Until You Go Through It': Exploring Female Health Care Providers'

Lived Experience with Serious Chronic Illness

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A Thesis submitted to the Faculty of Graduate Studies of

The University of Manitoba

in partial fulfilment of the requirement of the degree of

MASTER OF SOCIAL WORK

Faculty of Social Work

University of Manitoba

Winnipeg

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ABSTRACT

Diagnosis with a serious chronic illness is a powerful lived experience that touches all aspects of the individual's life and which necessitates great adaptation across the lifespan. Ambiguity is a lived dimension of illness that is often expressed in illness stories, capturing the new state between health and illness which has also been described as a 'liminal' or in-between state of being (Little, Jordens, Paul, Montgomery & Philipson, 1998). Health care providers hold socially prescribed roles in which they are expected to be professionally competent and immune to personal illness. The lived experiences of health care providers who have been diagnosed with serious chronic illness were explored in this study to better attempt to describe the phenomenon.

Six health care providers from various professional backgrounds participated in the research. A semi-structured interview guided the conversation between the researcher and the participant. The participants were encouraged to tell the story of what has happened to them and to reflect on the impact to their lives and practice. Participants were also asked to reflect on their perceived level of support and preparedness via their professional training, and to share any recommendations they might have for others going through this experience. The data gathered were found to be rich in both depth and detail. The data were analyzed using van Manen's interpretive phenomenological method.

Significant statements created formulated meanings or categories, which became organized around eight themes. The themes formed several clusters. The theme clusters were then developed into a recognizable pattern of sub-themes which helped to further

describe the essence of the experience of health care providers living with serious, chronic illness.

The findings of the research were found to be consistent with the literature that describes the lived experience of seriously ill health care providers as liminal in essence.

Based on the research findings recommendations for social work practice, administration and policy, educational training reform and future research were outlined.

ACKNOWLEDGMENTS

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CHAPTER ONE

BACKGROUND, PROBLEM AND PURPOSE

<u>Introduction</u>

There are many of us who've lived situations that defy our explanation and that we hardly thought we'd experience in our life time. There are few who occupy the space in-between two states or worlds. A recognition of this dual reality eludes the many, yet we few struggle each day to varying degrees to navigate that which is our lot in life. Human nature compels us to seek understanding and to go on.

The space in-between health and illness, arguably labelled 'chronic illness', is reflective of this dual reality. The person diagnosed with a chronic illness might ask the question 'am I a sick person or a healthy person?' which might well not be answered. So then, who am I? The person with chronic illness might also be equated to the mythic character Sisyphus, condemned to forever push their burden uphill but trying determinedly to do so, just happy to be able to continue to push on. One might use this same metaphor when considering the role of health care providers, often performing a demanding and thankless job requiring great dedication and skill. It is my contention that when health care providers become personally ill a phenomenon is created wherein their lived experience transpires in a largely liminal, or 'in-between' world due to the strain of navigating dual roles. The purpose of this chapter is to elucidate the concepts behind this phenomenon. Background information, including my own experience, will be provided so that the problem and purpose of this research will be better understood.

Background

The purpose of this section is to provide background information regarding the formulation of the thesis topic and research questions, including a discussion about the impact of illness and the concept of liminality. A statement of the research problem and purpose are also presented. I begin, however, with a personal statement intended to ground the research and to provide the reader with the context for my topic.

A Personal Statement

As a child with a chronic illness, I had come to know and trust the hospital staff and their routine. I saw them as helpers, experts and god-like. All I knew is that they were usually very friendly and made my body feel better with their treatments. They also seemed to help my very young and scared parents. I was inspired to know what I wanted to be when I grew up.

While I had first considered nursing, the physical demands of shift work and patient care seemed ill-advised as a long term career choice for me. It was my great fortune to discover the field of medical social work, and therein I found my niche. My experience in the medical setting positioned me in good stead to understand my client's reality, and I always had felt a natural affinity with patients- like the spy who is secretly a double agent. However, as much as I thought I knew, there was always so much more to learn. My life, both personally and professionally, has been so enriched by all of the patients and families I have met and learned from in my practice. It has been my privilege to journey with them through their illness experiences.

In the fall of 2006, my life took a sudden turn. I was diagnosed with papillary thyroid cancer, which I was told was in an early stage and very treatable. Despite these reassurances, I struggled with the fact that I was 34 years old with cancer. Admittedly, I realized I had clung to the magical thinking of knowing it ***could*** happen to me, but needing to believe it ***wouldn't*** happen for many years to come. I sort of mentally compartmentalized my vulnerability, if you will, a necessary survival skill in life but especially in light of my daily work as a social worker in an oncology unit.

In the 5 years since my diagnosis, I have come to learn and variably accept that I now live with another chronic illness. While the disease is in check, I have not been deemed cured and require regular medical monitoring to watch for progression. I am grateful every day that I got what has been deemed 'the good cancer', and mindful it obviously could be much worse; I am grateful that I have reached a point where I do not think about my condition and all the 'what-ifs', everyday.

As is often described by those who live with illness I too have developed an enhanced appreciation for life's challenges and blessings. This has included my professional life, which has also undergone many changes since my diagnosis. There is something very freeing about facing some of your worst fears and living to tell about it. Somehow other things seem most manageable. I continue to strive to learn and push myself, just gently, and more purposefully as life is short, after all.

In searching the literature, I discovered a growing awareness of the concepts of vicarious traumatization and burn-out which are occupation hazards in the health care field. However, I was also fascinated by the creative and daring work of clinicians who wrote about their own experience and delved into the lives of others, seeking to

understand the essence of lived experience. It was from this work that the genesis of my project arose, and I became inspired to explore the experience of other health care providers living with chronic illness, hoping to shed some light and hope on this unique situation.

A Word about Illness

Diagnosis with a serious chronic illness is a life-altering event affecting dimensions of physical, psychological, social and spiritual well-being (Ferrell, 1996). Serious chronic illness refers to physical illness which is not curable, is potentially life-threatening, and that creates alterations in functional ability over time (Sidell, 1997). Examples of serious chronic illness include forms of cancer, multiple sclerosis (MS), amyotrophic lateral sclerosis (ALS), diabetes and renal insufficiency, Parkinson's disease, and HIV/AIDS. Chronic illness impacts marital and family functioning, capability for continuing employment, and capacity for emotional coping given its life long duration and limiting qualities (McDaniel, Campbell, Hepworth & Lorenz, 2005).

Storied accounts of lived experience with chronic illness have been referred to as 'illness narratives'. Illness narratives reflect personal meaning (Williams, 1984; Vachon, 2001) and embody the illness experience (Docherty & McColl, 2003; Riesmann & Quinney, 2005; Frank, 2007). Illness narratives also reflect the cultural values and social relations which shape the illness experience, often captured in the idioms used to describe bodily symptoms and translate lived experience into meaningful context (Frank, 1995). The experience of illness is powerful in our lives, and as physician-anthropologist Arthur Kleinman (1988) asserts "The trajectory of the chronic illness course assimilates to a life

course, contributing so intimately to the development of a particular life that illness becomes inseparable from the life history" (p. 8).

The re-presentation of illness experience through narrative can serve an adaptive purpose to improve coping and overall well-being through the ability to tell one's story as one lived it (Laiser, & Gagnon, 2006; Lee, Cohen, Edgar, Zebrack, 2000). Ambiguity is a lived dimension of illness that is often captured in narrative accounts as the "creation of a new state between being healthy and ill" (Gifford, 1986), which has been described as a 'liminal' or 'in-between' state of being (Little, Jordens, Paul, Montgomery & Philipson, 1998).

The Concept of Liminality

The concept of 'liminality' was introduced into anthropological discourse by Victor Turner (1967) and was derived from Arnold Van Gennep's analysis of transition rituals in 'The Rites of Passage' (1960). Van Gennep argued that regeneration was a 'law of life' and was accomplished through rites of passage which occurred in three major phases: separation, the detachment from an earlier fixed point; transition or margin (limen), an ambiguous state that has none of the characteristics of the past or future states; and incorporation, the stable state that signifies that the passage is consummated (Gardner, 1998).

Turner focused on the transition phase as he was intrigued with the idea of the liminal or 'threshold' phase involved in ritual, 'with its dance of old and new and promise of regeneration, and with the classificatory ambiguity embodied in, for example, being no longer a boy but not yet a man' (Babcock, 2004, p. 8863). Turner (1969) elaborated the concept of 'liminality' not only as a phase or space in a rite of passage, but as the

condition or state of being "betwixt and between". Primary dimensions of this liminal phase include 'communitas' which refers to communication influenced by sociocultural processes and 'reflexivity', or a state of reflection (Turner, 1969).

Heilbrun (1999) conceptualized liminality through a feminist lens. Maintaining that women have been deprived of narratives or examples by which they may take control of their lives, Heilbrun urges them to abandon the appropriate and seek out the liminal. Heilbrun (1999) defined liminality as a state of being "poised on uncertain ground…. leaving one condition, or country, or self, and entering upon another (p. 3). She further notes that 'threshold people' are necessarily ambiguous and slip through classifications that normally locate states and position in cultural space. They are betwixt and between, neither here nor there. With barriers that are imposed by patriarchal structures Heilbrun contends (1999, p. 90) that women are tempted "to avoid hovering on the threshold, to avoid making brave decisions and having to live with the uncertainty and anxiety they produce. It is easier to do what is expected of you than live in intensity and suspense." Heilbrun (1999) noted that it is almost impossible for women to dissent alone as for such resistance to be successful, alternative communities and cultures must be established.

The concept of liminality has been adopted with increasing frequency in various social sciences, literary and religious studies (Babcock, 2004). For example, Palmer (1980) utilizes the liminal concept to connect the characteristics of the god Hermes with the meaning of 'hermeneutics', or the art of understanding and textual exegesis. Newlin (2006) uses liminality conceptually in an analysis of Chaucer's, 'The Franklin's Tale' (Cooper, 1996) and Hoff Kraemer (2004) applies the concept to deconstruct character self-sacrifice in the Japanese animated film 'Princess Mononoke' (Napier, 2005). Barlow,

Phelan, Herlock, Sawa, Rogers and Myrick (2006) apply liminality as a lens with which to view the complex experience of a social work practicum student in her field placement work.

People who occupy this liminal space defy the classification that typically locates states and positions in cultural space, and although they develop valuable insider knowledge as to their state of being they occupy a 'threshold' or in-between position that is not generally recognized (Turner, 1969). Anthropological studies have found that a liminal position, even when associated with the sick role, can be associated with social inferiority and an outsider position in society – this is particularly the case in western society, which places value on the control of embodied health and perceived 'wellness' (Jackson, 2005). This social construction creates a paradoxical situation for individuals affected by serious chronic illness with respect to their place in society and adjustment to their life circumstance (Ekwall, Ternestedt & Sorbe, 2007; Parry, 2003; Purves & Suto, 2004).

Statement of Problem

A remarkable example of this liminal state may be found in the lived experience narratives of practicing health care providers who are personally diagnosed with serious chronic illness. Health care providers hold socially prescribed roles in which they are expected to be 'objective' sources of clinical expertise, yet empathic and emotionally available to clients at all times; tenets that are well articulated in professional training and reflected in professional codes of conduct (Hahn, 1985; Tuttle, 2007).

The illness experiences of this group are generally considered a 'taboo' topic by society and within the health care system, forcing chronically ill health care providers to

face ambiguity in both their personal and professional lives (Picard, Agretelis & DeMarco, 2004). They must learn to navigate dual insider positions based on their life experiences, and find ways to reconcile these roles with little guidance or support. As social worker Claudia M. Elliott (1996) astutely observed, "The admonition "physician heal thyself" has dominated the tone of the healing professions and has created an atmosphere in which personal pain must be held private" (p.21).

Health care providers with serious chronic illness generally lack the preparation, training or appropriate resources to assist them in navigating issues related to personal illness in their practice (Foehrenbach & Lane, 2001). Treatment teams also have little guidance in terms of how to best help their patients who are health care providers (Consalvo et al., 2008; Kempainen, Bartels & Veach, 2007). The public are largely unaware of the issues, clinging to their idealized views of health care providers as omnipotent beings, acting in a professional capacity that provides immunity from any possible personal impediments (Sollod, 2002; Wall, 2001).

The proposed research study will seek to explore and better understand the lived experience of healthcare providers who are also living with serious chronic illness. A qualitative, phenomenological research approach will be implemented as it is most appropriate for the exploration of lived experiences (Creswell, 2007). Through in-depth personal interviews I will explore the illness narratives of practicing health care providers, hoping to learn of the impact of their illness on both their personal and professional lives. In interpreting the data I will draw on the concept of liminality and on insider-outsider theory, which I believe will provide a meaningful framework to develop insights into this lived experience.

Statement of Purpose

Increasing the depth of understanding on this topic is important for several reasons. Improving the quality of life of ill health care providers by explicating their lived experience would help to demystify and normalize their experience. Delineating the mechanisms needed in educational and workplace settings so that health care providers who are ill receive appropriate training and supports needed to positively adapt to their unique experience. Educating treatment teams as to the experiences and unique needs of these health care providers would assist in improving the quality of their care. Finally, educating the public regarding these special issues to positively influence their expectations of and interactions with health care providers who experience illness, is useful.

Developing expertise in assisting clients to effectively cope with serious chronic illness should be a goal of the social work profession. Social workers are increasingly likely to have clients experiencing a serious chronic or life-limiting illness on their caseloads, including individuals practicing professionally as health care providers. This proposed research will contribute to building social work practice theory by developing practice knowledge regarding the unique needs of health care providers with serious illness. How to assist medical treatment teams is also an important goal for social work. As insiders on these teams, social workers often have dual roles in providing services to patients and assisting the medical team. As outsiders, social workers can benefit from speaking to those who have lived through this unique experience with respect to their first-hand, insider perspective, and develop sensitivity to the inherent challenges of occupying a socially marginalized position.

With increased knowledge and acceptance, social workers may make the shift to incorporating this knowledge into professional training programs, which would be beneficial in proactively addressing this important issue and breaking the silence that surrounds it. The act of increasing awareness and visibility of the issues of health care providers with serious illness may have implications for hospital or institutional policies with respect to health care reform, such as guidelines for treatment teams caring for these providers and the inclusion of this group's unique needs in the patient bill of rights in health care facilities. The interests of the larger public are served by furthering discussion of and intervention for the needs of this special group so as to preserve accountability and quality of care for all persons with serious illness.

Research Questions

The research questions included:

1. What is the essence of the lived experience of being a practicing health care provider with serious, personal chronic illness?

2. In what ways can the health care system improve services for health care workers?

Summary

This chapter provided background of the phenomenon under study, practicing health care providers with serious, chronic illness. It was postulated by the researcher that health care providers living with illness occupy a liminal state of being. As outlined in the research problem statement, providers faced with this life experience lack both

recognition of their unique needs and appropriate supports to assist them to maintain

effective practice. A clear statement of purpose has been developed and research

questions outlined. The goal of the research was to explore and better define this lived

experience, so as to increase awareness and support mechanisms to assist these health

care workers. The role of the profession of social work in this purpose was delineated.

CHAPTER TWO

LITERATURE REVIEW

Introduction

The concepts I will explore in this literature review include the chronic illness experience and health care providers' experience with illness. A search of various electronic data bases was conducted, including Social Work Abstracts (EBSCOhost), Pubmed (Medline), CINAHL, and SCOPUS utilizing several keywords: illness meaning; illness narratives; illness experience; lived experience; health care provider and illness; (social worker or nurse or doctor or health care provider) and (personal or serious chronic) illness. I was able to locate numerous articles from the literature written by health care providers relating their lived experience with various forms of serious chronic illness. I will discuss the major themes from these narratives and examine how they relate to the theoretical framework of the research.

The Chronic Illness Experience

In his work 'The Illness Narratives', Arthur Kleinman sheds light on the experience of adjusting to life with serious chronic illness by explaining, "The fidelity of our bodies is so basic that we never think of it-- it is the certain grounds of our daily experience. Chronic illness is a betrayal of that fundamental trust. We feel under siege: untrusting, resentful of uncertainty, lost. Life becomes a working out of sentiments that follow closely from this corporeal betrayal: confusion, shock, anger, jealousy, despair" (1988, p. 45).

The adaptation to such life-altering change is tremendous, and conceivably may take the remainder of the affected individual's lifetime (Andrykowski, Lykins & Floyd, 2008; Sharpe & Curran, 2006). Whittemore and Dixon (2008) note that efforts to integrate illness into one's life involves a process of seeking meaning and re-defining personal identity, such that '… there (was) a complex co-existence between 'living a life' and 'living an illness' (p. 177). Restoring or preserving continuity of identity is a major task in survivorship and has been linked in the literature to positive psychological adjustment (Lee, Cohen, Edgar, Laizner & Gagnon, 2006; Little, Paul, Jordens & Sayers, 2002; Zebrack, 2000).

Adjustment to illness is as much a social process as a personal journey. For example, chronic illness sufferers are often labelled as either 'accepting' or 'denying' their illness, and can go on to internalize the judgements of loved ones and health care providers with respect to their illness response. These opinions may positively or negatively influence future emotional coping, quality of life and compliance with recommended treatments (Telford, Kralik & Koch, 2006).

People with serious chronic illness learn quickly that discussing their experience is generally not socially acceptable, thus they must make choices daily about how and to whom they communicate about their illness (Spira & Kenemore, 2002). Disclosure about illness can result in acceptance and validation with encouragement to share their story, or it can result in negation and withdrawal, thus hindering future sharing (Anderson & Ott, 2003). This dynamic can extend to the familiar social support network of family and friends. For example, cancer survivors frequently report fear of recurrence as a long term stressor while loved ones generally focus on distancing from the illness experience and a

'return to normal'. This dichotomy can result in difficulties with meaningful communication around coping and needs (Spira & Kenemore, 2002).

Psychotherapist Mary Vachon (2008) reflects that the experience of diagnosis with serious illness such as cancer can represent a 'turning point' in life and result in a 'spiritual transition and transformation'. Adding to this effect is the heightened awareness survivors have of their own mortality, which provides them with a unique perspective and outlook on life (Gifford, 1989; Little, 2004). Hence, adjustment to life with serious illness may involve choosing to view the illness as a 'wake-up call' that involves an evaluation of life priorities, often making positive changes to improve quality of life that may not have occurred otherwise (Halverson-Boyd & Hunter, 1995).

Health Care Providers and Illness

There is a growing collection of first-person account narratives by health care providers documenting their lived experiences with a variety of illnesses. For example, physicians have written about experiences with cancer (Dohan, 2000; Mack, 1984; Mullan, 1985; Silagy, 2001; Tierney & McKinley, 2002), cancer recurrence (McKinley, 2000), arthritis (Bendor, 1999), AIDS (Aoun, 1989; 1992), ALS (O'Flaherty Horn, 1999), cardiac disease (Fetscher, 1999) and depression (Tolhurst, 2004). Nurses have written about cancer diagnosis (Coulter, 2008; Leigh, 1992, 2006, 2007; Leonard, 2001; Tosh-Kennedy, 2007), mental illness (Olsen, 2002), hepatitis C (Saunders, 2007), dystonia (Serdans, 2009), recovery from stroke (Lanza, 2006), ICU admission following surgical complications (Zikorus, 2007) and massive gastrointestinal bleeding (Fawaz, 2007).

These works are all first-person accounts about lived experience that focus on several common themes: the shock of diagnosis, adjustment to illness, and navigating the dual roles of patient and professional health care provider. The need to create a meaningful experience out of their illness by translating their hard-earned learning into personal growth and their professional lives through writing, teaching, improved practice and greater empathy is evident. Reconciling their dual insider position as person with illness, and person as professional may necessitate the creation of a liminal space in which these positions may co-exist. I will now expand on these themes which are grouped generally under personal and professional concerns, with the use of direct quotes to highlight salient points.

The Shock of Diagnosis

Common to the experience of health care providers reflecting on their illness experience is the expression of absolute shock at their own diagnosis that goes beyond personal acceptance. Health care providers deal with the usual adjustments applicable to life with illness, however speak of 'the shock' of becoming a patient themselves and relinquishing a defence mechanism which assisted them to feel 'safe' and have emotional distance from their clients' crisis (Baker & Stiller, 2006). These narratives capture the sense of 'professional safety' or 'immunity' that care providers cling to, perhaps as a protective factor that enables them to do their work (Hahn, 1985). There is a clear sense of an 'us' and a 'them'- these workers struggle to straddle both of these worlds. Schnipper (1996), an oncology social worker living with breast cancer, describes this 'defence mechanism' well -

> We who work in oncology may believe at some primitive level that we have
> struck a bargain with the gods. Even if we deny this belief in our heads, in our

hearts the pact has been sealed. We take on seemingly endless loads of sadness; we sit too often with grief. We may think this will buy us and those whom we love protection. (p. 1535)

Adjustment to Illness

The issue of loss of control in their illness situation was also a common theme. Invariably, health care providers related this experience to heightening their distress when contrasted to the high level of control they are expected to maintain as professionals. Identification with client experience as now having 'been there' is also a clear theme in the narratives, as is the enormity of the emotional issues involved. As Dohan (2000), a physician writing about undergoing bone marrow transplantation recalls,

When I looked up at my intravenous lines – two going constantly, with smaller bags awaiting their turn – I couldn't believe that I was the other end. I thought of the sick patients in the intensive care unit I had cared for so often with multiple lines going. Now I was on the receiving end of this life-sustaining device, and it was frightening. I wondered whether my patients had the same reaction or whether they found the intravenous bags reassuring. (p. 589)

Some providers spoke of a certain underlying level of denial throughout their treatment and a feeling post-treatment that their experience was still somewhat 'surreal'. As Schnipper remembers,

Then there was the other-world-ness of the OR, of straddling the line between patient and caregiver. I went to the biopsy under an assumed name. I changed from suit and silk blouse to Johnny and foam slippers in the women's OR locker room. I joked with the surgeon and with the nurse and tried to hold on to my role of "one of us", not a "patient." (1996, p. 1535)

The health care workers were quite candid in their sharing of the extreme range of emotional reactions to diagnosis and treatment. Without exception, they all acknowledged this as a healthy expression of their situational distress while marvelling at how unprepared they were to cope. It was also clear that the personal reaction is intimately connected with the professional self as 'filter'. Maram (1999) reflects on an instance where her reality was both personally distressing and represented a 'disconnect' from her practice advice with clients:

> While waiting for surgery I often felt and acted helpless, and sometimes passive, which is unusual for me. I consider myself assertive and I was surprised with some of my reactions. I would go to the doctor's appointment and 'forget' to ask important questions. Or the doctor would make decisions that upset me, and I would say nothing. It is ironic because I practice assertiveness and encourage it in the women I counsel. I began to realize how difficult assertiveness is when one is feeling vulnerable, helpless, and powerless. (p. 41)

This dynamic may reflect a unique concern that has direct implications for the self-esteem or personal identity of the health care provider. It may also have important implications for synthesis of insider illness experience into professional life by challenging practice experience and knowledge.

The narratives also reflect a sense of the vulnerability, emotionally and bodily, of the health care provider living with serious illness. From this sense of vulnerability arises an ambivalence to engage in medical treatment, particularly for those with prior treatment experiences. While these acts seem irrational and counter-productive to some - medical staff in particular - these are complex dynamics which health care providers, as insiders facing treatment, now intimately understand. This understanding translates into increased

empathy and patience with patients and families who are also struggling with these challenges.

In line with the existing literature explicating that survivors have an acute awareness of their own mortality, the health care workers were no exception. As Schnipper (1996) explains,

> We know about issues common to cancer survivors. The first and most important is "Am I a survivor? Will I survive this?" We understand that everyone is living on borrowed time, but we live with that knowledge. It is not like "Maybe I will be hit by a truck tomorrow". It is intermittent, usually unexpected, paroxysms of feelings that can quite literally take your breath away. Sometimes the fear is like a wildcat on our backs, claws digging in. (p. 1536)

Thus, awareness of mortality serves another point of connection for health care clinicians with their clients. The witnessing of disease, decline and death in professional work serves as a constant reminder of a personally relevant concern.

Interestingly, the health care providers' narratives generally did not discuss awareness of client reactions to their diagnosis in any detail. Maram (1999), however, speaks in eloquent detail regarding her own doubts around disclosure and its possible positive or negative effect on her clients and students. What is captured is the sense of shock on the part of clients and a stripping away of the protective factor for them of viewing their care providers as safe from the perils of cancer diagnosis. Maram recalls the reaction of her breast cancer support group;

> As I spoke, I focused on the group and their reactions. The members expressed shock at my news. "I just can't believe that this has happened to you of all people". Their response was disconcerting; why would they be surprised when this diagnosis can happen to anyone, and in fact happened to them? It caught me off guard, and I struggled with an answer. "It was a shock to me as it was to many of you when you

were diagnosed", I responded. Later, when I had a chance to think more clinically about their reaction, it made more sense to me. I was their group leader, there to help them with their own crises, not to have my own. In their eyes, I was "immune" to cancer! I realized that I missed an opportunity to explore this with them-- to help them express their feelings. (pg. 42)

Cristy (2001), a clinical social worker living with MS, discusses the impact on her ability to provide therapy to families adapting to life with chronic illness in relation to their reaction to her personal illness:

I am often referred patients who have a chronic illness or who want help with their own feelings relating to someone close to them who has a chronic illness. In these cases, there may be frequent references to my disease, such that therapist disclosure becomes an integral part of the work. The analytic position is not necessarily abandoned. Rather, knowledge about me, and the fantasies and feelings that are stimulated, all become additional material to examine. There was one notable exception when I was referred a family in which the mother had MS. The mother was so wedded to her denial regarding the disease that the family could not tolerate therapy with me. They left and found another therapist. (p. 41)

Navigating a Dual Role

A common thread in the narratives of care providers is the difficulties incurred with the dual role of simultaneously being both professional and patient, particularly if they receive care in their own workplace institutions (Kempainen, Bartels & Veach, 2007). The literature speaks to the phenomenon of 'insider vulnerability' in which care providers' innate vulnerabilities due to the illness situation are exacerbated because of their knowledge of the health care process and content of care with which they are most familiar (DeMarco, Picard & Agretelis, 2004). Social worker Joan Dornhoefer (2001)

reflects on complications of dual insider roles while seeking treatment at her own hospital workplace for a life-threatening recurrent deep vein thrombosis;

> What seems worthy of exploration is the transformative space between (the positions of) patient and professional. Within this distance there can be much variation….there are some inherent difficulties in being a patient where one is also a provider of care; the allowance of anxiety, uncertainty and vulnerability; the mistaken belief that one is a 'special' patient; the equally mistaken and dangerous belief that one's employer/hospital/provider represents the best care available….there is the experience of returning to one's own role as provider moments after an experience of being the patient: a patient who, as peer or colleague, *must* know what to expect and how to make the connections and transitions. It is assumed that the details, the rule outs, the differential diagnosis are understood- whereas (authentic) "patients" are paced through procedures. There is another complexity: the recognition and experience of complaints or dissatisfactions with 'the system'. This is a system that I, on a parallel service, address and feel responsible to change. So, *who am I* to expect a more coordinated, streamlined care than I can provide for my own patient group? Yet, I do. Lost, for me, is the illusion or the wish that the illness, as well as my uncertainty about its course, can be fully known by my care giver. Paradoxically, I focus my doubts on myself, as I wonder if I have become a burden (to the institution/employer/provider). My private self is now somewhat public. (p. 106)

Insider knowledge has interesting implications when receiving care. Tuttle (2007), a physician-patient, observed that medical knowledge can complicate the ability to cope by increasing anxiety. This dynamic can negatively affect the patient-physician relationship through trying to self-manage one's care and it can be difficult relinquishing control. Ambiguity in navigating dual roles and others' expectations of behavior can play into this complicated dynamic. As Dohan (2000) recalls of his treatment experience:

My therapy started immediately with a double-lumen Hickman catheter. Many of the staff addressed me as "doctor", which made me feel special. Initially, I played the role by checking the doses of medications, but quickly I found playing doctor-patient to be a struggle. As much as my professional life in medicine had been about control, I needed to let go and trust someone else to care for me. (p. 589)

Health care providers note the various stresses of managing the multifaceted dimensions of the treatment experience, which often affords them a new perspective. For example, physician Robert Klitzman has authored numerous studies interviewing doctor-patients about their experiences with aspects of time, as in patient-time versus doctor or institution-time (2007); the need to improve doctor-patient communication and relationship (2006); illness disclosure by HIV positive doctors to their patients (2006); and views toward weighing risks and benefits among doctors who've become patients (2006). Health care providers write about coordinating their own care and with the struggle to maintain normalcy (DeMarco, Picard, & Agretelis, 2004; Tuttle, 2007). Many find that working throughout treatment helps them to feel 'normal' (Coulter, 2008; Leigh, 2006; Tosh-Kennedy, 2007).

