oppressive experience within the same program, MacDonald (2004a) struggled to understand the dynamics, it was “an expression of power . . . conveyed dominance, clearly establishing the hierarchical ordering of the practitioner over the patient. My education or medical work experience was not going to alter my location as a patient” (p. 28).

Rose (1994) suggested, “An unsympathetic nurse can add immeasurably to their suffering” (p. 27). The nurse sufferer in my study was frustrated with the situation and disappointed in members of her own vocation, leading her to doubt the authenticity of the nursing profession. As she testified, “I found nurses to be very difficult early on, before I had a legitimate diagnosis; they were not able to give me the benefit of the doubt that there was really something wrong with me.” This sufferer later went on to receive one of the first diagnoses for fibrocitis syndrome (later to be termed fibromyalgia). In her words, “I can’t tell you how happy I was to have a diagnosis; to come home and say ‘look at this folks, I was not making this up, this is for real!’” MacDonald (2004a) further highlights the significance of receiving a diagnosis, “relief, validation, and renewed faith in self-knowledge accompanied the diagnosis” (p. 23).

A nurse sufferer shared her experience of being berated by a nurse colleague while admitted for treatment. The nurse on duty came into her room, saw her crying and lambasted her: “Grow-up!”; “What do you have to cry about?”; “It’s not that bad!” The sufferer remembers thinking, “It’s not that bad? How much worse would you like to

make it?” In her words, “The message had such an impact, so that was it then, I would not cry and it was not that bad.” The denial of the sufferer’s experience, the total disregard for human compassion, empathy and respect, points to professional misjudgement and unethical practice.

Another sufferer shared her experience while immobile in hospital, “Very basic care was left to me and who I could con into helping me.” Her personal experience translated into professional concerns, “I worry about my patients. I think that nursing has gone from an extremely important healing profession, to an intellectual pursuit. I think it’s a reflection of how nursing views itself and maybe the stress it’s under now.” She went on to say, “I really don’t know what they are teaching or what nursing priorities are anymore. The basics are missing; to me, it says that nursing has lost its way.” This sufferer had originally been trained as a nurse.

Helping professionals’ judgmental and condescending attitudes could potentially contribute to the sufferer’s emotional vulnerability. The delicate balance involved in maintaining equilibrium between emotions, such as hope and despair, might easily be offset. Not believing sufferers’ accounts of their experiences, or responding to sufferers in a dismissive or frustrating manner, can lead to sufferers’ self-blame (Seers & Friedli, 1996).

While the focus has been on the lack of benefit or negative effects of the sufferers’ professional identity, the sufferers in this research did experience some advantages associated with their professional knowledge. Specifically, the sufferers had an up-to-date knowledge of the services available within health care or could access their resource skills to seek out such information. However, they were still subject to waitlists,

as queue jumping was not a professional courtesy. One sufferer had been classmates in medical school with the pain specialist and still could not access a quicker referral. At the time, the waitlist for this specialist was two years. Likewise, program exceptions were not made; for example, one sufferer wanted to access a local pain clinic, but was told she would have to go through the one-month psycho-social group prior to seeing a pain specialist. This sufferer teaches similar skills to what the group would be learning; yet, no exceptions would be made.

The sufferers in this research had the advantage of understanding the professional language, or knew where to seek clarification. However, the nurse and physician sufferers had the disadvantage of also being trained within the hierarchical structure of medicine. For example, nurses were taught to not question physicians' decisions (Greenhalgh, 2001), so when it came to their own care, this complicated their ability to challenge the perspectives of their physicians.

Attitudes of Physicians

Physicians are not immune from treating chronic pain sufferers with disregard, judging them as problem patients, drug seekers or malingerers (Seers & Friedli, 1996; Wendell, 1996). Relating the experience of one sufferer, "My first rheumatology disaster – on the third visit, I was basically told that I had arthritis and I had to learn to live with that, and that I was wasting her time." This sufferer has since been diagnosed by other physicians with numerous herniated discs, ankylosis spondylitis, degenerative disc disease and spinal stenosis. Another sufferer had her doctor, who was usually very caring and helpful, suggest to her one day: "Oh, what you need is a sugar daddy to get rid of all your pain." She had lived with rheumatoid arthritis for twenty-five years and was so sick

from the disease complications that her immune system became severely compromised. Her physicians were not sure she was going to survive. Yet, her pain was disregarded and diminished, while her character was called into question. The physician was probably frustrated that nothing was working, worried that her condition was failing and tried to lighten the moment with a bit of humour. For the sufferer, this comment was troublesome, as she pondered over the intended message and questioned if her physician still wanted her in his care.

Mailis-Gagnon and Israelson (2003) state, “Doctors do not fare well when it comes to managing patients with chronic pain” (p. 101). Wendell (1996) takes it from a sufferer’s perspective, asking the reader to “imagine the self-confidence and inner strength it would take to continue to believe in one’s own sanity, perceptions and judgement, when they are called into question by medical experts” (p. 125). The sufferer who received the ‘sugar daddy’ comment has not been able to discuss it openly with her physician.

In her helping capacity, one sufferer commented on her awareness of pain specialists’ disbelief of sufferers and their subsequent behaviours towards them, “they would just walk away because they couldn’t fix it.” Instead of sharing their frustrations openly with the sufferer, their actions led to the sufferer’s self-doubt, feelings of abandonment, and increased hopelessness. According to Greenhalgh (2001):

Chronically ill people go through life with a deep yearning to find a doctor who can fix what is wrong. This longing for help, along with the sadness and inner turmoil that are always part of chronic illness, leave the chronic patient emotionally vulnerable. (p. 34)

Physicians, who have been sanctioned power within our health system, need to recognize the potential impact of their words and actions upon sufferers (Greenhalgh, 2001) and be sensitive to sufferers' emotional vulnerability.

The following is a compilation of sufferers' experiences with physicians' attitudes:

She told me there wasn't anything that could be done, to go home and live with it. I remember angrily telling her that, even if all I did was go home and pray, there was something I could do about it.

They asked me a lot of different questions, all kinds of questions; whether I had been drinking, if I had a psychiatric history, if I had seen anyone, if I had ever been in an institution. Really??? I thought they were trying to put me into a stereotype. The crux of that experience was that I felt like a 'second rate citizen'.

The underlying illness wasn't hard to diagnose, having someone accept the label of chronic pain was very, very hard; to get [a physician] to (a) admit that that was the case; and, (b) recognize that it was something that needed treatment. It was called everything else; it was called stress, it was called depression, it was called burnout.

The above quotes point, at best, to medical negligence and in the worst case scenario, to judgmental attitudes of physicians. The possibility of the sufferer to find a glimmer of hope has been derailed. If the sufferers were treated with respect and approached in a genuinely caring manner, the physician might have been able to help the sufferer re-define hope in an effort towards coping with their chronic pain.

Brown and Williams (1994) found similar attitudes of physicians depicted in the stories shared by participants in their study, as the women were told to live with their conditions and/or nothing could be done with respects to treatment. Chronic pain has been vastly undertreated, creating profound experiences of suffering (Jackson, 2002; Jovey, Ennis, Gardner-Nix, Goldman, Hays, Lynch, & Moulin, 1998; Jovey, 2002).

Treatment Issues: Narcotics

Another area of concern expressed by some sufferers was the judgment towards, and lack of knowledge about the utilization of narcotics in pain management. Tylenol #3, a drug that does little to manage the experience of pain (Jovey, 2002; Mailis-Gagnon & Israelson, 2003), was the physicians' preferred drug. This drug is at the bottom of the pain ladder, just above ibuprofen and acetaminophen (Jovey, 2002). One sufferer told her story:

I was taking two Tylenol #3 every three to four hours. Getting in and out of bed wasn't as difficult. I didn't have to have my partner get me dressed, you know, I could put my own socks on, I could put my own underwear on. *Then the questions started.* Her physician asked, "Well, how often are you taking it? What I gave you, I expected it to last you three or four months." *He had prescribed 60 tablets [emphases added].*

Another sufferer related her struggle with getting pain medication prescribed:

I stayed on Celebrex (anti-inflammatory), a relatively high dose, for three years, and by the end of those three years, I had developed borderline renal failure and high blood pressure and had to come off it. My family doctor had been really uncomfortable progressing up the pain ladder of treatment, so that I spent a lot of years on Tylenol #1 and Tylenol #3. It took a long time to actually get pain control, from being in severe pain in 1997 to having some pain management in 2003.

Many reasons exist for physicians' reluctance to prescribe appropriate narcotics for chronic pain sufferers. However, after screening for an addiction history, narcotics are one of the safest drugs for the treatment of pain (Jovey, 2002). The media has focused on stories of street use of narcotics; some physicians are reluctant to prescribe opioids because of this medication abuse. One sufferer, experienced in the field, commented:

A lot of physicians assume the stance that, if I don't dish out narcotics or make it very difficult to get them, then this problem won't present itself in my practice. And because of that, a lot of people are being under-treated for chronic pain.

Sufferers know this issue from both sides of the desk, as sufferers of chronic pain themselves and as healthcare providers. This allows them insight, compassion and a degree of understanding not found elsewhere. This knowledge needs to be disseminated to other healthcare providers, so that the oppression of sufferers can be eradicated. Chronic pain specialist Mailis-Gagnon (2003) believes that medical training alone does not provide an adequate knowledge base in which to deal with the complexities of chronic pain. For chronic pain challenges helping professionals to expand beyond the traditional boundaries of their disciplines, engaging with a multi-disciplinary, multi-model way of working and understanding chronic pain. In the words of one sufferer:

It takes time to treat chronic pain. It takes time to listen to people in chronic pain and a lot of physicians don't have the interest because it's too difficult, it's exhausting, it's frustrating, and many times there are no easy answers, many times there is nothing you can do and that is very, very dissatisfying, not to be able to help someone.

Another sufferer's comment related to being a patient under the cloak of this frustration:

Appreciating that there were times when I felt like they were really wanting to help me but didn't know what to do, so, their despair became my despair; so, I was doubly despaired.

The sufferers in this research, who were all helping professionals accustomed to treating sufferers of chronic pain, might have been more prone to empathizing with their physicians pertaining to the frustrations of treatment. The complex nature of the sufferers' dual relationship, knowing both sides of the desk, needs to be deconstructed further. This dual relationship has informed practice principles, outlined in the next chapter, and it is feasible to suppose that role obligation influenced the sufferers' behaviour as patients within the system. MacDonald (2004a) identified how her

relationship with her employer, the hospital, impeded her ability to bring a complaint forward pertaining to her treatment.

As much as negligent and judgmental care is detrimental to sufferers' survival, all sufferers in this research recognized the importance and invaluable contributions of understanding physicians, nurses and allied health professionals. One sufferer commented, "I had a really super family doctor . . . she was a wonderful person and she was willing to do whatever and was very caring and dedicated." Another sufferer, in referring to her physician, said, "I am so grateful to have him, and that is why I have asked him to take three of my friends. I just think the world of him, he is so understanding." When compassion and genuine care are expressed, when the sufferer is believed, and when health professionals join with sufferers in managing their pain, hope is restored (MacDonald, 2000, 2004a; Rose, 1994; Seers & Friedli, 1996). Having health professionals championing their cause, advocating on their behalf in negotiating the medical system, can make the journey less isolating and ultimately, less painful. As one sufferer put it, "Know the people you work with: Listen to them!" Chapter Six will explore specific aspects of working with sufferers in more detail.

Disability Insurance Claims

Five of the six sufferers had experiences with disability insurance claims. They used words such as "nasty", "rude", "dismissive", "demoralizing", "dehumanizing", and "judgmental" to describe how they were treated by the investigators. They defined the application process as a "nightmare", "exhaustive", and "devastating". In total, they were dealing with four types of insurers: two of the sufferers with their own private insurers for disability insurance; one with Canada Pension Disability; one with the Workers

Compensation Board; and one with the federal government's employees insurance. One sufferer commented on the application process:

Twenty-seven page form, essays of how your condition affects your daily life, describe a traditional day and a full job description, completely extensive list of what you do with every hour of the day, every doctor you have ever seen for whatever, dates, times, places and addresses. They gave you two little lines for how does your condition affect your life – it took the best part of a week to fill out.

This sufferer was looking for part-time disability insurance so that she could cut down on the number of hours she was working. Her application was denied because she was working from her own home. In the insurance company's view, she could work full time if all she had to do was walk down the hall to go to work. They missed the pacing dimension so important to living with chronic pain, and the strain and stress that work in itself creates, let alone the cumulative impact of sitting for hours. Her reason for applying was not motivated by transportation concerns pertaining to commuting to work. She firmly believed that if her hours of work were cut down, the quality of her work would increase and she would be able to continue in the workforce much longer. Neither of these points appeared to be considered by the insurer.

Another sufferer shared her frustration with filling out the forms:

Disability was a nightmare trying to obtain it. The many forms were a nightmare. It took a long time. A long time, a lot of pain, a lot of exhaustion and there was no one to turn to. I was beginning to think I was making this up, I'm not in pain, of course I can do this, I can do that and I was collapsing. I was crawling to the bathroom, thinking I could walk, and I got up to walk and I was so weak I couldn't do it; and still having to write these stupid forms. It took me three or four months.

A disability pension benefit was finally awarded this sufferer, but not before undue stress was placed upon her in needing to justify her condition. Only days before she was

scheduled to appear in front of an appeal tribunal, she received notification that the appeal had been granted. And, this was only after a detailed letter was sent by a social worker, outlining the most specific details of her day-to-day existence, a minute-by-minute chronology of her daily activities.

Another sufferer tried to get short-term disability from her place of employment.

She recounted her frustration with the experience:

I tried to get short-term disability because of my diagnosis of fibromyalgia, it was too questionable, it's not pointable, and so I wasn't able to get short-term disability, which put real financial strain on our family. Rigid standards – I was in extreme pain, depressed because of the financial situation, tired, exhausted. Trying to get a diagnosis in order to have short-term disability was futile; it was the same old story, it was the same old stuff.

This sufferer's application took so long to process that she had returned to work part-time before the decision had been rendered. Her application had been denied. However, she had the option to appeal the decision. She was so exhausted and defeated by the experience and trying to cope with her pain, she chose to forego the appeal.

If chronic pain is “the most prevalent form of disability among the working population” (Keung, 2004, p. A19), and the insurance companies reluctantly view chronic pain as compensatory (Supreme Court of Canada, 2003), then sufferers risk dual oppression, from disability and poverty.

Treatment Discourse

Treatment of chronic pain sufferers is currently dominated by a biomedical discourse, defined within the parameters of evidence-based, scientifically founded, physiological enquiry, that embraces the medical hierarchy and belief that physician

holds access to the ‘true’ story of the sufferer’s body (Greenhalgh, 2001). Greenhalgh, as discussed in Chapter Two, views the medicalization of the body as a silencing of the sufferer’s self-knowledge and experiences. The perspective of the sufferer is often regarded as irrelevant to the medical process. “Although the patient’s knowledge might contain crucial clues to what is wrong, the discourse has made that knowledge, at best ancillary, at worst, extraneous to the process of fact creation” (Greenhalgh, 2001, p. 30).

The experiences relayed under treatment, with the exception of professional identity, not only disregard the sufferer’s story but have an underlying current of disbelieving the sufferer’s experiences of pain. Sufferers need to be believed and brought into the medical regime in a most central and meaningful way. The dominant discourse needs to be challenged, pushing for a more inclusive, all encompassing mind-body-spirit and environment understanding of the sufferer’s experiences (Rose, 1994; Seers & Friedli, 1996), anchored in collaborative work with the sufferer (MacDonald, 2000, 2004a).

5.5 Coping Strategies

<i>Determination</i>	<i>Drive</i>	<i>Emotional Release</i>	<i>Faith</i>	<i>Family</i>	<i>Friends</i>
<i>Gardening</i>	<i>Intellectualization</i>	<i>Mind Control</i>	<i>Pacing</i>	<i>Painting</i>	
<i>Pets</i>	<i>Self-Care</i>	<i>Swimming</i>	<i>Treadmill</i>	<i>Walking</i>	

MacKenzie and Wakat (1990) identify that there is no single approach to treating chronic pain. Intervention needs to be tailored to the individual sufferer. Frank (2003) suggests that pain has the potential to unmake a sufferer’s world. Through the sufferer storying her pain, she can remake her world by changing her perceptions of her pain.

Marg was able to do this with her cancer pain, cognitively controlling the pain by a process of conscious denial. Frank (2003) does not put the total responsibility upon the sufferer, for he suggests that the physician or clinician has a moral responsibility to truly listen to the sufferer's story, altering how that person is heard and, in doing so, how the physician or clinician experiences herself differently. This would suggest a relational quality to coping with pain, transforming a process that has been described by sufferers as lonely and isolating, to one based on human companionship and compassion.

Two main sub-categories related to coping strategies emerged from the narrative analysis of the transcripts and teleconference, those being personal coping and treatment modalities. The goal of verifying the categorical-content analysis associated with coping was achieved during the teleconference. However, a simultaneous sharing process also developed, whereby sufferers exchanged various coping strategies. A connecting energy was evident, as the women, talking to each other for the first time, openly shared their stories and knowledges. Aspects of their sharing related to ideas around medications, both oral and compounding topicals, emotional and mental stressors and stress-relievers and strategies for navigating through the medical system. Dawn shared her tactic for bring her family physician onboard with pain management options, "There are miraculous things happening in chronic pain research right now, and you have to be very pro-active with this stuff and actually go in and say, 'let's do this'." The five sufferers who took part in the teleconference highlighted the benefits of connecting with other chronic pain sufferers. This experience and reflection reinforce the importance of mutual support structures in coping with chronic pain (Brown & Williams, 1995; Chronic Pain Association of Canada, 2004).

Personal Coping

The sufferers were very skillful at being able to cope with their pain. Their personalities, outlooks on life and professional identities afforded them a privileged location, ultimately the ability to survive, not to succumb. The ability to redefine hope, to reach beyond adversity to find meaning in life, even amongst the pain, vulnerability and strife spoke to their character. Evelyn articulated: “You are dealing with many, many facets and your life goes on, but you tend to forget you are a person, all you feel you are is pain.” Barbara reflected: “As a person living with chronic pain, you are not human. You forget what being human is like because you are just this walking zombie of pain.” Marg shared her experience with nightmares of the pain. All the sufferers had difficult journeys, yet they were able to transcend those deep-seated displacements of the human spirit and surface amongst that adversity, which takes a great deal of determination, skill and strength (Howell, 1994).

Among them, they used a variety of coping mechanisms (see Table 5.3, p. 228). Some worked, others did not, but they kept searching until they found a compilation of strategies to help them cope with their pain. Jackson (2002) suggests that pain does not fit in the disease paradigm of fighting against, as in battling with cancer, for “pain is more of a collaborator. It’s the thing that tunes us inward” (p. 301). Treating the pain allows sufferers to focus outward, relating to the world around them once again. The inward/outward movement shifts, responding to pain intensity and the employment of coping strategies. T.J. Murray (1997) postulates that a person’s suffering is greatly reduced when her pain and distress is controlled.

Dawn testified, "It's really quite amazing what's out there, because there is a whole lot more to treating chronic pain than narcotics; although, God knows that we have to have them." Three of the six sufferers used narcotics, one used prescription arthritic medication, and one used a compounded topical, as part of their daily coping strategies. Five identified forms of physical activities as part of their coping regime; four were avid gardeners, three walked, two utilized a treadmill faithfully, and one swam on two masters swim teams. Dawn passionately identified her relationship with her Labrador Retriever as her main coping mechanism:

My main source of strength and my main coping mechanism is Colton. Colton is my Labrador Retriever, in name only, in name only! He is my soul mate. My main source of treatment, joy and everything else in life is him. When I can't get out of bed, he comes and I hang onto, hang on to his fur around his neck and he pulls me out of bed. When I am in really bad pain, and I lay in bed and say, 'Colton, Mom's in really bad pain today', he comes up and lays his back against my spine, so I have this warm, furry, warm covered hot water bottle laying against me. When you are crying and he licks your tears, he has been my chief source of support. And the days you did not want to get out of bed, you get up, because he needs to be fed, he needs to go out. Anyone who has an animal in their life, their pain is ameliorated and their life is better.

Helen's wonderful cats gave her a great deal of pleasure. bendy reflected upon her relation with animals, "If I have one weakness, it is seeing someone in pain, or an animal more than a person, really." Living in the woods, the natural habitat of animals, bendy has a reputation for taking in stray or wounded creatures and nursing them back to health. Barbara grew up with cats and dogs in the family home and, to this day, considers them important members of the family. The unconditional love an animal offers or the ability to care for something distracted the sufferers from their pain experiences, if only momentarily.

The specific combination of distraction, pharmaceuticals, unconditional love, physical activity, meaningful relations and work, emotional expressions and so forth, is going to vary, depending on the individual and the specific experience of pain. The following table illustrates the breadth of coping strategies utilized by the six sufferers participating in this research. Numerous methods were employed by each sufferer, thus demonstrating their determination to manage their pain and their problem solving abilities.

Table 5.3: Coping Strategies

Coping Strategies Expressed by Sufferers	
•	Staying mobile: walking, using the treadmill or stationary bike, swimming, power walking
•	Gardening
•	Pets
•	Faith in God and prayer
•	Family (partners, children, extended family)
•	Personality (very driven, determined, sense of humour)
•	Social Adjustments (pacing with realistic expectations)
•	Connect with other chronic pain sufferers
•	Emotional release (crying, screaming)
•	Me time (time to care for self)
•	Withdrawing
•	Shift/change priorities
•	Recovery time – energy is like a resource, needs replenishing

- Mind control (going with the pain, intellectualizing the pain)

Marg had an amazing ability to use mental processes to distract her pain. She explained this process of cognitive displacement of pain:

I made pain an object outside of me; pain was not a part of me. I sort of struggle with the whole concept of living with chronic pain, because it was more, for me, living beside or having chronic pain as a next door neighbour, I didn't live with it. I did not choose to co-habit with chronic pain! I kept it separate, it wasn't a part of me, you know, it wasn't me; it wasn't part of my definition at all, at all!

Marg's ability to dislocate her pain outside her physical and psychological experience could be associated with the process of dissociation. Herman (1997) suggests that people with this ability are "adept practitioners of the arts of altered consciousness. Through the practice of dissociation, voluntary thought suppression, minimization, and sometimes, outright denial, they learn to alter an unbearable reality" (p. 87). Traumatic events are often the precursor to establishing this ability. "Traumatic events generally involve threats to life or bodily integrity, or a close personal encounter with violence and death" (p. 33). Marg almost lost her life during her eight-hour bi-lateral mastectomy surgery; she went through years where her life was being threatened by cancer, all the while experiencing horrific pain. For Marg, this was a creative coping mechanism, yet little is known about the long-term effects of performing cognitive blocks for chronic pain. This would certainly be an interesting area for future research.

Both Barbara and Helen commented that when you are in pain, you will do just about anything to try and get control of it. Helen further stated, "I have done it all except marijuana, and unless they find another method of delivery . . .". Difficulty arises when you spend huge amounts of money on ineffective treatments, like Helen did with

alternative therapies, spending \$18,000 over three years. Or sufferers put themselves in harm's way with unsound and risky medical procedures. Helen told this story of a support group member who would not stop looking until he found a surgeon willing to perform a highly risky surgery. She commented:

Most of them said, 'no, it's not going to solve your problem if we operate on your neck, it is very serious surgery and I don't think it will be good for you. He did find a doctor who would do it; I think it was his fourth try. He never came back to the support group.

Continuous seeking of medical intervention is used by the psychogenic pain theorists as a diagnostic qualifier (Long, 1996), when it might be sufferers' attempt to gain some sense of control over their chronic pain. Sufferers are entrapped bodily by their physical experiences of pain, as their stories testify to emotional vulnerability and physical, emotional and spiritual exhaustion. Actively seeking a resolution to this situation seems an appropriate course of action.

The sufferers in this research were skilled at finding new ways to cope, and hence, adjust to their pain. However, it has to be acknowledged that all of them were trained in the helping professions, and therefore had an insider's knowledge upon which they could draw. Their professional identity might have hindered them in trying the more non-conventional (or illegal) means of coping with pain, such as the use of marijuana. Other factors might have influenced their choices as well, for example, marijuana needs to be smoked, and asthmatics like Helen and Evelyn would not be able to ingest the drug in this manner. The sufferers' professional identity may play a specific role in their ability to cope with chronic pain, but one has to be careful not to make assumptions or jump to conclusion about the impact of this dual relationship.

