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Quality of Life Despite Back Pain: A Phenomenological Study

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QUALITY OF LIFE DESPITE BACK PAIN: A PHENOMENOLOGICAL STUDY

by

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QUALITY OF LIFE DESPITE BACK PAIN: A PHENOMENOLOGICAL STUDY

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The investigator in this phenomenological study examined the lived experience of Quality of Life (QOL) in 15 Registered Nurses (RNs) with chronic back pain (CBP) participating in structured journal writing. Hermeneutic analysis of interviews and journals revealed eight themes under two domains: *Making Normal (Fighting and Denying; Being Consumed: Anger and Frustration; Surviving the Three Ds: depression, devastation, and despair;* and *Choosing, Adapting, and Accepting)* and *Living with the Shadow (Losses and Limitations, Being Less than Whole, Having Intimate Knowledge,* and *Living Through Fatigue).* The essence of the experience is *Dancing with the Shadow: Re-Visioning Quality of Life*. The Shadow is the constant presence of CBP in the participants' lives. The essence involves a delicate dance of control; nurses' QOL improved when they had control over the CBP.

Dedication

First and foremost, I dedicate this work to my family, particularly my late mother, who wanted to see me obtain my Ph.D. more than anything else. During the last years of her life, she told me repeatedly that she wished to live long enough to see that dream come true. The rest of my family sacrificed in numerous ways over the years to ensure my success and without them, I doubt I would be writing this. To them I can only say thank you and I love you, knowing that is not nearly what they deserve.

Secondly, but no less importantly, I would like to dedicate this work to the millions of individuals who suffer from back pain, nurses in particular. Their complaints are minimized and their lives are marginalized. If this work in any way sheds light on their condition or helps one person understand their situation, it will have been well worth it.

Acknowledgements

There are so many people to acknowledge and thank for helping me during this endeavor that I fear omitting more than I remember.

First, incalculable thanks must go to the nurses who participated in this study. They opened their lives to me, shared intimate details of their problems and of their condition with me, and were unfailingly hospitable and gracious. Without their willingness to participate with me in this study, I would have failed.

I must once again give thanks to my family who put up with more craziness from me than anyone should have to endure! I would also like to thank Dr. Marilyn Grady, my advisor, for her help and encouragement throughout my time at UNL. I would also like to thank Dr. Fran Henton for her love, encouragement, and proof-reading talents. And I must thank Dr. Ginny Curley who also provided proof reading and critiquing, and who offered her friendship several times recently personal circumstances. I also need to thank my co-workers at Nebraska Methodist College who remained supportive over the years, especially my supervisors, the Department Chair Dr. Lin Hughes and the Associate Dean, Dr. Marilyn Valerio. I also acknowledge the Nebraska Methodist Health System for their crucial financial support.

TABLE OF CONTENTS

List of Figures and Tables

Figures

Tables

Vignette

Giselle was humiliated and felt degraded as she drug herself onto the airplane for an eight-hour flight, her slacks soaked in urine—a sure sign that her back pain had progressed to the status of a neurosurgical emergency. Miserable with pain, legs numb, embarrassingly conscious of her odor, she endured the flight only to be escorted off the plane by security because the airline attendants thought she was drunk. "One drink, maybe two, and I could have been more comfortable and maybe slept", she says, but the airline attendants wouldn't serve her alcohol.

Security escorted her to the aid station. When she described her back pain the nurse dismissed her as a drug seeker. Giselle called a cab, left her luggage at the airport, and went to the closest emergency department (ED): an inner city trauma center in a tough neighborhood. The ED was crowded and there was no place to sit or lie down, so Giselle was forced to stand, waiting her turn, for nearly two hours. Her knees buckled twice, sending her to the floor. When it was her turn to be seen, that's where the nurse found her. "Get up" the nurse snapped. "I can't…" to which the nurse replied "Unless someone drug you in here by your toes, you can walk, so get up and come with me if you want to see the doctor."

In the treatment area, Giselle had no assistance undressing or getting on the stretcher. A bored young resident took her chief complaint and said, "We don't give narcotics for back pain." When he ordered a shot of an anti-inflammatory medication and sent the nurse to discharge her, Giselle asked about an X-ray or MRI. "There's nothing wrong with you" she was told. Giselle, an experienced intensive care nurse,

knew better, but when she pleaded for further testing, the nurse told her to leave or the nurse would call security.

Having missed her flight home, Giselle spent several hours in the airport, awaiting another flight. She had to be physically assisted onto the plane. She no longer cared about how she looked or smelled. Arriving home, she took a cab to the hospital where she worked. She was sent directly to the operating room from the ED and had an emergency operation that lasted seven hours. She had sores from sitting in urine that became infected. She spent three weeks in the hospital and was told her spine was the worst the seasoned neurosurgeon had ever seen.

Today Giselle lives with constant pain, numb and weak legs, chronic skin sores, and the traumatic recollection of her experience. Living with back pain she says has irreversibly changed her life: "*I'm not the same person I used to be for a number of reasons and, and I will never be that person again…I am a shadow of my former self."*

CHAPTER ONE

INTRODUCTION

Giselle is like millions of people who experience an episode of severe back pain during their lifetimes that end up as a chronic condition ultimately affecting their quality of life. I became interested in this topic because I myself suffer from chronic back pain and saw many of my fellow colleagues in nursing leave jobs they loved because they, like so many other nurses, acquired back pain and injury while working in that profession. The degree of unhappiness over this circumstance, coupled with limited successful treatment options and poor reception by other medical professionals left me sad and bewildered that the situation existed as it did. I decided long ago, before I began my doctoral program, that I wanted to investigate this phenomenon from the perspective of the nurses involved.

The purpose of this chapter is to provide background information about the study I ultimately completed on the quality of life in nurses who live with chronic back pain. A brief summary of the situation as it exists today regarding back pain and surrounding issues is presented first. The chapter goes on to present the research questions and a brief discussion of the methodology and methods I used in my study. The significance of the study is presented last with commentary on the social, professional, and personal implications of this research.

Context and Background

Chronic Back Pain

Back pain ranks as the second most common reason for physician visits and the third most common reason for surgery. As many as 90% of people in the industrial world

will have back pain at some time in their lives (Canale, 2003; Grabois, 2005; Weinstein, 2005). Back pain is usually a benign, self-limiting disorder resulting from strains and over-use, but can include more serious problems such as herniated vertebral discs (Canale; Johansson, & Lindberg, 2000; Mortimer & Ahlberg, 2003; Phillips, Ch'ien, Norwood, & Smith, 2003; Weinstein). Diagnostic measures range from simple, patient-reported data to expensive and sophisticated testing. Often the true cause is never known (Grabois; Waddell, 1987). Treatment usually includes conservative measures such as heat or ice, physical therapy, and mild analgesics. For severe back injury that involves structural problems, surgery is often the treatment of choice (Canale; Weinstein).

Despite many treatment options for back pain, it often becomes chronic. Over five million Americans are currently disabled due to chronic back pain (CBP); approximately 80% of people diagnosed with back pain remain symptomatic after one year (Cedraschi, et al, 1999; Grabois, 2005). The estimated annual national expense for back pain care is estimated to be as high as $100 billion, the majority of which is spent on chronic cases (Cairns, Foster, Wright, & Pennington, 2003; D'Arcy, 2006; Ekman, Jonhagen, Hunsche, & Jonsson, 2005; Hemmila, 2002; Kosinski, et al, 2005; Proctor, Gatchel, & Robinson, 2000). Specific challenges exist when caring for people with CBP; often there is no specific underlying condition amenable to treatment. Also, the patient's pain, physical impairment, and disability do not seem to "be linked in a direct, linear relationship" (Cedraschi, p. 358). This leads to health care providers' view that caring for people with CBP is frustrating and to patients being unhappy with their care and outcomes (D'Arcy; Cherkin, Deyo, & Sherman, 2003). As the back pain continues, it begins to affect all aspects of patients' lives: physical, emotional, and social. In other

words, it begins to affect their quality of life (Johannson & Lindberg, 2000; McGorry, Webster, Snook, & Hsaing, 2000; Phillips, et al., 2003).

Quality of Life

Quality of life (QOL) has been a mainstay of medical and nursing research for the last six decades (DePalma, 2001; Widar, Ahlstrom, & Ek, 2004). The World Health Organization (WHO) has officially defined this concept and has urged and funded research on it (WHO, 1998; WHO, 2001). Despite the prestige of the WHO, there is no agreed-upon definition of QOL by health care professionals and no consensus on how to measure it (Boschen, Tonack, & Gargaro, 2003; Willener & Hantikainen, 2005).

The evolution of the concept of QOL has both caused and suffered from deficiencies in the current research, which has grown ever more fragmented with the advent of "Health Related QOL" and through the development of disease-specific tools with which to measure it (Meeberg, 1993). Reading the literature, one gets the sense that QOL has nothing in common among people with various medical conditions, making the consideration of QOL in people with multiple medical conditions mind-boggling. Qualitative research has not shed much light on QOL either, these studies are often done to develop quantitative tools for later use (Boschen, et al, 2003; DePalma, 2001). Purely qualitative studies also tend to be directed towards more fragmented and obscure patient populations (Gilworth, et al, 2004). There are few studies that allow patients to describe their QOL in their own words and none in patients with CBP done solely to develop a deeper understanding of this phenomenon.

Patients with CBP often rate their QOL lower than people in the general population (Bentsen, Hanestad, Rustoen, & Wahl, 2008; Chen, 2005; Kosinski, et al,

2005). Because of the frustration with medical care that is less than satisfactory leading to diminished QOL, patients with CBP frequently turn to complementary and alternative medicine practices for relief.

Complementary and Alternative Medicine

Complementary and alternative medicine (CAM) practices are used by 80% of the world's population and have been successful in treating chronic pain. The underlying theory is that of mind-body-spirit connectedness. Illness and pain are often conceptualized as the result of disharmony among those three components; the majority of complementary and alternative practices seek to somehow restore that balance. There are over 1800 complementary and alternative therapies currently recognized, many of which have been useful in treating chronic pain (Lazarus & Neuman, 2001; Snyder & Wieland, 2003).

One CAM practice is journal writing (JW). Numerous studies validate JW as healing or health promoting for a vast array of populations and medical conditions (Austenfeld & Stanton, 2008; Burton & King, 2008; Davidson & Robison, 2008; Graham, Lobel, Glass, & Lokshima, 2008; Norman, 2000; Pennebaker & Beale, 1986; Pennebaker, & Seagal, 1999; Smyth, 1998; Smyth & Pennebaker, 2008). The usual directions include writing as little as twenty minutes, three days in a row. 'Emotional disclosure' is paramount to this practice; participants need to write while reflecting deeply on their emotions and thoughts (Norman, 2000; Pennebaker & Segal; Smyth, 1998; Snyder & Wieland, 2003). Once again however, the bulk of journaling studies are quantitative and measure physical or psychological functioning as "proof" of improved QOL. A review of the literature found only one qualitative study on QOL in women with

chronic pelvic pain who journaled (Norman). There are no qualitative studies that look at QOL in patients with CBP who engage in prescribed journal writing.

Terms of the Study

Purpose Statement

Given the importance of CBP in influencing QOL in countless numbers of people, it is important to understand how this phenomenon is experienced. Therefore, the purpose of this phenomenological study is to examine the lived experience of QOL in Registered Nurses (RNs) in a Midwestern city who live with CBP and who engage in a structured journal writing experience. At this point in the research, QOL will be defined as any attribute, activity, experience, or personal contact that contributes to a positive feeling about one's life. This definition is purposefully broad and vague to allow participants freedom in describing their QOL in their own words, the appropriate data for phenomenology (Creswell, 2007).

The central question for this study is: What is the experience of Quality of Life in RNs who live with chronic back pain and who engage in a structured journal writing experience? Specific research questions include

1. How do these RNs describe their QOL, particularly in relation to their CBP?
2. How do these RNs perceive and carry out a prescribed journal writing activity?
3. How do RNs perceive journal writing as influencing their CBP?
4. What themes and meanings account for the feelings the participants have about back pain, their QOL, and the journal writing experience?
5. What themes arise that facilitate a deep understanding of QOL in RNs who live with back pain?

6. What is the overall essence of this experience for these RNs?

Method

The sample for this study was 15 RNs who have had back pain for at least six months, which corresponds to the nursing diagnosis of chronic pain (Carpenito-Moyet, 2004). They were generally recruited through the Alumni Directors of nursing schools in the Omaha area, with one RN being recruited by a co-worker of mine. This criterion sampling was important as I needed to obtain my data from individuals who have all experienced chronic back pain and who were willing to talk about it (Creswell, 2007). Data sources included an audiotaped interview, a journal written according to specific instructions, and a brief survey. Further details on the methods I used are presented in Chapter Three.

I used qualitative methods for this study because I wanted to explore QOL in greater detail than the current literature affords. I thought a qualitative understanding would be a better fit for this topic because I believe QOL cannot be adequately explained or understood in the context of the pre-determined scales and tools that are used for the majority of studies on quality of life. I believe that how people describe their QOL cannot be separated from the contexts of their daily lives; the relationships, work activities, and physical and psychological well being that make up essential parts of them. All of these are sound rationale for the use of qualitative methods (Creswell, 2007; Morse & Richards, 2002; Silverman, 2005).

Through inductive data analysis I was able to build upwards from small bits of data until I could explicate the whole picture of the phenomenon. For this study, I used an interpretive, hermeneutic approach inspired by Max van Manen (1990). It is

interpretive because I am using language to "make visible" to others something known only to the participants (Creswell, 2007, p. 82) and because as the researcher I am making an interpretation of what I see and hear. My own background influenced my understanding of the participants' experiences (Creswell; van Manen).

Specifically I used a phenomenological approach. Phenomenology is a "descriptive, interpretive, and engaging mode of inquiry from which to derive the essence of an experience" (Morse & Richards, 2002, p. 44). The goal of phenomenology is to describe the "meaning of the lived experiences" (Creswell, 2007, p. 125) of several people who have experienced a common phenomenon. The researcher's task is to distill narrative data into a description of the essence of the phenomenon, to "grasp…the very nature of the thing" (van Manen, 1990, p. 177). This is done by teasing participants' meanings and interpretations out of their narrative accounts (Denzin & Lincoln, 2005; Hatch, 2002; Morse & Richards, 2002; van Manen, 1990).

I utilized the three reading approaches advocated by Max van Manen (1990), which include the sentitious approach, the selective approach, and the detailed reading approach. I also added components of the method espoused by Hatch (2002) for organization and clarity. After I had read the interviews and journals multiple times I had developed a group of eight themes that fit under two separate domains. While engaging in hermeneutic reflection, the essence of the phenomenon became clear to me. More specific details regarding the approach I used are provided in chapter three. The themes, domains, and the essence are all described in detail in chapter four.

Significance of the Study

This study is significant in several ways. The results include many implications for both health care professionals and for society as a whole and have broadened my personal horizons in innumerable ways.

Professional and Social Implications

The clear understanding of the experience of living with chronic back pain will be beneficial to health care providers, nurses in particular, who care for patients living with this condition. Information gleaned from the interviews and journals paints a portrait of lives disrupted by CBP in ways that may seem to outsiders as being out of proportion to the back problem. It is easy to dismiss patients whose pain we do not understand, but the voices of my participants are unambiguous. Without control of the back pain, the back pain controls them.

Nurses are taught to believe what patients say about pain; it is time to start believing what they say about their quality of life, particularly vis-a-vis back pain. Nurses in practice will benefit from this study as they are on the front lines, encountering patients with CBP in their work probably on a near-daily basis. Advocating for appropriate treatment, including pain control, will improve patients' lives and satisfaction with their health care. Counseling patients that CBP can affect them and their families in unforeseeable ways and helping them with coping skills, perhaps including journal writing, are interventions that are well within the scope of professional nursing practice. Perhaps most of all we should learn to really listen, to truly attend to what our patients are telling us. Betina, one of my participants, made this need crystal clear; she cried when

she said at the start of her interview "Meg, I just want to thank you for letting my voice be heard."

Each person is unique and his or her experiences are just that: singular, inimitable, and incomparable. While part of nursing's role is to educate our patients on the commonplace—the usual side effects of a medication for instance, or the normal length of recovery from an operation—we must not lose sight of the *unique* that is at the heart of each patient encounter. We must not forget that what and how patients experience a phenomenon will be permeated by strands of life that are individual and salient only to themselves.

Nurses in faculty positions are charged with the education of future professionals. They have the responsibility to be role models for those novice nurses whom they help to prepare for careers in healthcare. Of course they have the obligation to teach what is factual and known, but far more important is their responsibility as mentors. The way they interact with patients teaches far more than any classroom lecture or learning activity could. Working with patients and families in ways that honor and confirm their experiences will help ensure nursing remains a profession worthy of respect.

Nurses in research have the responsibility to discover, uncover, and disseminate knowledge. Understanding how our patients experience health care conditions, learning what is important to them as they live with medical conditions and treatments, and discerning the effects their health care encounters have on them will contribute greatly to a health care system that is both holistic and humane.

Contributions to the Literature

This phenomenological study is the only study that examines the lived experience of QOL in RNs who have CBP and who engage in a structured, or prescribed, JW activity. This study provided a comprehensive view of how nurses with CBP are affected by this condition on a daily basis. As a qualitative study, it complements and brings a deeper and more thorough understanding to the subject of QOL in those with CBP than do quantitative reports. The use of interviews and journals provided ample opportunity to hear the participants' voices. As such, it fills a gap in the literature. This study also fits within the framework of research on journal writing, although more peripherally. I did not use journal writing as an intervention but rather as a source of data. However the majority of individuals who returned a survey as part of their participation indicated that the JW activity was either helpful to them or would have been had they done it earlier in the course of their back pain. This corresponds to the results of a vast body of work highlighting the therapeutic and healing nature of journaling (Frattaroli, 2006; Pennebaker & Seagal, 1999; Singer & Singer, 2006; Smyth, Hockmeyer, & Tulloch, 2008; Smyth & Pennebaker, 2008).

Personal knowledge

Having suffered with CBP for more than two decades now, I originally did not think I had much to learn from this study. I thought I knew all about the lived experience of QOL in the setting of CBP. I was interested—no, intrigued really—by the phenomenon, and wanted to know more from the perspective of others, but I actually felt I was already the expert in this subject.

I have been truly humbled by this experience. I learned far more than what themes dominated this experience; I gained an understanding and appreciation that goes well beyond the essence. The nurses who participated in this study have taught me so much about coping and resilience, and their sheer tenacity to live, not just to exist, with a condition that so permeates their lives has been an inspiring experience. I was welcomed into their lives and now feel the responsibility to be their witness. I can honestly say the way I look at individuals, including my patients, who live with chronic conditions, has been irretrievably altered.

Conclusions and Summary

Chronic back pain is a common condition that can invade every aspect of the lives of individuals who suffer from it. This phenomenological study investigated the lived experience of 15 RNs who have CBP and who participated in a structured JW experience. Eight themes under two domains were revealed to me as I searched for the essence of this experience. The following chapter details the background literature relevant to this study.

CHAPTER TWO

LITERATURE REVIEW

The purpose of this chapter is to provide summaries of the literature that underpins this work. In the first part of the chapter I will discuss back pain and chronic back pain specifically. In the next sections I focus on some theories of pain and then move on to quality of life. The chapter continues with a discussion of journal writing as a specific type of complementary and alternative medicine practice that also can be used as source material for research. Finally, the chapter ends with the problem statement and research questions.

Overview of Back Pain

Back pain is a significant problem in the industrialized world. Studies from various nations show it to be the second most common reason for physician visits and the third most common reason for surgery. As many as 90% of all individuals will experience back pain in their lives and annual prevalence rates are typically reported to be 15-45% (Banbury, Feenan, & Allcock, 2008; Canale, 2003; Cassidy, Cote, Carroll, & Kristman, 2005; Deyo, Mirza, Turner, & Martin, 2009; Dryden, Baskwill, & Preyde, 2004; Ekman, Jonhagen, Hunsche, & Jonsson, 2005; Furlan, Brosseau, Imamura, & Irvin, 2002; Grabois, 2005; Johansson & Lindberg, 2000; "Long Road Home", 2008; Martell, et al., 2007; Mellegard, Grossi, & Soares, 2001; Menzel, 2004; Mortimer & Ahlberg, 2003; Phillips, Ch'ien, Norwood, & Smith, 2003; Saben & Penckofer, 2007; Schweikert, et al., 2006; Weinstein 2005). In an analysis of 46 studies of nurses spanning 33 years, Menzel (2004) found the prevalence to be as high as 80.9% during a lifetime.

Approximately 32% of Americans have back pain in one year (Dryden, et al, 2004). If even 1/3 of the individuals who experience pain in one year visit their physicians, Banbury, et al. (2008) contend that adds up to 2.6 million health care visits per year. Not only is back pain expensive in direct medical costs, indirect costs to society such as absenteeism, rehabilitation, and disability are astronomical (Canale, 2003; Ekman, et al., 2005; Schweikert, et al., 2006).

Back pain, particularly low back pain (LBP), is usually a benign, generally self-limiting disorder (Cassidy, et al., 2005; Smith, 2004; Weinstein, 2005). LBP encompasses both minor problems such as muscle strains, and major problems such as herniated discs with spinal cord compression which can lead to neurological symptoms such as paresthesias (abnormal sensations), foot drop, and bowel and/or bladder incontinence (Canale, 2003; Cassidy, et al.; Johansson & Lindberg, 2000; Mortimer & Ahlberg, 2004; Phillips, et al., 2003; Smith; Weinstein). In this situation, back pain becomes a surgical emergency requiring immediate decompression of the spinal cord (Canale, Smith, Weinstein).

Back pain is generally caused by a combination of mechanical forces generated with bad body mechanics, being overweight, or having poor posture. Some occupations are known to have a higher risk of back pain and/or back injuries than others (Bureau of Labor Statistics, 2005; Bureau of Labor Statistics, 2008-2009; Canale, 2003; de Castro, 2004; Dux, 2004; Menzell, 2004; Smith, 2004; Weinstein, 2005; Yip, 2004). Often the true cause is never known and is probably caused by the cumulative effects of repetitive, minor injuries (Ekman, et al., 2005; Weinstein).

Diagnosis and Treatment

Diagnostic measures run the gamut from clinical assessment and patient report to sophisticated (and expensive) imaging techniques. The foundational diagnostic tests are the patient history and complete physical examination with special emphasis on assessment of the musculoskeletal and neurological systems (Weinstein, 2005). The sheer prevalence of back pain in the population has triggered the development of an increasing number of tests and treatments being prescribed, all of which are expensive and none of which is risk-free (Deyo, et al., 2009; Hatten, Gatchel, Polatin, & Stowell, 2006). Deyo, et al. (2009) noted that the prevalence of testing and invasive treatments has risen while the rate of medical visits for back complaints has remained roughly the same since 1990.

It may be that biomedical manufacturers are pushing and physicians are promoting elaborate diagnostics because they fear lawsuits from patients who demand them and are not satisfied unless they get them (Deyo, et al, 2009; Verbeek, Sengers, Riemens, & Haafkens, 2004). In reality, there are certain clear indications for imaging studies such as Magnetic Resonance Imaging (MRI), which should be reserved for patients who have serious or worsening neurological symptoms or who show evidence of some kind of underlying problem, for instance cancer in the spine (Chou, et al., 2007). According to Deyo, et al., areas of the country where high numbers of imaging studies are performed have the highest rates of spinal cord surgery.

Traditional medical treatment has included limited bed rest and quickly resuming normal activities, non-steroidal anti-inflammatory drugs (ibuprofen [Motrin]), stronger pain medication and muscle relaxants as needed, heat or ice application, and physical

therapy. Surgery is reserved for severe cases that include structural instability (Canale, 2003; D'Arcy, 2006; Martel, et al., 2007; McGorry, et al., 2000; Phillips, et al., 2003; Weinstein, 2005). These cases comprise a small minority, perhaps less than 1% (Smith, 2004). Some patients seek chiropractic care or alternative medicine practices such as acupuncture or massage (Carson, et al., 2005; Caswell & West, 2002; Cherkin, et al., 2003; Dryden, et al., 2004; Furlan, et al., 2002; Martel, et al., 2007; Melancon & Miller, 2005). The goal of treatment is to get the person back to work and pain free quickly (Schweikert, et al., 2006). This is crucial: once a person has been off work for 6 months, he or she has only a 50% chance of ever returning to work (Canale).

Chronic Back Pain

Despite the arsenal of treatment options, back pain often becomes chronic. More than 5 million Americans are currently disabled due to chronic back pain; this translates into approximately 40-80% of people diagnosed remaining symptomatic after one year (Cassidy, et al., 2005). Chronic back pain (CBP) has been called "physically debilitating, emotionally demoralizing, and financially devastating" (Hatten, et al., 2006, p. 700) and is a huge burden to both national economies and personal resources.

In America, the annual national expense for CBP care is estimated to be as high as $100 billion, and 15-25% of all workers' compensation claims go for CBP treatment (D'Arcy, 2006; Ekman, et al., 2005; Kosinski, et al., 2005; Proctor, et al., 2000). The Chicago Institute of Neurosurgery and Neuroresearch found that businesses lose $175 million each year because of back pain in employees (Chicago Institute as cited in Dryden, et al, 2004; Grabois, 2005). The majority of money spent on back pain conditions goes to treat those cases that become chronic (Cairns, et. al., 2003; Chen,

2005; Claiborn, Krause, Heilman, & Leung, 1999; Hemmila, 2002; Pulliam, Gatchel, & Gardea, 2001). The indirect costs are also astronomical; in fact Ekman, et al. (2005) argue that even though more effective and rapid treatment may be more expensive in the short term, it would save money over the long term by decreasing these indirect costs.

The Challenging Nature of CBP

Chronic back pain is a major challenge to the medical community for several reasons. First there is no consensus on definitions to be used for patients who complain of ongoing back pain, there are no well-established and accepted guidelines for its treatment, and few options exist for successful care (Bogduk, 2004; "Guidelines", 2003; Waddell, 1987). Chronic pain is so common in primary care practices that the patient with CBP does not stand out as a person who needs special attention ("Long Road Home", 2008). It is a complex, multifactoral process with multiple influencing mediators (Holloway, Safaer-Bennett, & Walker, 2007). Chronic back pain is not a universal experience; its clinical course is variable and unpredictable among patients ("Four distinct," 2006), leading Ekman, et al. to label it as an "enigma" (2005, p. 1777).

Most CBP patients do not exhibit specific underlying conditions amenable to treatment (Cedraschi, et al., 1999, Grabois, 2005). The other complicating factor is that pain, physical impairment, and disability usually cannot be "linked in a direct, linear fashion" (Cedraschi, et al, p. 358). This leads physicians to view care of the CBP patient as frustrating and unrewarding and to patients being unhappy with their care and outcomes (Borkan, et al., 1995; D'Arcy, 2006; Harding, Parsons, Rahman, & Underwood, 2005; Johannson & Lindberg, 2000; McGorry, et al., 2000; Miller, Pinnington, & Stanley, 1999; Phillips, et. al., 2003; Tooth, 1990). Unfortunately, the

longer pain lasts it has less and less relationship to the original problem and becomes more and more resistant to medical care (Waddell, 1987).

In an analysis of 12 qualitative and 8 quantitative studies, Verbeek, et al. (2004) found that patients had several reasons for their dissatisfaction based on their expectations of the health care provider. They wanted to be given a clear explanation of their pain with information and instruction on self care; they wanted a thorough physical exam and adequate pain relief; they wanted diagnostic testing (even when it was not warranted), therapy, and referrals to specialists; they wanted confirmation from the health care provider that their pain was real; and they wanted to be respected and included in making decisions regarding their care. An accurate diagnosis and effective treatment, the two things least likely to happen with CBP, are the very things patients want most (Cherkin, et al., 2003; D'Arcy, 2006).

Physicians, trained in the Western medical model, are taught to see patient complaints in terms of distinct symptoms that lead to a specific diagnosis with a particular treatment. When that does not happen, and the symptoms (including pain) continue, physicians often look for a psychological cause for the patients' complaints (Croft, 2000; Holloway, et al., 2007; Longworth, 2004b).

And clinicians may be treating these patients inappropriately; CBP is distinctly different from acute back pain, but Deyo et al. (2009) fear that most physicians are using the acute care model for their chronic patients, leading to decreased levels of success. In fact they state, "We must rethink CBP at fundamental levels" (p. 65). Medical treatment for CBP has been called "ineffective, uneconomical, and even harmful" (Caswell & West, 2002, p. 121). Care of the patient with CBP is so bad overall that Waddell has

claimed it a "20th century medical disaster" (1987, p. 46). It seems the most successful treatments view CBP as a biopsychosocial condition (Longworth, 2004b). "Medicine has a limited role in diagnosing and treating chronic back pain" (Muramatsu, Liang, & Sugisawa, 1997, p. S222), however; the majority of patients seeking care for CBP turn to medicine and to their physicians for treatment.

Treatment Options

Conservative care. There is a "bewildering variety of treatments for CBP (Waddell, 1987, p. 637), but the cornerstone of treatment for any painful condition is pain relief. In fact, according to Banbury, et al. (2008), the early and aggressive use of adequate pain control is vital to prevent pain from progressing to a chronic condition. Pain should be treated according to the World Health Organization's (WHO) Pain Control Ladder (1986) which specifies a pain control regime that starts with mild, non-narcotic analgesics such as acetaminophen (Tylenol) and non-steroidal anti-inflammatory medications (NSAIDs) such as ibuprofen (Motrin). When this is not effective, the practitioner should add an opioid analgesic appropriate for mild to moderate pain, such as hydrocodone or codeine. When pain still persists, the addition of an opioid for severe pain, such as morphine, is recommended. Adjuvant medications can also be used at any level to control other symptoms (Harkreader, Hogan, & Thobaben, 2007; WHO, 1986).

As innocuous as they seem, even acetaminophen and ibuprofen are not without risk. Acetaminophen is known to cause liver damage, especially when taken in large doses or with chronic use. This effect is more likely if the patient drinks alcohol (Harkreader, et al., 2007; Skidmore-Roth, 2008). NSAIDs can cause renal and liver problems and can affect coagulation (Harkreader, et al.; Skidmore-Roth).

Use of opioid medications increased in CBP patients 108% between 1997-2004 (Deyo, et al, 2009). But opioid medications such as morphine have their own set of side effects and problems. Physicians and patients are often hesitant to prescribe or to take them for fear of addiction (Harkreader, et al, 2007). While opioids can provide dramatic pain relief, their efficacy for long term use in CBP is unclear (Deyo, et al., 2009; Martell, et al., 2007). Some studies have demonstrated that patients using opioid medications for chronic pain have an overall decreased QOL which may be attributed to many factors including side effects that are so bothersome that patients may under dose or even discontinue the medication (Adams, 2002; Nadstawek, et al., 2008).

Treatment with medication alone may not be beneficial; in a study Hatten, et al. (2006) found that using medications alone did not improve patients' abilities to do even simple things like sitting, standing, walking, or socializing. Due to dissatisfaction with medication as a stand-alone treatment for CBP, medical attention has turned to other methods for pain relief. In an effort to improve treatment and outcomes, medical research for CBP has exploded. Besides improved imaging techniques and other diagnostic measures, a whole new array of treatment options are available to the patient with CBP. More novel modalities for therapy include Transcutaneous Electrical Nerve Stimulation (TENS units), implanted spinal cord stimulators, the use of tricyclic antidepressants and anticonvulsant drugs to treat nerve pain, implanted drug delivery pumps, and improved surgical options (Canale, 2003; Martell, 2007; Weinstein, 2005).

Electrical therapies and surgical options. The use of electricity to treat pain has been utilized since the days of the early Egyptians, but the pain gate theory of Melzack & Wall (1965) gave this treatment medical legitimacy (Walsh, Howe, Johnson, & Sluka,

2009). The two main types of electrical therapy available to treat pain are the TENS unit and spinal cord stimulation.

TENS units are safe, inexpensive, and can be used to treat both acute and chronic pain (Johnson, 2008; Walsh, et al., 2009). A battery controlled device is used to deliver mild electrical stimulation through electrodes placed on the skin. This activates nerve fibers that carry messages toward the brain (afferent fibers) causing miniscule muscle twitching that hopefully masks the pain (Johnson; Walsh, et al.). Despite being a popular treatment, a recent review in the *Cochrane Database of Systemic Reviews* by Walsh, et al. found that no conclusions about the efficacy of TENS units could be determined due to various methodological problems encountered within the studies they analyzed.

Although available for more than 30 years, spinal cord stimulation has seen a recent increase in use. With this treatment, an implanted device directly stimulates the afferent nerve fibers in the spinal cord. Hopefully this prevents the transmission of the painful stimuli to the brain and the patient feels a tingling sensation that masks any residual unpleasant sensations. This requires an invasive surgical procedure to implant (Bala, Riemsma, Nixon, & Kleijnen, 2008; Canale, 2003; Weinstein, 2005; Van Buyten, 2006). These can be effective for certain well-selected patients (Van Buyten).

The final treatment option for back pain is spinal surgery. This should be reserved for the patient who has a structural abnormality or instability (Deyo, et al., 2009). There are several surgical options depending on patient need, including removal of ruptured discs and vertebral fusions; however for each type of operation contemplated, patients should be selected carefully as these are major procedures (Canale, 2003; Weinstein, 2005). There are definite benefits for some patients, but nearly one-half of

these operations do not result in improvement. These patients have very few options remaining to them other than repeated operations which are of limited value. This has become so common that it carries its own diagnosis: Failed Back Surgery Syndrome (FBSS) (Bogduk, 2004; Colella, 2003; Taylor, van Buyten, & Buchser, 2004).

Failed Back Surgery Syndrome is defined as "persistent or recurring pain mainly in the lower back and/or legs even after previous anatomically successful surgery" (van Buyten, 2006, p. S25). FBSS is disabling in about 30% of the patients who have it. It also leads to depression, financial woes, and family problems and presents yet another challenge to health care practitioners trying to care for their patients with CBP (Thompson & Jacques, 2009; van Buyten).

It has been difficult to gauge the efficacy of surgery as compared to other methods of treatment, particularly structured, multidisciplinary programs for those with CBP (Mirza & Deyo, 2007), although patients generally undergo these procedures with very high expectations for a cure (Saban & Penckofer, 2007). Even when the surgery has been a "success," patients often have some degree of pain and dysfunction and frequently have a lower quality of life than patients with CBP who do not undergo surgery (Bentsen, et al., 2008; Deyo, et al, 2009; Hakkinen, Kautiainen, Sintonen, & Ylinen, 2005).