Many health care providers wrote about their exploratory use of non-clinical strategies for self-care, surprised at their first-hand benefits despite recommending the same strategies to clients (DeMarco, Picard, & Agretelis, 2004). Of note is that providers revealed they struggled to navigate self-care strategies as a function of difficulty accepting the continued need for personal support (Wall, 2001). Some health care providers disclose use of therapeutic supports to assist them in coping, but also describe ambivalence about engaging these supports. For example, Maram (1999) discloses in her

narrative the use of a therapist to work through her personal feelings related to her

diagnosis in preparation to resume leading her breast cancer support group.

> I knew that at some level, sharing my experience might benefit some of the women
> and add credibility to my knowledge about the emotional aspects of breast cancer.
> To keep my feelings from interfering with the group's process, I needed to be aware
> of what those feelings were. I never realized how difficult this could be! I found it
> hard to focus on my feelings when my general reaction to the crisis was shock and
> denial. Before facilitating the first support group, I had several therapy sessions
> focused mostly on my anxiety about the next group session. (p.42)

Leonard (2001), a nurse living with cancer, discusses her use of a therapist and

support group and its positive benefits to her,

> The chemotherapy and radiotherapy left me feeling lethargic. Insomnia overtook
> me and my physical health diminished considerably. About midway in my
> chemotherapy, I did myself a favour, and sought counseling from a therapist to help
> handle my emotional responses. This helped me in recognizing the normalcy of my
> response, my sadness and my need to accept what was happening to me. As well I
> attended group therapy for cancer patients. The group provided me with a non-
> judgmental, supportive and helpful forum. This too helped me to normalize,
> externalize my fears and better accept what was happening. (p. 27)

Health care providers' narratives speak to the need to educate their colleagues by

virtue of their insider knowledge of the illness experience. Providers speak to the need for

support from their colleagues and they discuss the importance of encounters with both

caring and uncaring providers during their own recovery (Baker et al., 2006; Kempainen

et al., 2007). This was a theme referred to extensively in the literature, as many of the

providers sought care from colleagues perhaps out of familiarity, safety or convenience.

Workers also discussed the emotional challenges of receiving care from colleagues or friends and the concern the impact their care was having.

> Another aspect of the months of treatment was my relationship with colleagues. The experience of my illness frightened everyone; gone were the last hopes of 'Cancer can't happen to me'. I worried about my friends and my caregivers and was profoundly grateful for their collective attention and affection. I appreciated their honest expressions of concern and learned to depend on their help. I hoped that they all felt, as one of my doctors did, that 'I hate taking care of you, but I would hate it worse if anyone else were.' (Schnipper, 1996, p. 1536)

> I told my friend, 'Just call and tell me in a straight-forward manner.' Later I wondered how she felt about my request. How did she feel about having to be the person to tell me I had cancer? ….I closed the door of my office and called. My friend was straight-forward and to the point. 'The results are what we were suspicious of. The biopsy was positive for malignancy. Even though it is very early cancer, it is the more aggressive type. The doctor needs to talk to you about treatment.' I sat and cried. 'You knew it was likely', she softly replied. I responded, 'I know. I guess I didn't really want to believe it.' (Maram, 1999, p. 40)

Healing and personal growth are powerful themes in most narratives related to finding meaning in the experience and a sense of healing, moving forward still intact, yet changed. As Schnipper (1996) articulates:

> As months pass, I have become more comfortable in my skin; I again fit my clothes, run most mornings, and brush a full head of hair. I try to trust my body. Always there are parallel tracks of hope and planning inside me; each decision must be marked by a two-angle lens: the maybe I will live for years view and the maybe I will die soon one. Every goal, plan, thought, and relationship must be forced through a double filter. I am part of an astonishing collection of women. I am so proud of my sisters as we, alone and together, live with breast cancer. I give thanks

for my companions on this journey. I have found courage. I have been given grace. I love my life. (p. 1536)

Use of self and story to educate the health care team, particularly physicians, about the full realities of the illness experience was mentioned as a primary motivator to disclose experience. The narratives illustrate that the illness experience goes well beyond the physical to include all facets of life and the concept of wellness in survivorship beyond treatment, when traditional medicine views its work as done. Sim (2008) explains her reasons for documenting her struggles with illness;

> My aim in writing this narrative of my own is to encourage health practitioners to remember that every treatment carries a profoundly different meaning for doctor and patient. My surgeons saw the colostomy as a means to an end, a way of eradicating disease and facilitating healing. As a patient, I experienced the treatment with much more ambivalence. Admittedly it was a way to be free of cancer. It also brought unasked-for insight into bodily functions that were previously a mystery to me…I was forced into a new sense of being-in-my-body, a loss of continuity with how I saw myself previously. (Sim, 2008, p. 337)

> I remain in awe of this whole experience …. Without the stoma, that reversal of plumbing, my cancerous bowel would not have healed. It all seemed perfectly ordained. In the scheme of things, those few weeks spent living in such a new way, taught patience, humour, a renewed love for the world of my body, and a reminder to look at illness through the eyes of the patient as well as from my professional perspective. (Sim, 2008, p. 344)

Role Ambiguity

Many health care providers' narratives describe experiences in which they experience ambiguity in roles which, arguably, describes a liminal position. Picard,

Agretelis & DeMarco (2004, p. 539) in interviewing nurses who are cancer survivors,

learned of these experiences;

> I would feel most unsettled; I would walk in and see somebody that was a caretaker
> (oncology provider), who was very giving, and then they would make me feel
> settled, and well, then why do you feel this way? I guess ambiguousness about my
> role. 'Who was I? When I walk through the door every day (at the hospital), I had
> the impression or impact of…what am I? Am I patient or am I nurse'?

> I'd have it in one of the treatment rooms and then I'd get up and go in and continue
> to treat the other people there…because I'm a patient in my own clinic. I'm pretty
> much my own nurse also…I probably should have been in a more dependent role,
> but…that's just not what happened. I think you're very anxious to get back to, you
> know. You want to do all that you can for yourself so that you're not dependent.

However, there is an acknowledgement of benefits or meaning-making from the

illness with respect to translation into practice with clients, thus heightened empathy,

opportunities for therapeutic use of self-disclosure and advocacy are mentioned as

benefits (Picard, Agretelis & DeMarco, 2004). Providers describe a deepening level of

compassion for their patients and others by virtue of their experiences, as well as a new

appreciation for power shifts in giving and receiving care (Klitzman, 2006). As Coulter

(2008, p. 12) explains,

> As a nurse, I've always had a high level of compassion for the cancer patients I
> looked after in acute care. Now that I've lived the cancer experience myself, I look
> at them differently. I now see strength when I look at the bald head of a cancer
> patient; I see hope in situations where I once saw futility and despair.

Thus an insider perspective leads to an alteration in own practice as they become more patient, non-judgmental and flexible in approach (Picard et. al., 2004; Klitzman, 2006; 2007). Providers object to the practice of 'blaming the patient' for poor clinical outcomes, compliance or difficult behaviors (David, 1999; Sollod, 2002). Doctor-patient Silagy (2001, p. 549) explains:

> This experience has impressed on me the need for doctors to really listen to their patients. As my disease has gone through remissions and relapses, I have usually been the first person to detect the new small nodes or lesions. At times I have had to almost plead with the medical staff to take notice of my symptoms. Ironically, at one point I was so determined to prove that I was right, I designed a small study on myself to confirm the findings and then published them in the *Lancet*.

Aoun (1992, p. 336), a physician diagnosed with AIDS following a blood contamination accident with a young leukemia patient he was treating, describes his experience:

> The transition from physician to patient has made me more aware of some aspects of medical care that, although seemingly trivial from the physician's perspective, are terribly important from the patient's perspective. It is what we would call 'the little things', like being left waiting indefinitely in the x-ray room, having to wait hours to be seen, being examined with gloves and having my lungs ausculated through a thick sweater, being suddenly looked down on as if I had become something of an inferior nature, only because I became ill. The abuses and mistreatments toward patients that troubled me as a physician now infuriate me as a patient. My protest is that regard is not about receiving special treatment for being a physician; it is simply a call for the basic attention and care that anyone with a major illness should receive. Sometimes medical people have a terrible tendency to depersonalize the patient, to make him or her, a 'case'. From that moment, he or she is no longer a person with thoughts, dreams or rights.

The strong views represented in these narratives convey the toll of living with serious illness and speak to the myriad of indignities patients suffer in the health care system. As insiders to the illness experience, these health care providers can identify with this sad reality and appear to need to find ways to make changes within the system both for themselves and for others living with illness.

Disclosure

Disclosure to their patients represents a difficult issue for most health care providers as they must make decisions about what to share and in what context (Wall, 2001; Picard et al., 2004; Baker et al. 2006). Overall, these providers concede that there are no clear answers and that appropriate disclosure in a therapeutic context is helpful both to clients and to them personally. Disclosure appears to be a mechanism to incorporate the personal meaningfully into the professional role and allow for 'authentic' work with other survivors. Schnipper (1996) is quite positively biased in favour of disclosure and open sharing,

> The truth was that I could not bear to talk about it….After I told them, there was a profound change in the atmosphere of the therapy. In both group and individual sessions, the almost always unspoken, 'You can't quite understand because you haven't had it' was gone. It became clear to me that I needed to be public about my diagnosis; if left unnamed, my cancer would be the charging elephant under the rug. As a result of my disclosure, the quality of my interactions with patients changed exponentially. The intensity, candour, affect, and opportunities for growth were unparalleled as the work was shared between both of us in the room; the mutual need to search for truth and meaning was remarkable. Even now that I again look healthy and many of my new patients do not know my history, that has stayed true. (p. 1536)

Maram (1999) presents a more balanced perspective in weighing the benefits and risks.

> I have set some rather definite boundaries in my professional roles. Were these boundaries too rigid? I realize that at times I set them with my own comfort in mind, rather than what would be most beneficial for my clients or for my students. I have tried to be less rigid in my support group by sharing more of myself. In some ways, my role has become blurred. I am facilitator and a group member at times. I wonder if this dual role is appropriate. I have no answer at this point but will continue to struggle with setting boundaries and expect that I will continue to find this difficult. In my role with students, I understand that learning is a process and that self awareness, self-disclosure, and setting boundaries are difficult concepts to put into practice. (p. 44)

Little attention has been paid to the role of trauma, such as serious illness, in the life of the health care provider and specifically in their work with clients. The focus of the existing literature is on the potential therapeutic problems associated with self-disclosure rather than potential benefits (Wall, 2001). As clinical social worker Eda G. Goldstein explains,

> …there are those (life events) that occur during the course of our work that are disturbing and over which we are powerless. They expose our human vulnerability, stir our innermost anxieties and feelings, and evoke our characteristic defences and coping mechanisms. Whether or not we disclose the nature of these sometimes traumatic events to our patients, they almost always are aware of them, at least subconsciously. Further, they intrude on the treatment process either by disrupting appointments and necessitating sudden absences or by their effect on our emotional availability and physical stamina. Yet the sparse clinical literature on this topic leaves one with the impression that, for the most part, traumatic events only befall patients. (p. 41)

Sollod (2002) observes that this topic is seldom included in the training of helping professions. Foehrenbach & Lane (2001) suggest that there are life events, such as expected illness or sudden death of the professional, which may require contingency planning for best practice and least harm to clients. This would involve increasing training and support in both university and workplaces to assist workers navigate these difficult issues.

Advocacy & Professional Role

Another theme covered extensively in the narratives is 'doing the work', as it becomes central to incorporating experience successfully, meaningfully, and in enabling these worker to heal. The sense of being able to share and give back is important, as is the valued opportunity to continue to learn and grow personally and professionally.

However, as a social worker and cancer survivor Schnipper (2003a) speaks of achieving balance, not over-investing and keeping perspective on why we continue to do the work:

> It becomes increasingly clear that we DO make a difference. There are most certainly situations in which no one can take away the pain, but someone who dares to be human can blunt some of the terror and share some of the sadness. We must become exquisitely aware of our own feelings. We must take care that our own need to be needed- one primary reason we do this work- does not dominate us and our relationships. We do not have to be, and cannot be, 'omni-competent' or a super-caregiver. We must keep our antennae well oiled so we notice when we are feeling irreplaceable. (p. 92)

The literature says little on the process to achieve this balance of perspective and more research needs to be done to articulate mechanisms of support. At times, using insider knowledge to 'help' others brought its own distress and difficulties. Lanza (2007),

a psychiatric nurse recovering from a massive stroke, recounts with candour her feelings when trying to help at a survivors' support group:

> I have much less of a problem with walking or moving my hand now, and people may not realize I have had a stroke. I used to think that there would be nothing better. But "normality" brings problems too….I used to have times when I would feel sorry for myself. However when I went to a group for aphasic people as a guest speaker, and it was amazing and disheartening to see these people (my people) try to speak. To be positive, I could help them. For example I gave them much more space to talk than rushing in to say something. In a way, I feel that I almost bridge between two worlds, that of the stroke survivor and the rest of society. (p.772)

Others speak of the role of advocate as the bridge between worlds. A nurse and cancer survivor speaks of her experience of having undergone 12 unsuccessful breast biopsies without adequate pain management;

> But I think it gave me that strong voice to say, 'okay, patients need to be taken care of and we have to do what's right for the patients'. I wasn't always that strong in nursing issues, like, okay, somebody open doors, you know; it's given me that strength. (Picard et al, 2004, p. 540)

Physician-patient Tierney (2000) in relating her account of life with advanced breast cancer recurrence and the resulting uncertainty asserts;

> We cancer survivors are millions strong, and our ranks will continue to grow as improved cancer treatments extend lives. But because the struggle with uncertainty after treatment is completed is usually a silent battle waged outside the physician's office, most physicians don't think or talk about it. In my life as a primary care physician before cancer, I certainly did not. Now I believe that we physicians need to talk to our cancer survivors about the unique struggles of survivorship….they must help survivors understand the impact of fear and uncertainty on their lives and what might help reduce these stressors.(p. 480)

Coulter (2008) speaks to the importance of speaking out to educate her profession and to pave the way for those not yet diagnosed;

> Nurses with breast cancer may require additional support specific to their needs because they are caregivers within the health-care system. This idea came from realizing the true impact of having cancer, my reluctance to seek out traditional supports, my own concerns about my professional boundaries and how passionate some of my nurse survivor friends and I are about breast cancer advocacy and initiatives. One in nine women will develop breast cancer; because women predominate in our profession, we need to look at strategies to support the nurses who will be diagnosed with this disease. (p. 12)

Summary of the Literature

A comprehensive review of the literature on the lived experience of health care providers with illness has occurred. Most of the articles documented the very personal journeys of these health care providers but also articulated some of the unique issues they faced when continuing on with health care work, such as navigating dual roles and the many rewards/challenges of practice. The providers, regardless of professional background, appeared to blend their personal experience into their professional life to create a new identity or 'state of being', contending that this was necessary to foster personal healing and authenticity in professional work.

Theoretical Framework

The purpose of this section is to provide an outline of the theoretical framework that underpinned the research process and the interpretation of data during analysis.

Liminality and Illness

Liminality has also been applied to the experience of illness as it often results in tremendous change and ambiguity for the affected individual and their loved ones on the transition from 'healthy' to 'unhealthy', and somewhere in-between. For example, Jackson (2005) employs liminality in exploring the ambiguous status and social stigma assigned to chronic pain sufferers when no medical explanation can be found for their pain. Gardner (1998) applies the concept to the study of the lived experience of a nosocomial wound infection, which she describes as an experiential dimension outside the realm of normative experience and embodied by a state of liminality in which suffers "live an indeterminate existence that is in-between health and illness, cure and disease" (p. 212)

Little et al. (1998) applied the concept of 'liminality' to cancer illness as a theoretical construct to explain subjectivities of the experience. Little and his colleagues interviewed 10 cancer patients using possible indicators compiled by analyzing available published narratives, film, television drama and interviews. The researchers concluded their findings were best understood under the rubric 'liminality', asserting that all cancer patients experience liminality as a *process* that begins with the diagnosis of their malignancy and continues indefinitely. The process is marked by phases and corresponding experiences - the initial acute phase of liminality is reported as marked by disorientation, a sense of loss of control and uncertainty; this gives way to an adaptive, enduring phase of "suspended liminality in which the patient constructs and reconstructs meaning from their experience by means of narrative" (p. 1485). The authors assert that there were also several key features to the cancer survivors' narratives indicative of this

liminal state: 1) the immediate impact of the cancer diagnosis and persisting identification as a cancer patient, regardless of time from treatment or disease state; 2) a variable state of alienation from social familiars, expressed as an inability to communicate the nature of one's illness, and 3) a persistent state of 'boundedness', wherein cancer patients had an awareness of limited space, empowerment and available time.

Thompson (2007) studied a group of ovarian cancer survivors, attempting to replicate Little's findings and validate his application of the liminal concept to this experience. Thompson interviewed nine women with stage-three ovarian cancer to hear about their lived experience with the illness. The researcher reported that overall, she concurs with the merit of applying liminality as a rubric to the cancer experience, but with some qualifiers and modifications. Thompson asserts that use of the concept needs to be amended to capture the generative potential and positivity that is captured in many cancer illness narratives, primarily as a way of healing and coping with enormous uncertainty. Thompson also cautions that use of the liminal concept to cancer and other populations may generalize a highly personal and individually unique experience, thus doing a disservice to clients in the end.

Summary of Theoretical Framework

Given the extensive life changes that individuals diagnosed with serious chronic illness must make, it is conceivable that some degree of ambiguity is involved in the adjustment process. The existing literature supports the assertion that the personal and professional experiences of health care providers with serious illness are indeed inseparable, becoming melded together over time to result in a new 'liminal' state of

being. Thus, the health care provider engages in her or his work through a continuing

process of re-defining self and connection to practice by applying the 'lens' of their

insider experience as an illness survivor.

CHAPTER THREE

RESEARCH METHODOLOGY

<u>Introduction</u>

The purpose of this chapter is to outline the method of study of the research problem. An explanation of the qualitative research method will be presented. A research plan consisting of sample, including selection and setting, data collection methods including demographic collection, the interview guide, procedures and data analysis, verification of findings and ethical considerations will be provided.

<u>Methodological Framework</u>

The purpose of this section of the chapter is to provide an outline of the methodological framework utilized in the research process, which includes Phenomenology and Insider/Outsider Theory.

Phenomenology

The methodological framework for this project is derived from a qualitative approach to research which values subjective knowledge, an inductive process to gathering that knowledge, and a democratic view which recognizes power dynamics involved in how knowledge is created and valued by society. Thus, qualitative inquiry values authenticity, depth and reflectivity in the scientific process (Patton, 2002).

These qualities are consistent with 'phenomenology', an approach to the field of human science pioneered by German mathematician Edmund Husserl. Phenomenology is essentially the systematic study of the human lived experience of an identified

phenomenon (Creswell, 2007). Thus, phenomenology embraces the subjective as truth in the search for meaning behind life experiences and 'being' in the world.

Husserl outlined four basic themes to characterize phenomenology: a return to the traditional tasks of philosophy, the search for a philosophy without presuppositions, the intentionality of consciousness, and the refusal of the subject-object dichotomy (Stewart & Mickunas, 1990). Phenomenology generally seeks to provide depth and rich description of phenomenon so as to uncover the 'essence' of the experience under study (Stewart & Mickunas, 1990). This is accomplished through the intentional directing of individual consciousness toward the object one seeks to understand and discerning one's 'natural attitude', or 'the standpoint of a person going about his everyday business in his accustomed world. Such a world is one of human endeavour and human relationship and as such, it includes a wealth of physical objects and the experiences of daily life and thus constitutes a "world of values, obligations and practical affairs" (Stewart & Mickunas, 1990, p. 24).

Disagreement has evolved regarding the methodological principles employed in phenomenology that amounts to a difference in philosophical approach (LeVasseur, 2003). In Husserl's (1931) heuristic or transcendental phenomenology, an important first step to inquiry is for the researcher to 'bracket' their own experience (Moustakas, 1994). Also referred to as creating an 'epoche' or as the phenomenological reduction, the process of bracketing was designed to "…suspend[s] one's natural assumptions about the world, so that what is essential in the phenomena of consciousness can be understood without prejudice" (LeVasseur, 2003, p. 411). Thus by mentally 'purging' all pre-conceptions from the mind, Husserl believed the researcher was able to 'transcend' and

allow the consciousness to intuitively perceive pure phenomenal experience (LeVasseur, 2003).

The philosophical approach of hermeneutic phenomenology, on the other hand, rejects the idea of the ability to transcend and advises the researcher that while one may try to 'bracket' or set aside their personal experience with the study phenomenon, stating it is impossible to do given that all understanding is through directed consciousness and ultimately, interpretation (van Manen, 1990). Championed by Heidegger (1962), a student of Husserl, this approach maintains that consciousness cannot be separated from 'being in the world'. van Manen (1990) instructs 'it is better to make explicit our understandings, beliefs, biases, assumptions, presuppositions, and theories. We try to come to terms with our assumptions, not in order to forget them again, but rather to hold them deliberately at bay and even to turn this knowledge against itself, as it were, thereby exposing its shallow and concealing character' (pg. 47).

Hermeneutical phenomenology focuses on the language and structure in communicating experiences and developing interpretive meanings (Patton, 2002). As van Manen (1990) explains, 'the essence or nature of an experience has been adequately described in language if the description re-awakens or shows us the lived quality and significance of the experience in a fuller and deeper manner' (pg. 10).

In her article discussing differences in methodological principles, LeVasseur (2003) asserts that health researchers have adopted bracketing as the method associated with all phenomenology regardless of philosophical background, largely as it appeals to the 'objectivity' favoured by the natural sciences. The obvious cost is the consideration of existential thought and embracing subjective knowledge. The author offers a

compromise, suggesting that "…perhaps bracketing, in the sense of suspending theories and assumptions, can be perceived as another figure of what interpretive phenomenologists call the hermeneutical circle. In the hermeneutical circle, we make progress toward sense and meaning by questioning prior knowledge, thus expanding into new horizons of meaning. Yet, we never fully arrive, because to arrive would merely represent another stage of pre-understanding" (2003, p. 418).

As a novice researcher I initially considered use of Husserl's heuristic model, wherein I would attempt to bracket my experience, as it might represent a less complicated approach for my topic and potentially add perspective on the use of this methodological approach. In truth, I was attracted to this approach by my assumption that 'suspending' my pre-conceptions from my experience would lend some level of 'objectivity' to a subjective endeavour. This, of course, is counterintuitive of the qualitative research endeavour. In the end, I have simply become more conscious of the 'imbeddedness' of rationale thought, the scientific process, and 'natural' order to inform what we collectively value as truth.

I knew instinctively that my inquiry would be informed by all of my learning from experience if only to remind myself that, I too, am perpetually in a state of 'be-ing' and connection to the world. As hermeneutic phenomenologists contend, there is no need or ability to transcend, only to explore, interpret and guide toward a broader horizon of understanding which will likely stretch on unendingly. Toward this purpose, I have chosen to adopt hermeneutic phenomenology as the methodological approach for this project.

Insider/Outsider Theory

Insider-outsider theory has evolved primarily from ethnographic field research and has subsequently been applied in a broad range of social science research areas (Bartunek & Louis, 1992). In its broadest sense, the theory generally articulates a distinction in perspective between an *emic* (insider) viewpoint which suggests an informed and influential standing; as contrasted with an *etic* (outsider) viewpoint which is more distant, logical, and removed (Headland, Pike & Harris, 1990).

Examples of the application of insider-outsider theory can be found in the field of education (Zeni, 1998), economics (Lindbeck & Snower, 2002), and community health (Sixsmith, Boneham & Goldring, 2003). Researchers have applied the insider-outsider perspective to examining difficulties in cross-cultural studies, such as Brayboy and Deyhle's (2001) study on engaging youth in American Indian communities in education, or Mullings' (1999) work in economic geography interviewing business leaders in Jamaican communities.

The self of the researcher in ethnographic field research is of particular import. For example, Reinharz (1997, in Hertz, R. (ed.)) reflects on her year long ethnographic study of the elderly population of an Isreali kibbutz in her chapter entitled, 'Who Am I? The Need for a Variety of Selves in the Field'. Reinharz asserts that 'the self' of the researcher is the key tool in fieldwork, and that there a variety of selves the researcher brings to the field. These include '*research-based selves*', '*brought selves*' and '*situationally created selves*' (1997, p. 5). Reinharz explains, "I propose that we both *bring* the self to the field and *create* the self in the field. The self we create *in the field* is a product of the norms of the social setting and the ways in which the "research subjects"

interact with the selves the researcher brings *to the field*" (p. 3). In her analysis Reinharz reflects on the various selves she brought and created in her time on the kibbutz, noting both the fluidity and influence these varied selves had on the research process and outcome. This included her awareness of kibbutz members' perceptions of her as an outsider to the community, and the creation of situational self in the research context with which to assist her to glean insider information on her subject which she notes as imperative. Reinharz relates, "More dramatically, I would say that unless the researcher (and subsequent reader) knows what the researcher's attributes mean to the people being studied, the researcher (and reader) cannot understand the phenomenon being studied" (p. 4).

Naples (1996) applies a feminist perspective to the use of the insider/outsider theory, explaining her research approach:

> I start with the assumption that, rather than one 'insider' or 'outsider' position, we all begin our work with different relationships to shifting aspects of social life and to particular knowers in the community and this contributes to numerous dimensions through which we can relate to residents in various communities. 'Outsiderness' and 'insiderness' are not fixed or static positions, rather they are ever-shifting and permeable social locations illustrated in this case study by the 'outsider phenomenon'. Community processes that reorganize and resituate race-ethnicity, gender and class relations form some of the most salient aspects of the "outsider phenomenon. (p. 83)

Feminist researcher Watts (2006) examines positionality issues when interviewing women who do not self-identify as feminist, citing concerns with access, informed consent and 'truth-telling' when these outsider-participants engage her as an insider-researcher. Watt discusses issues of finding 'common ground' and 'common language'

while attempting to develop empathy across a political and theoretical divide, asserting the process is dynamic and complex with special challenges to researcher integrity.