Treatment Modalities

Chronic pain sufferers often believe they will try anything, do anything to lessen their pain. “Most patients with severe pain opt for surgery, even when the success rate is estimated to be only thirty percent” (Campbell, 1996). Barbara commented: “I was willing to try, seriously, I was willing to try anything.” Likewise, Dawn was willing to risk neurosurgery that had a fifty percent chance of leaving her paralyzed. In her own words, “I was quite willing to let them do anything, anything, absolutely anything, they could have amputated me at the waist, I would have been happy.” At the time of the neurosurgery consultation, Dawn was in uncontrollable pain that was under-treated. The raw nature of uncontrollable pain leaves the sufferer potentially vulnerable to consenting to high risk procedures. Loeser, Seres and Newman (1990) assert:

Offering a patient, who is depressed and desperate, another surgical procedure is an abrogation of responsibility by the physician and the exploitation of the confused, discouraged, and frustrated patient who will grasp at almost any straw offered, often without regard for the risks involved or, indeed, any chance for significant improvement. (p. 2108)

In accordance with the Canadian Medical Association’s Code of Ethics (Canadian Medical Association, 2004) and the Hippocratic Oath (Records, 2005), physicians are bound to “take all reasonable steps to prevent harm to patients” (Canadian Medical Association, 2004, number 14). Given sufferers’ often desperate motive to lessen their pain, physicians might be well advised to focus initial interventions on pain reduction prior to exploring treatment options. Mailis-Gagnon and Israelson (2003) caution that invasive intervention, such as surgery, can worsen the sufferer’s pain. Helen commented: “I certainly know never, to say never! People with pain would do just about anything to get rid of it!” She was referring to the implant of a nerve stimulator. The same surgeon

also suggested cutting the sciatic nerve; Helen inquired if she would then be able to walk, to which he replied, ‘do you want to walk or do you want rid of the pain?’” Helen did not follow through with this treatment option, but rather, sought out other coping mechanisms.

Surgery has been beneficial for some of the sufferers in this research; for example, it greatly relieved Marg’s back problems when they removed boney chips from her spine. MacDonald (2004a) attributes her release from intractable pain to having controversial radical surgery. Surgery, opioid therapy, or alternative interventions, the distinguishing factor as to sufferers’ ability to cope, lies with having a multitude of coping strategies and treatment modalities at their caregivers’ disposal. Various treatment modalities were identified by the sufferers in their stories, with a different combination of strategies employed by each sufferer. Strategies included; exercise-relaxation programs such as aquacise, reiki, yoga, reflexology; physical therapy techniques like cranial-sacro therapy, massage, TENS, hydrotherapy, stretching exercises; self-reflection activities such as meditation, self-hypnosis, journaling, relaxation; and finally, medications, including narcotics, anti-depressants (in low doses as a pain adjunct), anti-convulsants (to change pain perception), anti-inflammatories and compounding topicals.

Coping Discourse

Sufferers’ personal stories, found in Chapter Four, testify to their ability to seek relief of uncontrollable pain. The sick-role theory that identifies chronic pain patients as being comfortable in their sick-role (Bonica, 1990; Fordyce, 1990) was challenged, as sufferers were not content to exist within this role, but rather, diligently sought ways to

cope with their pain by utilizing a variety of coping and treatment options. Pain is so devastating and life alternating (Mailis-Gagnon & Israelson, 2003; Jackson, 2002; Rosenfeld, 2003) that it demands the total attention of the sufferer. Yet, this very attention is identified as a diagnostic criteria leading to the psycho-behavioural classification of sick-role. Fordyce's (1990) assessment is based upon excessive consumption of pain medication, inactivity, exhibited pain behaviours, undue focus on pain and continual utilization of health services. All of these have been labelled by pain behaviourists as deviant, dysfunctional behaviours needing immediate correction (Fordyce, 1990; Loeser & Egan, 1989; Long, 1996). If sufferers adhered to the behaviourist theory, their coping abilities could collapse and the quality of their lives would be compromised. By listening to the stories of sufferers, the assessment criteria can be redefined as potential coping strategies, for example, inactivity viewed as pacing or energy conservation, pain behaviours as adaptive responses, focus on pain as finding meaning and purpose in their lives with pain or regaining control, and so forth.

5.6. Summary

In this chapter, a narrative analysis based on a categorical-content method was applied to the sufferers' stories. The aim was to use new ways of understanding chronic pain sufferers' experiences to raise the consciousness of the reader, ultimately transforming their relationship to the sufferer. Frank (2003) describes the location of an illness story listener:

You are not feeling what the patient feels – it is not that sense of empathy. Rather, you imagine how this story matters for this other person, given who they are and what they face. Listening and responding to patients' stories is a skill, not a technique. This skill may be best described as a moral commitment that becomes a habit, as much who you are as what you do. (p. 629)

Frank calls upon the moral obligations of the listener, of the practitioner, to truly hear the sufferer's story. Testimonios, in a similar way, call upon all of us to pay witness to suffering, to understand how we can respond differently to minimize that pain, by hearing the political nuances depicted in the categories within which the story has been framed.

Using Lieblich and colleagues' (1998) categorical-content analysis, the sufferers' stories have been extended into reflective testimony. Four main categories were identified: spirit, emotion, treatment and coping. In each category, sufferers' testimonies shaped an analysis, which then was used to challenge dominant discourses within chronic pain theory and treatment. Within the category of spirit, thoughts of ultimate relief through death need to be explored as potential cognitive coping strategies for sufferers when their pain becomes all encompassing. This reconceptualization challenges the psychologizing of pain and suicide, while it pushes the reader to understand the spiritual complexities involved in negotiating life in pain. The category of emotion challenged the binary split between mind-body, emotional-physical experiences of chronic pain, unsettling the medicalization of pain that defines emotional stressors as causal factors. Through the sufferers' testimonies, holistic perceptions of pain were reinforced, along with an appreciation for the emotional experiences that are created through living in pain. Treatment acknowledged the impact upon sufferers of having their knowledges and experiences silenced through a biomedical discourse and called for an immediate disruption of the dominant power structure found within medicine. Sufferers' professional identities afforded them benefits from insights into pain treatment and disadvantages associated with role overlap. And, finally, the coping category

experiences silenced through a biomedical discourse and called for an immediate disruption of the dominant power structure found within medicine. Sufferers' professional identities afforded them benefits from insights into pain treatment and disadvantages associated with role overlap. And, finally, the coping category deconstructed the labelling of a dysfunctional behaviour within sick-role theory, calling for the reframing of behaviours as coping strategies.

The contraindicated dualisms established as meta-narratives in chronic pain assessment and treatment, such as mind versus body, sufferer versus physician knowledge, psychological pathology versus physiological, need to be dismantled and replaced with an inclusive understanding of the issues from the sufferers' perspectives. This chapter identified some political nuances within the context of the sufferers' own testimonies. The next chapter will highlight lessons learned through the work the sufferers have done in helping others and practice principles from an anti-oppressive lens, further challenging the grand narratives, while shifting the discourse on chronic pain.

Chapter Six: Professional Testimonies from both Sides of the Desk

6.0 Introduction

Personal testimonies were involved in the first layer of analysis, located in Chapter Five, followed now by the second layer, professional testimonies. This sequencing and directive respects the personal-political connections brought forth by testimonio methodology (Tierney, 2000). In the previous chapter, the sufferers' experiences of pain were highlighted through the lens of their personal lives. In this chapter, attention is directed through the lens of the sufferers' professional lives. Lieblich, Zilber and Tuval-Mashiach's (1998) categorical-content analysis was the primary method of analysis for both chapters. Categorical-content allows the researcher to identify content from the sufferers' life stories that can be formulated into specific categories. The two categories identified under professional testimonials are case stories and practice principles. Details on the application of Lieblich and colleagues' (1998) four strand approach can be found in Chapter Three: Methodology.

Professional testimonials begin with case stories that were extrapolated from the sufferers' personal interviews. In case stories, the sufferers have shared enough information for the reader to grasp an understanding of the particular case before them. It is not a detailed illustration, but rather a case vignette, from which learnings have been derived. The learnings can consist of sufferer specific quotes that capture the essence of the case message, literature linkages that support a theory/practice connection, and general meanings derived from the case through the researcher's lens. This is followed by practice principles for working with sufferers of chronic pain. The principles were

highlighted by sufferers in the interview and teleconference processes, when asked for their version of best practices in working with chronic pain sufferers, irrespective of structural or strategic barriers. The specific questions highlighted on the interview guide provided to sufferers were: 'Given your knowledge in working with sufferers of chronic pain, and in suffering from chronic pain yourself, how would you define or re-define working with sufferers in a way that is empowering?' and, 'How does practice need to be structured in order to give sufferers a clear voice in their treatment?' The practices are identified by the chronic pain sufferers and informed by their personal testimonials of living with chronic pain. Each sufferer has been both a receiver and provider of services and together, their insights represented a multidisciplinary constellation consisting of physicians, nurses and social workers. This multidisciplinary lens is in keeping with the treatment of chronic pain, as the complexity of the condition often demands a multi-focused intervention (Mailis-Gagnon & Israelson, 2003).

The practice principles have been associated with the learnings, showing the flow from case, to reflection, to intervention. Finally, as the researcher, I made an interconnection between the sufferers' identified best practices and social work practice, where anti-oppressive social work practices are specifically related to working with chronic pain sufferers (see Appendix L). This process aligns with the anti-oppressive tenet of regarding the client (sufferer) as the source of expert knowledge (Carniol, 2003; Dominelli, 2002). The theories and practices of Carniol (2000, 2003) and Dominelli (1998, 2002) were taken as exemplars of anti-oppressive social work.

Both Carniol's (2000) critical consciousness and Dominelli's (2002) conscientisation call upon social workers to engage in a process of consciousness-raising

of personal/political dimensions and critical examination of the dominant systems. The identified practice principles in this chapter are specifically directed towards social workers working with chronic pain sufferers; however, it is anticipated that all professional groups serving this population should be able to derive practice insight from these principles.

6.1. Case Stories

As women in the helping professions who are sufferers of chronic pain, the participants in this research have brought another level of awareness to the storying process emanating from their practice lives. Through testifying to their own struggles of living in pain, they related experiences in working with sufferers, be it through medical practice, nursing care or social work intervention. The case stories were shared to highlight specific insights or concerns in the delivery of care to chronic pain sufferers. Some stories date back a number of years, and others are more recent, but all potentially deepen the reader's understanding. Names of the research participants are not used in this section as a measure towards confidentiality of the people with whom they worked; the research participants are referred to by their helping identity.

Case A: A nurse sufferer shared this case example as part of her professional testimony in the research. A woman who suffered with chronic pain related to Crohn's disease had been on large doses of steroids. Her physician had not explained to her the potential psychological implications associated with drug withdrawal. She was experiencing extreme anxiety and deep depression as a result of discontinuation of the steroids. Having completed the medical intervention of steroidal treatment for Crohn's disease,

this woman was admitted to psychiatry to attend to the iatrogenic side effects. Nothing seemed to ease her pain or discomfort. The nurse relating this case began with the simple things. She would run her a bath, rub her back, get her to move around – to stay physically active, all the while talking to her about interests she had identified. This woman loved animals and had a passionate curiosity about the Arctic, so the nurse would tell her stories highlighting those elements. In the nurse's words, "It was all external and she could get her mind off the pain in her abdomen for awhile, and the depression and the anxiety from the withdrawal. It may be only a minute break, or a second break." At the time, the nurse questioned the effectiveness of her interventions, wanting so desperately to ease this woman's torment. Once the woman was well, she returned to thank the nurse for her compassionate intervention.

Learning: The nurse's motto: "I treat others like how I would like to be treated."

Meeting the sufferer where she is at, treating her with respect, being empathic, genuine and sincere is the foundation upon which a helping relationship should be built (c.f.

MacDonald, 2000, 2004a).

Case B: The sufferer, in her helping role as a physician, was working with a woman with severe chronic pain syndrome, fibromyalgia and huge life stressors, including an abusive partner. In the words of the physician:

Today was a particularly bad day for her, she had a flare [up], was in severe pain, she just cried and cried and cried, and wanted to give it up, just wanted to die, and it was just too much, it just overwhelmed her today. But . . . she is the kind of woman who can pull herself back from that brink, and look at the roses on the table and take joy in that – there is still beauty in the world. There is no other reason she is alive than her spirit, her will, to find something, somewhere, somehow. And I think either you have that or you don't. And unfortunately, a lot of people either have it literally or physically beaten out of them, by lack of

support, by partners, by whatever. Having gone through chronic pain, I can see the people who have chosen to end their lives in chronic pain, you can understand it, you may not agree with it, or choose it yourself, you can certainly understand it.

This physician firmly believes that part of her job in supporting chronic pain sufferers is to help people redefine hopes. As she puts it, “we are brokers of hope”.

Learning: To help sufferers find that glimmer of hope so that they can face another day, another hour, or another minute in their struggle with pain is the beginning step towards survival. She states, “That’s what we do, we meet people in places of desperation, quiet or otherwise, and somehow, help them to define a reason, which is hope, to keep going.” Chronic pain challenges one’s notion of self – calling upon incredible inner strength to deal with daily existence (Brown & Williams, 1995; Howell, 1994; MacDonald, 2000, 2004a); complicate this with the dynamics of woman abuse (Doyal, 1995), and the barriers become almost insurmountable. Using Howell’s (1994) classification scheme of four pain categories, one would clinically locate this sufferer as ‘filling her life with pain and despair’, where the sufferer struggles with the pain; withdraws, isolates and retreats from the world around her (see Appendix E). In order for the sufferer to progress along the healing journey to the next category, filling my life with hope, intervention would need to focus on guiding the sufferer through the grieving process, where the losses associated with pain and abuse would be realized and experienced. No matter what the targeted intervention might be, safety must remain the paramount concern of the helper when working with abuse victims.

Case C: The nurse sufferer shook her head in disbelief as she related back to nurses’ training and practice assumptions in the sixties, pertaining to attitudes to pain. She

commented, "There was an awful lot of judgment that was going around at that time; they thought they could crawl inside someone else's body and know if they had pain or not."

In training, student nurses were cautioned about male patients who would try to get close to them, because they were attractive young women. As the head nurse explained, patients could manipulate them through expression of pain, when in fact, they were only using the pain as an excuse to get the nurse's attention. During a rotation in the Veterans' Hospital, the nursing student came across a young officer who had been injured in training. His leg had been badly broken in a couple of places, requiring extensive reconstructive surgery involving plates, screws and skin grafts. This was a readmission due to complications with dislodging plates and delayed healing from the original surgery. The surgery consisted of taking a bone graft from his hip and replanting it in his leg.

Three days post-op, the head nurse decided that this young officer was requesting far too much medication and it was time to show him he really did not require this amount. The head nurse instructed the floor nurses to report any requests for pain medications from this young officer to her prior to administering pharmaceuticals. The nurse sufferer, who at the time was a student nurse, was not aware of the head nurse's intent until the officer voiced the degree of pain he was experiencing and requested pain medication. Relaying this request to the head nurse, the following order was given: "Alright, we are going to give him a placebo and we will show the doctor that the placebo worked just fine and that he doesn't need the pain meds." The poor man was in horrific pain and the student nurse felt caught in a trap between ethical practice cloaked in compassion and direct orders from her superior. She had worked in an intensive care unit

and was very familiar with post-operative care and pain management. She knew this was not in the best interest of the patient. When the doctor came to the floor, the nurse sufferer asked to speak to him in private and informed him of what had just taken place.

As she recalled,

He came out and said, 'My patient is not being adequately treated and I understand that he has been given a placebo, I don't want that to happen again,' and from that point on, he got pain medication and [the head nurse] stayed away from him.

The administration of placebos is sometimes used in the treatment of pain (Jackson, 2002; Mailis-Gagnon & Israelson, 2003). Such treatment is supported by the physiological properties of endorphin release, whereby the body produces enough of its own pain controlling chemicals if left to its own devices. Furthermore, placebos are used as a behavioural intervention technique designed to psychologically manipulate the patient into believing they are receiving treatment. Mailis-Gagnon (2003) warns, "Getting better with a placebo does not necessarily mean 'nothing is wrong with the patient'. This is a serious misconception of both health care providers and patients" (p. 78). She further suggests that we are only beginning to understand the effects of placebos and that more research is needed to truly comprehend their use.

This same nurse related another case, whereby she was instructed to administer a placebo to a post-operative patient who had a thoracotomy. The patient went through radical surgery, where his chest wall was cut open, rib cage spread and his lung removed. The nurse sufferer noted this was a very painful surgery and subsequent recovery. As she recalled, "This poor man was just in tears, and he had had his lung removed, he had had his ribs spread and was in incredible pain." She felt this man's agony and, as a nurse, she

needed to respond, so she gave him an injection of pain medication when her supervisor was at lunch. Because she went against her supervisor's orders, she had to file an incident report. Her motive was to ease this sufferer's torment of pain, if only for a few moments; however, because the supervisor disallowed continuation of this pain regime, the patient was back in agony by mid afternoon. In the years following, the nurse has often thought of this patient and wondered if he went on to develop reflex sympathetic dystrophy or a chronic pain syndrome due to the negligent handling of his post-operative pain.

Learning: Although this case pertained to acute pain, the lesson learned cuts across all categorizations of pain, acute, chronic or a combination. Helping professionals must trust their knowledge base and ethical standards in supporting vulnerable sufferers when the sufferers' voices have been silenced by oppressive practices within the system of health care. From her practice location as a nurse, this sufferer commented, "Nobody was prepared to do anything . . . that just stood out as cruel and unusual punishment." Advocating on behalf of sufferers' rights is a central component to disrupting the expert-knowledge discourses of biomedicine (Greenhalgh, 2001; MacDonald, 2000; Wendell, 1996).

Case D: The physician sufferer was working with a woman in her late twenties, who had developed reflex sympathetic dystrophy, with radiating pain encapsulating her entire leg. Numerous sympathetic blocks yielded little to no relief. Her pain was hypersensitive to touch; weight bearing was becoming more and more difficult, while relief seemed further and further out of reach. Pain management escalated up the pain ladder, finally to a cad pump (a pain delivery system often used in palliative medicine) of

hydromorphone, fed subcutaneously by a butterfly needle just under the skin and graval injections to ease the nausea. The physician recalled, "I often wondered how she got through that, but I could just see it in her eyes, her spirit would never let her go." Years of struggle, strife and utter pain left the sufferer vulnerable, worn-down and exhausted. The physician related to her experience in the helping role:

I think one thing that actually helps is having people who believe that when you say you are in pain, you are in pain. One of the very worst things, medicine does it, public at large does it, everyone does it, unless you are a victim yourself, unless you have the expression on your face of acute pain, as people do in acute pain, people don't believe you and there is nothing worse than not being believed. And people with chronic pain do not have the wrinkled face, the contortion and body language of people in acute pain, and it's not nice when people don't believe you. It's in that garbage category of 'nobody wants a cripple'.

Pain specialists questioned the authenticity of this sufferer's pain. She felt this trivialization of her pain and struggled with being "regulated to the status of some lesser being." Her physician believed in her and in the genuineness with which she expressed herself and her life in pain. In the words of her physician, "There has been a long history of telling the patient 'it is all in your head' or 'you don't have pain'. The most important thing that medicine can do is say, "I believe you". That is exactly what she did, she supported the sufferer through narcotic pain management, she advocated with surgeons and pain specialists to get the services necessary to treat the pain, and she held the sufferer's hand, literally and figuratively, as she journeyed with her through the pain until easement of the pain was achieved.

Learning: Believing the sufferer's account of her pain journey can give the sufferer the hope and belief in herself necessary to handle the pain experience; this will not solve the pain problem, but it may give the sufferer enough strength to hold on. Howell (1994)

equates this belief, specifically with situating the causation of pain, with organic dysfunction, deviating away from psychologically oriented labelling. Seers and Friedli (1996) found that it was common for health care professionals and sufferers' families to not believe their pain, yet, for sufferers it was vitally important to have their pain acknowledged. As the sufferer narrating this story stated, "People may or may not remember what you have said to them, they may or may not remember what you do, but they will never forget how you make them feel." It is very important not to underestimate or invalidate anybody's life story or experience of pain.

Case E: A nurse sufferer shared her way of working with sufferers, her use of self in reaching out to others in pain. As she explained:

When you are working with patients and you see where they are coming from you can give them the gift of themselves. They know you know, that you understand and care, and that you get it. Many of my patients were seniors and they were gardeners [as she was].

The sufferers were dealing with multiple losses, including the loss of a life-long partner, loss of emotional health through depression and the loss of physical ability and agility through arthritis. This nurse sufferer attempted to connect with them through their forgotten hobby of gardening as a way of engaging them and working through their grief.

I would bring them in pictures of my garden and they would tell me about their gardens and how things in their garden had died. I knew where they were because of my arthritis, things in my garden had died too, and eventually I would get well enough to get back out and plant something else. I knew where they were because myself as a gardener, when I was in pain there was nothing I could do besides walk around it sometimes and even that was difficult, but you couldn't dig, you couldn't deadhead [the flowers], you couldn't really do anything; maybe sit or walk and that was it. The desire to do something was gone; it goes when you are in pain. I would tell them this and that I understood. I would show them pictures of my garden and ask them if they wanted me to help them with theirs. Some didn't want to bother, but some did. And, by the time they were ready to be

discharged, they were wanting to garden. So, I would take some of my perennials, maybe a dozen, one of each, and go to their home, their families were delighted, their sons or daughters would dig the earth, and I would help them plant. I hope they are still growing. That was one way maybe I helped them get something back in their lives, something to focus on other than their illness. I think they knew that when they were in their garden, that it would help them.

Learning: There are many ways to offer hope and sometimes it is reaching beyond the obvious clinical interventions, to something connected with the human spirit. This nurse was able to offer a part of herself as a way of comforting. As she remembered, “They did not want to do something physical, but they would believe me, eventually, that moving does help, that doing something physical does help, that digging a hole, watching a flower grow does help.” Unruh, Smith and Scammell’s (2000) research found that gardening was an effective coping strategy in dealing with chronic illness. Gardening provided a sense of being in control, for women, while living with uncontrollable bodies, an escape from worrying and problems, and a form of release and relaxation. Gardening was also a link to nature, life forces and spirituality.

Gardening evokes a spiritual connection to healing, a consideration of alternative interventions that are respectful of the sufferer’s own ways of working and relating to this world. Spiritual and community connections for sufferers can help break down the loneliness and isolation often created by the pain experience (Rosenfeld, 2003; Vanier, 1998).

Case F: A social work sufferer dialogued with a woman on a pain chat line. This woman was struggling with fibromyalgia, was immobilized by pain to a point of not being able to function, yet, she was having difficulty getting into a pain clinic due to their lengthy waitlist. Her pain, immobility and frustration in accessing services contributed to

a state of depression. Once she was able to receive a diagnosis of clinical depression, she was moved up the waitlist and received entry into the pain clinic on a priority basis. The research participant who related this story knew her own family doctor believed her fibromyalgia was caused by depression, although she was screened for depression with negative findings. As a professional social worker, she knew the assessment criteria for depression, and she was a sufferer who knew her own body and psychological make-up. She knew she was not clinically depressed, that the pain was creating depressive symptoms and/or moments. Yet, she seriously considered going to her family physician declaring he was right, that she was indeed depressed, but only as a tactic to receive adequate services for her pain.

Learning: The interconnection between chronic pain and depression is experienced, but often it is the pain that is producing depressive symptoms, not the other way around. Practitioners must take action to not dismiss chronic pain by treating the psychological entity in isolation. In relating the experience of depression to chronic pain, one sufferer commented to a psychiatrist, when the etiology of her pain was unclear: “I wasn’t depressed before I had that pain and, if you’d get rid of it, I won’t be depressed anymore.” Another sufferer worried that anti-depressants “tainted” her in the eyes of other health care providers:

Anti-depressants as a pain adjunct – raise your pain threshold; provide some degree of protections from having your mood bottoming out. You hate to tell another specialist that you are on anti-depressants because they immediately assume you are depressed and then they don’t want to treat you.

Jovey (2004) believes that depression follows the onset of uncontrolled chronic pain.

Mailis-Gagnon and Israelson (2003) caution against the dichotomy of mind versus body,

for “this kind of dualism allows people to think that chronic pain may be either “real” or “imaginary” . . . chronic pain is multidimensional . . . biological, psychological and social” (p. 9).

Case G: A sufferer, who is a physician, swims on a competitive masters swim team with four other physicians. Since her knee injury, she has had to use fins when swimming, to keep her knee in alignment. One fellow swimmer was questioning the authenticity of her need to use fins; stating that she was five years post-operative and concluding she should not need that apparatus. The sufferer explained why she needed them, that they brought a level of support and reduced stress and pain on her leg. He said nothing and just walked away. About two months later, he came hobbling into the pool; he had been out running and had twisted his knee. As the sufferer told her story:

He didn't strain the ligaments, he didn't tear anything, he didn't require anything about that knee, and he looked at me and he said, 'I think I might understand a little about how your knee feels.' This is a physician who has been out [of medical school] for ten years and if he is saying that to a colleague, you can imagine the limited understanding and perspective on chronic pain. I've gotten quite used to not being believed at all, even by colleagues.

Learning: This sufferer firmly believes that it is when people in the helping professions, including physicians, become ill themselves that they realize the illness experience and not before. “When they become vulnerable, when they become ill, disability hits them, then they are much more aware.” Having a glimpse into another's reality, walking a mile in another's shoes, can have a profound impact upon one's learnings. Brown and Williams (1995) reported on findings of medical impotence within the stories told by female research participants living with chronic illness. Seers and Friedli (1996) found that chronic pain was not being considered a serious medical condition by physicians and

that their frustration and lack of confidence in treating pain was evident to their patients. A great deal more education and awareness about chronic pain is needed for those working with sufferers. As a directive from a sufferer, "Listen to what it is that I have to say, and learn by it." Listening to first voice accounts is one of the best forms of learning health professionals can access.