Measuring Outcomes

Gauging the success of any treatment for back pain should involve a pain evaluation and an assessment of the patient's functional limitations and the impact of pain on multiple aspects of the patient's life. This should include both objective (health care provider assessed) and subjective (patient assessed) variables (Canale, 2003; Carey & Mielenz, 2007; de Souza & Frank, 2007; Karoly, Ruehlman, Aiken, Todd, & Newton,

2006; Weinstein, 2005). Frequently used tools to rate functional impairment include the Oswestry Disability Scale and the Roland-Morris Disability Scale, both of which are back pain-specific (Carey & Mielenz).

The Oswestry Disability Scale is a measure of functional status with 10 sections of questions regarding various activities of daily living. The questions are scored from 0 (no effect) to 5 (total disability) and the final result is expressed as a percentage. The higher the percentage the patient obtains, the worse the impairment (Fairbank & Pynsent, 2000; Mehra, Baker, Disney, & Pynsent, 2008). The Roland-Morris Disability Scale measures functional status by having the patient answer 24 questions either yes or no. The "yes" answers are summed with higher scores representing higher levels of disability (Roland & Morris, 1983). However, deSouza & Frank warn that formal assessments may or may not give valid information about the impact of back pain in patients' everyday lives (2007).

No matter the precipitating event or underlying etiology, when pain continues unabated, it becomes the disease itself (Chandra & Ozturk, 2005). In order to care for the patient with chronic pain of any type, one must first have a basic understanding of pain itself.

Overview of Pain

Theories and Assessment

Traditional views of pain concluded that it was a "unidirectional" event, with pain transmission from damaged tissues to specific areas of the brain being a direct, cause-and-effect experience. Pain, therefore, would be associated simply and directly with the severity and location of tissue trauma. More recently, researchers have found multiple

areas of the brain involved in both pain transmission and perception, and that transmission of signals is far more complex than originally thought (Melzack & Wall, 1965; Melzack, 1993; Norman, 2000; Wall, 1996). This view of pain as a complex phenomenon leads room for other types of input, specifically cognitive and affective influences, which are now seen as contributors to the pain experience, rather than solely a response to it. The breakthrough Gate Control Theory of Pain, originally described in 1965 by Melzack & Wall, has been updated to explain physiologic mechanisms for psychological factors in pain perception, including learning and emotional responses. In fact, specific tissue damage is no longer considered a precondition for the existence of pain (Melzack, 1993; Norman, 2000; Wall, 1996).

The Gate Control Theory of Pain states that a "gate" is present on the dorsal horn of the spinal cord that controls noxious stimuli brought in by the small diameter afferent nerve fibers. Competing stimuli can close the gate, not allowing the noxious stimuli to get through, therefore not allowing the patient to feel the pain. Examples of competing stimuli include massage, acupressure, or electrical stimulation (Melzack & Wall, 1965; Walsh, Howe, Johnson, & Sluka, 2009).

Assessment of pain remains a difficult issue. Pain is a subjective experience but has been linked to physiologic signs such as high blood pressure, increased pulse, inability to sleep, or moaning and crying. However, patients may be in pain and not exhibit any objectively measured signs. Using behaviors to assess pain is usually not accurate except in pre-verbal children and in adults with dementia (Harkreader, et al., 2007). This often leads to under-treatment of pain by professionals who feel that the patient is not in pain or else would be exhibiting these expected pain behaviors

(Harkreader, et al., 2007). To combat this tendency, health care providers today are taught to believe that the patient who says he is in pain, in fact is in pain. In order to assess pain "accurately," health care professionals can use numerical scales (1-10), visual analogue scales, or diagrams (Chandra & Ozturk, 2005; Harkreader, et al., 2007). Another option is the Brief Pain Inventory which measures the amount of interference with daily activities the patient experiences due to pain (Carey & Mielenz, 2007).

Pain is quite common in the general population and in medical practices it is the top patient complaint (Adams, et al., 2001; Deyo, et al., 2009; Gerstle, All, & Wallace, 2001; Karoly, et al., 2006). Acute pain is a signal to the body that something is wrong. It typically lasts less than 6 months, helps pinpoint a diagnosis, and can be used to assess healing and recovery. Chronic pain is usually defined as pain lasting for over 6 months and may not be associated with a known injury or illness, therefore it serves no real function once a diagnosis is made (Harkreader, et al., 2007). There is some controversy however regarding the definition of chronic pain (Longworth, 2004) which is also called chronic non-malignant pain when it is not related to cancer (Chandra & Ozturk, 2005; Gerstle, et al.). Pain is complex and dynamic and varies considerably from one person to the next (All, Fried, & Wallace, 2000; Raheim & Holland, 2006). There are more than 75 million people in the United States living with chronic pain (Adams et al; Gerstle, et al.).

Chronic Pain

Physical Changes

Continued pain leads to physical changes in the brain (central nervous system) and peripheral nervous system that are initially reversible, but as the pain continues

become permanent ("Does chronic back pain," 2007; Longworth, 2004). Specifically, there are changes in the grey matter of the brain in the areas responsible for pain processing (Valet, et al., 2009). Brain tissue atrophies in the presence of chronic, non-malignant pain, leading to diminished cognitive function (Weiner, Rudy, Morrow, Slaboda, & Lieber, 2006). A study by Weiner, et al. also demonstrated a relationship between pain and physical capabilities in a sample of community-dwelling elderly individuals. Pain alters endocrine and immune system functioning as well ("Does chronic back pain").

Other physical problems related to chronic pain include disuse syndrome ("Does chronic back pain," 2007). In order to prevent more pain, patients often limit their activities and responsibilities, which in turn causes muscle weakness and activity intolerance, leading to further pain and fear of further pain. This is known as fear-avoidance behavior (Waddell, 1987), and true to the specialized, compartmentalized nature of Western medicine, that construct can be assessed with the Waddell's Fear-Avoidance Beliefs Questionnaire (Carey & Mielenz, 2007). Fear-avoidance behavior sets up a cycle that can eventually lead to disability (Banbury, et al., 2008; Karoly, et al., 2006). In fact, the duration of pain is a strong predictor of disability (Kovacs, Abraira, Zamora, & Fernandez, 2005).

Psychosocial Effects of Chronic Pain

Besides the physical impact, chronic non-malignant pain causes a heavy psychosocial burden on patients too. Living in chronic pain can be an overwhelmingly negative experience (All, et al., 2000; Kosinski, et al., 2005). Patients with chronic pain, specifically CBP, have double the risk of depression than do individuals in the general

population (Cassidy, et al, 2005). Chronic pain affects all aspects of a patient's social and family life and causes significant psychological distress, leading to withdrawal, altered self image and identities, anxiety, anger, or loneliness and further physical decline (Block & Brock, 2008; Carson, et al., 2005; Closs, Staples, Reid, Bennett, & Briggs, 2009; D'Arcy, 2006; Harding, et al., 2005; Hoffman, Meier, & Council, 2002; Karoly, et al., 2006; Kosinski, 2005; Lee, Chronister, & Bishop, 2009; McCarberg, Nicholson, Knox, Palmer, & Penles, 2008; McHugh & Thoms, 2001; Munir, et al., 2007; Proctor et al., 2000; Strunin & Boden, 2004; Woby, Watson, Roach, & Urmsten, 2005).

These negative psychosocial impacts can actually modify the pain experience itself by increasing the pain signals, resulting in higher levels of pain (Karoly, et al., 2006). Chronic pain causes sleep disturbances and diminishes the ability to function the following day (McCarberg, et al., 2008). This can then exacerbate the psychosocial effects of the pain. Often a fatigued patient will then sleep the next day, making it even harder to get a good night's rest afterward. Sleeplessness and increased pain seem to be related, but the nature and direction of that relationship remains unclear (deSouza & Frank, 2007).

Stigmatization. Chronic pain patients are another group of patients dissatisfied with their medical experiences. They and their health care providers find their care frustrating and stressful (Gerstle, et al., 2001). When physicians cannot find a cause or cure for chronic pain, they often ascribe it to a psychological process, resulting in patients feeling stigmatized and not believed (All, et al., 2000; McHugh & Thoms, 2001; Verbeek, et al., 2004). They are often cast as morally weak individuals since the cause of their suffering remains invisible to outsiders (Holloway, et al., 2007). As described

earlier, chronic pain causes structural changes in the central nervous system and in fact the very nature of the physical brain changes may explain why chronic pain is included in the *Diagnostic and Statistical Manual of Mental Disorders*—4th edition (DSM-IV), the bible of psychiatric illness and treatment. Structural brain damage is a requisite component of mental illness (Valet, et al., 2009).

While some physicians incorporate the psychosocial domain with the physical domain of chronic pain—for instance arguing compassionately for a new category of medical-mental illnesses (Valet, et al., 2009), others seem to legitimize this stigmatization. Longworth (2004) describes "red flag" assessment signs in patients who seek consultation with him for chronic back pain that supposedly signal mental derangement: "Other signs—tinted glasses and wearing strange underwear for a medical examination for which you might be expected to undress" and goes on to describe the "strange underwear" in unnecessary detail (p. 5). He takes this tone throughout the article which is actually sprinkled with some sound assessment and management advice (Longworth, 2004).

Treatment and Research

Chronic pain has been best treated by a multidisciplinary, multi-modal approach incorporating both physical and psychosocial aspects (All, et al., 2000). Many components have been used and studied in combination with traditional medical care, including cognitive behavioral therapy, assertiveness training, communication skills, physical and perhaps occupational therapy, marital and family counseling, biofeedback, relaxation techniques, assessing and modifying expectations, group education, and coping strategies (All, et al., 2000; Gross & Battie, 2005; Hatten, et al., 2006; Jensen, Dahlquist,

Nygren, & Royen, & Stenberg, 1997; Schweikert, et al., 2006; Woby, et al., 2005). It seems clear that with chronic pain, the goal of treatment needs to switch from eliminating the pain to learning to adapt to a life lived despite the pain (Claiborn, et. al., 1999; Harding, et al., 2005; Raak, Wikblad, Raak, Carlsson, & Wahren, 2002; Ruta, Garratt, & Russel, 1999; Taylor, Taylor, Foy, & Fogg, 1999; Tooth, 1990).

Research studies have focused on the roles of depression, anxiety, learned behavior theories, somatization, catastrophizing, passive/active coping styles, internal/external locus of control, optimism/pessimism, and other psychological factors in the pain experience. One thing all agree on is that for effective pain control, physicians need to consider and respond to all aspects of this complex experience (All, et al., 2000; Ardic & Toraman, 2002; Basler, Jakle, & Kroner-Herwig, 1997; Davis & White, 2001; Ozguler, et. al., 2002; Peters, et. al., 2000; Woby, et al., 2005).

Despite the plethora of studies on this aspect of pain and the advent of multi-disciplinary pain centers, many chronic pain patients remain significantly affected by pain in numerous ways. Pain that has no definitive diagnosis and treatment is seen as mysterious and frightening, and is stigmatizing to the sufferers (All, et al., 2000; Verbeek, et al., 2004). It can threaten self-esteem and identity. It can alter family, social, and work roles. When pain is not treated adequately, which means addressing all its aspects, it becomes an overwhelming, life changing entity that impacts patients in a very significant way (Ardic & Toraman, 2002; Block & Brock, 2008; Closs, et al., 2009; Harding, et al., 2005; Karoly, et al., 2006; Kosinski, 2005; Lazarus & Neuman, 2001; Lee, et al., 2009; McCarberg, et al., 2008; McHugh & Thoms, 2001; Munir, et al., 2007;

Patrick, et al., 1995; Woby, et al., 1995). In other words, pain affects patients' Quality of Life.

Overview of Quality of Life

Originally defined by the WHO in 1948, the phrase "Quality of Life" was used often after World War II and became a popular expression in the 1960's (Campbell, 1981; Haas, 1999; Meeberg, 1993). This concept was important to WHO's new definition of health as "a state of complete physical, mental, and social well-being, not merely the absence of disease or infirmity" (WHO, 1948, p.1). Now this statement is "glibly used in a wide range of contexts" (Meeberg, 1993, p. 33) and in fields as divergent as advertising and politics (Haas, 1991). Each discipline using the term defines it and approaches its study in unique ways (Murphy, Cooney, Shea, & Casey, 2009).

Quality of Life in Health Care

QOL is important in health care today (Gilworth, et al., 2004; Haas, 1999; MacDuff, 2000; Meeberg, 1993). Medical advances exploded in the last century, extending the lives of people living with chronic ailments (Duggan & Dijkers, 2001). Escalating costs, limited resources, demands of evidence-based practice, and the burdens of treatment have pressured researchers to measure patients' opinions on their care, the burden of that care, and on living with their conditions (DePalma, 2001; MacDuff, 2000). This is a shift in the predominant subject of interest from using empiric data as the sole determiner of quality care. It is no longer sufficient to simply measure objective outcomes; one needs to focus on the subjective experience of living with a chronic ailment (Lee, et al., 2009). Improved QOL should be the focus of any health care intervention (DePalma, 2001; MacDuff, 2000; McMurray, Theobald, & Chaboyer,

2003/4; Roebuck, Furze, & Thompson, 2001; Widar, et al., 2004; Willener & Hantikainen, 2005).

WHO (1998) defines QOL this way:

> An individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns. It is a broad ranging concept affected in a complex way by the persons' physical health, psychological state, personal beliefs, social relationships and their relationship to salient features of the environment (p.17).

Research on Quality of Life

Despite the WHO's prestige, a major problem is the lack of agreement on the definition of QOL and the lack of consensus on how best to measure it (Boschen, et al., 2003; Bowling, et al., 2003; DePalma, 2001; Haas, 1999; Hakkinen, et al., 2005; Lee, et al., 2009; MacDuff, 2000; Roebuck, et al., 2001; Waters, Maher, Salmon, Reddihough, & Boyd, 2005; Willener & Hantikainen, 2005). Many studies of QOL do not even provide the readers an operationalized definition (MacDuff, 2000). Most authors agree that QOL is an abstract, multidimensional phenomenon (Corless, Nicholas, & Nokes, 2001; MacDuff, 2000; McMurray, et al., 2003/4). But there is no agreement on even on a short list of general constructs to include when it is researched (Haas, MacDuff).

Much of the early research on QOL was purely quantitative and was based on objective data associated with happiness/unhappiness or satisfaction/dissatisfaction (Duggan & Dijkers, 2001; Fahrquhar, 1995; Meeberg, 1993). In 1977, Shaw published an actual mathematical formula to quantify an individual's QOL. One drawback to this

approach was that a person could have a QOL rating of 0, which would probably be a meaningless conclusion (Shaw, 1977, as cited in Meeberg, 1993).

Many researchers equate QOL with physical functioning or health in either the psychological processes approach or the standard needs approach (Fahrquhar, 1995; MacDuff, 2003; Rosenberg, 1995). The psychological processes approach investigates the ways individuals perceive QOL. The standard needs approach assumes specific attributes for good or bad QOL exist and can be discovered (Browne, McGee, & O'Boyle 1997). Searching for definable attributes resulted in past research focusing on tool design. This has led to an overabundance of research tools, usually scales, measuring QOL that have become increasingly specific and restrictive (DePalma, 2001; MacDuff, 2000; McMurray, et al., 2003/4; Willener & Hantikainen, 2005).

The biggest drawback to using scales is that people do not place the same importance on items as others do, making comparisons among people difficult, even when they get the same "score" (Haas, 1999; Willener & Hantikainen, 2005). There are multiple factors influencing QOL that interact in dynamic ways, making their influence difficult to quantify (Murphy, et al., 2009). Also, the importance people place on the items changes over time, making longitudinal comparisons difficult (Bowling, et al., 2003; MacDuff, 2000; McGee, O'Boyle, Hickey, & O'Malley, 1991; Murphy, et al.; O'Boyle, 1992).

Health-Related Quality of Life

Research on QOL has become increasingly fragmented. The original split was between general QOL and health-related quality of life (HRQOL). HRQOL refers to patients' perceptions of disease, treatment, and the ability to maintain a satisfactory

lifestyle despite the presence of illness or injury in their lives (Duggan & Dijkers, 2001; Haas, 1999; Lee, et al., 2009; MacDuff, 2000; Widar, et al., 2004). Tools include items like symptom management, emotional well-being, social functioning, vocational abilities, and spirituality in an effort to judge the impact of illness on functional status (Duggan & Dijkers; Elliott, Renier, & Palcher, 2003; Lee, et al., 2009; McMurray, et al., 2003/4). Not surprisingly, researchers have never agreed on a definition for HRQOL (Haas).

In the 1990s, the WHO developed the WHOQOL100, which is a generic tool for measuring HRQOL in adults comprised of 100 questions about multifaceted items arranged into specific domains. This tool can be modified with additional modules that are disease-specific, including one for chronic pain called the Pain and Discomfort Module (ODM) (Mason, Skevington, Osborn, 2008). Another popular generalized HRQOL tool is the Medical Outcome Study Short Form-36 (SF-36). This easy-to-administer tool assesses the effects of medical ailments on eight core dimensions of daily life, including limitations in physical and social activities, changes in usual role activities, pain, general mental health status, perceptions of general health, and the effect of the illness on both physical and mental functioning (Sherbourne, Meredith, Rogers, & Ware, 1992).

Quality of Life research is further complicated by HRQOL tools based on benchmarking data for specific diseases adapted for every conceivable patient population. Tools exist for common ailments such as spinal cord injury, heart attacks, and strokes (Boschen, et al., 2003; Roebuck, et al., 2001; Widar, et al., 2004) and obscure disorders such as Behcet's disease (Gilworth, et al., 2004). The idea is to allow patients with

defined diseases to determine what areas are important to their QOL and to expose the language they use to talk about QOL (Duggan & Dijkers, 2001).

Such specific tools have difficulties. It may be difficult if not impossible to separate out health-related effects from other aspects of QOL, especially when the patient has several co-morbidities (MacDuff, 2000), which is a common situation in health care today. Many supposed QOL tools actually measure functional ability, with the assumption that better functioning automatically leads to improved QOL. These problems have led to a new generation of QOL tools: respondent-generated measures in which patients are allowed to choose their own descriptors of QOL (MacDuff), and the emergence of qualitative studies of QOL.

Two of these new-generation instruments are the Schedule for the Evaluation of Individual Quality of Life (SEIQoL) and the Patient Generated Index (PGI). These tools are based on the idea that patients should assess their own quality of life based on domains they consider important (Lhussier, Watson, Reed, & Clarke, 2005). Both the SEIQoL and PGI claim to have a phenomenological pedigree (MacDuff, 2000). But both are clearly quantitative tools. The SEIQoL is "a measure designed to elicit the value system of individual respondents and to *quantify* QOL using this elicited system" (Browne, et al., 1997, p. 742, emphasis not in the original). The PGI is "a questionnaire that *quantifies* the effect of a medical condition on a patient's QOL" (Ruta, et al., 1994, p. 1118, emphasis not in the original). Thus they are far from their phenomenological base.

Qualitative Research in HRQOL

Qualitative research has been used to study QOL. However, many of these studies use qualitative methods to generate quantitative tools for subsequent research

(Boschen, et al., 2003; DePalma, 2001; Macduff, 2000; McMurray, et al., 2003/4; Waters, et al., 2005; Willener & Hantikainen, 2005). This is unfortunate because qualitative studies allow the patients' own voices to be heard and put the patient, not the disease or treatment, in the center of the health care experience (Duggan & Dijkers, 2001; McMurray, et al.; Willener & Hantikainen). If QOL is what the patient says it is, then researchers should investigate what patients are saying.

Researchers should reject this reductionistic approach of using specific, weighted scales measuring predetermined factors to examine QOL. The very notion of a single scale that can capture the essence of a concept like QOL may be "nonsensical if QOL is really an individually defined concept" (Hunt, 1997, p. 381). And nurses, who are educated to view their patients holistically, should be suspicious of studies claiming that a concept of the magnitude of QOL can be reduced to a single sum or a solitary digit. Quality of life is impossible to understand without considering the myriad of influences that shape a patient's experiences and expectations (Murphy, et al., 2009). This totality certainly canot be comprehended through the use of predetermined scales. For professionals interested in and committed to improving patients' quality of life, the only option is to provide care that considers physical, psychological, socio-cultural and spiritual well-being in the their patients (Gerstle, et al., 2001).

Purely qualitative studies are often done with people who have chronic illnesses, seeking to understand the phenomenon of living with a chronic condition and its effects on QOL. Often patients in qualitative studies have ailments that are painful or considered especially burdensome. Chronic back pain qualifies on both accounts. Chronic pain has an overall effect of diminishing quality of life. Studies consistently show pain to have a

"pervasive effect on patients' day-to-day lives" (Norman, 2000, p. 87). Patients report feelings of powerlessness; a sense of loss; depression; anxiety; reductions in school, home, leisure, or work activities; increased fear; decreased sexual activity; diminished ability to sleep; and even ability to concentrate (Chen, 2005; Gerstle, et al., 2001; Hoffman, Meier, & Council, 2002; Lee, et al., 2009). Chronic back pain certainly fits into this pattern.

Overall, QOL in patients with CBP is much lower than that of the general population and lower than that in people with other chronic illnesses (Beaulieu, Wood-Dauphinee, Abenhaim, & Abrahamowicz, 1997; Borkan, et. al., 1995; Davis & White, 2001; Gil, 2000; Hagg, Burckhardt, Fritzell, & Nordwall, 2003; Hemmila, 2002; Lazarus & Neuman, 2001; Nickel, et al., 2002; Norman, 2000; Patrick, et. al., 1995). Due to perceived failure of health care professionals to fully address the impact of chronic pain on their QOL, patients have begun seeking "healing" rather than cure, in a variety of complementary or alternative therapies.

Overview of Complementary and Alternative Therapies

Complementary and alternative medicine practices (CAM), while newer in the Western health care paradigm, have been used by approximately 80% of the world's population for the majority of their health care needs. The underlying philosophy is one of mind-body-spirit connectedness. Illness and pain are often conceptualized as the result of disharmony among those three components; all complementary and alternative practices seek to somehow restore that balance. There are over 1800 complementary and alternative therapies currently recognized, many of which have been useful in treating chronic pain (Astin, 1998; Eisenberg, 2002; Harkreader, et al., 2007; Snyder & Wieland,

2003). In a large national survey, Lazarus & Neuman (2001) found that 76% of pain sufferers have tried an alternative treatment for their pain; 40% have tried more than one. Another 22% have considered trying a complementary or alternative therapy for pain.

In 1997, a panel sponsored by the National Institutes of Health defined complementary and alternative medicine as

> a broad domain of healing resources that encompasses health systems, modalities, and practices and their accompanying theories and beliefs, other than those intrinsic to the dominant system of a particular society or culture in a given historical period. CAM includes all such practices and ideas self-defined by their users as preventing or treating illness or promoting health and well-being. Boundaries within CAM and between the CAM domain and the dominant system are not always sharp and fixed (Panel on Definition and Description, 1997, p. 49).

Caring—a holistic undertaking—is a key factor of nursing practice and is also a major component in the philosophies of CAM (Snyder & Wieland, 2003; Watson, 1985). One recognized type of CAM is journal writing.

Journal Writing: A Healing Art

"Journals have a long and interesting history" (Vaught-Alexander, 1994, p. 153). People have engaged in journal writing since at least the 1st century AD. Youga writes

> Recording and analyzing one's experiences including wonderings, yearning, and turmoils have been a part of human history and central to the experience of many individuals for centuries—a compelling indication of journaling's reliability and validity for many (1995, p. 149).

Early Chinese kept journals as historical documents and community records, which are credited as being the first known journal writing activities (Youga, 1995). Journals as old as the classic Greek and Roman societies survive and give insight into day-to-day activities in those communities (Brundage, 2003; Vaught-Alexander, 1994). The Renaissance brought the personal journal: writing devoted to individual thoughts and feelings. And throughout the French Revolution, more intimate journals came into vogue, particularly for women writers who found traditional literary avenues closed to them because of societal restrictions on their activities (Youga, 1995). Historians have often used diaries and journals, especially those written during historically important times, for primary source material (Brundage, 2002; Vaught-Alexander, 1994). Writing serves many purposes that could be considered healing: "We write journals in times of personal exploration or crisis as we struggle to understand or to control that which seems inscrutable or uncontrollable" (Vaught-Alexander, 1994, p. 153).

Vaught-Alexander also states:

> Writing can also allow us to problem solve. From the moment we begin to write, we are taking action…We talk on paper, releasing feelings and finding satisfaction or resolution, as the words and sentences reveal what we would not or could not articulate before. We figure out what we feel or perhaps what we need to do. So writing allows us to make meaning out of the meaningless, to find hope in the hopeless (1994, p. 151).

Journal Writing in Health Care

Diaries and journals have been used in health care settings since the 1930s. Most frequently, they are used to record symptoms and response to treatment (Burman, 1995).

Pain dairies and sleep logs are frequent such examples found in the literature. Expanding this idea, journals or diaries can also be used to record descriptions of illness and its impact on daily life, or QOL. As a data tool, these journals can be "dense and rich" (Burman, 1995, p. 150).

More recently, journal writing has been incorporated into therapy as a way of allowing clients to privately work through the emotions of significant events in their lives with the view that it allows free self-expression and provides an avenue for clients to "make sense of a chaotic or fragmented world" (Youga, 1995, p. 139). Prior to Pennebaker and Beale's 1986 study on the health benefits of journal writing on college undergraduates, positive outcomes were assumed to accrue only from oral therapies (Singer & Singer, 2006). In the seminal Pennebaker and Beale study (1986), 46 college undergraduates were assigned randomly to write for 15 minutes either about trivial topics or about traumatic topics for four consecutive days (1986). The writing restrictions were serendipitous; that was the amount of time lab space could be reserved for this research (Chung & Pennebaker, 2008). Those who wrote about a traumatic topic showed increased blood pressure and negative mood immediately following the writing, however; they demonstrated fewer visits to the campus health center and fewer days of illness leading to restricted activity than did the control group (Pennebaker & Beale, 1986).

This line of inquiry has captivated the research world in multiple disciplines, including medicine, nursing, and psychology. Since 1986, this study has been replicated more than 200 times with similar findings (Frattaroli, 2006; Pennebaker & Seagal, 1999; Singer & Singer, 2006; Smyth, et al., 2008; Smyth & Pennebaker, 2008) and this protocol continues to be investigated today. "Emotional disclosure" writing tasks have been

shown to improve mental and physical health in a variety of people. For example, patients with asthma, rheumatoid arthritis, Human Immunodeficiency Virus (HIV), chronic Epstein Barr infection, and who have had skin biopsies all demonstrated improvement in physical measures including pulmonary function, range of motion, viral load and lymphocyte counts, and wound healing (Easterling, et al., 1994; O'Cleirigh, Ironson, & Fletcher, 2008; Petrie, Fontailla, Thomas, Booth, & Pennebaker, 2004; Smyth, 1999; Smyth, Stone, Hurewitz, & Kaell, 2009; Weinman, Ebecht, Scott, Walburn, & Dyson, 2008).

Individuals with breast cancer, general anxiety disorders, post traumatic stress disorder, and the bereaved elderly show improvement in measures of psychological well-being after engaging in structured journal writing (Caplan, Haslett, & Burleson, 2005; Davidson & Robison, 2008; Goldman, Dugas, Sexton, & Gervais, 2007; Smith, Anderson-Hanley, Langrock, & Compas, 2005; Smyth, Hockmeyer, & Tulloch, 2008). Patients with pain syndromes show improvement across several measures including the ability to deal with pain on a daily basis, improved quality of life, and a decrease in pain itself (Day, 2001; Graham, Lobel, Glass, & Lokshima, 2008; Junghaenel, Schwartz, & Broderick, 2008; Norman, 2000; Rosenberg, et al., 2002). Researchers have also concluded that journal writing may be especially good for stigmatized groups, those with limited access to other resources such as support groups, with those who are interpersonally distressed, and with individuals who are typically non-expressive (Banck & Grey, 2005; Junghaenel, et al.; Smyth, Anderson, Hockemeyer, & Stone, 2002; Swanborn, Boyce, & Greenberg, 2008).

Positive health and behavioral effects have been found with maximum-security

> prisoners, medical students, community based samples of distressed crime victims, arthritis and chronic pain sufferers, men laid off from their jobs, and women who have recently given birth to their first child. These effects have been found in all social classes and major racial/ethnic groups in the US and in other countries (Pennebaker, & Seagal, 1999, p; 1245).

This writing typically follows the directions given in the Pennebaker & Beale study (1986) and involves the participants writing about their deepest emotions and feelings related to an event or events ("emotional disclosure"). However, several alterations to the original design have been attempted with approximately the same degree of success. Writing for as little as two minutes or for as much as one hour at a time and the use of letters, email, and scrapbooking have all proven to have positive health benefits (Burton & King, 2008; Chung & Pennebaker, 2008; Davidson & Robison, 2008; Singer & Singer, 2008). And the event about which the participants write need not be a traumatic or negative one; writing about intensely positive events had the same results (Frattoreli, 2006; Singer & Singer).

Why is emotional disclosure writing so beneficial? There have been numerous theories in the nearly three decades of research on this topic. Cognitive theories evaluate the way an individual processes traumatic experiences in relationship to his or her basic underlying assumptions about life and the world itself. In order to diminish the stress related to an event, the person has to change his or her assumptions or learn to integrate the experience while keeping the old assumptions intact. Disclosing information about highly charged events unleashes the emotions that are tied to the event so the person can process them, leading the person to make sense of the event, increasing predictability and

control (Easterling, et. al., 1994; Mann, 2001; Miller, Pinnington, & Stanley, 1999; Pennebaker & Seagal, 1999; Singer & Singer, 2008; Smith, Holcroft, Rebeck, Thompson, & Werkowitch, 2000; Smyth, 1998; Snyder & Wieland, 2003). Pennebaker & Francis (1996) postulated that repressed memories cause stress and verbalization allows one to organize and better manage the event.

Creating meaning through written disclosure also might allow one to gain some perspective on the event (Youga, 1995). Just the activity of expressing oneself can be seen as cathartic. However, mere expression does not seem to be beneficial without evidence of cognitive processing (Horneffer & Jamison, 2002; Pennebaker & Seagal, 1999; van Middendorp & Greenen, 2008). That translation of events and emotions into words has the power to help us move on beyond our traumatic experiences (Pennebaker & Seagal, 1999). Unfortunately, no one theory has been able to adequately explain this phenomenon (Smith, et al., 2005). As Smyth and Pennebaker state "The secret of the sauce is likely the interaction of multiple factors across multiple levels of a complex system" (2008, p. 3).

But how does writing about traumatic or stressful events lead to improved physical health? Pennebaker and Seagal (1994) write "converting emotions and images into words changes the way the person organizes and thinks about [them]" (p. 1248). Smyth (1998) agrees: "Specifically, written emotional expression leads to the transduction of the traumatic experience into a linguistic structure that promotes assimilation and understanding…" (p. 174-5). Put simply, writing helps people make sense of the world, and the stressors, around them. Without being able to make sense of a stressor, the body uses valuable physiologic resources (neurohormonal, neuroanatomical,

and immunological) attending to the physical stress produced by the stressor. When one is able to process and comprehend the stressor, it frees those physiologic resources to combat disease, pain, injury, and disability. Smyth writes, "The strong effect on physiological measures provides support for the biological impact of writing" (p. 180).

So it can be shown that writing about a traumatic or stressful event (written disclosure) leads to improved health as measured by numerous physiologic variables. What about those with CBP, or other chronic pain patients, who voice dissatisfaction regarding their quality of life? One would assume that written disclosure would improve QOL. However, there are very few studies addressing journal writing and QOL specifically in patients with chronic pain and none examining this in patients with chronic back pain. Norman (2000) found that women with chronic pelvic pain rated the intrusiveness of pain on their daily lives lower after a disclosure writing intervention. She found "Although the women who expressed insight remained in pain and distressed, disclosure improved their QOL…" (p. 95).

Therefore, what the reader of health care literature is left with is a lack of research that distinctly describes quality of life *from the patient's point of view* and virtually no studies exploring the relationship of chronic back pain, journal writing, and QOL.

Conclusions and Summary

Chronic back pain is a pervasive problem in the industrialized world with enormous personal and national costs. Nurses are one group of people who suffer from back pain in higher than average numbers. Treatment of CBP has evolved (at least in the literature, if not consistently in practice) from diagnosis and treatment of a definitive pathological abnormality, to treating pain as a multi-dimensional phenomenon, to an

emphasis on the QOL of persons suffering from CBP. Many patients with CBP have turned to complementary and alternative medicine in a quest for "healing" not cure. Journal writing is one such avenue. Journals can also become primary source material for researchers to study.

Much of the research done on QOL and HRQOL is fragmented and is unable to explicate the lived experience of participants in a holistic and salient way. Therefore I turned to phenomenology to research this topic. The following chapter will detail the specific research methodology and methods I used in this study.

CHAPTER THREE

METHODOLOGY AND METHODS

This chapter provides a detailed description of the research methodology and specific research methods I used for my study. First I will make a distinction between methodology and methods, then I will go on to discuss in detail the tradition of research I chose to employ for this study, including its background and development. Finally I will turn to the specific methods I employed. This chapter ends with a robust discussion of rigor.

Methodology v. Methods

In describing the methods used in any research study, one must draw a distinction between the terms *methodology* and *methods* in order to fully appreciate the decisions the researcher has made. *Methodology* refers to the general background of the study's origins: the philosophy that guides it, the researcher's assumptions and worldview, and the choices he or she makes when determining how to design a study (Jackson, Drummond, & Camera, 2007; Silverman, 2005; van Manen, 1990). Methodology answers the "why" questions in research: why collect or analyze data in this specific way for this specific topic (Jackson, et al., p. 22). What is important methodologically is that one chooses a philosophical framework—a methodology--that suits the research question (Barkway, 2001; Silverman). In contrast, *methods* are the specific techniques one deploys during the course of a study; the specific research strategies chosen from an almost limitless array of theoretical or specific procedures that allow the researcher to collect and analyze data (Silverman, van Manen). A discussion of methods yields answers to the "how" questions (Jackson, et al., p. 22). Our procedures "allow us to

proceed" (van Manen, p. 28). Although a plethora of research procedures already exists, according to van Manen, one may need to invent new techniques for a specific study within the theoretical orientation of the study.