The literature has many examples of positionality related to researcher and participant perspective, commonly exploring the inherent challenges of adopting one or another, or sometimes multiple, perspectives. For example, Humphrey (2007) has written about her experience as a lesbian academic researcher seeking to interview various self-organized groups (SOGs) within the British trade unions. Humphrey articulates well the interaction of multiple positions she occupied when approaching the project both as an academic-outsider and lesbian-insider. She concludes that what developed was a reflexive process of navigating liminal space and the evolution/change of what constitutes an insider-outsider position.

Similarly, Kahuna (2000), a lesbian social worker of mixed ancestry, discusses the challenges in choosing to study the lived experiences of other gay and lesbian multicultural people. Kahuna highlights some of the benefits of coming to the research from an insider position, including seeking increased knowledge through an interested, impassioned approach. For example, from her position as social worker, she cites the benefits of the research to improved understanding of the social needs of her group and the potential for improvements in clinical interventions and social welfare policy reforms. Risks, however, cited by Kahuna include relying too much on insider pre-understanding so as to miss key insights, and in erring by not keeping in check one's need to maintain some openness in approach. These observations relate to Reinharz' work (1997, in Hertz, R. (ed.)) wherein she advocates reflection on the research-based self created in the field

so as to maintain perspective on this created identity and better understand the role relationships negotiated with subjects (p. 11).

A suggested approach to insider-outsider research that is designed to counter-balance these concerns is that of 'insider-outsider research teams'. Thus, team members would represent both insider and outsider perspectives to the issue or population under study (Thomas, Blacksmith, & Reno, 2000). Ideally, the team's interactive approach to research and analysis of findings would reduce potential bias and represent maximal generative potential for these two sides to learn from each other with respect to the phenomenon under study (Bartunek & Louis, 1992).

<u>Role of the Researcher</u>

It is my belief that my lived experience as both a social worker and more recently a person living with cancer, informs my inquiry and is inseparable from this research. Indeed, I am an 'insider' into this phenomenon by virtue of my experience of this relatively uncommon life experience that eludes most as a topic of interest (Pascal, 2010). I have made a conscious choice, I feel, to intentionally direct my consciousness (and those of my readers) to examine this phenomenon more closely and thus broaden our horizon of collective understanding by illuminating this liminal space.

This approach is not without its perils. Navigating issues of 'insider' and 'outsider' identity distinctions can be complex, and places special obligation on the researcher to take a reflexive stance to remain cognizant of their personal influence in the research, as bias can create obstacles in the research process (Humphrey, 2007 ; Kanuha, 2000; Labaree, 2002). As van Heugten (2004) cautions, "where the researcher is identified as

'being native' from the outset, the potential benefits of privileged understanding require carefully balancing if one is to avoid dominant discourse blind spots pervading the analysis…" (p. 208).

With respect to this issue I felt it was important as an insider-researcher to proactively plan for how I would handle these pit-falls in order to strengthen the quality and trustworthiness of the results. Both Van Heugten and Kahuna make several recommendations, including keeping field notes or a journal of the research process and/or engaging in the regular practice of reflective sessions with a research supervisor. Kahuna (2000) offers caution regarding the dangers in interviewing other insiders, explaining it is important to stay focussed and not become distracted by self-reflection; to be mindful of detachment so as to not inadvertently rely on common language or presumed pre-understandings, and always to clarify the subject's intent in making statements with probes. Finally, Kahuna cautions that "one must not assume that being an insider to a cultural group necessarily means that the insider researcher has gained intimate knowledge of the particular and situated experiences of all members of the group or that generalizations can or should be made about the knowledge the researcher holds about her own culture" (p. 443).

My goal in this research was to use my insider position to sensitively explore and work toward describing the 'essence' of what it is like to be a health care provider living and working with illness. I agree with the hermeneutic position that in exploring the lived experience, one will never fully discover what is ultimately 'the truth' as it is subjective and varies by the author and interpreter of that truth (van Manen, 1990).

In line with the recommendations made regarding maintaining perspective when doing insider research, I endeavoured to keep a journal to examine my thoughts and feelings during the research process. I also took opportunities to debrief with my research advisor, as needed.

Study Sample

The purpose of this section is to provide an overview of the research study sample. The selection of a study sample is a key element to any research study. However, as phenomenology seeks to reveal the essence of the concepts under study solely through the lived experiences of the participants, the selection of appropriate participants is of paramount importance.

Purposive Sample

The study utilized purposeful, criterion sampling so as to ensure that selected participants had experienced the phenomenon under study and thus facilitate depth in interview data (Creswell, 2007). The study population initially targeted for recruitment were nurses or social workers who self-identified as living with serious chronic illness (as previously defined). These two professions were chosen given their key roles in the health care field and their affinity to focus on the psychosocial aspects of patient care. An anticipated limitation of this strategy was the procurement of a gender-specific sample given that both nursing and social work are generally female dominated professions.

I was concerned that recruitment might prove difficult as this is a unique and highly personal life circumstance which may preclude disclosure. To allow for an adequate sample, I was prepared to broaden my criteria to include nurses and social workers whose practice was inclusive of a wide variety of settings (i.e., hospital, community, long term

care, palliative care, etc.), who worked either full or part time, or who had left the field or changed practice areas following their illness diagnosis or treatment. Finally, I also considered expanding recruitment to other health care professions outside nursing and social work, if needed (i.e., medicine, physiotherapy and occupational therapy).

Interestingly, not only did I not encounter the struggles I had anticipated with recruitment, but actually found I was contacted by a variety of professionals despite recruiting specifically for nurses and social workers. It became clear to me that my concerns about recruitment problems were unfounded; indeed, healthcare providers were so interested in participating that they expressed their interest despite not meeting the criteria for professional affiliation. Therefore, I decided to broaden my criteria to include health care providers from a variety of professions. As a result, a volunteer sample of health care providers (n=6) was constructed.

Inclusion Criteria

Study participation was ultimately based on several criteria: 1) minimum one year post-personal diagnosis and/or treatment of a serious chronic illness; 2) current practice in health care field (either full or part-time) following diagnosis/treatment; 3) study consent reviewed and signed. All potential participants were screened for eligibility using a prepared script (see Appendix B).

There were several points in the rationale for developing these inclusion criteria. First, as the first year post-diagnosis often represents a crisis time in the individual's life, I felt that those who were newly diagnosed might lack sufficient time to process and reflect on their experience for the purposes of this study. Second, as an essential aspect of

the phenomenon under study was to examine providers currently practicing it was important the participants were actively practicing in their profession.

Sample Acquisition

Given a small research project budget, initial recruitment focussed on locations within Winnipeg, Manitoba. A study recruitment letter (see Appendix A) was emailed to the following organizations, with a request to widely distribute to their membership: Manitoba Institute of Registered Social Workers (MIRSW); Manitoba Nurses Union (MNU); the Winnipeg Regional Health Authority (WRHA) regional newsletter, 'The Health Care Connection' and the Health Sciences Centre (HSC) weekly centre-wide newsletter, 'HSC Messenger'. MNU were unable to distribute to their membership within the allotted project timeframe and so was not included in recruitment. MIRSW distributed to their membership via email; WRHA and HSC placed notices about the project and the researcher's contact information in their weekly email newsletter to staff.

Interview Setting

Once I was contacted by a potential participant, I made contact by phone and ensured that they received the recruitment poster. Once it was clarified that the participant met the inclusion criteria and agreed to participate, the study consent (Appendix C) was emailed to all participants for their review and a date was booked to meet for the initial in-person interview. Interviews took place in an environment that was private and of the participant's choice. Setting was very important so as to encourage participants to feel comfortable in sharing their experiences openly. Ultimately, all participants chose to have me meet with them in a private meeting space in their home institution.

Data Collection Methods

The purpose of this section is to provide an overview of the data collection methods used in the research. Data collection occurred in two phases- an initial interview phase (winter 2010) and a follow-up interview phase (summer 2011).

Phase One: Initial Interview

The initial interviews phase consisted of two parts: gathering written demographic information, and conducting the in-depth interview regarding participant's lived experiences as health care providers with illness.

Demographic Information

Demographic information provided summary information regarding aspects of the sample. I collected minimal demographic information in written form (Appendix D) at the outset of the meeting, including age, gender, professional background and education, years worked in health care, and years in current practice area. I also gathered information about their diagnosis and current symptoms of illness.

Interview Guide

The semi-structured interview guide (see Appendix E) constructed by the researcher, derived from themes extrapolated from the relevant literature. Participants were first asked what the experience of their illness had been like for them; they were encouraged by the researcher to 'tell their story', starting at whatever point in the narrative made sense to them and continuing on. Participants were then asked several open-ended questions about navigating life as patient and professional. Finally, participants were asked to give their views on training and preparedness for this

experience, as well as any recommendations they may have to assist colleagues diagnosed in future navigate practice effectively.

Interview Procedure

The researcher's focus in the hermeneutic interview is "to keep the question (of the meaning of the phenomenon) open, to keep him or herself and the interviewee oriented to the substance of the thing being questioned…the interviewee becomes the co-investigator of the study" (van Manen, 1990; pg. 98). The data collection technique in the initial phase consisted of one 60-120 minute conversational interview with each participant, encompassing the interview guideline but with the researcher also probing at times for clarification or more depth in the answers. Probing ceased when participants indicated they could not think of any new information or insights. The interview concluded with an open-ended invitation for the participants to expand or edit any previous answers, in addition to speaking to any issues of concern to them not asked by the researcher (Patton, 2002).

Interviews were held privately in the participant's work office and were audio recorded. Study consent was signed and collected. All participants were offered an honorarium of twenty dollars for each interview, however, all refused to collect the honorarium.

These first interviews were then transcribed verbatim from the audio recordings by the researcher.

Phase Two: Follow-up Interview

The initial results were compiled in a research report. These results were emailed to participants along with a second study consent, and they were then contacted to arrange

for the second phase of data collection. These follow-up interviews were from 30-60 minutes in duration and concluded when the participant was satisfied the interview content reflected the nature of the study phenomenon.

This interview took the form of what van Manen (1990) suggests as an 'interpretive conversation', wherein 'both the researcher and the interviewee weight the appropriateness of each theme by asking: "Is this what the experience is really like?" (p. 99). This process served as a member check to ensure accuracy and descriptive validity.

Data Analysis

The purpose of this section is to discuss the data analysis technique utilized to organize and interpret data collected from participants. van Manen's process of free imaginative variation, selective or highlighting approach and organizing thematic statements is discussed.

van Manen's Technique

According to van Manen (1990) "the most difficult and controversial element of phenomenological human science may be to differentiate between essential themes and themes that are more incidentally related to the phenomenon under study" (pg. 106). To engage in this endeavour, van Manen recommends a process of 'free imaginative variation' in order to generate essential themes, wherein "one asks the question: Is this phenomenon still the same if we imaginatively change or delete this theme from the phenomenon? Does the phenomenon without this theme lose its fundamental meaning?' (pg. 107). The hermeneutic or interpretive phenomenology research process is one of

describing the phenomenon through writing, where research and writing are seen as part of the same process, which aims to make explicit the universal meaning of experience.

The researcher listened to the interview recordings and reviewed the transcripts in full numerous times to immerse herself in the information. Transcripts were reviewed using a selective or highlighting approach (van Manen, pg. 94) wherein 'phrases that stood out were identified for thematic significance to the study phenomenon and noting where certain experiential themes recur as commonality or possible commonalities in the various descriptions gathered' (van Manen, pg. 93).

The researcher engaged in a process of condensing and then removing redundant themes by writing and re-writing thematic statements. Thematic statements were clustered and organised into patterns and essential themes were named and then re-named in a constant clarification and re-writing. During this interactive process, I continued to ask the question, 'Would the experience of being a health care provider living with serious chronic illness still be adequately described if I changed or deleted this theme?'.

Methodological Rigor

The purpose of this section is to examine the methodological rigor of the project research design. Typically, methodological rigor ensures that the findings are trustworthy (Patton, 2002). However, as hermeneutics places emphasis on interpretation, validation reflects more agreement of interpretation amongst a community or group rather than the assertion of validating that data as objective fact. van Manen (1990) suggests the process of multiple interviews, in which transcripts and the researcher's interpretation of the texts are taken back to the interviewees so that a process of dialogic interpretation of the

deeper meaning of the phenomenon may transpire (pg. 98-99). Thus, interviewees become co-investigators in the research which is a collaborative endeavour.

As Kvale (1987; in Patton, 2002, p. 114) explains;

The attempts to develop a logic of validation within the hermeneutical tradition are relevant for clarifying the validity of interpretation in the qualitative research interview.

The interpretation of meaning is characterized by a *hermeneutical circle*, or spiral. The understanding of the text takes place through a process where the meaning of the separate parts is determined by the global meaning of text. In principle, such a hermeneutical explication of the text is an infinite process while it ends in practice when a sensible meaning, a coherent understanding, free of inner contradictions has been reached.

Thus, the conceptualization of the 'hermeneutical circle' lies in questioning knowledge and seeking to expand new horizons of meaning, while never 'arriving' at a complete understanding rather only at new stages of pre-understanding which are valid in the context by which they were reached.

Ethical Considerations

The purpose of this section is to examine ethical considerations and procedure when conducting human science research. Informed consent and voluntary participation are essential to the process for ethical research practice. Protecting the confidentiality of participants and their information, as well as considering participant vulnerability must be addressed.

Obtaining Consent

Participants were provided with a consent form and the study preamble (see Appendix B) to inform their consent for participation in the interviews. The researcher discussed with each participant their understanding of the study process and their willingness to participate. Participants were assured that their participation was strictly voluntary and that they could withdraw from the study at anytime.

Voluntary Participation

In line with ethical research practice, no real or perceived coercion was involved in study participation at any point. Participants were assured that their confidentiality would be protected, and that only they and the researcher would know of their involvement in the study. Participants were assured that their involvement in the study was completely voluntary and that they could discontinue participation at anytime without penalty. Participants could ask questions or seek clarification of questions they did not understand, and could decline answering any questions with which they were not comfortable.

Maintenance of Confidentiality

Participant confidentiality was protected by destroying interview tapes once transcribed, by removing identifying information from the transcribed interview responses, and by storing this interview data in a secure location.

Coding and Pseudonyms

Each participant was assigned a numeric code and a pseudonym, and real names of the participants were not used. The collected demographic information sheet, and

interview transcripts were collated with the signed consents and marked with the numeric codes and pseudonyms.

Access to Gathered Data

Participants were assured that only the researcher and the research ethics board would have access to the consent form. Participants were informed that only the researcher and potentially the research committee would have access to the transcript information.

Storage of Data

The consent form and interview response data were stored in a locked file drawer in the researcher's office. All documents with personal identifiers will be destroyed and put to confidential waste at the completion of the thesis project.

Cost to Participants

While there were no associated monetary costs to participants, but there were some burdens with participation in the study. The largest single factor was the investment of time to collaborate with the researcher in the recruitment process and then participate in the interviews themselves. Time to review consent and the initial research report was also needed. Every effort was made to avoid inconvenience to participants, and no participant expressed concern with being inconvenienced in any way during or after the interviews.

Risk to Participants

There was minimal risk associated with participating in this study. By virtue of recollecting and revealing lived experience to the researcher, there was the possibility of

participation leading to emotional upset or psychological distress. If participants became tired or upset, they were encouraged to take a break or to discontinue participation at any time with no consequences. If participants experienced any negative emotional or psychological consequences related to participation, the researcher was able to provide assistance to secure counseling or other appropriate resources to concerns (see Appendices F, G J). None of these issues arose with any of the participants during the research.

Summary

This chapter outlined the method of study of the research problem. An explanation of the interpretive phenomenological research method was presented. Discussion of a research plan consisting of sample, data collection methods and analysis were provided. Finally, methodological rigor and ethical considerations was discussed. In the next chapter, Chapter 4, research findings will be presented.

CHAPTER FOUR

RESEARCH FINDINGS

Introduction

This chapter provides the research findings. It consists of a description of the study

sample and a report of the themes that emerged from an analysis of the interview data.

All the names of the participants were removed and replaced with pseudonyms; in

addition, information was altered to protect their confidentiality.

Sample Description

This section provides an overview of the characteristics of the sample, including

information on gender, age, years of practice experience and years in the current practice

setting. Diagnosis and effects of symptoms on functioning were also outlined.

Age, Gender and Occupation

All six participants were female. The participants ranged in age from 40 to 59 years.

Two of the participants were aged 40-49; the other four participants were aged 50-59

years. The participants represented a variety of professional backgrounds within the

health care field. Two were from the nursing profession; two were occupational

therapists; one was a social worker and one was a health region corporate coordinator.

Practice Experience and Years in Practice Setting

The sample represented a significant number of 162 years total of health care

practice experience. The reported experience ranged from 18 to 33 years; the average was

27 years experience. Two participants had over 30 years experience; three had between 21 and 30 years experience; finally, one had 18 years experience.

The sample consisted of professionals from a variety of practice settings, including tertiary care institutions and community care programs. Years in their current practice setting ranged from 4 to 17 years.

Diagnosis and Current Symptoms

The participants reported a number of serious chronic illness diagnoses; four of the six dealt with one diagnosis, while two participants had multiple illness diagnoses. Three participants reported a breast cancer diagnosis; one reported a diagnosis of multiple sclerosis; one reported a diagnosis of lupus; one reported type 1 diabetes.

There were a wide variety of symptoms reported across diagnoses that affected participants' functioning. All participants reported experiencing fatigue, and difficulties with memory and concentration. Three participants reported experiencing pain symptoms; two reported significant difficulties with mobility; two reported complex medication management and one reported significant dietary restrictions.

Summary of the Sample Data

A summary of the study sample is provided in Table 1 pictured on page 67. The study sample was small but reflective of a range of age, occupation, diagnosis and years of health care experience.

Participant	Gender	Age	Occupation	Setting
Participant 1 Beth	F	50-59	Social worker	Community
Participant 2 Sue	F	40-49	Nurse	Hospital
Participant 3 Rita	F	40-49	Corporate Coordinator	Community
Participant 4 Gail	F	50-59	Occupational Therapist	Community
Participant 5 Holly	F	50-59	Occupational Therapist	Hospital
Participant 6 Wendy	F	50-59	Nurse	Community

Table 1- Sample Summary

The Findings from the Data

Introduction

As mentioned, there were (6) individuals experiences related through the interview process. Each participant was asked to relate stories about their lived experience with serious chronic illness, as they felt it impacted their personal and professional lives.

The semi-structured interview guide asked a series of questions related to their experience of living with serious chronic illness in general and with respect to navigating practice as a health care provider. Generally these experiences were conveyed through the telling of anecdotes and stories that would lead from one into the next. As a result, detailed information was provided about the nature of experience of being a health care provider living with illness.

This section presents the findings from the interview transcripts. A brief description of the technique used to analyze the data will be provided. The results will be presented as themes, which consist of clusters of sub-themes which reveal greater complexity and detail of the phenomenon.

Data Analysis

The purpose of this section is to provide a detailed analysis of the study results. Interviews were transcribed verbatim from tape recordings. Analysis of the interview transcripts was undertaken utilizing van Manen's data analysis techniques previously described. A total of 425 significant statements were identified in the initial interviews,

the majority of which were used in the analysis. Significant statements were each treated as an independent piece of data.

Significant statements were clustered and organized into patterns and essential themes were identified through a process of 'free imaginative variation' using the guiding question: 'Is this phenomenon still the same if we imaginatively change or delete this theme from the phenomenon? Does the phenomenon without this theme lose its fundamental meaning?' Essential themes were named and re-named in a process of constant clarification and re-writing. In this way, themes that were not considered essential to being a health care provider with serious chronic illness were put aside.

Three over-arching categories were identified from these data and each of these categories was then further deconstructed down into themes and smaller sub-themes so as to uncover richer and deeper meaning in the phenomenon described. The table on page 70 provides an overview of identified themes and associated sub-themes. Appendix M provides an overview of the coding grid used to organize and structure the participant data.

In the next chapter section I provide a detailed analysis of each category, with its associated themes and sub-themes. I will also revisit the research questions for the study which were previously outlined. Finally, I will provide a summary statement of the data analysis.

CATEGORIES	THEMES	SUB-THEMES
ADJUSTMENT TO ILLNESS	Loss of control	* Shock of diagnosis; * Vulnerability
	Dealing with uncertainty	*Fear of future illness; Confronting mortality
	Changed perspective	* Priorities; Managing stress & emotions
INTERACTION WITH THE HEALTH CARE SYSTEM	Insider position	* Knowledge as double-edged sword
	Interactions with care providers	* Hierarchy in the system
EFFECTS ON PRACTICE	Enhanced connection	* Better understanding of clients; Using supports
	Need for a plan	* Managing workload; Developing strategies
	Use of self	* Selective disclosure; Teaching about experience

Table 2 -   Summary of Results

<u>The Categories</u>

<u>Revisiting the Research Questions</u>

The research questions to be addressed included:

1. What is the essence of the lived experience of being a practicing health care provider with serious, personal chronic illness?

2. In what ways can the health care system improve services for health care workers?

Introduction

The three categories identified were titled 'adjustment to illness', 'interactions with health care providers' and 'effects on practice'. As described, each of these broad categories was deconstructed down into themes and sub-themes to further identify essential elements to the phenomenon under study.

Where ever possible, the participant data are amalgamated and paraphrased. Some of the stories shared by participants represented poignant or succinct examples of a certain theme, thus direct participant quotes are also used to underscore meaning while protecting participant's confidentiality.

Category One: Adjustment to Illness

The first category that was identified was titled Adjustment to Illness, which encompassed participants' descriptions of their coping with personal illness. This category was deconstructed into three main themes: Loss of Control, Dealing with Uncertainty and Changed Perspective. Each of these themes was then developed into smaller sub-themes, so as to further isolate the meaning of the phenomenon.

Loss of Control

I have chosen in my interpretation of the data to focus on exploring the experience of loss, as opposed to examining locus of control. Rotter (1966) conceptualized locus of control as a predisposition in the perception of what causes reinforcement (i.e., reward, favourable outcome, goal accomplishment). Thus, the construct centers on individual's perception of events to within or outside of the realm of their personal control (Kormanik and Rocco, 2009). These perceptions have been found to shift temporally and under conditions of change (Frasier, Keenan, Anders, Perera, Shallcross & Hintz, 2011). Health related locus of control has been found in the literature to correlate with perceived quality of life, health behaviours and psychosocial adaptation (Livneh, Lott & Antonak, 2010).

The literature on the experience of loss in relation to illness is extensive and illustrates the far reaching consequences for affected individuals. As Gorman (2011, in Harris) states, "It is important to recognize the profound loss experiences that accompany a chronic illness…the illness experience is fraught with changes, transitions, and losses that result in grief in individuals and families" (p. 195). Boss (1999) comments on the adaptation process involved in coping with illness:

> When an illness won't go away, people creatively find hope in other ways- in doing their best to manage the illness, in helping others who are experiencing the same pain, or in finding ways to prevent others from having the same experience. With surprising ingenuity, people infuse what looks what looks like a tragic situation with hope (p. 119)

Loss in the context of illness is commonly associated with uncertainty and a lack of perceived control over one's life. In her chapter discussing chronic degenerative conditions, disability and loss, Gorman (2011, in Harris) explains:

Perhaps one of the biggest hurdles to overcome for people who have been diagnosed with a chronic illness is the loss of a sense of certainty about the world and themselves in the world. Even though rationally we may understand that we have limited control in our lives, it still comes as a shock when the feared becomes actualized (p. 198).

Loss of Control related to illness adjustment was discussed as an issue by all participants. Participants provided examples of times and ways in which they felt they had lost control in their lives due to circumstances with their illness; participants also acknowledged possessing a fear of further loss of control beyond that already experienced. Sub-themes that were isolated from significant statements included Shock of Diagnosis and Vulnerability.

Shock of Diagnosis

Shock of Diagnosis was discussed by 5 of the 6 study participants despite variation in type of illness. All told the story surrounding their diagnosis with a serious chronic illness and discussed the emotional impact of realizing life had now irreparably changed. The sense of disbelief was palpable, as Rita succinctly expressed "You don't ever think that the day is going to come where you can't do what you want to do". Holly explains her trying to reconcile the reality of her illness in this way:

> …previously before being diagnosed with…cancer and all the treatment you kind of think, y'know what? that's gonna happen to somebody else, right? It's going happen to somebody else…I'm young, I sort of watch what I eat…I exercise and I have a positive attitude. See, it really kind of shakes that a bit, right, that if I do all those things I'm going be immune and then you kind of wonder, ok, in the future…is it going to happen again…you don't want to kind of live in the hold of that, or that grasp, y'know? I think it might be a little bit more of a gratitude…that has grown in terms of…yeah, maybe my kids didn't do what I wanted today, but like an appreciation that this day was here, right?

Sue described dealing with an initial overwhelming fear that her cancer diagnosis represented a death sentence, "…having the diagnosis, I was um, obviously in shock and um, I thought I was going to die. I really thought I was going to die. For me, it was like, I was going. I mean that was in the beginning stages, um, but then you know that that's not reality, it's just your fear".

Dealing with life beyond initial diagnosis appeared to involve deepening levels of acceptance over time and trying to find a way to go on with life with illness as a presence. As Gail explained about her diagnosis, "I was told I had lymphoma, which just, y'know, rocked my world so to speak… so once I met with the specialist and found out what kind of lymphoma I had, it was, um, sort of the 'good kind' if you could call it a good kind of lymphoma, so it's contained, y'know, and so it's always in the back of your mind'. Holly spoke about deciding how much to know about the survival statistics related to her illness:

> …it was breast cancer, yeah, and my knowledge of cancer and how it was diagnosed has really, really increased a lot, but they, I don't know for you, but like they tend to really put a grade on it, right? a stage or whatever…so it had progressed quite far for me…significantly into the lymph node, significantly…so it was…full out…max treatment kind of thing, …they give you a stat based on where you fall into grading, right?...some people really like to know all the facts around it, right, but I soon discovered for me that I wasn't that type….if I focus too much on….what is the percentage at 3 and a half, what it looks like, the 5 year prognosis, y'know, it's, it's not good to know those things (laughs)

Participants also spoke about integrating the knowledge of their diagnosis into their experience as a health care provider. This most often involved sorting through a myriad of patient-related work experiences, now seen through the eyes of the newly diagnosed. Wendy poignantly described this connection:

…and I worked with some people that had multiple sclerosis and they had it *bad*, and there are some things in my head, like, I remember this lady…the only thing she could move was this finger, like that, like this (demonstrates movement)…and *that* image would stay with me, like, oh my God. I'd go home at night and think can you imagine living like that? (voice lowers) it would be awful…so then, what happened, it was the weirdest thing, because it started in 2004 in the winter, I started getting these weird feelings in my legs, I thought (voice lowers) oh, I wonder why I'm getting that?....and things kept going and going and going so then, this arm I could tell…being a health care professional, you know, right? So I could start feeling and I'm going, it's C5, I know exactly, it's C5, it's cervical 5, so I wonder what's happening? my family doctor thought I had a tumour on my spine...so then we went in and, I just always remember I went with my husband and I…could hardly *walk*, like I looked…awful…sit down in that chair and he sat down beside me….he basically had to carry me in there and the neurologist was here and…he said to him, um, 'you're Mr. ___?', so we go (laughs) this is going to be bad, right? And then he said you have multiple sclerosis- all I could think about was that lady and I was, like, oh my God, and it was like *horrible*, I think my whole life is over

Interestingly, some of the participants spoke about the impact of their diagnosis on their health care team and the team's altered perception of them. Sue shared with me how her diagnosis coincided with her promotion and return to a former workplace which she loved.