Case H: For one sufferer, a social worker, her journey with chronic pain ignited a professional identity crisis. While she was in a counselling session, for the fifty-five minutes the session lasted, she was one hundred percent pain free. As soon as she stood up to say good-bye to the client, the pain returned full force. It was literally amazing. As she recalled:

That was a part of the ideological struggle because . . . on the one hand, work was providing me with pain relief and on the other hand, it was creating tremendous professional insecurities, because I really felt that I did not have the right to be doing this work because of the misbelieving, discounting [of clients' pain stories] whatever you want to call it.

This social worker was really being torn between her personal beliefs and struggles, and her professional identity and ethics. As she related:

Professionally, I wanted to acknowledge and validate and do what was appropriate . . . then there was a part of me that would be, 'I don't think this person really has pain, it's not the way they are talking', or really question their reported experience with their pain.

With tremendous will, she fought to keep her doubt away from the client; however, she was convinced she had failed. As she explains, "That is probably why I didn't feel my own pain, because the struggle was not to let that attitude leak out." Being judgmental of clients' as they related their pain stories went against everything she believed as a

social worker. According to Herman (1997), “in the aftermath of traumatic events [such as living in chronic pain], survivors doubt both others and themselves” (p. 53).

A few years later, a woman who she had counselled during this time re-referred herself. As the social worker explained, “when I think of the word pain, it is her face . . . it’s incredible what she has endured.” Yet, the social worker believed that she needed to apologize to this woman, so she disclosed her past struggle and asked for forgiveness. The client burst out in laughter. She had told her family doctor that the one thing she was apprehensive about in returning to counselling with this worker was that she was too empathetic, too validating, too . . . all the things the social worker thought she was not doing.

Learning: The social work sufferer wished she had addressed her disbeliefs and struggles with the client earlier in their working relationship. She does believe it is important when working with chronic pain sufferers, “to be able to validate the reality, and the tremendous isolation and loneliness that come with it – that being and feeling so very, very different from the rest of the world.” Being able to articulate these pain struggles will relay to the sufferer the genuineness and understanding of the helper. Becoming comfortable asking sufferers ‘what worked, what helped, what needs to be changed?’ and so forth, is a beginning step towards making practice more egalitarian and sufferer focused.

Case I: One nurse sufferer told this case story as part of her own storying:

I had a ninety-year-old man as a patient once. He was very sick physically and became depressed. He was very lonely and in a private room. Every evening, I would take all my charts and do them in his room. Sit with him. Talk with him.

I would make him a cup of tea and bring in a few cookies and I would talk to him and tell him he was a good person. He cried a great deal – missed his family. He had been on a medical floor, but due to his depression, he was put in the Psych [psychiatric] Unit. He was so sad. One day, I came into work and he was gone – he was in Intensive Care, he had a coronary. I went to visit him there. He looked at me but he could not talk. I held his hand. Told him I was praying for him. He died a few days later. I think I helped give him some comfort in the short while I knew him.

Learning: As this nurse sufferer stated, “I feel if we can give some comforting words to each other as we pass each other on our life path, then we have done something good.”

Vanier (1998) founded his work on the reciprocal process of spiritual fulfillment ignited through the caring for others, in that, being in relation to others is the guiding principle to the building of community. Sometimes it is not the interventions or the latest techniques that are most valuable to a sufferer; sometimes it is being with the person, letting her know that she is not alone in her pain journey, which makes the most difference.

6.2. Practice Principles

Through testifying to their professional lives as helpers, the sufferers have identified numerous practice principles representative of best practices in working with chronic pain sufferers. Specifically, at the beginning of the interview process, each sufferer was given a story board and interview guide that consisted of guiding questions, including, “How would you define or re-define working with sufferers in a way that is empowering, and how does practice need to be structured in order to give sufferers a clear voice in their treatment?” Sufferers were asked at the end of their last interview to envision that they had a magic wand and could create their own wish list for working with chronic pain sufferers, devoid of any structural limitations, such as financial restraints, inadequate staffing and so forth.

Practices have been pulled from professional insights of physicians, nurses and social workers; all of whom are sufferers of pain. I believe their commonality of sufferer breaks down the professional barriers often witnessed in multidisciplinary work. In a response to the research question: How can the stories of women in the helping professions, who are sufferers of chronic pain and (dis)Ability, inform an anti-oppressive approach to social work practice in working with sufferers? The following practice challenges have been identified by the participants. To help examine this question, methods of inquiry, aligned with testimonio methodology, were explored. These included, Clandinin and Connelly's (2000) outward dimension of reading texts, with focus on the environment, and Randall and Clews' (2001) therapeutic and political reading, which addressed the socio-political context.

Each practice principle is supported with direct quotes from sufferers, literature linkages and connections to anti-oppressive skills identified by Carniol (2003) and/or Dominelli (2002). Finally, meta-narratives found within the dominant discourse on chronic pain are challenged. The purpose of testimonio is to change the political landscape, through the sufferers' testimonies meta-narratives have been unsettled, providing room for the sufferers' knowledges to emerge.

Principles

- **Treat all sufferers with respect and communicate an empathetic understanding of their situation.** Quoting one sufferer: "What we do in medicine is a privilege, not a right, and it's a privilege to look after other people. So you must, at all times, try to be as sincere and as honest, and as believable as

you can be” (physician sufferer). Dominelli (2002) highlights the importance of process within anti-oppressive practice, recognizing that an equitable relationship and the interaction with a client are as important as the outcome. Carniol (2003) calls for a widening of empathic skills to social empathy, entailing an understanding of others similarly oppressed.

Meta-Narrative Challenged: The practice of labelling pain psychogenic through which the sufferer’s story of pain is translated into distinct mental health diagnostic categories is challenged (Ahern, 2002). This is a hierarchal process, whereby the physician labels the sufferer through questioning the reported physical authenticity of the sufferer’s pain (MacDonald, 2000, 2004a). Jovey (2004) believes that the psychogenic classification is used when the physiological properties of pain are not clearly distinguishable. Haynes (2002) suggests that medicine still has a great deal to learn about chronic pain. ‘The Pain Patient Charter of Rights and Responsibilities’ (Chronic Pain Association of Canada, brochure) first declaration reads: “As a person with pain, you have the right to have your report of pain taken seriously and to be treated with dignity and respect by doctors, nurses, pharmacists and other health care professionals” (p. 2).

- **Validate the sufferer.** This includes tremendous isolation and loneliness that can come with living with chronic pain. As one sufferer put it, “That being and feeling so very, very different from the rest of the world because on the outside you may very much look the same, but to have that reality discounted.” As a helping professional, it is vitally important to put these topics on the table as opposed to the sufferer having to bring them forward, for it demonstrates a depth

of understanding and recognition of the struggles. It validates their experiences, their lived reality. In the words of another sufferer, “I think validation of the person is the most important thing to start with, saying ‘I know you have chronic pain’.” Another sufferer shared how she relates to working with sufferers, “I told them I admired them, I admired their strength.” Carniol (2003) identifies affirmation of clients’ strengths in coping with adversity and encouragement “to resist and dismantle oppressions” as necessary validation skills when working from an anti-oppressive perspective. Dominelli (2002) identifies the client’s knowledge base as the source of expertise.

Meta-Narrative Challenged: Medical model’s hierarchal positioning of physicians (and other helping professionals) in the role of expert is challenged.

As Greenhalgh (2001) asserts:

The medicalization of pain is also detrimental to women, specifically because it places them within a masculinist biomedical order, in which the patient’s knowledge of her body and life is silenced in discourses of objectification that make the doctor the expert on the patient’s body (p. 320).

The Pain Patient Charter of Rights and Responsibilities (Chronic Pain Association of Canada, 2004) calls the sufferer to action in becoming knowledgeable about her pain. Jovey (2004) believes it is necessary for the sufferer to be an informed and actively engaged participant in pain management, specifically because pain is so subjective and individualistically experienced. Likewise, helping professionals need to acknowledge consumer knowledge and find new ways of relating collaboratively. Mailis-Gagnon, a chronic pain specialist, articulates her relationship with sufferers:

I strongly believe, and share my belief with my patients, that my skills and the skills of other pain doctors are merely helpers. I do not fix anyone. I lack that ability to perform miracles. I am only a partner in my patients' care, providing them with information, my knowledge and my experience. Beyond that, they really do the job themselves. (Mailis-Gagnon & Israelson, 2003, p. 217)

- **Listen, really listen to and hear the sufferer.** One sufferer related her experience: "You have some folks who are in the helping professions who are just not hearing what you are saying. I can't tell you where it started, I can't tell you where it ends, I just know that my skin hurts, my hair hurts, my teeth hurt, my eyes are burning. But, don't slam the door in my face and don't tell me that I am lying. Listen to what it is that I have to say! And learn by it." Dominelli (2002) draws the worker's attention to the interactive nature of intervention and the importance of truly hearing the client's voice. Carniol (2003) identifies how communication skills such as listening, focusing and clarifying are used to engage clients "in critical consciousness and action towards emancipation."

Meta-Narrative Challenged: The medical model's preoccupation with classification, diagnoses, and labelling is challenged (Frank, 1995; Greenhalgh, 2001), for if the sufferer does not fit the diagnostic criteria of the suspected pain producing disease, then the sufferer's pain is displaced (MacDonald, 2000). Once this displacement has occurred, sufferers become vulnerable to other labelling processes. For example, Parson's (1951) sick role behaviour, whereby sufferers' behavioural discrepancies are identified as symptomatic indicators of underlying emotional disturbances is still used today by some cognitive-behavioural pain programs (Bonica, 1990; Fordyce, 1990).

- **Remain cognizant of their potential vulnerability.** Speaking from a location as knower, one sufferer articulated: “When you are sick, you forget who you are, what you are about, you forget you could do things. People in pain are very vulnerable.” Normalizing this vulnerability within its socio-political-economic and physical context is key to shifting the discourse away from one of personal weakness. Carniol (2003) identifies advocacy skills within anti-oppressive practice as “pressures for better access to relevant services/resources. Defends social rights.” In Case C, the nurse recognized the patient’s vulnerability as not being able to advocate for his own rights, his right to adequate pain treatment. The nurse witnessed this suffering, believed the patient’s rights to suitable and humane care were being violated, and subsequently took appropriate action.

Meta-Narrative Challenged: The psychological pain theories view of sufferers’ vulnerability as dysfunctional, or as a negative orientation towards pain and subsequent coping (Sullivan, Bishop, & Pivik, 1995), needs to be unsettled. A sense of vulnerability is a natural reaction to a threatening stimulus and, given the losses and stressors associated with living with chronic pain; this reaction needs to be normalized.

- **Believe the sufferer.** The sufferer’s pain is what she defines it to be, for only she knows that experience. As one sufferer eloquently put it, “The most important thing that medicine can do is say, ‘I believe you’.” I would extend that to all professions in helping roles. Brown and Williams (1995) advocate for sufferer inclusion in “how their [pain] problems are both conceived and resolved” (p. 700). Dominelli (2002) addresses the importance of agency in anti-oppressive

work, defined as a client enacted state in decision-making and exercising control. Part of the agency process is recognizing the interactive nature of practice and being able to relinquish traditional worker power.

Meta-Narrative Challenged: Chronic pain is not measurable in a quantitative, medically specific manner (Jovey, 2004; Clark, 2004). Acute pain is usually associated with certain gestures, grimaces and verbal expressions. Chronic pain sufferers are usually devoid of such affect, for their facial expressions, verbal tones and physical appearances do not necessarily tell their story (Jackson, 2002; Mailis-Gagnon & Israelson, 2003). Their affect often has become flat, this might be due to the longevity of their pain experience and the exertion of energy needed to cope with their daily lives. Medicine cannot use traditional ways of viewing acute pain to understand chronic pain (Jovey, 2004). This practice principle of believing the sufferer challenges traditional ways of viewing pain and forces practitioners to view chronic pain as a disease in and of itself (Clark, 2004).

- **Strategize around systemic change.** As one sufferer keenly pointed out, “You can educate, but information does not necessarily become knowledge, and knowledge needs to be translated into behavioural change.” Education about the disabling consequences of chronic pain, various treatment modalities, including pharmaceutical and non-pharmaceutical interventions, attitudinal approach to sufferers, areas needing research exploration and access to expedient health care, are but some of the systemic changes needed to adequately treat chronic pain. A multi-modality, multidisciplinary approach that places the sufferer at the centre of

the treatment team, with full rights, access to knowledge and voice – is the beginning to a rights-based approach, an anti-oppressive lens to chronic pain.

Carniol (2003) believes the worker needs to challenge oppressions on all levels, including personal, societal and global injustices, while working within an egalitarian, caring and inclusive framework. Dominelli (2002) claims that anti-oppressive practice involves clarity about who pays the price for intervention choices. Price can be understood as monetary, such as the price for medical interventions. For example, if a chronic pain sufferer can personally pay for a MRI (magnetic resonance imaging test) at a private clinic versus waiting for months for access to the publicly funded service, class through one's economic ability to pay might become a deciding factor in the degree and duration of suffering (Armstrong & Armstrong, 2003). Many pain conditions have a specific time associated with becoming chronic; for example, with the condition Reflex Sympathetic Dystrophy, the chance of remission is greatly reduced if not treated within six months of initial onset (Kirkpatrick, 2000). Price could also be associated with the personal costs of interventions on sufferers. For example, MacDonald (2004a) relates the emotional and physical suffering experienced by a sufferer when treated at a cognitive-behavioural (contingency management) pain clinic. The oppressive structures of this program (MacDonald, 2000) stripped the sufferer of her voice and dignity.

Suggested strategic changes include:

- a) **Structural change to Medicare payments – not fee per visit, but evaluated on depth of involvement, time and services provided.** As one sufferer articulated, “It’s the people who have chronic disease or chronic pain and those who are dying that really need us. And it’s ironic that those are the people who get short changed and who, economically, are not the ones you need to see, because you can’t make enough money looking after the truly sick people; that is the way Medicare works.” Specifically, this sufferer was referring to the Medicare pay schedule for physicians; a physician in her province receives \$25.00 per patient visit, spending five minutes diagnosing and writing a prescription for an ear infection in a six-year-old, or spending forty minutes with a chronic pain sufferer.
- E. Roy Salmon (2001), the Auditor General of Nova Scotia, identified the problems with the fee-for-service arrangement, including: risk of physicians over-servicing, lack of attention to health promotion/prevention, disincentive for physicians to include other health professionals in their service (for example, social workers and nurse practitioners), deterrent for physicians to practice in rural areas, and failure to address shortage of staffing in emergency rooms. The Province of Nova Scotia has introduced an alternative funding initiative (AFI) where the physician, the Department of Health and the Medical Society negotiate a contract (Salmon, 2001). These funding arrangements are targeted for medical specialists, general practitioners in rural settings and physician staffing of emergency rooms (Health Care Human Resource Sector Council, 2003; Nova

Scotia Department of Health, 1997; Salmon, 2001). Physicians' time with chronically ill patients has not been addressed.

Trying to meet overhead expenses, paying down a student loan, minimizing practice stress, it is easy to envision the incentives for physicians to avoid complicated cases, such as those suffering from chronic pain. Both physician sufferers in this research have called for a re-working of the fee-for-service reimbursement system, whereby the degree of complication in the case is taken into consideration, similar to the advances in palliative care and geriatric physician management.

- b) Healthcare access to interventions not covered by a health care plan or public health care – such as massage therapy, acupuncture, physiotherapy, reflexology, so that access to service does not depend on wealth.** Chronic pain can be very costly, as evidenced by one sufferer who spent \$18,000 in alternative therapies. Sufferers' seek interventions to help manage their pain; some are helpful, others are not; it takes time, energy and resources to find the repertoire of interventions that provide some relief. Yet not all sufferers have extended health coverage and even if they do, it does not cover all interventions, and the ones that are covered are usually for a limited duration (in number of visits or monies spent). Appropriate healthcare cannot be determined by one's ability to pay, or our system is indeed reflecting a two-tiered approach (Armstrong & Armstrong, 2003). The publicly accessible services, like physiotherapy in a hospital, entail long wait lists. As one sufferer suggested, "The wait list is so astronomical, to get into a hospital physio program is a very, very long wait. And of course, in time,

their pain gets worse, and then they have chronic pain and there you have it.”

Concerns over wait lists extend to many areas of health care, including surgeries, hospital admission, diagnostic tests and rehabilitative services. For example, the wait list to access the Pain Clinic at the QEII Hospital in Halifax has just moved from a two year wait to five years, because a pain specialist moved to another province (Jovey, 2004). The wait lists of our medical service system are a national concern (CBC News, 2005, 2006; Romanow, 2002).

- c) Education – of physicians, helping professionals (nurses, social workers, psychologists, physiotherapists and occupational therapists), insurance industry, employers, and the general public.** As one sufferer commented:

We are all prisoners of our training. I had no formal education about it. In medical school, you certainly learned how to manage acute pain, post operative pain . . . which is not very difficult. In psychiatry, there was nothing on pain, you learned nothing about it, it was not mentioned. Informally, you got the impression that non-malignant pain was not very serious, not very disabling or psychiatric or that people were drug seeking, they were drug addicts. So there was never really a place for managing chronic pain outside of ‘are they addicted or are they crazy?’ The stigma, therefore, is obviously huge.

Another sufferer realized that she needed more formal training in chronic pain management, as she stated:

I need to know more about pain, the physiology and biochemistry of pain, the neurology, pain pathways, what makes pain, what makes acute pain and, most significantly, what makes chronic pain, and why do some people get chronic pain when others, in seemingly similar situations, do not. Then, also more on pain management, medications, but other modalities as well, the proper use of medications and the potential for abuse and misuse.

- d) Policy changes.** In the words of a sufferer, “chronic pain has to be recognized as being debilitating, as being a bona fide disabling condition. Talking about accessibility issues, accommodation issues, employment opportunities . . . chronic pain has to be recognized as being an insurable disability.” Challenges have been before the Supreme Court of Canada (2003), by both Laseur and Martin, specifically directing Nova Scotia’s Workers Compensation Board to consider chronic pain compensatory. The privately owned insurance companies also need to be challenged so that sufferers can receive equitable treatment.
- e) Sufferer Centered Multi-disciplinary Service Delivery.** While sufferers varied on their approach to services for chronic pain sufferers, be it defined as a team, clinic or primary physician approach, all believed that the sufferer needed to be central to the process. One sufferer believed that the team approach, while inviting different modalities, was “very expensive, time consuming and labour intensive, and if every person in pain had to wait to be treated by a team, most people would never, ever be treated.” In her vision, a team will probably emerge, but it is the sufferer and the primary physician who co-captain the personal plan, pulling in disciplines according to need. Another sufferer had a different opinion, believing that the chronic pain sufferer needed to have access to a designated team, but assigned to a specific team member to provide continuity of care, whether that be the social worker, the physician, the physiotherapist, the nutritionist, or massage therapist. Each team member would be the primary caregiver for a designated number of sufferers. This sufferer also believed that it was essential to have someone to deal with spiritual issues of sufferers. Yet,

another sufferer believed that educating the general practicing physicians about chronic pain would go along way towards making life better for sufferers. All in all, better access to treatment, continuity of care, improved communication between those helping and the helped, and educated consumers, educated practitioners and an educated public on chronic pain issues would all be steps in the right direction.

Meta-Narrative Challenged: Helping professionals and medicine's minimization of pain is the common challenge brought forward by the proposed strategic changes. Research found that doctors themselves believed that two-thirds of sufferers did not have well managed pain (Clark, 2004). Furthermore, the reasons stated for pain sufferers changing doctors were as follows: thirty-one percent believed their physicians lacked knowledge about chronic pain; twenty-nine percent thought their physicians did not take their pain seriously; and, twenty-seven percent stated their physicians were unwilling to treat their pain (Clark, 2004). Individualistic or dismissive approaches to chronic pain add to the sufferer's torment and anguish. Chronic pain is a multi-faceted, complex condition (Clark, 2004; Jovey, 2004; Mailis-Gagnon & Israelson, 2003) that calls for timely and appropriate health care access, multidisciplinary, multi-modal approaches to treatment, and education of service providers about chronic pain conditions, effects and treatment options. Policies need to be challenged to view chronic pain as a disabling condition, a disabling condition worthy of compensation.

- **Use of self.** Sufferers, in the helping professions, take their own experiences of living with chronic pain and use those experiences to help other sufferers.

Quoting one sufferer:

If you are in the healing professions, every negative experience you have, you examine it and see how you can use it to help someone else. If people know, if people can see that you have problems, when you talk with them about similar problems that they have, they tend to believe that yes, you know what you are talking about and they tend to believe when you say this will get better. They tend to rely on your support more and accept it.

Another sufferer related her connection to pain in helping others, “The experience, it’s knowing the fear, the doubt, the depression, the sadness, the despair, the pain, the disability, and the emptiness and having no control of a situation”, translates into understanding other sufferers’ locations, without having them detail it to exhaustion.

- **Use of touch.** To offer a hug of comfort, to hold a sufferer’s hand when they are struggling, may be an important supportive gesture and the linkage from one spirit to another. As a ‘do not touch’ society, we have moved away from offering physical comfort through the laying on of hands (Vanier, 1970, 1998).

Technological advances have left machines to do a great deal of the assessment and treatment modalities that used to be attended to with hands. The scare of sexually inappropriate touching has distanced touch from healing practices. For example, the social work Code of Ethics has a sub-title ‘Avoid Physical Contact with Clients’ (CASW, 2005). Upon close examination, touch is permitted if due care is exercised; Section 2.5.1 states:

Social workers avoid engaging in physical contact with clients when there is a possibility of harm to the client as a result of the contact. Social workers who engage in appropriate physical contact with clients are responsible for setting clear, appropriate and culturally sensitive boundaries to govern such physical contact. (p. 12)

Personal space is as unique as each individual, couple this with distinctive pain experiences and professional practice guidelines, and it becomes paramount that you ask the sufferer if they want to be touched (M. Thomas, 1999). A physician sufferer believes that the laying on of hands has been lost; as she has had four-year-olds tell her not to touch them when she has been trying to examine them in her office. As she related:

The laying on of hands is something I've always done, and always will do. I hug my patients, I laugh with them, I joke with them, and I will always be that way, and I know that is politically incorrect now, but I still can't – I still would not be able to not hold a patient who is crying or someone who is in pain, I just think that's inhuman not to.

- **Establish connection to community.** Living with chronic pain can be a very isolating and lonely experience, as evidenced by the emotional descriptors identified by sufferers in this research and in the literature (Howell, 1994; Jackson, 2002; Mailis-Gagnon & Israelson, 2003). Pain support groups are available in various locations throughout Canada (Chronic Pain Association of Canada, 2004). Their function is twofold. The first is to provide support from other sufferers who know the struggles of living with pain, including the societal barriers, public and service deliverer's attitudinal assumptions, and the personal suffering. The second is to act as an information resource, sharing treatment

modalities, alternative interventions, and various accesses to information about pain. Breaking down the isolation can be a critical step towards healing.

Use of self, use of touch and established connection to community have been linked to Carniol's (2003) spiritual sensitivity skills. Carniol suggests that the worker use herself to relate to the client, drawing upon spiritual supports and holistic ways of helping and viewing the world, while seeking social and economic justice. Spiritual implies the inner connection and quest for wholeness within each sufferer and is not intended to prescribe to particular religious practice(s). Through the helping sufferer's use of her experience of pain, she is able to reach out to other sufferers in a uniquely intimate manner, knowing, without words, their strife and struggle and being able to connect with them through their common experience(s).

Meta-Narrative Challenged: In psychodynamic theory, particularly in classic psychoanalysis, the therapist is called upon to present herself as a 'blank screen' to the client (Payne, 1997), devoid of distinct personality, character and identity. The intent is to allow for the client's unconscious fantasies to surface. This technique is called transference, whereby the client transfers unconscious feelings about her parents onto the therapist, envisioning the therapist in a parental role. Once these unconscious feelings have surfaced, their meaning and impact can be discerned, potentially releasing the sufferer's entrapped pain. Sufferers in this research have challenged any notion of therapeutic distance, noting how vitally important it is for the chronic pain sufferer to feel a sense of connection, understanding and commitment from the worker. Given the isolation, the

vulnerability and the ongoing suffering experienced by those living with chronic pain, they do not need to experience a helper's indifference, even if therapeutically motivated.

The targeted population for this research was sufferers in the helping professions who were working with sufferers of chronic pain. Their personal knowledge of living with pain was both recognized and honoured. Sufferers helping sufferers, either within a professional context or a self-help mode, is fundamental to the chronic pain movement. The Chronic Pain Association of Canada (2004) support group statement locates the importance of this intervention to sufferers.

The support group will end the isolation of sufferers by showing that they may rely on others like themselves for understanding and help. Through their personal knowledge and experience, the gathering of information, and the advocacy of education and research, members will improve their quality of life and ultimately change how all sufferers are treated. (What is CPAC – Support Group Statement)

- **Understand the relationship between chronic pain and depression.** As one sufferer related her experience in dealing with a colleague while delivering a talk to physicians on fibromyalgia:

He still holds the belief that, basically, chronic pain people are depressed, they are basically crazy. And you either send them to a psychiatrist or you put them on anti-depressants and that's it ... prejudice that there is really nothing wrong with them.