Tradition of Inquiry

Qualitative Approach

Qualitative research comprises a diverse set of research methods (Maggs-Rapport, 2000, Silverman, 2005) and "multifaceted philosophies" (Jackson, et al., 2007, p. 23) suitable for exploring the meanings individuals have about the world in which they live and the experiences they have had within the contexts of their lives and relationships (Armour, Rivaux, & Bell, 2009; Creswell, 2007; Gadamer, 1960/1989; Maggs-Rapport, 2000, Merriam, 2002; Morse & Field, 1995; Morse & Richards, 2002; Silverman, 2005). Qualitative researchers describe or interpret the participants' world to make "visible" something only the participant knows (Creswell, p. 82). These methods are best for understanding and appreciating rich detail in complex data (Creswell; Morse & Richards; Silverman).

Although there are several families or types of qualitative research, they all share some similarities. These families, or types of qualitative research are designed to a) best explore topics about which little is known, b) utilize an inductive data analysis strategy that works through various "levels of abstraction" (Creswell, 2007, p. 43), c) recognize the vital role of the researcher as the primary tool for data collection and analysis, d) produce findings that are richly descriptive, e) occur in natural settings, f) employ multiple sources of data, g) utilize an emerging design, and h) give us a holistic account from the participants' viewpoint (Creswell; Merriam, 2002; Morse & Field, 1995; Morse

& Richards, 2002; Silverman, 2005). Qualitative research may also be used when traditional quantitative methods do not fit the topic (Creswell).

In contrast to quantitative research, the qualitative researcher makes no attempt to impose controls on the conditions under which the study is conducted and the researcher is not trying to predict future outcomes or test hypotheses; instead what is sought is a rich, detailed understanding of a complex human situation and/or behavior while acknowledging that there is no single definition of reality (Creswell, 2007; Maggs-Rapport, 2000; Merriam, 2002; Morse & Field, 1995; Morse & Richards, 2002). Also, in contrast to many quantitative studies, smaller samples are used as the researcher is looking for depth and detail, not the ability to generalize to other populations or conditions (Armour, et al., 2009; Creswell; Merriam; Morse & Field; Morse & Richards; Silverman, 2005). Another difference from quantitative research is the need for the researcher to write persuasively (Creswell).

I chose to use qualitative methods for this study for several reasons. First, I wanted to explore the topic of the lived experience of chronic back pain (CBP) as it relates to nurses' quality of life (QOL) in greater detail than the current literature affords. I thought a qualitative understanding would be a better fit for this topic because I believe the effects of CBP on QOL cannot be adequately explained or understood in the context of pre-determined scales and tools. I believe that how people describe their QOL and the effects of CBP cannot be separated from the contexts of their daily lives: the relationships, work activities, and physical and psychological well being that make up essential parts of them. All of these rationale show that the use of qualitative methods

was well chosen. To best explore this topic within my beliefs, I used a phenomenological approach.

Phenomenology

Phenomenology as a specific approach has been called a "descriptive, interpretive, and engaging mode of inquiry from which to derive the essence of an experience" (Morse & Field 1995; Morse & Richards, 2002, p. 44). It "seeks to reveal and convey deep insight and understanding of the concealed meanings in everyday life" (deWitt & Ploeg, 2006, p. 217). Often exploratory in nature, phenomenological research can result in a product that is "rich and insightful" and should ring true to its readers (Morse & Field, p. 7). Phenomenology pays attention to the data exactly as it emerges and does not let theory drive the research project (Merriam, 2002; Sadala &Adorno, 2002).

Concepts and goals. Phenomenology's origins lie in psychology and especially philosophy (Creswell, 2007; Merriam, 2002; Morse & Richards, 2002). Creswell has elaborated on the four broad philosophical assumptions inherent in phenomenology. First is returning to the "traditional tasks of philosophy" (p. 58) which originally entailed searching for wisdom. Second "a philosophy without presuppositions" (p. 58) means the researcher must somehow put aside pre-existing judgments and biases to see the phenomenon as participants see it. This concept is variously known as *epoche*, *bracketing*, or the *phenomenological* or *transcendental reduction* (Creswell; Merriam; Moustakas, 1994). There are controversies regarding the most appropriate ways of carrying out the epoche (Laverty, 2003; Polkinghorn, 1983; van Manen, 1990); I discuss this topic in further detail in a subsequent section of the chapter.

The third assumption, "the intentionality of consciousness" (p. 59) refers to individuals always being focused on some object. Consciousness of the object affects its reality and is a rejection of Cartesian duality (Creswell; Koch, 1996; Merriam; Stewart & Mikunas, 1990). Intentionality of consciousness leads a person to be able to grasp the phenomenon directly (Laverty, 2003) and is vital to understanding. Fourth is the "refusal of the subject-object dichotomy" (p. 59). There is a relationship between the knower and what is known, and the knower can change this reality (Creswell, Laverty, Merriam).

The goal of phenomenology is to accurately describe the "meaning of the lived experience" (Creswell, 2007, p. 125) of several people who have encountered a common phenomenon. The researcher's task is to distill narrative data into a description of the essence of the phenomenon, to "grasp…the very nature of the thing" (Merriam 2002; Morse & Field, 1995; Moustakas, 1994; van Manen, 1990, p. 177). An accurate rendering of the essence will provide the reader with a deep, rich, and full understanding of the meaning the experience has for those who have had it (Creswell; deWitt & Ploeg, 2006; van Manen). The result is a description of what the participants experienced and how they experienced it, not an explanation of why it occurred (Morse & Field; Moustakas; Sadala &Adorno, 2002; Stewart & Mickunas, 1990).

Phenomenology has become an increasingly popular method of research within the health sciences, particularly in nursing, where sensitive issues are often the topic of inquiry (Donalek, 2004; Vivilaki & Johnson, 2008; Wimpenny & Gass 2000). It is considered an appropriate approach and is a "particularly fruitful way to gain the insight necessary for sensitive and effective care" which can be accomplished by a thorough

understanding of the world in which the participants live (Donalek, p. 516; Sadala & Adorno, 2002).

Historical background. The term "phenomenology" is derived from the Greek *phaenesthia*, which means "to show itself" (McConnell-Henry, et al, 2009) or as alternately cited, from the Greek *phainoemn* (appearance) and *logos* (reason) (Gearing, 2004). It is generally understood to mean those things that show themselves to us (Gearing; Vivilaki & Johnson, 2008). The term first began appearing in philosophy texts in the mid-1700s, but it was Georg Wilhelm Friedrich Hegel (1770-1831) who first elucidated a specific technical meaning in 1807. Hegel used the term to describe a science in which describing what one perceives is paramount as knowledge appears to consciousness through the perceptions and seeing that occur in our experiences (Kochelmans, 1967; Moran, 2000; Moustakas, 1994). According to Moran, phenomenology is defined as " a science of every kind of object where object means whatever is encountered in consciousness and is concerned with the concrete acts of meaning" (2000, p. 82).

Foundational Development of Phenomenology

The two main branches of phenomenology are those of Husserl (empirical or transcendental) and the hermeneutic method of Heidegger (Creswell, 2007; McConnell-Henry, Chapman, & Francis, 2009; Laverty, 2003; Lopez & Willis, 2004; Moran, 2000). The specific approach chosen by the researcher should be congruent with the philosophical implications found in the research question and within the researcher's world view (Caelli, 2001; Creswell, 2007; Koch, 1996; McConnell-Henry, et al).

Edmund Husserl and Transcendental Phenomenology

The German philosopher Edmund Husserl (1859-1938) is widely known and credited as the father of phenomenology. Originally a mathematician, Husserl was seeking to reawaken the science of philosophy, to better understand logic, and to generate a theory of knowledge (epistemology). He developed phenomenology as an alternative to using the positivist paradigm of the natural sciences in psychology, a practice he felt was inappropriate because the objectives of the two differed so much (Barkway, 2001; Gearing, 2004; Koch, 1995; Maggs-Rapport, 2001; McConnell-Henry, et al., 2009; Moran, 2000; Morse & Field, 1995; Polkinghorn, 1983; Sadala & Adorno, 2002; Sokolowski, 2000; Stewart & Mikunas, 1990). He felt the proper application of psychology was to examine the rich experiences embedded within the lived world of human beings (McConnell-Henry, et al.; Moran). His inspiration came from Franz Brentano, who claimed that natural sciences should focus on physical phenomena and human sciences should be directed towards mental phenomena (Moran, 2000; Moustakas, 1994).

Husserl's phenomenology was an attempt to abandon the traditional way of engaging in philosophy and was a radical re-thinking of its processes (Moran, 2000). His system emphasized attempts to get at the truth as it presents itself directly to consciousness and stressed careful description as a means of finding truth (McConnell-Henry, et al., 2009). Husserl believed that one could encounter absolute and universal truths by the proper contemplation of a phenomenon, accomplished by remaining faithful to objects as they are given to us in our conscious awareness (givenness) and that this

evidence, combined with transcendental contemplation, is the proper source for knowledge (Laverty, 2003; Lopez & Willis, 2004; Moran).

Husserl was famous for saying "Back to the things themselves" (McConnell-Henry, et al., 2009; Moran, 2000), a reference to his belief that knowledge stems from careful observation and description of the things themselves, which is the world as one experiences it or more simply, lived experiences. Husserl made no attempt to explain these phenomena but strove to describe their essences (Laverty, 2003; McConnell-Henry, et al., 2009; Moran; Sadala & Adorno, 2002). As Moran explains it, Husserl's phenomenology "is a return to what is directly given in exactly the manner in which it is given" (p. 127). These experiences were "intuitively seizable" (Moran, p. 1); in other words, we can know them through our intuition by grasping phenomena directly and pre-reflectively. Through our intuition, we are able to grasp the whole through the parts (eidetic intuition) and can "clearly perceive of things as the things themselves" (Moran, p. 122). To Husserl, intuition was the highest form of knowledge (Moustakas, 1994).

Intentionality. To understand this transcendental phenomenology, we must grasp the concept of intentionality: an Aristotelian philosophy espousing that the conscious mind is always directed towards an object (Kochelmans, 1967). First conceptualized by Brentano, Husserl expanded on this notion, believing that knowledge comes only from the conscious awareness of the mind as it is directed toward some object, whether that object is real, imagined, in memory, concrete, indistinct, vague, or exists only in language or fantasy (Giorgi, 1997; McConnell-Henry, et al., 2009; Moran, 2000; Moustakas, 1994). This belief was directly counter to the prevailing notions of naturalism, which proposed that all phenomena can be explained through the laws of nature (Moran).

Husserl's notions also went counter to the Cartesian concept of a subject-object duality, which was a dominant theory for centuries (McConnell-Henry, et al.; Moran).

When we engage in intentional contemplation, we utilize two important concepts: *noema* and *noesis.* Noesis is considered the actual act of thinking; the noema is what is thought. In our usual everyday thinking, we focus on objects as a matter of habit; Husserl thought we needed to learn to reflect on the noema in a way that is not normal or natural to us in order to fully comprehend our lived experiences and to gain knowledge. The noema is not the actual object itself about which we think but the phenomenon of encountering the object. The relationship between the noema and noesis leads to making meaning about our world and is an essential part of intentionality (Moran, 2000; Moustakas, 1994).

Husserl agreed with Descartes and Kant that meaning or reality was, in fact, subjective (Moustakas, 1994; Moran, 2000). Yet he viewed his phenomenology as a true science and wanted to introduce some mechanism for demonstrating objectivity and rigor which were central characteristics within the positivist world of the natural sciences and which he felt would lend phenomenology credibility within the scientific community (McConnell-Henry, et al., 2009). Husserl felt he accomplished this through what he described as his greatest discovery, variously called the epoche, bracketing, or phenomenological/transcendental reduction (Creswell, 2007; Gearing, 2004; Laverty, 2003; Lopez & Willis, 2004; Merriam, 2002; Moran; Moustakas; Vivilaki & Johnson, 2002).

The epoche. Epoche is from the Greek and means to abstain from judgment. The Greek Sceptics believed that when one is confronted with arguments that carry equal

weight, one should abstain from making a decision or choice since there is no prevailing evidence favoring one argument over the other. The Sceptics felt that this stance would encourage openness and tolerance of differing opinions (Moran, 2000; Moustakas, 1994).

Husserl felt that we spent our conscious time within what he called the natural attitude, our natural way of viewing and interacting with the world which included clouding every experience with our judgments, preconceived notions, "folk wisdom and a smattering of scientific knowledge" (Moran, 2000, p. 11). These features of our existence obscure our vision of our lived experiences and tend to lead us to interpreting rather than truly seeing the phenomena we experience (Giorgi, 1997; Maggs-Rapport, 2001). In what has been described as the "central paradox" (Moran, 2000, p. 15) of transcendental phenomenology, Husserl rejected Cartesian dualism by completely rethinking it. He proposed that we need to suspend our natural attitude by engaging in the epoche which is a way of bracketing all our presuppositions, biases, assumptions, theories, preconceived ideas, and prior knowledge or experiences in order to focus directly on phenomena as they appear to us, viewing them freshly (Laverty, 2003; Lopez & Willis, 2004; Moran; Moustakas, 1994).

By engaging in the epoche, we can view the lived experience (our life-world) and grasp it intuitively before embedding it within our linguistic structures and plying it with meaning (Gearing, 2004; Giorgi, 1997; McConnell-Henry, et al., 2009; Laverty, 2003; Lopez & Willis, 2004; Moran, 2000). Once we can see the lived experience or phenomenon clearly, we can know it; in other words, with bracketing we can focus on what is inside the brackets (a nice metaphor considering Husserl's background) resulting in information that is truly epistemological (Gearing; McConnell-Henry, et al.). When

the researcher has been able to successfully execute the epoche, he or she is "led back into the domain of the pure transcendental subjectivity"; Husserl believed that "without this leading back, this reduction, genuine phenomenological insight would be impossible" (Moran, p. 2). This suspicious questioning of the natural attitude, the requirement of engaging in the epoche, became the "very essence" of transcendental phenomenology (Chaeli, 2001; Moran, p. 145).

It is important to note that although Husserl felt that the epoche was his greatest discovery, no clear definition of it ever surfaced and he used it in various different ways, as do contemporary researchers (Gearing, 2004; Vivilaki & Johnson, 2008). Some authors use the terms epoche, bracketing, and phenomenological or transcendental reduction interchangeably while others put forth specific definitions for each term. "Bracketing" has been used both to mean focusing on what is inside the brackets (the lived experience itself) without the influence of what is outside them, as in a mathematical equation (Gearing; McConnell-Henry, et al., 2009), and, alternatively, to bracket the researcher's own biases and presuppositions in order that they do not influence the description of the phenomenon (Creswell, 2007; Merriam, 2002; Moustakas, 1994). No matter which of these phrases is used, the common theme is an attempt to keep our natural attitudes from "creeping back" into our description of the phenomenon, allowing us to see it from a presuppositionless stance while engaging directly with the experiences themselves (Chaeli, 2001; Gearing; Laverty, 2003; Lopez & Willis, 2004; McConnell-Henry, et al., 2009; Moran, 2000). Husserl felt this process was so important he claimed that "he who misunderstands the reduction is lost" (Moran, p. 147).

The essence of the phenomenon. Once the epoche has been accomplished, the researcher is able to view the phenomenon freshly, without bias (transcendentally, focusing on the meaning inherent in the phenomenon itself), giving each piece of data equal weight (horizontalization). He or she can concentrate on a careful description which leads to the other major component of transcendental phenomenology, the search for the essence of the lived experience (Creswell, 2007; Donalek, 2004; Gearing, 2004; Maggs-Rapport, 2001; Merriam, 2002; Moustakas, 1994; Munhall, 2001). The essence has been described as the fundamental features of the experience that should immediately ring true to those who have had the experience (Creswell; Donalek, 2004; Laverty, 2003; Lopez & Willis, 2004; Morse & Field, 1995; Morse & Richards, 2002; Moustakas; Munhall; Silverman, 2005; van Manen, 1990). It is the most essential components of the phenomenon.

When attempting to arrive at the essence of the experience, the researcher engages in transcendental reflection and imaginative variation: a process in which the researcher tries to imagine the phenomenon without some aspect considered part of the essence. If the phenomenon remains as it was, this component was not part of the essence. If however, the variation would render the phenomenon irretrievably altered, then the researcher has found the true essence (Laverty, 2003; Lopez & Willis, 2004; Merriam, 2002; Moran, 2000; Moustakas, 1994; van Manen, 1990). The essence of the phenomenon is that which remains after everything else is stripped away (Moran). The essence of the phenomenon leads to meaning and this ultimately leads to the creation or extension of knowledge, attaining Husserl's goal of epistemology (Moran; Moustakas).

Husserl's work attracted much attention and his lectures drew numerous superior students, many of whom went on to influence the future directions of phenomenology. His most eminent student, Martin Heidegger (1889-1976), is considered one of the most predominant philosophers in history and his influence drew phenomenology away from the transcendental, epistemological stance towards a new view of ontologic, hermeneutic phenomenology (Laverty, 2003; Lopez & Willis, 2004; Moran, 2000).

Heideggerian Hermeneutic phenomenology

Hermeneutics is derived from the Greek verb *hermeneusin* or *hermeneuein* and noun *hermeneia* and means to understand or to interpret (Allen & Jensen, 1990; McConnell-Henry, et al., 2009). Originally "hermeneutics" referred to the discipline of critical interpretation of biblical texts (deWitt & Ploeg, 2006). The German philosopher Schleiermacher was the first to use the term hermeneutics in a philosophical context (Chang & Horrocks, 2008; Gadamer, 1960/1989). The words hearken back to the Greek messenger god Hermes who translated what humans could not understand into a form they could grasp and suggest the process of making something unintelligible, understandable (Chang & Horrocks, 2008; Heidegger, 1927/1962).

Heidegger transformed traditional transcendental phenomenology by abandoning many of Husserl's most important concepts, including intentionality, transcendentalism, what he felt was Husserl's acceptance of Cartesian dualism, the epoche or bracketing, and the focus on mere description. Heidegger was more interested in the meaning of being, or what he termed Being-in-the-World and he aimed to determine the underlying meaning of experienced phenomena as they manifest themselves to people who construct meaning for them within their own social contexts (Gearing, 2004; Mischler, 1986;

Moran, 2000; Morse & Field, 1995). He was most particularly interested in the meaning of being as it related to time (McConnell-Henry, et al, 2009; Moran). As an ontologist, Heidegger thought that knowing only comes from interpretation and understanding and that description without interpretation was meaningless (Gearing; Laverty, 2003; Lopez & Willis, 2004; McConnell-Henry, et al.; Moran).

A central belief of Heidegger was that while phenomena are things that show themselves, they may not show themselves as they actually are, so phenomenology cannot stop at simple description but must rather rely on interpretation of texts, the basis for his use of hermeneutics (Moran, 2000). For Heidegger, discourse was paramount. He translated the second part of phenomenology (*logos*) as discourse rather than concept, citing its etymological roots as binding together or gathering into a synthesis in order that the phenomenon can be seen (Moran). Discourse, or talking, is how individuals describe their experiences of being in the world and is the basis upon which interpretation is focused (Chang & Horrocks, 2008; Heidegger, 1927/1962).

Linguistics is vital to hermeneutic phenomenology. The way we encounter things is entwined within our use of language and the way we disclose things relates to Dasein, or how we are in the world (Moran, 2000). Heidegger lamented that one of the major threats to the continued meaningful existence of humans is the metamorphosis of thinking into a type of "technical information processing" (Moran, p. 244) that leads us to become homeless in an ontological sense. As Moran writes, "…genuine philosophy is a kind of homecoming, a thinking back from our current sense to finding our place and preserving what we have found. Language is the house of being. In its home human beings dwell" (p. 244). This is an appropriate statement, consistent with Heidegger's wish to move

language from merely being a rule-bound grammatical structure to a creative, poeticizing activity (Moran). The use of speech and language is how our existence is made manifest and understandable, teasing out the hidden meanings within our words (Maggs-Rapport, 2001). Through language, a dialogue takes place between the researcher and texts derived from those participating in the research project (Vivilaki & Johnson, 2008). This language allows the researcher and the object of research to exist in relationship and co-create meaning (Armour, et al., 2009; Lincoln & Guba, 2005).

Dasein. Dasein can be translated as "there-being" and is the "central structure of human existence" (Moran, 2000, p. 222). Dasein is what allows humans to wonder about themselves and the meaning of their own existence (Koch, 1996; McConnell-Henry, et al., 2009). While Dasein is the essential feature of human existence, one "cannot approach it directly" as it is unique to each person, coming about from acts that cause "anxious concern" (Moran, p. 223). It cannot be measured objectively. Dasein means to always be in the world, sharing and relating with others in an interpretive manner (Maggs-Rapport, 2001; McConnell-Henry, et al.; Moran). Heidegger viewed people and their worlds as inextricably tied together with bands of historical, cultural, and social contexts (Laverty, 2003; Lopez & Willis, 2004; Moran). Again, language is important here; we are already in the world with others and we use language to convey meaning to those others in our world (Maggs-Rapport). Language allows the phenomenon to speak for itself (McConnell-Henry, et al.).

The concept of Dasein is made clearer when one understands the notion of the hermeneutic circle. Using language and the researcher's position of Being-in-the-World to connect to the participants and their lived experiences, the researcher moves back and

forth between the parts and the whole of the text, questioning assumptions and findings, creating more and more possibilities, until the researcher is able to elucidate the true essence of the experience (McConnell-Henry, et al., 2009; Moran, 2000).

The epoche. Perhaps nowhere was the difference between Husserl and Heidegger's thinking so great as it was concerning the epoche (Laverty, 2003; Lopez & Willis, 2004; McConnell-Henry, et al., 2009; Moran, 2000). While Husserl claimed that without proper application of the epoche phenomenology would not be possible, Heidegger viewed it as neither desirable nor even possible owing to the innate interpretive nature of human beings (Gearing, 2004; McConnell-Henry, et al.; deWitt & Ploeg, 2006; Wimpenny & Gass, 2009). Not only did he reject the notion of epoche's possibility, Heidegger argued that the ability of the researcher to interpret the texts required a priori knowledge and understanding as a person who has the experience of Being-in-the-World with the research subjects and their experiences (McConnell-Henry, et al.). In fact, without any prior knowledge or experience, the researcher would not even know which questions were appropriate to ask and which experiences were appropriate to investigate (Gearing, 2004; McConnell-Henry, et al.; van Manen, 1990). Understanding occurs within a context of shared experiences that we are raised in, not because we learn about them and develop rules to guide our comprehension of them. Essentially this means we all live in a shared hermeneutic circle of understanding already (Chang & Horrocks, 2008).

Temporality. As one might surmise from the title of his seminal work *Being and Time* (1927/1962), time was paramount to Heidegger's hermeneutic phenomenology. Temporality was one of Heidegger's four existentials: lived space (spaciality), lived body

(corporeality), lived human relation (relationality or communality) and lived time (temporality) (Heidegger, 1927/1962; Moran, 2000; Morse & Field, 1995; van Manen, 1990). In Heidegger's view, neither knowledge nor experience can be gained without the influence of time (McConnell-Henry, et al., 2009). The definitive goal of Heideggerian phenomenology is to uncover the meaning of being in relation to time. This is done through historic and linguistic interpretation (Moran). When we first encounter an object in our consciousness, we view it in a way that is influenced by our interests and goals. Only with later reflection can we come to view this object or phenomenon as "present at hand," in other words, as it really exists without our needs superimposed upon it (Moran). All understanding comes about as we pass through our initial understanding, through the influence of time on our thinking (Heidegger, 1927/1960). The hermeneutic circle of understanding also forces us to recognize the temporality and subjectivity of truth (Moran).

Many subsequent phenomenologists have expanded on both Husserl and Heidegger's works and from this background the work of Max van Manen has been developed.

van Manen's Human Science Phenomenology

Max van Manen is a professor of education at the University of Alberta, Canada, who views phenomenology as essential for human science research because what is studied is "essentially not replaceable" (van Manen, 1990, p. 7), and leads to "critically oriented action" (p. 154). For van Manen, the goal of phenomenological research is to find the essence of experiences: universals people sharing the experience will recognize. A good description of the essence allows us to grasp a phenomenon and its importance in

a new or fresh way. He stresses silence in which reflection can occur: silence from which the words originate, silence of the unspeakable, silence as a way to be attentive and hear what the other is really saying. Phenomenology is a "thoughtful" activity, "a heedful mindful wondering about the project of life" (p. 12). His emphasis on the use of language and interpretation clearly place him in the hermeneutic phenomenology category (McConnell-Henry, et al., 2009).

van Manen (1990) emphasizes that phenomenology has no specific method but rather is an attitude or an approach to research. Because his methodology is so flexible, it is possible to adapt it to various circumstances without fundamentally changing its core values or contradicting its philosophical basis (Maggs-Rapport, 2000). van Manen elaborates on the six methodological themes that comprise phenomenology as he conceptualizes it: a) "turning to the nature of the lived experience" (p. 32), b) "investigating experience as we live it" (p. 31), c) "reflecting on essential themes" (p. 32), d) "the art of writing and rewriting (p. 33), e) "maintaining a strong and oriented relation" (p. 33), and f) "balancing the research context by considering parts and whole" (p. 33). Research for van Manen has a higher calling; not only can it lead to political or other action, it allows us to attach ourselves to the world and "become more fully part of it" (p. 5) and to become more fully developed as human beings.

The use of hermeneutics. As an otologist, interpretation of the phenomena is what van Manen (1990) seeks. The skillful application of hermeneutics is required to make sense of the phenomena individuals encounter in their lived world. As researchers we are interested in how people pay attention to their worlds and how they interpret their experiences (Armour, et al., 2009; van Manen). We are looking to examine the lived

world as it is experienced in its immediacy, "pre-reflectively", instead of how we "conceptualize, categorize, or reflect on it" (van Manen, p. 9) in order to gain a fuller and deeper understanding of the lived world as others encounter it. This is a difficult task because we encounter our world "preverbally" and intuitively, making description of even everyday occurrences difficult (van Manen, p.18). The goal of phenomenology is to distill a phenomenon (the lived experience) as it presents itself into one's consciousness into its essence, its universal structures (van Manen). Reminiscent of Husserl, we are looking for the nature of the very things themselves.

In order to uncover the essence of the lived experience, the researcher must engage in writing and reflecting upon texts. A research project relies on the investigator's ability to "transform the lived experience into a textual expression of its essence" (Morse & Field, 1995; van Manen, 1990, p. 10). In an eloquent passage, van Manen shows the beauty of the language and the art that can be phenomenology:

> "So phenomenology, not unlike poetry, is a poetizing project; it tries an incantative, evocative speaking, a primal telling, wherein we aim to involve the voice in an original singing of the world…We must engage language in a primal incantation or poetizing which harkens back to the silence from which the words emanate. What we must do is discover what lies at the ontological core of our being. So that *in* words, or perhaps better, *in spite* of the words, we find "memories" that paradoxically we never thought or felt before" (1990, p. 13).

van Manen agrees with Heidegger that the trilogy of language, thinking, and being are actually one construct that is at the core of our being and he describes the essence of a phenomenon as a "linguistic construction" (van Manen, 1990, p. 39).

Language is so important to van Manen, that two of the four sources of data include linguistic structures: "tracing etymological sources" and "searching idiomatic phrases" (p. 58, 60). Etymological sources may be valuable if they place the researcher in touch with the phenomena that led to the creation of a word; it could be a connection to a more genuine link with life. Idiomatic phrases arise from a deep wellspring of collective experiences (van Manen).

Temporality. Like Heidegger, van Manen acknowledges the importance of time in the phenomenological research of our experiences in the world. Reflection and understanding only occur in retrospect; one can never truly contemplate and understand a phenomenon as it occurs, but rather one must view the lived event *as* it occurred. Once the phenomenon has been experienced, the person can reflect upon it and describe it and the researcher can construct a meaningful interpretive description of it (van Manen, 1990).

The epoche. *v*an Manen (1990) acknowledges that since we usually investigate phenomena we ourselves have experienced, we do come to our projects with presuppositions, assumptions, and other considerations which certainly have the potential to interfere with our ability to see phenomena as others see them and to render a true interpretation of them. In fact he claims that we come to studies with too much, not too little information. However he questions our ability to forget everything we know about the lived experience under investigation. He posits that trying to forget will ultimately lead to that information insidiously "creeping back" into our reflections (p. 47). He is of the opinion that it is better to acknowledge these pre-understandings and to make them clear and explicit from the beginning.

Phenomenological investigations neither test nor construct theory nor do they problem solve. In van Manen's view, life precedes theory. In the case of professional practice, theory only comes with the insights and knowledge that result from reflection on past lived experience. A fuller, deeper, and richer understanding and appreciation of the human condition informs theory and in turn, leads us to concernful, thoughtful, advocative practice (van Manen, 1990). van Manen's philosophy closely mirrors my own and hence the choice of his methodology was appropriate.

Specific Methods and Study Design

Underlying Assumptions

According to Creswell (2007), a researcher needs to determine and make explicit the philosophical assumptions and worldview that underpin her or his research study. This conscious awareness and articulation of the theoretical underpinnings driving the research assists in designing a project that is appropriate to the goals of the study and helps maintain methodological consistency. These paradigms are "a basic set of beliefs that guide action" (Guba, 1990, p. 17).

Philosophical Assumptions and Worldview

I am oriented to ontology, looking at multiple views of reality as they are expressed by my participants. I relied heavily on the words of my participants to form my themes and I have tried to incorporate differing perspectives as they came about (Creswell). My worldview is decidedly that of a social constructionist. As described by Creswell, a social constructionist looks to find meaning and understanding in the world and searches for a broad, complex interpretation rather than choosing a narrow interpretation with few themes. Social constructionist research relies heavily on

participants' words themselves. Questions are "broad and general" (p. 21) so that the participants are free to create their own meanings, consistent with my view that concepts such as quality of life can neither be measured nor described in the context of numerical scales. My goal for this study was to understand how others make meaning of the experience of quality of life as it is impacted by chronic back pain. I also acknowledge that my interpretations are colored by my own experiences with chronic back pain and attempt to make those pre-suppositions clear from the start, while unbracketing them as my analysis unfolds (Creswell; Gearing, 2004).

Positioning myself. As described above, one problem in research is that we enter the research process with too much, rather than too little, knowledge. We must not use our pre-existing knowledge and understandings to interpret the phenomenon under study before we gain a clear picture of it from our participants (van Manen, 1990). I entered this study having lived with chronic back pain for 15 years. I left a job I loved in a busy, exciting trauma center thinking work was the primary cause of my back pain. I changed the way I do most things, other things I will not or cannot do at all. Back pain has affected my whole life. So my interest in back pain is deeply personal; I am strong in my orientation to the subject in a "unique and personal way" (van Manen, p. 20). This study and what I hope will be future research on CBP, QOL, and journaling represents a huge part of my life for the last 3 ½ years as I have worked my way through course work, always focusing on the prize at the end: finally getting to do the research and writing that is my "abiding concern" (van Manen, p. 31) and that has captivated me for so long.

Sample and Access

S*ampling strategy*

In qualitative research, and in phenomenology particularly, it is important to choose a sample of individuals who can inform the research process (Merriam, 2002). In phenomenology, a researcher needs to choose individuals who have all experienced the phenomenon under investigation and who are able and willing to talk about it (Creswell, 2007; Morse & Field, 1995; Morse & Richards, 2002; Silverman, 2005; van Manen, 1990). This type of sampling is called "purposeful sampling" (Patton, 2002, p. 169) or criterion sampling (van Manen), and presumes that the researcher knows which individuals will best provide data upon which she or he can reflect (Morse & Field, 1995). Samples are generally small so that the phenomenon can be investigated in its rich depth instead of providing information from large groups that can be generalized to other populations or situations (Armour, et al., 2009; Creswell; Merriam; Silverman). Snowball sampling is another technique used in qualitative research and occurs when one participant nominates another person whom he or she thinks fits the criteria and might be interested in participating (Merriam). Random sampling, used in quantitative research, is inappropriate for qualitative study and in fact may generate invalid results (Morse & Field).

There is no specific way to determine the number of participants needed in a qualitative study. This is opposed to quantitative research, where researchers base their sampling on statistical predictions of the number of participants needed based on possible errors and how confident one wishes to be in the results (Macnee & McCabe, 2008; Polit & Beck, 2010). In qualitative research, one seeks saturation; when saturation has been

reached, no new data will emerge if the researcher continues to collect data and all the negative cases have been fully investigated (Creswell, 2007; Morse & Field, 1995; Morse & Richards, 2002; Silverman, 2005; van Manen, 1990).

Criteria for participation

The criteria for participation in this study were 1) being a Registered Nurse and 2) having back pain for six months. The participants had to sign a consent form, be willing to complete the journal writing activity and the survey, and be willing to participate in an audiotaped interview. The interview requirement necessitated that participants live within reasonable driving time of Omaha, Nebraska.

Access/Recruitment

I contacted the Alumni Directors of local nursing schools via letter (see Appendix A), explaining my study and asking for their assistance in disseminating information about participation. I provided contact information that included my home phone number and a non-work related email account. I also contacted the participants in my two prior pilot studies (with Institutional Review Board [IRB] approval), asking if they would be willing to allow me to use their data in this study. All five pilot study participants assented. If a person was nominated by someone else, I gave the informational letter I had sent to alumni directors to the nominator and asked her to contact the potential participant directly. The potential participant could then contact me, so the two sampling methods were consistent in their approach.

Study sample

The sample for this study included 15 RNs with chronic back pain, five of whom had participated in my pilot studies. Of the ten other participants, nine were recruited

through their alumni directors and one was nominated by a peer of mine who knew about my study. This is in keeping with the traditions of phenomenology which emphasizes depth of detail from few participants (Silverman, 2005). The participants came from a diverse professional background with their original clinical practice areas being as follows: Intensive Care/Neonatal Intensive Care/Coronary Care, 4; Emergency Department, 2; Advanced Practice, 2; Labor and Delivery, 2; Operating Room, 1; College nurse, 1; School nurse, 1; General medical-surgical, 1; and Psychiatric/Geriatric nursing, 1. Interestingly enough, seven of the participants were in education, six as faculty and one in educational administration. One nurse was completely disabled, three nurses have since retired, and the other nurses are all still employed in nursing.