…speaking with physicians and having surgery…and then having this job, I remember…going to see my director and I said to him…he was so excited because I was here…and I told him, he's like, 'Oh my God, (Sue), oh my God'…I felt for him (pause) I felt like I was a disappointment or a disappointment for the whole program…it was a big loss

The sense of responsibility for the impact on the team or on clients was a thread in many of the participant's narratives about their illness diagnosis.

Some of the participants spoke about their frustrations with delays in diagnosis, especially in light of working within the health care system which translated into a situational irony for them. Wendy explained, "I looked like someone who'd had a stroke…so then I'd go to emergency departments…and they'd go, nothing, well, y'know,

we don't know what's wrong with you, you're going to have to wait for your MRI…we were getting angry with the health care system, like, what's happening?"

As Rita explained about her experience:

> …and you know, it took 18 months…I work at this incredible hospital, the cardiac centre is over there, and it took me 18 months to get that figured out. 18 months (pause)…I would say within 6 weeks of having the symptoms, I knew what it was myself, after reading and you know, starting some initial treatment…I've now known since the summertime that this had been the case- I haven't followed up with cardiology yet (pause)…I've had too many other illness things going on and I just didn't deal, want to deal with it

Thus, the incongruence of experiencing first hand the obstacles that clients speak of hits home and exposes the deeply held belief that health care providers should be exempt from such difficulties as an 'insider'. Consequently, as Rita's honest comments illuminate the experience of ambivalence when thinking about illness or dealing with 'the system' appears to creep into the bigger picture of life with chronic illness.

<u>Vulnerability</u>

Vulnerability was spoken of by all participants. Each appeared to have an appreciation of their vulnerability in several regards. They spoke of an awareness of lacking adequate protective factors due to illness that left them somewhat weaker or altered, and open to possible physical or emotional harm. They also spoke of a sense of being vulnerable to possible harm through outside forces, most often represented by others in the health care field such as judgmental colleagues or disingenuous care providers. Beth describes her experience of living with diabetes:

> Well, it's an interesting piece because with diabetes…there's kind of two sides to it…I mean they talk about having 'good control' of your blood sugars….so, there's a real focus on that (laughs) and then on the other hand…I've been in emergency situations….in an emergency room where you have a…physician who doesn't listen

to what you say and you know what they're doing isn't going to work and yet, you have no control. Yeah, I'm not good at giving up control (laughs)…but at some point you have to. The difficulty with working in the health care system is you have less faith in it than I used to when I didn't work in it, because you see the mistakes that are made or…the lack of respect sometimes…and also the fact that you just feel so vulnerable. Y'know, when there is a conflict or something, you think, if I was in my professional role I could go in there and negotiate and handle this, it wouldn't be hard. But when you're a patient, I mean I end up just being a ball of tears, right?

They also spoke of the sense of vulnerability that developed just by the nature of living

through the illness experience:

…but yeah, it has affected, it's affected my life and the thing is, it didn't all sort of stop on a dime- like say you were in a car accident and you became a parapalegic- you're life changes just then- mine (pause) it slowly changed and I lost a little bit at a time

…I mean the chemotherapy, like absolutely kicked my royal butt….I'm the type of person where….when you get a twisted ankle you just kind of push through most things, right, but chemotherapy I just had…nothing I could do to…it totally wiped me out

…you were on a bit of a roller coaster ride…I didn't know if it was going to be a good day or a bad day, right?....like often my kids are involved in sports and I still very much like to go and watch…I'm feeling ok I'm going get to your game this evening at 7 o'clock, but then by the time (laughs) 7 o'clock rolls around…I couldn't even muster up off the couch, right?...with having friends over and stuff like that…seeing people, but then I'd have to cancel because I just…didn't have it, and I just think there's that vulnerability in the sense of, I just, I don't *know*, right? I can't even make plans for the day, right?

Struggling with the loss of personal control and an appreciation for the vulnerability

their clients face was common theme that was discussed. Participants also spoke about

how they compensated for this sense of loss in an effort to cope.

…when I initially got my breast cancer diagnosis I researched everything, like I had to know *everything*, y'know?...whatever the doctors told me…you become a patient, you're kind of no longer a nurse, and you just rely on your other team members, your doctors, your nurses, your other team members to do what they have to do

…yeah, there is just so much unknown to you when you're in that situation…usually you're the person who's in control because you're the one running the show for your patient, and when you're on the other foot…I'm a control freak. I have to have (pause)…I think I'm justified in being one in my illness because of all the shit that's happened to me, so…you have to have control of it- that's my way of dealing with it

…actually there's a specialist here in our community that as a professional, I like him and I can work with him, and I have lots of respect for his treatment of patients and yet, I couldn't be his patient because he comes across really abrupt and kind of…a little bit harsh at times. As a professional I understand that and I understand and respect him, and everything else, but, I just feel too vulnerable as a patient to see him. It's a completely different…I mean that's been an advantage of having an illness is you understand how vulnerable patients are in a different way but if…somebody's just being really…tearful and upset, and as a professional you think well….it's really not that bad, but as a patient you know that it affects you on a different level

Some participants described a vulnerability related to the ability of their illness to be concealed or hidden. Interestingly, there was a simultaneous mix of sentiments over this situation – an appreciation of the notion that it could be concealed, thus affording a returned sense of control to the sufferer by passing as 'healthy' and the ability to decide whether or not to disclose; as well as a sense of intense isolation with keeping this secret knowledge and a sense of emotional vulnerability due to the insensitivity of others' default assumption that health and full functioning are not a concern, which seemed to represent a negation of their true experience. The duality of this situation appeared to be quite challenging to contend with for most.

…there's very few people who know…the whole deal…I'm very lucky because slap on some nice clothes and some makeup and I look normal when I'm sitting at the table

…I have an invisible disability. People would be *shocked* to know…people have given bad comments that are hurtful…one thing that's really helpful to MS is yoga. Very helpful because the stretching is good, so I go to yoga and some people have made comments, right? I've had comments to me before like, oh, you're balance is really bad, y'know what I mean? (voice lowers) if only you knew

…one of the struggles I have in my life, especially in rural communities, is that expectation that you do a lot of volunteer work because, you rely on people to do stuff…I've often thought, well, if I was sick in the hospital, I mean everybody would be making casseroles and sending me cards and flowers and…chocolates or whatever. There'd be a rallying to my support. But because…I look healthy, then often there's just this kind of expectation, and then I guess it's kind of anger that you're not pulling your weight, doing your share…so it's like…hidden in some ways. I mean, people forget and I forget, too. I'm the biggest one to forget…then getting into situations where it's, no, and setting boundaries

Participants spoke of a 'new normal' in their life with illness, which often involved an altered view of self in which vulnerability is highlighted. For example, Rita spoke about her changed sense of self in relation to control over her life:

…you're giving a lot of the control when you're going to be a patient…that you…really have no control. No control over the scheduling of the procedure that you might need, no control if you go to emergency how long you're going to have to wait…you're giving up control (pause) you're relying on others to take care of you, whereas you *were* the caregiver. You were, you were the person *doing*. It's really hard to go from one to the other (pause) as you see

Holly described her sense of vulnerability when in touch with herself as patient:

I think that in a way…when you get that blue hospital gown, that when you put that on, it'll be interesting because I have a few tests in…February and March, but when you put that gown back on…you're back in, I don't know, maybe that…vulnerable feeling, right? Like I hope I get out of this meeting or test ok, right?

Wendy explained to me the sense of vulnerability which stemmed from the near constant reminder of her illness through the experience of distressing symptoms:

…so then the years kind of go on and…I just worked really hard at trying to stay healthy and trying to do the best that I can do. But…some people think that when you're in between a relapse that you're fine? But you're not fine (laughs)…you're not fine, there are things that are *wrong*…for example I have a lot of problems with…as I'm talking to you my legs go like this, I feel like there's electricity in them. Oh yeah, you kind of get used to it. And my arms, they feel like that too, it feels like there's this electricity going down. I never knew that when I worked with people

Others spoke of vulnerability related to their sense of self as a health care provider, specifically wondering if they would be able to return to their job following completion

of treatment or about their ability to continue doing their job due to worsening illness symptoms or future illness. Holly said the following with respect to her return to work following breast cancer treatment:

> …because to be honest to come back, I didn't know if I could actually do my job…because it requires so much…it's all about communication and…those sorts of things and I just was (voice drops) I just didn't feel good, so anyway (voice to normal) but, I'm glad…as anxiety provoking as it is in a way…and to some degree…I think there is almost something…a feeling of return to health when one returns to work…in a sense, health, just like, ok, I'm back, right?

Participants described vulnerability in both relational and practical issues in their experience of life with chronic illness. Sue related her discomfort with her colleagues' inquiries as to the status of her health and her illness seemingly becomes a imperceptible presence in their interactions, "well, and actually people, y'know, come up to me and ask me (concerned voice) 'how are you feeling?', like as I walk, or like people I haven't seen in a long time and they go, 'how are you?' and I go fine or whatever, and they go (voice lowers, concerned) 'how are you *really*? Are you ok? Are you ok?" Holly spoke about the difficulty with accepting help from others and the sense of vulnerability that this act engenders:

> …and also…the vulnerability…came in accepting help from people. So hard to do that right? I don't know…for me, it's so hard…having to learn how to say, yes, thank you…thank you for driving my kids to…their basketball again, even though you live far away…and being able to accept…people want to do that, I know that, right?...I would if it were flipped around, right?...it's being vulnerable, too…you are depending on other people for managing

Interestingly, most participants stated that they felt relatively comfortable receiving treatment from other providers in their workplaces. While they recognized privacy as important, the convenience of access to care in one's workplace trumped any concerns of privacy violation. Most participants appeared to rely on their provider's

adherence to professional and ethical codes of conduct, such as those under the Personal

Health Information Act or PHIA. A few participants did describe, however, instances of

receiving care from providers that they knew and being challenged to compartmentalize

this relationship:

> …although one time when I had my surgery…when they removed my breast…after I came back from surgery I was…(pause) hallucinating from the morphine…and they had given me another…anti-emetic medication and then that made me, without realizing it…that was making me more alert…I was just…like high, I couldn't sleep…one of the med students happened to be a student that had been in to help here…he didn't recognize me (pause)…I said to him, I know you…and then he goes, 'oh yeah'…and then I said, 'yeah, it's me', and then I felt kind of embarrassed, because…you've just had surgery, you don't look very good…that part was a bit uncomfortable because you don't want someone to see you in that state

Several participants spoke about vulnerability due to the financial aftermath of time

off work for poor health or treatment. Few had accumulated sick time left and the

concern about financial worry at retirement compelled several participants to work longer

than they may have otherwise. As Gail recalled, "I just couldn't do the work, so, and the

only thing I worried about was, y'know, obviously the money and y'know, I had used up

all my sick time and then I had to go on to long term disability, so y'know, I think that

was probably my biggest worry at the time. And losing my hair". Financial security was

also a motivation for Rita, as she explains:

> The other reason, probably even the bigger reason I moved (to this job), I didn't have long term disability. I couldn't get it, because when it was offered I declined it…I was young and very healthy and very fit- what would I need that for, y'know? I didn't realize that I would get sick. So moving here I was eligible for it again, so that was a big thing

> …it's a thankless job, a very boring thankless job for most people, but it's what you make of it too, I guess. I enjoy earning the money that I earn - now I enjoy having the things that that money will buy me, so, it's a motivator. Well, sure, I could work less and have more of a life, but then my pension would be less…if I can just hang on two years and obtain a good pension…I can work less at pension time. So, I'm

sort of hoping that it's a trade off for the next two years. It's going to be hard, but at least it will be better at that point

Some of the participants also spoke of financial vulnerability related to the expense of their illness, most typically medication costs. For example, Beth stated with respect to her diabetes care, "yeah, just I pay a lot, I spend probably ten thousand dollars on, a year on prescription drugs". Dealing with complications from systemic lupus, Rita notes that without insurance coverage she would be unable to continue working:

> …lots of bumps in the road and not only work related, but with things like medication. One of my drugs is 5,500 dollars an infusion and I have …it every 5 weeks. So, getting that set up every year is, between my insurance which we have little of, my husband's insurance which covers between, what I have and 80 percent of the cost of the drug up to the Pharmacare deductible….because of…my husband's plan that I can actually afford to have this drug, and this drug has made a huge difference like it's allowed me to stay- if I hadn't had the drug I probably wouldn't be working

<u>Dealing with Uncertainty</u>

Dealing with Uncertainty was frequently mentioned as a consequence of life with serious chronic illness. Sub-themes isolated from this thematic grouping included Fear of Future Illness and Confronting Mortality.

<u>Fear of Future Illness</u>

Fear of Future Illness was also spoken about by a number of participants, in reference to disease recurrence, worsening disease or additional illness diagnoses. Comments reflected the heightened sense of fear born from not knowing and a lack of control over this aspect of life. The presumption of continued health has been stripped away and replaced with the hard reality of an altered self.

> I've had my illness for a long time so it's hard to remember what it was like before…for me now it's…further illness, further complications, further deterioration. Wondering what that's going to be like because probably, eventually, that's going to be it…the other piece is…fear of who it is that is going to be my

health care provider. It comes along with that…are they going to be…competent, are they going to be…someone you can work with? Y'know, are they going to treat you with respect?

…there's new things you know, all the time. And what if I get something like breast cancer? That's a totally different kettle of fish…you never know, that's a possibility. One in nine, so

…maybe some days I struggle at work…it's always in the back of your mind. You get a pain, you get an ache, you think, oh, oh, what next? What's going on, y'know?

…I think for starters…is that initial kind of panic…I have to do all that I can do, right?...now having a little bit of ground behind you…for me, the biggest thing is…managing the uncertainty and the anxiety around…what's gonna happen? …like is it going to return?...I mean probably everyday there's a thought about it, right?...then maybe it turns to I'm feeling so much better, that's great, so it can go that way or it can go, y'know what? I'm not feeling so well (laughs) is that the start of something? Like it's a heightened awareness a little bit towards that

Confronting Mortality

Confronting mortality was broached by all participants, often on the heels of

discussing diagnosis or the fear of future illness.

I think about if it recurs, if it will reoccur and when it will reoccur…now of course this is all statistics…they always tell you…that you have an 80 percent of being here in 10 years (pause) it's been three years now, a little bit over three years…if you have any aches and pains or anything that you have I feel like maybe they're going to think 'is that my cancer?' and that it might be coming back. So, you know what, I do think about it (pause) not every day, but I, it's (pause) quite a bit. It is present in my life

…but, anyway, it was time to start smelling the coffee when I was diagnosed with a pulmonary hypertension I realized my life now is limited…I may only have five years, I may only have ten years, who knows? Survival rate isn't that great so you got do what you got do in order to have fun with what you've got left which, I talk about it, outright, I figure there's no sense in hiding it, y'know? I don't want it to be a surprise to anybody

…yeah, I accept I'm deteriorating from the last time I was at the MS clinic…it's hard, my fatigue, things are getting worse…so they think I might be progressing, right, because 50 percent of people progress to secondary progressive and 50 percent kind of stay the same….yeah, I mean, you have to kind of look at…I mean, I'm older and I'm grateful, my children have grown up, right? They don't really

need me…I don't have 2 year olds, I can't even imagine if I did, right?...so that, that's helpful and my husband is very easy going

Beth discussed her thoughts on confronting her own mortality and preparing for what she sees as inevitabilities such as worsening disease. She also includes the observation that life with serious illness has given her a very different perspective than her same-age peers:

> …I think an illness makes you more aware of your mortality and that's not a bad thing….I think about it more than someone else my age would…and you kind of think how, how is this going to play out? Are there things that I can do now to make it, I mean whether I become disabled….or terminal illness, or death, or whatever, you're more aware that it's going happen….sometimes I talk to people in my age group and some of the response kind of baffle me…because they really haven't thought about it…people don't think about it until it happens

Wendy discussed her thoughts regarding liberation therapy, a treatment for MS symptoms that has been a source of controversy within the medical and MS community – and her sense of its hastening mortality:

> …sometimes shocking things happen…in the world of…disease and everything else. Macleans magazine really said it good I think cause they said…it's kind of we're all, all of us with MS are in the ocean right now and we're just treading water and kind of drowning and the scientists are saying…we have life jackets but we don't really want to put them out there because we're not sure what's the best life jacket. Give us some time to figure out the best life jacket for you and then, we will…provide that for you but in the mean time, we're going drown (pause) and die. Maybe hit 20 years from now, the life jackets will be better for people but…I don't want to drown, right?

Changed Perspective

Changed Perspective on life was also a common theme to the participant's narratives regarding adjustment to illness. Sub-themes that were isolated included Priorities and Managing Stress & Emotions.

Priorities

Some participants spoke candidly about feeling a sense that their priorities in life

had been altered following their illness diagnosis. As Rita explained, "…well, right, your

outlook on life changes especially, y'know, if you've had to deal with a serious illness.

Y'know, you tend to see things totally differently, y'know, your priorities become

different" Sue echoes this sentiment- "you try to get on with your life. It's a different, you

have to get on with your life, your sort of new life, and it changes you in some ways. I

think, um, I mean you have a different perspective, a different way of looking at things I

think, at life, uh, different lenses- but life goes on and you have to get on"

Changed priorities included how participants' thought about their place in life,

where they directed their energies and how they valued relationship. As Beth eloquently

explained:

> …I think the other piece is learning when you have a chronic illness you have to
> decide what's really important to you and, that's been good because I've been able
> to do some things that I never dreamed I would do. I'm a bit of a chicken (laughs)
> I'm not a courageous person, I'm the kind of person who, um, wants to do what is
> socially acceptable and I've been able to do some things that are just completely
> outside of my family expectations and my expectations of myself because I've had
> to really think about what's really important…I'm probably more balanced in terms
> of work and recreation and things than I probably would have been and a little
> more, um, physically active….and I'm maybe a little easier on myself than I, as I
> say, I'm a pretty high achiever, and pretty heavy on myself professionally and
> personally. Diabetes has made me less so, kinder in, kinder to myself, so that's been
> a good thing. And I think also in terms of relationships, like what are the
> relationships that are important and, uh, the rest can (voice lowers) can kind of fall
> by the wayside

Managing Stress & Emotions

All participants spoke extensively about managing their stress and emotion

reactions with respect to their illness and with managing their work life. All spoke quite

candidly about their feelings and the impact of their illness on their lives, such as Sue's

recollection about her emotional lability during breast cancer treatment:

> …during that time I was very, uh, I was a mess. I was so emo…my husband would say that I wasn't, he like, he saw me that I was very strong and I, of course, I had my moments where I just sobbed in his arms or I was just *sobbing*…I thought, oh my God, how can I be strong with my emotions up and down? …one day you're ok and the next day you're crying, or it could be moment to moment, I could be having dinner with my family , one of the kids would say something and I was like, I would get up and leave the table, go cry in the next room and think, what the hell am I doing?

Others spoke about their emotional challenges:

> …a lot of my friends say, like, how do you do it? How do you go on? And I say, well, what choice do I have? I don't know, maybe the med, well, obviously the medication because I'm on anti-depressants and…that obviously helps…but I mean it's your attitude and how you think about it…I mean it's there with me all the time but I just put it in the back of my mind and try not to think about it, and just like I said…one day at a time

> …and sometimes my legs hurt a lot…at night sometimes it's hard to get to sleep because my legs hurt and the fatigue aspect…it's weird and hard to understand…I just have to lie on the couch and I lie there for an hour and I just, the best I can describe is I just turn my nerves off? (laughs) y'know what I mean? It's like plugging in…to get rid of the stimulation…and then, I'm not bad and then I can go out again at 7 o'clock and I'm fine and nothing's wrong with me, right?...you have to balance everything? Like you kind of have to, y'know? So, I prefer to take my disability (chuckles) to my lonely spot, do you know what I mean? I just kind of deal with it and then I can get through the day

> Feelings of loss and grief associated with the effect of illness on their lives were

peppered throughout the participants' narratives.

> …but, yeah, no, there are days when I'm not mentally very good, that I have to fight depression- not sadness depression but motivation and, and not wanting to do things, like just (pause) don't want to do that, nope don't want to do that. Don't want to socialize, don't want to do it….yeah, but this is a totally different life, totally different life- *that* was someone else's life. It's like, yeah, I *miss* that life, but there is *nothing* I can do to get that life back…no matter what I do I can't, I'll never have that life back. So, coming to terms with that's really hard

> I think there's that choice to get through it and go, I'm bitter. I'm really bitter, like deep seated, I hate that it happened. You can negate the experience, right? And I

think…that's the positive slant to it, right? Like I hate that year happened, it's like totally behind me, I totally forgot about it and I'm back in the groove…I think we expect more from our patients…when they go through things…to not…kind of get stuck at that point but to kind of *use* their experiences whatever they may be and to, make a change, right…and maybe that helping in terms of having no resentment toward it, because yeah, if I would resent the health care system and then I'm *in* it, I mean really that would be, maybe hard to maybe associate myself *as* that bunch, right?

I think my professional life has been a help in terms of I knew resources to go to when I wasn't coping and I had some ideas of where to get help. Diabetes is such an elusive disease…you'd think you go through this grieving process? I don't think I went through until I had it for like, 25 years…well, because when you have the insulin and you instantly feel better so you felt fine and it's like a cure, but then as you go through it, you realize what a toll this is taking on your life, and it's in little bits and pieces

A few of the participants discussed their use of spirituality to help them to manage

their emotions or stress in their life. Some spoke of their faith in God and their use of

prayer in an effort to cope, particularly with intense fear and worry.

I just take each day as it comes…having the breast cancer, it really changes your perspective on life in terms of how you deal with things, at least for me…my faith has…gotten me through a lot of this and family and…so as I said with work it's been fine. I work with great people, people have been understanding and my manager is very good…people have been very supportive and I've managed to…get through, and like I said I try to think positively and…I tell myself these things happen for a reason

I would pray every single night, I'm telling you, it was like (pause)…I mean I had to pray when I was a kid…and then I thought oh my God, I prayed *every* single night…my husband and I went to the store and I…bought myself a prayer book that had a daily thing and…that kept me sane, everyday it kept me, it kept me grounded. Ok, I'm terrified in bed here…I would say I'm scared, what am I going do, how am I going live through the next day, how am I, how am I going survive the night? Cause' this just waiting for surgery and waiting for…all the steps to unfold, it's just, wow, it was just incredible. You know? Now? I'm much better obviously

Managing stress and emotion when providing patient care to clients appeared as a

prime concern to most participants. Emotional control was spoken of as necessary, but

increasingly difficult given new first hand experience as a patient being 'too close to

home'. This is seemingly a downside of patient-hood, whereas increased empathy and

keener perspective is a gain. The process of working through a way to achieve both goals

is an evolving one.

>…I walk home from work and that's my…get work off the shoes before I get home,
>kind of thing…like whereas maybe before it was just much easier to cut it off as
>this is a patient, it's a very sad case, but…it's a patient and that, but now really how
>can you? Sometimes it's just too hard to…compartmentalize it as a patient, right?

>…you don't see the line between patient and health care provider in the same way. I
>think you see health care in a more holistic perspective…the daily challenges of
>how do you do both? When you could be a full time patient and you're also
>working…how do you do that?...how do you balance that? How do you
>balance…how much you tell your colleagues in terms of what's going on with your
>illness…do you just talk about it all the time and then they don't see you as being
>competent? Or, do you not talk about it at all, and kind of hide it?...so that kind of
>balance…in terms of time…time off for appointments and all that stuff…it's not
>just medical perspective, medical model, you have a much broader
>perspective….you end up feeling pretty isolated

>I always thought it could happen to me but I would…put myself in a box because
>you can only listen to so many bad stories before you become sad or…it affects you
>mentally. So when you go to work you're a person that listens to these things, you
>help these people, you do the best you can to help make *their*
>diagnosis…sometimes you've got go the extra mile and ask the extra questions
>(pause) but you leave it at the end of the day….and there'd be times that I would
>think of patients after, after a day, or someone particularly affected me in a certain
>way (pause) but no, I always thought that you never know what could happen to
>you…I do everything I can to help that person but…I can't waste time worrying
>about something I can't control because you know what, some of them are going to
>die, I realize that. I realize that but some of them aren't…when they were with *me*,
>they got the best of what I could give them

Some participants spoke of being fundamentally changed by their patient-hood-

having developed a new perspective which influenced their work and their ability to

cope.

>I hope that it *sticks* and like it's not just a little…maybe til' it fizzles out (laughs)…
>because I really experienced it as a…patient, right? Sitting in many waiting
>areas…hearing other people talking…I realize that my story was just a drop in the
>bucket of many other people and what they're going through when you sit in those
>waiting areas…I just hope I hang on to that and that it will always stay with me,

that feeling of…being a patient and just appreciating so much, like when one of the docs, he was incredibly just….like you are a valuable person and…not treating you like I'm just a (laughs) a diagnosis on paper, right?...appreciating that…it's difficult to be sitting in the patient chair and…yeah, I really hope that sticks

…it's interesting (pause) before I had MS…in our (nursing) journal there was an article about women with the lived experience of multiple sclerosis and they were kind of working or something, and so you know how you read stuff? (sarcastic tone) yeah, yeah, that was interesting, that was a nice little article, y'know? And then of course, I dig it out, now that I have it and you read it with *different* eyes

At times, the memory of particular client situations appeared to trigger strong emotional responses that made adjusting to personal illness while continuing to practice in the health care field very challenging.

…for some reason we've had a lot of cases where…kids are coming through and their parents have cancer, right? So, like for me that strikes a cord…I brought this on my own kids, right?...in that sense, you feel that responsibility, right? Maybe a little bit of guilt…clears throat) we clearly talk about that in our meetings…but like not me, with family and how difficult it is…to have cancer and (clears throat) so, I'm sitting there and I think there is that…bit within me not to flinch or not…become all emotional kind of thing…Y'know, (Holly) this is a *case*, right…so in a sense that has been one area where…there's cases where I can just kind of...really put myself in, right…I can identify

I'll give you another example, a lady with ALS and it was, ugh, it was just so difficult…again, it was me that worked in rehab engineering and we did this thing where she could hit it with her hand to spell things out…it was difficult, no one else did it, and I did it…I remember her name still and we did a lot of work together and she was difficult, y'know? It was really hard, not because her personality was difficult, but for, the whole situation was difficult. No one else could do anything, and so then of course, the first thing she wrote was 'thanks (Gail)' and it was like, oh my God, like (laughs) we wanted her to write things…like I'm cold (laughs)

Category Two: Interaction with the Healthcare System

The second category that was identified was titled Interaction with the Healthcare System and referred to participant interaction with this system in two respects- as a patient and as a worker. This category consisted of two main themes: Insider Position and

Interactions with Care Providers. Again, each of these themes was deconstructed into sub-themes so as to further examine meaning.

<u>Insider Position</u>

Insider position was referred to often in the participant's narrative, primarily with respect to their occupational role and being a practicing healthcare provider. The sub-theme identified was titled Knowledge as Double-edged Sword.

<u>Knowledge as Double-edged Sword</u>

All of the participants told me stories about their experiences as patients within the health care system while trying to reconcile these experiences with their insider position and knowledge as a health care practitioner. This juxtaposition appeared to represent an inherent strength in some instances by aiding with coping, and as a source of great distress in other instances. Participants spoke of frustrations, disappointments and perceived failings of the health care system that compromise good patient care.