This type of attitude has prevented sufferers from dealing with the emotional side effects of living with chronic pain, for if representatives from the medical establishment believe 'the pain is in the sufferer's head', her resistance mounts

and she is less likely to recognize or seek help for the psychological impact that living with chronic pain has infused into her daily existence. The sufferers in this research firmly believe this has created a huge disservice to chronic pain sufferers and their families, as emotionality and spirituality have been kept at a distance when addressing the complexities of life with pain. The historical practice of over-playing the psychological influence, seeing pain in a dichotomous split of mind versus body, has reinforced sufferers' fears of not being believed by the medical establishment (Greenhalgh, 2001; MacDonald, 2000, 2004a, Wendell, 1996). As Mailis-Gagnon and Israelson (2003) articulate:

This kind of dualism allows people to think that chronic pain may be either "real" or "imaginary". The concept of "imaginary" pain (also called "psychogenic" or "non-organic" pain) implies that pain may be exclusively generated by one's thoughts, imagination or psyche and may have no physical origin at all. Among pain practitioners, the thinking is moving beyond this split. There is now growing agreement that pain, and in particular, chronic pain, is multidimensional and that one must see the problem from its biological, psychological and social dimensions to get the whole picture. Even so, unfortunately, many doctors, bound by conventional medical thinking, still see things as caused by either mind or body. (p. 9)

The sufferers' experiences would suggest that it is not only physicians who are bound by conventional medical thinking in relation to chronic pain, but also other professionals, such as nurses and social workers. Furthermore, this dichotomous thinking has penetrated the perceptions of the general public, including the media, insurance agents, family and friends, increasing the isolation and disenfranchisement felt by sufferers themselves.

Meta-Narrative Challenged: The meta-narrative challenged is that depression is the presenting etiology behind chronic pain. Chronic pain sufferers are

sometimes treated with anti-depressants, specifically tricyclic antidepressants, which work by blocking nerve pathways in the central nervous system, not by mood alternation (Boulanger, 2002). However, their adjunct utilization in the treatment of chronic pain is often misunderstood and equated with the sufferer experiencing mental health problems rather than living in pain. This is not to say that depression in chronic pain sufferers does not exist or should be therapeutically ignored. The linkage between chronic pain and depression is a serious consideration. However, the entry point of intervention needs to be aimed at reducing the sufferer's pain. In the words of a sufferer quoted in Case F, "I wasn't depressed before I had that pain and if you'd get rid of it, I won't be depressed anymore." The intensity of living with chronic pain, the sheer suffering within each moment, the multiple losses pain imposes; the search for meaning and the quest for hope, all serve as underlying causation of depression. Begin with pain management, get the pain to a bearable level, then the sufferer is freed to work on emotional, familial, employment and other needs (Clark, 2004; Jovey, 2004).

- **For physicians, including general practitioners and family doctors, to be familiar and comfortable with prescribing long-acting, long-term medication, including opioids, for chronic pain.** Knowledge pertaining to medication options for sufferers should be available to helping professionals, especially prescribing physicians. The sufferers in this research had different experiences around medication needs and effectiveness. Some sufferers' pain was substantively relieved by long acting opioids. As one sufferer noted, "And it has

absolutely given me a quality of life that I didn't have before." Others have tried a combination of medications, including anticonvulsant drugs, such as Topiramate, which helps with pain perception. One had success with topical applications of compounded neurotransmitter medications, while another experienced substantive relief after she received treatment for a neurological sleep disorder. As she expressed, "My pain level started to reduce significantly, I was feeling human again, I started to laugh, I had a social life, I was feeling focused, still had a bit of difficulty with memory on occasion, but I couldn't get over it." However, narcotic medication was not the answer for all sufferers. Some could not tolerate the medication, and others chose not to go that route due to the potential side effects. Two sufferers, from their helping location, expressed concerns pertaining to addiction. One, as a social worker, had counselled three people who had, in her words:

Struggled with very serious and life destroying addiction to Dilaudid/Oxycontin. They have described very powerful stories of the evolution/transition of their experiences from pain control to drug addiction and they most poignantly related that had they but known, they would never have taken the meds initially, regardless of the pain. As this is one of the major fears of physicians that make them reluctant to prescribe for people with chronic pain, we need much, much more education and research into this whole, very contentious, dimension.

The other sufferer, a physician, believes that if you know your people, you know if they are appropriate candidates for opioid therapy. As she put it:

Their whole approach to life; sense of values, do they work, how significant was the injury that they had, how many times have they been in the office before. Personality structure, their attitude – whether the glass is half empty or half full, how they have managed in the past, what their coping skills are, the whole raft of things that you can't tell when you first

meet someone, if they are going to have difficulty or not. It takes time . . . to know your people.

Appropriate prescribing of medication for chronic pain sufferers has long been a debated practice, caught between the sufferings of chronic pain people versus the potential harm of addiction. Pain clinics and specialists, that consider many of the issues raised by the above sufferer, have developed protocols involving taking a detailed history from the sufferer. Others, like medical ethicist Margaret Sommerville, who was interviewed by Jovey (2002), have a distinctly clear position:

To leave a person in avoidable pain and suffering should be regarded as a serious breach of fundamental human rights [and] can be regarded not only as unethical, but also as negligence. (I am tempted to say criminal negligence). It also should be treated as unprofessional conduct; that is, it should constitute a basis for disciplinary action by the relevant professional licensing body. (p. 5)

Attitudes towards prescribing opioids are changing; for once opponents of such therapies are reconsidering their benefits, yet division remains (Turk, 1996). Some pain specialists are now weighing the benefit of treatment against the potential side effects, the primary side effects being reduction in function, development of tolerance or addictive behaviour (Turk, 1996). The American Pain Society conducted a survey of one hundred physicians, who averaged two-thirds of their practice treating non-malignant chronic pain patients. They “strongly agreed that the primary goal in the treatment of chronic pain patients is improvement in functioning, with symptomatic improvement of somewhat less importance” (Turk, 1996, p. 223). Whereas Jovey, Ennis, Gardner-Nix, Goldman, Hays, Lynch and Moulin (1998), on-behalf of the Canadian Pain Society, define

“the primary purpose of long term opioid therapy should be improved quality of life for the patient. Therefore, improved pain control is a reasonable and appropriate goal of treatment.” (p. 204). The Canadian Pain Society approved Jovey and colleagues’ consensus statement and guidelines for the treatment of chronic non-cancer pain with opioid analgesics, whereby they state that a major contributor to the under treatment of chronic pain is “the reluctance of physicians to prescribe adequate opioid therapy” (p. 198). Gardner-Nix (2003) identifies barriers to physicians’ prescribing opioids, including: fears associated with causing addiction, attracting addicts to their practice and enforcement by regulatory bodies, to lack of knowledge about opioid treatments and inadequate reimbursement for the treatment of chronic pain patients. All those working with chronic pain sufferers, be it physicians, nurses, social workers, or other helping professionals need to suspend judgement about opiate use and the associated beliefs of addiction. If agreement is not reached pertaining to treatment goals, then uniform approaches to treatment seem distant. The sufferer’s opinion does not enter into this debate, yet if asked, they would probably hold reduction of pain as a highest priority.

Carniol’s (2003) assessment skills identify both the immediate and long-term needs of the client, along with potentially harmful and oppressive structures. The worker needs to be skilled in assessing the depth of the sufferer’s depression and understand the direct correlation to pain intensity and longevity. A European study (Clark, 2004) found that one in six chronic pain sufferers’ pain was so severe that they wanted to die. The same study revealed that fifteen million

sufferers considered suicide because of their pain. The Chronic Pain Association of Canada (2004) indicated, “One of the most common reasons that people buy books on suicide and physician assisted suicide is the fear of living in severe intractable pain” (Pain facts).

The Meta-Narrative Challenged: The meta-narrative challenged is most expressively stated by Rosenfeld’s (2003) question: “Why is our disdain for addiction to narcotics greater than our intolerance of people living and dying in needless agony?” (p. xviii) A study conducted in the United States found that in 1996, one percent of chronic pain sufferers prescribed long-term, long-acting opioids became addicted. Five years later, the percentage had only increased to two percent (Jovey, 2004). Yet, many physicians are still reluctant to prescribe opioids to treat chronic pain. Often, their prescribing treatment alternative to opioids are NSAIDS (anti-inflammatory medications); however, in 1997, 17,000 people died in the United States from NSAIDS prescribed for pain (Jovey, 2004). Long-term use of anti-inflammatory medication creates significant risk factors. For example, you have a one in five hundred chance of developing a gastric bleed (ulceration and bleeding of the stomach), and a one in twelve hundred chance of dying from that bleed (Jovey, 2004). Opioids never cause organ damage and are believed to be the safest, most effective treatment choice for chronic pain (Goldman, 2003; Jovey, 2002, 2004; Rosenfeld, 2003).

Jovey (2004) suggests a treatment protocol that would identify a sufferer’s potential for addiction, believing addiction is primarily associated with genetic markers. Risk factors to screen for, in guarding against addiction, include the

following: extended family history of addiction, previous addiction history (alcohol or drugs), serious untreated psychiatric problems, previous legal problems and a high risk home environment. Jovey (2004) further suggests that the DSM IV (Diagnostic Statistical Manual for Mental Disorders from the American Psychiatric Association) criteria for classification of dependency (formerly called addiction) is inappropriate for chronic pain sufferers' assessment, in that four of the seven categories are applicable to sufferers given their experience of pain. For example, the patient experiences difficulty reducing dosage of the drug. Chronic pain sufferers will have difficulty in reducing a drug dosage because it will increase their experience of pain, especially if their medications are at therapeutic levels. Addiction needs to be specifically defined within a chronic pain context. Likewise, opioid therapy needs to be better understood by physicians and helping professionals, for the benefits it can produce for the sufferers. Opioids are most effective when they are delivered as part of a multi-modal treatment plan (Jovey, 2004). Jovey (2004) suggests the following formula for the consideration of opioid therapy: Chronic unrelieved pain + quality of life decreased + failed alternative treatments = opioid therapy trial. Physicians have a duty to treat sufferers (Canadian Medical Society, 2004), and other helping professionals have a duty to advocate with sufferers for appropriate treatment (Canadian Association of Social Workers, 2005).

6.3 Summary

Women in the helping professions, who are sufferers of chronic pain and (dis)Ability have stories to be shared; stories to be shared with fellow sufferers, and,

stories to be shared with those working with sufferers of chronic pain, stories that are transformed into testimonies by the political nature of their content and purpose. The testimonials told within this chapter come from their own lives as sufferers, specifically relating to their professional lives as women in the helping professions working with sufferers of chronic pain. The case stories capture their work with sufferers and, in turn, reveal aspects of health consumers' lives. Within their own tales, through determination, dedication and reflection, sufferers identified what was helpful for them when they sought medical intervention for their pain (details captured in Chapter Four and Five). Fundamentally, it was critical that those in a helping role believe the sufferer's account of her story, admire her strengths in dealing with pain, affirm what was working well and offer support in areas of struggle.

Validation, reassurance, compassion and empathy were all emotionally supportive approaches the women sufferers welcomed and respected from professional helpers. Being patient, open to dialogue, taking time to establish trust in the helping relationship, were all qualifiers that separated those who worked well with sufferers and those who did not. Sufferers sometimes need help in verbalizing their pain experience, whether by emotional descriptors, physical explanations or creative expressions (writing or drawing their pain); medical personnel should be able to facilitate this communication. Ultimately, the sufferers in this research wanted to be treated in a way that involved: being real to the sufferers; relating to them on an honest, up front basis; devoid of pretence or judgment; cleansed of the myths of narcotic misuse and depression depicted as pain; and engaged with sufferers as active participants in their own care.

Education for health care providers was viewed as vitally important in the treatment of chronic pain. This education would include the difference between acute and chronic pain, the physiology and biochemistry of pain, understanding pain pathways, treatment options, medications, and alternative therapies. The women believed traditional medical power relations needed to be challenged, putting the voice of the sufferer central to the helping process.

Finally, policy changes were noted. Chronic pain needs to be recognized as a debilitating condition, one that justifies insurance support, accommodation and treatment. By being willing to listen to the sufferer's testimony, much is possible. The chart 'Anti-oppressive Challenges for Working with Chronic Pain Sufferers' captures the essence of this chapter, linking anti-oppressive skills derived from two established social work scholars in the field, Ben Carniol (2000, 2003) from Canada, and Lena Dominelli (1996, 1998, 2002) from the United Kingdom, and associated with learnings derived from the case stories and guiding principles for practice outlined by the sufferers. The final column of the chart highlights the meta-narratives that have been challenged by this empowerment based intervention (see Appendix L).

Social workers, working from an anti-oppressive location, are called to "build alliances across structural differences" (Carniol, 2000). In working with chronic pain sufferers, this translates into being able to pull together the various constituents (in health care, disability pension and insurance, employers, recreational, leisure and community and so forth), while moving towards structural transformation in meeting the needs of sufferers from a location of empowerment. Social work skills are used to reframe the sufferer's situation to reduce self-blame, validate the sufferer, provide a critical lens to

their oppressive experiences, raise the sufferer's consciousness to a level of political awareness and re-shape assessment skills to highlight structural inequalities. Ultimately, social workers should use their advocacy skills to help mobilize a sufferer-based social movement, for it is when sufferers come together that strength in voice is found (MacDonald, 2000, 2004a).

Chapter Seven – Implications and Future Directions

7.0 Introduction

As narrative inquiry suggests, with every reading of the text, new insight and understanding emerge, changing the relationship between the reader, the text, and those who testify (Beverley, 2000; Lieblich et al., 1998; Riessman, 2002). Morris (2002) proposes a conceptualization of ‘thinking with stories’, whereby one allows the narrative to work on them. The testimonies in this research are rich with insight, challenges and practice directives. Listeners have an obligation to not only listen, but to listen with the intent of action. The sufferers risked exposing their inner thoughts and experiences, not as an entertaining read, but to pay witness to their oppression and marginalization, to give voice to what they have lived through as chronic pain sufferers, ultimately, to help other sufferers. Each narrative format, be it the sufferers’ stories in Chapter Four, the personal analysis contained in Chapter Five, or the professional insights relayed throughout Chapter Six, contain the potential for multiple levels of understanding. An alternative lens to chronic pain is brought forward by unsettling and outwardly challenging the meta-narratives of chronic pain found within the medical, helping professional and societal environments. Knowledge defined as professional expertise shifts to sufferer centered ways of knowing.

In this concluding chapter, the focus will be upon the research process, specifically attending to the impact the research has had upon the sufferers involved as participants, the influence upon myself both as a researcher and as a chronic pain sufferer, a brief summary of the major challenges put forth through the analysis of

sufferers' testimonies and applied use of the findings. The chapter will conclude with envisioned future research directions shaped by this work.

7.1. Impact of Research Upon Sufferers

“Perhaps in learning to tell my story I began to learn, better than I ever had, what my own voice sounded like.” (Frank, 1997, p. 36)

The sufferers in this research willingly engaged in a testifying process, a process that had the potential to surface emotional struggles, spark pain memories and unsettle undisclosed perceptions of pain experiences. The untold stories, indicated in the title of this research, had never previously been called into the open. Through inviting the sufferers to share their experiences, the untold became told. Until this opportunity arose, the sufferers' professional identity over-shadowed their pain experiences, as their helping roles positioned the focus of care upon others. Through politicizing their experiences as sufferers', they recognized their own voices as vehicles towards the empowerment of pain sufferers. All sufferers regarded this research as very important work, identifying the primary goals as educating those working in the field of chronic pain and validating sufferers' experiences. The sufferers' stories derived from their own experiences of living with chronic pain and informed by their professional knowledges are central to the research process. The sufferers were unique, for their lens was both personal and professional; yet, it is from the personal that professional directives were envisioned. The relational flow allowed them to hear the sound of their own voices.

Barbara remarked on the influence of hearing other sufferers' stories: “it was amazing how affirming it was for me . . . it was amazing, that sounds like my story. I guess I was in awe of myself, to be honest with you” (teleconference, April, 2004).

During the interview processes, sufferers' interpretive understanding of their pain experiences sometimes shifted when questions of clarification prompted a cognitive exploration, as in for example, "I don't know what it is . . . I think what it is, is that . . ."; or from another sufferer, "I really don't know. The only thing I can think of, and I am not sure, I haven't really thought of it before" (primary interview transcripts). The challenge to think about their experiences pushed the theoretical envelope associated with chronic pain, adding depth and breadth to this already rich pool of understandings and knowledges.

Maintaining an anti-oppressive lens to the research process, I consulted the sufferers about the impact of the research on their lives. During the summer of 2005, I sent an e-mail to the participants who corresponded in this method, and called the one who did not have e-mail, asking about the impact of being a participant in this research. Their responses were in keeping with their comments at the time of the teleconference; primarily, the experience was validating, emotionally intense for some, yet overall empowering. Evelyn wrote:

The impact was very apparent, first of all, the overwhelming realization of my life experiences caused a great deal of sadness, a sense of loss, missed opportunities, mostly due to my fears, which were like monsters clutching at my throat, holding me down. It is a relief that the fears are less, but many remain. I am working on it. You asked the right questions – thank you. It was good to talk about it, to the extent that I did, because it helped me recognize that I no longer had to deal with the guilt or the shame about poor health, adoption, divorce, disability, constant pain. So yes, many shadows appeared after our interview, but with the shadows came wisdom, more clarity, and more strength.

Evelyn's comment reveals the complexity, within which chronic pain exists, as pain is not an isolated, detached occurrence, it is woven within our daily experiences and our relationships.

Dawn highlighted the importance of connecting with other sufferers in her response, as she wrote:

The experience, for me, has been nothing but positive and validating. I especially found the conference call to be so – hearing women, in pain, yet positive, strong and reaching out to others. The value of the narrative, for example, telling one's story, is extremely powerful. The whole experience has made me feel like I was making a difference.

Helen's participation in the research coincided with her own storying of her pain journey, as she affirmed, "Together, they worked to make the memories come forward."

Barbara framed her response along similar lines, as she reflected upon participating: "It provided the opportunity to re-visit my journey and facilitated the articulation of my experience(s) of living with and managing chronic pain." She also went on to identify a number of personal revelations stemming from her involvement.

I think a few of the most interesting revelations for me were; my abilities to adapt and cope 'against all odds', my strength to make significant lifestyle and relationship changes (i.e. saying no, reducing a hectic social life, 'discharging' my life of people who sapped, or negatively affected, my energy, self-identifying as a person with disabilities, complementing Western medical interventions with other therapies and nutritional healing, and meditation), discovering the passion I have for life and helping others, and most importantly, the love I have for myself, as I am (or am not).

Barbara's comment speaks to the research intent of empowering the sufferers, as they testify to their experiences of life with pain.

Not all participants felt that the totality of their experiences was shared amongst other sufferers. Marg believed her "context and experiences were different", for she was the only participant who experienced both malignant and non-malignant pain. As well, Marg was the only participant who was unable to link into the teleconference, which might speak in some way to her feelings of disconnect. Marg articulated her position:

My personal experience with, approach toward and attitude about my own pain experience is vitally important to me, but seems and feels often as though it is different from, if not contrary to, much of the common/accepted beliefs and practices regarding chronic pain. I hold very strong and important beliefs (personal) regarding medication, and my whole thrust in coping with pain has always been a more 'existential' one. This has worked very well for me and is a most important part of me. I neither recommend it to others necessarily, nor do I advocate a non-medical approach to others . . . in fact, I realize and respect that for many, medication and the appropriate use of meds can make the difference between life being intolerable and liveable. Still, I believe it is important that this be a part of the discourse.

Marg's honest and frank sharing created moments of reflection and pause for me, in my role as the researcher. For example, I returned to the narrative analysis and made sure her difference was evident. Adhering to post-modern lens, there is not one truth or belief that captures the experiences of sufferers, but multiple truths that create the essence of sufferers' struggles in pain (Ristock & Pennell, 1996). Through phenomenal cognitive processes, Marg was able to control her malignant pain experiences, with some difficulty utilizing this approach with her non-malignant pain. Much remains unknown about the connections between mind and body. Reactions to the meta-narrative classification of pain within psychological parameters, whereby medicine pathologized the sufferer's pain as psychological dysfunction, cannot limit our understanding of the interrelationship between physical pain and cognitive-emotional processes. The challenge, thus, becomes being open to multiple ways of understanding pain.

Marg noted that being involved in the research "stimulated several very good discussions with colleagues and clients, both those living with pain and those who are not . . . most useful, frank, open, challenging discussions – bonus". bendy stated that participation lead to her being more aware of the issues, practice needs and current trends

in pain management and reinforced the importance of networking and supports for sufferers.

Anti-oppressive practices were fundamental to the research, not only as part of the research guiding question, but also as principles shaping the process. Knowledges of the sufferers were invited, validated and centered.

7.2 Researcher's Reflection

The turbulent journey, filled with moments of emotional strife and physical exhaustion, did not begin with the formulation of a research question, but rather was initiated twenty years ago, when my life was reshaped by the onset of chronic pain. Chronic pain alters one's life's path, the dreams, hopes, aspirations all need to be recalibrated to accommodate the (dis)Ability. Negotiating this (dis)Ability calls upon every coping strategy imaginable (Howell, 1994; Seers & Friedli, 1996). Pain is encircling, as it invades the sufferer's personal space, leaving one vulnerable, exposed and estranged to elements of normalcy. The challenges before the sufferer are of physical, emotional, spiritual, social, economic and political dimensions.

Journaling, writing and storying my experiences was a way to keep myself present to the challenges. Initially, I critiqued the chronic pain treatment model, cognitive-behavioural contingency management, used in pain treatment centres, predominantly aimed at patients with undefined etiology (MacDonald, 2000). I then followed this with a more personal exploration into my own oppressive experiences in seeking medical intervention for chronic pain, specifically highlighting my reflections of being a patient in a chronic pain treatment program, which was based upon the contingency management model (MacDonald, 2004a). While I was in the program, I

wrote reflective notes about my experiences, connected with other patients and extended an invitation to write collaboratively about our experiences. The program was so oppressive and emotionally unsettling that this plan never materialized. The sufferers I contacted upon discharge wanted to forget this emotionally tormenting experience. I had to respect their position and honour their request.

As it turned out, writing about this experience was not an easy process, as it took numerous drafts, over a lengthy time period, to eventually arrive at a manuscript that I felt confident in putting forward for publication. The following quotation, taken from this publication, demonstrates the openness with which I wrote about my life with pain.

Moving was becoming impossible; staying still produced little relief. My leg felt like a dead weight dragged along at the hip, hypersensitive to touch, vibrations, and sounds, and incredibly painful. Every hour stretched into a lifetime, seemingly, time stood still. Hope was continuously being redefined, from initially wishing for a cure to eventually settling for a moment's relief. Life had become gravely serious, as I lost my capacity to spontaneously laugh. Every ounce of determination and will had to be mustered to cope with an ordinary day. I was so tired of pushing – constantly pushing, the simplest of tasks became calculated ventures. Chronic pain became my defining identity, it was all encompassing. (MacDonald, 2004a, p. 26)

Even with this evolving process, I felt vulnerable and emotionally naked when I submitted this work. The strength of my spirit rose to the surface, for I knew in my heart there was an important story to be told and that through testifying, both I and other sufferers would be vindicated.

Chronic pain was the focused area of my personal writing, while my professional association was primarily in the area of (dis)Ability. Wanting to understand the connection between the two, my doctoral internship focused on community consultations in both areas. Understanding chronic pain as a (dis)Abling condition is a pre-emptive position to the selection of a testimonio methodology for this research. The cumulative

effects of the above experiences led to wanting to honour sufferers' experiences, work as collaboratively as possible in a researcher/participant relationship, communicate sufferers' experiences to the helping professions (including the medical field), and formulate sufferers' combined knowledges into practice guidelines.

Attention to ethics and process were vital components of this research, for I knew intimately the vulnerability experienced by sufferers sharing their pain journeys. This research was a politically defined encounter, whereby sufferers would testify to the injustices they have experienced. Through personal testimonies and coming together as a group in the teleconference, they heard their own voices and the voices of other sufferers. Their testimonies served as a base for accumulative analysis and practice directives; their experiences, insights and knowledges would reach other helping professionals working with chronic pain sufferers and other sufferers. Direction and purpose were attached to their stories. This was not a retelling process, but a moving forward, defined as testifying (Beverley, 2000; Tierney, 2000) or as quest stories (Frank, 1995), with direction and purpose attached to their stories.

Sufferers of chronic pain have had their voices silenced (Brown & Williams, 1995; Greenhalgh, 2001; Howell, 1994; Seers & Friedli, 1996), shifting this discourse, one aim of this research was to recognize the voices of the sufferers and, thus, empower them through this process. Initially, I had envisioned myself as a participant in the research, for I fully met the sampling criteria, in that I was: a woman; a member of the helping professions; had worked with chronic pain sufferers within my helping roles; was a Canadian citizen, having received the majority of my medical intervention within Canada; and had lived with chronic non-malignant pain for more than two years.