Ethical Concerns

Confidentiality

Primary ethical concerns included confidentiality and informed consent. Confidentiality was assured through several methods. First and foremost I audiotaped and transcribed all the interviews personally. I also was the sole transcriptionist for the journals. I kept data in a locked filing cabinet to which I have the only key. My electronic files were stored on a computer for which access requires a password. All participants were given a randomly-chosen pseudonym. Other individuals mentioned in the interviews or journals had their names deleted and replaced by a descriptor, for example "[My daughter] said…." All identifying dates were altered to the format of "19xx". Specific city, college, and institutional names were deleted and replaced with descriptors as well.

Informed consent

Approval for this study was obtained through the University of Nebraska-Lincoln IRB (see Appendix B). Participants signed informed consent forms (see Appendix C). Participants were informed that they could request the tape recorder be turned off at any time and that they could terminate their participation at any time. No participant requested either. The participants from my pilot study signed the consent form as well, in addition to having given consent to participation in the pilot.

Field Issues

I was prepared for three potential major field issues: malfunctioning equipment, inarticulate or rambling interviews, and tearful participants. Based on previous experiences, I had two tape recorders for each interview and recording ability was verified before initiating each interview. I had prepared an interview protocol (see Appendix D) that flowed from the central and sub-questions for this study (Creswell, 2007). My protocol was complete with prompts that I could use for participants who seemed "stuck" and unable to describe their experiences or for those whose interviews needed to be directed back on track. I tried to remain "constantly mindful" of the original questions (van Manen, 1990; p. 42); however, I was also prepared to allow participants to tell the story they wished to tell, taking me on their own journey (Moustakas, 1994). I provided small comfort measures such as coffee or water for the participants who chose to be interviewed in my office and I had tissues on hand for those who might become emotional.

Potential power hierarchy

A final issue I had to consider which also contained ethical ramifications was a potential power hierarchy between the participants and me. I had hoped that being a nurse myself would help ease some of the potential tension experienced by a participant. In my prior pilot studies, I added icebreaker questions and statements that I used to get the participant and me relating on a person-to-person level prior to the start of an interview (Moustakas, 1994). I was careful to keep these comments short so that I could honor the time commitment the participants had made for the interviews (Creswell, 2007).

I hoped my philosophical approach to the participants in my study would help prevent any feelings of a power hierarchy; I agree with Chang & Horrocks (2008) who explain the term *participant* as used in a phenomenological study. *Participant* includes both researcher and "subject" who exist together in the same world, sharing "the same precognitive background with the same preunderstandings or primordial understanding of the everyday world" (p. 286).

Risks

There were no identified risks for this study. However, discussing stressful events may evoke strong emotions and participants were informed of this possibility. I had contact information available for counseling services if needed; however no participant demonstrated emotional distress. While some emotions were evident during the interviews, no participant expressed or demonstrated difficulties related to this. This is consistent with Chung & Pennebaker's work (2008) that revealed little significant emotional distress from emotional disclosure. Morse & Field (1995) assert that the

occurrence of visible emotion is one way of confirming the validity of interviewing as a research technique.

Data Collection

Creswell (2007) describes qualitative data collection as a "series of inter-related activities" (p. 118) that must be appropriate for the methodology, the subject under study, and for the questions the researcher asks (Wimpenny & Gass 2000). During the data collection period, the researcher should not focus on the existing literature, but rather hold it at arm's length until she or he has emerging results with which to compare it (Morse & Field, 1995). The researcher should collect data until she or he feels saturation has been reached (Morse & Field). There are three frequently discussed sources of data for a phenomenological study: interviews, observations, and documents (Creswell, 2007; Merriam, 2002; Silverman, 2005); Creswell also includes audio-visual (AV) material. The researcher is also encouraged to keep field notes or a research journal (Creswell; Morse & Field; Silverman, 2005).

My study included audiotaped interviews, journals, and a brief survey. Although I did not request AV material, one participant did print her journal on paper printed on one side with photos of her daughter riding horses and lists of the daughter's equestrian accomplishments. I thought this might be significant since that participant is no longer able to ride, an activity she once enjoyed frequently.

Interviews

Many authors list the interview as the primary method of data collection in a phenomenological study, as this is the time participants can describe their experiences with the phenomenon of interest (Creswell, 2007; Maggs-Rapport, 2000; Merriam, 2002;

Morse & Field, 1995; Moustakas, 1994; van Manen, 1990; Wimpenny & Gass 2000). During conversations with others we are able to assign meaning to experiences (van Manen). Semi-structured and suppositionless, interviews should utilize open-ended questions, probes, silence, and excellent listening techniques in order to draw the participant into telling the researcher her or his story (Creswell; Merriam; Morse & Field; van Manen). The interviews should provide the researcher with rich data that aids in understanding the phenomenon as we become closer to the reality experienced by the participants (Maggs-Rapport, Merriam, van Manen, Wimpenny & Gass). The interview provides a much better picture of the experience under investigation than any tool could provide (Merriam).

Using anecdotes or narratives. A good interviewer will try to get her or his participants to tell stories illustrating their experiences with the phenomenon at hand. Similar to the concept of using fairy tales or proverbs to instill wisdom in an unsophisticated audience, a story or narrative account can help "make comprehensible some notion that easily eludes us" (van Manen, 1990, p. 116) and so is used as a specific method or device in phenomenological research. Narrative derives from the Latin *gnoscere* or *noscere*, which means *to know*. Narratives help illustrate truth through the wisdom and insight of the teller. The teller weaves a story of a particular event which then leads to understanding about a general topic or phenomenon when the researcher uses the narratives as case material or data for hermeneutic reflection. As such, narratives or anecdotes have great power and value in phenomenological research (van Manen).

I conducted in-depth audiotaped interviews with each participant. I let the participants choose the setting in which to be interviewed (Morse & Field, 1995). Eleven of the participants chose to be interviewed in my office, two people were interviewed in their offices, one person was interviewed in a restaurant, and one was interviewed in her home. The interviews lasted from 45 minutes to nearly 2 hours. As discussed above, I used an interview protocol complete with probes. Several of the nurses did become emotional during the interview, but there was a lot of laughter as well. Listening to the audiotapes, the spontaneity from the participants was noticeable and I felt honored to be trusted with their stories. An example of this spontaneity was when several participants trusted me enough to share information about their sexuality unprompted.

The audiotapes also show an appropriate balance of my time compared with theirs; these were their stories and my voice was mainly heard asking questions from the interview protocol and follow up prompts, with an occasional question for clarification. This balance and spontaneity, along with clarity in the stories, are considered criteria for rigor in interviewing (Wimpenny & Gass, 2000).

I transcribed each interview in it's entirely, including pauses and vocalizations (Creswell, 2007; van Manen, 1990). The purpose of transcribing the interviews is to create a text, or protocol, on which a researcher can reflect. van Manen refers to this as "protocol writing…generating original texts on which the researcher can work" (p. 63). Consistent with his concern with language, van Manen traces the phrase's etymological source to the Greek where it refers to the first draft of a work.

Journal Writing

Journals and other documents can provide insight into phenomena under investigation by providing rich and thoughtful data (Creswell, 2007; Merriam, 2002; van Manen, 1990). Although they may take either a structured or unstructured format, usually they have some structure provided by the researcher (Morse & Field, 1995).

Journal writing activity. The participants in my research study participated in a structured journal writing activity (JW) that included writing for 20 minutes a day, three days in a row in a quiet place where they would be uninterrupted. Participants were instructed to write about problems their back pain was causing them and their associated feelings. If they could not think of a back pain-related problem, they were instructed to write about any other problem they might have now. The instructions also included directions to not worry about grammar, spelling, or structure, but to concentrate on writing as vividly as possible (See Appendix E). This journal writing activity has been utilized extensively in the literature and has been shown to provide both physical and emotional well-being (Banck & Grey, 2005; Caplan, et al., 2005; Davidson & Robison, 2008; Frattaroli, 2006; Goldman, et al., 2007; Graham, et al., 2008; Junghaenel, et al., 2008; Norman, 2000; O'Cleirigh, et al., 2008; Pennebaker & Beale, 1986; Pennebaker & Seagal, 1999; Petrie, et al., 2004; Rosenberg, et al., 2002; Singer & Singer, 2006; Smith, et al., 2005; Smyth, et al., 2002; Smyth, et al., 2008; Smyth, et al, 2009; Smyth & Pennebaker, 2008; Swanborn, et al., 2008; Weinman, et al., 2008).

Survey Tool

The participants completed a 14-item survey (see Appendix F) that was developed during a class on survey methods I took as part of my course work. The main purpose of

the survey was to access basic background information about each participant without taking time in the interview itself. I was also interested in seeing how easy and beneficial the participants felt the JW activity to be compared with how consistently they followed the directions. Congruent with my disagreement with using numeric scales to measure a subjective experience, the questions included descriptors such as "extremely good," "remarkably good," or "satisfied" or had space for short written responses.

Despite this being predominantly a qualitative study, any tools used should be sound. Survey tools are generally used in quantitative studies, so as I developed this survey, I maintained vigilance to producing a tool that was valid and reliable and was created using a well-known source for survey methods. The structure of every aspect of the tool, including visuals and layout, incorporated the features of sound survey design as put forth by Dillman (2000).

Validity and reliability of the survey tool. Both validity and reliability indicate the degree of measurement error in a study. Measurement errors are always present to some degree but should be controlled for and eliminated as much as possible by using instruments that are valid and reliable. This is contrasted to random error, which causes inaccurate data due to uncontrollable and often unforeseen events, including variation in subject responses (Dillman, 2000). With a valid instrument, one can be confident that the survey is measuring what it is intended to measure and the data are an accurate reflection of the subject under study. Four types of validity are important: face, content, criterion, and construct (Dillman; Nolinske, 1995).

I assessed face validity of my survey tool by having a non-subject-matter expert (the writing expert at Nebraska Methodist College) assess the survey and provide

feedback about the ease of understanding and responding to the survey questions (Dillman, 2000; Nolinske, 1995). Classmates and faculty in my survey methods course also critiqued the proposed questions. Content validity is a second type of validity. Ensuring content validity includes having subject-matter experts review the survey (Dillman). I assessed content validity by asking two experts on chronic pain to review the questions for their salience to the topic. Five RNs, three of whom have chronic back pain, critiqued the survey as well.

Criterion validity involves comparing a new survey, or an existing survey being implemented on new populations, with a well-established survey. The researcher calculates a correlation coefficient between the two surveys and a correlation of 0.7 or higher indicates that the new survey is valid. By comparing the new test to a "gold standard" instrument, the researcher provides solid evidence that the novel approach is nearly as good, or just as good, as the established method (Dillman, 2000). I was unable to calculate criterion validity for this instrument for several reasons. While there are multiple well-designed and heavily tested surveys on back pain, on quality of life, on quality of life and chronic pain or other health problems, there are no surveys that specifically address the combination of quality of life, chronic back pain, and a prescribed journal writing experience. Although some specific items might be compared with items from other surveys, the sheer number of available surveys from which to pick and choose would make this a daunting task in order to evaluate validity on a few items at best. This survey was not applicable for tests of predictive validity as the survey was administered at the end of the prescribed journal writing activity and was not used for

predictive purposes (Dillman, 2000). Therefore I elected not to pursue confirming criterion validity.

When a survey, instrument, or other test is reliable, that means it will continue to collect the same data time and time again. A reliable instrument shows that any variance in results is due to a true difference in subjects and not to differences due to the instrument (Dillman, 2000; Nolinske, 1995). There are four types of reliability: test-retest (which includes intraobserver), alternate form, internal consistency, and interobserver (Dillman).

As this survey was a simple adjunct to a phenomenological study, extensive testing for reliability was not deemed necessary. However, during the survey course in which it was developed, I did demonstrate reliability by utilizing alternate-form methods. This involves asking the same question more than once, but wording it differently. Either the question itself or the answers can be re-worded as long as the meaning is not changed. I also changed the order of response sets by presenting answers in one format (great-good-fair-poor) then asking the same questions while reversing the answer option (Dillman, 2000). In that study, the survey did demonstrate reliability.

My survey asked three questions about quality of life, five about the presence of back pain, and six about the journal writing experience. Specific questions and their responses are presented and discussed in the following chapter.

Data Analysis

Phenomenological data analysis is inductive (Creswell, 2007; Merriam, 2002; Morse & Field, 2005; Silverman, 2005) and occurs simultaneously with data collection, often called the constant comparative method (Hatch, 2002; Merriam; Field & Morse;

Silverman). In the constant comparative method, the researcher starts with a small data set, perhaps one interview, and begins to develop emerging ideas for themes as this data is examined. Once these ideas are fleshed out, the fresh and untried themes are compared to subsequent data sets (subsequent interviews). The researcher should note patterns that she or he refines and names according to the actual words from the participants (Merriam; Morse & Field; Silverman). These are called *in vivo* codes (Glaser & Strauss, 1967). The researcher is hoping to obtain rich, thick descriptions that best fit and explain each and every piece of data on hand (Creswell, Merriam, Silverman). So as the process continues, the researcher is constantly searching for meaning derived from the words of the participants by coding and creating themes, the "central process" in phenomenology (Morse & Field, p. 127).

The researcher needs to be vigilant for negative cases, which appear to refute emerging themes (Creswell, 2007; Morse & Field, 1995; Whitehead, 2004). Rather than negating the study's finding, negative cases provide increased richness as they force the researcher to consider alternative themes and ideas (Morse & Field). The researcher also needs to distinguish between representative and anecdotal cases. Representative cases are those that appear often and show frequently-occurring constructs while anecdotal cases are those that are similar with each other, but appear infrequently. Anecdotal cases increase the detail and richness of the data (Morse & Field).

van Manen's Human Science Method

Within phenomenology there are several noted authors upon whose work researchers may pattern their own. I chose to use the human science methodology of Max van Manen (1990) to analyze my data. van Manen's approach consists of creating

protocols, or texts, full of narrative stories; using hermeneutic reflection; engaging in an arduous process of writing and re-writing in order to develop themes; and listening for the essence of the phenomenon. I used the three reading approaches advocated by van Manen (1990) in order to find my themes.

Developing Themes

The most critical step in phenomenological research is to discover the themes embedded in the texts by conducting a thematic analysis, or a "search for and identification of common threads that extend through an entire set of interviews, frequent concepts indicated by the data rather than concrete entities" (Morse & Field, 1995, p. 139). Themes can also be thought of as the structure of a phenomenon that allows us to find shape in the "shapeless" (van Manen, 1990, p. 88). Although van Manen claims that thematic analysis should not be a rule-bound process, he does give insight into how best to find themes through a list of techniques that specifically include "tracing etymological sources" and "searching idiomatic phrases" which have been described previously (pp. 58, 60). I was careful to allow all voices to be heard and considered all data, even contradictory data, in my thematic analysis (Creswell, 2007; van Manen), conducting an "authentic search" (Patton, 2002, p. 555) for what made the most sense of the lived experience instead of trying to force my data to fit into rigid categories (Patton, 2002; Whitehead, 2004).

Van Manen's (1990) method include three reading approaches to the data, the sententious approach, the selective approach, and the detailed approach. In the sententious approach, I read each text as a whole and tried to create a phrase that captured the meaning or significance of the entire experience to the participant. Initially, I started

by writing a paragraph about each text which I then attempted to boil down to a single phrase or sentence. This is followed by the selective approach in which I read each text several times, looking for phrases from the participants that seemed "particularly essential or revealing about the phenomenon" (van Manen, p. 93). When I found these phrases or sentences, I highlighted them. Finally I engaged in the detailed reading approach during which I went back to the texts, examining every sentence or grouping of sentences to see where it fit and what it revealed about the phenomenon. Each of these processes is designed to distill the description into the essence of the phenomenon by finding the commonalities among the texts (van Manen).

Reflecting, Writing, and Re-writing

Phenomenology, as a philosophy and way of approaching research, always requires thoughtful reflection in order to come into a more direct state of contact with the phenomenon (van Manen, 1990). As I read each text and worked through each level of reading, I spent time reflecting on my emerging picture of the lived experience of quality of life as impacted by chronic back pain. It was during this time that I wrote most of my research journal, engaging in imaginative variation, trying to put myself into my participants' place, trying on different names for themes and attempting to re-create their experiences in my mind. I also reflected on the phenomenon within the framework of the four existentials described by van Manen of lived time, lived space, lived body, and lived human relationship. Reflecting on one existential should cause one to reflect on the others as our existence is entwined within them (van Manen). I hoped this process would clarify and make the structures of the phenomenon and its meaning to the nurses explicit to me (van Manen).

The use of silence. Van Manen (1990) describes three kinds of silence that permeate this work and in which hermeneutic reflection is possible: literal silence, epistemological silence, and ontological silence. Epistemological silence denotes the knowledge we may actually have that is out of touch for us because it is currently beyond our linguistic capabilities. In my view, the epistemological silence is the place in which we struggle to put words to our pre-verbal cognitive awareness so as to make it known to others. Ontological silence is the silence of being or living, in which we discover and uncover the meanings we are seeking, a "dumb-founding" (p. 114) as we discover that we are in the presence of truth (Bollnow, 1982). As Bollnow describes it, our research activity should drift into silence the way a good conversation does, because it has fulfilled us. That quietude "marks the triumph of an effective human science text: to be silenced by the stillness of reflection" (van Manen, p. 114). It is because of this silence that our writing and understandings are made possible (van Manen).

As these understandings become visible to us in our silence, we need to write our texts as understanding can only be made visible to others through our words. Van Manen (1990) calls this "crafting a text" (p. 78) and he describes this more as poetry or creating art than scientific writing because, by being "…sensitive to the subtle tones of language, to the way language speaks when it allows the things themselves to speak" (p. 111), we are creating a text full of the "deep tonalities of language that normally fall out of our accustomed range of hearing" (p. 111) and we are bringing the richness of the phenomenon to an exterior presentation where it can be appreciated by others (van Manen).

Like a fine piece of art that requires working and re-working by the artist before she or he puts a signature to the finished product, we return time and time again to our texts in an attempt to create a work that is rich, deep, and strong (van Manen, 1990). In a beautiful passage, van Manen describes how the text makes the phenomenon explicit to others: "…it is in and through the words that the shining through (the invisible) becomes visible; phenomenology is like poetry, it…means more than it explicitly says (van Manen, p. 130).

I spent much time in silence with my texts, however; my reflection and attempts to write were complicated by the enormous amount of data I had from 15 interviews, some of which lasted nearly 2 hours, and 15 journals which were each many pages long. I found myself in the situation of not being able to organize and keep track of all the data I had. I felt quite literally as if I had a room full of multiple voices speaking to me all at once, competing for my attention, and yet I could not hear any of them clearly. It was at this point that I decided I needed to add a secondary method for organization and clarity. I chose the work of J. Amos Hatch for this purpose.

Using Hatch's Inductive Analysis

Hatch (2002) identifies nine steps in his inductive analysis technique, including: identifying frames of reference, creating domains based on semantic relationships, identifying salient domains, recording where relationships are found in the data, finding data to support the domains and watching for data that contradicts them, completing inter-and cross-domain analyses, creating an outline that delineates the discovered relationships, and selecting examples from the data to support the emerging themes (Hatch, 2002). After reading the texts many times, using van Manen's reading

approaches, I began to notice items that seemed to express a single idea. These items corresponded to Hatch's first step of identifying frames of reference. Hatch defines frames of reference as "levels of specificity within which data will be examined" (p. 163). Hatch's definition is based on the prior work of Tesch who describes researchers identifying small pieces of data, "segments, items, incidents, meaning units, or analysis units" where analysis unit is described as "a segment of text that is comprehensible by itself and contains one idea, episode, or piece of information" (Tesch, 1990, p. 116 as cited in Hatch, p. 163).

As recommended by Hatch (2002), I had to decide on rough boundaries for the data at this point. What became clear to me was that responses to living with chronic back pain and its effects on quality of life were categorized generally into feelings, emotions, and their sequelae and activities taken to actively live within the circumstances. So my first frames of reference were roughly "emotion-oriented" and "action-oriented."

Creating Domains

The second step of the method, "Create domains based on semantic relationships within frames of analysis" is the major inductive process of the analysis (Hatch, 2002, p. 164). Here Hatch gives much credit for his work to the earlier work of Spradley (1979, 1980, as cited in Hatch). In this phase, we are looking for relationships that exist within the data and want to express them in textual relationships, such as "strict inclusion (X is a kind of Y)…cause and effect (X is a result of Y)…[and] function (X is used for Y)…" (p. 165). Domains are useful because they demonstrate the way the participants organize their knowledge of the phenomenon under investigation. I followed the recommendation of Hatch who advises attempting to fit data under each type of semantic relationship

before coming to a final decision on the domains. It became clear that I had two major relationships, one of "means-end (X is a way to Y)" and one of "attribution (X is a characteristic of Y)" (Hatch, p. 165). The means-end domain fit the action-oriented frame of reference and the attribution domain fit the emotion-oriented frame of reference.

Included in the discussion of domains are the actual semantic relationships involving included and cover terms. "Included terms name the members of the category and a cover term names the category into which all the included terms fit" (Hatch, 2002, p. 165). I originally had several domains which were discarded as it became clear that there were only a few concepts listed under them. This was difficult for me even though it followed the advice of Hatch. I felt that each possible domain reflected emerging knowledge and was loath to part with any of them. I must agree with van Manen (1990) who states that the most difficult part of a research project is to discover the themes that are truly essential, essentially showing what makes the phenomenon what is it. Deleting an essential theme would make the phenomenon something else entirely. So I kept my eye on fleshing out the essential themes and identifying incidental ones, which although interesting, were not vital to the essence of the phenomenon.

I finally ended up with two broad domains. Under the emotion-oriented domain, I chose the cover term "*Making Normal*" and the included terms *Fighting and Denying; Being Angry and Frustrated; Surviving the Three ds (depression, despair, and devastation)*; and *Choosing, Adjusting, and Adapting*. Under the action-oriented domain I chose the cover term "*Living with the Shadow*" (in reference to so many participants who called it that) and the included terms *Fear and Uncertainty, Being Less Than Whole,*

Having Intimate Knowledge, and *Living Through Fatigue*. Domain sheets can be found in Appendix G.

Listening for the Essence

In preparing my domain sheets and finding themes, I read each text (30 combined interviews and journals) a minimum of 13 times each, once to develop an overall view of the text, three times per van Manen's (1990) reading approaches, and nine times to find and fit pieces of data into each of the nine suggested semantic relationships put forth by Hatch (2002). Once I finished the reading and prepared the domain sheets, I had spent an enormous amount of time reflecting upon, and listening to, the data. By the time I was done, I had a clear and vivid impression of the essence of the phenomenon; I felt it had spoken directly to me and I was ready to embark upon the final step of the research process, writing the essence of the phenomenon, a "synthesis of textual and structural descriptions" (Merriam, 2002, p. 94) of what and how the participants experienced the lived experience of quality of life as impacted by chronic back pain.

The essence of a phenomenon is a tight, dense, rich description that portrays all elements of the phenomenon for the participants; it includes nothing superfluous and has nothing left out (Creswell, 2007; Donalek, 2004; Laverty, 2003; Lopez & Willis, 2004; Maggs-Rapport, 2001; Merriam, 2002, Morse & Field, 1995; Morse & Richards, 2002; Moustakas, 1994; Munhall, 2001; Silverman, 2005; van Manen, 1990). As Giorgi (1997) describes it, the essence is "the articulation based on intuition of a fundamental meaning without which a phenomenon could not present itself as it is" (p. 237). Through intuition of the phenomenon that is my own, I was able to utilize imaginative variation to contemplate the critical aspects of the experience. It was at this point that I de-suspended

or unbracketed my own pre-suppositions and biases (Gearing, 2004) and used them to "interpret concealed meanings" (Morse & Field, 1995, p. 153) and craft the essence of the phenomenon: *Dancing with the Shadow: Re-visioning Quality of Life*. The themes and the essence of the phenomenon are discussed further in the next chapter.

Establishing Validity

All research studies, whether quantitative or qualitative, need to demonstrate that they were conducted in a manner appropriate for the research questions and that their findings are accurate. Researchers seek to show this through the use of any of several validation techniques.

The Question of Rigor

Despite the assertion that qualitative research has little risk of invalidity (Morse & Field, 1995), the literature is replete with discussions of validity and methods for ensuring rigor, most of which were created to answer the criticism that qualitative research was less "scientific" than traditional quantitative methods. Several items gave rise to this opinion. First human behavior and understanding is variable, and what holds true for one group of people in a given circumstance may not hold true for others (Merriam, 2002). Since the researcher herself or himself is the primary tool for data collection and analysis (Armour, et al., 2009), subjectivity has been cited as a cause of invalidity, leading to a large corpus of work on the use of bracketing or epoche (Morse & Field). Poor understanding of the philosophy behind qualitative research, specifically phenomenology, has also been criticized (Crotty, 1996). Despite the criticisms and unending articles on the topic, rigor in qualitative research and in phenomenology specifically is controversial and there are no universally-agreed upon methods by which a

researcher can show rigor, although there is no argument that somehow it must be demonstrated (Armour, et al., 2009; Caelli, 2000; Creswell, 2007; deWitt & Ploeg, 2006; Maggs-Rapport, 2001; McConnell-Henry, et al., 2009; Patton, 2002; Sandelowski, 1986).

Traditional Rigor in Qualitative Studies

Many of the early authors in qualitative research sought to find alternative terms for validation procedures that were still closely akin to their quantitative counterparts (Armour, et al., 2009; Creswell, 2007). The pioneering work of Lincoln and Guba in 1985 included the criteria for trustworthiness of truth value or credibility, applicability or transferability, consistency or dependability, and neutrality or confirmability to replace the quantitative validation strategies of internal and external validity, reliability, and objectivity. These terms were supposedly more "naturalistic" than those used in quantitative research (Creswell, p. 202). They later adapted their criteria and replaced trustworthiness with authenticity (Lincoln & Guba, 1994). Variations on these terms are advocated by many authors including Koch, (1994, 1996), Whitehead (2004), and Fleming, Gaidys, & Robb (2003).

Other terms for validation include construct validation, face validation and catalytic validation (Lather, 1991); ethical and substantive validation (Angen, 2000); the refutability principle (Silverman, 2005); auditability (Koch, 1994; Whitehead, 2004); generalizability or case-to-case transfer (Firestone, 1993; Merriam, 2002); authenticity, criticality, and objectivity (Jackson, et al., 2007); richness (Ray, 1994); integration of philosophical concepts within research findings (Draucker, 1999); opening up the inquiry process to others (Khan, 2000); interpretation that does not end with completion of the study (Crist & Tanner, 2003); and integrity (Whittemore, Chase, & Mandel, 2000).

Recommendations for Validity and Reliability

Creswell focuses on eight strategies for enhancing rigor (Creswell & Miller, 2000, as cited in Creswell, 2007, pp. 207-209). These include prolonged engagement in the field (Lincoln & Guba, 1985; Merriam, 2002, Morse & Field, 1995; Silverman, 2005), triangulation (Denzin, 1970; Lincoln & Guba, 1981; Merriam; Morse & Field), peer review (Lincoln & Guba, 1981; Merriam), negative case analysis (Armour, et al., 2009; Lincoln & Guba, 1981; Merriam; Silverman), clarifying researcher bias from the outset (Creswell; Lincoln & Guba, 1981), member checking (Armour, et al.; Jackson, et al., 2007; Koch, 1994; Merriam; Morse & Field; Silverman), rich thick description (Creswell), and external audits. It is Creswell's advice to use at least two of these methods. Other methods are often advised as well, such as reflexive journaling (Kahn, 2000) and systematic data analysis (Creswell; Crist & Tanner, 2003).

An audit trail (or decision trail) also seems to be vital. Readers should be able to follow each decision the researcher made in the course of the study, and even if they disagree with the findings, they should be able to understand how the researcher came to her or his conclusions, in other words, that the findings make sense. This is often accomplished through the use of a research or field journal (Armour, et al., 2009; Creswell, 2007; Guba & Lincoln, 1989; Jackson, et al., 2007; Koch, 1994; Koch, 2006; Lincoln & Guba, 1981; Maggs-Rapport, 2001; Merriam, 2002; Morse & Field, 1995; Whitehead, 2004).

There is one other criterion for validity in a qualitative, or more specifically, in a phenomenological study: it the thick, rich description of the phenomenon rather than statistical power that has all the persuasive strength (Merriam, 2002; Silverman, 2005;

van Manen, 1990). It is in the analysis and the writing where the quality lies (Silverman). When the researcher has uncovered the essence of the phenomenon and writes poetically and powerfully about it, the account should resonate with the reader; therefore "the principle of rigor hermeneutic phenomenology subscribes to most heavily is resonance" (McConnell-Henry, et al., 2009, p.13).

Bracketing

There is one aspect of phenomenological research that both lends it credibility and richness and is its primary source of vulnerability: the researcher's use of self to collect, to reflect upon, and to analyze the data (Armour, et al., 2009; Merriam, 2002). All researchers come to their studies with pre-understandings of the lived experience being investigated (Gadamer, 1976; Koch, 1994; van Manen, 1990; Whitehead, 2004). As the "primary analytic tool" (Armour, et al., p. 106), the researcher uses her or his pre-established understandings of the phenomenon to guide the co-creation of meaning in the data with the participants (Armour, et al.; Dahlberg & Halling, 2001; Gadamer; Lincoln & Guba, 2005; Vivilaki & Johnson, 2008). The researcher must be cautious however that her or his pre-understandings only help, not overshadow, the emerging descriptions and interpretations of the phenomenon, which should come from the phenomenon itself (Merriam). This caution may be exercised by a process called bracketing, which has been described at length in the earlier sections of this chapter.

The use of bracketing makes it appear as if the researcher is involved in a process that ensures rigor, which may not be the case (Vivilaki & Johnson, 2008). But not all researchers agree with Husserl that total bracketing is necessary or indeed desirable. It may not even be possible (Heidegger, 1927/1962; van Manen, 1990; Vivilaki & Johnson;

Whitehead, 2004). Our prejudices are not an obstacle to overcome but rather lend meaning and value to our research process (Koch, 1994; Vivilaki & Johnson). Creswell (2007) and LeVasseur (2003) wonder if bracketing should be redefined. We do not want our pre-established viewpoints to overly influence the process (Merriam, 2002), however; so it is important to recognize and acknowledge them (Creswell; Giorgi, 1997; Merriam; Morse & Field, 1995). "Recognized foreknowledge" (Armour, et al., 2009, p. 116) can be used to enhance the research process by providing understanding that the researcher has access to as one who is in the world of the participants (Armour, et al.; Vivilaki & Johnson).

Whitehead (2004) claims that bracketing is "antithetical to the generation of understanding" (p. 515). Many authors instead advise making the researcher's horizon (Gadamer, 1976) explicit from the beginning of the study (Creswell, 2007; LeVasseur, 2008; Lopez & Willis, 2004; Wimpenny & Gass 2000; deWitt & Ploeg, 2006) as it contributes to the researcher's judgment, which is a valuable asset (Wimpenny & Gass 2000). In fact, far from the position of Husserl, Donalek (2004) claims that a study cannot truly be called phenomenology unless the researcher's views are incorporated throughout.

It should come as no surprise that the term "bracketing" has no universally-agreed upon meaning, similar to so many of the topics in my study (Gearing, 2004; Vivilaki & Johnson, 2008). There is even disagreement as to where in the research process it should occur (Vivilaki & Johnson). According to Gearing, it has been used to mean three separate things: setting aside the presuppositions one brings to a study regarding a specific phenomenon, focusing in on the phenomenon itself as the content within the

brackets, or both, which may be the most common application. One can recognize internal suppositions (those related to the researcher) or external suppositions (those related to the phenomenon itself); however bracketing the external suppositions may not actually be possible as that would involve removing the cultural and historical context from the phenomenon (Gearing). Gearing claims that if we choose to bracket, we must understand clearly what we are bracketing and why, and that our chosen method must be congruent with our worldview and research methodology.

For social constructionist research, Gearing (2004) would advise me to use reflexive cultural bracketing, which involves making my values, background, and cultural pre-suppositions transparent. This acts to minimize their effects on a process that recognizes multiple truths, one of which must be my own (Cutliff, 2003; Gearing).

A New Paradigm for Rigor in Qualitative Research

As stated above, while there is no argument that rigor in qualitative research is a legitimate topic, some researchers, this one included, feel that the previous work on rigor, validation, and reliability are problematic as they are generic in nature, meant to be applied to any and all types of qualitative research methodology, and were borne from the quantitative paradigm (Armour, et al., 2009; deWitt & Ploeg, 2006). It seems more reasonable to begin with the specifics of each type of qualitative research and create paradigms of rigor based on the unique aspects and specific challenges found within each branch of qualitative research. In fact, using generic criteria may create more problems than they solve by forcing methodologies that have varying philosophies into a single paradigm of rigor without further consideration (Armour, et al.; deWitt & Ploeg).

Armour, et al. (2009) are proponents of individualized standards for rigor in qualitative work. They claim that "this assures and in fact requires more fully informed analysis of the challenges, creativity in thinking and action, thoroughness, and a system of accountability tailored to the demands of the particular study itself" (p. 102-103). They also assert that using standards of rigor created for differing types of qualitative research is philosophically congruent as creating them is an inductive process (Armour, et al.).

One of the major concerns about traditional qualitative versions of criteria for rigor is that they are adapted from quantitative research, which comes to us from the empirical, positivist paradigm. In this paradigm, truth is seen as one truth (deWitt & Ploeg, 2006; Lincoln & Guba, 1994) and is made explicit through the use of statistical analysis; with total objectivity numbers cannot lie. In qualitative research, phenomenology in particular, and from the social constructionist view, there are multiple truths (Creswell, 2007). Underlying the search for rigor in quantitative study is a search for absolute truth, while in qualitative work, we are seeking participants' meanings derived from their experiences, which are multiple and varied (deWitt & Ploeg; Ray, 1994; van Manen, 1990; van Manen1997; Draucker, 1999; Crist & Tanner, 2003; Lopez & Willis, 2004). So it must be understood that techniques used to illustrate rigor in both quantitative studies and developed for generic qualitative studies are not only inappropriate, they may actually impede expressions of rigor (Armour, et al., 2009; deWitt & Ploeg).