> When you don't have the supports that you need and then also having to work with people who are also in the health care system so, not to make it personal…it just seems the system, like why don't we put more money into prevention….you just see how the system is kind of twisted around and…it rewards people for not looking after themselves…it's hard working in the system when you see that stuff going on, um, and not just be angry all the time

> I do not trust all my physicians. No, learned that lesson the hard way, too. Don't trust them. Very few of them I trust…I double check all my results. I don't just look at the report, I look at the actual stuff because I don't trust, y'know? I know you know. I just see too many times, in diagnostic imaging, the physician reads a particular scan, gloss over things, not mention them, because it wasn't something that the originating physician asked about and I've seen them miss things just because they're too lazy (pause) lots, lots, used to keep a file, yup, so I know…like, I've found that a lot of the radiologists in Winnipeg don't know a lot about rheumatology and so when they read things normal, whereas, I've looked at something and it's like, full of rheumatological signs that there is something wrong. They don't know that. Why don't they know that? They are radiologists (pause)

they should know that. Why do I have to get my original films and cart them along with me? You know what I'm saying? *I* know that, but joe public doesn't know that, so 99 percent of the people out there don't know that, they are still looking for a diagnosis, meanwhile, they probably have a diagnosis in their medical records but, just nobody looked close enough and, uh, that bugs my ass, big time

…looking at the bigger picture, I don't think it's going to change. Yeah, you'll get good health care if you have a family member in health care that can ask good questions. If you are yourself in health care and you know what is supposed to happen, otherwise (silence) well, I read…all the critical incident reports…they're all about things happening, people coming into the hospital and dying, because… physicians don't do the right thing, or nurses don't do the right things. And those are the ones that they fess up about, y'know?

…the number of medical students that they're taking and I see a real deterioration in the quality and I think what it is is if you're not treated as a person in your training…somebody said to me the other day it's kind of like a sausage factory-treat medical students as sausages that you're making in a sausage factory, they are going to treat patients like they're sausages, too….Y'know, stuff I wish I didn't know, eh? Um, apparently the banks go to medical schools and say, run up your line of credit as high as you want because you're going to be making lots of money when you're done, so then if you do that and you come out, then you're under pressure to really put people through. So, like spend 5 minutes to spin as many people as possible, as quickly as possible, especially if there's fee for service. So, it's just kind of like (voice lowers) oh my gosh

Some spoke about difficulties with communication and self-advocacy despite their

level of knowledge about how navigating the health care system and skills from their

professional training.

…that's how I do it but, if you don't have medical training and if you don't have the knowledge and…that I have from reading and stuff I've done, you wouldn't have the ability so, I can see why people get sort of slipped under the rug (pause) why people get sicker when they could have been caught a whole lot sooner and they're not. Or, stories of…that women that go to their doctors telling them the same thing over and over, and over again, and they don't check it and when they do check it, it turns up being stage four something or other. How many times have you heard that story? Too many times, y'know?

…but it also makes me really angry because I think if I'm having this much trouble, and I do this for a living and I *have* these skills, what about the person that doesn't have these skills? Doesn't speak the language, doesn't know the system? Um, doesn't have the education- that just makes me *furious*

I don't know because they never…when I would go for my treatment, I would say I want my blood work. I want to see it and they would give it to me, they wouldn't *offer* it. I think they…the first time I went there, I think my nurse…said if you want to see your blood work you can ask for it, we can give it to you if you want, you can ask for it…but then once I finished…I met with the physician, not the nurse, and maybe…I mean it could be, obviously it was fear. If I really want to know I could ask, say ok physician, I really want to know but I also think for me being a nurse, talking to another nurse, it was sort of like, yeah, if you want to have your blood work you could, not that it's underhanded, I don't mean that. But it's, it would be ok, but it's with physicians there is still this hierarchy thing…and it's like, you don't really confront them

Interestingly, a few participants admitted to instances where working in health care

has aided them in their own patient-hood by helping them to navigate the system by

identifying as an 'insider' or using inside connections.

I can tell you, everywhere I go, if I go for blood tests at Cancercare, this is on me. And when I'm in the changing room and I have it on me. I'm not kidding you, I have it. I have my clothes like, on the chair when I'm changing. It's just sitting right on top of my clothes with my pager and everything, and I want them to see it. That to me is that sense of control that (laughs) ok, you guys, I work here, so, just so you know and I think that's ok….I mean for me…I'll be very honest with you…I admit that I do that to send that message, for some protection…ok, it's me, I work here too, I'm one of you right…I'm like you, I'm one of you, imagine if you're in my shoes…so is that right or wrong? Maybe not, I don't think it's wrong, I don't, I just think it's (pause) being honest and protecting ourselves

I have also told them that if you have a cancellation I'm right here and if I can't make it because I'm in a meeting or something has come up, I will let you know, but instead if I had this appointment, or this test, or if I had to go for an ultrasound or CT scan…I have those some times and they had a cancellation and I went, they said, can you come…the IV doesn't take very long. I went, they just do it and away I went

I can remember friends saying, well, you work at (the hospital), you should be able to get in for tests, or whatever, and no I can't…I'm just like everybody else, there's cancellation, but some people think that (pause) that the system should be able to have you come in sooner….there is, I do know that for a fact…you're going for surgery? We're going to get you in. I know that and is that right? But what are you going to do? Because if someone was going to get me in sooner for my surgery, for my breast surgery or for my chemo, I guess I wouldn't say no. It would be pretty tough, right? Yeah, I'll wait another six weeks, its ok, when time is of the essence

…my experience was unbelievable from the oncologist, who I'd heard was not very good in the sense of his manner but I think it kind of helped because my paediatrician friend who asked me, 'who's your oncologist?'…when I told her who it was…she goes, 'oh, you're in good hands, you're in very good hands'. She said… 'you see him, tell him I said hello', so I think that helped, but it's terrible…because I knew that would help me (pause) right? And it did. I feel that it did because he said, 'oh, tell her I said hello'….I told him, I'm terrified, *terrified*. I said I'm scared to death, I'm afraid I'm going to die, I don't know about chemo, I mean I know, because I know as a nurse, knowing about chemo…he spent and hour and a half with us. An hour and a half. I mean that's saying, we waited for him, he was late, they're always late, but then I thought, he spent an hour and an half with me and my husband, obviously somebody else had to wait

General medical knowledge and standards for practice of care were integrated into participants' attempts to find meaning in their experiences, including their own illness.

I think some illnesses…happen because of stress and there are triggers in our environment that cause triggers in our genetics to go off that when they go off they are in certain situations. Being in the roles that we're in, those triggers are made to happen

I think there are a lot of people in this complex, who have serious illnesses who work…(pause) and I think we as health care staff…we either won't get an illness or we can handle that more than the average person, which is false

…and I just *knew* when I went…in for…the ultrasound. I remember the doctor showing the area of concern and…I remember being on the computer and looking at…some pictures of, was it ultrasounds or whatever, yeah, must be ultrasound, right? And…breasts that were normal and breasts that weren't normal, and there was one that I saw that looked very much like the picture that I saw and it was cancerous, so I knew…I just knew

At times the participants' insider knowledge gave them a rather bleak view into how bad things could get with serious illness, which was appreciated as a privileged knowledge that many wish they now did not possess.

…was I ready? Was I prepared to deal with something myself? Nnnn…I think it was hard on me because I saw the worst of the worst and that was like, *oh my God*,

y'know?...I've seen lots of that…I've seen the worst MS people…when I worked there 20 years, I saw the worst, y'know? So that made it hard…I worked with a lot of people with ALS. I saw how horrible that is, if I got that, ohhhh (pause) but then say you never worked with that, saw it, you maybe you don't really know how bad it can get (laughs)

…but I don't ask for my blood work, the result, and I think…it's out of fear. It's like I'm afraid to know that if my blood marker…I'm afraid to know that's what's hanging around. I mean, I'm assuming he means when he tells me 'you're ok', that the cancer's not there. Yup, but I mean, I'm thinking about having that conversation with him next week…when you say everything is ok, what does that mean? What does it really mean? I mean I feel ok and everything…one of my girlfriends…she said to me, what's your blood marker and I said I don't know….she goes, you should be asking and I'm thinking sure, I should know but I didn't really want to know…as a nurse, one might say, well, you should be asking about that, you should *know* better

…how're you doing? How are you feeling and the whole thing and stuff, so you fill them out and…one of them addressed…the issue of mood. Y'know, that depression is highly correlated with MS…do you ever feel like killing yourself? Yup. Do you ever feel like this? Yup, yup (chuckles) so I go through the whole thing and we hand them in and this is what they do with it, nothing, because they don't (chuckles) they're just done, like, really you asked me all those things but none of those things were ever (discussed)

Several participants spoke of the sense that their health care providers were assuming they were knowledgeable about their condition or needed treatment, just by virtue of their professional background. This was acknowledged as a prime concern for providers facing their own illnesses in terms of the need to self-advocate, which can be hard to do as a patient.

As a nurse…in some ways I think it was helpful being a nurse because you know more information, you know the right questions, well, you *think* you know the right questions, but you know how to get around. But I think when they also know you're a nurse…they think you…should know a lot more already, so why are you asking these questions?...I also think that, um (pause) connecting with the nurses…in my time in chemotherapy that the nurses were, you know I mean as a nurse, it's like we had this connection that was incredible….I think there's an expectation and I think it's human nature, myself being a nurse…if we've had somebody or we've had nurses, people that have been nurses or whatever, come in to hospital and you think, 'well, she's a nurse, she should know', well (pause) can't think that way…and I'm bad, I changed that because the roles had been reversed. I have a new perspective, I

can look at it that way, I can see that and y'know, even though I knew that before, but…now that I have lived it

A few participants described their perception of their work colleagues (typically a team of health care providers) reaction to knowledge of their illness. This perception appeared informed by insider knowledge of how the team functions, their role on the team, and the stigma placed on personal illness within the health care work place. For example, one participant shared the following story:

> ...I think they're uncomfortable with it, I really do…when I started…there were lots of issues on the unit…one of the staff said to me, 'well', she said to me one day, she didn't mean it in a, well, how can I say this? She wasn't being rude or anything, she said, 'y'know, (Sue), we're having a, it's been a bad day' and I said, I know, I'm trying to find out what's going on, she said 'nobody thinks we work hard', and I said I know you work hard…I've worked with some of these people as nurses, side by side. I said, I know what that's like, I know what it's like to work shift work and stuff and then she goes, 'yeah and…you had breast cancer', and someone else said, "if you've had breast cancer, who knows if you're going go?". In my *face*. It was like, ok…you guys, I know the previous manager left because he was sick, the last one…had breast cancer. I said, she's doing ok…I'm not going anywhere, so far I'm ok, so I'm not going anywhere…it's like they had a loss, another loss and they were like, "well, we don't know about *you* coming back". And I'm like, ok, now this is in my face, right in *my* face and it's also in their face, so I talk about it, when I was sick, this is what happened and I can relate to that

Interactions with Health Care Providers

Interactions with Health Care Providers were spoken of by all participants in their interviews and featured strongly in defining their interaction with the healthcare system. The sub-theme identified was titled Hierarchy in the System.

A philosophy within the health care system was identified by participants with respect to patients. Participants acknowledged the existence of what could be termed an 'us and them' mentality, with the belief that there is a distinct difference and separation

between health care providers and their patients. As Beth explained, "…yeah, in health care there is kind of that line between patient and health care provider and, the patient's over there and the provider's over here and, yet, we'll all be patients at some point, right?"

Beth goes on to explain what she feels is behind this perspective:

…in terms of health care you're trained to detach completely, in order to do your job and you can see why physicians need to do that. If somebody comes into the emergency room, you have to be able to do your job but it's also learning to reattach to people, to reconnect toward people as human beings to see their commonality as a human being and I think that is the piece that traditional training in health care doesn't provide. It's how you do the reattachment piece…the way they have been trained, they've been told that they are supposed to be patient-centered…but nobody has really, unless they've had a very good mentor or preceptor. No one's really taught them how to do that

Thus, there was the acknowledgement in participants' comments of the need for a separation which serves a purpose in practice, but which also sets the health care provider apart as special. Participants point to the perpetuation of a belief that health care providers are some how immune to many of the problems that plague the average patient, such as struggling with illness. Sue told this story about her experience with treatment for breast cancer and being challenged on her internalized beliefs:

…I think that there is a culture in health care that believe…that we overcome this. That…we should be above this, nobody taught me this, it's just (pause) it's *there*…I'll give you an example…when I had my…chemo, I was just about finished…I was very lucky that my chemo treatments…everything went well…I remember being in the oncologist's office… after the six months of chemo and we were planning for radiation…I said, when can I go back to work? (scoffs) he says, '(Sue), what are you thinking?', and I said, well, I have got to figure out what to do about work….he said, 'just like health care, *nurses*', he said, 'you got to take care of the world'

Participants spoke extensively about challenges they faced in their interactions with health care providers and the health care system. Difficulties with communication

featured prominently in participants' comments and most acknowledged a sense of a

power differential in interactions with their health care providers, whether the overall

relationships were positive or not:

> …well, sure, you know you're looking at a physician whose had more education than you have, but I've probably spent more time reading on *my* condition so I probably know a little bit more about it than *you* do, um, so give me the benefit of the doubt here?...you want to ask questions, and you want your questions answered and you want to be treated like a professional and not like you're a big dummy and why are you asking all these questions? You don't want that. You want to feel like (pause)…whoever you're dealing with is doing the best that they can for you

> I just left everything in their hands and…like I said, I had wonderful doctors, I had wonderful nurses and…I trusted them and they were very good…in terms of explaining things. I certainly wasn't afraid to ask questions…I mean, it kind of is a little intimidating and everything, but I guess when you have a serious illness like that, you let people take over the medical part of it and, and hope and pray that, y'know, they know what they're doing (chuckles)

> …they take you more seriously if they think that you're educated and, which is, I mean, sad, but anyway like you're more valuable somehow, or worth spending the effort…there have been times where they thought I understood more medically than I do. It may be because, well, I'm educated so I obviously must know all this medical terminology…not short changed, because I probably ended up getting better care

> A lot of it was, the diagnosing, was (pause) perpetuated by me pushing that there is, you guys are missing the boat here, you're missing the boat…finally one day I just said, hey I think we need to take all the big picture and look at some of the blood work, then that's when the rheumatologist said (pause) took me seriously when I took in a hundred pages of ultrasound film showing all the different spots, and the fluid, and the inflammation…and the bone scan and then after that, from that point on, it was fine

> …she actually said to me, 'well, you've been a bad girl' and I said, 'excuse me?' She said, 'you didn't go for your blood work'. I said, 'oh yes, I did, I went on Friday afternoon'. She said, 'no you didn't'…I could not believe that, that was last year and I said to her, 'actually, you're a bad girl because, uh, you guys lost my blood work' and she said, 'well, maybe it's in the computer' and she goes 'no it wasn't there', and so I had to go again, and get it done…when things like that happen to me, I think about it and I think, I would *never* speak to a patient that way here…I found that shocking…well, that's just it too, like where do you want to sit, which is kind of weird, this is the boss chair (laughs), right?

Participants spoke about the ways in which they chose to handle these challenging

interactions in an effort to be assertive and get adequate care:

> I usually tell them right within the first two minutes that, what I do, what my education and background is, and that I know very well what I have, and, I'll tell them right away at the beginning. That way they don't try and zing anything by me. They don't try and forget anything, because I'll tell them right away that they did

> …so far I've just hired and fired…health care professionals (chuckles)…I fire them (laughs). Shop around, what's going on, talk to health care professionals, talk to other diabetics, type 1 diabetics I know about their experiences with a different person, but there's going to be a time when I *can't* shop, like when I'm too ill to shop. I mean, I have to take whoever shows up and that's scary

> …as long as you don't get an arrogant physician, which there are a few…it can get into a little bit of a pissing contest…when you're not feeling well, it's not easy to go head to head with one of these guys. I have but, y'know…and the best thing to do is just to, you know, can I see your supervisor, basically…just go up the next chain of command…I also know that you have to do it in such a manner not to just piss people off because they write it in your chart

Some participants also spoke about the connections that they made with their health care

providers that turned out to be important sources of support. For example, Sue described

her experience in the chemotherapy unit:

> I'll also think that…connecting with the nurses within, in my time on chemotherapy that the nurses were, you know I mean as a nurse, it's like we had this connection that was incredible. So it was kind of a bond, it was really…you know, 'oh, you're a nurse', 'oh, we know what that, we can tell you how our day is going'. So I could connect with them in that sense

Other issues were also highlighted with respect to interactions with health care providers

and the overall system including wait times, lost referrals and disrespectful treatment:

> …like I spend a lot of times in the waiting rooms and for appointments, etcetera, etcetera. So, it was like, you're wasting my time, I'm going to send you a bill (laughs)

> …you know when I go to the emergency room or whatever, and they'll look at my med list and then they'll look at me and it's like (scoffs) 'you sure are on a lot of medication', and I usually say, 'well, I've got a lot of different problems here,

y'know, so don't say anything until you know exactly the whole story'. But, you wouldn't believe what comes out of the mouths of professionals sometimes

…so when Dr. _____'s office had sent the, uh, request for this biopsy, probably took a couple of months and I was really pissed off then because I kept calling and saying, y'know, like what's taking, this is rather urgent, y'know? So, that was the only thing that I was angry about, was that it took so long and I remember calling the surgeon's office and I said, look, y'know, I have waited so long, um, you guys need to phone and find out what's going on here. Did they lose the referral, did they, whatever and, so they did and shortly after that I had an appointment

Considering the extent of the difficulties, disappointments and frustrations the participants faced in their interactions with other health care providers, it was not surprising to note a decided sentiment throughout their interviews that this treatment was not only unacceptable patient care, but ran counter to their expectation of treatment as an insider and to a system really 'taking care of their own'. As Rita eloquently explained:

I've learned how to work the system…if I need anything it's usually just a phone call away, y'know, except for the cardiology department, made me wait for like, six months for an angiogram, for a staff member, which I thought was hilarious. If this was (name omitted), I wouldn't have waited three days, never mind six months. Yeah, well, they would just do you at the end of the day, they would do you on your own time, you wouldn't bump anybody, you would just be done on somebody's lunch, or you would be done at the end of the day. That's what I did for my fellow co-workers, and if I needed it, that's what would be done for me….you just watch out for one another and you help with one of our own. Yeah, with anyone in the hospital, if someone from the hospital came and they needed, a family member needed something, or they needed something that's just how we would do it through the entire department and I thought that's how everybody operated. I guess not, not really…I'm like, holy smokes, you guys, I can't believe this

Category Three: Effects on Practice

The third category that was identified from the interview data was titled Effects on Practice. This category consisted of three main themes: Enhanced Connection, Need for a

Plan, and Use of Self. Each of these themes was deconstructed into smaller sub-themes to further isolate phenomenological meaning.

Enhanced Connection

Enhanced connection was referred to by participants as a positive effect on practice. This referred primarily to enhanced connection with their clients based on greater understanding and empathy founded on personal experience. Sub-themes identified from this larger theme included Better Understanding of Clients and Using Supports.

Better Understanding of Clients

All participants reflected on having developed a better understanding of clients which enhanced their therapeutic connection. This appeared to be directly connected to their patient-hood and the learning they gained through first hand experience which is then translated into later practice. As Beth stated, "I think there's some benefit to having that perspective, um, y'know, perspective of a patient because I think you approach things in a different way…in a way that might be more helpful for patients". The appreciation of the lessons of patient-hood was echoed by others:

> I…appreciate my days as a patient…it has really made a difference in terms of how I see my own, um, patients that are coming in…we see their families, right and, just recognizing how, how at a place of sometimes, just desperation and emotional just rung-outness people are coming because I know just coming at it in my own situation, right, that it has definitely, um, brought a level of compassion that…is different than when I had started out

Some participants spoke of their sense of identifying with their patients' suffering and their ability to reach new levels of empathy and compassion through new understanding. For example, Gail spoke about her clients who were also facing breast cancer:

> …your outlook sort of changes, I mean, your outlook is different, but in terms of dealing with clients I think you have a, or at least I do, a better understanding of what some of these people go through…You're a little more…compassionate…you

just, *I* can sort of maybe relate to things differently as with before…a lot of my clients are elderly, I've lost a couple to breast, they got breast cancer in their later years, so, that was tough, y'know, because you are kind of sharing that experience with them…so, I really felt for them but I tried, y'know, I was always optimistic and positive with them and encourage them

Rita spoke about her clients and her sense of empathy with respect to facing mortality:

I'd have patients that would fight cancer for (pause) seven, eight years or I've known patients that they come back every six months or once a year and you could see them…slowly getting worse and worse, and then one day their name, eventually, would be in the obituaries, and these would be young people…and you get to know them over the course of time, and yeah, you see how hard they fought, y'know, to stay on this earth. So, yeah, then (pause) when you're in a position that's *fairly* similar but…not quite, but very close, it's different

Finally, some participants spoke about a renewed commitment to their practice

while integrating their new found perspective from their foray into patient-hood.

Participants felt this resulted in enhanced connection to clients and improved practice.

I think that's maybe the biggest, um, change…the people coming in here, um, they're humans just like me and when they leave the building we're just like same, same, right? Humans…just kinda trying to make sense and manage life, right? ….respecting them more I think…I'm not in their shoes and, and I can…maybe have my critical therapy hat, right, from before but I think…also just recognizing that…it's a tough time for them, right?...it's good, it's good, I hope it sticks

…sometimes I think about the information that they give, and as a nurse…because I've lived through that…we tell people, patients, when are they really, really going to understand? And I wasn't going to ask questions, because (pause) they think you're stupid, or ignorant, or, do you know what I mean? And I'm sure patients are thinking the same thing….I think about when we tell patients, well, you may have schizophrenia, you may have bi-polar illness or whatever and the knee-jerk and they'd be shocked, and then we continue on…and we can treat it with this and we can do this, in the meantime, this person hasn't really absorbed what they've been told that they have and what it means to them. So, that's where I can, being a nurse, going through that, I can see the other side of it, um, the patients when they come, and I think we just do it, it's just rote. Y'know, you're just doing your job, right?

<u>Using Supports</u>

Some of the participants discussed their use of various sources of support in able to manage the on-going psychological impact of their illness. The support of colleagues in the work place was highlighted as an important factor in preserving effective practice.

> …so I was very lucky in that I had help here to work in, in that I work with a wonderful group…we're solid and we have so much, ah, support its incredible, I have so much support. I'm very, very blessed here….they told me, each one of them, and as a group they told me, 'we're here to help you, whatever you need'…I think you'd have support…it's human nature…to support somebody who is coming, who has an illness but I think if it was, uh, other people I don't think I would have had the support I had. No, no, I'm 100 percent sure of that

> …the psychologist that works on the in-patient unit had gone through the exact, not exact, but y'know, same diagnosis, same treatment regime and…so every now and then we sort of meet up and…talk about, ok, how's this looking for you? Right? Maybe from that sense, that's a good, from that I've been there, this is what I'm…experiencing, right, and how are we managing this

Participants also described the importance of family, faith and use of formal resources as supports to promote healthy coping and effective practice.

> …the other thing that's been helpful has been having friends who…have the same illness and who are resources and…have ideas about resources and things. Yeah, that's the word- networking

> I mean I can cope…I talk to my husband…sometimes we'll talk about it or if somebody else has cancer or whatever, then we talk about it, but I'm much better. Much, much better. And I did see a social worker at CancerCare for, initially, cause' we had to tell our kids and all that so, I needed that, that was really important. And I had two very good colleagues here that, uh, that I worked with that even when I was home…they would see me every month or three weeks and we'd go out for a coffee, if I could, or they'd come over and we'd go out and have coffee…I could just talk, I could just pour, whatever. So that was really, really good

> …that's how I kind of get through is…just figuring things out. Having a good family and having faith. That's what I would say is important

> I thought I have to be, I'll do whatever I need to. If I need to see a counsellor once every two weeks, or whatever, I'll go do whatever I have to do to ride me through this crisis…there is an expectation I think…I think for sure in mental health, that

(pause) you know what it's like, you should be able to handle that, yes, there is that expectation, there's no doubt, but I also know myself well enough that I thought I, this is too big for me to handle all on my own

Some talked about the powerful impact of connecting with another patient who could understand their reality and who perhaps shared the same diagnosis.

…I spoke with someone who had liberation done in, um, Mexico, and she was like me. And so, we could talk about things that no one else could really get. Like, I'd explain and then she'd go, yeah, yeah, and then it was like, yeah, you get it, cause other people sort of got it, but, not really (laughs)

…so here I am now in a position where I am a group participant…at a very…broken part of my life, right? … it just so impressed upon me how I felt as a participant in that group…it was a feeling of…you are a real person, you are going through tough times and I don't see you, like, I didn't feel like coming in as…you're the troubled patient, y'know? …I thought…this is really good for me to sit on this side of it

<u>Need for a Plan</u>

Need for a Plan referred primarily to participants reflecting on coping in life while experiencing illness and their observations that effective coping appeared to necessitate strategic planning in order to best manage challenging issues. Sub-themes identified included Managing Workload and Developing Strategies.

<u>Managing Workload</u>

Every participant discussed issues related to managing workload and a variety of workplace issues related to maintaining effective practice was identified. Some reflected on their return to work following their initial diagnosis and treatment as greatly desired to distract from a focus on illness, but fraught with eye-opening experiences.

…yeah, probably a huge distraction, and I remember with the breast cancer it's all thought about, oh, I just prayed…oh, just let me go back to work, I can hardly wait to go back to work

…you've gone all through all this and now let's get back to work and slowly get back and I was *exhausted*, so tired….I just, oh my God, I'm only coming in for the first two hours and, and I remember the HEPP fellow said, 'when you first start we usually start you on two hours' and I thought, two hours? (chuckling) two hours? Two hours? You've got to be kidding me, and he says, 'no, you're going to be tired', he said, 'trust me'. He was so right, and he said "just the emotional piece of it already, and even driving to work and by the time you get home it will be more than two hours"…he was right

Another issue discussed related to competency with managing workload when returning to work. As identified in the earlier section on adjustment to illness, participants often wondered about their own ability to return to their work following illness and found they had to deal with some of their own insecurity. Interestingly, some participants also described their perception of their colleagues questioning their competence when knowledge of their illness is shared. For example, Sue shared this story:

…when I came back…she met with me and said, 'y'know, (Sue), this is a challenging unit and if you want to, this is a very challenging unit, it's very difficult and maybe we can switch the, y'know, (workers)', and I went, 'why would we do that?' I, like, they don't think I can do this? 'no, no, no it's just that, it's very stressful', and I went, 'I will let you know if it's too stressful, give me, let me, I'm, I'm not giving this up, this challenge'….I mean, that's well meaning, I'd rather have somebody come up front and say that to me, than to go behind my back (mocking voice) how's she doing?

Gail spoke candidly about her observation that certain topics are taboo in the health care field, including open discussion about any compromise to the mental health of health care providers. This represents a significant disconnect for providers facing serious illness, as impact on mental health is a common and normative outcome.

…certain things are taboo to talk about…I mean, here at work, people have been understanding and….helpful in that they'll listen and they may suggest something…some people, like when I was…diagnosed, people didn't know what to say…what to do or whatever…yeah, you're not *supposed* to get sick…but you do get sick, young or old, yeah, it's funny, mental illness, like depression or stress is a *huge* taboo that you *cannot* talk about

Participants spoke about the support that they received or did not receive in their

workplace to maintain effective practice. The role of management in setting the tone in

the workplace with respect to providers managing illness was described as less than

supportive in some instances.