However, after much deliberation and reflection, I came to the conclusion that I had journeyed the road I was asking the sufferers to travel, in that I had written about my own experiences, been a participant in health research relaying my story, and publicly challenged the meta-narratives currently ordering the discourse in chronic pain. My role this time was to be responsible for the process, including debriefing and follow-up protocol. Safe-guards against my own identity/story influencing the research were taken: I wrote my own illness narrative a few years prior to commencing this research and therefore did not have the pressing need to re-story my experiences; findings were associated with current literature in the fields of chronic pain and disability; I was forthcoming about my role as a researcher who was also a chronic pain sufferer; and finally, all data collection processes and narrative analysis were transparent. The participants knew me as a sufferer of chronic pain, which was, and continues to be, a forming element of my identity. This linkage to the participants is a unique feature of this research, for I felt it was a working-with process, a collaborative venture, whereby their testimonies and my analysis created a new way of understanding chronic pain and an anti-oppressive way of working with sufferers. Clandinin and Connelly (2000) articulate the interconnection between participants and researcher: "Participants are in relation, and we, as researchers, are in relation to participants. Relationship is at the heart of thinking narratively. Relationship is key to what it is that narrative inquirers do" (p. 189).

Personally, this was another chapter in my journey with chronic pain; the research was both rewarding and difficult at times. Paying witness to their testimonies raised to the surface my own struggles with pain and oppressive aspects of treatment.

Commonalities sparked memories; revisiting memories from the perspective of a researcher led to new insights, including being able to conceptualize beyond a single lens into multiple perspectives and alternate ways of knowing. I firmly believe that my understanding of chronic pain has grown through this venture and that my commitment to anti-oppressive ways of working with sufferers has been reaffirmed. The conceptualization of specific practice principles emerged from this initiative, setting inclusive guidelines for working with chronic pain sufferers. Finally, my confidence as a researcher has evolved, knowing that I can structure research in a way that will honour my practice ethics and put the voice of the participants' central to the process.

7.3 Major Challenges

Morris (2002) claims that the relationship between medicine and narrative is evolving: "Today, narrative in medicine . . . has not fully unpacked its bags, but it has definitely arrived" (p. 202). He further suggests that the post-modern era's understanding of pain has moved beyond the rigid parameters of biomedicine to engage with the narrative form of illness stories. Both the literature review and the sufferers' testimonies would suggest that narrative is still very much on the margins. However, challenges from the margins, in time, can change the political landscape facilitating the emergence of alternative discourses (Dominelli, 2002; Mullaly, 2002). This research study holds the potential to significantly influence helping professionals, as they seek out ways to better connect with chronic pain sufferers. Unsettling the medical discourse, while disrupting the hierarchal ordering of physician knowledge, will make room for the sufferer's voice, as it becomes central to intervention. Together, the helping professionals and sufferers can work toward an understanding and management of the sufferer's pain.

The women sufferers participating in this research wanted their testimonies to reach other sufferers, to break-down the isolation ensnarled in the struggle with chronic pain, to validate sufferers' experiences and self-knowledge of pain and to raise their consciousness of the meta-narratives influencing current chronic pain theory and treatment. According to Carniol (2000), "postmodernism reflected a radical questioning of the "grand theories" and ideologies of the modern era . . . a revolt against authority" (p. 145). From the beginning, participants viewed involvement in the research as a way to bring forward a new discourse on pain that would raise awareness of the life altering struggles of sufferers and, at the same time, validate sufferers' ways of knowing. "We shape our world and ourselves by telling stories. To change, we must bring a new story into being" (Hyden & Overlien, 2004, p. 254). Through the depictions of the sufferers' stories, the foundation for this reshaping was laid.

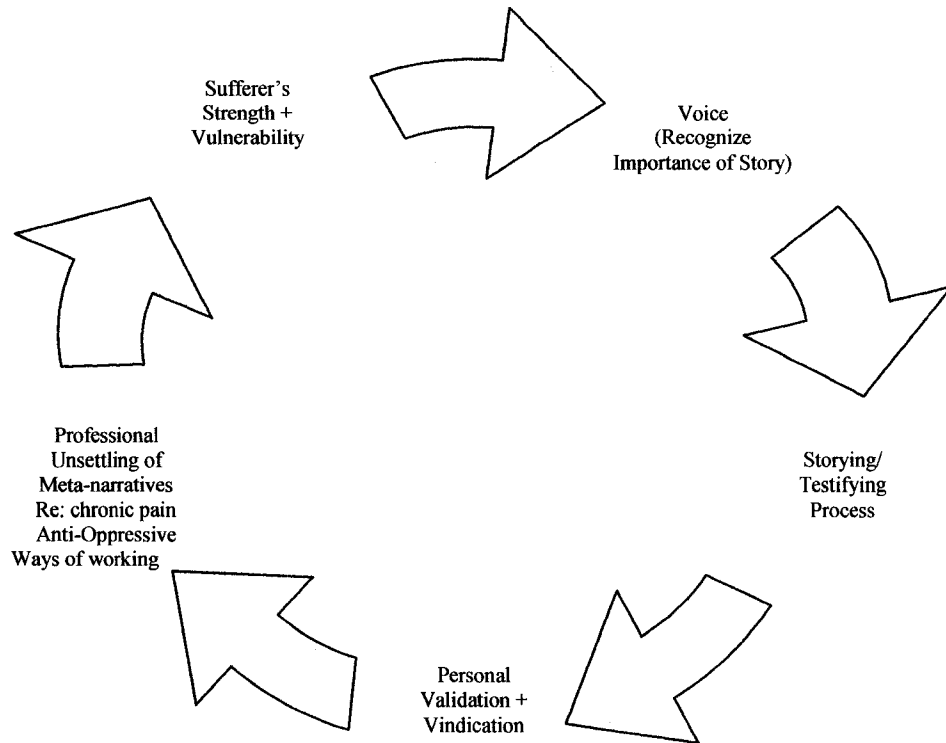
While many of the stories told in this research consisted of similar experiences, recognition of sufferers' diversity and differences need to be acknowledged. Post-modern principles of "the subjected self as knowledge source, diversity and difference, uncertainty, and multiple viewpoints" (Brotman & Pollack, 1997, p. 13) outwardly challenge the dominant discourse of medicine, where the physician is holder of knowledge and expertise (Greenhalgh, 2001). The medical discourse needs to be disrupted, calling for an inclusive understanding of pain through a mind, body and spirit environment conceptualization, anchored in collaborative work with the sufferer. Balancing anti-oppression's recognition of collective strength (Carniol, 2000; Mullaly, 2002) with postmodernism's personal autonomy (Carniol, 2000), the splintering of

chronic pain sufferers, through the individualistic lens of medicine, is challenged. Appel (2005) states:

If the patient's narrative is not heard fully, the possibility of diagnostic and therapeutic error increases, the likelihood of personal connections resulting from a shared experience diminishes, empathic opportunities are missed and patients may not feel understood or cared for. (p. 1637)

Without denying diversity and differences, common themes were identified across the analysis and storying, specifically: the inter-linkage of sufferers' strength with their vulnerability; the proclamation of voice, through which they realized the importance of telling their stories; engagement with the storying/testifying process, which led to personal validation and vindication; and finally, at a professional level, the unsettling of chronic pain meta-narratives and the identification of anti-oppressive ways of working with sufferers. These common themes are depicted below in Figure 7.1. The storied experiences of living with chronic pain begin and end with the sufferer's strength and vulnerability; both need to be recognized and validated throughout the helping relationship. An invitation needs to be extended to the sufferer to tell her story. Here, it becomes vital that the helping professional validates the sufferer's experiences, truly listening to her pain journey, with all the injustices and supports it might entail. Further, the helping professional has a duty to identify and unsettle the meta-narratives that are currently influencing chronic pain treatment, at the same time framing an alternative way of working with the sufferer from an anti-oppressive perspective. Through the implementation of anti-oppressive skills, the helping professional is always engaged with recognizing and understanding the sufferer's strengths and vulnerabilities.

Figure 7.1: Common Themes



Each step within the above figure is interconnected to the next, for example, without sufferers' having the strength to engage in testifying, the validation and vindication of their experiences would cease to materialize, thus, stifling their ability to unsettle meta-narratives through critical reflection. Consequently, a new way of working with sufferers would not be envisioned. Chronic pain sufferers experience moments of vulnerability, yet, it is critically important that they find the strength for their voice to come forward, for telling their story is central to the change process. The sufferers' personal testimonies identified resilience in their ability to cope with emotional stressors, for each sense of loss or fear was counterbalanced by a coping strategy, identifying strength amongst vulnerability and hope amongst despair.

Sufferers “become more effective authors of their own lives” (Carniol, 2000, p. 147) through the reclaiming of their voice. The empowerment of sufferers can be achieved through validating their stories, where their experiences of oppression are vindicated. Ultimately, social workers and other helping professionals need to join sufferers in critiquing the existing social and health systems, “mobilizing themselves, clients (replace with sufferers) and others to bring about egalitarian social relations that foster social justice” (Dominelli, 2002, p. 185).

In defining an anti-oppressive way of working with sufferers, power relations need to be recognized and re-ordered. The sufferers in this research told of oppressive experiences while trying to negotiate treatment options for their pain. They spoke about how their voice was denied under the cloak of medical expertise, and how their patient label lowered them to a status without power, voice and the acknowledgment of personal expertise. Power needs to be redistributed, placing the sufferer at the center of any emerging discourse on pain. Carniol (2000) calls for a “harness of grassroots power” (p. 149), while Dominelli (2002) believes in order to “actualise client empowerment,” workers need to “acknowledge power differentials, and recognize client agency, knowledge and skills” (p. 185).

From a post-modern perspective, multiple stories exist, yielding unlimited understandings. The testimonies of the sufferers have illustrated this complexity, while at the same time, recognized similarities. An anti-oppressive way of working with sufferers will provide room for the voices of all sufferers to be heard.

7.4 Applied Use of Research Findings

The second question asked of participants during the summer of 2005 was focused on how they would like to see the research utilized. Most suggested publishing in health related or pain specific research journals. Helen firmly identified the need for the research to get disseminated to other sufferers, to breakdown the isolation so easily created by pain, helping sufferers feel that they are not alone in this struggle. Frank (1995) identifies the testimony of an illness story as a communal process, whereby “illness stories require an interplay of mutual presences: the listener must be present as a potentially suffering body to receive the testimony that is the suffering body of the teller” (p. 144). Reaching out to sufferers in this manner requires an ethically conscious method of distribution. The presentation of the illness stories demands a mutual process and therefore, the potential vulnerability created in the listener must be addressed. Reporting the findings on personal coping strategies constitutes a beginning, but highlighting community supports, national pain organizations and advocacy groups would be advisable. Publishing a feature article in a magazine or restructuring the dissertation to form a book for general distribution would reach sufferers. Chronic pain support groups and sufferer advocates could be specifically notified of the dissertation.

bendy would like to see the research circulated to chronic pain clinics and the Canadian Medical Association, recognizing the importance of reaching those at the “foot level” of intervention. Reaching physicians through the testimonies of sufferers’ calls for a cultural change in the dominant medical discourse, whereby the hierarchal medical structures would be dethroned, allowing room for communion with the sufferer. “The demand of ... testimony is for other bodies to commune with her in her pain, because

only through her pain has she learned what really matters. Normals and whitecoats can learn what really matters only through communion with her” (Frank, 1995, p. 145). A shift in ethic of care is needed for physicians and other helping professionals to really witness the testimony of the sufferer. “Being with” the sufferer is established as a priority. Disseminating sufferers’ testimonies and the practice guidelines might raise the consciousness of the helping professionals so that movement in this direction will eventually be realized. Agreeably, if change is going to be forthcoming, frontline workers need to be challenged by this work.

Aspects of the work have already been presented at conferences in Canada, the United States and the United Kingdom, and two conference papers have been published in conference proceedings. Chapter Five has been presented at the Narrative Matters Conference in Fredericton, New Brunswick, May 2004 (MacDonald, 2004b); Chapter Six has been presented at Community, Work and Family Conference in Manchester, England, March, 2005 (MacDonald, 2005b) and the Pacific Sociological Conference in Portland, Oregon, April, 2005 (MacDonald, 2005c), and a poster presentation of the autoethnographic pieces has been displayed at the Diversity Institute, Faculty of Health Professions, Dalhousie University, May 2005 (MacDonald, 2005d). Two abstracts have been accepted for a paper and poster presentation at the Narrative Matters Conference at Acadia University, in May 2006 (MacDonald, 2006a, 2006b). And a manuscript has been submitted to a predominant social work health journal that, if accepted for publication, would reach thousands of social work practitioners in health care (MacDonald, 2006c). Most of the presentations to date have been to academics or community workers, who already have an interest in the subject from a sufferer centered

position. Future dissemination needs to be aimed at sufferers, helping professionals working in the area of chronic pain, and physicians/pain theorists who profess to the meta-narratives challenged within this research. Presenting at a national conference on disability would reach those who identify with the disability community and experience chronic pain, but are not yet associated with a pain group. Social work, and specifically, social work in health settings, could benefit from the anti-oppressive model of practice developed from the professional findings. I teach a master's course on the theory and practice of anti-oppressive social work and will use this model in class as an example of specific practices from an anti-oppressive theoretical perspective. The above activities and the envisioned future directives address to Riessman's (2002) notion of trustworthiness, whereby the research becomes public and accessible to the social world.

7.5 Future Directions

At the beginning, when I was meeting with individual participants, I acknowledged the wealth of knowledge and resources this group of women possessed. As I accumulated the data through interviewing the women, I became all the more aware of our potential as a research group. Each participant was asked if she would be interested in further work on chronic pain, specifically, in getting together to formulate a research question or identify an area of exploration and draft a proposal. All expressed interest, as long as I facilitated the process. I envision applying for research development funds so that we can physically come together over a period of a few days, to brainstorm ideas and sketch the key components of a funding proposal. One possibility could be having the sufferers each examine their own discipline; for example, the physicians would lead the research segment focused on physician sufferers' views of pain. The findings could be

examined across disciplines, noting any differences between physicians, social workers and nurses. Through the categorical-form analysis, it was noted the sufferers' disciplines impacted the way in which they told their stories; for example, the physicians told their stories in a logical, sequential manner focusing upon events. Further research could explore the relationship between form and the professional discipline of the teller.

Chronic pain has traditionally been contained within the dominant medical discourse, based upon white patriarchal power structures (Greenhalgh, 2001). The experiences of sufferers from racially marginalized groups still need to be explored, in consciousness of the interlocking layers of oppression twined within their testimonies. I would envision working in collaboration with African Canadian and Aboriginal scholars, taking their lead on establishing ethical protocols for working within their communities. Colleagues at the School of Social Work, Dalhousie University, have expertise in these areas. One has done remarkable work on black men's experiences of health and the other is nationally involved in Aboriginal health consortiums. Initially, I would have a dialogue with them about their perceptions of chronic pain issues within their communities, relying upon their knowledges to guide the subsequent steps.

Finally, I am involved with the Canadian Association of Schools of Social Work, Disability Caucus. I envision utilizing this national group to brainstorm the source of the 'disconnect' between the disability community and chronic pain (MacDonald, 2001). Specifically, exploring the question: Why do people who identify themselves as having a (dis)Ability stay away from chronic pain services/associations and subsequently suffer with untreated pain, and why do chronic pain sufferers deny their (dis)Ability?

There are many possibilities for future research in chronic pain from a sufferer centered perspective. Preliminary sketches have been presented here, once I begin to explore some of these options, directionality will surface.

7.6 Summary

Atkinson (1998) identifies numerous potential benefits to sharing a life story, including “Sharing one’s story is a way of purging, or releasing, certain burdens and validating personal experience. Sharing one’s story helps create community and may show that we have more in common with others than we thought” (p. 26). Through a narrative testimonio methodology, the sufferers in this research shared their stories with the intent of reaching out to the chronic pain and disability communities through the identification of their own experiences while negotiating life with pain. The purpose was to validate and empower other sufferers through the envisioning of an anti-oppressive way of working with sufferers. Multiple meta-narratives were unsettled, while calling for alternative discourses based upon a rights-based, sufferer centered perspective.

The limitations of this research begin with the small number of participants, for it would have been wonderful to hear from dozens of sufferers, but, within a narrative framework, this would have proved cumbersome (Atkinson, 1998; Lieblich et al., 1998; Tierney, 2000). Capturing the illness stories of six participants does not lend to generalizations or statistical verifications. However, Riessman (1993) suggests, “There is a long tradition in science of building inferences from cases” (p. 70). Another limitation was the lack of racial diversity. This has stimulated my interest in working

collaboratively with racially marginalized communities to explore the potential of research on chronic pain. The final limitation is the time consuming nature of narrative inquiry, the hours it took to transcribe the interviews, the reading and re-reading of the transcripts, color coding with markers and stickers, only to revisit the transcripts with each emerging theme (Beverley, 2000; Riessman, 1993, 2002; Tierney, 2000). While it was time consuming, with each reading, my relationship to the sufferers deepened.

The strengths of the research are that it invites forward the frameworks of the participants, gives voice to marginalized sufferers who are often silenced by the dominant discourses, and brings personal interpretations and meanings into the public realm (Riessman, 1993, 2002; Tierney, 2000). Tierney (2000) attests, “a goal of life history work in a post-modern age is to break the stranglehold of metanarratives that establishes rules of truth, legitimacy, and identity” (p. 546). Throughout this research, meta-narratives were identified, and subsequently challenged by the testimonies of the sufferers and by the emerging analysis.

This work is not considered a finished product, but rather a starting point to conceptualizing pain from the sufferers’ perspectives. The hope is that other sufferers will feel empowered to tell their stories, so that the storied lives of chronic pain sufferers continues to evolve. For, within a testimonio methodology, “previously excluded groups . . . become redefined and redescribed” (Tierney, 2000, p. 546). As a chronic pain sufferer, I began by telling my story and then invited the stories of other women, who were helping professionals living with pain, to tell their stories. Together, we envisioned an alternative way of working with sufferers, one that gave voice to sufferers’ knowledge, validated their experiences of life with pain, and called them into a

collaborative working relationship aimed towards the control of their pain. Helping professions can be a “source of oppression” or “a means of liberation” (Bendelow & Williams, 1996, p. 1135) for chronic pain sufferers. Inviting sufferers’ own narratives of pain into the helping relation, and being totally present with their storied pain, is a step towards sufferer empowerment. As Jackson (2002) proclaims, “in for a penny, in for a pound, when someone passes on their pain story” (p. 39). Helping professionals need to slow down, take time with sufferers, to truly get to know them and understand their pain experience.

Being true to the narrative process, each reading of this work should evoke new interpretations, thus, suggesting that the relationship with the sufferer and their storied self is an evolving, ever changing dynamic. According to Lieblich et al. (1998):

Narrative materials – like reality itself – can be read, understood, and analyzed in extremely diverse ways, and that reaching alternative narrative accounts is by no means an indication of inadequate scholarship, but a manifestation of the wealth of such material and the range of sensitivities of different readers. (p. 171)

As a pain sufferer and as the author of this text, I hope that this work opens up the dialogue on chronic pain, eliciting multiple understandings and perspectives from the position of sufferers and helping professionals. For it is only through dialogue and a willingness to listen to sufferers’ accounts of living with pain that new insights will emerge.

Bibliography

Agar, M., & Hobbs, J. (1982). Interpreting discourse: Coherence and the analysis of ethnographic interviews. *Discourse Processes*, 5, 1 – 32.

Ahern, D. (2002). Psychosocial and behavioral approaches. In J. Ballantyne (Ed.), *The Massachusetts General Hospital handbook of pain management* (2nd ed., pp. 224 – 236). Boston, MA: Lippincott Williams & Wilkins.

Anderson, V. (2000). A will of its own: Experiencing the body in severe chronic illness. In B. Miedema, J. Stoppard, & V. Anderson (Eds.), *Women's bodies, women's lives: Health, well-being and body image* (pp. 29 – 41). Toronto, ON: Sumach Press.

Appel, P. (2005, October 13). Book review, Narrative, pain & suffering. *New England Journal of Medicine*, 353(15), 1637.

Armstrong, P., & Armstrong, H. (2003). *Wasting away: The undermining of Canadian health care* (2nd ed.). Don Mills, ON: Oxford University Press.

Arnstein, P. (2003). Comprehensive analysis and management of chronic pain. *The Nursing Clinics of North America*, 38, 403 – 417.

Atkinson, R. (1998). *The life story interview*. Qualitative research methods, series 44. Thousand Oaks, CA: Sage.

Barber, K. (Ed.). (1998). *The Canadian Oxford dictionary*. Toronto, ON: Oxford University Press.

Becker, B. (1999). Narratives of pain in later life and conventions of storytelling. *Journal of Aging Studies*, 13(1), 73 – 87.

Bendelow, G., & Williams, S. (1995). Transcending the dualism: Towards a sociology of pain. *Sociology of Health and Illness*, 17, 139 – 165.

Bendelow, G., & Williams, S. (1996). The end of the road? Lay views on a pain-relief clinic. *Social Sciences Medicine*, 43, 1127 – 1136.

Bernard, W. T., & Hamilton-Hinch, B. (2005). *Making diversity work: From awareness to institutional change*. Manuscript submitted for publication.

Beverly, J. (1992). The margin at the center: On testimonio (testimonial narrative). In S. Smith & J. Watson (Eds.), *De/colonizing the subject: The politics of gender in women's autobiography* (pp. 91 – 114). Minneapolis, MN: University of Minnesota Press.

- Beverley, J. (2000). Testimonio, subalternity, and narrative authority. In N. Denzin & Y. Lincoln (Eds.), *Handbook of qualitative research* (2nd ed., pp.555 – 565). Thousand Oaks, CA: Sage.
- Bickenbach, J. (1993). *Physical disability and social policy*. Toronto, ON: University of Toronto Press.
- Blackwell, B. (1989). Chronic pain. In H. Kaplan (Ed.), *Comprehensive textbook of psychiatry* (pp. 1289 – 1290). Baltimore, MN: Williams & Wilkins.
- Bonica, J. (1990). Multidisciplinary/interdisciplinary pain programs. In J. Bonica (Ed.), *The management of pain* (pp. 197 – 208). Philadelphia, PA: Lea & Febiger.
- Boulanger, A. (2002). Non-opioid analgesics and con-analgesics. In R. Jovey (Ed.), *Managing pain: The Canadian healthcare professional's reference* (pp. 31 – 36). Toronto, ON: Purdue Pharma.
- Brody, H. (2003). *Stories of sickness* (2nd ed.). Toronto, ON: Oxford University Press.
- Brotman, S., & Pollack, S. (1997). Loss of context: The problems of merging postmodernism with feminist social work. *Canadian Social Work Review*, 14(1), 9 – 21.
- Brown, S., & Williams, A. (1995). Women's experiences of rheumatoid arthritis. *Journal of Advanced Nursing*, 21, 695 – 701.
- Bruner, J. (1987). Life as narrative. *Social Research*, 54(1), 11 – 32.
- Bruner, J. (1996). *The culture of education*. Cambridge, Massachusetts: Harvard University Press.
- Bruner, J. (2002). *Making stories: Law, literature, life*. New York, N.Y.: Farrar, Straus and Giroux.
- Bury, M. (1998). Postmodernity and health. In G. Scambler & P. Higgs (Eds.), *Modernity, medicine and health* (pp. 1 – 28). London, U.K.: Routledge Press.
- Campbell, C. (Ed.). (2003). AOSW: Promoting equality and social justice [Online]. Available: <http://aosw.socialwork.dal.ca/index.html>
- Campbell, J. (1996). Pain treatment centers: A surgeon's perspective. In M.J.M. Cohen & J.N. Campbell (Eds.), *Progress in Pain Research and Management* (Vol. 7, pp. 29 – 37). Seattle, WA: IASP Press.
- Canadian Association of Social Workers. (2005, March). Code of ethics: Guidelines for ethical practice. Ottawa, Ontario.

Canadian Broadcast Corporation. (2004, January 15th). WCB revisits chronic pain [On-line]. Available: <http://www.cbc.ca>

Canadian Broadcast Corporation. (2005, December 2nd). Harper promises shorter, guaranteed waits for healthcare [On-line]. Available: <http://www.cbc.ca/story/canadavotes2006/national/2005/12/02/elxn-harper-healthcare.html>

Canadian Broadcast Corporation. (2006, January 4th). Liberals offer guaranteed health care wait times [On-line]. Available: <http://www.cbc.ca/story/canadavotes2006/national/2006/01/04/martin-healthcare-060104.html>

Canadian Medical Association. (2004). Code of Ethics [On-line]. Available: http://www.cma.ca/index.cfm/ci_id/2419/la_id/1.htm

Carniol, B. (2000). *Case critical: Challenging social services in Canada* (4th ed.). Toronto, ON: Between the Lions.

Carniol, B. (2003). Generalist skills in social work. Unpublished – work in progress, chart. Toronto, ON: Ryerson School of Social Work.

Chadwick, P., & Dias, S. (2000). *Disability social history project* [On-line]. Available: <http://www.disabilityhistory.org/dshp.htm/>

Chronic Pain Association of Canada. (2004). *Pain facts*. [On-line]. Edmonton, Alberta. Available: www.chronicpaincanada.com

Chronic Pain Association of Canada. *Conquer Pain*. [Brochure]. Edmonton, Alberta: Author.

Clandinin, D.J., & Connelly, F.M. (2000). *Narrative inquiry: Experience and story in qualitative research*. San Francisco, CA: Jossey-Bass.