The Work of deWitt and Ploeg

It is out of this concern that deWitt & Ploeg (2006) have created a new paradigm of rigor for a specific kind of qualitative research, namely phenomenology. They borrow from the combined works of the "theoretical interpretive phenomenological nursing literature" (p. 223), van Manen (1990), and Madison's (1988) earlier work on rigor in phenomenology. They focus on several unique characteristics of phenomenology (van Manen) and use them to become criteria for rigor, an inductive process indeed (deWitt & Ploeg). The common thread is the use of hermeneutics which becomes the basis of rigor. The discussion of rigor revolves around the use of "persuasive (practical) reasoning rather than the logic of …demonstrative (scientific) reasoning" (deWitt & Ploeg, p. 223). The power lies in the logic found within the argument, an approach that is open and flexible enough to encompass "…the multiple philosophers who inform the interpretive phenomenological approach (deWitt & Ploeg, p. 223). This new framework includes the constructs of "balanced integration, openness, concreteness, resonance, and actualization" (deWitt & Ploeg, p. 224).

Balanced integration. Balanced integration comprises several components. First, the researcher must include a substantial and knowledgeable discussion of the philosophical underpinnings of her or his study woven throughout the entire corpus of the work, especially within the methods and results (Cohen & Omery, 1994; Crist & Tanner, 2003; Crotty, 1996; Draucker, 1999; Koch, 1996; Lopez & Willis, 2004; Whitehead, 2004). But this discussion must be balanced with the need to hear the voices of the participants. There must also be evidence of a comprehensive relationship between the work and its interpretation (deWitt & Ploeg, 2006; Madison, 1988).

Openness. Openness refers to a sustained effort throughout the research process to maintain a stance of transparency, to create an explicit decision trail that others can follow. This of course opens the study up for criticism by others (deWitt & Ploeg, 2006). One motif that has recurred consistently in the course of the discussion of rigor in qualitative study is the need for an explicit accounting of the decisions the researcher has made, also known as the decision trail (Creswell, 2007; Crist & Tanner, 2003; Fleming et al., 2003; Kahn, 2000; Koch, 1994; Maggs-Rapport, 2001; Munhall, 2001; Sandelowski 1986; Turner, 2003; Whitehead 2004; van Manen, 1990).

Concreteness. On the surface, the term "concreteness" does not seem congruent with phenomenology until one considers the meaning: "when findings are written in such a way that examples are given that situate the reader concretely in the context of the phenomenon and also link with experiences in their lifeworld" (deWitt & Ploeg, 2006, p. 225). Combining van Manen's (1990) concept of lived-throughness and Madison's (1988) criterion of contextuality, concreteness infers that readers cannot read a work in a vacuum, it must be read within its "historical and cultural context" (deWitt & Ploeg, p. 224).

Resonance. Resonance, as may be guessed, is the visceral effect that the findings have on the reader (deWitt & Ploeg, 2006). It occurs when the reader recognizes and feels what is written (van Manen, 1990). This has variously been called the phenomenonlogical nod, an epiphany, and a "yes of course" experience (van Manen, p. 225). This should be a "striking, moving experience" (van Manen, p. 226).

Actualization. The final criterion is that of actualization which acknowledges the fact that research studies continue to be interpreted into the future (Sandelowski, 1986;

Crist & Tanner, 2003; deWitt & Ploeg, 2006). This implies that the research process produces more than a document; it produces understanding that is dynamic. As it is read, readers will make meaning from it influenced by their own historical and cultural contexts (deWitt & Ploeg, 2006).

Validation Techniques Used in This Phenomenological Study

Using Traditional Techniques

I began my quest to demonstrate rigor by deciding at the outset that I would incorporate Creswell & Miller's (2000) criteria for rigor as I was most familiar with these standards (as cited in Creswell, 2007). As discussed in an earlier section of this chapter, I spent considerable time in the field (Creswell), my field being time interviewing and transcribing interviews and journals, reflecting on them, and writing. I engaged in triangulation methods (Creswell), having two primary sources and one secondary source of data. All three sources were utilized in the data analysis. I used peer review (Creswell) in each of three classes during which I prepared work that was subsequently used in this study. I conducted two pilot studies and developed one survey tool, and in each case fellow students and the faculty reviewed and commented on my work. I made several changes based on that collective input. I had two potential negative cases (Creswell), discussed in detail in the following chapter. I sought out explanations for them and was able to incorporate them into the creation of the essence of the experience.

I began the study by clarifying my biases, pre-suppositions, and historical and cultural contexts, which I have made explicit earlier in this chapter (Creswell, 2007). Not only did I write formally about them for the three research classes I took prior to starting this dissertation, but I began the study by writing them down again. And I revisited them

occasionally as something came up that resonated with me. I began to see my definition of bracketing as "suspended curiosity" and envisioned a spider traveling on a strand of silk in my peripheral vision, to the upper right. When my own pre-suppositions and biases were beginning to move to the forefront, the spider started down the silk. When that occurred, it was time for me to journal. As I journaled about my thoughts and feelings, the spider initially dangled in front of me (suspended), but eventually began moving back up her silk to wait for another opportunity to visit. I remained curious about how my own experiences fit into this study's findings throughout and in the end I unbracketed myself (Gearing, 2004) and wrote about my experiences, which can be found in Appendix H. I made a true effort to hear and report the voices of my participants unencumbered by my pre-knowledge and biases and I think I succeeded. But I also think that without my own experience with chronic back pain, I would not have had the intuition to ask the right questions, follow leads, uncover meaning, and hear what was hidden in the silence (van Manen, 1990).

I requested the assistance of my participants for member checking (Creswell, 2007). Two agreed to read and comment on my findings and I incorporated their thoughts into the findings. I also used external audits (Creswell) by having Ph.D.-prepared faculty members at Nebraska Methodist College read and comment on my Methodology and Methods chapter and the Results chapter. In a variation of this strategy, I requested input on the findings themselves from what could be considered external content experts; three RNs who have lived with chronic back pain and who were not involved in this research read and commented on the study. Their statements showed

that I had indeed "hit the nail on the head" as the essence resonated deeply with all three of them. Their comments can be found in the Appendix I.

And in the final technique for demonstrating rigor according to Creswell & Miller (2000, as cited in Creswell, 2007), I certainly did provide ample thick, rich description, using statements from my participants to form themes and domains which are supported heavily by direct quotations. I had copious amounts of information from which to draw and hit saturation fairly early on. If indeed phenomenology demonstrates rigor most effectively through the words of the participants and the logic of the reasoning (deWitt & Ploeg, 2006), then my study can definitely be called rigorous.

Using the New Paradigm

However, I was unsatisfied with these criteria of rigor. Jackson, et al. (2007) point out that the approach taken by the researcher to demonstrate rigor will vary depending on whether quantitative or qualitative methods are used. Even though these eight criteria of Creswell & Miller (2000, as cited in Creswell, 2007) are widely accepted and used as sound criteria for qualitative work, I must disagree with their utility. Qualitative researchers need to take this discussion of rigor away from mere adaptation of terminology and into the distinct realm of qualitative research, using new traditions of rigor designed for the unique characteristics of the process used (Armour, et al., 2009; deWitt & Ploeg, 2006). In this light, I re-evaluated my research according to the paradigm put forth by deWitt & Ploeg.

My study meets the criteria for balanced integration (deWitt & Ploeg, 2006) with a detailed, thorough description of the philosophical underpinnings of phenomenology. This discussion included the pioneers of phenomenology, Husserl and Heidegger (Moran,

2000) and the philosophy of the specific methodology I chose to use, that of Max van Manen (1990). I wove the philosophical background throughout the tapestry created by discussion of my methods and findings. This study also has an appropriate balance of this discussion and the voices of the participants. The philosophical discourse is background for what is essentially their story. The whole of this study forms one unified and dynamic enterprise, fulfilling the notion of a comprehensive relationship between the study and the topic of study (deWitt & Ploeg).

The criteria of openness (deWitt & Ploeg, 2006) invites scrutiny from the outside. I have made every decision clear and showed the relationship between my decisions and the philosophical traditions upon which this study was based transparent. My growing understanding of the philosophies upon which phenomenology is based was a labor of love, and in fact, took the most time of the entire dissertation process. I wanted to be absolutely clear in my vision and proceeded only when I attained that clarity.

I have situated readers of this study concretely within the context of the participants' experiences (deWitt & Ploeg, 2006). By using direct quotations and by providing background information to the anecdotes, readers can join the nurses as they recount their narratives in a kind of joint lived experience. Certainly the findings have resonance (deWitt & Ploeg) as indicated by the participants who read the results and as demonstrated by the non-affiliated RNs who also read the essence. van Manen (1990) states that a reader should not only recognize a recounted lived experience, but should be able to feel it as well; such visceral responses were evident from both groups. I had my own visceral response; I laughed and cried at the same stories many times over. There are some I cannot speak about to this day.

The success in meeting the criterion of actualization is, in a sense, left to future readers (deWitt & Ploeg, 2006). Only time will tell if this study will stand up to the changing historical and cultural contexts that future readers will bring to it and whether it remains a vivid, dynamic portrait of nurses whose quality of life has been impacted by chronic back pain. I can only say that I have tried to write in a way that will leave this door open to those who might choose to view it in the future.

Conclusions and Summary

This chapter provided a description of the research methodology and methods used in my study, including a detailed discussion of the topic of establishing rigor in phenomenology. In a sense, it provides a comprehensive audit trail where I have attempted to lay out the foundations for every decision made during the course of the project.

Qualitative methods include several diverse typologies, but share some characteristics: they best explore topics about which little is known utilizing an inductive data analysis strategy (Creswell, 2007), the researcher is the primary tool for data collection and analysis producing findings that are richly descriptive, they occur in natural settings where researchers use multiple sources of data, they use an emerging design, and the product gives us a holistic account from the participants' viewpoint (Creswell; Merriam, 2002; Morse & Field, 1995; Morse & Richards, 2002; Silverman, 2005). Qualitative research may also be used when traditional quantitative methods simply do not fit the topic (Creswell).

Phenomenology is a method heavily steeped in the philosophies of its founder, Edmund Husserl and advanced by his student, Martin Heidegger. Husserl espoused a

transcendental, empiric phenomenology, while Heidegger took phenomenology beyond transcendentalism into the realm of hermeneutics, using language to interpret lived experience (Moran, 2000). I chose the philosophy and research methods of Max van Manen (1990) who proposes using hermeneutic phenomenology to create action sensitive pedagogy. I utilized Hatch's inductive analysis (2002) as a secondary method for organizing my voluminous data. Through phenomenological reflection and writing, I arrived at my two domains and the essence of the phenomenon, which are described in the following chapter.

Utilizing two strategies for expressing rigor in qualitative, specifically phenomenological, research, I showed how my study met the criteria of both Creswell & Miller (2000) and that of deWitt & Ploeg (2006) who propose a new paradigm of validity based on the unique aspects of phenomenology.

The following chapter contains a detailed account of my findings. I will present and discuss two domains, each containing four themes each, and the essence of the phenomenon.

CHAPTER FOUR

RESULTS AND FINDINGS

The purpose of this chapter is to describe the findings from this study. The findings from this study include basic background information from the survey, motifs about journal writing and quality of life, and two major domains, Making Normal and Living with the Shadow, that contributed to the essence of the phenomenon. The data build upward in an inverted pyramid in inductive fashion (see Figure 1). The survey data comprise the base from which I began looking at the phenomenon. The motifs about journal writing and quality of life, plus the two major domains comprise the building blocks for the overarching essence of the phenomenon. The domains with their themes and the essence of the phenomenon give a compelling and vibrant look at the participants' quality of life.

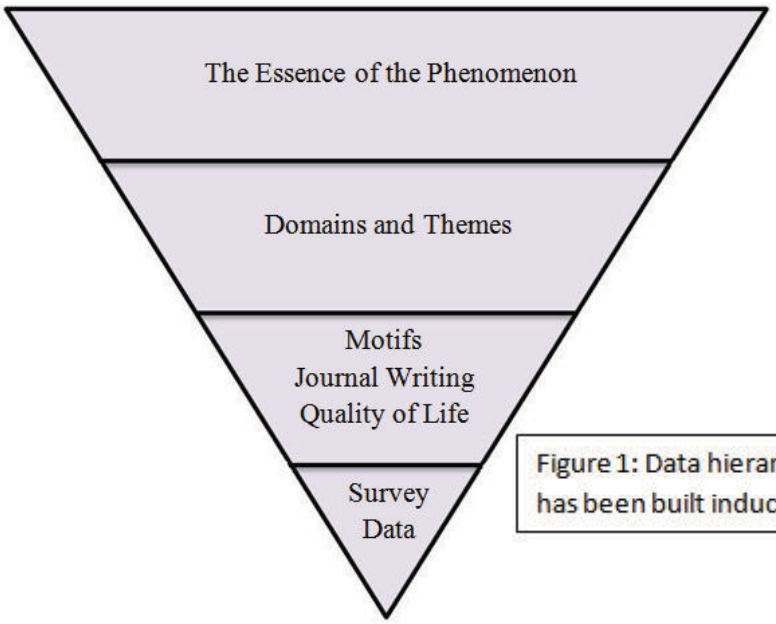

Figure 1: Data hierarchy in this study has been built inductively.

Survey Information

Eleven participants completed the survey (see Appendix D). The two participants in my first pilot study filled out a simple "demographic" questionnaire. Out of the other 13 participants, 11 returned surveys. Details from the survey are presented in Table 1. Only options that had responses are presented.

Table 1: Survey Results

1. QOL Rating Extremely good: 3 Remarkably good: 2 Good: 3 Poor: 3	**2. Satisfaction with QOL** Totally satisfied: 2 Satisfied: 6 Dissatisfied: 3	***3. Affect of back pain on your QOL** Enormous effect: 4 A lot of effect: 2 Moderate effect: 2 Some effect: 4
4. Days of back pain last week 0-1: 1 4-5: 1 6-7: 9	****6. Percent of time you followed JW directions** 100%: 6 75%: 5	**7. Difficulty/ease of following JW directions** Extremely easy: 3 Pretty easy: 5 Somewhat easy: 2 Pretty difficult: 1
8. Extent JW affected QOL Moderate effect: 3 Some effect: 1 Very little effect: 1 No effect: 4 I don't know: 2	**9. Extent JW made it easier to deal with back pain** Some effect: 5 A little effect: 3 No effect: 3	**10. Will you continue JW on your own** Definitely will: 2 May continue: 3 Probably not: 3 Definitely not: 2 I don't know: 1
11. Likely to recommend JW to others with back pain Definitely would: 3 Probably would: 4 Probably would not: 2 Definitely would not: 1 I don't know: 1	**12. How long have you had back pain** >2 but <5 years: 1 >5 but <10 years: 2 >10 but < 5 years: 2 >15 but <25 years: 2 >25 years: 4	****14. Forced to quit job because of back pain** No: 7 Yes: 8

*This totals 12; DeeDee marked both "a moderate effect" and "a lot" and wrote "both"

**Question 5 asked for a description of the participants' pain. See the discussion below for details on pain description. Also see appendix J for specific statements provided by each participant.

***This equals 15; I took this information from interview data and statements made outside the interview situation.

Treatments Used

Question 13 asked about various treatments the participants had tried. Information for this question came from the surveys, the demographic questionnaire and interviews. For the two participants who did not turn in a survey, all information about treatments came from their interviews and thus may not be complete. All 15 participants had used over the counter medications, such as acetaminophen (Tylenol) or ibuprofen (Motrin) and 14 had used heat and/or cold treatments. Other commonly-used therapies included exercise (13); prescription pain medications (10); prescription muscle relaxants and physical therapy (9 each); and massage therapy (8). Seven participants had surgery, some of whom had more than one operation. Lesser-used treatment modalities included weight loss (6), chiropractor (5), and acupuncture/acupressure, other prescription medications, or yoga (4 each). Steroid injections and Transcutaneous Electrical Nerve Stimulation (TENS) units were listed by three people each. Two people had Dorsal root stimulators implanted and epidural injections. One person each mentioned the following treatments: caudal blocks, magnets, healing touch, an inversion table, and treatment with a DSR 9000 machine (a treatment done in a chiropractor's office). Since the participant chose to specify this particular treatment I included it separately instead of combining it with chiropractor.

An interesting finding from the survey was exactly how many treatment modalities each person has tried for their back pain. The 13 participants who returned their surveys/demographic forms used at least 122 methods to treat their back pain. This produces a mean of 8.1 different treatment methods per person. The range was 4-13 and

the mode was 8. Participants are clearly spending an enormous amount of time trying and using different treatment options to obtain relief from their pain.

Journal Writing

Information about journal writing came from both the surveys and questions in the interview specific to journal writing. Six of the participants followed the journal writing instructions 100% of the time; the other 5 marked 75% on the survey. Reasons for not following instruction were either not writing three days in a row or because they felt they had a hard time staying on topic or thinking of a "correct" topic about which to write. All the participants found the JW to be some degree of "easy" to do with the exception of Anna, one of several respondents who found that JW brought up negative feelings. I did not examine the surveys during the interview process and so did not get the chance to clarify why she made this statement.

Participant Voices

Participants varied on how much effect JW had on their quality of life. Two people were unsure if it affected their QOL at all. Anna was one of the unsure and on her survey she wrote "It made me think about it too much." The majority indicated the JW had at least a little effect on their QOL. The majority also indicated that JW made it at least a little easier to deal with their back pain. The three who did not notice an effect on their ability to deal with their pain were Mildred, Anna, and Betina. Mildred seemed to approach the journal writing as just an assignment, something to "get done for Meg." She stated "So it's done. It was a simple process. Easy to do." Her journal was mostly an accounting of various events that have occurred since childhood that may have impacted her back and there were no emotions or signs of true reflection. Journal writing

without emotional reflection is not beneficial (Singer & Singer, 2008). Betina was already an avid journaler, even reading books about journaling, so perhaps she was already quite skilled at reflecting and felt that this specific journaling offered no new insights. It is interesting that of the five nurses who did not follow the directions 100% of the time, four of them responded that the JW had only a little effect or no effect on their ability to deal with their back pain.

It was also interesting to note that while five nurses would probably or definitely not continue JW on their own, seven probably or definitely would recommend JW to others. Again, Anna had the most negative response to the exercise and she was the only person who stated she would definitely not recommend it. However, even she alluded to the possibility of JW being a helpful intervention had she done it earlier. "Maybe if I had someone who gave a shit after I got hurt I could write about what was going on. And why don't we go through your feelings a little bit and make you feel better?"

In fact, all the participants said that JW was either at least a little helpful to them or might have been had they done it earlier and all participants stated that this could be beneficial at some point with people who have back pain. Most often they commented on how it would be maximally beneficial either early on after an injury, or when the person realized he/she had a chronic condition in order to help them work through the emotional impact. Angel said that JW was a "...great idea, effective for many people. Good way to help them figure out how they feel and what to do about it. It would help to clarify, especially for people struggling with their back pain."

The predominant construct that was gleaned from the interview question about JW was "clarity." The nurses found clarity by finding patterns of events that caused pain

or from gaining insight into things that were happening while they were having their pain. Sylvia stated "It helped me kind of hone in on what was happening at the time." Often realizing the sequence of events was an "ah hah" moment for the nurses. Barbara had not previously realized the connection between bending and turning motions and increased pain. She said, "It was beneficial. It helped me see it [back pain] as one experience instead of several…sort of integrating. Yeah that would be a good word, integrating."

Patsy noted that perhaps she has not come to the level of acceptance she assumed she had. "I think I gained some insight. Some of the insight from journaling made me realize that there are still pieces I need to process." Toni found the process "enlightening." Some of the insight included changed perceptions; as Betina stated "I think over time it [journaling] changes our perceptions." Megan felt she was able to review what she had been through and "sometimes you write your problems down and you can learn something from them."

The other major benefit of JW was the ability to express oneself. Mary found the process "exhilarating…to write things down, you get to vent." Laurabelle felt relief: "It made me feel good because I wrote it down and cleared it off my person a little bit." Patsy also felt the benefits of being able to voice her feelings: "It let me express things that I've never really expressed to my family." She let them read her journals when she was done. Betina found "an outlet" in her journal writing; "I'm safe to be angry with anybody and anything, at anytime." Mary felt that JW could improve one's QOL; "Sometimes just seeing things on paper or in front of you, bringing it out, rather than just

thinking about it inside helps you to feel a little better." Even Anna stated, "It was kind of nice to tell somebody off for a while" when she journaled.

Four participants had a negative response to the JW exercise, mostly because it forced them to consider their back pain which was something they tried to avoid at all costs. Giselle wrote "Hey is this journaling supposed to be good for me? Talking about all these problems is just making me more and more depressed about my life." She related that the JW did indeed make her teary at times. She compared JW to "opening a can of worms." Anna expressed that the JW made her feel negative and that all she was doing was "thinking about myself." Anna had a very hard time accepting the limitations the back pain placed on her life and she tried to stay busy at work, which gave her something else to concentrate on besides her pain. Angel ended up having extra massages and taking more over the counter medications than usual because she felt she was thinking about her pain which she usually relegated into "background noise." Even cheerful DeeDee found herself thinking too much of her pain as well: "So it just made me think of this whole story again so that's why I didn't care for it so much because it made me focus on it when I've tried to learn not to focus on it."

Correlation to the Literature

As discussed in the previous chapter, structured journal writing confers physical and psychosocial well-being on individuals suffering from a variety of physical and emotional ailments. There have been a multitude of studies over nearly three decades that have used this model and found similar results. Although there are variations, participants are usually instructed to write about a problem, describing their deepest emotions about it, for brief periods of time several days in a row. The mechanism by

which this occurs is not fully understood (Caplan, et al., 2005; Davidson & Robison, 2008; Day, 2001; Easterling, et. al., 1994; Goldman, et al., 2007; Graham, et al., 2008; Junghaenel, et al., 2008; Norman, 2000; O'Cleirigh, et al., 2008; Pennebaker & Beale, 1986; Petrie, et al., 2004; Smith, et al., 2005; Smyth, 1999; Smyth, et al., 2008; Smyth, et al., 2009; Weinman, et al., 2008).

Just how effective is structured JW? In a large recent meta-analysis of emotional disclosure writing, Frattaroli (2006) found that over all, about one-third of participants do not reap the benefits. This finding is roughly similar to the responses from my participants; on the survey 4 of 11 (36%) said JW had no effect on their QOL and 3 of 11 (27%) said that it did not help them deal with their pain. Several explanations may be in order. It certainly may be that these individuals truly would have had no benefit from the exercise. However, Corter and Petrie (2008) found that personal delivery of JW instructions led to participants being more engaged in the activity. Austenfeld and Stanton found that benefits are greatest when the expressive task is matched to each individual's preferred coping style (2008). And a simple recitation of the facts has also not been found to be helpful; it is the deep processing that leads to positive outcomes (Singer & Singer, 2008). This certainly may help explain the lack of benefit Mildred claimed as her journal was more of a diary of factual events that may have led to her back pain. The benefits may simply be delayed; in the original Pennebaker and Beale study (1986), the participants who showed the positive outcomes initially had higher blood pressure readings and negative moods but had the positive benefits later. Smyth, et al. (2009) found that positive outcomes were delayed by up to 16 weeks in a study of patients with rheumatoid arthritis.

But for individuals with chronic conditions, especially pain syndromes, any effect, even a modest one, on their distress and/or quality of life, is a huge asset (Graham, et al., 2008; Smyth, et al., 2002). Even though moderate, Smyth and Pennebaker (2008) assert that any intervention that has a positive effect on such important outcomes is truly impressive, particularly when the intervention is so brief and shows effects even several weeks after the trial. This leads one to consider multiple avenues for further research, discussed in more detail in chapter five.

Quality of Life

This section comprises a brief overview of statements regarding quality of life. Much greater detail regarding the effects of chronic back pain is in subsequent sections. The combination of the information found here and the themes described later provide a vivid accounting of how back pain has affected the participants in all areas of their lives, including their quality of life.

Participants' Voices

Eight of the participants rated their quality of life as some degree of "good" and claimed they were at least somewhat satisfied with it. I found that remarkable considering what they told me in their interviews and the extent to which they stated back pain interfered with their lives. I expected much lower ratings on the survey and much of what they said in their interviews directly contradicted their high ratings. Several of them qualified their answers however, stating that their QOL was good "now that I don't have acute pain" or "now that the pain is better," or "now that I am in control of my pain." This certainly leaves the impression that when the back pain is bad their answers would be different. The three who rated their QOL poor and were dissatisfied were Megan,

Sylvia, and Anna. Sylvia and Anna were both quite disabled with pain and their stories are discussed in more detail in subsequent sections. Megan seemed to be dissatisfied with life in general; she had multiple stressors in her life that did not all stem from her back pain and seemed to have difficulty coping with most of them.

There were three questions in the interview related to QOL. The first simply asked the participants to describe their QOL. Again, most had positive, albeit qualified, answers. In the majority of cases, those who were satisfied claimed that their pain did not limit any of their activities and they were able to do anything they wanted to. It was interesting to compare this with their other statements listing the ways in which their back pain actually did restrict them. For example, Giselle related in her interview that her QOL was "very decent" but that some aspects were "ewwwww." She also stated "if you brought it down to the molecular level, there is a lot I would improve." Sylvia had to give up a job she loved, several recreational activities she enjoyed, the ability to work in her house and garden, and had ongoing issues with depression due to her back and its effects on her life.

Those who complained about their QOL had comments relating how "restricted" or "limited" their lives were. Sylvia's life was certainly restricted as she was mostly housebound and she said, "What I miss most is the freedom to come and go." Megan lamented that her QOL suffered because she was not able to do the things she wanted to with her children, including playing on the floor with them. "Actually I can't even sit on the floor." Several of the nurses were restricted in their ability to be intimate with their husbands, a topic discussed in further detail in the theme *Being Less Than Whole.*

Anna's activities are fairly compromised due to her back pain. Her comment related to overall QOL was, "Um, well it kinda sucks."

Patsy modified her answer by adding "I can do most things to a certain extent." However, she cannot even grocery shop by herself if her list is too long because she can't push the cart, so she must wait for help. "It's restricted my shopping abilities." She added "…it limits everything..." In her interview she had this comment "But you know I can, I can cook, I can you know I can do anything, I just know that when it comes to you know, bending, lifting, pushing, pulling, then I know that's where my limitations are." It is hard to imagine many activities in the life of a woman who is a nurse, a wife, a mother, and a volunteer that don't require at least one of those movements. I actually wondered if some of the participants were rating their QOL so highly because it had been worse before and they were grateful for what they had at the time of their interviews.

The second question related to QOL asked participants to describe what was important to them when they considered it. Several participants had trouble answering this question so I added a second question as a prompt for those participants: "Some people describe QOL as having different dimensions, physical, psychological, sexual, social, or spiritual. Are any of these particularly important to you?" It was interesting that most participants given all elements went through each topic and described how their back pain had or had not affected that aspect of their lives and still had trouble delineating what was most important to them in their QOL.

After giving it much thought, nearly all the participants (13) related that maintaining relationships was critical for them. This surprised me as I had thought the physical aspect of the back pain (pain itself and physical limitations) would be at the top

of their lists. Golda claimed that her relationship with her spouse affected her relationship with her children and that those ties were important to her. Barbara stated "Maintain relationships, um, that would be key I think." Several specifically mentioned interactions with current or future grandchildren. Pasty related "I want to be the grandma I had." Mildred was most bothered by not being able to be as physical with her grandchildren as she would have liked. Anna wanted to play with her future grandchildren and mentioned that a good quality of life also meant "going out with friends and having fun." Toni had many comments related to her marriage, which had seen its rocky days, but was now improving, giving her self confidence and bettering her quality of life. Angel wanted to be able to be a good aunt to her nieces and nephews.

Physical well being, including sexuality, was mentioned by eight participants. Being able to do what they chose to do topped the list in the physical dimension. Barbara summed those comments up: "Physical…I mean everything kind of revolves around that, that's probably the most important. You don't want that physical to impact all those other areas." Anna's statement echoed many others who said an improved quality of life would be enjoying certain activities without suffering later: "So those are simple…you know, mess around with your flowers, so you know sit out on the patio for a while…those are all things I wish I could do without paying the price." Toni mentioned specific hobbies she wanted to be able to enjoy, including quilting. Several people had gardens they wished to work in.

Laurabelle and Giselle included the emotional component when describing what was important to their quality of life. "Physically and mentally, I want to be ok" said Laurabelle. Giselle claimed that a poor quality of life to her would be "…if I were not

the person I am now physically and mentally." A couple participants made their quality of life dependent on their own outlook. Mildred stated, "It's your state of mind." Golda's comment was "Well, it's how you feel in general." Barbara mentioned having a good outlook and optimistic future. She also described how her vision of QOL has changed over time. "Quality of life has to be in the perspective of maybe what's more important and meaningful [now]." Patsy, Sylvia, and Golda related that spirituality is important to their QOL. Laurabelle and Eliza described being able to handle their pain as important. Laurabelle also mentioned having enough private time as vital to her and Eliza specifically spoke about needing sleep for good QOL.

The third question asked participants to relate QOL to their back pain, specifically, "How does the back pain enter the picture when you think of quality of life or does it?" The information from this question was related to the answers to the first question in that most participants discussed how limiting the back pain was and how that affected their QOL. Megan said, "[back pain] prevents me from doing what I want." They spoke of how annoying it was, how they had to carefully consider their activities before engaging in them, and the subsequent loss of spontaneity and intimacy this created. This question also elicited many statements that were the basis of the theme, Having Intimate Knowledge, in which back pain is a constant companion in their lives. Toni's comment perhaps speaks most loudly: "Back pain means everything as far as quality of life is concerned."

Correlation to the Literature

Any chronic illness can have a direct and negative impact on quality of life and this effect seems magnified when the chronic condition includes pain, especially pain that

is ineffectively treated (Butchart, Kerr, Heisler, Peitte, & Krien, 2009; Carson & Mitchell, 1998; Dysvik, Lindstrom, Eikeland, & Natvig, 2004; Elliott, Reiner, & Palcher, 2003; Silverman, Piziak, Chen, Misurski, & Wagman, 2005). Pain seems to exert its effect on QOL by limiting physical functioning, which leads to further physical declines due to true mobility limitations, self-imposed activity restrictions and depression (Baird & Sands, 2006; Butchart, et al.; Dusova & Cseszarova, 2008; Dysvik, et al.; Jakobbson & Hallberg, 2002; Jakobbson & Hallberg, 2006; Sapountzi-Krepia, et al., 2007; Silverman, et al.; Wallis et al., 2006; Weiner, et al., 2006).

Clinical depression is quite common in patients with chronic pain and decreases their QOL. In fact, according to Elliott, Reiner, and Palcher (2003), "The health related quality of life of chronic pain patients with major depressive disorder is among the lowest observed for any medical condition, including cancer and other serious, burdensome diseases" (p. 337). In their study of 242 patients with multiple types of chronic pain, Elliott, Reiner, and Palcher remarked on the degree of impairment in mental well being they observed among their participants, calling it "remarkable" (p. 236). Maly and Krupa (2007) identified loss of physical abilities as leading to a devaluing of self-worth as a direct result of mobility's central role in identity. Certainly from the time we are infants, our world only expands through increased mobility, so it is easy to see how a mobility limitation would serve to handicap our self-image and self-worth. In a study from Japan, patients with osteoarthritis of the hip found that hip pain prevented participants from enjoying recreational activities and entertainment, and led to a loss of confidence (Koyama, et al., 2007).

In many studies, the degree of physical impairment had a linear relationship with QOL (Conn, Hafdahl, & Brown, 2009; Jakobsson & Hallberg, 2002; Jakobsson & Hallberg, 2006; Shearer, Fleury, & Reed, 2009; Wallis, et al., 2006). Being able to function in a normal fashion and having the ability to do the things one wants to do is important to people as they define their health and health-related quality of life (Miller & Iris, 2002; Shearer, et al., 2009). In a large meta-analysis that included more than 7,000 participants, Conn, Hafdahl, and Brown (2009) found that interventions designed to increase physical activity had a profound effect on self-reported QOL. Unfortunately, many patients in pain restrict their own activities out of fear that movement will make the pain worse (Dysvik, et al., 2004). Dusova & Cseszarova make a plea to health care providers that improving quality of life in patients with chronic pain means they need interventions that will help them perform their normal daily activities without pain (2008). Finally, Shearer et al. found that women with chronic illnesses define their health according to extent they were able to be active, care for others, and make positive contributions to their families and communities.

Much of the research cited above reflects studies done on patients with chronic illnesses that include a chronic pain component. An extensive search of the literature found no studies that combined the search terms “quality of life” and “chronic back pain.” There were more than 400 studies that were found using the terms “quality of life” and “back pain.” Some of these studies reported improvements in self-reported QOL in patients who underwent specific types of surgical treatment for their back pain, others investigated back pain as a component of chronic pain. I chose studies that seemed to reflect similar conditions to my participants and reported findings from research on

patients with osteoarthritis, rheumatoid arthritis, osteoporosis, and chronic pain from multiple medical conditions, many of which reported back pain specifically. In each of these studies, pain resulted in limited mobility, a "restricting" similar to what my participants reported as being significant to them as regards their QOL.

Contradictory Cases

Two participants appeared to present contradictory cases and were clearly different from the other participants at first glance. Both Mildred and Golda were adamant that back pain did not affect their QOL and they claimed they went about their normal routines without the back pain affecting them at all. As Mildred stated, "I just do it." Both seemed more determined than the others to not allow back pain to dictate their lives to them and seemed to be less troubled by it than the other 13 participants. There are several points that are noteworthy about these two participants. First they were two of the three oldest participants in the study, with Mildred being 65 and Golda being 70 at the time of their interviews. This would correlate to birth years of approximately 1944 and 1939 respectively. Only Mary was of a similar age; 61 at the time of her interview which gave her a birth year of approximately 1944 also (Mary was a participant in my first pilot study).

Golda was clearly a member of the "Veteran generation," sometimes known as the "Greatest Generation," whose years of birth are variously listed as between 1925 and 1942 or 1945 (Carver & Candela, 2008; Frandsen, 2009). Golda came of age in an era when options for medical care were quite limited; in fact treatment for the ill or injured was often what I have heard referred to as "tincture of time." Either the ill or injured person would get well with time, or they would not. Growing up in the generation forged

by events such as the Great Depression, World War II, and Prohibition led many to be pragmatic and self-reliant and to view sacrificing for the common good as an esteemed value (Carver & Candela, 2008; Frandsen, 2009). Golda seems to take a common-sense view of her situation; more than 30 years ago, her husband's uncle (a physician) told her the back pain was like " a headache in my back" and with that simple explanation, "I have had a total change of mind" about finding a "cure" or "something to do about it." She appears to simply accept it and makes plans to go on with her life "While I have some minor discomfort a lot of days—I don't worry about it…."