> ...and we were having a disagreement about something and he mentioned to me that my HR folder was getting pretty thick and I said to him, you know what, I really don't care. Let it get as thick as it wants, I don't care…now, don't try to make me feel guilty cause, let me tell you, that is about the twentieth thing on my list that I have to worry about. It's not number one. Definitely not, uh, but they tried to, most definitely

> ...I had a supervisor, manager…masters in nursing…she just couldn't understand I was going through something and I was off work for a few months and she put it in my performance appraisal…I didn't sign it, but she had put it in and uh, here's somebody who's a *nurse*, how could you not understand that? I mean it's not, just because you don't *see* it, doesn't mean I'm not, y'know, that I'm not sick?

> …in the last 18 months I've missed a fair bit of work, I would say maybe (pause) oh, 15 days…now with the new, oh, things that they have at work if you miss anything over the average target ratio, they have to talk to you about it and it just pisses me off…when you have me here, you are going to get 110 percent…I find that really demeaning and demoralizing and I imagine what the next step should be is that I should be going to the EAP people but I just don't have time, I'm like, behind on all my work…just because there is so much coming at me all the time

A few of the participants spoke extensively about the challenges that they faced with

securing reasonable accommodation in the workplace, despite repeated formal requests

and that such accommodation is mandated under Manitoba provincial legislation. The

following are examples of some stories shared with me:

> I asked for accommodated parking and was told no…your option is I could get HandiTransit (chuckles) I don't qualify for HandiTransit…I was *shocked* at this organization, who I've worked for for years, I was like, *what*?...I went through all the right channels, I had my assessment, I had my, occupational health, y'know…I'm not making this up (laughs)...the person that organizes the parking said there was nothing that was open…I mean, I can't fight with people, I don't know what to do…so my supervisor, bless her, really advocated and that's how I got it. It was her…I asked, I said how did I get this? She said, 'my supervisor really

pushed for it'. So, so that's nice, y'know? I'm good at my job, y'know? I want to stay here for awhile (chuckles). Why would something like that be a barrier?

…there are spots outside…that I could have parking and then been…a minute or two walk from the office, 'no can't do it'….it's silly things like that…I usually work 9 to 5:30, so everybody else is here by the time I get here so I have the furthest spot from the parking lot. Rather than giving me the spot right by the back door, which all they have to do is put a sign up…these are professionals here, nobody would give a rats ass if I park closer to the door, no, well, they can't do that

At least one person who had difficulty with work expectations did receive

accommodation.

…the other piece that makes it challenging is, um, it's a very complicated regime and sometimes it's just exhausting. Like last year…in my job I interview applicants…I went down to the interviews and was fine for the day, we interviewed lots of people…but I found at the end of the day I was exhausted…I scared myself because I couldn't think straight to take my insulin and how to calculate it all…and my schedule was upset so it was kind of more complicated. So, I mentioned to my supervisor, that maybe I could, while I was doing the interviews they also had in the evening this social thing you had to attend, and I just said…how important is it for me to attend? He said that, he had said that I wouldn't have to

This appeared to represent a very distressing situation which left these providers feeling isolated and devalued in their workplaces. The sense of frustration in the narratives is palpable, as Rita described "…and see, that's the thing, people will not pursue, they'll get disgusted, they'll get fed up, they'll get *better*, but they won't pursue it" Most spoke of getting nowhere in their bid for accommodation, with an underlying sense that illness manifestation represents weakness that must be hidden or removed- not accommodated.

…I think what they need to focus on is support of workers, especially experienced ones, that they want to keep working, if they have physical disabilities due to getting older, or illness, or whatever reason. Addressing them, not saying, no, we can't do that… what the hospital thinks is that the ones that they don't accommodate, they really probably could do without…that's the mentality that they take…because we have 16, 000 workers and if we had 200 workers that need…accommodation, they'll leave, they'll stop working and it won't cost us anything but, and we can just replace them, um (pause) no skin off our butts, basically

In managing their workload and striving for effective practice, participants acknowledged that they do put a lot of pressure on themselves. This appears related to maintaining work performance, achievement, and the perception that they are completely functioning even though they may be struggling.

> …oh yeah, I was just not a type A, I was probably more like a type triple A. Definitely, oh definitely, y'know, way over achiever…always on the go and everything needs to be done right, there's only one way to do things and that's the right way. That's the thing, that still holds water with me. So, I have that stand…I expect that from people, so, so I have to make sure that I have that standard (pause) it's *hard*, when you have that standard. It's not easy to give up

> …my undergraduate degree is in social work and I've kind of gone back to that…the hours are more regular and, eating isn't a part of your job description because in (other jobs) there is so many social events… you're almost obligated to eat…and, I put an expectation on myself….I mean it's also on myself, doing it to myself….because I'm a pretty high achiever

> I know real people that work sick that have those same days, too, maybe not as many as I do, but um, if it's really bad though, I will call in sick. Y'know, if it's to the point where I'm not cognitively there…pain is maybe nine out of ten or ten out of ten, I won't go anywhere…I have pushed myself because I have had things on where I have to be here and there's just no way, and I have to be here

The motivation to continue working appeared quite strong in all of the participants whether primarily financial or personal in origin. The investment in one's professional identity and work appeared to be a factor in maintaining work in health care practice versus changing fields or taking disability, if eligible.

> …well, sure, when you've worked in a career for 10 years you gain so much experience from that career, you have so much to offer your profession and to patients that why would you want to stop doing that if you…if you knew you could work for another 10 years or 15 years, or however long it was that you wanted to work for…but unless you know the deal, work around it, and everybody is different too…we work in a health care profession but sometimes we forget, the managers forget, their workers could be needing (pause) um, how can I say? (pause) they may be needing help in terms of their health…I could be at home collecting disability (pause) but I don't want to, what would I do?

Others described a shift in their perspective in attempting to cope with expectations at work, while managing with the personal adjustment to serious chronic illness. Holly described adjusting her expectations on her energy levels following cancer treatment:

> I think I stopped, like I think realizing…after several years for me…you think that the system will really love all the extra that you, and then you get, you get a bit *jaded*, right, about the health care world…I can just put in my designated hours and do…the best that I can in those hours and then, that is good. That is good

Wendy spoke about allowing herself to adjust her work schedule to allow her to rest more, which she recognized helps with her overall health and managing her MS symptoms:

> …so what I've done with my work is I can't do it, I can't work full time. It was killing me, so I decided, well, since I'm a nurse, I've got to try to figure out what makes the most sense. What about if I took Wednesdays off?...this Wednesday I woke up and it was like, 10 o'clock, I was like oh my God, I slept like 12 hours almost….my husband's right because he said… 'you give yourself permission then, right, so obviously you need it', so, but I've heard comments like, oh, did you have a good time off? That must be nice? Like, it's not so nice (chuckles)

Developing Strategies

Some of the participants explained the strategies that they have developed over time in an effort to make a plan to adjust to effects of their illness on their practice. Concrete strategies such as being organized, using memory aides and breaking up tasks were common:

> …all the great modern things that I have for organizing and I'm organized on my computer, on my blackberry, I have set reminders so that I don't forget things cause' that is the brain, I don't know if it's because of my illness, or because of the situation, I forget stuff

> I totally don't remember so I know I need to write things down and, and so you kind of…make your own sort of coping strategies with it, right?...like when we're talking about groups and having to think on your feet and processing what they're saying, and how, what, what becomes therapeutic…just remembering what happened week to week let's say…the brain is super taxed, but thank goodness I think there is some rebound effect, I really do

…it's helpful to be an OT…I used to have to teach people energy conservation and planning and so I use a lot of that now…I make piles, right, like my upstairs pile, righ…then I think ok, now I'm going to go to the bathroom, I'm going to take this upstairs and then I'm going to copy and then I'm going to come back, see? So I kinda try to organize?

…you just have to divide it up into smaller jobs- that's another trick I use

Gail spoke about supportive experience in her workplace, where her illness is known and where her colleagues have evolved an informal system to assist her in maintaining an effective practice:

…I have a desk job, I sit down all the time and so that's what I do. When people come for appointments, I sit, right…occasionally, like I am doing some new innovations for example, getting people involved in volunteer work, right?...if I know I'm going with someone, I plan my day…and I get good support from my co-workers, as well… um, the recreation coordinator that works with me, she's helped a lot…we just kind of figure things out a lot that she does more of the physical things

The balance needed to continue to manage one's health issues and workload was also discussed by participants. The challenge of the lack of sick time and the use of strategies such flex time were discussed.

…it's just another layer of things, y'know? Doctors appointments, here I usually just make up the time. I don't take sick time for my doctors appointments (laughs) I have no sick time left

…I worked from home, remotely. But HR has put a kibosh on that, they won't let me do it anymore

Fortunately, few participants in this sample reported dealing with pain or physical discomfort due to their chronic illness while at work. Of those who did discuss this issue, one participant had this to sobering comment to share:

…I'm on major pain control…I will not allow myself to be medicated to the point where I can't feel the pain. I have it, try to keep it around, say, six out of ten, all the time so that I know there are times it gets really bad and I won't increase it. Very,

very rarely will I increase it. I will more likely increase my steroids before I increase my pain meds because I…need to have a full brain (silence) y'know, I have to be able to function (pause) mentally, and you can't do that if you're hopped up on pain medication

With respect to developing strategies to manage workload and workplace issues, particularly around reasonable accommodation, Beth had this comment to share about learning one's rights:

….I had a supervisor who told me that I couldn't see the local diabetes education nurse because it was a conflict of interest….I mean, it's also learning your rights. You learn that over time….I had an interview where someone questioned my ability to do the job because I was a diabetic, yeah, so as I say, it's learning your rights and what people can ask and what people can't, and learning through trial and error (chuckles)

The necessity of separating out one's personal problems from daily work life so as to not allow them to interfere with performance was also mentioned as a strategy used to cope:

…there is nothing in advance to try and teach you how to deal with the stressors that are going to come from being in this profession, nothing whatsoever. Y'know, because you can be sick at home, you can have all the problems in the world but if you're a nurse and you've got to come in, work a twelve hour shift, you're going to be working hard for those twelve hours- your problems don't exist while you're at work

<u>Use of Self</u>

Use of self was discussed by various participants when reflecting on developing meaning from their lived experience with illness and incorporating the wisdom from this experience into their practice. Sub-themes identified from the larger theme included Selective Disclosure and Teaching about Experience.

<u>Selective Disclosure</u>

Almost all participants talked about being selective in the disclosure of their illness. By and large, it appeared to depend on the circumstance and context involved as to

whether a participant decided to disclose the fact of their illness or information about it.

All that spoke of disclosure indicated that they preferred to make that decision

themselves and did not appreciate unauthorized disclosure by others, especially to clients.

> I don't know that in the past I would have ever divulged anything about myself, really…thinking you're the therapist, you maintain that line…but I think for me now it's become more, like, we're both human

> I do see some patients, um, just patients I've known from the past and some of them, I have told them that I've…had an illness because they'll say, I haven't seen you in a long time, where've you been?...I talk about it with my staff…I have no problem, I know people who would never say anything like that but, that's just the kind of person I am. I'm not going hide that and if it can help somebody else out, why not?

> …for the most part…if I know someone well enough, I will tell them but most everyone know that I have, uh, health issues. Most everybody doesn't know the extent of it though, because I don't tell everybody the full extent of it….if it's my best friend or it's my sister…who knows me…I'll just give them the two minute coles notes version of what's really going on…they'll ask me questions or whatever, but it doesn't become the focus of it. Well, it has consumed my life, it has taken away my life but I, don't let it consume it anymore than it already has

Most felt comfortable disclosing to select colleagues, but clients represented a more

challenging situation and they were mindful of the impact on the client of the disclosure,

questioning whether it would be viewed as appropriate or as over-stepping a boundary.

Most appeared comfortable with disclosure to client if it presented some therapeutic

benefit to them.

> I guess it depends on the client, what they're going through (clears throat)…the couple of people that I did…share it with were, had breast cancer or cancer. They were really…depressed, worried about this. When I shared my story with them because I thought it would help and, I think it did, it gave them a little bit of hope

Some discussed stories of a decidedly negative impact on their client:

> I'll give you an example is someone disclosed to a couple of people what was wrong with me, why I was off because I was doing an external group somewhere and so there was a woman that, it really bothered her and so then she said to me, 'I can't believe you're…' like, I was the topic of her…psychotherapy with her

counsellor…she's really worried and she's praying for me, like, that was really hard on her and it's that, and so I didn't really appreciate that disclosure happening

A few participants reflected on the possible impact on their clients of their seeming disappearance from the workplace, without explanation as to what has really happened.

…I feel bad for those patients…it was just like…the group will be ending early kind of thing…I hope she, that she needed, she needed disclosure…I'm leaving because, to take care of some medical issues, right? And I didn't disclose that and I'm wondering if…I *do*, I think back to those ones that I had seen and…are they now soured a bit because I'm leaving them in the lurch?

Wendy told a very interesting story to me about an experience with a young patient that informs her perspective on whether or not to disclose her diagnosis of MS:

…here's a little story, it's like, uh, one day I had this lady, she's very young, she's schizophrenic, and she's got young kids, she came she came with her husband and y'know, there's *a lot* of difficulties….she said (voice lowers) she sat there and said (voice raises) 'well, y'know, it's not so bad', she goes, 'at least I don't have something like multiple sclerosis' (bursts out laughing, fakes a scream) yeah, she goes 'can you imagine? That would just be like the worst' (sarcasm) yeah (laughs) that would be bad. Yeah, so everybody has their own perception because I think, wow, I wouldn't want to have schizophrenia" (chuckles)

Teaching about Experience

A few of the participants talked about their need to teach others in health care through sharing about their illness experience. It appeared that this teaching not only gave a sense of meaning to their experience, but also a sense of hope that they are influencing positive change amongst their colleagues and within the health care system which might benefit other patients.

…initially I was very…closed about it but now I'm much more open…as I said I do that seminar where I talk about my illness experience. Yeah, um, I try to do it at a time where I've had experience with them at a professional level first, that that isn't their first knowledge of me. I prefer that the first thing they know about me is that I'm a patient that they try to see me as a competent professional first

…well, yeah, I think…my rheumatologist has learned a lot from me and I think he applies it to his other patients…I've come up, come up with a few new unique treatments that have worked, and I think that it gets applied and I think other doctors have learned that as well from me but…I think there's a bigger reason for it

…I also volunteer now for the Canadian Breast Cancer Foundation…so I really advocate here at work, all the women…I've got little brochures…make sure they do their monthly checks…trying to proactive and that, especially when you work with so many women. One in nine gets diagnosed with breast cancer, I mean, like wow

…maybe it's age, I don't know, I'm much more 'in your face' about it than I used to be…I test my blood sugar in front of people, I take insulin in front of people…I mean I don't do it so much in front of clients…but in terms of colleagues and my students…there's sometimes that I feel comfortable and sometimes it doesn't, sometimes I feel like I get a little too much attention

Participants were asked to provide recommendations for health care providers facing illness to help them to cope and manage their practice effectively. Beth recommended reading material dealing with chronic illness, integrating the topic into professional training curriculum and finally she asserts, 'I think more research in the area and more discussion'. Sue recommended a recognition by other staff that 'you've been through a lot' and to offer help if needed. Sue notes that the health care provider facing illness also needs to ask for help if they require it. Like Beth, Sue also recommends more discussion and inclusion of the topic in professional training.

Rita makes a pragmatic recommendation to providers facing illness in that 'they have to decide that they want to keep working and if they do, then they're going to have to devise methods to keep doing that'. Rita further notes however, that 'if you're good at self-motivating then you'll be ok, if you're not, you won't. That's basically how it is - every man for themselves'.

Gail advised providers to 'be open and talk' and 'be proactive'. She notes that providers will 'hopefully have people that understand you', but that 'ultimately, it's up to

you' as to whether you disclose and open a discussion with others. Gail notes that 'it's something that you have to work on'. Holly recommends that providers attempt to integrate their experiences into their practice, in particular 'just to recognize the *person* behind the condition'.

Wendy recommends that providers facing health issues consider providing mentorship to others going through the illness experience. Wendy also notes that it's important not to get 'all whipped up' and to 'pick your battles' when facing challenges with adjustment and navigating continuing practice. She also notes it's important to keep good alliances with people that might be helpful in this evolving process.

Results from Follow-up Interviews

As previously described, all six participants provided a follow-up interview in which they shared their feedback on my interpretations of the initial interviews. Participants were provided with a list of the themes and significant statements isolated from the initial interview data to review (see Appendix L). This process was intended to engender participant feedback and to serve as a way to measure the validity of the interpreted results.

While a few participants asked clarifying questions on some statements, none of the participants indicated that any of the data was incongruent with either their personal experience or their knowledge of experiences faced by others with serious illness. In fact, several participants stated they were reminded of further aspects of their experience which they had not thought to share in the initial interview but could relate to in the findings. No participant reported concerns with the data findings or any points they

thought were missed, most often stating that the findings were quite comprehensive and reflective of the serious illness experience faced by practicing health care providers.

Of interest, several discussed their disappointment and surprise with the reporting of lack of workplace accommodation by others. Not sharing in the need for such accommodation due to the illness symptoms, they expressed dismay that other educated professionals in a health care environment would experience such challenges. In addition, several participants touched on the concept of certain topics- particularly mental health- being taboo in health care. This appeared to resonate for some and they discussed with me their challenges with anxiety and depression related to their illness, which they acknowledged as normal but which they also felt they must conceal in the workplace.

<u>Summary of the Data Analysis</u>

In this chapter, findings of the research were presented. A description of the study sample was provided and three main categories were presented, each with identified themes and sub-themes to further isolate phenomenological meaning.

As I read and re-read the data, writing about and isolating themes, I reflected on the amazing and insightful narratives that these six participants shared with me in their interviews. Much of their experience resonated for me personally as an insider, and it became clearer to me that the findings embodied the liminal state of being which I have read of so often in the illness experience literature.

<u>CHAPTER FIVE</u>

<u>DISCUSSION, RECOMMENDATIONS, CONCLUSION</u>

Introduction

The final chapter of this thesis has three purposes: to offer a full discussion of the findings described in detail in Chapter 4, to offer recommendations for the social work profession and health care system as indicated by the results, and to draw some conclusions from the research.

Discussion

The discussion section of this chapter focuses on the relationship of the findings to four main elements: the study sample, the research questions, the literature presented in Chapter 2, and the theoretical framework. Through comparing and contrasting the findings with respect to these key elements, a clearer understanding of their meaning and what is known of the phenomenon will result. The discussion should also illuminate any recommendations relevant to the research.

Relationship of the Sample to the Findings

The study sample was presented in detail and a table was constructed to organize these data. Several of these previously described qualities are worth further discussion with respect to the findings: gender, maturity, diagnosis and professional affiliation.

<u>Gender</u>

As described, all of the six participants were female. While this could be viewed as a limitation in the sense that the sample is not representative of health care providers of

both genders, I believe that the findings are strengthened as being about the experience of women. It is worthwhile to note that female health care providers are also overrepresented in the health sector, in particular in the fields of nursing, social work and occupational therapy.

Maturity

Maturity is viewed here as a combination of age reflecting life experience and years of health care practice experience.

As mentioned, the participants ranged in age from 40 to 59 years. Two of the participants were aged 40-49, the other four participants were aged 50-59 years with an average age of 51 years.

The sample represented a significant number of 162 years total of health care practice experience. The reported experience ranged from 18 to 33 years; the average was 27 years experience. Two participants had over 30 years experience; three had between 21 and 30 years experience; one had 18 years experience.

Taken together I believe that the sample is representative of a mature group of health care providers with a wealth of experience, both in life and in practice.

Diagnosis

As previously described, the participants reported a number of serious chronic illness diagnoses. Four of the six dealt with one diagnosis, while two participants had multiple illness diagnoses. Three participants reported a breast cancer diagnosis; one reported a diagnosis of multiple sclerosis; one reported a diagnosis of lupus; one reported type 1 diabetes. There were also a wide variety of symptoms reported across diagnoses that affected participants' functioning. All participants reported experiencing fatigue, and

difficulties with memory and concentration. Three participants reported experiencing pain symptoms; two reported significant difficulties with mobility; two reported complex medication management, and one significant reported dietary restrictions.

It is interesting to consider the differences in the experiences amongst these health care providers due to different diagnoses. These differences were noted by participants themselves when consider the initial findings. However, it is also interesting to note that many similarities in larger themes were found despite the disparities in diagnosis and symptoms experienced. This found commonality points to the essence of lived experience with serious chronic illness.

Professional Affiliation

As reported in the study sample results, the participants represented a variety of professional backgrounds within the health care field. Two were from the nursing profession; two were occupational therapists; one was a social worker and one was from the diagnostics field.

Participants again noted differences in their experience attributed to differences in professional background, setting and training. However as with diagnosis, there were many similarities amongst themes despite the difference in professional affiliation. On the surface, working with the health care system appeared to be a unifying context for comparing participant stories.

Relationship of the Research Questions to the Findings

The purpose of this section is to examine whether the research questions were answered in relation to the reported findings. The research questions to be addressed included:

1. What is the essence of the lived experience of being a practicing health care provider with serious, personal chronic illness?

2. In what ways can the health care system improve services for health care workers?

The first research question sought to explicate the essence of the lived experience of health care providers with personal illness of a life-threatening, chronic nature. This research question was addressed adequately in the findings in terms of the three categories – adjustment to illness, interactions with the health care system, and effects on practice - that emerged from the interview data. These categories were deconstructed in a phenomenological reduction through writing and re-writing to reveal the deeper meanings held in the themes and sub-themes outlined. Thus, the essence of this lived experience was revealed (see summary of results Table 2, page 70).

The second research question asked whether the experience could be improved in terms of preparedness and support for the health care providers living with serious illness. To find answers to this question, I turned directly to the participants themselves to explore the issue. The recommendations made by the six participants clarified the absolute lack of preparedness that these providers had from their professional training or personal experience. Struggles with support were described throughout the findings and thus the participants made suggestions for how best to provide support and improve others' experience through the benefit of learning from their own experience.

Relationship of the Findings to the Literature

A comprehensive review of the literature on the lived experience of health care providers with illness was reported in Chapter 2 of this thesis. This literature documented

the unique issues faced by chronically ill health care providers, such as navigating dual insider roles and the many challenges and rewards of continuing (DeMarco et al., 2004; Kempainen et al, 2007). The literature found that providers of various professional backgrounds reported blending their personal experience into their professional life to create a new identity or 'state of being', contending that this was necessary to foster personal healing and authenticity in their professional work (Klitzman, 2006; Picard et al, 2004). This phenomenon was reflected in the current research findings in that, again regardless of their professional background or diagnosis, the participants articulated throughout the findings the same process of blending their personal experience with their professional life to create a new state of being. All six participants communicated that they felt this evolving process was both necessary and integral to enable them to continue with effective health care practice.

With respect to learning how to navigate dual insider positions- as both provider and patient- the literature reviewed found that health care providers facing personal illness must find ways to reconcile these roles with little guidance or support (Leonard, 2001). Findings from the current research support this in that participants reported receiving little guidance or support from supervisors, managers, or their professional training. Most support was gained through informal sources and focused on preserving personal coping, which then aided the provider to be better equipped to face professional challenges.

Findings from the research also supported the literature in replicating many of the issues reported to be faced by practicing health care providers navigating personal illness. For example, participants in this study echoed those in the literature in reporting

difficulties with adjustment to illness and perceived loss of control (Maram, 1999;

Schnipper, 1996); disclosure issues were similar with respect to sharing diagnosis or

illness challenges with clients or colleagues (Wall, 2001); use of self in practice was

discussed extensively in the findings with respect to incorporating personal experience

into practice in a meaningful way (Lanza, 2007); reporting of an evolving advocacy role

found through participant experience with teaching about their experiences (Coulter,

2008; Tierney, 2000).

With respect to the issue of perceived loss of control, as previously stated I have

chosen to focus on exploring the experience of loss in my interpretation of the data as

opposed to participant locus of control. While health related locus of control has been

found to be an important correlate with behavioural and psychosocial adaptation (Livneh,

et al., 2010; Frasier et al., 2011), the literature on the experience of loss in relation to

illness illustrates far reaching consequences for affected individuals (Boss, 1999;

Gorman, 2011, in Harris). Kelly (2008) explored what she referred to as 'the social and

emotional landscape of liminality' by examining the experiences of loss and grief

associated with AIDS dementia. Kelly proposed that, "…in order to understand the social

and emotional space in which people live not with loss but ''in" loss. This loss is

experienced in a liminal state of uncertainty, of provisionality, of knowing precisely

when and if a loss will be resolved" (2008, p.2). In line with this literature, the current

research findings clearly illustrated that the study participants were dealing with many

losses related to their illness experience, such as coping with uncertainty and a perceived

lack of control. The experience of loss was evident in both their personal and professional

lives. The participants articulated both their sense of loss and the liminal landscape from

which they live "in" that loss. For the purposes of this study, with its focus on expanding

our understanding of this unique and complex topic, I felt it was most important to draw

out the broadest depth of detail regarding participant's experience of loss rather than to

examine their psychological motivations.

The literature reported that the illness experience of this group is generally

considered a 'taboo' topic by society and within the health care system, thus forcing

chronically ill health care providers to face ambiguity in both their personal and

professional lives (Picard, et al., 2004). Again, the study findings reported in this thesis

support this assertion with respect to participants discussing feeling compelled to conceal

their illness, especially mental health symptoms, due to the ingrained belief that illness

manifestation is largely unacceptable - a belief which is perpetuated amongst health care

workers and is upheld in the 'culture' of the health care environment. Participants echoed

the literature in observing that the public are largely unaware of the issues and prefer

instead to hold idealized views of health care providers as omnipotent beings, acting in a

professional capacity that provides immunity from any possible personal impediments so

as to provide unfailing, uncompromised service to the public (Sollod, 2002; Wall, 2001).

Not surprisingly, the reported literature asserts that health care providers with

serious chronic illness generally lack the preparation, training or appropriate resources to

assist them in navigating issues related to personal illness in their practice (Foehrenbach

& Lane, 2001). This was replicated in the research findings with all six participants

confirming they had received no preparation or training, and very few resources

appropriate to helping them navigate this difficult issue. Research findings also supported

the literature in reporting that treatment teams have little guidance in terms of how to best

help their patients who are health care providers (Consalvo et al., 2008; Kempainen et al., 2007). Participants reported that their treatment teams generally lacked skills in assisting this specialty group of patients, largely due to a concordant lack of awareness of the issues faced and guidance through professional training.

Relationship of the Findings to the Theoretical Framework

This section will examine the relationship of the findings to the theoretical framework reported in Chapter 2 of this thesis. Specifically, the theoretical framework articulated the connection between the concepts of liminality and illness.

Concept of Liminality

As described earlier, Turner (1969) elaborated the concept of 'liminality' as the condition or state of being "betwixt and between" in relation to a phase or space in a rite of passage. Primary dimensions of this liminal phase include 'communitas' which refers to communication influenced by sociocultural processes and 'reflexivity', or a state of reflection. Turner (1969) explained that people who occupy this liminal space defy the classification that typically locates states and positions in cultural space, and although they develop valuable insider knowledge as to their state of being, they occupy a 'threshold' or in-between position that is not generally recognized socially. Use of the concept was extended in anthropological studies which confirmed that a liminal position, even when associated with illness, can be associated with social inferiority and an outsider position in society (i.e. Ekwall et al., 2007; Gardner 1998; Jackson, 2005; Parry, 2003; Purves et al., 2004).