Clark, J. (2004, November). *Chronic pain: Prevalence, attitudes and beliefs*. Paper presented at the Chronic Pain Association of Canada conference, Halifax, Nova Scotia.

Clements, S., & Cummings, S. (1991). Helplessness and powerlessness: Caring for clients in pain. *Holistic Nursing Practice*, 6(1), 76 – 85.

Couvalis, G. (1997). *The philosophy of science: Science and objectivity*. London, U.K.: Sage.

Craig, K. (1999). Emotions and psychobiology. In P. Wall & R. Melzack (Eds.), *Textbook of pain* (4th ed., pp. 331 – 340). Edinburgh, U.K.: Churchill Livingstone.

Creswell, J. (1998). *Qualitative inquiry and research design: Choosing among five traditions*. Thousand Oaks, CA: Sage.

Crombez, G., Morley, S., McCracken, L., Sensky, T., & Pincus, T. (2003). Self-identity and acceptance in chronic pain. In J.O. Dostrovsky, D.B. Carr, & M. Koltzenburg (Eds.), *Progress in Pain Research and Management* (Vol. 24, pp. 651 – 659). Seattle, WA: IASP Press.

Dalrymple, J. & Burke, B. (1995). *Anti-oppressive practice, social care and the law*. London, England: Open University Press.

Denzin, N., & Lincoln, Y. (Eds.). (2000). *Handbook of qualitative research*, 2nd edition. Thousand Oaks, CA: Sage.

Dominelli, L. (1997). Feminist theory. In M. Davies (Ed.), *The Blackwell companion to social work* (pp. 245 – 254). Oxford, U.K.: Blackwell Publishers.

Dominelli, L. (1998). Anti-oppressive practice in context. In R. Adams, L. Dominelli, & M. Payne (Eds.), *Social work: Themes, issues and critical debates* (pp. 3 – 22). Houndsmills, U.K.: MacMillan Press.

Dominelli, L. (2002). *Anti-oppressive social work theory and practice*. Hampshire, U.K.: Palgrave MacMillan.

Doyal, L. (1995). *What makes women sick: Gender and the political economy of health*. Houndsmills, England: MacMillan Press Ltd.

DuBoulay, S. (1984). *Cicely Saunders: The founder of the modern hospice movement*. London, U.K.: Hodder and Stoughton.

Dunn, P., Hanes, R., Hardie, S., & MacDonald, J. (2006). Creating disability inclusion within Canadian schools of social work. *Journal of Social Work in Disability and Rehabilitation*, 5(1), 1 – 19.

Dworkin, R.H., & Caligor, E. (1988). Psychiatric diagnosis & chronic pain: DSM III – R & beyond. *Journal of Pain and Symptom Management*, 3: 87 – 98.

Eakin, P.J. (1999). *How our lives become stories: Making selves*. Ithaca, N.Y.: Cornell University Press.

Ellis, C., & Bochner, P. (2000). Autoethnography, personal narrative, reflexivity: Researcher as subject. In N. Denzin & Y. Lincoln (Eds.), *Handbook of qualitative research* (2nd ed., pp. 733 – 768). Thousand Oaks, CA: Sage Publications.

Enns, H., & Neufeldt, A. (Eds.). (2003). *In pursuit of equal participation: Canada and disability at home and abroad*. Concord, Ontario: Captus Press.

Favaro, P. (2002). Spirituality and people with disabilities. In M. Nash & B. Stewart (Eds.), *Spirituality and social care: Contributing to personal and community well-being* (pp. 215 – 225). London, U.K.: Jessica Kingsley Publishing.

Finn, P. (1988). Chronic pain rehabilitation: A challenge for mental health counsellors. *Journal of Mental Health Counselling*, 10, 111 – 122.

Fordyce, W. (1976). *Behavioral methods for chronic pain and illness*. St. Louis, MO: Mosby.

Fordyce, W. (1990). Contingency management. In J. Bonica (Ed.), *The management of pain* (pp. 1702 – 1709). Philadelphia, PA: Lea & Febiger.

Fordyce, W.E. (1996). Chronic pain: The behavioral perspective. In M.J.M. Cohen & J.N. Campbell (Eds.), *Progress in Pain Research and Management* (Vol. 7, pp. 39 – 46). Seattle, WA: IASP Press.

Frank, A. (1991). *At the will of the body: Reflections on illness*. Boston, MA: Houghton Mifflin Company.

Frank, A. (1995). *The wounded storyteller: Body, illness and ethics*. Chicago, Ill: The University of Chicago Press.

Frank, A. (1997). Enacting illness stories: When, what, and why. In H. Lindemann Nelson (Ed.), *Stories and their limits: Narrative approaches to bioethics* (pp. 31 – 49). New York, N.Y.: Routledge.

Frank, A. (2000). Illness and autobiographical work: Dialogue as narrative destabilization. *Qualitative Sociology* [On-line serial, 23(1)]. Available: <http://www.ucalgary.ca/~frank/Dauto.html>

Frank, A. (2003). How stories remake what pain unmakes. *Progress in Pain Research and Management*, 24, 619 – 630.

Gamas, A., & Vikis-Freibergs, V. (1991). Psychological events are both factors in, and consequences of, chronic pain. *Pain*, 44, 271 – 277.

Gardner-Nix, J. (2003). Principles of opioid use in chronic noncancer pain. *Canadian Medical Association Journal*, 169(1), 38 – 43.

Gibson, S., Bricout, J., & Baskind, F. (1998). Listening to the voices of women with disabilities. *Families in Society*, 79(2), 188 – 196.

Gill, C. (1997). The last sisters: Health issues of women with disabilities. In S.B. Ruzek, V. Olesen, & A. Clarke (Eds.), *Women's health: Complexities and difference* [On-line]. Available: <http://dawn.thot.net/cgill-pub.htm/>

- Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*. New York, N.Y.: Simon and Schuster.
- Goldman, B. (2003). Drug-seeking behavior. In R. Jovey (Ed.), *Managing pain: The Canadian healthcare professional's reference* (pp. 77 – 86). Toronto, ON: Purdue Pharma.
- Graham, M. (2002). Chronic pain sufferers eye top court for relief [On-line]. Available: <http://www.chronicpaincanada.org/Articles/topcourt.htm>
- Greenhalgh, S. (2001). *Under the medical gaze: Facts and fictions of chronic pain*. Berkeley, CA: University of California Press.
- Hanes, R. (2002). Social work with persons with disabilities: The world of one in six. In S. Hick, *Social work in Canada: An introduction* (pp. 217 – 234). Toronto, ON: Thompson Educational Publishing, Inc.
- Haynes, H. (2002). Meaningful and realistic partnerships for those in chronic pain. Keynote address at Chronic Pain Conference, Halifax, Nova Scotia
- Health Care Human Resource Sector Council. (2003). A study of health human resources in Nova Scotia 2003. Halifax, Nova Scotia.
- Herman, J. (1997). *Trauma and recovery: The aftermath of violence – from domestic abuse to political terror*. New York, N.Y.: Basic Books.
- Hicks, S. (2002). *Social work in Canada: An introduction*. Toronto, ON: Thompson Educational Publishing, Inc.
- Hicks, S. (2004). *Social welfare in Canada: Understanding income security*. Toronto, ON: Thompson Educational Publishing, Inc.
- Hitchcock, L, Ferrell, B., & McCaffery, M. (1994). The experience of chronic non-malignant pain. *Journal of Pain and Symptom Management*, 9(5), 312-318.
- Howell, S. (1994). A theoretical model for caring for women with chronic non-malignant pain. *Qualitative Health Research*, 4, 94 – 122.
- Hyden, M., & Overlien, C. (2004). “Doing” narrative analysis. In D. Padgett (Ed.), *The qualitative research experience* (pp. 254 – 272). Belmont, CA: Thomson Publishing.
- Jackson, M. (2002). *Pain: The fifth vital sign*. Mississauga, ON: Random House Canada.
- Janesick, V. (2000). The choreography of qualitative research design: Minutes, improvisations, and crystallization. In N. Denzin & Y. Lincoln (Eds.), *Handbook of qualitative research* (2nd ed., pp. 379 – 399). Thousand Oaks, CA: Sage Publications.

Jovey, R. (2002). Barriers to optimum pain management. In R. Jovey (Ed.), *Managing pain: The Canadian healthcare professional's reference* (pp. 1 – 6). Toronto, ON: Purdue Pharma.

Jovey, R. (2004, November). Chronic pain. Paper presented at the Chronic Pain Association of Canada conference, Halifax, Nova Scotia.

Jovey, R., Ennis, J., Gardner-Nix, J., Goldman, B., Hays, H., Lynch, M., & Moulin, D. (1998). Use of opioid analgesics for treatment of chronic noncancer pain – A consensus statement and guidelines from the Canadian Pain Society. *Pain Res Manage*, 3(4), 197 – 208.

Katon, W., Egan, K., & Miller, D. (1985). Chronic pain: Lifetime psychiatric diagnosis & family history. *American Journal of Psychiatry*, 142, 1156 – 1160.

Keefe, F., Lefebvre, J., Egert, J., Affleck, G., Sullivan, M., & Caldwell, D. (2000). The relationship of gender to pain, pain behavior, and disability in osteoarthritis patients: The role of catastrophizing. *Pain*, 87, 325 – 334.

Keung, N. (2004, March 10). Disability rate expected to increase: One Canadian in eight suffers impairment situation will worsen as population ages. *Toronto Star*, p. A19.

Kirkpatrick, A. (2000). Reflex sympathetic dystrophy clinical practice guidelines (2nd ed.). Reflex Sympathetic Dystrophy Association [On-line]. Available: http://www.rsds.org/3/clinical_guidelines/index.html

Koestler, A., & Doleys, D. (2002). The psychology of pain. In C.D. Tollison, J.R. Sutterthwaite, & J.W. Tollison (Eds.), *Practical Pain Management* (3rd ed., pp. 26 – 36). Philadelphia, PA: Lippincott Williams & Wilkins.

Kozar, S. (Producer and Director). (2004). *Almost normal: Stories from the well within* [Film]. (Available from Moving Images Distribution, 402 West Pender Street, Suite 606, Vancouver, B.C. V6B 1T6)

Kuppers, P. (2003). *Disability and contemporary performance: Bodies on edge*. London, U.K.: Routledge.

Lather, P. (1991). *Getting smart: Feminist research and pedagogy with/in the post-modern*. New York, N.Y.: Routledge.

Leslie, D., Leslie, K., & Murphy, M. (2003). Inclusion by design: The challenge for social work in workplace accommodation for people with disabilities. In W. Shera (Ed.), *Emerging perspectives on anti-oppressive practice* (pp. 157-182). Toronto, ON: Canadian Scholar's Press.

Levine, H. (1982). The power politics of motherhood. In J. Turner & L. Emery (Eds.), *Perspectives on women in the 1980s* (pp. 28 – 40). Winnipeg, MB: University of Manitoba Press.

Lieblich, A., Zilber, T., & Tuval-Mashiach, R. (1998). *Narrative research: Reading, analysis & interpretation*. Thousand Oaks, CA: Sage.

Lincoln, Y.S., & Guba, E.G. (1985). *Naturalistic inquiry*. Beverley Hills, CA: Sage.

Linton, S. (1998). *Claiming disability: Knowledge and identity*. New York, N.Y.: New York University Press.

Loeser, J., & Egan, K. (Eds.). (1989). *Managing the chronic pain patient: Theory and practice*. New York, N.Y.: Raven Press.

Loeser, J., Seres, J., & Newman, R., Jr. (1990). Interdisciplinary, multimodel management of chronic pain. In J. Bonica (Ed.), *The management of pain* (2107 – 2119). Philadelphia, PA: Lea & Febiger.

Long, D.M. (1996). The development of the comprehensive pain treatment program at Johns Hopkins. In M.J.M. Cohen & J.N. Campbell (Eds.), *Progress in Pain Research and Management* (Vol. 7, pp. 3 – 23). Seattle, WA: IASP Press.

Lorde, A. (1980). *The cancer journals*. San Francisco, CA: spinsters/aunt lute.

Louden, J. (1992). *The woman's comfort book*. New York, N.Y.: Harper San Francisco.

Labov, W. (1972). *Language in the inner city – Studies in the black English vernacular*. Oxford, U.K.: Basil Blackwell.

MacDonald, J. (2000). A deconstructive turn in chronic pain treatment: A redefined role for social work. *Health and Social Work*, 25(1), 51 – 58.

MacDonald, J. (2001). Chronic pain & (dis)Ability: Identity, discourse and relation. Unpublished manuscript, Memorial University of Newfoundland at St. John's.

MacDonald, J. (2004a). One woman's experience of living with chronic pain: The proclamation of voice. *Journal of Social Work in Disability and Rehabilitation*, 3(2), 17 – 35.

MacDonald, J. (2004b, May). Untold stories: Women, in the helping professions, as sufferers of chronic pain restorying (dis)Ability – Personal findings. *Proceeding from the Narrative Matters conference*. Fredericton, N.B.: St. Thomas University and the University of New Brunswick.

MacDonald, J. (2005a). Physical disability. In F. Turner (Ed.), *The Canadian encyclopaedia of social work*. Waterloo, ON: Wilfrid Laurier Press.

MacDonald, J. (2005b, March). Untold stories: Women, in the helping professions, as sufferers of chronic pain restorying (dis)Ability – Professional findings. *Proceedings from Care, Work and Family conference*. Manchester, U.K.: University of Manchester.

MacDonald, J. (2005c, April). Untold stories: Women, in the helping professions, as sufferers of chronic pain restorying (dis)Ability. *Paper presentation at the Pacific Sociological Association conference*. Portland, Oregon.

MacDonald, J. (2005d, May). *Autoethnographic contributions from women sufferers of chronic pain*. Poster session presented at the Faculty of Health Professions Diversity Institute, Dalhousie University, Halifax, Nova Scotia.

MacDonald, J. (2006a). Storying both sides of the desk: Women in the helping professions use chronic pain experiences to inform practices. Abstract accepted for paper presentation at the Narrative Matters conference. Wolfville, N.S.: Acadia University.

MacDonald, J. (2006b). Storying Pain through Artistic Autoethnographic Depictions. Abstract accepted for poster session at the Narrative Matters conference. Wolfville, N.S.: Acadia University.

MacDonald, J. (2006c). *Anti-oppressive practices with chronic pain sufferers*. Manuscript submitted for publication.

MacDonald, N., Bernard, W., Campbell, C., Fay, J., MacDonald, J., & Richard, B. (2003). Managing institutional practices to promote and strengthen diversity: One school's journey. In W. Shera (Ed.), *Emerging perspectives on anti-oppressive practice* (pp. 467 – 487). Toronto, ON: Canadian Scholar's Press.

MacKenzie, S., & Wakat, D. (1990). The physiology of chronic pain: The foundation for successful intervention strategies. *Journal of Mental Health Counselling*, 12(2), 164 – 174.

Madriz, E. (2000). Focus groups in feminist research. In N. Denzin & Y. Lincoln (Eds.), *Handbook of qualitative research* (2nd ed., pp. 835 - 850). Thousand Oaks, CA: Sage.

Mailis-Gagnon, A., & Israelson, D. (2003). *Beyond pain: Making the mind/body connection*. Toronto, ON: Viking Canada.

Main, C., Keefe, F., & Rollman, G. (2002). Psychological assessment and treatment of the pain patient. *Pain*, 281 – 301.

Mattaini, M. (1998). Knowledge for practice. In M. Mattaini, C. Lowery, & C. Meyer (Eds.), *The foundations of social work practice: A graduate text* (2nd ed., pp. 87 – 116). Washington, D.C.: National Association of Social Workers Press.

Melzack, R., & Wall, P. (1988). *The challenge of pain*. London, England: Penguin Books.

Miles, N. (1992). Women in chronic pain: A language of their own. *Dissertation Abstracts International* (University Microfilm Number AAC 1348283).

Mitchell, D., & Winslade, J. (1997). Developmental systems and narrative approaches to working with families of persons with disabilities. In R. Brown (Ed.), *Quality of life for people with disabilities: Models, research and practice* (2nd ed., pp. 151 – 182). Cheltenham, U.K.: Stanley Thornes Publishers.

Morris, D. B. (1991). *The Culture of Pain*. Berkeley, CA: University of California Press.

Morris, D. (2002). Narrative, ethics, and pain: Thinking with stories. In R. Charon & M. Montello (Eds.), *Stories matter: The role of narrative in medical ethics* (pp. 196 – 218). New York, N.Y.: Routledge.

Moulin, D., Clark, A., Speechley, M., & Morley-Foster, P. (2002). Chronic pain in Canada – Prevalence, treatment, impact and the role of opioid analgesia. *Pain Res Manage*, 7(4), 179 – 184.

Mullaly, B. (2002). *Challenging oppression: A critical social work approach*. Toronto, ON: Oxford University Press.

Murray, S. (1997). Patients' lived experience of acute physical rehabilitation and recovery contained in a creative journal. Unpublished doctoral dissertation, Temple University, Philadelphia, PA. (University Microfilm No. GV7.H4M984S)

Murray, T.J. (1997). Chronic pain report. Workers Compensation Board of Nova Scotia [On-line]. Available:
<http://www.pixelmotion.ns.ca/wcb/chronicp/summary.htm>

Networking for Effective and Efficient Disability Services (Needs Project). (1996). A comprehensive disability services strategy for Nova Scotia. Halifax, N.S.: Human Resource Development Canada.

Nova Scotia Department of Community Services. (2002). About family violence: Abuse of persons with disabilities – fact sheet 8 [On-line]. Available:
<http://www.gov.ns.ca/coms/files/facts8.asp>

Nova Scotia Department of Health. (1997). Good medicine: Securing doctors services in Nova Scotia [On-line]. Available:
http://www.gov.ns.ca/health/good_medicine/goodmed.htm

Nova Scotia Department of Health. (1999). Transition to care: NSDOH final report [On-line]. Available: http://www.gov.ns.ca/health/facilities/phase_1.pdf

Nova Scotia Department of Health. (2001-a). Single entry access: Policies for patients entering nursing homes [On-line]. Available: <http://www.gov.ns.ca>

Nova Scotia Department of Health. (2001-b). Making better health care decisions for Nova Scotia: A report by the Clinical Services Steering Committee [On-line]. Available: <http://www.gov.ns.ca/health/reports.htm>

Nova Scotia Department of Health. (2004). Health care costs drivers [On-line]. Available: <http://www.gov.ns.ca/health>

Oliver, M. (1990). *The politics of disablement: A sociological approach*. New York, N.Y.: St. Martin's Press.

Oliver, M. (1996). *Understanding disability: From theory to practice*. London, England: MacMillan Press.

Oliver, M. (1999). Disabled people and the inclusive society: Or the times they really are changing. Public lecture, Strathclyde Centre for Disability Research and Glasgow City Council [On-line]. Available: <http://www.leeds.ac.uk/disability-studies/archieveuk/archframe.htm>

Parker, L. Queen Elizabeth II Hospital, Finance Department (personal communications, January 3, 2006).

Parsons, T. (1951). *The social system*. Glencoe, Illinois: Free Press.

Payne, M. (1997). *Modern social work theory*. 2nd edition. Hampshire, U.K.: Palgrave MacMillan.

Peters, S. (1996). The politics of disability identity. In L. Barton (Ed.), *Disability and society: Emerging issues and insights* (pp. 191-214). London, England: Longman.

Polkinghorne, D.E. (1988). *Narrative knowing and the human sciences*. Albany, N.Y.: State University of New York Press.

Randall, W., & Clews, R. (2001). The tales that bind: Toward a narrative model of rural helping. *Rural Social Work*, 6(2), 4 – 18.

Ranjan, D. (2004). *Violence against women with disabilities*. Ottawa: National Clearinghouse on Family Violence.

Records, S. (2005). Modern Version of the Hippocratic Oath [On-line]. Available: <http://www.geocities.com/everwild7/noharm.html>

- Reid, J., Ewan, C., & Lowy, E. (1991). Pilgrimage of pain: The illness experiences of women with repetition strain injury and the search for credibility. *Social Science Medicine*, 32(5), 601 – 612.
- Riessman, C. (1993). *Narrative analysis*. Thousand Oaks, CA: Sage.
- Riessman, C. (2002). Narrative analysis. In A.M. Huberman and M.B. Miles (Eds.), *The qualitative researcher's companion* (pp. 217 – 270). Thousand Oaks, CA: Sage.
- Rimmon-Kenan, S. (2002). The story of "T": Illness and narrative identity. *Narrative 10* (1), 9 – 27.
- Rioux, M., & Bach, M. (Eds.). (1994). *Disability is not measles: New research paradigms in disability*. North York, ON: L'Institut Roehrer Institute.
- Ristock, J., & Pennell, J. (1996). *Community research as empowerment: Feminist links, post-modern interruptions*. Toronto, ON: Oxford University Press.
- Romanow, R. (2002). Building on value: The future of health care in Canada. Ottawa, ON: Government of Canada.
- Rose, K. (1994). Patient isolation in chronic benign pain. *Nursing Standard*, 8(51), 25 – 27.
- Rosenfeld, A. (2003). *The truth about chronic pain: Patients and professionals on how to face it understand it and overcome it*. New York, N.Y.: Basic Books.
- Roy, R. (1988). Impact of chronic pain on marital partners: Systems perspective. In R. Dubner, G. F. Gebhart, & M.R. Bond (Eds.), *Proceeding of the Vth world congress on pain*, (pp. 286 – 298). Philadelphia, PA: Elsevier Science Publishers.
- Roy, R. (1992). *The social context of the chronic pain sufferer*. Toronto, ON: University of Toronto Press.
- Roy, R. (2001). *Social relations and chronic pain*. New York, N.Y.: Kluwer-Plenum Publishing.
- Roy, R., & Thomas, M. (1999). *Changing nature of pain complaints over the lifespan*. New York, N.Y.: Plenum Publishing.
- Salmon, R.E. (2001). Report of the Auditor General 2000 [On-line]. Available: <http://www.gov.ns.ca/audg/00highlt.htm#PHYSalt>
- Saper, J.R. (1996). Health care reform and access to pain treatment: A challenge to managed care concepts. In M.J.M. Cohen & J.N. Campbell (Eds.), *Progress in Pain Research and Management* (Vol. 7, pp. 275 – 285). Seattle, WA: IASP Press.

Saunders, C. (Ed.). (1988). *St. Christopher's in Celebration*. London, England: Hodder & Stoughton.

Seers, K., & Friedli, K. (1996). The patients' experiences of their chronic non-malignant pain. *Journal of Advanced Nursing*, 24, 1160 – 1168.

Sherwin, S., & The Feminist Health Care Ethics Research Network. (Eds.). (1998). *The politics of women's health: Exploring agency and autonomy*. Philadelphia, PA: Temple University Press.

Sieppert, J. (1996). Attitudes toward and knowledge of chronic pain: A survey of medical social workers. *Health and Social Work*, 21, 122 – 130.

Silverman, D. (2000). Analyzing talk and text. In N. Denzin & Y. Lincoln (Eds.), *Handbook of qualitative research* (2nd ed., pp. 821 - 834). Thousand Oaks, CA: Sage.

Simon, E., & Dahl, L. (1999). The sodium pentothal hypnosis interview with follow-up treatment for complex regional pain syndrome. *Journal of Pain and Symptom Management*, 18(2), 132 – 136.

St. Marie, B. (2003). The complex pain patient: Interventional treatment and nursing issues. *The Nursing Clinics of North America*, 38, 539 – 554.

Staats, P. (1996). Pain is pain: Why the dichotomy of approach to cancer and noncancer pain? In M.J.M. Cohen and J.N. Campbell (Eds.), *Progress in Pain Research and Management* (Vol. 7, pp. 117 – 123). Seattle, WA: IASP Press.

Statistics Canada. (1999). *General social survey cycle 13: Victimization*. Ottawa: Government of Canada.

Stienstra, D., & Wight-Felske, A. (2003). *Making equality: History of advocacy and persons with disabilities in Canada*. Concord, Ontario: Captus Press.

Sullivan, M., Bishop, S., & Pivik, J. (1995). The pain catastrophizing scale: Development and validation. *Psychological Assessment*, 7(4), 524 – 532.

Sullivan, M., Stanish, W., Waite, H., Sullivan, M., & Tripp, D. (1998). Catastrophizing, pain, and disability in patients with soft-tissue injuries. *Pain*, 77, 253 – 260.

Sullivan, M., & Neish, N. (1999). The effects of disclosure on pain during dental hygiene treatment: The moderating role of catastrophizing. *Pain*, 79, 155 – 163.

Sullivan, M., Tripp, D., Rodgers, W., & Stanish, W. (2000). Catastrophizing and pain perception in sport participants. *Journal of Applied Sport Psychology*, 12, 151 – 167.

Sullivan, M., Tripp, D., & Santor, D. (2000). Gender differences in pain and pain behavior: The role of catastrophizing. *Cognitive Therapy and Research*, 24(1), 121 – 134.

Sullivan, M., Thorn, B., Haythornthwaite, J., Keefe, F., Martin, M., Bradley, L., & Lefebvre, J. (2001). Theoretical perspectives on the relation between catastrophizing and pain. *The Clinical Journal of Pain*, 17, 52 – 64.