The other characteristic of Golda's that is different from the other participants is the seeming less severe pain from her back condition. She has not had any surgery or any other medical treatment for her pain, choosing yoga, over-the-counter medications, heat/cold treatments, weight loss, and exercise as remedies. In fact, she was the only participant who did not mention some sort of professional care for her back. She also equates her back pain with stress and being too busy. Perhaps her pain was different from the others and had less effect on her in general, except her pain does bother her on a day-to-day basis; she just chooses to go on with her life. I did not attempt to place any controls or conditions on the type or severity of back pain participants had; they only had to have chronic back pain of 6 months' duration or longer to participate.

Mildred was the other person who appeared to present contradictory findings. Mildred may have been a member of the Veteran Generation, depending on the source for birth years. She certainly was pragmatic and self-reliant. In her journal, she related the first episode she can remember in which she might have hurt her back. When she was about 12 years old she was ice skating and fell onto the blade of her skate. She wrote, "I

remember that the pain was severe, but that I eventually was able to stand up and walk next door to our house. No tears—just simply told mom what had happened!" She also related a time playing tennis when she tripped, falling backwards and "hitting the back of my head and producing a terrible cracking sound inside my skull. I took a minute to collect myself and then continued to play." Many nurses would have at least considered the possibility of a serious injury with that fall.

Mildred was also unique in the amount of control she had over her body. She stated she has a very high pain tolerance and is a Healing Touch practitioner. Healing Touch is a CAM practice that strives to balance physical, emotional, psychological, and spiritual well being. Using gentle touching, or placing the hands above the patient's body, the practitioner works with the patient's energy fields to assist the patient's own body in healing. This practice can be used for both acute and chronic conditions, physical or psychological (Healing Touch International, n.d.). Mildred has also delivered two children by hypnosis and after a major back operation, was up walking in two hours. After this back surgery, she took no analgesics other than a dose of Tylenol the following day. She credits much of this to preparing for surgery using Healing Touch techniques.

Mary, the other older participant may have been a member of the Veteran generation as well, depending on her exact birth date and source years considered. However, Mary was more similar to the other participants than were either Mildred or Golda, and in fact, she had some characteristics of an early Baby Boomer. Boomers grew up in a generation whose parents were more able to afford giving their children a better life than they themselves had. Boomers pride themselves on personal and professional accomplishments (Carver & Candela, 2008; Frandsen, 2009). Mary does sound more

like this generation when she stated in her journal "It's an instant gratification world and I am no different. I think that, at 61, I "should" be able to have and do anything I want." Mary also was clearly much more affected by her back pain than either Mildred or Golda, which puts her in the mainstream of this study's findings.

Consideration of Mildred's and Golda's stories adds richness to these findings. Although different in several respects than the other nurses, the experience of back pain is with them daily; they voice many of the same concerns and have had parallel experiences to the other participants. Their voices are heard loud and clear in the following sections that discuss the two major domains and their included themes.

Domain One: Making Normal

As a domain, *Making Normal* included activities that showed the participants either fighting their back pain or working through several emotions to maintain their previous personal and/or professional identities and existences or to build new ones. Both positive and negative themes are represented here as control over the situation went back and forth between the participant and the back pain: *Fighting and Denying; Being Consumed: Anger and Frustration; Surviving The Three d's (depression, devastation, and despair);* and *Choosing, Adapting, and Accepting*. The participants were at varying places in regard to their normal-making activities. Some were intent on keeping their original ways of being, some were trying to accept and adjust, but most of them moved back and forth among the themes represented here. I came to see this domain as similar to building sand castles…you work and work to create something you are satisfied with and then with the slightest shift of wind or wave leads you to rebuilding and recreating, a process that involves evolution of a vision.

Fighting and Denying

The majority of participants described ways in which they tried to fight with their back pain. Some refused to seek medical attention or declined to have recommended surgery; several avoid taking medications. Many participants go ahead and do things knowing their backs will hurt and cause problems later.

Participants' Voices

Patsy wrote and spoke frequently about this. She initially refused surgery the first time she injured her back, but "I finally gave in and had the surgery." After injuring herself for a second time, she stated, "I finally gave in and went to the doctor. And I refused to have surgery and they said there's really no option." So she ended up having a second operation. Throughout her experience with acute pain, she wrote that she did not want her life to change; she still wanted to do all the things she had been doing, including traveling and being very involved in her children's high school band activities: "I didn't want my life to change." Another comment she made about trying to stay as she had been was this: "I was just amazed…how you want to be normal, but yeah, you know, trying to be normal is rough." She also wrote: "I just felt so much pressure on me to keep working as long as possible as much as possible in pain knowing we can't live on my husband's income alone." In the end she states, "My back pain had won and I had been defeated. I would never be a cardiac nurse again." However, to this day she still shampoos her own carpets and has not limited her church volunteer work even though she knows that she will pay for it later with an increase in pain.

For Patsy, looking and being perceived as being "normal" was very important to her.

> It's probably the biggest thing to me is that I don't want, you know when I go to the store I don't want everybody to notice that something just ain't quite right. I do want to be like everybody else, you know, nobody can tell….I think that's probably the biggest thing to me.

She elaborated: "And you know, I want those symptoms, those signs to go away. But better there, but I don't want people to pick up on it."

Anna also did not want others noticing her impairments. She spoke about her secretary who would point out when she did not look well. "Oh, you don't look like you feel good today" to which she thought "I'd think I just showered and put on makeup and didn't think I looked that bad! You know you don't like all that attention drawn toward you."

Eliza also felt pressure to maintain her previous lifestyle and had to give in and take medication: "I had my second surgery I was like I still had to work, I still had to take care of my family, I still had to do everything. But it made me resort to medication to try to live my life." She still wants to be in charge: "If something comes up and I want to do it I go ahead and do it and suffer the consequences later." She had a recent experience with this; she drove several hours to see her father and help him knowing that it would cause an increase in pain that bothered her for several days.

Barbara clearly articulated this concept of fighting when she said "I have not ever *given in* to getting prescription strength [medications] (vocal inflection in audiotape). In fact she has never been to a physician about her pain, despite having had several instances of what she describes as incapacitating pain; instead she chooses chiropractic care.

Mary was forthright: “I do not want to be inhibited by back pain. I don’t want to take drugs, either.” Reflecting the same sentiment, she stated that her back pain has to be very, very bad before she will even take ibuprofen, a mild over-the-counter pain medication: “I try to stay away from taking any medications.” However, Mary was inhibited in her job in the operating room (OR) by her pain, describing a time when she worked to the point of tears during a surgical case.

Anna is a funny, articulate woman who left a fulfilling career as a nurse in labor and delivery (L&D). Her first reaction to her back injury was “so I just thought...buck up!” Her back has continued to bother her for decades but she does not want to be bothered with symptomatic care if that care comes at too great a price: “…but you know I have a life, I, I just can’t be infringed on my life.” Anna describes her life--her typical day--as ending in bed around 7:30 at night after a day that was hopefully busy enough so that she did not have time to think about herself.

Megan, an experienced emergency department (ED) nurse stated in her interview that when her back pain started “I really didn’t do anything about it”. She did nothing about her back pain despite several episodes that caused her to “scream in pain.” She finally was late to work because she was unable to move her left leg to get out of the car and sought medical attention. She refused the operation the neurosurgeon recommended to her. And decades later she states “But now I just deal with it. I rarely take even a Motrin for pain; it has to be really, really bad before I do that.”

Several participants wrote or spoke about denial they felt, and in some cases still feel, about their condition. Some characterized what they did as “ignoring” their pain. Denying the back problem was a surprise to me given the dramatic descriptions of back

problems I heard and read. These back problems appeared suddenly and their impact was life altering. In a dramatic journal entry, Giselle, who teaches nursing in a clinical setting, describes a day when she "sneezed wrong in the shower" and had to send her students home from the hospital because she was in so much pain she could not function. This would have been a major incident; the students would have to make this experience up before the end of the semester. In a later entry, Giselle writes, "Touch wood, but I haven't had a flare up of my back pain for over a year (I don't really count the sneezing episode from last fall)."

Mildred was perhaps the most insistent on ignoring her back pain: "You know I don't think anything of it, I just…shake it off." "If I have a day when I have a lot of back pain or something like that I just do it. It doesn't ever stop me." She also says, "I have always dealt with my back pain by kind of ignoring it." Mildred was unique in my sample; as a Healing Touch Practitioner, she has mastered the art of bodily control, using self-hypnosis, imagery, and some healing touch on herself. She was up and ambulating only two hours after her back operation and did not take any pain medications afterward with the exception of a dose of Tylenol the next day. Golda was also adamant about ignoring her pain: "I sort of ignore it now, you know keep busy."

Mary did not outright deny her problems but minimized them on several occasions. She described working one day until she was in tears and could not perform her duties as an operating room nurse, interrupting an operation and incurring the wrath of the surgeon. She stated to her supervisor, "Well I think the work is getting to be *just a little too much for me*" (emphasis in the original). Patsy, who loved her job as a cardiac nurse, was in denial about the severity of her back injury for a long time. "I had this in

my head 'I can go back to work. I can go back to work.'" She kept returning to her surgeon hoping for the medical clearance that would allow her to return to her job.

Megan seems to have trouble with a realistic self-image.

> I still picture myself as pretty young, very strong, and healthy, even though I am overweight, bordering on being a diabetic, and have all sorts of musculoskeletal problems. I still picture myself as very sexy and attractive. So having constant back pain and muscle spasms doesn't really fit into my self-image.

Sylvia, the most disabled of my participants, had a dramatic account of going ahead and doing something she wanted to do with drastic consequences.

> …but I was determined to go to my son's wedding 4 hours away. I rode lying down in the backseat as I do whenever we go anywhere. Although the pain was high, I pushed myself to do as much as possible. When I got home I was housebound for 9 months.

Nurses seem to think that they are strong and can do everything. My participants were no different. Several participants wrote about being surprised that they no longer were capable of doing certain things and that it took them several years before they quit trying to deny that fact. Megan summed it up nicely: "Problem is, you don't want to admit that you have a chronic condition. Especially being a nurse. Now you are 'one of them'. You are like all your patients. You are like all the people you said you would never be like."

Additional statements that support the theme Fighting and Denying are presented in Table 2.

Correlation to the Literature

Fighting and denying pain can be considered part of the process of "normalizing." People with chronic illnesses often want to remain normal and strive to keep things as they had been in the past, including their pre-injury or pre-illness identities (Asbring, 2001; Bury, 1982; Deatrick & Knafl, 1990; Erikson & Svedlund, 2006; Gantt, 2002; Hopkins, 2004; Persson & Ryden, 2006). This seems to occur particularly after a condition occurs suddenly, which in the case of a back injury is usually the case (Livneh, Lott, & Antonak, 2004). Often my participants even wanted to look normal to others and resented when friends or co-workers commented on how "bad" or "miserable" they looked. Denying also includes minimizing the situation, seen in my participants when they compared themselves favorably to others—for instance, stating "at least I don't have cancer"--echoing findings from the literature (Hopkins). In fact there are recommendations to health care providers to help their patients "normalize" life with a chronic illness (Venning, Eliott, Wilson, & Kettler, 2008).

While denial is often seen as a negative response to a situation, in the case of a traumatic event, it may be adaptive. Freud (1946, 1961) described denial as a mechanism by which the ego gained time to become strong enough to handle a situation perceived as unbearable or intolerable. Denial can give a person time to understand and accept or adjust to the situation at hand and is a common response to illness and disabling conditions (Coyne, 1997; Lazarus, 1983; Livneh, et al., 2004; Livneh & Martz, 2007; Samson & Siam, 2008; Schaefer, 1995; Telford, Kralik, & Koch, 2006; Whittemore & Dixon, 2008). Denial in the extreme incorporates "ignoring" the situation, seen with several of the participants and in others with chronic illnesses (Grant, Long, & Willms,

2002; Samson & Siam). Grant, et al. specifically investigated the effect that ignoring pain, among other approaches, had on pain and mood in a sample of 88 women with low back pain and found that it did affect same day changes in mood, but did not affect their participants' pain levels.

Denial can be problematic if used over a long period time to cope with a disabling condition or an illness, resulting in poor adjustment and continued intrusive thoughts about the person's medical condition (Covic, Adamson, Spencer, & Howe, 2003; Delmar, et al., 2005; Roesch, et al., 2005; Schaefer, 1995; Stanton, Collins, & Sworowski, 2001; Wegner & Pennebaker, 1992). Studies with breast cancer patients, recipients of heart transplants, and patients with rheumatic diseases all demonstrated continued emotional distress when patients used extended denial as a coping technique (Dew, et al., 2005; Dew, Simmons, Roth, Schulberg, & Thompson, 1994; Hack & Degner, 2004; Lutgendorf, et al., 2002; Roesch, et al., 2005; Stanton, et al., 2001; Stanton, Revenson, & Tennon, 2007; Stanton & Snider, 1993). Of course denial can also lead to increased injury when the person continues to go about his or her daily activities without regard to limitations or reasonable restrictions.

Perhaps nurses are more prone to denying they have a medical problem than other people. As Giselle wrote: "Being a fairly typical nurse, I don't usually seek medical care unless I'm coughing up a lung or bleeding out my eyes. My family I send in right away! Me? It can wait!"

Table 2: Additional Participant Statements Supporting the Theme: Fighting and Denying
Betina: "I am determined not to have that [surgery] at all costs." Giselle (about subsequent depression caused by her back injury): "I am not going to talk to my doctor about it; I don't want to deal with it." Patsy: "I refused to live on pain pills for the rest of my life." DeeDee: "I really didn't believe it was a chronic problem." Megan: "I sure as hell wasn't having any goddamn surgery he could offer!" Toni: "I kept hurting my back …so it came to a point where [husband] wanted to become like a caretaker to me and I finally gave in and let him." and "It's a constant struggle not to let it get the upper hand." Eliza: "Sometimes I try to ignore it…the next day I realize how dumb that was…" and (about her injury) "I knew something was wrong. But of course I didn't do anything about it for a while." Anna (wanting to do yard work): "And my husband…he'll say 'You're going to be sorry' and I'm like 'Yeah I know it but I want to do this. I was to see the results of this.'"

Being Consumed: Anger and Frustration. Anger and frustration are common emotions in chronic illness and are both well documented in the literature (Chaney, et al., 2004; Riedinger, Dracup, & Brecht, 2002; Livneh, et al., 2004; Livneh & Martz, 2007; Plach, Heidrich, & Waite, 2003; Schaefer, 1995; Sullivan, Weinert, & Cudney, 2003; Whittemore & Dixon, 2008; Yi, Yi, Vitaliano, & Weinger, 2008). I knew this to be true, however; I was stunned at the level of anger and frustration I saw, heard, and read during this study. Some of the anger boiled over into sarcasm, much was directed towards loved ones, and interestingly, some of the most hostile statements were directed towards the Workman's Compensation system. Frustration revolved around the lack of control over

the situation, the feeling of not being believed, not-so-helpful suggestions from others, and the need to plan every event in the participants' lives around their back pain.

Participants' Voices

Giselle was one of the angriest participants. Many of her statements reflect this. She is disheartened when people ask her how she is, writing:

> I hate saying the same thing time after weary time: It's the same…and no, I can't come back to my job. *Don't they get it?* [emphasis in the original] I guess what really gets to me is everyone's like 'How, how's your back?' Well, let's think about that! There aren't any changes, OK? 'Oh, it's not any better?' No, it's not! No, don't ask me how my back is, OK? My back sucks and it's always going to be bad.

Giselle also has "bitterness over the things I can't do." She wrote, "Do I resent the fact that I can no longer do the things I want to do? YOU BET!" She reflects on the fact that she could be worse off, but that is little consolation to her. "Why don't I feel grateful? This injury took away a job that I love and activities that I enjoyed." Giselle also suffers from leg cramps that awaken her at night and she describes wandering around the house at all hours. Her leg cramps are occurring during the day now too, to which she remarks "Isn't that special?" Recently she has decided she will need to have assistance at home with assembling things and fixing up her house, another source of frustration and anger:

> How refreshing. First it was the job (!) that I had to give up. Then I had to give up certain recreational activities and now the simple task of making the house a

> little nicer? I'm a do-it-yourself kind of girl! I hate having to pay someone to do what I want done.

Anna, the former L&D nurse, was also very angry. When asked what her predominant emotion was during the acute phase of her injury, she replied "Anger. Lots of anger." She has compelling stories of her treatment at the hands of the Workman's Compensation system and some of the health care providers she has encountered, including those at the hospital where she has worked for years. During a visit to employee health, the physician interrupts her exam to strike up a conversation with a nurse, prompting this reply: "I feel like crap and you act like I don't exist???" She feels that the entire Workman's Compensation system staff—and indeed other health care providers— do not believe her, labeling her "The work comp faker." She is not allowed to see the one physician who showed some empathy and tried to help her out; she is told her case is closed when she needs medication refills. She eventually had a dorsal column stimulator implanted which needs occasional battery replacements. She went in for a battery replacement and after the surgeon started the operation, he discovered that the OR did not have a new battery. So she was closed up and sent home with a return trip scheduled for subsequent surgery.

> They put the leads in, closed me up, and come back in 10 days and we'll put the battery in. Didn't get one apology from this hospital. So I come…you don't think you feel like a worthless piece of crap when that happens to you? You know I would never allow that to happen to my family, my patient, to anybody, but who's my advocate? …and I'm so humiliated that this would happen…So yeah my anger, stuff…can flare up a little bit.

She also relates trying to be forced out of the hospital too early after an operation "I mean, I…it's like one more slap" and voices anger and frustration at people who do not understand that getting Workman's Compensation also meant that she lost $28,000.00 in income the year it was in effect.

Family members often became the brunt of the participants' anger. Like several participants, Anna relates having trouble with her husband, who did not understand why she could not be "fixed" and whose angry feelings brought out more anger and conflict. "I know I'd be divorced because you know, you're nice to everybody at work all day then you go home and you let loose on the people you love the most."

Laurabelle, another former L&D nurse who now works in education writes

> I began to get angry about it and would get angry at both my husband and sister. In fact I was "ANGRY" at everyone. The anger so affected my family. I was angry all the time but had no control over it. It seemed to consume me along with the pain and depression.

She began to contemplate divorcing her husband. She felt lost within her problem:

> Some days I was totally consumed with the pain and felt <u>no</u> one understood! My chronic pain affected every ounce of my being. It seemed to consume me and my thoughts. I tried not to talk to people about it because I did not think they understood "chronic pain"! Everyone had a suggestion for you to try to get 'rid' of it. I would get so sick of hearing what everyone "thought" I should do. I would feel "<u>angry</u>" at people who wanted to tell me what to do.

The pain led to what Laurabelle described as a vicious cycle in her household:

> And by now my family hated me…and um, you know I hated them. And you know if they were happy, I wasn't and it was just you know, a vicious cycle. It was awful. They were almost afraid of me. And you know it seemed like I would always pick fights all the time.

Angel, another former ED nurse who now works in education, also encountered those who did not accept that she has back pain: "It's frustrating having chronic back pain because no one believes it exists." She also had tales of what she called the "Workman's Comp nightmare": "It's frustrating to have to keep proving it." and "It's frustrating to deal with the system. The system failed me." "I just get aggravated. Why does it have to be so hard?" She feels particularly vexed because she opted not to have surgery and only wants symptomatic care: "And all I wanted was chiropractic care when my back hurt. And so I was very frustrated because I felt like I wasn't asking for very much." Adding insult to injury, she was sent every year for an evaluation of her condition "from a chiropractor that was usually located no less than an hour away."

Going to the ED occasionally for exacerbations of her back pain caused Angel to worry "Are they gonna believe me? You know, are they gonna think I'm faking it?" Fortunately for her, she is grateful that she was treated well there despite her poor experiences with Workman's Compensation and despite her first experience with the medical system for her back pain when her MRI was read incorrectly.

Angel is also frustrated that her back pain seems to be the reason she cannot accomplish some personal goals such as exercising: "Unfortunately it [a recent fall] gave me another excuse not to exercise. I have got to get going with that again. I'm so frustrated with myself." In journaling about the most major problem her back is causing

her now, she writes, "The frustrations surrounding that are mostly based on the fact that I know what I need to do and I just am not doing it [exercising]."

Several participants described how having chronic back pain makes doing even the simplest things complicated; planning big events such as trips or weddings becomes daunting. Patsy explains: "It's hard to plan…So you know it's hard to plan too far in advance…it's very frustrating." She and her family were anticipating a long car trip and had to make detailed plans revolving around driving schedules and Patsy's medications. Sylvia needed to help plan her daughter's wedding while nearly completely disabled with her back problems.

Eliza echoes this sentiment: "Also it is frustrating that I always think about if any activity will aggravate my pain level." Eliza states that her predominant emotion related to her pain is frustration but she also had a lot of anger as well because it impacted both her work and her home life: "I was really angry! This really disrupted my life! I let it control me then." Eliza is one of the participants who has come to a level of acceptance about her pain, but even she says "But just because I have accepted that I will always have pain, doesn't mean it doesn't frustrate me. I think that is the most prominent emotion I have in living with chronic pain."

Betina, a former intensive care nurse who now works in education, expressed frustration when her back would flare up ("I was so frustrated that this had happened again!") and irritation that others did not seem to really understand the nature of chronic back pain. She made an interesting comparison to individuals who have cancer by remarking that the response from coworkers is "…a whole different response to people who are going through that [chemotherapy] as opposed to chronic back. The expectation

is that OK, well, you can get over this back pain and you're good as new. And for some that may be." But for Betina it was not the case. She had to make the decision to say "no" to what were to her unreasonable requests at work in order to preserve her health.

Megan was particularly articulate on the frustration and aggravation she felt in her journal.

> …plus pain is not quantitative. Chronic pain is so much more than pain. It is an interference, it's annoying, it's bothersome, it's limiting, it's aggravating, it's more than that number. How do you give a number to something that is not too painful right now but is extremely irritating and makes you crabby so then you yell at your kids and kick the dog out in the rain?...What really annoys me is that you go to the doctor's office for just a check up and they ask you in this random way 'How is your pain today?' A number pulled out of your ass doesn't mean anything.

Megan feels "punished" by her back pain but does not feel she has the luxury of a little self pity once in a while. "But I still always think, why me? What did I do to deserve this? Why do I have to have this problem? Then I feel selfish for thinking I am so special that I shouldn't have any problems." She sums up her aggravation with her back pain this way "It's just that back pain becomes life pain and that doesn't go away with a Motrin."

Additional statements supporting the theme Being Consumed: Anger and Frustration are presented in Table 3.

Correlation to the Literature

Anger often seems to be a motivator, spurring people to take positive action to gain control over a situation. But anger left unchecked and unharnessed can cause physical and emotional harm. Anger activates the flight or fight response, part of Selye's General Adaptation Syndrome (1946). Physiologic changes occur in individuals such as increased heart rate, increased blood pressure, headaches, and decreased immunity. All body systems can be negatively affected, particularly if this response goes unabated. Anger specifically can lead to physical problems; in a study of 100 diabetics, those who utilized a coping style that consisted predominantly of anger had poorer glycemic (blood glucose) control that did those whose coping styles were more adaptive (Yi, et al., 2008). Anger has been studied extensively in the development of several medical conditions, most notably heart disease (Chida& Steptoe, 2009).

Anger has a special poignancy for people with chronic pain. They often express frustration and anger at not being heard, not being believed, not being attended to in the way they expect; however, their expressions of pain and aggravation often cause the very people from whom they are seeking help to turn away from them, resulting in relationships marked by ineffective communication and subsequently, increased frustration and anger (Slade, Molloy, & Keating, 2009; Verbeek, et al., 2004). Often anger is not expressed and leads to depression, a finding seen in my participants as well (Burns, Bruehl, & Quartana, 2006; Duckro, Chibnall, & Tomazic, 1994). Graham, et al. (2008) recently found that patients with chronic pain gain greater control over their pain when they express their anger.

Often anger is related to the seeming unfairness of the situation, of having a chronic illness. Many of my participants voiced "Why me?" statements and railed at the way their pain has affected their lives and their bodies. Often anger is directed at situations that are perceived to be controllable (Folkman, 1984), and a particular frustration of patients with chronic pain revolves around the continual and time-consuming search for something, anything, that will lessen their discomfort (Schaefer, 1995).

Table 3: Additional Participant Statements Supporting the Theme: Being Consumed: Anger and Frustration
Giselle (on not being able to wear high-heeled shoes): "Great! That's just great!" and "It pretty much sucks to be me!" DeeDee: "DAMN IT! Really—why me? That's when I get mad!" Anna: "I'm just permanently angry about the time I missed with them [children]." Toni: "And it's this little stupid stuff that makes me so frustrated and it makes me very angry." Barbara: "Stuff like that…that really annoys me. Not having stuff done and not being spontaneous in doing things." and "Oh my God this complicates everything!" Eliza [on having severe pain]: "I need to shut down or I will bite somebody's head off!" Sylvia: "It makes me sad and angry." Megan: "Everything hurts and I'm so tired of it." Betina: "Emotions related to this experience of back pain—anger and frustration come to mind, first of all." Golda [describing her predominant emotion related to back pain]: "Aggravation! Rats!"

Surviving The Three d's (depression, despair, & devastation)

Anger and depression often go hand-in-hand. Every single one of the participants has suffered with depression and despair, with many calling their condition devastating. They wrote eloquently about the despair they felt.

Participants' Voices

DeeDee described having some "lonely and hard times with pain" and wrote about one time where she felt she was at the "end of my rope." Laurabelle describes feeling "dread," being "consumed with depression," and being "forlorn." When her back pain returned after a pain-free period, it was a "pretty low blow."

Sylvia had been a hospital nurse when a back injury forced her to stop working. She eventually found a job as the nurse at a local college. Now that she is completely disabled and unable to work at all, she is "struggling with having a purpose again." She describes living with depression, despair, and loneliness due to the imposed restrictions of her back injury. When asked how she felt when she realized that she had a chronic condition, she replied:

> Yeah, yeah, I just felt like, um, running off the road and that's it. I had another idea that maybe if I could get a big syringe from the hospital and fill it full of air and give myself an air embolism, you know….I just um, I just didn't think I could live with the pain all the time.

Anna was so enthusiastic about her job that she went in extra whenever she was called, often leaving her kids "crying at the daycare 'But you said it was your day off!'" When a back injury forced her out of her job, she discovered she was not as irreplaceable as she thought she was: "I was devastated when I found out they could live without me."

She writes and speaks of feeling "worthless" and does not appreciate it when co-workers comment on how bad she looks and question her as to why she does not go home. She explains that she might as well not go home because she will just be "miserable" there and get into the "why me" routine.

Toni lost her dream job working in the Neonatal Intensive Care Unit (NICU) when she injured her back. Her response when she discovered her back injury was a chronic problem was "it was devastating." She became depressed, has been on antidepressants, lost confidence in herself and with decision making, ended up lying around the house eating and gaining weight, has developed anxiety and what she describes as a "personal handicap," and relates that the injury "pushed my relationship with my husband and kids out the door." She also writes that she "became a big baby" and that dealing with the pain "sucked all my energy." She writes of feeling like a failure ("…so not being able to do that [work in the NICU] was a horrible couple of years for me because I was feeling like a failure") and that having a back injury or back pain "sets you up for failure" at home and on the job.

Patsy, the former cardiac nurse, writes of being "heartbroken" and "crushed" when "all my dreams of going back to the cardiac unit were lost in one sentence." She describes feeling "empty inside like I had no purpose in life." She "cried and felt defeated" and was "so upset and devastated" when she was told she could not resume her job. "My whole world fell apart…it's like the bottom fell out…I never, I had never had such devastating news." She spent time "trying to fight to not be depressed." Patsy and her family enjoyed activities at the lake, including riding wave runners. For a year she tried to be "brave" and ride anyway despite her pain, but eventually they stopped going to

the lake and they sold the wave runners. Patsy says "when we sold it, you know, it was like, a devastate…it was devastating." Not only was selling the wave runners hard on Patsy, but it was hard on her family as well. "…it devastated my whole family." Patsy "felt bad my family was sacrificing their fun because of me."

Several participants were distraught over their loss of professional identities as well. Patsy wrote "I felt like I wasn't a nurse anymore." Giselle stated, "I guess I'm out of it [hospital nursing]. I think about this fact every day." Sylvia has recurring dreams about being a hospital nurse again, and sometimes she sees herself in facilities she has not worked in, but the theme of hospital nursing is there. Barbara was sad having to give up teaching in a clinical setting and her neighbor's experience with being totally disabled from a work-related back injury led her to say "Nurses are so much more than their backs for goodness sake!"

Eliza wrote about how her emotional response to her pain impacted the physicians with whom she worked. "I have just let go and cried about it. I worked with those MDs for 20+ years and they were astounded at how the pain affected my emotions." Betina cried during her interview when she said plaintively, "I didn't know if it was ever going to get better."

Giselle describes "sadness over leaving a job and colleagues I truly loved working with." Formerly a cardiac nurse, she now teaches nursing. "Um, I teach, I teach the clinical but I can't do the bedside nursing anymore. And that's very depressing." She writes in her journal: "Am I depressed about things? Hell, yes." and "Situational depression and its effects on the rest of my life. Phew. Sounds big!" She does not like

to talk about her emotions and writes "I do find myself tearful often and I do ponder the what-ifs of finding a cave, curling up and just staying there for a while." She also writes,

> I should see a counselor or someone like that, I should go to my doctor. I should probably be on an antidepressant. But most of the time, I feel like I should just do the fetal position thing and pretend to be Rip Van Winkle. Perhaps if I wake up in 100 years, things will get better?

On losing the ability to ride horses, go rock climbing, or "run, skip, and jump" she pens "What a total and complete bummer!" In her interview she again acknowledges that she does suffer from mild depression, and while it may be mild, "there's a lot of it."

Additional statements supporting the theme Surviving the Three ds are presented in Table 4.

Correlation to the Literature

When it comes to chronic illnesses, there is "a lot of it." Schnitker (2005) found that "first and foremost, [the results] suggest that chronic illnesses are depressing" (p. 21). Depression and its role in chronic illness has been studied extensively over a wide range of illnesses including cancers, multiple sclerosis, heart disease, chronic lung diseases, rheumatoid or osteo-arthritis, systemic lupus erythrmatosus, and chronic pain to name a few (Balderson & Towell, 2003; Denton, Sharpe, & Schrieber, 2005; Kagee, 2008; Kim, et al., 2000; Mohr, et al., 2000; Pincus & Morley, 2001; Sharpe, Sensky, & Allard, 2001; Wilkens, 2001). Chronic illnesses are especially likely to cause depression when they strike a younger person or when the problem causes disabilities or physical limitations (Dunlop, Lyons, Manheim, Song, & Chang, 2004; Livneh, et al., 2004; Schnitker, 2005; Sullivan, et al., 2003). Schroder, et al. (2007) found that activity

limitation after a stroke was a powerful predictor for depression. Depression and anxiety create a "high psychosocial burden" in people with chronic low back pain (Zenker, et al., 2006, p. 426). And disability is a very powerful predictor for depression in the elderly (Prince, Harwood, Thomas, & Mann, 1998). Depression is very likely when the person's identity becomes wrapped up in the negative aspects of the condition, so that the person views him or herself in light of those negative characteristics (Pincus & Morley, 2001).

While depression can be caused by the functional limitations that accompany chronic and/or disabling conditions, it is a two-way street; depression can lead to further declines in physical ability (Dunlop, et al., 2004; Schroder, et al., 2007; Sharpe & Curran, 2006; Stanton, Revenson, & Tennen, 2007). A person who is depressed often has what is termed "psychomotor retardation" a slowing down of activity, plus apathy and lack of energy to be active (Shaw & Lewis, 2007). This in turn leads to increased weakness, the extremes of which end in "disuse syndrome." And so it becomes a vicious cycle: functional limitations and pain lead to depression, depression leads to decreased activity. Depression can also have a negative influence on self-care abilities and can result in poorer adaptation to the person's condition over time (Livneh, et al., 2004; Whittemore & Dixon, 2008).

Loss of independence is another reason for depression in people with functional limitations, often due to the accompanying decreased self esteem (Dickson, Allen, & O'Carroll, 2008). As Freund & McGuire (1995) state, "illness is especially damaging to self when it is experienced as overwhelming, unpredictable, and uncontrollable because it paralyzes a person's ability to manage life, to plan, and to act" (p. 145). Several of my participants wrote and spoke about their loss of independence and how that has affected

them. Loss of independence can lead to a loss of self identity which spans both the personal and professional worlds (Asbring, 2001). Often depression can lead to decreased social functioning, which in itself can lead to more depression since social support has been found to be vital for living successfully with a chronic condition (Coyne, 1997; Schroeder, et al., 2007; Sharpe & Curran, 2006; Stanton, et al., 2007; Sullivan, et al., 2003; Venning, et al., 2008).

Table 4: Additional Participant Statements Supporting the Theme: Surviving The Three d's
DeeDee: "Acute exacerbations produce great anguish for me."
Laurabelle: "Oh I was depressed. It was very, very depressing."
Sylvia: "…it was pretty devastating."
Toni: "I remember being so down."
Barbara: "Oh…this is not what I want. I mean it's very disappointing and uh, discouraging."
Patsy: "…the nights I've cried…I've screamed and cried."
Betina (how it felt to realize she had a chronic problem): "Discouraging"
Megan: "[back pain] really drags me down. I am somewhat depressed and feel like I can't accomplish anything."
Golda: "…early on I got a little depressed thinking that if it [back pain] was going to continue there must be 'something' to do about it."

Choosing, Adjusting, and Adapting

Most of the participants were able to articulate things they chose to do to limit the effect the back pain had on their lives. While this showed an element of control, it was clearly different from *Fighting* discussed above. These were deliberate and planned activities that had a rationale behind them instead of a blind insistence on doing what the

participants wanted, no matter what the outcome. Sometimes choosing meant giving up control, often to a higher power, to God. While most of them had adjusted at least some activities to accommodate their limitations, some of them had actually moved into a phase of adaptation and acceptance.