Applied conceptually to the experience of illness, liminality captures the resultant extreme life change and ambiguity for the affected individual and their loved ones on the transition from 'healthy' to 'unhealthy'. From the literature, Little et al. (1998) applied the concept of 'liminality' to cancer patients' experience, asserting that all experienced liminality as a *process* that begins with the diagnosis of their malignancy and continues indefinitely. The described process is marked by phases and corresponding experiences, and key features in survivors' narratives are indicative of this liminal state such as an immediate impact of the cancer diagnosis and persisting identification as a cancer patient, regardless of time from treatment or disease state, a variable state of alienation from social familiars, expressed as an inability to communicate the nature of one's illness, and a persistent state of 'boundedness', wherein cancer patients had an awareness of limited space, empowerment and available time. Thompson (2007) concurs with the merit of applying liminality as a rubric to the cancer experience, but she asserts that use of the concept needs to be amended to capture the generative potential and positivity that is captured in many cancer illness narratives, primarily as a way of healing and coping with enormous uncertainty. Thompson also cautions that use of the liminal concept to cancer and other populations may generalize a highly personal and individually unique experience, thus doing a disservice to clients in the end.

With respect to the findings in the current research, it is my contention that the concept of liminality adequately captures and communicates the essence of the lived experience of the seriously ill health care provider as a new 'state of being'. Findings from participant interviews clearly articulated a sense of living with a foot in two worlds, and while holding insider knowledge of each, struggling with occupying a social position

that is not socially sanctioned or recognized. The findings also support the idea of liminality as an evolving process, described by both Little (1998) and Thompson (2007) in their work with cancer patients. Thus, participants expressed in their interview narratives a definite sense of personal impact from their diagnosis, a variable state of alienation from social familiars with difficulty discussing their illness, a sense of boundedness in terms of available resources, but also the generative and positive qualities that Thompson (2007) described in her findings. Thus, participants spoke with great passion and pride about their contribution to their field and to their dedicated work with clients.

As Thompson (2007) cautions, I concur that it is important however not to generalize the use of this concept to all persons with cancer or any other illness as this may do them a disservice in minimizing an very individual and complex life experience. It is interesting to note that the six participants in the present study also cautioned that while there are many common threads of meaning and shared experience, it is also extremely important not to overgeneralize and lose appreciation of individual differences.

Relationship of the Findings to the Methodological Framework

This section will examine the relationship of the findings to the methodological framework outlined in Chapter 3. The methodological framework included application of phenomenology and insider/outsider theory to the research. This framework also informed the formulation of the study research questions and the role of the researcher.

Phenomenology

As described in earlier sections, phenomenology is a qualitative research approach that generally seeks to provide depth and rich description of phenomenon so as to uncover the 'essence' of the experience under study which is accomplished through the intentional directing of individual consciousness toward the object one seeks to understand (Stewart & Mickunas, 1990).

Hermeneutic phenomenology advises the researcher that while one may try to 'bracket' or set aside their personal experience with the study phenomenon, it is impossible to do, given that all understanding is through directed consciousness and ultimately, interpretation (van Manen, 1990). Hermeneutical phenomenology focuses on the language and structure in communicating experiences and developing interpretive meanings (Patton, 2002). As van Manen (1990) explains, 'the essence or nature of an experience has been adequately described in language if the description re-awakens or shows us the lived quality and significance of the experience in a fuller and deeper manner' (pg. 10).

LeVasseur (2003) suggests relating the concept of bracketing, wherein the researcher attempts to suspend use of theories and assumptions, to use of what interpretive phenomenologists call the hermeneutical circle. Progress is made toward greater understanding by questioning prior knowledge and thus expanding new horizons of meaning, "yet we never fully arrive, because to arrive would merely represent another stage of pre-understanding" (2003, p. 418).

At the beginning of this project, as a novice researcher I explained that while I initially considered use of Husserl's heuristic model, as it might represent a less

complicated approach for my topic and potentially lend some 'objectivity' to a subjective endeavour thus, represent something more 'scientific'. However, I decided that my inquiry would be better informed by all of my own learning from experience, and I choose to adopt hermeneutic phenomenology to explore my and others state of 'be-ing' in the world.

As LaVasseur (2003) recommended, I attempted to bracket my own experience with the intent to explore and declare it, recognizing it as way to inform my research. I have found the application of this research approach most gratifying and productive to explore the study phenomenon. I was reminded with each interview, each interaction with a participant, that they are a fellow traveller on the road of life- yet we happen to share one similar bag of things to carry. I believe that my sharing of experience assisted the research process in making participants feel comfortable and in sharing thoughts and ideas about experience to reach deeper meanings. This approach was particularly useful and freeing as a researcher, since as hermeneutic phenomenologists contend, there is no need or ability to transcend, only to explore, interpret and guide toward a broader horizon of understanding which will likely stretch on unendingly. Thus, I felt decidedly that I was a co-researcher in this exploration research and that the participants and I collaborated together to find and create meaning, seeking to expand the hermeneutic circle on the essence of this lived experience.

Insider/Outsider Theory

As previously described the theory articulates the difference in perspective between an *emic* (insider) view which suggests an informed, and influential standpoint; as contrasted with an *etic* (outsider) view which is considered more distant, logical, and

removed (Headland et al, 1990). The literature has many examples of positionality related to researcher and participant perspective (i.e. Kahuna (2000)), commonly exploring the inherent challenges of adopting one or another, or sometimes multiple, perspectives. Watts (2006) discusses issues of finding 'common ground' and 'common language' while attempting to develop empathy across political and theoretical divide; Humphrey (2007) concluded that what developed was a reflexive process of navigating liminal space and the evolution/change of what constitutes an insider-outsider position. Reinharz (1997, in Hertz, R. (ed.)) asserted that there a variety of selves the researcher brings to the field which include '*research-based selves*', '*brought selves*' and '*situationally created selves*' (p. 5). Reinharz noted both the fluidity and influence that these varied selves have on the research process and outcome (p. 4). Kahuna (2000) highlighted some of the benefits of coming to the research from an insider position, including seeking increased knowledge through an interested, impassioned approach however cautioned that relying too much on insider pre-understanding so as to miss key insights, and in erring by not keeping in check one's need to maintain some objectivity in approach.

Application of the insider/outsider theory was particularly useful as a methodological approach for this study, as it clearly connected with the status of the health care provider participants and the researcher as both insiders and outsiders on various levels. As an insider to both the health care system and the patient experience, I was able utilize a common ground and shared language to relate to participants and learn about their experience. I feel that not sharing this insider position would likely have yielded less in-depth results as I would have lacked a frame of reference from which to explore participant's experiences. As I was told frequently by my participants, 'you don't

know until you've lived it'. I was intrigued by Reinharz' (1997, in Hertz) assertion that it

is essential to know 'what the researcher's attributes mean to the people being studied,

the researcher (and reader) cannot understand the phenomenon being studied' (p. 4).

Looking back at my research journal, I found numerous entries that documented my

reflecting on this process such as:

> Transcribing every detail, sound, intonation of voice – re-living interviews and
> some of the emotions brought up, for me and for them. Sometimes I remember
> stuff; other times it's like hearing it for the first time. I wonder how they see me and
> how this impacts what they share. I keep wondering if I am talking too much,
> sharing too much of myself and my story and somehow spoiling things. Then I
> think, wow, this is good stuff. It is what it is – people connecting on a topic and
> trying to make some sense of it all.

I do concur with Kahuna's (2000) astute observation that it is possible to get too

close, however, and thus unintentionally limit one's scope of inquiry and understanding.

This was another purpose for my keeping a reflective journal of the research process and

in taking care during interviews to not assume meaning, endeavouring instead to ask for

clarification and consciously seeking the deeper meaning for participants in as much as

they were able and willing to share with me during our time together. The journal also

afforded me a venue to reflect on my thoughts and feelings during the research process,

such as in this entry:

> I received an email today from an interested participant whom I know
> professionally. I called her back and in discussing her situation, I learned about her
> illness for the first time. The seriousness of her condition- a life-limiting disease
> ending in major organ failure – was shocking to me. I found myself at a loss for
> words for a moment, as reality hit and this suddenly felt very close to home. I found
> myself wondering how she copes with that knowledge on a daily basis, but suspect
> she (like me) find strength and hope in the work that we do in helping others. Part
> of me wants to avoid talking to her…avoid hearing the truth of her reality, going
> into her world. This process is so humbling and at times, frightening.

Summary of Discussion

The discussion section of Chapter 5 has considered the findings in relation to five key elements: the study sample, the research questions, the literature review, and theoretical framework, and the methodological framework. Specifically explored where the relationship of the findings to the concept of liminality, the application of phenomenology, insider/outsider theory and the role of the researcher. The purpose of this discussion has been to provide connection between the findings of the research and the other elements of the thesis.

Recommendations

As a result of the preceding discussion, recommendations will now be made with respect to furthering our understanding of this phenomenon and operationalizing those suggestions made by the participants to assist health care providers facing serious illness in the future, including how they specifically relate to the social work profession.

Education

Education was viewed as a key component in raising awareness of the issues faced by health care providers living with serious chronic illness. This education may take the form of additions to professional curriculum and training for all professions in health care, including social work. Participants expressed the importance of generating discussion about the topic to increase awareness and in hopes of influencing a change in the stigma held around personal illness within the health care system. Social workers can have an important role within the health care system by integrating education on this topic into their practice with medical teams, and through influencing the existing health care culture by promoting inclusivity and acceptance of providers facing illness.

Practice

In terms of supporting practice, the role of available supports for ill health care providers is imperative. As participants in this study and other research report struggles in finding such support, the presence of supportive mechanisms in the workplace to promote reflexivity in practice and encourage continued coping is important to maintaining effective practice. In addition, the availability of clinical supervision which recognizes the issues faced by the provider facing personal illness in a supportive, non-judgemental way would support effective practice. Social work can lead the way by incorporating support mechanisms into the profession to assist social workers facing chronic illness maintain effective practice. In addition, social workers can also provide a supportive, advocacy role in their work with patients who are also health care providers.

Administration and Policy

Participants in the current study findings spoke extensively about challenges they faced in lack of support from the administration in their workplace. The impact of administration in setting the tone in the workplace and in making specific decisions, such as providing accommodation to disabled workers, is integral in influencing the work and culture of a workplace as well as job satisfaction. Support for health care providers would be demonstrated with implementation of human resource policies that prioritize appropriate accommodation and afford flexibility in creative solutions to challenges workers face, such as work share, flex time and working from home. Such policies would serve several purposes in supporting workers, increasing job satisfaction and productivity, as well as improving retention of experienced health care providers who might otherwise leave the field due to health challenges. Such principles would also

apply to policy and administration within the social work profession. The social work profession can lobby for policy changes within larger institutions, such as the health care system, with respect to human resource practices that support chronically ill workers.

<u>Research</u>

Continued research into this topic is recommended to further a deeper understanding of the phenomenon and expand the available research evidence. Further research would ideally involve interviewing health care providers from various sectors and with a variety of diagnoses for the broadest depth of information – this would include chronically ill social work practitioners. It may also be important to interview those who've left the health care field following diagnosis or treatment to develop an understanding of their issues and what may have been helpful to have retained them in the field. Finally, it is recommended to develop further research into the views of health care providers in general as to the issues faced and best way to support their colleagues who face personal illness, particularly as they may serve as providers of care to these colleagues in future. With a tradition of reflexivity and social advocacy, the profession of social work could substantially contribute to the research on this unique experience and in delineating appropriate supportive interventions.

<u>Conclusion</u>

In conclusion, the purpose of this thesis was to explore and articulate the lived experience of health care providers with serious chronic illness. The research questions, reviewed available literature, theoretical and methodological frameworks were demonstrated to be connected and supported by the research findings. Overall, the findings supported the conceptualization of this unique lived experience as a liminal state

of existence. Implications of the findings with respect to the profession of social work and related to the areas of education, practice, administration and policy, and research were explored.

As a novice researcher, I had the privilege and pleasure of getting to know six wonderful individuals. Each has taught me a great deal by sharing their perspectives and insights with me. I have been honoured to hear their stories and sit with them while sharing difficult remembrances. I will be forever grateful to each of them for their gift of time, their courage and their absolute generosity of spirit.

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LIST OF TABLES

Appendix A

Invitation to Participate in Research Study

UNIVERSITY
OF MANITOBA **/**   Faculty of Social Work

Are you a practicing **Nurse or Social Worker** living with a serious chronic illness such as multiple sclerosis, cancer, or diabetes?

Are you a minimum of **one year post-diagnosis or treatment**?

If so, I am interested in hearing about <u>your experiences as a person living with illness, while navigating your professional role</u>.

I am a student researcher who is completing my Master's thesis in Social Work at the University of Manitoba. My interest in this area arises from my own experience as a health care provider living with serious chronic illness.

Serious chronic illness in the context of this study refers to physical illness which is not curable, is potentially life-threatening and which creates alterations in functional ability over time. The purpose of this study is to help articulate the concerns of this group and mechanisms that assist them to maintain effective practice.
Only persons who have lived this unique experience can give this information.

Participating in this study will involve 2 steps - an initial interview (60-120 minutes) to discuss your experiences, and then a follow-up interview (30-60 minutes) to get your feedback on preliminary study results.
Interviews will be at a time and location convenient to you.
A small honorarium will be provided to thank you for your time.
Participation at all stages is completely voluntary and may be discontinued at anytime without any negative consequences. Confidentiality will be maintained as no real names or recognizable details will be used.

If you are interested in being interviewed, please call me,
Leslie Irvine at (204) 787-2110
Or email me at <u>lirvine@exchange.hsc.mb.ca</u>

<u>Research Advisor</u>:   Dr. Brenda Bacon, Faculty of Social Work, University of
                    Manitoba
                    (204) 474-8454

Appendix B

Telephone Script (to be used in initial contact for screening of participants)

- Hello, my name is Leslie Irvine and I am the masters of social work student whose study recruitment poster you responded to.

- Is now a good time to discuss the study and your possible participation? It should take 10-15 minutes.

If no:

- Could we book a more convenient time for me to call back to discuss this with you?

- Do you still have my contact information? If not, can I leave it with you?

- Thank you for your interest in my study.

If yes:

- Great! First off, the title of my study is 'Lessons from the Other Side: Health Care Providers' Experiences Living with Serious Chronic Illness'. This is a master of social work thesis project, which I am undertaking to complete my masters' degree.

- The purpose of this study is to explore the lived experiences of nurses and social workers who are living with serious, chronic illness while working in a health care setting. For the purposes of this study, I define serious chronic illness as a physical illness that is not curable, may be life-threatening, and which alters your functioning over time.

- To ensure I am focussing on this group, I have outlined a few criteria for study recruitment. I'd like to ask you about these now to ensure you meet these criteria for participation. I'm wondering….

- Are you a nurse or social worker currently practicing in health care?
- Have you been living with a serious, chronic illness for at least a year?

If no to one or both:

- I'm sorry, but because of the small size of the study I need to be careful about following these criteria. I thank you so much for your interest, however, and wish you all the best.

If yes to both:

- Ok, that's great. Now I'd like to describe to you the basic process involved in study participation. I will check if you have any questions, but please feel free to ask questions as I go through the information.

- There are two steps to the study- an initial interview and a follow-up interview. If you agree to participate, we will a book a convenient time and place to meet for these in-person interviews.

- When we meet for the initial interview, I will give you a consent form to sign and a brief form to fill out asking demographic information, such as gender, age, and educational background.

This interview will take approximately 60-120 minutes, depending on how much is discussed. I will be asking you questions about what life with your illness has been like and about how you negotiated between your personal and professional lives while living with your illness.

- Once I have done all my initial interviews and analyzed the data, I will contact you to request a follow-up interview. If you agree to participate, you will be asked to sign another consent form. This interview will involve reviewing the preliminary results with you and getting your feedback. This should take 30-60 minutes, depending on how much is discussed.

- Both interviews will be audio taped, and the recordings will be transcribed after the interviews to allow for data analysis.

In each interview, you will be asked to share your thoughts, opinions and experience at your own comfort level. You may ask for clarification of questions at anytime. You are free to not answer any of my questions; you are also free to stop the interview at anytime.

- It's also important to know that your confidentiality will be protected at all times. Only the researcher and the ethics review board will have access to your consent forms. Your consent forms and interview transcripts will be kept in a locked drawer in the researcher's (my) office. All real names and recognizable details will be removed from all (verbal and written) reports of results.

Documents containing personal identifiers will be destroyed and put to confidential waste once the thesis is completed and submitted, estimated to be May 2011.

If you wish a summary of the study results, a copy will be sent to you (via email) within one month of the study's completion, estimated to be June 2011.

- There is minimal risk to your participating in the interviews, however, it is possible that unpleasant feelings or memories may arise while recalling your experience. Again, you may stop participation at any time. I will be available to assist in connecting you to available sources of support, such as the Psychological Service Centre at the University of Manitoba, community resources that offer counseling such as Klinic, or through your employee assistance plan, if applicable.

- Finally, I will offer an honorarium of $20 for each interview to thank you for your time.

- So, I've given you the basic outline- do you have any questions or concerns about anything?

\- Would you like to consider participating in the research?

<u>If no</u>:
No problem. I thank you for your interest in this research and for taking the time to allow me to share the information with you.
<u>If not sure</u>:
Would you like to take time to think about it and then let me know your decision?

<u>If yes</u>:
Thank you, I appreciate your interest and willingness to participate. Could we discuss booking a time and place for the initial interview?

\- I would like to make sure you have my contact information, just in case you have any questions, concerns, or change your mind about participating. My contact number is 787-2110, which also has confidential voice mail. I can also provide you with my email address, if you'd like. It is lirvine@exchange.hsc.mb.ca. Thank you again for your interest and I look forward to speaking with you.

Appendix C

UNIVERSITY
of MANITOBA

**RESEARCH PARTICIPANT INFORMATION
AND CONSENT (Initial Interview)**

Research Project Title: Lessons From the Other Side: Health Care Providers'
                  Experiences Living with Serious Chronic Illness

Researcher: Leslie Irvine, BA (Hons. Psych), BSW, RSW
        University of Manitoba, Faculty of Social Work
        Phone: (204) 787-2110
        Email: lirvine@exchange.hsc.mb.ca

Advisor: Dr. Brenda Bacon, MSW, PhD
        Faculty of Social Work
        University of Manitoba
        (204) 474-8454

This consent form, a copy of which will be left with you for your records and reference, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

Purpose: This study will explore the experiences of practicing nurses and social workers who are living with serious chronic illness. The purpose of this study is to help articulate the unique concerns of this group, including the factors that will assist them to cope and maintain effective professional practice. Only nurses and social workers who have lived this unique experience can give this information.

The researcher, Leslie Irvine, is a graduate student in the Faculty of Social Work and is conducting this study as thesis research in partial fulfillment of the degree requirements of Masters of Social Work.

Procedure: You will be asked to sign a consent form. You will then participate in a one-on-one follow-up interview with the researcher in a location of your choice, which will be tape recorded. The process will take approximately 30-60 minutes.
You will be given preliminary study results and asked to share your feedback at your own comfort level. You may ask questions at anytime. You are free to give as much or as little feedback as you'd like and you are also free to stop the interview at anytime without negative consequence.

Risk: There is minimal risk associated with participating in this study. By virtue of recollecting and revealing lived experience to the researcher, there is the possibility of participation leading to emotional upset or psychological distress. If you become tired or upset, you should take a break. **You are free to discontinue participation at any time and with no consequences.**

If you experience any negative emotional or psychological consequences related to your participation, the researcher will be available to assist you to secure counseling or other appropriate resources to address your concerns. The knowledge that you are contributing to the expansion of professional education and training in this area should offset any risk you might experience.

Data collection devices: Data (your responses) will be collected by the researcher through audiotape recording the interview, which will then be transcribed verbatim.

Confidentiality: Confidentiality will be protected as all identifying information (real names or recognizable details) will be removed from the final written report. It will not be possible for anyone (other than the researcher) to link your name with the response data. The researcher has taken the PHIA Orientation and pledge with respect to handling confidential personal health information.

Storage of consent form and data: ONLY the researcher and the ethics review board will have access to the consent form. Your consent form and interview response data will be stored in a locked file drawer in the researcher's office. All documents with personal identifiers will be destroyed and put to confidential waste at the completion of the thesis project (estimated date December 2011).

You may choose to receive a summary of the results of the study by providing an email address in the marked space below. If you provide an email address, I will send you a summary of the results within one month of the conclusion of the study (estimated date June 2011).

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the researcher, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time, and/or refrain from answering my questions you prefer to omit, without prejudice or consequence. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation.

Principal Investigator: Leslie Irvine (204) 787-2110
Faculty Advisor: Dr. Brenda Bacon (204) 474-8454

This research has been approved by the Psychology/Sociology Review Ethics Board (PSREB). If you have any concerns or complaints about this study you may contact any of the above-named persons or the Human Ethics Secretariat at 474-7122, or

email Margaret_bowman@umanitoba.ca. A copy of this consent form has been given to you to keep for your records and reference.

Participant's Signature   Date

Participant's Name (Please Print)

Researcher and/or Delegate's Signature   Date

If you would like to receive a report on this research study, please provide your email address in the space below.

EMAIL_____

THANK YOU FOR TAKING THE TIME TO PARTICIPATE IN THIS STUDY

Appendix D

Demographic Information Sheet

Gender: Male /Female

Age range: 20-29
          30-39
        40-49
        50-59
        >60

Professional education/designation:

How long have you practiced nursing/social work?

Current primary practice setting:

 How long have you practiced in your current setting?

Primary diagnosis & date of diagnosis:

How do your illness symptoms effect your functioning?

Appendix E

Semi-Structured Interview (60 – 120 minutes)

      1)   <u>Personal Life: Telling Your Story</u>

What has it been like to live with your illness?

      2)   <u>Professional Life: Talking about Your Practice</u>

What was it like to switch roles between health care provider and patient?

Do you think that your practice has been changed as a result of your illness experience?
Can you think of examples where your practice has been enhanced? Where your practice has been challenged?

How do you handle disclosure of your illness experience with clients?

3) <u>What may help: Views on Preparedness, Training & Support</u>

What is your view on the preparation your professional group or health care providers in general receive for real-life situations, like personal illness, in their training?

What recommendations would you make to help your professional group or health providers in this situation to continue effective practice?

    <u>Closure</u>
      1.   Are there any comments or thoughts you wish to share about this topic that we have not covered?
      2.   Do you have any questions or concerns you wish to share?
      3.   Thank you for your time.

Appendix F

Script re: Participant becoming upset during Initial Interview

1) Acknowledge situation

Participant communicates to researcher direct verbal that he/she is upset:

- Thank you for letting me know that you are feeling upset….

Or participant just appears visibly upset:

- You appear to be upset….

2) Stop the interview & re-group

- I'd like to recommend that we stop for a minute- and I just want to remind you that you are free to discontinue the interview at any time without consequence to you.
- Is there anything that would help or make you more comfortable right now? (ie. Tissues, washroom, some fresh air)

3) Provide counseling list

- As I mentioned in our phone call and in the study consent, it is possible for someone to become distressed when recalling difficult memories.
- I had explained that I could assist you to connect with sources of support to address these feelings, should they arise. I have prepared a list of some possible options for counseling support that I'd like to give to you.
- You'll see there are different options on the list, depending on what you feel you might need, and it also talks about additional ways to find a counsellor (i.e. your family doctor, EAP program, or professional organizations).

4) Wrap up & plan follow-up
- Do you have any questions or concerns you would like to discuss with me right now?
- If they decide to end the interview: Can I contact you in a few days time to check in?

Appendix G

Counseling or Therapy Resource List

Finding a counsellor:

- Ask your doctor for a referral to a qualified counsellor
- See the Yellow Pages under Counsellors
- Contact these professional organizations:

Psychological Association of Manitoba
487-0784
Manitoba Institute of Registered Social Workers
888-9477
College of Registered Psychiatric Nurses of Manitoba
888-4841

- Your employer may have an Employee Assistance Plan (EAP) that provides free confidential counseling – **786-8880**
  - Check if your private medical insurance plan covers professional counseling
  - **Or call one of the agencies listed below**

Low-cost or No-cost Professional Counseling:

Aulneau Renewal Centre
601 Aulneau Street – **987-7090**

Aurora Family Therapy Center
University of Winnipeg – **786-9251**

Centre Miriam Center
Health
Ile des Chenes, MB – **204-878-3736**

Elizabeth Hill Counseling Centre
Wm. Norrie Centre, 394 Selkirk Ave. – **956-6560**
7347

Elizabeth Hill Men's Resource Centre
301-321 McDermot Ave. – **956-6560**

EVOLVE (Klinic)
870 Portage Ave. – **784-4208**
(specializes in domestic abuse issues)

Fort Garry Women's Resource Centre
1150-A Waverley Street – **477-1123**

Hope Centre Health Care
240 Powers Street – **589-8393**

Jewish Child & Family Service
C200-123 Doncaster Street – **477-7430**

Klinic Community Health Centre
870 Portage Ave. – **784-4090**

Ma MaWi Wi Chi Itata Centre
94 McGregor Street – **925-0300**

Mount Carmel Clinic
886 Main Street – **582-2311**

Nor'West Co-op Community
103-61 Tyndall Ave. – **940-2020**

North End Women's Centre
394 Selkirk Ave. – **589-7347**

Pluri-Elles
570 Des Meurons Street – **233-1735**

Psychological Service Centre
University of Manitoba – **474-9222**

The Family Centre
4th Floor, Portage Place – **947-1401**

The Laurel Centre
104 Roslyn Road – **783-5460**

Women's Health Clinic
3rd Floor, 419 Graham – **947-1517**

Youville Centre
33 Marion Street – **233-0262**
6-845 Dakota Street – **255-4840**

Counseling Intake – **784-4059**
After Suicide Grief group – **784-4200**

Immigrant Women's Counseling Centre
200-323 Portage Ave. – **953-4100**

Peer Support Services:
Seneca House – **231-0217**
(Support house for people with mental health issues)
Seneca Help Line – **942-9276**
(available 7:00pm – 11:00pm daily)

Men's Resource Centre – Peer Support Services
301-321 McDermot Ave – **956-6562**
(Peer Mentor program for Men)

Drop-in Counseling:
Klinic Community Drop-in Counseling Service
784-4067
545 Broadway
845 Regent Ave. W. (Access Transcona)
(Call for Drop-in Hours)

Rainbow Resource Centre – **474-0212**
1-222 Osborne Street South
Drop-in: Mondays 4-7pm only

Men's Resource Centre – Drop-in Counseling
301-321 McDermot Ave. – **956-6562**
Drop-in: Mondays 1-4 pm, Thursdays 1-8 pm

Crisis Services:
Adolescent Mobile Crisis Unit – **949-4777**
Adult Mobile Crisis Unit – **946-9109**
Brandon Mobile Crisis Unit – **725-3108**
Eastman Mobile Crisis Unit – **326-9276**

Klinic Community Health Centre
24-Hour Crisis Line – **786-8686**
Sexual Assault – **786-8631**

Pregnancy Crisis Centre
650 Broadway **772-2828** (24-Hour)

Child and Family Services – **944-4200**
After Hours – **944-4050**

Addiction Services:
AFM – Men's Program – **944-6200**
AFM – River House (Women's Program) – **944-6229**
AFM – Christie House (Family Program – **944-6229**

Salvation Army – Anchorage Program
180 Henry – **946-9453**

Alcoholics Anonymous – **942-0126**
Dual Recovery Anonymous – **989-4194**
Narcotics Anonymous – **981-1730**
Al-Anon (Families) – **943-6051**

Behavioural Health Foundation
St. Norbert, MB – **269-3430**

Native Addiction Council
Pritchard House – **586-8396**

Main Street Project
Detox – **982-8251**
Mainstay – **982-8260**

Appendix H

Telephone Script (follow-up interview)

Hello _____, this is Leslie Irvine calling.
I am the masters of social work student whose thesis study you participated in awhile
ago. You completing an interview with me.
I was wondering if now a good time to discuss your interest in participating in a follow-
up interview? This should take about 10 minutes.