Sullivan, M., Tripp, D., & French, D. (2001). *Pain disability prevention: Treatment manual*. Halifax, N.S.: Dalhousie University.

Sullivan, M., Adams, H., Rhodenizer, T., & Shaw, M. (2002). The progressive goal attainment program: Minimizing disability following occupational injury in rural communities. Halifax: Dalhousie University and Workers' Compensation Board of Nova Scotia.

Supreme Court of Canada. (2003). Nova Scotia Workers' Compensation Board versus Martin; Nova Scotia Workers' Compensation Board versus Laseur [On-line]. Available: <http://www.scc-csc.gc.ca>

Thomas, C. (1999). *Female forms: Experiencing and understanding disability*. Buckingham, England: Open University Press.

Thomas, C. (2001). Medicine, gender, and disability: Disabled women's health care encounters. *Health Care for Women Internationally*, 22, 245 – 262.

Thomas, M. (1999). My healing journey. In The Grassroots Women's Collective (Ed.), *Voicing our stories/ Remaking our lives* (pp. 58 – 72). Toronto, ON: Second Story Press.

Thompson, N. (1997). *Anti-discriminatory practice* (2nd ed.). London, England: MacMillan.

Thomson, R. (1997). *Extraordinary bodies: Figuring physical disability in American culture and literature*. N.Y., New York: Columbia University Press.

Tierney, W. (2000). Undaunted courage: Life history and the post-modern challenge. In N. Denzin & Y. Lincoln (Eds.), *Handbook of qualitative research* (2nd ed., pp. 537 – 553). Thousand Oaks, CA: Sage Publications.

Titchkosky, T. (2001). From the field – coming out disabled: The politics of understanding. *Disability Studies Quarterly* [On-line serial], 21(4). Available: http://www.cds.hawaii.edu/dsq/_articles_.html/

Turk, D. (1996). Clinicians' attitudes about prolonged use of opioids and the issue of patient heterogeneity. *Journal of Pain and Symptom Management*, 11(4), 218 – 230.

Turner, J., & Aaron, L. (2001). Commentary: Pain-related catastrophizing: What is it? *The Clinical Journal of Pain*, 17, 65 – 71.

Unruh, A. (1996). Gender variations in pain experience. *Pain*, 65, 123-167.

Unruh, A., Smith, N., & Scammell, C. (2000). The occupation of gardening in life-threatening illness: A qualitative pilot study. *Canadian Journal of Occupational Therapy*, 67, 70 – 77.

Vanier, J. (1970). *Tears of silence*. Toronto, ON: Griffin House.

Vanier, J. (1998). *Becoming human*. Toronto, ON: House of Anansi Press.

Vash, C. (1981). *The psychology of disability*. New York, N.Y.: Springer Publishing Company.

Wendell, S. (1996). *The rejected body: Feminist philosophical reflections on disability*. New York, N.Y.: Routledge.

Wendell, S. (1997). Toward a feminist theory of disability. In L. Davis (Ed.), *The disability studies reader* (pp. 260 – 278). New York, N.Y.: Routledge.

Westhues, A., Cadell, S., Karabanow, J., Maxwell, L., & Sanchez, M. (1999). The creation of knowledge: Linking research paradigms to practice. *Canadian Social Work Review*, 16(2), 129 – 149.

Worden, W. (2002). *Grief counselling and grief therapy: A handbook for mental health professionals*. New York, N.Y.: Springer Publishing.

Zola, I. K. (1982). *Missing pieces: A chronicle of living with a disability*. Philadelphia, PA: Temple University Press.

Appendix A: Consent Form

'Untold Stories: Women in the helping professions, as sufferers of chronic pain restorying (dis)Ability'

Ph.D. dissertation by Judy E. MacDonald, BSW, MSW, RSW, (902) 463-5577, e-mail judy.macdonald@dal.ca , mailing address: 28 Kaleigh Dr., Eastern Passage, Nova Scotia B3G 1N1

As a requirement towards my doctorate of philosophy (Ph.D.) at Memorial University of Newfoundland, School of Social Work, I am conducting research on women's experiences of living with chronic pain. Specifically, I am inviting women to participate in this research who are in the helping professions, who have lived with chronic pain themselves for over two years and who have worked, in some capacity, with sufferers of chronic pain. I, myself, as the researcher, live with chronic pain and have done so for over eighteen years, I also have a background in medical social work, having worked in palliative care and on chronic pain and rheumatoid arthritis teams. I enter this research with a heightened respect for those struggling to live with chronic pain and sincerely hope that my research approach and method supports this claim.

The purpose of this research is to capture your stories of living with chronic pain, as you will be asked to narrate your first experience of the pain, the initial diagnosis, flare up or crisis points in your struggle, your experiences in seeking treatment, the losses you have encountered, ways you have been able to redefine hope, to survive living with chronic pain - basically, your story in suffering and surviving a life with pain. You are the crafter of your story, a storyboard will be provided as a guide, but it is just that, a guide. You can determine what you share, how you share it and how it gets related within the research. You also will have editing powers, where if you tell a segment of your story that you later feel uncomfortable with, you can request that it be edited from the transcript of the interview, and this request will be honored. You will also be asked to relate to your work, in working with chronic pain sufferers. Your wealth of experience, expertise and insight will be invaluable to the research. Ultimately, through this research process, I want to inform the readership of what women who are helping professionals, experience in living with chronic pain; and, deriving from your experience (both personal

and professional) and your insights, how practice with sufferers can be more respectful and a more empowering experience overall. The specific research question is: **“How can the stories of women in the helping professions, who are sufferers of chronic pain and dis(Ability), inform an anti-oppressive approach to social work practice in working with sufferers?”**

What will be required of participants:

- ✚ Upon expressing willingness to explore involvement in this research process further, you will be asked to meet with me, in the location of your choosing to be interviewed as a pre- participation process, to clearly articulate the research process and to explore the potential impact upon you as a participant. If you are interested in becoming a participant, I will leave the consent document with you to review at your leisure. I will contact you in one week to obtain your decision with respects to participation.
- ✚ If you agree to further involvement, there will be a series of approximately three interviews, each lasting a maximum of two hours.
- ✚ You will be asked to review the transcripts of each interview, checking for verification and exercising the right to edit components of your story you do not want to go on public record. If your energy levels are low and concentration is difficult, I can help with this review process by going over the transcripts with you.
- ✚ As an option, you will be asked to present your own story, ‘expression of living with pain’, through whatever medium you choose; it could be an art form, a poem, a story . . .literary quality is not required; it is a way to capture the self-expression of living with pain, to enrich the narrative contributions of the research. Together, I believe the two forms will provide a rich data base, one that will make a tremendous contribution to the knowledge of understanding the life of suffering with chronic pain.
- ✚ At the end of the interviews, the four participants will be asked if they are willing to meet as a group with myself (as the researcher), either in person or more likely through an audio teleconference, to express your experience re: involvement in this research process, to share your ‘expression of living with chronic pain’ and to generate a discussion on working with sufferers from a location of empowerment. The transcript from this group process will be shared with anyone involved in the session, again, as a check for validity of conversation, and as an editing option.
- ✚ Once data analysis has been completed, you will be offered an opportunity to comment on a short report of findings. This is an option and not a strict

requirement of the participants; however, I do think that the analysis will be enriched by this consultative process and would welcome your participation.

- ✦ Finally, you will be asked if you would be interested in writing a collaborative article on storying one's experience of living with chronic pain. This would be at a later date, once my dissertation has been completed. I would be responsible for organizing participants who express an interest and for beginning the process. Again, I think that this would be a very rich contribution to the literature on chronic pain and would ultimately give voice and ownership of that voice to each willing participant.
- ✦ The estimated total time commitment of involvement in this research would be approximately 10 hours (required) to 22 hours (including all optional components);

Fall 2003:

Pre-interview = 1 hr.

Interviews - debriefing (3 x 2 hr) = 6 hrs.

Review transcripts (1 hr x 3) = 3 hrs

Focus Group = 3 hrs (optional)

Focus Group transcription review = 2 hrs (optional)

Data analysis contribution = 2 to 3 hrs (optional)

Winter/Spring 2004: (optional activities)

Mini workshop = 4 to 5 hrs (optional)

Autoethnographical contribution = unable to assess time commitment (optional)

Potential Risks and Benefits:

Through willing participation in this research, you might experience certain risks and benefits. I have identified some risks and benefits that I can imagine, but others might occur that I am not currently cognizant of.

Risks:

- ✦ In telling your story of living with chronic pain, there is a potential risk of emotional vulnerability; through the process of storying, difficult emotional and physical times will once again be brought to the surface. This exposure could have a direct impact upon your pain and other related symptoms. In an attempt to minimize this impact, I have respectfully built into the interview process a debriefing sequence, where each interview will end with a check-in to the emotional and physical state of the participant, and a review of support structures should they be needed after the interview process has been completed. I will also leave my telephone number with you and invite you to call if you have any questions or are in any distress because of the interview. As a member of the North American Chronic Pain Association, I have access to resources that might be helpful.
- ✦ A high risk protocol has been developed as a component of the debriefing process. I have consulted with two private practitioners who I know and trust to provide additional debriefing should the need arise. This service will be at no cost to you for one session, as I have arranged to pay the counsellors directly; however, financing of subsequent sessions would have to be negotiated between yourself and the practitioner.
- ✦ No matter what efforts are made to respect confidentiality, the chance exists that someone might be able to identify you through segments of your story. The option to use your own name in relating your story is completely yours, for I do not want to take ownership of your story by assigning an anonymous name. If you decide that you do not want your name to be used, I would offer you the chance to identify a fictitious name to be assigned to your story. I will try to safeguard your confidentiality if that is your request, by not using your name or clearly identifiable information. Demographics will be gathered, for example, occupation within the helping professions, age range of participants, condition which contributes to the chronic pain, current employment status, representation of diverse locations, social identity and so on, but I will consult with you to make sure your identity is not unduly exposed through this information. Your identity will only be shared with other participants upon mutual agreement to participate in the group session, and even in this context, you may choose to stay with your fictitious name. All participants will have this option and, therefore, minimize the potential for feelings of untrustworthiness or manipulation.
- ✦ Limits imposed on confidentiality are as follows, if you reveal to me that you have intent or have exercised harm upon yourself or another, I am bound by my

professional code of ethics to notify the appropriate authority. If this was to happen, I would inform you of my obligation and invite you to contact the authority with my assistance.

Benefits:

- ✦ An opportunity to tell your story and to relate to other women in the helping professions who are living with chronic pain.
- ✦ You will be involved in finding alternative practices to working with chronic pain sufferers, so that their experiences of seeking help might be respectful of their (dis)Abilities and empowering in context, adding your practice experiences to the literature on chronic pain.
- ✦ As a way to give something back to participants for their time, insights and stories, upon conclusion of the data analysis, I will be offering you the opportunity to participate in a mini-workshop on chronic pain, one that I have facilitated as part of the Continuing Education program at the Maritime School of Social Work, Dalhousie University. This workshop deals with assessment approaches and strategies for living with chronic pain, including self-hypnosis, relaxation, and guided imagery. This will be conducted with research participants only, given that interest is expressed.
- ✦ Potential to write a collaborative article on storying one's life with chronic pain.

Ethics Review:

The Interdisciplinary Committee for Ethics in Human Research at Memorial University of Newfoundland has approved this study. If you have any concerns about the ethical application of this research, you can direct those concerns to Eleanor Butler, Secretary, Office of Research, telephone (709) 737-8368, or e-mail ebutler@mun.ca

Dissertation Approval:

This research has been approved by my supervisory committee, Chaired by Dr. Joan Pennell, Director, Department of Social Work, North Carolina State University, (919) 513-0008, e-mail jpennell@unity.ncsu.edu; co-chaired by Dr. Leslie Bella, Memorial University School of Social Work, (709) 737-4512, e-mail lbella@mun.ca; and, committee member, Dr. Barbara Keddy, School of Nursing, Dalhousie University, (902) 494-2221, e-mail barbara.keddy@dal.ca

Summary of Agreement

In voluntarily engaging in this research as a participant:

I understand that my story, as shared in the interview processes, will be recorded, transcribed, and used for data analysis in compiling the results of this research process.

I also understand that these tapes will be stored in a secured cabinet at the home of the researcher, with the researcher holding the only key, and that the professional transcriber will be asked to sign an agreement of confidentiality. Once the dissertation has been defended, all data will be destroyed.

I maintain the right to refuse to answer any question and may ask questions of the researcher at any point in this process.

Likewise, I understand that I will be offered the chance to review the transcripts, to check for accuracy of my story and to edit any segments I do not feel comfortable with going into public record. Once this process is completed, I have therefore given approval for this material to stand as is, recognizing that it will be subjected to analysis and segments may be recorded in the final dissertation report.

I understand that I have the option to withhold identifiable information, and if this option is expressed to the researcher, that she will take the necessary steps to protect my identity as much as possible, and that I will have the opportunity to review any demographic information contained within the report.

I further understand that the researcher is bound by professional ethics and, through such, is limited in respects to confidentiality, in that, if I disclose having harmed myself, children or elders or intent to do so, the researcher will have to convey this information to the appropriate provincial authority.

Any ideas expressed in this research that are representative of my views will be credited to either me or my fictitious name, this holds true to the autoethnographic contribution, should I decide to make one.

I understand that I will have the option to participate in a group consultation process with the researcher and other participants. This is not a requirement of participation, but an opportunity offered to participants. If I choose to participate in the focus group, I realize that I will be bound by confidentiality in that I will not share others' stories with anyone outside the group and will reflect upon the group in outside conversation only from my own location and stories.

I also understand that, upon completion of the data analysis, the researcher will be offering a mini workshop on assessment and strategies for living with chronic pain as a form of compensation to participants. My participation is totally voluntary and will not affect my participation in the research.

Furthermore, I understand that I can withdraw as a participant in this research at any time or point in the process, prior to the data analysis and that all my contributions to the data will be deleted and withdrawn from the study.

I will be provided with an executive summary of the research findings and will be offered the opportunity to read the entire dissertation.

I have read this consent form and agree to participate in this research. I will receive a copy of this form once it has been signed by all identified parties.

Consent initialed:

Pre-participation interview _____ Autoethnographic piece _____

1st Interview _____ Focus Group _____

2nd Interview _____ Mini Workshop _____

3rd Interview _____

Participant's Name (please print): _____

Signature: _____ **Date:** _____

Signature of Researcher: _____

Date: _____

Appendix B: Storyboard

Storyboard:

A storyboard will be used to guide the interview process, this is not applied in a strict, rigid form but rather in a fluid, evolving manner that allows for maximum participant input. The storyboard will add a level of consistency to the process, in that each participant will be guided by the same storyboard. Riessman (2002) believes the “impulse to narrate is so natural, and apparently universal”, (p. 247) that formal structured instruments are not necessary within narrative enquiry.

Storyboard:

To help you begin to tell your story, this is a guide that represents experiences of chronic pain:

When you first knew that something was wrong, the process involved in getting a diagnosis, initial treatment that followed the diagnosis, subsequent treatment and its impact upon you and your pain, crisis points where your health has been in jeopardy and/or the pain has been exacerbated, impact of chronic pain on employment, relationships, social interactions . . . , what your life was like before you had chronic pain, what life is like now, what do you envision for the future?

Appendix C: Interview Guide

Another tool utilized within narrative interviewing is the identification of a few broad questions pertaining to the areas of exploration the researcher is hoping to elicit from participants. Riessman (2002) suggests that five to seven questions are usually sufficient.

Interview One:

Can you tell me about your illness, when it began, when and how you were diagnosed?

How have you been able to 'survive' living with chronic pain?

Can you identify specific losses your illness and (dis)Ability have presented you with?

How would you define 'hope', from the location of living with chronic pain?

Interview Two:

What was your experience like in dealing with the medical system?

How did your location as a helping professional impact upon that experience?

Interview Three:

Given your knowledge in working with sufferers of chronic pain, and in suffering from chronic pain yourself, how would you define or re-define working with sufferers in a way that is empowering?

How does practice need to be structured in order to give sufferers a clear voice in their treatment?

Please feel free to relate to your own work, drawing upon knowledges derived from case examples, if case examples are shared, please change any identifiable information.

Appendix D: Debriefing Protocol

Participants in “*Untold Stories: Women, in the Helping Professions, as Sufferers of Chronic Pain Restorying (dis)Ability*”

Researcher: Judy E. MacDonald (PhD candidate) Memorial University of Newfoundland, e-mail judy.macdonald@dal.ca or call (902) 463-5577

Supervisor: Dr. Joan Pennell, North Carolina State University, Department of Social Work, e-mail jpennell@unity.ncsu.edu

Debriefing: Following the interviews, you may wish to speak to someone about the emotions that were stirred during the process. You can contact the researcher or the counsellor allocated to help with the debriefing process. Arrangements have been made to have one contact for each interview, if requested. The counsellor is an experienced social worker who has worked in health settings for over 15 years. Your contact will remain confidential, unless you express sentiments of self-harm or intent to harm another. The researcher will be informed that the service was activated; no information will be shared between the counsellor and the researcher.

Contact: Gaila Friars, MSW, RSW phone: (506) 357-4719 (work)
(506) 488-3290 (home)
e-mail: r3gfriars@health.nb.ca

Other available resources:

On-line resources:

Chronic pain Resources: North America Chronic Pain Association (including list of pain support groups in Nova Scotia, Prince Edward Island, and elsewhere in Canada)

<http://www.chronicpaincanada.org>

Canadian Mental Health Association

<http://www.cmha.ca>

Canadian Association of Suicide Prevention

<http://www.suicideprevention.ca>

Crisis Helplines:

Metro Help Line – 24 hrs (Halifax): (902) 421-1188

Chimo (bilingual service) Fredericton: 450-HELP or 1-800-667-5005

Appendix E: Howell's Framework

Categories	Processes	Subprocesses
The pain takes over	Getting my attention	Scaring me
	Responding to the pain	Minimizing/ignoring
	Perceiving the pain as chronic	Isolating, taking leave
	Counting the losses	Seeking new answers, feeling frustrated knowing the pain is not going away
Filling my life with pain and despair	Responding negatively to the	Doubting the physical reality
	Chronicity of pain	Blaming the victim
	Isolating from self and others	Separating from the body
Filling my life with new hope	Despairing	Becoming chronic pain
	Grieving the losses	Trying to escape
	Caring for myself	Validating my reality
Fulfilling my life with pain	Hoping for a new life	Making the best of it
	Transcending the pain	Becoming a new person
	Gaining wisdom	

Howell, 1994

Appendix F: Teleconference Agenda

Teleconference: April 8th at 3:30 pm: **Untold Stories: Women in the Helping Professions, as Sufferers of Chronic Pain Restorying (dis)Ability**

Number 1-888-241-3855

Access code – chair: 969570#

Others: 740238#

Number of lines: One - Dawn's (Dawn and Judy)

Two – Helen

Three – bendy

Four – Barbara

Five – Evelyn

Agenda:

1. **Welcome participants**
2. **Discuss format of dissertation:** Six short stories (1st interviews)
Finding chapter (30 page draft)
Anti-Oppressive Practice Vision
3. **Key Headings:**
 - a. **Concept of Spirit:**
 - i. Work Ethic – put needs of others before own
 - ii. Need to learn to pace oneself - balance own needs with professional responsibilities; personal responsibilities
 - iii. Positive Attitude – count blessings, everything has a reason, look for moments of joy
 - iv. Suffering – suicide option but not suicidal (distinction)
 - v. Faith/spiritual growth – believing is something greater
 - b. **Medical System/Care:**
 - i. Health professionals impact upon sufferers.
 - ii. What differentiates good care from negligent care?
 - iii. Secret power of physicians
 - iv. Stigma of chronic pain
 - v. Emphasis on diagnosis – what does this mean if nyd?
 - vi. Attitude of health professionals impact on sufferers.
 - vii. “Go home and live with it!”; ‘grin and bear it’ like phrases
 - viii. Frustration of health practitioners (doctors) vs. sufferers need for compassion/understanding

- ix. Physicians need to do something vs. sufferers need to have relief and to be a co-operative patient (need to fix vs. need to please)
- x. No discussion re: treatment of pain

b(i) Professional location impact on pain experience:

1. own assessment of pain from own discipline (i.e. psychiatrist – pain worse from grief, stress etc.)
2. doubt own profession's response to c/p – (nurses' training in '65 – perception of pain)
3. "all prisoners of our training" – training impact on own perceptions of pain (belief pain could be controlled; nurses training – wouldn't speak up to physicians) – how having c/p has altered those perceptions.
4. Pain experience going against own professional training
5. How you were treated as a c/p patient worries you about how your patients are going to be treated

b(ii) Attitude of Physicians:

- Medicine – respected profession, physicians get away with patronizing attitudes towards patients (emergency visit/broken knee; experience with Tylenol #3).
- Yet, what sufferers identify as helpful is having the support of a physician, being believed by their doctors, having appropriate questions asked, indicating an understanding of the issues and a respect for the sufferer's own knowledge about their pain
- Only way to change physicians attitudes is through their own experience (most med. students – young able bodied).
- Education at Health Professions Schools lacking – impression non-malignant pain isn't important – no formal training – leads to being told fibromyalgia isn't serious or cutting nerve isn't serious, you just won't be able to walk

b(iii) Treatment Issues: Narcotics –

- "Influence of those who are drug seeking have made a negative impact on how chronic pain is treated." i.e. OxyContin in Cape Breton.
- Illegal use vs. legitimate need – weighs on the mind of physicians when prescribing
- Reluctance to prescribe pain medication (situations with Tylenol #3s)
- Sufferers receive message that they shouldn't be taking this medication, that they are weaker if they have to take something, and that somehow they are less than the ideal

patient if they need pain meds. (spending \$\$\$ on alternative interventions before taking pain meds)

- Realize the pain meds are not the answer for every sufferer – sometimes the side-effects make the pain situation worse
- Chronic pain sufferers having to go through detox to switch pain meds
- Distinction between cancer and non-malignant pain re: willingness to prescribe
- Historical lens to pain – chronic pain wasn't heard of – even with post-op pain, you got patients off meds as soon as possible
- Know sufferer's – history and personality; believe sufferer's pain is real, listen to their stories – be cognizant of inconsistencies (my fear is that that is judging sufferers again; and following a cognitive-behavioral model of practice) Is there anyway to get around this issue when dealing with narcotics?

b(iv) Depression and Chronic Pain:

- anti-depressants as a pain adjunct – 'raise pain threshold – provide degree of protection from mood bottoming out.' Health professionals might not understand their purpose – believe patient is depressed. What is distinct about chronic pain sufferer's experience of depression vs. depression in general – the pain, and experiencing the pain, creates the depression in c/p sufferers!
- "it not necessarily thoughts of suicide, but you get pretty damn close", what prevents sufferers from taking that last step?

c) Disability Insurance: – private insurer; – work insurance; – Canada Pension Disability; – Workers Comp)

- Attitude of insurance agents: nasty, rude, dismissive, demoralizing, dehumanizing
- Penalized for continuing to work part-time or in a reduced work structure
- Lengthy application process – pages and pages of details, asked to quantify illness in specific terms, need descriptive, diagnostic evidence; 'what you do every hour of every day'.
- Not seeing physician for condition because of fear of it's judgment against you on your medical records
- Chronic pain not an insurable diagnosis: need to state psychiatric stress/depression or other illness associated with c/p
- Workers' Comp Supreme Court decision – whereby Supreme Court ruled that c/p is an illness and that WCB has to cover it.

- Workers' Comp doesn't look after their injured workers adequately – NACPAC.
- Short-term basis insurance is fine but in the long term, they get very sticky wanting you to jump through every hoop and then some.

d)Emotional Experience of Sufferers:

(qualifiers were sometimes used: horribly, absolute, incredibly, very . . .)

- abandoned
- afraid
- agony
- alone (unusually)
- angry
- 'beside myself'
- dehumanized
- demoralized
- denial
- depressed
- desperation
- devastation
- dipping lower
- disability
- distressed
- driven
- doubt (self-doubt)
- embarrassed
- emptiness
- exhausted
- falling apart
- fatigued
- fearful
- fibro fog
- frighten
- frustrated
- grief stricken
- guilt
- helplessness
- hopeful
- humor
- hurt
- meaningful
- nightmares

- out of control
- overcome with emotion
- overwhelmed
- panic (utter)
- pissed off
- prisoner
- relief (incredible relief with diagnosis)
- resentful
- resigned
- sadness
- scared
- self-pity
- shamed
- sorry for self
- spiritual
- spirited
- stoic
- stressed
- suffering vs. succumbing
- terrorized
- thankful
- tired
- trapped
- unhappy
- unrelenting
- upheaval
- vulnerable
- weary
- withdrawn
- worn
- worried

Verbs: juggling, pushing, questioning, struggling, trying, crying, moving, praying, shuffling, wearing, laughing, not bothering others, screaming, terrorizing.

Descriptions of Pain: one great big bruise, excruciating pain, skin hurt, felt like I was hit by a Mac Truck, it was very difficult for me to describe and, even now, in looking back it is very difficult for me to express. Inconclusive (defined by medical establishment)

Specific Fears Expressed:

- immobility

- dependency
- pain won't subside (plus ten)
- ending up in a wheelchair
- generally frightened
- incredible sense of loneliness (I'm so alone in my experience)
- inability (going from super active to total inability)
- not being able to do what I want to do; function the way I want to function.