Participants' Voices

DeeDee writes about how she has determined that some priorities are worth the later discomfort, so she plans for these events and the time afterwards. "I have to plan my life out." Going to the state university football games is a priority, something she loves so "I'll deal with it on Saturday night." She has friends and neighbors help her move heavy objects for instance instead of trying to do it herself. She feels that most people are glad to help in that situation. She has tried to learn how to live with her condition and to cope with it, in part by learning to trust in God: "I've just left it to Him (Christ) because, because I can't do anything with it."

Sylvia made enormous adjustments in order to be able to continue in her position as a college nurse. She was determined to continue working because "it gave me purpose and self-esteem. I felt independent because I got a paycheck, even though it was not very much." She was only able to work about three hours a day, and spent her time lying on her stomach on an exam table while working on the computer. She was able to get up and attend to students as they came in for their usually brief visits. When they left, she lay down again. She even had to lie on a hard table at meetings because her ability to stand, walk, or sit is limited to mere minutes at a time. However she found that these adaptations let her work without increased pain. She needs two airplane seats when flying so she can semi-recline and has to entertain guests in the bedroom so she can lie

down in her bed. She has tried to learn to cope and adapt by finding resources such as the American Chronic Pain Association and by trying to realize that she needed to go from being a patient to being a person with pain who has a positive attitude.

> I've just been in a better, a better frame of mind thinking that I'm just going to do the best I can each day and things will unfold the way they're supposed to…I don't know, but uh, but for now I'm just going to do the best that I can.

She is learning to give up control: "I'm powerless over so many things and um, so I, uh, not that I don't try, try to control, but uh, I just can't, and so for me, dealing with chronic pain is a whole lot about attitude now."

Golda, a retired special education nurse, related a lot of her back problems to stress, being too busy, and grieving. She states, "I've learned a lot about letting go of things you can't fix which has been a great blessing." She had exacerbations of her back pain when relatives died or had serious medical problems. When her mother died after a long, lingering illness Golda ended up in bed with back pain for two days and decided that her grieving had to end. "You know I thought at the time 'Well, mom, that's goodbye.'" She has decided that she could have worse problems so "There's no point whining about it." She still goes about her daily activities, choosing to have a positive attitude:

> …I don't worry about it—it hasn't ruined my life by any means. I guess I figure everyone has something to deal with and it could be worse—so far I am healthy and able to be active in spite of that. I feel fortunate.

Toni has tried to adapt by making healthy life choices to become more physically

fit and to prepare for a possible future operation. She is also trying to have a more positive outlook, trying to "laugh it off and find the humor" in her situation and says, "You have to adapt and you have to make do with what you have or you will never be happy and the most important thing is to be happy." Toni has foot drop from her back injury and also is blind in one eye, so she has physically adjusted the way she does certain things to prevent further injury (she has already broken her wrist, broken a toe, and torn ligaments in her leg from falling): "I've had to adapt and make my brain think that if I'm carrying [grandbaby], I'd better do it with my right hand so I can grab on to the railing…" She has gotten to the point of feeling that her back injury is "not the end of the world" and says "I'm at the point where I can live with it and it's OK. I understand it." Prayer has become important too:

> You know I could be, I could be a lot worse off. Well thank God. I mean I pray a lot. I'm not totally religious by nature but I have a strong faith and I, I hope that's what's getting me through.

Laurabelle has also reached a state of acceptance with her back pain, saying

> …so I think I have been able to understand that it will be chronic and I've accepted that because there's nothing else you can do. So you have to learn to live with it just like other people learn to live with [other chronic illnesses]…and I think oh God I don't think I could do what they did, well you learn to live with what you can.

Angel also feels she has come to some acceptance of her situation. First she had to overcome her anger with the Workman's Compensation system after fighting with them for years: "We're done. I got over it." Now she feels that she is able to choose how

she views her situation, "I think I've done a really good job of tucking it into the background of my life." She states

> Once you realize it's a chronic thing you have to live with it or you have to mess with it all the time. And so I live with it….The whole thing with chronic pain is that you have to decide how you're going to respond to it.

However, this seems to take a lot of energy. During the study, thinking about her back pain and writing about it made her notice it and made it worse "like I was saying before, it made me think about it and it started hurting because I was thinking about it." So perhaps for some, this adaptation requires great effort.

Patsy also expends energy trying to accept her condition. "I did a lot of praying you know to try to resolve the problem in my head…to know that it's moving from the anger to acceptance, all those phases you have to go through…" Having a nerve block that diminished her pain level helped as well "…accepting the pain, I think that this last shot there's less pain than what I was in; this nerve block has really helped. You know I can live with the pain I have now." She still enjoys volunteering at church and family game nights, but with modifications "…you just adjust your life to it. And physically, that I mean, I've learned to adjust to all along. What you can and can't do." Her entire family is involved in planning an upcoming long car trip. Her children are making a meticulous driving schedule based on the effects of her medications and when her back hurts the least but the medication effects are minimal so that Patsy's driving is safe. Faith is important to her as well as to some of the other participants and she is learning to give up control to God "…because I figure sometimes I'm not walking, I'm being carried."

Mary learned to balance work, which made her back hurt, and the activities she enjoys. "So it is called find a happy medium." She reduced her work week to 3 10-hour days. This way it is her "…choice to work extra or play." Mary proudly related a story in her journal about watching her grandson and needing to change his diaper while keeping him safe and her back from hurting:

> Yesterday when I was changing my grandson's diaper, I had to bend over the crib. My lower back ached. When I stood up, it was better. I moved him to the bed and found it less painful, but more dangerous. I can't leave him for a second on my bed. He has started to roll and is very inquisitive. I found that by putting him on the floor to change his diapers, I solved all the problems. My back didn't hurt and if he rolled he was safe.

Eliza, who used to work in an advanced practice role and who now teaches, has found that accepting the pain puts her back in control of her life. "Until I came to the acceptance that the pain was a part of my life, I lived my life around the pain." Part of accepting was learning to cope with the pain ""I know I haven't gotten rid of the pain, but have learned to cope with it better. I think that has been an important key in my life. Acceptance and learning to cope." She did a lot of research on chronic pain, talked with others who suffered with it, and did a lot of "deep soul searching." But now she feels that she is more accepting of her condition: "…I've learned to live with it and learned you know what I can accept and what I can't accept." She also wrote in her journal about understanding what makes her pain worse and attempting to mitigate the triggers' effects: "But today I just accept it and try to alleviate it."

Betina is another nurse who has learned to accept her condition and is "determined to live life to the fullest." She still enjoys working and leisure activities but "I just do them smarter." Betina has also made significant changes to her work load to decrease the stress both for her back and for her emotional health. She was originally an ICU nurse who left that area as she saw the physical demands become too high for her. Now she teaches and has become a person who can say "no" to things she knows will end up being too much for her.

> I've also learned that it's OK to say "no" to a lot of things and whatever people think or feel that's what they think or feel. But they don't live in this body of mine and if they don't understand, that's too bad, they just don't understand.

She has already decided that when she has grandchildren, she will watch them, but "…that's OK, I can just be the grandma sitting in the chair" when holding the babies. She has also found a lot of home remedies that help her, including magnets, and she goes to jazzercise classes. Betina is another nurse who has found strength in her religion. She cried softly when she said "I depend on God for strength because I cannot do it on my own."

Additional participant statements supporting this theme are presented in Table 5.

Correlation to the Literature

For the purposes of this study, "adjusting" meant changing the way a participant does things, not necessarily happily, but out of necessity. Participants realized they could no longer go on doing things the way they had, and had a choice to make; either give up the activity or alter the way they went about things. Believing that one has the ability to choose certain behaviors that will then reflect in specific outcomes is called "internal

locus of control," or variously, "self-efficacy." People who view themselves as having self efficacy or an internal locus of control have been shown to have decreased depression, better adaptation, less anxiety, decreased social distress, better overall mood, lessened influence of the illness on daily activities, and diminished symptoms overall in a wide variety of illnesses. These individuals are able to make and sustain behavioral changes that have a positive influence on their conditions.

According to the transtheoretical model of behavioral change (Prochaska & Velicer, 1997), people go through several stages when planning and implementing health related behavior changes. In the maintenance phase, the changes have been incorporated into the person's lifestyle in a consistent fashion. Zenker, et al. (2006) has found that patients with chronic low back pain had less persistent pain when they were in the maintenance stage of behavior change in response to their back pain.

"Accepting" was used similarly to the concept put forth by Kubler Ross in her groundbreaking work on grief (1969/1987): that the person had entered into a state of peace with where they were with their back pain and their lives. This went beyond the simple absence of distress related to their condition. At this point, the negative emotions of denial, frustration, anger, depression, devastation, and despair were replaced with a graceful state of resignation, not out of giving up hope, but out of realizing that they could live with what they had. Not all the participants were in a state of acceptance, and several had accepted their condition actually moved out of that stage at times, returning to "earlier" stages depending on their circumstances.

Coming to an acceptance of a chronic or disabling condition has been shown to result in better coping, better psychosocial outcomes, and better physical condition

(Livneh, et al., 2004; Stanton, et al., 1997; Zenker, et al., 2006). This may result from finding a positive meaning in the situation or from changing one's priorities about one's life and situation (Sharpe & Curran, 2006; Sprangers & Schwartz, 1999). Sharpe and Curran argue that successful adjustment (considered acceptance in this study) requires a "response shift" to the condition: "the process to maintain a positive view of the self and the world in the face of an illness" (p. 1161). Learning to make choices and regaining control over their lives is integral to this process of acceptance (Schaefer, 1995).

Several concepts are related to this process. First and foremost is the concept of grief. Living with a chronic or disabling condition is all about loss, and with loss comes grief for what has been lost (Asbring, 2001; Drench, 2003; Jarosinski, 2006; Kendall, 2005; Kralik, 2002; Kubler-Ross, 1969; Kubler-Ross, 1987; Schaefer, 1995; Wright, 1983, as cited in Livneh, et al., 2004). The most commonly cited work related to grief is still Elizabeth Kubler-Ross's seminal work, *On Death and Dying* (1969), in which she describes stages of grief that people must go through in order to successfully resolve the grieving process and accept their own impending deaths. According to Kubler-Ross, the five stages of grief are denial and isolation, anger, bargaining, depression, and acceptance.

Although still widely cited, Kubler-Ross is not without her critics. Some authors disagree with what they feel is her "lock step" approach to the stages of grief and claim that grief (and the adaptation that hopefully follows) is more fluid than Kubler-Ross's stages allow (Samson & Siam, 2008; Schaefer, 1995; Stanton, et al., 2007; Telford, et al., 2006). Livneh, et al (2004) call coming to terms with loss a "dynamic process" (p. 412).

Several participant statements can be related to death, to the death of the "self" that was prior to their injury. Giselle wrote, "There really isn't a 'me' anymore." Mary sought chiropractic care but her first treatment "hurt so bad I thought he had killed me." But when it was successful she wrote "He [chiropractor] gave me my life back." She was worried the back pain would "take me out of the world of actual patient care." Reflecting on her inability to ride a wave runner on the lake, Patsy said, "Not riding was killing me." Anna stated, "My husband says if I were a horse they'd take me out back and shoot me." In her journal, Toni twice described how bad her pain was in the ED. "I just thought 'shoot me'" and "…I knew they'd have to kill me…" Corbin and Strauss (1988) describe adjustment as the process by which the individual seeks to regain important parts of themselves that have been lost through the illness or injury. This "death of self" has also been characterized in the literature as "biographical disruption" (Bury, 1982).

According to the model of biographic disruption, chronic illness represents an event that disrupts a person's life, including "the structures of everyday life and the forms of knowledge that underpin them" (Bury, 1982, p. 169). Individuals are brought face-to-face with a situation that usually is seen as the problem of others or as only a remote possibility for them. As Radley describes it, biographical disruption is "…a tear in the fabric of one's life that can suddenly bring into question all of the assumptions upon which it was based" (1994, as cited in Hopkins, 2004, p. 561). Relationships and plans for the future are called into question. Chronic pain and the resultant activity limitations could easily be construed as conditions of the elderly, or infirm, a definite contrast with the participants' views of themselves as healthy and active, and able to work in a

physically demanding job. This sudden realization that one's condition is at odds with self image can lead to biographical disruption (Bury, 1982). Like Bury's participants, mine could clearly describe themselves prior to the onset of their back pain and the problems that accompanied it. As Corbin & Strauss wrote: "When a chronic illness comes crashing into someone's life, it cannot help but separate the person of the present from the person of the past and affect or even shatter any images of the self held for the future" (1988, p. 49).

The task for individuals who have suffered a chronic or disabling condition is to discern which components of their identities have been lost, which components still remain, and to integrate this knowledge into a new self identity along with knowledge of their current situation (Dickson, et al., 2008; Richardson, Ong, & Sim, 2006; Telford, et al., 2006). This requires a "response shift" (Sharpe & Curran, 2006, p.1155) or a "reconstitution of self" (Moreira, 2004, p. 34). This integration of the condition with self-image, or integration, requires a great deal of work and effort (Whittemore & Dixon, 2008).

Table 5: Additional Participant Statements Supporting the Theme: Choosing, Adapting, and Accepting
Angel: "I've just learned to live with it." And "…long ago decided I was just going to have to live with it and not let it stop me."
Betina: "I pace myself for the work I feel needs to get done."
Eliza: "Some of the resources I found helped me determine what I could and could not accept about living with chronic pain." and "I had to learn to live with it."
Barbara: "I have started to hire some of the [yard] work done…it's cheaper in the long run."
Mildred: "I'll just continue to deal with it and try not to complain too much." And "I do know that I try to avoid any potential hazards such as ice or even wet pavements."
Anna: "I try to look at it half full as much as I can instead of half empty."

Summary of Domain One

Overall, the major component of this domain is one of acute grief. Participants did not, as predicted by other authors, follow the grieving process in a linear fashion. Rather they passed back and forth through the stages fluidly as daily conditions and appraisals changed. As this was a phenomenological study of the lived experience of chronic back pain and its effects on quality of life, it is beyond the scope of this work to come to conclusions related to the various models and concepts presented here. However, it is worth noting that the experiences related by the participants seem to fit within in the body of knowledge related to chronic illnesses, demonstrating that their experiences are not entirely unique. The following section describes the second domain, *Living with the Shadow*.

Domain Two: *Living with the Shadow*

As a domain, *Living with the Shadow* describes the process of having a long-term relationship with back pain. Although as a domain this was distinctly different from *Making Normal,* participants were not exclusively functioning in one domain or the other but rather could move back and forth between them. Often it would be one small event that would send a participant reeling back into the world of *Making Normal*, sometimes back to the fighting stage. As a domain, *Living with the Shadow* incorporated four themes: *Fear and Uncertainty, Being Less Than Whole, Having Intimate Knowledge, and Living Through Fatigue*.

Fear and Uncertainty

Nearly all participants described being fearful of something and having uncertainty related to their futures. Most were afraid of further injuring themselves,

many were afraid of increased disability and loss of independence, some were concerned about the possible impact their back pain would have on future activities, there was some fear of medical treatments, and some participants were uncertain as to what their professional futures held.

Participants' Voices

Betina in particular was quite worried about her back pain impacting how she was viewed at work. She seemed to agree with Toni, who felt having a chronic back problem "set you up" in the eyes of supervisors. Betina said during her interview: "And I will tell you Meg that I don't like to talk about my back a lot, um, because I think that people will be so concerned about my workload or that I can't handle my job." She wanted the control of deciding how much to work and how to do her job but was worried that decision might be taken away from her. She expanded on that idea a bit later in the interview:

> I've just been so concerned that people will be so concerned about me being able to do my job that if they heard me talk about my back or something enough they'll cut my workload or do something like that or suggest that it be done.

Betina related some of her back pain to the stress she felt at work sometimes and described some decisions she made to reduce that stress. She ended her discussion of work with this comment: "And so I guess there's an element of fear, of how long am I going to be able to work…"

Barbara had several distinct fears. She was afraid that her back pain would continue worsening over time and she would not be able to do things she enjoys doing now. She also says "I'm also fearful of doing some things that maybe I would like to

do." With an exasperated sigh she related being at a rodeo with some friends and everyone rode the mechanical bull except for her. "No, I better not risk it." She also talked about wanting to ride horses as she did when she was younger. She would like to hike and go to Alaska, but is worried that a future injury would keep her from doing the "normal stuff" so decides not to do certain things: "…well I'm not going to do that if I have a bad back." Barbara's mother had grave case of osteoporosis accompanied by activity limitations and severe pain. Barbara mused in her journal: "I am so afraid to end up like that." However, she fears treatment for her back pain as well: "I'm afraid of ongoing chiropractic treatment may make things worse." She is fearful as she thinks of her future: "I worry that the pain will continue to get worse as I age…."

Patsy has also let fear interrupt having fun. On a trip with her kids' high school band, she restricted her activities: "I was so scared I'd worsen the injury and I couldn't return to work." She described being afraid of how her back pain will impact her future.

> You know it's a scary thought. You know I want to grow old and still be able to do things for myself without relying too much on the kids or my husband. Yeah, you know, think about it…an injury at a young age. I consider myself middle aged, so it's scary. It's a long way out that I'll still live with this pain. Three years is a drop in the bucket compared to what I've got in the future.

She contemplates becoming a grandmother and said "I worry when I have grandkids how limiting it's going to be." She also fears falling even though her surgeons have reassured her that if she falls, she won't knock the screws in her back loose, or out. "They're in there solid, they're going to stay. But it's still scary. It's a scary thing to think about…."

Much of Mary's experiences were surrounded in fear. The first time she got chiropractic treatment, the chiropractor "cracked" her neck without telling her about it beforehand. She states "To have someone crack your neck, that just seems so dangerous…it's scary." She was worried how the pain would affect her ability to continue as an OR nurse. "I was frightened about that….And I was in so much pain in my upper back and then down my leg that I thought, what am I, you know, I didn't know what I was going to do. So it was kind of scary." She also related that it was frightening to think about the combination of being an older nurse in the workplace and having chronic pain: "…that was really frightening and you get older and you almost feel like they don't want you around anymore." In the story about changing her grandson's diaper related earlier, she added "I'm just afraid that if I go to pick him up and when I stand up that ache won't go away and it will start that shooting pain again." When the grandchild rolls on the bed, Mary described it as "…that was kind of dangerous."

Giselle journaled about her fears and uncertainty eloquently. "How bad is my situation? Am I a powder keg ready to explode? A bottle of nitro, teetering on the edge of a precipice? A leaning tower, ready to topple?" She has noticed her toes turning numb and the toenails turning grey and wonders if she should seek medical attention. She reminisces about running into the neurosurgical resident who was on duty when Giselle came into the ED with her injury. The resident told a fellow physician about the severity of Giselle's injury prompting this thought: "(Really? It was that bad? I thought) Hm…Did they tell me how bad it was? How much longer could I have remained upright before the injury was sufficient to cause total paralysis?" A bit further in her journal she wrote this statement about the incident: "And how does this make me feel? Pretty

uncertain about my future as a biped or even as a functioning individual with a decent quality of life."

At the time of her interview, Giselle was struggling in a graduate nursing program and wondered what the outcome would be if she did poorly in her current coursework. That, combined with her inability to resume bedside nursing, led to this comment: "What if I can't teach? Where do I go?" She described in painstaking detail the problems her back injury has caused her then looked with uncertainty towards the future: "What really worries me is the gerontology saying that, As we age, we don't change we simply become more so. (Shiver!) That scares the crap out of me! I'm going to be worse than this?"

DeeDee is in an unusual situation. She is allergic to nearly all pain medications. In desperation, she had a dorsal column stimulator implanted that has seemed to help. This was a last resort for her and for her physicians as her chronic back pain is primarily referred from a gynecological condition and has no relationship to structural spine problems. The surgeons had never inserted a dorsal column stimulator on someone with her condition before and were not sure it would work. Like Anna, she has to have the occasional battery replacement and she recently discovered that the wires were fractured. She is awaiting an upcoming operation to remove the old wires and replace them. There is a risk that the operation will not be successful as the old wires are embedded and have to be taken out and new wires inserted through the scar tissue. DeeDee stated, "I'm really scared about it." If the upcoming operation is not successful, she will have no options for pain control. She wrote:

> I'm scared about it getting replaced—for so many reasons I don't have time to write about—but one is if the physician can't re-insert new wires—then I'll be back to NO relief or treatment and I don't know what I'll do. (underlines in original)

She has recently made a couple of long trips despite some uncertainty: "I was really brave last year when I took those two long trips….And I just, probably five years ago wouldn't have done either because I just kept thinking my back would kill me."

Sylvia, who is quite disabled, is so afraid of living alone that she remains in a marriage that is emotionally abusive at times. "Due to [husband's] behavior I have allowed myself to suffer greater pain because I react with guilt and fear living alone." At the time of her interview, Sylvia was contemplating her next course of action in seeking treatment and went over several options she was considering with me. She was having a hard time deciding which option to take. "It's hard to make decision because it's a mystery why something helps one person and not the other."

Toni was another participant who expressed concern about being able to care for herself as she ages and for being able to keep her job.

> The years I spent as a nurse was like walking on pins and needles you have to be caring for so many people and there is no downtime for your own health issues. I was petrified at being unable to care for myself more so that I'd get caught with painful back and lose my job.

Dealing with the stress of her back combined with her job left her with no energy to deal with her home life and she writes, "I emotionally became very afraid of decision making and why I did certain things." She ended up needing an operation and was

worried about the ramifications of losing the income when she had a new house and a work supervisor who was angry with her for her back problems. Toni woke up every day "feeling such doubt" but decided to have the operation anyway. At the time of her interview, Toni described that the future might hold fusion for her: "I know the next time can be debilitating and could be the final time and I've even made some lifestyle changes but I'm still not totally confident with it…"

In a very interesting passage from her interview, Toni relates her back pain to a dormant childhood fear: "…um the whole fear of my life used to be sharp teeth when I was a little kid and when I hurt my back, that's what it felt like; I was being eaten by teeth, sharp, sharp, teeth…"

Additional participant statements supporting the theme Fear and Uncertainty are presented in Table 6.

Correlation to the Literature

One can easily imagine fear being part of an illness experience; fear of the unknown, fear of a catastrophic diagnosis, fear of not being able to afford medical care. Many authors have focused on this negative psychosocial sequela of both acute and chronic illnesses for a whole array of patients worldwide. Jarosinski (2006) described the fears of schizophrenics who have hallucinations. Sullivan, et al. (2003) found fear of recurrence to be a major theme for rural women living with a variety of chronic illnesses. Shea (2004) has studied the causes of fear in patients implanted with cardioverter defibrillators. Luk (2004) found that kidney transplant patients in China "live with constant fear" (p. 206). Fear of a loss of attractiveness to partners is common among patients undergoing treatment for breast cancer (Schaefer-Schiumo & Atwood, 2009).

Glenton (2003) described fears specifically related to patients with chronic back pain. Several distinct types of fears were present, including fear of being not believed by health care providers, who would then label the patient as a drug seeker, a malingerer, or a hypochondriac; fear of being stigmatized; fear of being thought of as not trying to get well if they were not currently undergoing treatment; fear that the lack of an obvious disability or deformity would cause even their social contacts to disbelieve them, and being thought of as having "character blemishes" such as weak will, being dishonest, or having chemical addictions. As far back as 1968, Goffman described several diseases associated with these character blemishes, leading to stigmatization.

Fear can also be brought about by uncertainty. Uncertainty is a major stressor in both acute and chronic illnesses (Brashers, et al., 2003). Uncertainty in Illness Theory was described by Mishel first as it related to people with acute illness (1988). Uncertainty occurs when there are not enough cues about an event from which to derive meaning, or a cognitive schema. The illness event can cause ambiguity, inconsistency, or may be unpredictable (Mast, 1995). There are three major components of the theory: antecedents of uncertainty, the cognitive appraisal of the events, and coping with the uncertainty.

Antecedents of uncertainty include symptom pattern, event familiarity, and event congruence. Patients experience less uncertainty as they become familiar with their symptom clusters. It stands to reason that diseases that present with high variability cause more uncertainty. Event familiarity refers to the experiences with the health care environment. Event congruence is the difference between what is expected and what

actually occurs in the experience. Social support, education, and credible authority all serve to decrease uncertainty (Mishel, 1988).

Uncertainty is seen as a neutral event until the person comes to view the situation as either a threat or an opportunity (Mishel, 1988; Mishel, 1990). If the uncertainty is viewed as an opportunity of some kind, then the person will employ coping strategies in order to maintain the state of uncertainty. If the uncertainty is viewed as a dangerous situation, coping mechanisms will be employed that buffer the situation. Either way, successfully managing uncertainty leads to adaptation (Mishel, 1988).

Mishel amended her theory in 1990, combining it with aspects of chaos theory, to include those living with chronic illnesses. In this remodeled theory, the focus was not for people to eliminate uncertainty, but rather was on learning to accept and integrate it into their lives as uncertainty is an ongoing fact of life for those living with chronic illnesses. For a person living with a chronic illness, unpredictability and lack of distinct information about their future are both antecedents and managing the accompanying uncertainty is complex (Brashers, et al., 2003; Mishel; Mishel, 1999).

More recently, Brashers et al. (2003) proposed that different illnesses may have unique components that lead to uncertainty and that there may be subpopulations within disease categories that have their own particular experiences with uncertainty. Uncertainty has been studied in numerous patient populations, is negatively correlated with QOL, and can persist long after diagnosis and treatment. Uncertainty can also cause distress in family members (Bailey, Wallace, & Mishel, 2007; Barker-Collo, 2006; Brown, Sorrell, McClaren, & Creswell, 2006; Clayton, Mishel, & Belyea, 2006;

Donovan-Kicken & Bute, 2008; Gil, et al., 2004; Gold-Spink, Sher, & Theodos, 2000; Pelletier-Hibber & Sohi, 2001; Sammarco & Konecny, 2008; Winters, 1999).

Table 6: Additional Participant Statements Supporting the Theme: Fear and Uncertainty
Barbara: "I worry that one of these times [the pain] won't go away."
Mary: "But it's scary, it's scary". and "That fear [of having to quit her job] made me more stressed."
Eliza: "Sometimes I get scared thinking that the pain might get worse as I get older and that I might need another surgery."
Laurabelle: "I was like scared, I was afraid. I was leery, I'm always afraid that it's going to come back."
Sylvia: "I can get into fear big time."
Toni: "I was scared again in pain."
Mildred (talking about climbing stairs): "…yeah, I do that with a little fear of falling anymore". and "I won't walk on ice. I don't care where I have to be, I won't walk on ice. So I take those precautions."
Anna: "When I have grandkids, I hope I can play with my grandkids."
Patsy: "And you know then I worry when I have grandkids how limiting it's going to be [back pain]."
Angel: …"just because there's that concern, you know living alone, not having a husband and children, you know, who's going to take care of me if I can't take care of myself?"
Giselle: "So now we have…uncertainty every day about what might happen if I step the wrong way or move too quickly."

Being Less than Whole

This theme revolves around living with losses and limitations. All participants described the losses and limitations they endure on a daily basis. Although losses can precipitate acute grieving, this theme incorporates the daily struggles and daily little losses that chip away at the self, and that are simply part of the participants' lives now

and probably forever. Losses included loss of physical activity, loss of intimacy with their spouses, and loss of freedom to name a few, and involved not only the participants but their families as well.

Participants' Voices

Sylvia probably has had the most loss of all the participants. She left hospital nursing because of her back, became a college nurse, and now is totally disabled. "I was 33 when I had a work-related back injury: much too young to lose freedom of movement and independence, but my function is that of an old person." While trying to recover, it took her an entire year to go from being able to walk for 10 minutes at a time to tolerating 20 minutes. She is able to do only one or two activities a week now; for instance if she gets a haircut, that's her outing for the entire week. She writes plaintively about the rip in the fabric of her life that is caused by her back problems:

> But oh how I wish I could do the simplest things like go shopping without suffering for the next week, drive over six blocks, sit at the table for a meal or even lie in the living room for over an hour to visit friends, go for a long walk, hike, camp, ride in a car 30 minutes without consequences, etc.

Her back problems have left her feeling like a prisoner: "Sometimes I feel trapped at home: cut off from the real world while I spend most of my days in a prone or supine position or walking." Her yearning for what she has lost is apparent in this journal entry: "Sometimes I just long to do things." She wrote of phoning a former coworker with whom she had been close. When she hung up the phone:

> I felt that huge sense of longing when I got off the phone. It was hard to pinpoint. Did I want to see her in person and give her a hug? Maybe, but I haven't driven since the fall, and that idea was not worth entertaining.

In a pattern common to other participants, Sylvia's back problems have impacted her marriage as well. "Almost every loss of freedom or function has affected him [husband] too." She is unable to be intimate with her husband, even temporarily moving to her parents' house to impress upon him that she was serious about the inability to participate in that part of their relationship. Her husband ended up having an affair which she writes about with great anguish. "When my husband had an affair in [year], I was devastated…I implored 'What does she have that I don't have?' 'She can walk' he said." The loss of such a seemingly simple activity and its consequences was one of the events related by the participants that touched me deeply.

Anna was another participant affected heavily by ongoing losses and limitations. "You know I had a lot of dreams that jut pooped away when I hurt my back and a lot of things changed." She described her previous job with enthusiasm and compared it to her new one: "You know I had a lot more ambition, there, um, a lot of things don't excite me like they used to." Her back pain forced her to resign her job in L&D and become a clinic manager and she has felt the sting of the loss of respect that can accompany leaving a job where one is considered an expert and starting fresh in a new one. "I mean I had respect like that *[snaps fingers]*, um, I'm getting it back in this department, but it's different." Responding to people who think she should sue the hospital where she injured her back, she said that she only wants to work as a nurse but added "But I'd give anything to feel better."

Anna's life has been limited to working during the day and going to bed around 7:30 as a normal routine. She writes in her journal "Well I am in bed (this is my life)." She related how difficult the limitations on her life are for her to accept. "That's why a busy day at work is good. I go home, I end, I usually am in bed by 7:30 at night, but at least my day went quickly. It's tough to think about it though." Her back pain affected her family as well; she feels she has lost time with her sons and her marriage has seen a decrease in intimacy. "When I see people with little boys I think 'Oh did I even pay attention to my little boys?' Those years are gone; I'll never get them back." When she had her first surgery, she writes "…during all this I can't play with my kids—or be a wife to my husband."

Anna is another participant who has a dorsal column stimulator. She spoke about the lack of intimacy in her marriage that has been caused by her back pain and complicated by her treatment:

> Um, sexuality is big thing. I've forgotten what it is; I think my husband thinks he's going to get electrocuted with this battery! You know, you're feeling like a, you know you can't move, you're feeling like a slob and uh so a lot of that affects you.

Although she did not specifically mention numbness affecting her sexuality, she wrote that she can't feel herself urinate, so she does have some perineal numbness that could be a contributing factor. At one point, her nighttime moaning and tossing led to her husband moving into another bedroom. In her journal she wrote that he has returned to their room and drew a smiley face.

In a quiet but heart-rending statement, she reflected on her life: "It's, I know it could be a lot worse. I see horrible things. But when the elevator door shuts it's just me, and darn, I wish this hadn't happened. I wonder what it would be like different."

Toni has been severely impacted by her losses as well. She lives day-to-day with urological issues that are a direct result of her back injury.

> So it's…….sometimes I can't tell if I have to go to the bathroom. So if I feel a twinge…so sometimes if I'm not halfway to the bathroom when my bladder's telling me 'ya gotta go' um, there's no holds barred. So sometimes it happens and it's like I feel like I'm beginning the nursing home thing you know of incontinence, and it's very, it does its own thing and we could be in the middle of something important with the patients and I've got to go, I can't wait. And it's probably the most interrupting part of what I do.

Toni has also noted a change in her sexuality because of the back injury. "I've noticed a big change. And part of, it's probably menopausal and part of it's I can't feel things."

Her relationship with her husband was rocky in other areas as well: "It [back injury] pushed my relationship with my husband and kids out the door." With her back injury there were things around the house she could not do, but her husband would not do things the way Toni—a "Type A wanna be"--wanted them done. "So it would still continue to cause arguments and would cause issues" and probably would still be causing problems if he had not hurt his back himself. Now she feels that he is more understanding.

The first sentence in Patsy's journal sums up her situation: "Back pain has impacted my life." Patsy was the most outspoken about how her back injury and chronic pain has affected her family. "It really limits your life….Chronic pain changes your life but it also affects your whole family. When your activities are limited it limits your whole family. It's not just an individual disease." She has to wait for help with the grocery shopping if her list is too long because she will not be able to push the cart. The whole family quit going to the lake when she was unable to ride her wave runner. "It is more like a family disease, it's just, it's not just me. It affects my whole family. Yeah it is, the kids focus on it totally." She can find a good aspect however. "I think some of the injuries brought our family closer together."

Patsy's ability to be intimate with her husband has suffered as well. "…but it limits everything, it limits your sex life, limits your body." She describes the effect that has on their relationship:

> You know, we struggle, we….you know like in the sexual part, sometimes my husband doesn't understand that, even though we've dealt with this all these years, I still, if I…you know if it hurts, it hurts. Um, you know [laughing] you stay on your own side of the bed! And it's you know, it's hard for him to understand…

Patsy summarizes how her back injury has affected her: "You know, piece by piece you lose you know, you lose a little bit of yourself." Patsy has several nieces and nephews who forget about the injury and come running when they see her and try to jump on her. She regrets having to stop them. "You lose those, you know you lose those natural parts, those natural parts of…"[voice trails off]

Patsy was another participant who had to give up a rewarding job, hers being on a bustling cardiac unit. She has tried several other positions in the same hospital where she was injured. She has accepted that she will never work on the floor with patients again, but still misses that part of herself after years. "A part of me feels lost forever. Like I was punished for being a good nurse." There was a time when she felt that she "wasn't a nurse anymore" but now can find some satisfaction in her newest job because it does involve some patient and professional contacts.

Barbara, who is in a position in academic administration, has worked previously in geriatrics and psychiatric nursing. She gradually changed jobs over the years because of back pain and that has left a piece missing from her work life:

> I enjoyed bedside nursing very much and I really miss the patient contact….So much of who I am is as a nurse. It took a while to see that a nurse is someone who isn't right with the patients all the time but also nurse can be at a desk.

Barbara bemoaned the loss of intimacy her back pain has caused her in her interview:

> Um, so there are some decisions that I make that way, like I wrote in my journal, um, I, I, I can't have my husband swing his leg over me because that hurts my back. And that's kind of a small thing but um, I…you know that's it's an important piece too so, um, I kind of miss that. You know if he forgets and he's sleeping, I have to push him off which isn't the nicest thing to do, but you know I have to do that because I don't want my back to hurt the next day, so…

She discussed this further in her journal explaining why she had a relatively pain free day when she wrote: "But then the husband wasn't cuddling and draping his leg over mine. I

just hate that I can't do that anymore. It does impact the closeness but it is too high a price to pay for it."