    <u>If no</u>:
           - Could we book a more convenient time for me to call back to discuss this
      with you?
           - Do you still have my contact information? If not, can I leave it with you?
           - Thank you for your interest in my study.

    <u>If yes</u>:

    - Great! So just as a reminder, the title of my study is 'Lessons from the Other Side:
Health Care Providers' Experiences Living with Serious Chronic Illness'. This is a
master of social work thesis project, which I am undertaking to complete my masters'
degree.

    - The purpose of this study is to explore the experiences of nurses and social
workers who are living with serious, chronic illness while working in a health care
setting.

    - I have completed the initial phase of my research in which I conducted individual
interviews, analyzed the interview data and have compiled preliminary study results.
    In this next phase I am contacting each participant and asking do a follow-up
interview with me, in which I will share these preliminary results and get their feedback.
I consider this an important step in strengthening the results by making sure I'm on the
right track with interpreting the data I've collected.

    - Now I'd like to describe to you what this follow-up interview will involve. I will
check if you have any questions, but please feel free to ask questions as I go through the
information.

    -If you agree to participate, we will a book a convenient time and place to meet for
an in-person interview. This will take approximately 30-60 minutes, depending on how
much is discussed.

    -When we meet, I will give you another consent form to sign. I will then share with
you the preliminary summary results from the interviews I've done. This is an analysis of
all the interviews combined. As we go through the data, I will invite you to share your
feedback at your own comfort level. You may ask questions at anytime. You are free to

give as much or as little feedback as you'd like and you are also free to stop the interview at anytime without negative consequence. The interview will be audio taped, and the recording will be transcribed after the interview to allow for data analysis.

-Your confidentiality will continue to be protected. All personal identifiers will be removed from the data, so it will be impossible for anyone but the researcher to recognize your information. Only the researcher and the research ethics board will have access to your consent form. Your consent form and follow-up interview transcript will be kept in a locked drawer in my office. All real names and recognizable details will be removed from my written report.

-Documents containing personal identifiers will be destroyed and put to confidential waste once the thesis is completed and submitted, estimated to be May 2011.

If you wish a summary of the study results, a copy will be sent to you (via email) within one month of the study's completion, estimated to be June 2011.

- There is minimal risk to you in participating in the follow-up interview, however, it is possible that unpleasant feelings or memories may arise while recalling your experience. Again, you may stop participation at any time. I will be available to assist in connecting you to available sources of support, such as the Psychological Service Centre at the University of Manitoba, community resources that offer counseling such as Klinic, or through your employee assistance plan, if applicable.

- Finally, I will offer an honorarium of $20 to thank you for your time.

-So, I've given you the basic outline- do you have any questions or concerns about anything?

Would you like to consider participating in the research?

If no:
-No problem. I thank you for your interest in this research and for taking the time to allow me to share the information with you. If you should change your mind, please feel free to contact me to discuss booking your follow-up interview.

If not sure:
-Would you like to take time to think about it and then let me know your decision?

If yes:
-Thank you, I appreciate your interest and willingness to participate. Could we discuss booking a time and place for the interview?

-I would like to make sure you have my contact information, just in case you have any questions, concerns, or change your mind about participating. My contact number is 787-2110, which also has confidential voice mail. I can also provide you with my email address, if you'd like. It is lirvine@exchange.hsc.mb.ca. Thank you again for your interest and I look forward to speaking with you.

Appendix I

UNIVERSITY
OF MANITOBA

**RESEARCH PARTICIPANT INFORMATION
AND CONSENT (Follow-up Interview)**

Research Project Title: Lessons From the Other Side: Health Care Providers'
Experiences Living with Serious Chronic Illness

Researcher: Leslie Irvine, BA (Hons. Psych), BSW, RSW
University of Manitoba, Faculty of Social Work
Phone: (204) 787-2110
Email: lirvine@exchange.hsc.mb.ca

Advisor: Dr. Brenda Bacon, MSW, PhD
Faculty of Social Work
University of Manitoba
(204) 474-8454

This consent form, a copy of which will be left with you for your records and reference, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

Purpose: This study will explore the experiences of practicing nurses and social workers who are living with serious chronic illness. The purpose of this study is to help articulate the unique concerns of this group, including the factors that will assist them to cope and maintain effective professional practice. Only nurses and social workers who have lived this unique experience can give this information.

The researcher, Leslie Irvine, is a graduate student in the Faculty of Social Work and is conducting this study as thesis research in partial fulfillment of the degree requirements of Masters of Social Work.

Procedure: You will be asked to sign a consent form. You will then participate in a one-on-one follow-up interview with the researcher in a location of your choice, which will be tape recorded. The process will take approximately 30-60 minutes.
You will be given preliminary study results and asked to share your feedback at your own comfort level. You may ask questions at anytime. You are free to give as much or as little feedback as you'd like and you are also free to stop the interview at anytime without negative consequence.

Risk: There is minimal risk associated with participating in this study. By virtue of recollecting and revealing lived experience to the researcher, there is the possibility of participation leading to emotional upset or psychological distress. If you become tired or upset, you should take a break. **You are free to discontinue participation at any time and with no consequences.**

If you experience any negative emotional or psychological consequences related to your participation, the researcher will be available to assist you to secure counseling or other appropriate resources to address your concerns. The knowledge that you are contributing to the expansion of professional education and training in this area should offset any risk you might experience.

Data collection devices: Data (your responses) will be collected by the researcher through audiotape recording the interview, which will then be transcribed verbatim.

Confidentiality: Confidentiality will be protected as all identifying information (real names or recognizable details) will be removed from the final written report. It will not be possible for anyone (other than the researcher) to link your name with the response data. The researcher has taken the PHIA Orientation and pledge with respect to handling confidential personal health information.

Storage of consent form and data: ONLY the researcher and the ethics review board will have access to the consent form. Your consent form and interview response data will be stored in a locked file drawer in the researcher's office. All documents with personal identifiers will be destroyed and put to confidential waste at the completion of the thesis project (estimated date May 2011).

You may choose to receive a summary of the results of the study by providing an email address in the marked space below. If you provide an email address, I will send you a summary of the results within one month of the conclusion of the study (estimated date June 2011).

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the researcher, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time, and/or refrain from answering my questions you prefer to omit, without prejudice or consequence. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation.

Principal Investigator: Leslie Irvine (204) 787-2110
Faculty Advisor: Dr. Brenda Bacon (204) 474-8454

This research has been approved by the Psychology/Sociology Review Ethics Board (PSREB). If you have any concerns or complaints about this study you may contact any of the above-named persons or the Human Ethics Secretariat at 474-7122, or

email Margaret_bowman@umanitoba.ca. A copy of this consent form has been given to you to keep for your records and reference.

_____

Participant's Signature   Date

_____

Participant's Name (Please Print)

_____

Researcher and/or Delegate's Signature   Date

If you would like to receive a report on this research study, please provide your email address in the space below.

EMAIL_____

THANK YOU FOR TAKING THE TIME TO PARTICIPATE IN THIS STUDY

Appendix J

Script Follow-up Interview (30 - 60 minutes)

The purpose of us meeting today is for me to present to you my analysis and interpretation of the data I collected through the study interviews.

As much as you are comfortable, I am hoping you will share with me your impressions of this information and any questions or concerns you may have.

Your feedback is an important part of the research process and will help my learning about this topic.

1. What are your impressions of the data I have presented?
2. Is there anything that stands out to you, concerns you, or that you feel may have been 'missed'?

Appendix K

Script re: Participant becoming upset during Follow-up Interview

1) Acknowledge situation

Participant communicates to researcher direct verbal that he/she is upset:

- Thank you for letting me know that you are feeling upset….

 Or participant just appears visibly upset:

- You appear to be upset….

2) Stop the interview & re-group

- I'd like to recommend that we stop for a minute- and I just want to remind you that you are free to discontinue the interview at any time without consequence to you.
- Is there anything that would help or make you more comfortable right now? (ie. Tissues, washroom, some fresh air)

3) Provide counseling list

- As I mentioned in our phone call and in the study consent, it is possible for someone to become distressed when recalling difficult memories.
- I had explained that I could assist you to connect with sources of support to address these feelings, should they arise. I have prepared a list of some possible options for counseling support that I'd like to give to you.
- You'll see there are different options on the list, depending on what you feel you might need, and it also talks about additional ways to find a counsellor (i.e. your family doctor, EAP program, or professional organizations).

4) Wrap up & plan follow-up
- Do you have any questions or concerns you would like to discuss with me right now?
- If they decide to end the interview: Can I contact you in a few days time to check in?

Appendix L

**INITIAL INTERVIEW PRELIMININARY FINDINGS
RESEARCH REPORT**

UNIVERSITY
OF MANITOBA

Research Project Title: Lessons From the Other Side: Health Care Providers'
            Experiences Living with Serious Chronic Illness

Researcher: Leslie Irvine, BA (Hons. Psych), BSW, RSW
            University of Manitoba, Faculty of Social Work
            Phone: (204) 787-2110
            Email: lirvine@exchange.hsc.mb.ca

Advisor: Dr. Brenda Bacon, MSW, PhD
            Faculty of Social Work
            University of Manitoba
            (204) 474-8454

    The purpose of this report is to inform you of the principal investigator's
preliminary analysis and interpretation of the data collected from the first set of six
research interviews, and to receive your feedback about these results.

    These findings represent the compilation of all six interviews combined; all
identifiers have been removed to protect participant confidentiality.

    Your feedback is an important part of the research process and will help the
investigator's learning about this topic.

    When you meet with the investigator for a follow-up interview you will be asked to
share, as much as you are comfortable, your impressions of this information and any
questions or concerns you may have. Specifically, you will be asked:

        3.   What are your impressions of the data presented here?
        4.   Is there anything that stands out to you, concerns you, or that you
    feel may have been 'missed'?

    Please remember that you are free to give as much or as little feedback as you'd
like; you may ask for clarification of questions, and may stop the interview at anytime
without negative consequences.

    Should you have any questions or concerns about the findings that you would like
to address immediately, please feel free to contact either the principal investigator (Leslie
Irvine), or her faculty research advisor (Dr. Bacon), at the contact numbers listed above.

PRELIMINARY INTERVIEW DATA

Section 1: Personal Life: Telling Your Story

Q #1: **What has it been like to live with your illness?**

'Personal Feelings'

Common Themes
- Wondering about survival
- Difficulties with memory and concentration

Unique Themes
- Experienced depression; awareness depression is 'taboo' topic
- Shock over diagnosis
- Fear of the unknown/dealing with uncertainty
- Feeling anger
- Feeling vulnerable
- Feeling judged
- Lack of supports
- High Achiever/'Push myself hard'
- Feel like a disappointment
- Grief process
- Question link between job stress and illness etiology
- Difficulty balancing family obligations with life demands
- Frustration with health care system structure
- Intuition about illness ('I just knew')
- Worry about work continuation
- Observed other health care providers are uncomfortable discussing emotions, difficult life situations
- Socialize less now than before

'Finding Meaning'

Common Theme
- Illness happened for a reason

Unique Themes
- Need to think positively
- Result in changed perspective on dealing with life
- Blurred line between patient and health care provider, see 'both sides'

'Coping - What Helped'

Unique Themes
- Faith/spirituality
- Seeing a counselor
- Family support
- A supportive manager/boss
- Friendships
- Recognizing your own value
- Looking at what issues and relationships are important to you
- Having friends with the same illness
- Being kinder to yourself
- Supportive colleagues
- Hiring/firing health care providers, as needed
- Accessing up-to-date info on your illness
- Making 'connections' within the health care field
- Freedom to plan out your day; flex-time
- Planned, regular time off to 'recharge'
- Leaving work at work; leaving home at home
- Work as a distraction from your illness

'Interactions with Health Care Providers'

Unique Themes
- Self-identified as health care provider in interactions
- Providers assume you understand medical jargon
- Awareness other patients are waiting behind you
- Possess insider knowledge of system (mistakes made, team dynamics, skills, etc)
- Use insider 'connections' in own care
- Others' assumptions there is a 'special line' for providers you can access to 'get in' faster
- Expect best possible care
- Experienced conflict with health care provider
- Worried provider will write negative things in chart
- Acknowledged hierarchy in health care system
- Personal expertise of own illness not acknowledged by care providers
- Knowing some get preferred care because they are a system insider
- Receiving poor supports from providers
- Having your time wasted
- Difficulty building trust
- Concern about competency of providers

- Receiving helpful 'reality check' from providers about own thinking
- As a staff member, shocked to have to wait for procedures
- Provider using interactions to discuss their own issues, instead of yours
- Feeling overwhelmed by interactions; too much information, insensitivity
- Educating providers about your illness

'Impact of Illness on Work Life'

Common Theme
- Time off work for treatment

Unique Themes
- Experience fatigue
- Lack of sick time
- Illness always in the back of your mind
- Emotional/coping issues
- Difficulties with pain management
- Loss of limb strength
- Mobility problems
- Need for better return-to-work planning
- Lack of accessible parking
- Management/human resources reprimands for sick time usage
- Inability to attend work social engagements
- Not allowed to work from home
- Compelled to fight harder for client's rights
- Teaching others about the illness

'Loss Experiences'

Unique Themes
- Loss of privacy
- Loss of control
- Loss of functional abilities
- Loss of faith in the health care system
- Multiple diagnoses
- Significant loss (miscarriage, death of spouse, suicide in family, etc)
- Fear loss of work role prior to retirement
- Fear of future illness, physical deterioration
- Fear of child being orphaned
- Fear loss of access to competent, specialized health care

'Other Experiences'

Unique Themes
- Delay in diagnosis
- Delay in procedure
- Loss of activities and interests
- Change in work position
- Received treatment in workplace in seeking care
- Volunteering
- Self-advocacy
- Work stress
- Struggle with self-care at work
- Physical toll of job
- High workload demands
- Extreme costs for medications related to illness management
- Pressure of managing illness symptoms effectively

Q #2: What was it like to switch roles between health care provider and patient?

Unique Themes
- Giving up control becoming a patient
- Need accommodation to continue to work
- Researched condition to feel in control
- Heightened awareness of need for self-advocacy
- Professional role helped with understanding what to expect as patient
- Trusted health care providers to lead care
- Did not trust health care providers- i.e. double checked all results
- Intimidated by interactions with providers
- Have to leave own problems at home to be able to work
- Professional role helped to know about supports available
- Acknowledged belief that health care providers are immune to illness, should cope better than average person
- Expect best care possible
- Need better self-care at work (i.e. staff wellness programs)

Section 2: Professional Life: Talking about Your Practice

Q #3: Do you think that your practice has been changed as a result of your illness? Can you think of examples where your practice has been enhanced? Where your practice has been challenged?

Common Theme
- Practice has been changed by illness experience

Unique Themes

Enhanced practice:
- Better self-advocacy in terms of practice boundaries
- Better understanding, relate to clients' situation
- More empathy
- Holistic perspective of health care
- Blurring of 'us' and 'them' dichotomy
- Altered expectations of others

Challenged practice:
- Trouble balancing patient and health care provider roles
- Risking disclosure to colleagues
- Time off work for illness management
- Feeling isolated
- Social gatherings required as part of job
- Physical demands of job
- Workload demand of job

Q #4: How do you handle disclosure of your illness experience with clients?

Common Theme
- Will disclose illness if comfortable with the person and context, case by case

Unique Themes
- Will not always tell full extent of illness, rather are selective
- Sometimes illness remains 'hidden' from others- this can be both beneficial and problematic
- Sometimes learn people have disclosed for you without permission
- Fear others will question competence after learning of your personal illness
- Disclosure to clients is case by case; especially if believe it will help client
- No disclosure to clients
- Use disclosure as opportunity to advocate or teach others about the illness

Section 3: What may help: Views on Preparedness, Training and Support

Q #5: What is your view on the preparation health care providers receive for real life situations, like personal illness, in their training?

Common Theme
- No experience in training on topic

Unique Themes
- Need more supports in the workplace
- No preparation in professional life to adequately prepare
- Topic should be covered in curriculum

Q #6: What recommendations would you make to help health care providers in this situation to continue effective practice?

Unique Themes
- Be open and discuss the situation
- It can be difficult to discuss personal illness in the workplace
- Find good supports at work
- Managers need to be more supportive & open to needs
- Reduce mental health stigma (i.e. depression)
- Work on your personal issues
- Read material on chronic illness to educate self
- Need more research into the topic
- Support needed for workers returning from sick leave
- Need more workplace accommodations to assist workers living with illness

Appendix M

Coding Sheets of Participant Data

SUB-THEME	PARTICIPANT 1 (BETH)
Shock of Diagnosis	
Vulnerability	(different types of control) **22:626-685**; (hidden illness) **44:1286-1312**
Fear of Future Illness	(illness & future docs) **19:539-556**
Confronting Mortality	(reflecting on preparation) **17:477-509**
Priorities	(what's important) **15:407-458**
Managing Stress & Emotions	(reflecting) **35:1007-1044;** (grieving) 42:1241-1272;
Knowledge as double-edged sword	(comments on system) **9:222-285;** (residency training) **31:910-996;** (angry with navigating system) **41:1190-1198**
Hierarchy in the System	(hire & fire HCPs) **21:585-610;** (docs talking about self) **25:705-726,** (better care) **27:772-785**; (understood medical terms) 26:746-755; (pt/provider line) 29:835-843, 30:854-871, 31:886-894
Better Understanding of Clients	**12:310-318**
Using Supports	(seeing dietician colleague) 38:1096-1110; (friends with same condition) 40:1178-1189
Managing Workload	(finding a fit) 2:38-65; (insulin on the job) 8:198-220
Developing Strategies	(learning your rights) 4:99-144; (work in progress); 46:1338-1344
Selective Disclosure	
Teaching about Experience	(teaching residents) **36:1054-1095** Recommendations: (curriculum) 47:1374; (research & discussion) 48:1419

SUB-THEME	PARTICIPANT 2 (SUE)
Shock of Diagnosis	(reaction to dx) **2:62-80**
Vulnerability	(are you ok?) 67:1677-1685;
Fear of Future Illness	

Confronting Mortality	(present in life) **1:3-16**
Priorities	
Managing Stress & Emotions	(emotional with family) **11:218-235,** (praying) **244-259;** 37:780-792
Knowledge as double-edged sword	(connection as a nurse) **9:143-204;** (asking for blood work) 47:1072-1078, 1088-1097; (physician hierarchy) **48:1104-1152;** (cancellation) 57:1379-1395; (wearing ID) 58:1398-1419; (ID message to staff) 59:1436-1458; (special line) 60:1469-1513; (don't want to talk about it) **76:1926-2012**
Hierarchy in the System	(doctor friend connection) **54:1291-1341**
Better Understanding of Clients	(giving bad news) **32:632-655**
Using Supports	(support from colleagues) 3:89-92, 102-128; (husband, friends) 13:65-85; (expectation on coping) **14:97-117**
Managing Workload	(need to step down?) 71:1797-1827
Developing Strategies	
Selective Disclosure	(being recognized by staff) 6:73-117; (help others) 74:1877-1912
Teaching about Experience	Recommendations: (recognize need help) 79:2025; (discussion) 80:2046; (ask for help) 80:2064; (training programs) 81:2092
SUB-THEME	**PARTICIPANT 3 (RITA)**
Shock of Diagnosis	(I knew) 2:33-52; (don't ever think) 32:1248-49
Vulnerability	(a bit at a time) 2:65-69; (getting LTD) 5:178-199; (medications) 12:456-479; (control freak) **35:1349-1362;** (giving up control) 44:1651-1668
Fear of Future Illness	(one in nine) 6:208-212
Confronting Mortality	(smell the coffee) **94:3572-3580**
Priorities	(it's a trade off) 6:238-254; (life changes) 59:2215-2220
Managing Stress & Emotions	(someone else's life) 31:1179-1209; (everything I can to help) 33:1259-1293
Knowledge as double-edged sword	(double check results) 37:1416-1453; (carry my chart with me) **38:1464-1480;** (critical incidents) 39:1491-1504; (triggers) **73:2712-2718;** (how many times?) 92:3486-3507

Hierarchy in the System	(pushed for diagnosis) 9:337-355; (my med list) 12:480-486; (try and zing me) 13:516-523; (write it in your chart) 14:532-552; (I have connections) 14:553-598; (acknowledge expertise) 34:1311-1334
Better Understanding of Clients	(fighting to stay) 32:1223-1237
Using Supports	
Managing Workload	(parking spot) 3:121-140; (demeaning and demoralizing) 4:142-165; (want to work) 11:411-417; (HR file) 19:740-750; (no guilt)19:762-767; (managers forget) 20:793-820; (remove barriers) 24:936-944; (distraction) 27:1070-1075; (mentally sharp) 28:1086-1096; (push myself) 28:1102-1106; (triple A) 29:1117-1129; (people give up) **49:1877-1886;** (accommodation) 50:1880-1887; (mentality) **57:2136-2156**
Developing Strategies	(flex time) 17: 651-661; (work from home) 22:880-889; (pain control) 26:1020-1035; (smaller jobs) 29:1147-1160; (you've got a choice) **70:2623-2653;** 81:3098-3107
Selective Disclosure	(the full extent) 60:2255-2264; (consumed my life) 75:2798-2824
Teaching about Experience	(bigger reason) **93:3547-3571** Recommendations: 82:3129-3131; 83:3153-3177

SUB-THEME	PARTICIPANT 4 (GAIL)
Shock of Diagnosis	(rocked my world) 3:59-73
Vulnerability	(researched everything) 5:121-125
Fear of Future Illness	(back of your mind) 11:318-322
Confronting Mortality	(fear) 1:2-3
Priorities	
Managing Stress & Emotions	(got me through) 3:75-83; (anti-depressants) 12:333-342
Knowledge as double-edged sword	(I just knew) 10:263-272
Hierarchy in the System	(a little intimidating) 5:126-153; (pissed off) 9:246-261
Better Understanding of Clients	(outlook is different) **15:418-420,** (elderly clients) **433-454**

Using Supports	
Managing Workload	(distraction) 12:346-351; (taboo) **21:599-607**; **22:630-649;** (manager support) **23:676-713**
Developing Strategies	
Selective Disclosure	(hope) 17:470-482
Teaching about Experience	(try to be proactive) 18:499-517 Recommendations: (be open) 26:743-749, 756-764, (managers understanding) 802-807; (work on your stuff) 862-866

SUB-THEME	PARTICIPANT 5 (HOLLY)
Shock of Diagnosis	(I wasn't that type) 3:61-82
Vulnerability	(everyday) 1:3-21; **2:28-48;** (do my job) 10:323-338; (felt so invasive) **11:358-430;** (can't make plans) **13:456-475;** (depending on others) **14:491-505;** (that blue hospital gown) **49:1762-1778**
Fear of Future Illness	
Confronting Mortality	
Priorities	
Managing Stress & Emotions	(hope it sticks) 30:1087-1097; 32:1127-1139; (have a choice) **47:1687-1706;** (resentment) **50:1803-1807;** (strike a cord) **55:1972-2055;** (get work off the shoes) **59:2117-2156**
Knowledge as double-edged sword	
Hierarchy in the System	
Better Understanding of Clients	(appreciate my days as a patient) **3:83-93;** (we are all struggling) 18:654-674; (group) 22:766-97; (group dynamics) 26:908-964; (respect thing) **38:1329-1354**
Using Supports	(we meet up and talk) 41:1452-1463; (she was gone too) 56:2027-2055
Managing Workload	(I'm just a convenience factor) 43:1540-1619; (not sure if I could do it) 66:2448-2489

Developing Strategies	(write stuff down) 7:230-232; (brain super taxed) 8:254-270
Selective Disclosure	(we're both human) 17:596-644; (left them in the lurch) 69: 2553-2588
Teaching about Experience	Recommendations: (human behind the condition) 75:2794-2795; (tie in experience) 75:2797-2798
SUB-THEME	**PARTICIPANT 5 (HOLLY)**
Shock of Diagnosis	(I wasn't that type) 3:61-82
Vulnerability	(everyday) 1:3-21; **2:28-48;** (do my job) 10:323-338; (felt so invasive) **11:358-430;** (can't make plans) **13:456-475;** (depending on others) **14:491-505;** (that blue hospital gown) **49:1762-1778**
Fear of Future Illness	
Confronting Mortality	
Priorities	
Managing Stress & Emotions	(hope it sticks) 30:1087-1097; 32:1127-1139; (have a choice) **47:1687-1706;** (resentment) **50:1803-1807;** (strike a cord) **55:1972-2055;** (get work off the shoes) **59:2117-2156**
Knowledge as double-edged sword	
Hierarchy in the System	
Better Understanding of Clients	(appreciate my days as a patient) **3:83-93;** (we are all struggling) 18:654-674; (group) 22:766-97; (group dynamics) 26:908-964; (respect thing) **38:1329-1354**
Using Supports	(we meet up and talk) 41:1452-1463; (she was gone too) 56:2027-2055
Managing Workload	(I'm just a convenience factor) 43:1540-1619; (not sure if I could do it) 66:2448-2489
Developing Strategies	(write stuff down) 7:230-232; (brain super taxed) 8:254-270
Selective Disclosure	(we're both human) 17:596-644; (left them in the lurch) 69: 2553-2588
Teaching about Experience	Recommendations: (human behind the condition) 75:2794-2795; (tie in experience) 75:2797-2798

SUB-THEME	PARTICIPANT 6 (WENDY)
Shock of Diagnosis	(finger, dx. Story) **1:4-29, 38-101**
Vulnerability	(electricity in legs) 5:122-140; (shoes) 7:176-184; (bad comments) 13:358-371
Fear of Future Illness	
Confronting Mortality	(deteriorating) 10:265-299; (life jackets) **38:1079-1091**
Priorities	
Managing Stress & Emotions	(lonely spot) 6:142-160; (worst of the worst) **72:2046-2066**; (she wrote thanks) **75:2135-2173;** (see it with different eyes) **88:2410-2420**
Knowledge as double-edged sword	(questionnaires) **45:1273-1286**
Hierarchy in the System	(parking) **24:688-713; 26:729-760**; (MS clinic) 29:809-885; (blood work, boss chair) **32:897-958**;
Better Understanding of Clients	(reflection) 59:1695-1711; **88:2410-2419**
Using Supports	(get through) 12:327-335; (liberation) 39:1113-1128**; 85:2343-2371**
Managing Workload	(weds off) **14:397-430**; (desk job) 18:510-544; (job so long) 22:606-626
Developing Strategies	(making piles) 7:194-209
Selective Disclosure	(not wanting pts to know) 4:105-120; (pulling MS info) 45:1287-1305; (at least it's not MS) **60:1715-1741**; (effect on clients) 66:1882-1921
Teaching about Experience	Recommendations: (mentoring) 82:2249-2253; (whipped up) 82:2257-2259; (alliances) 83:2265-2269; (pick your battles) 86:2344-2370