Losses:

- avocational activities: can't run, hike, walk through the woods
- financial costs (\$treatments; lost work time, etc)
- gardening (or at least not the way I use to – can't bend, kneel)
- relationships (friends who don't understand)
- moments with the children
- spontaneity (with travel, recreational activities, socializing)
- teaching (painting)
- work (former way of working – cut back hours, pace oneself or retire)
- relationships with co-workers strained
- choice(s)
- own identity – i.e. runner, gardener
- ability to fix things (personality – fixer)
- memory loss (fibro fog)

e)Coping Strategies:

Personal Coping:

- Mobility (walking, treadmill, swimming, power walking, stationary bike – endorphin release)
- Gardening
- Pets
- Faith
- Family (partners, children, extended family)
- Personality: very driven, spoiled brat, defiant, determined
- Social adjustments (do what we can, when we can)
- Talk to other chronic pain sufferers
- Emotional release (crying, screaming – more often with acute episodes)
- Me time
- Withdrawing – hiding
- Shift/change priorities
- Pace oneself (work, leisure)
- *my energy is like a resource, like money – need recovery time

- embraced the pain, took full ownership of it; riding of destructive relationships
- mental control – putting it in boxes, locking it away within the dark places of the mind, not letting the pain control you, defying the pain, going with the pain, intellectualizing the pain experience, holding the suicide option, conceptualizing the pain as acute pain, compared to chronic.

Treatment Modalities:

- acupressure; acupuncture
- aquacise
- cranial-sacro therapy
- hydrotherapy
- massage therapy
- meditation
- medication (opioids, antidepressants, anticonvulsants – anti-psychotic, epileptic)
- pain diary
- physiotherapy
- pilates
- reflexology
- reiki
- research on chronic pain, specific diagnosis
- self-hypnosis
- spirituality
- stretching exercises
- TENS
- Topicals
- Yoga

4. Anti-Oppressive Practice Components:

- Admired their strength
- Affirm
- Compassion
- Reassurance
- Validation
- Listen respectfully (to sufferers' stories)
- More empathy
- More patience
- Help sufferers verbalize that which they can't put into words – emotional descriptors, physical explanations of pain, etc.
- Talk to in a gentle way

- Deal with the emotions of sufferers
- Dialoguing
- Trust
- Showing that you are 'real'
- Show sufferers that they have the ability to . . .
- Helping them express their pain – express through writing, drawing, singing –whatever works for them
- Storytelling and poetry
- Believing sufferers when they say that you are in pain

Suggestions:

- **Need to believe sufferers! Number One!!**
- **Medical field needs to be more flexible and open to alternative therapies and treatments**
- **Major policy changes – c/p needs to be recognized as a debilitating condition**
- **Employers need to be accommodating, accessible etc.**
- **Education, Education and more Education . . .**
Healthcare providers, physicians, formal caregivers, sufferers themselves, and their families.
Education on pain – pathways, physiology, biochemistry, treatment options, etc.
- **Raise Awareness – c/p awareness week; general populace, sufferers and medical staff**
- **Know difference between acute pain and chronic pain**
- **Pain ladder good concept, just need to move along it quicker**
- **Education re: pain medication; dispel myth of addiction**
- **Insurers need to recognize c/p as a disease**
- **Team approach vs. constructing sufferers own resource team to be drawn upon as needed**
- **Approach similar to palliative care – physicians billing for time/severity of call not numbers only**
- **Have sufferers be active participants in their own care.**

5. Reflections on Participation in Research:

Where to now??

Call Complete – thank you!

Appendix G: Ethical Approval



Memorial
University of Newfoundland

Office of Research

July 29, 2003

ICEHR No. 2002/03-094-SW

Ms. Judy MacDonald
School of Social Work
Memorial University of Newfoundland

Dear Ms. MacDonald:

The Interdisciplinary Committee on Ethics in Human Research has examined the proposal for the research project entitled "*Untold Stories: Women, in the Helping Professions, as Sufferers of Chronic Pain Restoring (dis)Ability*" in which you were listed as the principal investigator. We wish you to know that in our opinion, your proposal shows a very good understanding of the ethical treatment of research participants.

The Committee has given its approval for the conduct of this research in accordance with the proposal submitted on the condition that the following minor modifications are incorporated:

1. Please inform participants that they are free to withdraw from the study at any point. Information already collected about a participant should be withdrawn if the participant later withdraws and a statement to this effect should be incorporated into the information going to participants as part of the consent process.
2. The consent form should also specify the fate of the data. For instance, will the tapes be destroyed following the completion of the study?
3. Because of the number and complexity of the ethical issues involved here, we recommend a 2-stage consent process with an initial phone or personal contact and then a period (perhaps a week) during which the prospective participant can read in privacy, and take time to reflect upon the 3 page consent form. After this period she can then make a final decision about participation.
4. The benefits to research participation seem somewhat speculative and perhaps potentially overstated. Please rephrase this segment so that it is brief and more neutral.
5. In the risks section of the consent form, please explicitly state the limits to confidentiality that you can offer participants.

If you have questions regarding the requested modifications, you should contact Dr. Russell Adams, Faculty of Science. You may contact him at michelem@mun.ca.

St. John's, NL, Canada A1B 3X5 • Tel.: (709) 737-8251 • Fax: (709) 737-4612 • <http://www.mun.ca/research>


Page 2
Ms. Judy MacDonald
July 29, 2003

If you should make any other changes either in the planning or during the conduct of the research that may affect ethical relations with human participants, these should be reported to the ICEHR in writing for further review.

This approval is valid for one year from the date on this letter: if the research should carry on for a longer period, it will be necessary for you to present to the Committee annual reports by the anniversaries of this date, describing the progress of the research and any changes that may affect ethical relations with human participants.

Thank you for submitting your proposal. We wish you well with your research.

Yours sincerely,



Janice E. Parsons
Chair, Interdisciplinary Committee on
Ethics in Human Research

JEP/jjp
cc: Dr. R. Adams



Memorial

University of Newfoundland

Office of Research

July 28, 2004

ICEHR No. 2002/03-094-SW

TO: Ms. Judy MacDonald, School of Social Work

FROM: Chair, Interdisciplinary Committee on Ethics in Human Research (ICEHR)

SUBJECT: Annual Progress Report for Research Project entitled "*Untold stories: women, in the helping professions, as sufferers of chronic pain restorying (dis)ability*"

Thank you for taking the time to provide the annual progress report for the above project.

We understand that this project will continue and there have been no changes that would affect ethical relations with human participants. Your ethics approval for this project is extended until July 2005.

We wish you well with the continuation of your research.

T. Seifert, Ph.D.
Chair, Interdisciplinary Committee on
Ethics in Human Research

TS/pc

cc: Director, Office of Research
Supervisors

Appendix H -- Participants Profile

Barbara –

45 year old

social worker/ policy analysis

fibromyalgia, chronic fatigue (neurological sleep disorder with restless leg syndrome),
trigeminal neuralgia – chronic 12 yrs.

mother of two, one disabled child, walker, writer – journaling

bendy –

52 years old

family physician

endometriosis – 17 yrs, neuropathic pain left knee – 6 yrs, total chronic – 23 yrs.

former runner; current swimmer, 9th of 10 children in sibling group

Dawn –

46 years old

psychiatrist – in private practice

arthritis, spondylitis ankylosis, degenerative disc disease – chronic 7 yrs.

mother to Colton – black lab, gardener – specializes in roses

Evelyn –

63 years old

nurse in psychiatry and mental health, retired

rheumatoid arthritis, anaemia, asthma, fibromyalgia – chronic – 25 yrs.

mother of three, gardener

Helen –

60 years old

nurse, retired; volunteer work at local and national level re: chronic pain

fibromyalgia, failed back surgery, arachnoiditis – chronic – 16 yrs.

mother of two, married 37 yrs., artist – painter

Marg –

47 years old

social worker, mental health

malignant chronic pain – 6 yrs; broken patella – 2 yrs – total chronic – 8 yrs.

aunt – to six (?) nieces and nephews, social activist, feminist

Appendix I
 Lieblich, Zilber & Tuval-Mashiach (1998) Four Cells:
 Holistic-Content; Holistic Form; Categorical-Content; and Categorical-Form

Participant	Holistic-Content	Holistic-Form	Categorical-Content	Categorical-Form
Barbara	Started with beginning of pain experience. Storied with little prompts. Journey through critical incidents – diagnosis – fibromyalgia & sleep disorder; medical oppression/strife Woven with relationship components.	Lengthiest interviews – orator. Flow to story. Voice flexed with emotional content. At times stories ran together (jumping around). Very descriptive; put the reader into the experience. Laughed- light hearted moments.	Spirit: ‘my purpose’ – deriving meaning out of suffering Emotions: Unusually alone; Fear: Not be able to get out of bed; quality of life would be diminished greatly Treatment: labeled as depressed; not believed; judged about narcotic usage Coping: supportive partner, gardening, children.	Analytical Detail to relations – more with family
bendy	Began with accident – hospitalization and recovery process. Critique of attitudes towards those with (dis)Abilities and chronic pain. Directive – straight	Use of humour. Laughed a lot. Ability to find lighter side. Emotions vague, yet relayed personal elements of story. Professional/Critical lens – strong.	Spirit: Mystical part of personality Emotions: Worried about patients; Fear: Not being able to move, to be immobile Treatment: told by partner: ‘No one wants a cripple’	Logical sequence Event focused

	forward.		Coping: Swimming, walking, staying active	
Dawn	Stayed with immediate past – c/p history. Good critique of medical system – emotional & physical descriptors – shares case situations – weaves personal and professional identities.	Professional in presentation – language – medical, descriptive – yet, emotive at times.	Spirit: life force Emotions: devastated; Fear: ten + pain would not subside Treatment: no one would treat her for pain Coping: Dog, Garden	Logical sequence Event focused
Evelyn	Story began with childhood: pain both emotional & physical – interwoven. Difficult to tell – emotional to hear – oppression emanating from family relations. Shifted to current events – modern struggle & helping role as psyche nurse. Case stories relating own personal knowledge with pain/system	Emotional reflection – tears, difficult to talk – low voice. Painful telling, yet recognized as healing work. Language – passionate, life story mode.	Spirit: faith, prayer Emotions: trapped; Fear: being in a wheelchair Treatment: Oppressed by family – physicians primarily supportive Coping: gardening, supporting others	Reflective Historical component
Helen	Weaved – personal life history events with professional identity; accented with	Passionate telling; importance of relating back to work cases (in late 60s early 70s).	Spirit: faith & family Emotions: appreciation (family/spouse, family physician/pain	Reflective Historical component

	case stories. Knowledge derived from own story, professional experience & volunteer work with sufferers.		specialists); <i>Fear</i> : running out of options for pain control. Treatment : not being believed. Coping : painting, volunteer work with sufferers, pacing.	
Marg	Started with malignant pain – related impact to current situation = the artifacts of chronic pain. Accented turning point events – nurse berating her; physician warning of cancer; broken knee. Started with own experience; ended with professional impact.	Use of humour in telling. Control & flow of pain story with teller. Spoke about emotional upset but at a distance. Tone constant - except for laughter.	Spirit : in community Emotions : denial; <i>Fear</i> : Nightmares of pain – new acute pain would turn chronic. Treatment : being told that ‘it’s not if but when she would develop cancer’; being berated by a nurse for crying. Coping : work, community outreach and advocacy, & family.	Analytical Detail to relations – more with clients

Note: Participants chose to be referred to by their first names – wanting to own their stories through testifying to their suffering and their survival.

- Physicians’ stories told in logical sequential format; event focused
- Nurses stories told in a reflective manner, relating to historical events
- Social workers stories told with an analytical lens; detail to relations

Appendix J

The Afghan

by bendy

When I worked in the ICU of a local hospital, I worked almost exclusively midnight shifts my first summer, following year one of university. I was married at the time. One of my nursing friends was knitting an afghan out of phentex and so did I.

The afghan my friend was making was gorgeous, mine was not. Mine was downright hideous – yellow, red & black – and, when seen in daylight, would cause vertigo and vomiting – such was the caliber of its zigzag pattern.

My afghan was not a small thing, as a matter of fact, it was extra, extra large – big enough to drape down either side of a double bed (if we'd had a bed).

Anyway, this hideous monstrosity stayed on the piece of foam that passed as our bed, for years.

As the years went by, my husband decided that some other woman was his 'true love'. It thus became obvious that I was the 'third man out', so to speak.

At this point, it was December of my fourth year of medical school and I returned from an out of town paediatrics rotation and had to find an apartment to live in. (This was between Christmas and New Years).

Miracles of miracles, I found an apartment; unfurnished, unheated and at that point unlit!

Well, I went to the marital apartment to get some things to put in my new apartment (and we did not have much). I had no pots, pans, silverware, towels, facecloths, dish detergent or furniture, absolutely nothing.

As I went through our cupboards, my ex would say – 'oh, don't take those (towels), I only have six'. 'Don't take those plates, I only have eight'. 'You're not taking your desk are you? I need it'.

'You're not taking the television, I know' (the one he supposedly bought me). 'I need the table & chairs'.

This only went on for about ten to fifteen minutes.

I said nothing and everything I touched that he did not want me to have I just left. I ended up with only some of my clothes. However, I was getting madder and madder and madder and madder by the millisecond.

When I got to the bedroom, there was the afghan from Hell on the bed. God was it awful. Intuitively, I knew that if I took that piece of garbage, that it would hurt my ex & hurt him deeply.

I grabbed that afghan & took it off the bed. My ex said, 'You're not taking that are you?' & I replied angrily, 'I made it, it's mine & I'm taking it!' And so I did. The look on his face was raw, naked pain. It was unbearable.

At that moment in my life, I truly hated myself. It was too late to undo the harm. I cried all the way to my apartment & promptly threw out the hideous afghan. I knew there was no room for me in his life & as hard as that was, I was kind of okay with that.

But I was not okay with intentionally causing him pain. As far as I know, I had never intentionally hurt anyone in my life to that point & have never intentionally caused anyone pain like that since.

That I could hurt someone deliberately bothers me to this day. It was a very cruel, senseless thing to have done and accomplished absolutely nothing.

My friends tell me 'there is therapy' for my problem, but I never want to be 'cured' of always trying to live my life without deliberately causing pain.

I have never forgotten that afghan, and, only recently, have more or less come to terms with what I did (and I have been divorced for nearly 25 years)! People, even exes deserve to be treated with care.

Appendix K

The Therapist in Pain: A Personal Perspective

Dawn's autoethnographic contribution

THE PSYCHIATRIST
SEES THE DOCTOR...



"I feel lousy. How does that make you feel?"

Introduction:

In 1951, Jung said “only the wounded doctor can heal”.

As a physician – pain patient, I do not plan to give you answers today, but rather to pose some questions that may lead you to your own answers about your colleagues and your patients, perhaps about yourselves.

What is a physician?

What is a patient?

What does therapeutic mean?

What does suffering mean?

Personal History:

In 1999, I was diagnosed with possible ankylosing spondylitis, after eight years of progressive painful symptoms. My back pain has been complicated by degenerative disc disease, spinal stenosis and osteoarthritis of the spine and peripheral joints. Most of my disease is invisible – chronic pain is not seen on the surface. What are seen are the signs of a chronic debilitating disease – change in gait, fatigue, irritability, decreased mobility and the periodic reliance on aids such as a cane or walker. I have worked throughout these eleven years as a psychiatrist in private practice, at times immobilized in a reclining chair while on narcotics, at other times just stiff and sore. This journey has changed my perceptions of doctors, patients and therapy, which I hope to share today.

Literature:

Although the psychotherapy literature has much to say about the dying or the pregnant therapist, little is written about the chronically ill therapist. Harry Grunebaum, in “Beyond Transference: When the Therapist’s Real Life Intrudes” states, “Nothing has been written about therapists who work while in chronic pain, yet given the frequency of conditions such as arthritis, they must be quite common. Probably, the experience is felt to be too mundane and ordinary to deserve comment.”

It is not.

We do know that pain may interfere with the therapeutic process by causing distraction, decreased concentration, decreased ability to listen and a change in feelings towards the patient. The struggle to be compassionate in the face of one’s own suffering is paramount. The therapist must have insight into these changes and deal with them appropriately.

Physician Issues:

There are practical issues to contend with:

- fatigue – pervasive, physical, emotional and spiritual
- pain in prolonged sitting
- yawning due to fatigue or pain medications (awkward and sometimes damaging)
- the effects on therapy of reclining (a colleague working, while lying down for several months following disc herniation)

There are the reactions of our colleagues to contend with:

- denial “It can’t be that bad, you look fine”
- lack of support
- perception of chronic pain patients as being difficult, needy, hopeless and drug-seeking

eg: firing my rheumatologist when told to “Go home and take Tylenol. There is nothing you can do.” Leaving me feeling hopeless, angry and dismissed.

Yet, this is an opportunity for us to model for patients the ability to cope in the face of adversity . . . and to educate our colleagues who will all, at some time, become a physician – patient.

Patient Issues:

Remember Rule #4 from Samuel Shem’s “The House of God” that says, “The patient is the one with the disease.”

- How do our patients experience us when we too are clearly a patient? And what do they need to know of our patienthood?
- What the patient knows, but the therapist doesn’t acknowledge, can destroy the alliance.
- We require honesty from our patients – they deserve nothing less, but how much is revealed, and in what way, is in the art of psychotherapy.
- Patients require reassurance of our competence, compassion and ability to listen.
- To see powerlessness in the therapist, as revealed by her inability to discuss the situation, can make the therapist appear unable to cope with life’s problems – feelings that often bring a patient into therapy in the first place.
- Evidence in the healer of woundedness or pain, and the transcendence or constructive endurance of it, helps to heal the patient through our own modeling.

- There is also the opportunity for the patient to show a nurturing and protective side, evidenced in some by gifts, which can be examined as part of the transference or simple expressions of compassion.
- And, for some, there may be acts of exploitation, also to be examined.

What Does Therapeutic Mean?

- Dorland's Medical Dictionary defines 'therapeutic' as: first – pertaining to the art of healing, and only second, as curative.
- I define it as that which makes me feel better. Surely, this is what all patients experience.
 - o The need for validation
 - o And in some, the need to be touched
 - o The need for hope
- I now understand patients' searches for alternative and complimentary therapies, for it has been these therapies which make me feel better - message, aquatherapy, acupuncture, craniosacral therapy and reflexology have helped immeasurably compared to traditional medicine which offered Tylenol.
- The warmth of my beloved black Lab, Colton, laying against my spine has reinforced in me the human need for touch and unconditional love. This connects me with my humanity as a therapist and helps me better understand the needs of those in my care.

What does suffering mean?

- It means being invisible (I now better understand the loneliness that those with mental illness must feel).
- It means being judged as bad, needy, weak, inferior and uncooperative . . . as we may have sometimes judged those in our care.
- It means being disbelieved . . . who can define your pain if not you – be it physical, emotional or spiritual?
- It means being refused treatment and relief because you are not bad enough . . . such as for some of our patients without DSM IV diagnoses who suffer nonetheless.

(Despite all this – I have) **Hope for the Future:**

- I hope that research helps us all and that supports will be developed for all who suffer with pain

- I hope that attitudinal shifts will occur in my colleagues – towards pain, towards complimentary therapies and towards our own denial.

James Knight, in the 1986 book “Psychiatry and Religion: Overlapping Concerns” said .

“only the one who is open, sensitive and personally knowledgeable about pain and suffering can participate in healing. One’s own hurt, one’s sensitive openness to the patient, gives the measure of one’s power to heal.”

Thank you for the gift of your listening and blessings be to you all.

Dawn, M.D., F.R.C.P.C., November 1, 2002

Appendix L
Anti-Oppressive Challenges for Working with Chronic Pain Sufferers

Anti-Oppressive Practices	Learnings	Practice Principles	Meta-Narrative Challenges
<u>Empathy Skills:</u> Understanding of service user's feelings & situation. Expand to social empathy.	To meet the sufferer where she is at: Show respect, empathy and genuineness.	<u>Treat all sufferers with respect:</u> Regard helping as a privilege, analysis individual, culturally and societal.	Pathologizing practice of labeling pain as psychogenic or dismissing sufferer's story of pain.
<u>Validation Skills:</u> Identifies strengths of service users in coping with oppression (Carniol, 2003).	To meet the sufferer in places of desperation & help them define a reason, which is hope, to keep going.	<u>Validate the sufferer:</u> Put chronic pain topics on the table: Demonstrate depth of understanding, show recognition of sufferer's struggles.	Medical model's hierarchal position of physician and other helping professionals' role as expert.
<u>Communication Skills:</u> Such as listening, focusing and clarifying are used to engage clients in critical consciousness & action toward (Carniol, 2003).	The voice of the sufferer needs to be brought into the assessment and intervention processes.	<u>Listen, really listen to and hear the sufferer:</u> Truly listen to sufferers, their experiences & knowledges – to inform intervention.	Preoccupation with classification, diagnosis and labeling: If sufferer does not fit diagnostic criteria, pain is displaced.
<u>Advocacy Skills:</u> Access to better services/resources. Defends social rights, social movements/community connections (Carniol, 2003).	For helping professionals to act upon this conscious and ethical belief: Advocating for sufferers' rights/ disrupting the hierarchal ordering of health care.	<u>Remain cognizant of sufferers' potential vulnerabilities:</u> Normalize sufferers' experiences, locate them within socio-political-economic and physical context.	Psychological pain theories view of sufferer's vulnerability as dysfunctional or a negative orientation towards pain & subsequent coping.
<u>Attention to Client:</u> Agency – client enacted state decision-making & exercising control. Recognition of interactive processes (Dominelli, 2002).	Engage with the sufferer, beginning with believing her account of her pain journey and offering support. Build sufferer's belief in self.	<u>Believe the Sufferer:</u> A sufferer's pain is what she says it is – pain is genuinely experienced. Sufferer inclusion in "how their pain [sic] problems are both conceived and resolved (Brown & Williams, 1995, p. 700).	Traditional medical ways of viewing and understanding pain: acute pain - behavioral, emotional and communicative ways related to chronic pain.
<u>Analytic and Strategy Skills:</u> Challenging oppressions (on all levels, personal, communal and societal), through egalitarian, caring and inclusive practices (Carniol,	Chronic pain sufferers face numerous oppressions: personal – pain; communal – care providers' attitudes, societal – pain non-compensatory re: disability pensions.	<u>Strategize around systemic change:</u> Education, health care access, sufferer centered multi-modality, multi-disciplinary service delivery and policy changes.	Individualistic treatment focus perception of the patient: for example, the inflamed knee in rm 3031a. Pain as tertiary intervention.

2003). View interventions in a broader social and organizational context (Dominelli, 2002).			
<u>Spiritual Sensitivity Skills:</u> Locates spiritual support for social and economic justice. Holistic ways of knowing and helping (Carniol, 2003).	Reach beyond the obvious clinical interventions to connect with the human spirit; meet the sufferer where she is at and offer hope.	<u>Use of Self:</u> Use self-disclosure and consciousness-raising to help other sufferers.	Treatment principle of therapeutic distance.
<u>Assessment Skills:</u> To identify (re: client): 1) how oppressive structures are harmful and 2) immediate and long-term needs – contributing to personal, structural, communal and spiritual emancipation (Carniol, 2003).	Practitioners must take action to not dismiss chronic pain by treating the psychological entity in isolation (i.e. depression), for, until the pain is more adequately controlled, treatment will be ineffective.	<u>Understand the relationship between chronic pain and depression:</u> Depressive symptoms need to be understood primarily as a consequence of living with chronic pain. <u>Responsible Opioid Treatment of Chronic Pain:</u> Physicians need to become comfortable with prescribing long-acting, long-term opioids. Treatment of side effects and screening for addiction risk factors are essential components.	Classification schema for depression and addiction, as they have been conceptualized and operationalized in isolation.

Anti-Oppressive Practices: Anti-oppressive practices were derived from two sources: first, Carniol, (2003) who is a well known, respected Canadian for his work with structural and anti-oppressive social work practices; and second, Dominelli (2002), who has written extensively at an international level on anti-oppressive social work theory and practices.

Learnings: The learnings were knowledge formations emanating from the case stories shared by sufferers as they testified to living with pain and professionally working with sufferers. They represent a combination of sufferer's insights (illustrated through direct quotations from the interviews), researcher constructed summary reflections, and support from progressive pain literature.

Practice Principles: Through the testimonials of the sufferers' professional lives as helpers (physicians, nurses, social workers), they identified numerous practice suggestions representative of best practices in working with chronic pain sufferers. In the organization of research findings, I then reviewed the case stories and their related learnings, identifying the relevance of practice principles to specific cases. A correlation exists between the first three columns, from the anti-oppressive skills, to the learnings and practice principles, evolving the anti-oppressive skill to specific application with chronic pain sufferers.

Meta-Narrative Challenged: The final column, meta-narrative challenges, represents identification of the dominant discourse within chronic pain, which the sufferers' voices, of both personal and professional testimonies, have deconstructed. Each column, moving from left to right, subsequently challenges and displaces the meta-narrative identified in this final column.