Betina's pain made a huge impact on her family; she decided to stop having children in large part because of her back pain.

> But the immediate post-partum, I had such tremendous back pain that it was, well it was just awful, and that was kind of a deciding factor in not having any more children. It just, I just didn't know how much more my back could take.

Betina has also realized that she is not as strong, physically or emotionally, as she once thought she was. She cried during her interview as she said "I used to think I could do it all, Meg…'I am woman, I am strong'…..hmmmm, I'm not. I'm frail. I'm just flesh and bones, I'm not superwoman."

Megan had a few comments in her journal that seemed to sum up how back pain had led to her feeling less than whole:

> I am tired of my back hurting constantly; I am tired of my arm hurting, of my neck being numb, of this muscle spasm in my right hip. I am just tired of it all. I want to be able to do so many things but I feel like I just can't really do anything anymore. I feel way old, way old before my time. I can't sit on the floor and play with my kids, I can't chase them in the park. I just feel completely restricted in what I can do. And I am really tired of it. I always thought your 40s were when you came into your own and were a woman "of a certain age" and had lots of life experience without being all decrepit. So much for that! I feel decrepit already.

Megan frequently talks about having lost control of her life to the back pain and wanting it back. She wrote:

> I guess more than anything pain takes away my ability to be a real person. I am just a living being surviving with pain. I want to be a person who can enjoy all that life has to offer. I guess that is what I have lost in this.

Megan writes and speaks often about the consequences of her back pain on her relationship with her kids and what she feels she is missing. When journaling about playing with her kids she wrote "…but now I can't sit on the floor and get up again. Actually I can't even sit on the floor period!" She continued later in the same vein: "I feel that my back pain and the consequences of it have prevented me from doing many of the things I want to do and should be doing around the house and for my kids."

Fitting her previous pattern, Giselle was the most expressive participant and had multiple comments on living her life of losses and limitations. Giselle seemed to have suffered the most violent assault on her identity due to her back injury. Since she is on a permanent lifting restriction, she wrote about her lost job, "I guess I'm officially out of it. I think about this fact every day."

Giselle reflected on her loss of self: "There really isn't a me anymore." The enormity of this loss is apparent in this comment "Before I digress into how very painful it was to be reminded that I am only a shadow of my former self, let me speak to the fact that my current physical state has impacted my entire being." She has lost the ability to ride horses, which for her and her daughter, was a big part of their lives (two pages of her journal were written on the back of full page photos of her daughter riding horses and listing all the awards she has won). She would like to continue coaching her daughter's volleyball team, but realized that with the bending and twisting, "after five minutes I was like, OK, maybe this wasn't a good idea." She stated in her interview, "So, so it's

limiting, in that I can't do things that I used to do, things that I want to do, new things, um, I can't do the job that I was trained to do." She describes being less than whole in another statement about her back pain that appears in the section below.

Intimacy has been impacted as well for Giselle. Giselle's was the second interview I did in my first pilot study and when I turned off the tape recorder she asked if I knew the story of her back pain. I did not, so she proceeded to tell me that she injured her back during sexual activity. The lasting result of this is that as an attractive, intelligent, single woman, Giselle is unwilling to date, fearing that her gentleman friend would want the relationship to become sexual, a risk Giselle was not willing to take at that time. At the time of the interview, Giselle, who was in her early 40s, was looking ahead to many years of being alone and expressed a longing for what she might be missing.

Perhaps the most telling of Giselle's comments was this one, the last thing she said during her interview when asked if there was anything else she would like to add: "…but it just, you know, brought home the whole realization that I'm not the same person I used to be for a number of reasons and, and I will never be that person again."

Additional statements by the participants supporting the theme Being Less than Whole are presented in Table 7.

Correlation to the Literature

Sexuality is an enormously important aspect of life for most people, including those with chronic illness and disabling conditions (Basson, 2007; Koch, Kralik, & Eastwood, 2003). It is important enough that the WHO issued a declaration of sexual rights in 2002 that incorporates statements about individuals' rights to sexual health and

sexually satisfying relationships (Harkreader, et al., 2007). And sexuality is a well-researched topic; a recent search of CINHAL (Cumulative Index of Nursing and Allied Health Literature) resulted in over 13,000 results. However, despite the fact that millions of Americans are living with chronic and disabling conditions, combining that search with one for chronic illness resulted in only 58 titles going back to 1979. That is an average of less than 4 articles per year on this important topic.

Sexuality and sexual activity can be changed as the result of aging, fatigue, fear and misconceptions about sexuality and sexual activity, pain, depression, poor self esteem, chronic and disabling conditions, medications, problems with mobility, and various treatment modalities, including the presence of medical equipment (D'Ardenne, 2004; Eriksson & Svedlund, 2006; Kralik, Koch, & Eastwood, 2003; Mercer, 2008; Nusbaum, Hamilton, & Lenahan, 2003; Steinke, 2005; Vickers, 2009; Webster, 1997). Changes in sexual functioning can also be a warning sign of serious medical conditions (Basson, 2007) and ought to be thoroughly investigated when patients present to health care practitioners with these complains. However, most people feel that sexuality is virtually ignored by their health care professionals (Tanyi, 2002; Taylor & Davis, 2007). There are several possible reasons for this lack of communication, which in a study by Karlen was called "abysmal" (2002, p. 207).

One possible reason for the lack of communication surrounding sexuality needs in those with chronic and/or disabling conditions is that society views people with these conditions as either asexual or as being "perverse" even when normal sexual needs, desires, and activities are described or even considered (Mercer, 2008; Pangman & Sequire, 2000; Tepper, 2000). Some health care providers might consider these

discussions “superfluous and irrelevant” (Mercer, p. 344) when, in their eyes, more serious problems ought to take precedence. Health care providers are generally not comfortable discussing this subject to begin with, leading to the creation of different tools that can be used to guide such conversations (Annon, 1976; Mercer; Taylor & Davis, 2007). The most commonly-used tool is the PLISSIT Model, developed by Annon. The model’s acronym stands for Permission, Limited Information, Specific Suggestions, and Intensive Therapy. The model was recently adapted by Taylor and Davis to Ex-PLISSIT, which incorporates “explicit Permission-giving as a core feature of each of the other stages” (p. 135).

Another reason for this lack of communication might be that sexuality is an extremely complex phenomenon, incorporating both physical and psychosocial aspects (Nusbaum, et al., 2003). Such complexity makes it a difficult thing to investigate, perhaps leading to hesitancy on the part of health care professionals to try to intervene in this matter. Patients themselves may be embarrassed or uncomfortable with the topic, they may feel that it is “just part of” their condition, or they may in fact feel asexual or overwhelmed with their daily needs. They may be too fatigued or in too much pain to focus on it (Mercer, 2008; Nusbaum, et al.; Vickers, 2009; Webster, 1997). In fact in a study with women who have systemic lupus erythematosus, many participants placed much of the blame for their altered sexuality on fatigue (Karlen, 2002). Fatigue is discussed in a later section.

I felt honored that so many participants chose to share this very personal aspect of their lives with me, unsolicited. Certainly for many of them, their sexuality has been impacted by their back pain, which in turn altered the dynamics of their marriages. The

majority of the participants mentioned the increase in pain, or fear of increased pain, when explaining their diminished sexual activity; however, sexual activity was only one component. Most of those impacted related a loss of intimacy with their spouses, which was described in terms of greater loss than the actual sexual act itself. Although I did not ask, none of these women related ever seeking medical attention or advice for this issue, perhaps viewing it as a natural consequence of their conditions. It seemed the biggest impact on sexuality was seen in those who were also most afflicted by their back injury/pain, correlating to literature that describes decreased marital satisfaction as disability and pain increase in the person with chronic back pain (Geisser, Cano, & Leonard, 2005).

Sexuality and intimacy are only two ways in which chronic back pain affects families as well as the persons who suffer with it. According to Geisser, Cano, & Leonard (2005), "chronic pain conditions have a profound effect on pain patients and their families" (p. 518). Despite this recognition, there is a decided lack of literature that has investigated the effects of a chronic illness in an adult on family units, and more specifically, the literature focused on the family effects of chronic back pain is rare indeed. Most of the literature related to spousal adjustment focuses on spouses who are physical caregivers, unlike the spouses of my participants.

When a person has chronic pain that limits activities, roles in the household shift, sometimes frequently (Charmaz, 1983; Eriksson & Svedlund, 2006; Ray, 2006; Strunin & Bodin, 2004; Thoman-Touet, 1992). The spouse and/or children pick up "duties" that had been the primary responsibility of the chronic illness sufferer. These role limitations are not restricted to household chores however; most chronic illness patients see changes

in their work and social roles as well. This leads to a permanent change in self identity, "as if they were transformed into different people" (Strunin & Bodin, p. 1389).

As I discussed earlier, these changes are often accompanied by anger, guilt, and depression. The combination of mood and temper changes and the stress of assuming additional role activities often leads to stress and discord in a marriage. Several of my participants fit this pattern of increased household stress due to shifting roles. Additionally, the person with chronic pain may also have to limit leisure activities enjoyed with a spouse or entire family, compounding the strain and leading to loss of connection (Eriksson & Svedlund, 2006; Ray, 2006; Strunin & Bodin, 2004). Certainly Patsy was deeply affected by her inability to continue much-loved leisure activities and that affected her entire family.

Spouses of persons with chronic illness are also subject to depression and other psychosocial distresses. Geisser, et al. (2005) found that in a sample of 110 couples, one of whom had a chronic illness, spousal adjustment was most strongly associated with the spouse's perceptions of the ill partner's functional status. Religion, robust social networks, family connections, proactive problem solving, and a strong pre-illness marriage tended to decrease spouse distress (Malcarn, Banthia, Varni, Sadler, & Greenbergs, 2002; Revensen & Majerovitz, 1991; Thoman-Touet, 1992). However, Yoshimoto et al. found that religiously-based coping was most beneficial when both partners were in agreement on how to use this coping style (2006). Fatigue, certainly a hallmark of chronic disease, has been found to correspond negatively to spouses' quality of life (Passik, & Kirsh, 2005).

The ongoing nature of the losses and limitations described by my participants, including role changes and loss of intimacy, fits the concept of chronic sorrow, first articulated in 1962 by Olshansky. Olshansky was seeking to describe the cyclical but never completely ending pattern of sadness and sorrow, interspersed with periods of normalcy, even of happiness, in parents who had given birth to children with mental retardation. Because the child remained alive, but the losses associated with the child's disability would not resolve, the parents entered into what he termed "chronic sorrow." The cycles of sorrow could be triggered by events that caused the parents to again notice the differences in their child versus other, "normal" children. This sadness could also progress over time.

This was seen as a divergence from traditional theories of grief, which proposed stages for individuals to work through before finally coming to resolution (Kubler-Ross, 1967). The cyclical nature of the process was clearly different from these "stage based" theories of grief. In the traditional way of viewing grief, if one did not resolve the grief, but instead had ongoing sadness, it was considered a pathological condition (Lindemann, 1944). The concept of chronic sorrow allowed the individual to continue to cycle through periods of sadness which was considered a normal response to the ongoing nature of the losses. Scholars have differentiated chronic sorrow clearly from depression (Kendall, 2005; Olshansky, 1962).

Chronic sorrow has received sporadic interest in the literature throughout the subsequent decades. Lee, Strauss, Wittman, Jackson, & Carstons redefined the condition in 2001 as "…the periodic recurrence of permanent pervasive sadness or other grief-related feelings associated with ongoing disparity resulting from a loss experience" (p.

48). The word "disparity" is key; disparity refers to the difference between the reality of the individual's situation compared with the idealized reality in the individual's mind. In other words, a disparity exists when there is a difference between what the individual wishes for and what the individual actually experiences as reality. Any time this disparity is noted, the individual can suffer from the sadness characteristic of chronic sorrow (Burke, Eakes, & Hainsworth, 1999; Eakes, Burke, & Hainsworth, 1998).

Chronic sorrow as it relates to chronic illnesses has been explored in the literature since 1991 (Hayes, 2001). Certainly the concept fits; the losses associated with chronic and disabling conditions are on-going without hope of complete resolution (Eakes, et al., 1998; Hayes, 2001; Kendall, 2005; Mishel, 1990). In a study by Burke, et al. (1999), fully 86% of their participants identified the presence of chronic sorrow (1999) and their earlier work identified chronic sorrow in 83% of their participants (Hainsworth, Eakes, & Burke, 1994). Ahlstrom (2007) noted the predominance of role loss in contributing to chronic sorrow in her sample of 30 people with chronic, disabling conditions. And since chronic illnesses affect entire families (Ahlstrom; Kraft & Kraft, 1998), it stands to reason that others in the family can be affected by chronic sorrow as well as the person suffering from the condition (Hainsworth, et al.; Lee, et al., 2001).

Chronic sorrow can elicit emotions such as fear, uncertainty, anger, sadness, frustration, and guilt (Hainsworth, et al., 1994; Johnsonius, 1996; Lee, et al., 2001). Certainly my participants voiced all those feelings. They spoke of the many losses they had that led them to feel "less than whole": loss of self; loss of roles both inside the home and at work; loss of intimacy, family time, and recreational activities; and feared loss of

future abilities. The nature of these losses is ongoing and will not have resolution, at least for the majority of the nurses in my study.

Table 7: Additional Participant Statements Supporting the Theme: Being Less Than Whole
Marlene: "I didn't realize how the pain changed me." Patsy: "I would never be a cardiac nurse again." DeeDee: "And look at all the things I would have done if I didn't have the pain. Oh my gosh!" Betina: "There's so much I want to do." Laurabelle: "It absolutely affects my physical and my emotional well being and it affects my uh, my uh, the way I, my relationship with my family." Megan: "I feel like I have missed out on so much of my life because of pain." Angel: "…it limits your movement…You don't jump up and down and do jumping jacks when you have chronic back pain. WE have to think about what to do a little bit more." Golda: "I've learned a lot about letting go of things…." Mildred: "I can't do a lot of the physical things with [grandkids]. I can't just run and grab them and pick them up…so it's those contacts with the kids.

Having Intimate Knowledge.

This was a fascinating theme incorporating both pain descriptors and the existence of a constant shadow in the participants' lives. The journals and interviews were alive with dramatic descriptions; the 15 participants used nearly 140 depictions of pain. As Mary wrote in her journal, "It was just a vivid recollection of a back pain." The sheer number of phrases and words the participants used to discuss their pain attests to

the fact that they all had "vivid recollections." Some of the more interesting descriptors are presented below in Table 8; the rest can be found in Appendix J.

Participants' Voices

Interestingly enough, Giselle, the most eloquent of my participants, only had one description of her pain ("ache"), but rather described other physical aspects of the experience such as looking like a "spastic chicken with cerebral palsy." She has an uneven gait and frequent leg cramps. Her toes on one foot are numb and "all scrunched up" due to tendon or ligament shortening (she is not sure which) and the numbest toe is "turning funky colors and losing its nail."

Table 8: Pain Descriptors

Couldn't bear it	Shooting	**Stabbing**
Severe	Intense	**Incapacitating**
Unbearable	Horrific	**Being eaten by sharp, sharp teeth**
Miserable	Burning	**The most terrible, terrible pain**
Nauseating	On fire	**Like a teetering tower of blocks**
Killing	Tearing	**Like being beaten with a 2x4**
Causes anguish	Ripping	**Like a huge, jagged, pointy rock**
Awful	Wacko	**Nearly causes tears**
Twisting	Relentless	**A terrible hurt**
Pulses with pain	Heaviness	**Like sitting on golf balls**
Tremendous	Nagging	**Like a roller coaster**

The level of intensity and the exquisite detail in the participants' descriptions rivals what would be used to describe a lover. In fact, some of the greatest detail emerged with descriptions of pain while the participants were in bed. Those descriptions

are found in the following section, *Living Through Fatigue.* And much like a relationship with a lover, their pain experiences had ups and downs, or as Eliza put it, living with chronic back pain is "like a roller coaster."

Having Intimate Knowledge also included statements that attest to the fact that these women live closely with their condition on a daily basis. As DeeDee puts it, "It's always there, no matter what. It's a cloud that's always there." As part of her biofeedback lessons, DeeDee has learned to visualize her pain as a rock: "Oh, it's a rock. It's a huge rock…with lots of little pebbles around." But she is also plagued by a cloud that follows her. When asked to describe the cloud she says is always with her, she said:

> It's just…I just know that there's something with me. And instead of it just, it's just…you know a cloud's kinda up here [points upward]. Um the rock is with me in my gut, but um the cloud, I just know that if I go down the wrong path, meaning that if I tried to pick up things, bend and stoop….Um and so I think that cloud's there as a reminder; if I start doing things it kind of gets lower like if I bend it's like OK I'm going to pour on you now if you go do…

And like several other participants, DeeDee states that her pain has been a core aspect in her life. "…oh my gosh for years it was a focus."

Betina has similar sentiments: "I have never before realized how much I do in my life now as a result of chronic back discomfort." Her daily life involves considering how the things she does will impact her back, thus her back pain is an ever present entity:

> I have learned over the years that the back is truly a major organ and requires attention. If it doesn't get the proper attention it speaks to me. It certainly causes me to stop and consider it for a while!

Even my two practical and pragmatic participants, Golda and Mildred, described how their back pain is a constant reality in their lives. Golda tries hard to ignore her back pain, continuing on with her chosen activities. She realizes that most people have their problems and she considers herself lucky to only have back pain. "I guess I figure everyone has something to deal with…" However, she later indicated that she thinks about her back pain on both good and bad days:

> I feel it, but not every day because there'll be days then I think, gosh there it is again! And then I'll have it a couple of days so there's obvious periods of time when it's not there and I'll think about it then….So in that sense it's always there…so pretty much it would be there pretty much all the time if I dwell on it.

Mildred describes her situation this way: "My back pain is an everyday and ongoing process…" She goes on to write about how she tries ignoring the pain, but it is still always there, even though she seems to be in control of it, rather than the other way around. It certainly does not sound as if the pain interferes with her life. But she still writes "The problem with back pain that has become chronic is <u>just that</u>—it never really goes away!!!" There were a couple of times during her interview when she stated, "It's just there" and "…so it's in the back of my head somewhere." I asked her to clarify *(It's just there?)* to which she replied, "Yeah".

Patsy described in detail how her back pain is always with her, a constant reminder of her injury:

> It, I, you know, you try to put it out of you mind, but you never can. You know, I'll go, if I drop something the first thing I think about is how am I going to bend over and pick it up because I know it's going to hurt if I bend the wrong way or if

> I stoop the wrong way and if I get down there I'm going to worry about how am I going to get back up, is there something I can grab because sometimes I can't get back up. So it's like it's never out of your mind, it's always there in front you know, before I buy groceries I look at the list…is it stuff I can handle to go buy it by myself? You know, it's, it's, it's never gone. You know as much as you'd like to put it out of your mind, to forget it and pretend it never happened, you can't because it's, every little move in the wrong direction, it's just that constant reminder that it's there. You know it's not, it's not ever going to be gone. So it's always in the front of your mind. It's always the first thing you think about.

Eliza's pain is more in the upper back and neck region. She wrote: "…but the neck pain has become part of my life. That was the hardest thing to accept, that I would always have neck pain." Like several other participants, she spoke and wrote about how the pain controlled her life until she learned to co-exist with it. And this co-existence is fluid: "It's like a roller coaster. When you are at the top, you know the roller coaster has to go down. That is how I understand my pain."

Angel thinks she does a good job of "tucking it into the background of my life….and making it not matter." "It's just kind of there in the background." When she began this study, she had to think and write about her back pain—something she normally avoided--which increased the pain or perhaps made her notice it more, something a few other participants said happened to them as well. She admits that the pain is always with her: "…but for the most part, it's barely noticeable, but it's just a part of who I am. It just becomes a part of you…"

Sylvia is like many of my participants who has to "be constantly monitoring my body" when it comes to knowing what activities are tolerable, when to take which medications, how to adapt her living situation to her back pain and when to rest or say no to requests. These women are living acutely and intimately attuned to their bodies. As Sylvia put it: "So it's constant learning and watching and listening…" Barbara describes this as being "cognizant" and constantly "mindful" about her activities and their potential effect on her back.

Toni also describes the constant presence of her back pain: "…you're always the subject of it." The back pain accompanies her during everyday activities such as holding a baby, walking the dog, or going up and down stairs. She has to think about the back pain prior to engaging in these activities. "It's a reminder every day of what I do….So um, it's a constant reminder." And like living with an abusive partner she adds "I have been controlled for years by chronic pain." She even sounds hyper-vigilant "And, and, and back pain means I'm constantly aware."

Laurabelle related being "consumed" by her pain. "That's all I thought about! I mean it was my life….This pain became my life." Currently she says the pain is not all-consuming, and she can go a while without thinking about it, but adds "it's still there…"

Megan had some colorful comments about the constant presence of her back pain. She wrote:

> It's always going to be with you. Some days may be OK, maybe even a few days, but basically your life is going to be different from now on because of some stupid thing that either you did or someone else did to you, that caused you to have a back problem.

She also said after her interview was over: "Having chronic pain is like going on a date with a chaperone. He may be quiet, he may be in the back seat, but you know he's there and that impacts every move you make." Megan summed up her feelings about living with chronic back pain this way: "It's just that back pain becomes life pain and that doesn't go away with a Motrin."

Giselle was most expressive about the constant presence of her back pain. "I'm constantly reminded of the fact that there is something very wrong, and something very limiting that affects me." When sharing her thoughts about her quality of life she described what would constitute an improvement: "…just not having that shadow hanging over me at all times and being constantly reminded that 'oops shouldn't have done that'... I, I guess just getting rid of that shadow." I asked to her elaborate on "the shadow" to which she replied,

> Well it's just, just the constant knowledge, or the constant, um…..[laughs]I can't think of the right word, just the constant presence of the fact that I'm not whole. That's the shadow, I mean every day, it affects me every day….it's just that it's sort of that dark cloud….it's a dark cloud that's always going to be there. And hopefully not get darker.

At this point in the interview, she became tearful. Additional statements from the participants supporting the theme Having Intimate Knowledge are presented in Table 9.

Table 9: Additional Participant Statements Supporting the Theme: Having Intimate Knowledge
Laurabelle: "There isn't a day goes by I don't think about it…but it's always there…it's always, I'm always thinking about it. I'm still so close to it…"
Golda: "…it's sort of just there." Patsy: "Well you know it will never go away." and "Most times it's just there."
Eliza: "It's pretty much…just always there."
Angel: "I think for the most part…it's just background noise….it will always be there."
Sylvia: "Yeah, so yeah, it's, it's with me all the time."
Barbara: "I find throughout the day I have been more cognizant of what I do…I am much more mindful of my movements throughout the day."
Toni: "It's always reminding me."
Anna: "It's always with me…I'm always pretty much aware of it."

Living Through Fatigue.

Nearly every participant described the effect of their pain and fatigue. Some were affected directly by the pain and some were fatigued because of the disrupted sleep they endured. The word "*Through"* was chosen deliberately to reflect the participants' determination to live their lives in the midst of this fatigue. The data in this theme were not as detailed as in other themes possibly because I did not specifically ask about fatigue nor did I ask the participants to elaborate on it when they brought it up. With its emphasis on how chronic pain was a presence in the bedroom, *Fatigue* could have been included as a sub-theme to *Having Intimate Knowledge.* However I chose to leave this as a separate theme since so many of the participants described fatigue specifically.

Participants' Voices

Many participants described their sleeping routines in great detail and how turning this way causes one kind of pain, and turning another way causes a different type of pain. Mary journaled about the increased physical demands she encountered working

in the OR which made her back sore. The effect was: "I was tired because at night my back would wake me up when I turned." She described this more in her interview:

> Because, um, I couldn't lay down just right, if I'd turn, it would be, it would cause such a sharp, now that would be sharp pain if I turned, so sharp it woke me up, and kind of take my breath away.

In a very dramatic physical representation of the fatigue she felt, Mary said "But it was just a tiring, constant…but um, it's just tiring and you just want to roll your shoulders in and slouch over, because you're like exhausted." As she spoke, Mary rolled her shoulders inward, lowered her head, and her face suddenly looked drained and tired.

Megan had an extremely detailed description of her sleeping routine. She typically awakens between 2 and 4 in the morning and is unable to go back to sleep:

> …like sometimes at night I don't sleep because something hurts. Sometimes I like to sleep on the couch because I can turn on my side, into the back of the couch and it supports me. I am tired of always sleeping on my stomach with my arms folded up under my head. My shoulders hurt from that, but if I sleep on my back, my back hurts, and if I sleep on my side, my arms fall asleep. So I am kind of stuck here…when I first lie down, my legs go numb. So I can't even lie down and get comfortable and have a decent night's sleep. Maybe that's the source of all my problems, poor sleep.

Megan described her sleeping problems in her journal as well:

> I can only sleep on my stomach, pretty flat, with my left leg, usually it's the left, but sometimes I can do this on my right side, too, with my left leg hiked up and

my arms under my pillow. But then my shoulders hurt and fall asleep. Then my shoulders hurt all day long the next day.

Anna's sleep was disrupted by pain to the point where she was moaning and tossing around in her sleep. That got to be so bad, her husband temporarily moved into another room. She ends up in bed at 7:30 each night, needs a nap on Saturday in order to feel "pretty good" on Sunday, and when she has evening events during the week, she has to go over to her son's house to nap beforehand (she lives outside the city limits and has a long commute). She mentions that one thing that would improve her QOL would be not having to go to bed so early. In addition to the pain, being an advocate for herself is tiring: "I, you know it takes a lot of energy to get care for yourself. It does."

Betina characterizes her pain as being a "tired back" at times as opposed to always being acutely painful. She has an involved bed time routine consisting of putting ice on her back nearly every night, occasionally soaking in a hot tub before getting into bed, and "I roll out my back with a magnetic roll magcrater." She also sleeps on a firm mattress. She is unable to sleep on her back due to the pain. One good outcome of having back pain is that "it forced me to get caught up on my sleep. Um I discovered this last year that I need more sleep." Betina gave up singing in a choir because of the Sunday afternoon practices. "I want my Sunday afternoon nap, for crying out loud!" When she has the acute pain, Betina describes it this way: "This particular back pain thoroughly drains me. Pain is very exhausting!"

Giselle's sleep is interrupted by leg cramps and she paints a clear picture of their effect. "If I move my feet or legs the wrong way just a little bit while in bed at night, I get the worst foot, ankle, and leg cramps! I have to get out of bed and pace them away,

wandering around the house in the middle of the night and trying not to step on cats or trip over the dog, all of whom look at me as if wondering, 'What the hell is she doing now?'"

Her stamina is affected as well, and she related an incident when she had been gardening too long and came in to lie down on the couch, too tired to even get the ice pack she knew would be beneficial to her. She spoke of this in her interview: "I know for me that one of the overwhelming things for me is my fatigue level. I just don't have the energy I used to."

Sylvia had a frightening episode that started initially because of the inability to sleep due to her pain. She had had some friends over for an evening of talking and visiting and her back was bothering her, so she was unable to sleep. About 3:30 in the morning she got up, took a partial dose of a medication she should have taken in the evening, plus a dose of another medication and ended up falling in the bathroom. I interviewed her five weeks after this incident and she had still not recovered; in fact the majority of our interview was spent in her bedroom so she could lie in bed.

Eliza was yet another person with a problem sleeping. She explained it in her journal:

> It [pain] really affected my sleeping the most. I would wake up in the middle of the night with neck and arm pain. I would take pain medication (usually a narcotic) or a muscle relaxant and put ice on my neck. I would get up and go down to the family room and read for 2-3 hours and then return to bed and get 2-3 more hours of sleep.

In another section of her journal she continues on about her sleeping.

> If I have to focus on one problem I have due to chronic pain, it would be the affect pain has on my sleeping habits. I have no problems falling asleep, but the pain wakes me up. I then have a hard time getting back to sleep. Sometimes I get in this vicious cycle of being awake during the night, I get up early, fall asleep early (8pm), then wake up in the middle of the night. Then the more tired I get, the more frustrated I get, then it makes me angry. Most of the time after 2-3 nights of the cycle, I can break the cycle with medications, heat or ice. But I need to put a conscientious effort to breaking the cycle.

Some participants related that even without disturbed sleeping, the overall effect of their back pain was fatigue or decreased stamina that impacted their ability to do their usual activities. And for a couple of people, fatigue increased their back pain. Toni and her husband used to enjoy outdoor activities such as camping and hiking, "rough necking it in the woods." She is unable to participate in these activities anymore because "I can't do it anymore. I just can't. Physically my stamina isn't as good [as before the back injury]." She describes her physical condition this way: "Just everything is going down, physically." When her supervisor calls to ask if she can come in early to work, she has to decline, or offer a compromise: instead of coming in four hours early she can come in two hours early. "And I realize, oh……I can't come in four hours early, I need my sleep. If I don't my back will remind me. At the end of the day I am physically exhausted."

Patsy described the type of pain she experienced after her first surgery as "mild and tiring." Now, years later she depicted how draining the pain is to her. "Usually being active for an hour will require lying down for an hour. It really limits your life. You have to make your plans based on your ability to take rest breaks." Medications she

took had the additional effect of making her tired. During a recent trip to see family several hours away, Patsy's family arrived before the others did and this gave her the opportunity to lie down: "…so you know I laid down for an hour before anybody else showed up. So you know I got my rest in…"

Additional participant statements supporting the theme Living Through Fatigue are presented in Table 10.

Correlation to the Literature

Chronic fatigue is a common companion to many clinical illnesses, and is particularly seen in the context of chronic conditions where it is one of the most frequently mentioned symptoms, usually causing great distress. In fact fatigue has been called "ubiquitous" in chronic illness (Cella, et al., 2005; Evans & Wickstrom, 1999; Glacken, Coates, Kernohan, & Hegarty, 2003; Goligher, et al., 2008; Jorgensen, 2008; Karlen, 2002; Koch, Kralik, & Sonnack, 1999; Kralik, 2001; Kralik, et al., 2003; Ricci, Chee, Lorandeau, & Berger, 2007; Sharp & Wilks, 2002; Small & Lamb, 1999; Webster, 1997; Whitehead, 2009). It can also be a side effect of many medications and medical treatments (Michielsen, De Vries, Van Heck, Van de Vijver, & Sijtsma, 2004). Although studied in detail, there is no universally accepted definition of chronic fatigue. For the purposes of this study, chronic fatigue is defined by Jorgensen this way:

> Chronic fatigue…is fatigue of at least 6 months duration that is not amenable to rest or sleep and has no relation to previous activity. It is a whole-body sensation with a major impact on multiple areas of quality of life, including physical, cognitive, affective, and social domains. It is a constant part of the lives of those affected (p. 205).

There are several reasons why fatigue causes such great distress. First it is difficult for suffers to describe and explain their feelings of fatigue to medical professionals, fearing being dismissed (Adinolfi, 2001; Kralik, Telford, Price, & Koch, 2005). This fear is well-founded; since fatigue is difficult to measure and is a subjective experience it does not fit with the western model of medicine and is often misunderstood. (Trendall, 2000). In fact, Raine, Carter, Sensky, and Black (2004) report that general practitioners view patients who complain of fatigue as having negative personal characteristics and others report that individuals with chronic fatigue are often viewed as being deviant or of deficient moral character (Asbring & Narvanen, 2002; Johnson & Johnson, 2006).

Fatigue has been linked to depression (Jorgensen, 2008; Taylor, Jason, & Jahn, 2003). Sufferers often find themselves unable to fulfill their expected roles and take part in meaningful activities, leading to further distress as they feel guilt and worthlessness (Barroso, et al., 2002; Jorgensen, 2008; Kralik, Telford, et al., 2005; Small & Lamb, 1999). It is unpredictable and requires much adaptation in order to get through a typical day. In fact chronic fatigue has been called disabling (Jorgensen, 2008; Kralik, 2002; Kralik, et al., 2005).

Fatigue is clearly different from being tired, which is usually related to being active and is typically relieved with sleep. The fatigue that persons with chronic illness feel comes from the "core" of their beings and is not relieved with rest or sleep (Kralik, et al., 2005, p. 375). In fact, chronic fatigue is often present upon awakening (Glacken et al., 2003). Some believe that the less a person does in response to fatigue, the more fatigue the person feels; in fact some report improvement in fatigue with exercise

(deRijk, Schreurs, & Bensing, 1999; Ream, 2007; Small & Lamb, 1999; Smith & Hale, 2007). Fatigue also causes a decreased ability to think clearly (Kralik, et al.) and has been described as overwhelming, unrelenting, and "blanket-like" (Jorgensen, 2008, p. 202; Kralik, et al.; Small & Lamb).

The combination of chronic fatigue plus sleep disruption can lead to an incapacitating condition (Small & Lamb, 1999). For many people with chronic illness, disturbed sleep is something else they have to maneuver around in the context of their lives. Chronic insomnia can accompany many illnesses, both physical and psychological. When patients have chronic insomnia in the presence of a chronic disorder, that insomnia is usually worse in terms of severity and persistence than the chronic insomnia seen in people without chronic or disabling conditions. As seen in my participants, this insomnia usually involves interruptions in sleep maintenance, in other words, the ability to remain asleep versus being able to fall asleep to begin with (Ancoli-Isreal, 2006).

Table 10: Additional Participant Statements Supporting the Theme: Living Through Fatigue
Megan: [back pain] "is so painful it keeps me awake at night." Mary: [her pain] "…is better ….So I don't seem to wake up." Toni: "I felt very tired and drained." Barbara: "Today I woke up at 4:15 even though I was still very tired but my back was hurting so bad, I couldn't lay down any longer. I got up but was so tired…" Giselle: "I don't have as much stamina or whatever anymore." DeeDee: "Recognize that I'd like to go to bed around 9 or 10 at night." Golda: "I guess I have learned that fatigue and stress are real culprits in contributing to my low back pain." Eliza: "It is really frustrating when I wake up with pain. Sometimes I try to ignore it, but end up only tossing and turning."

Summary of Domain Two

This domain incorporated facets of living with a chronic condition, that of CBP. Nurses were forced to confront their ongoing losses and limitations and found themselves often in a state of chronic sorrow. Living with the four themes of *Fear and Uncertainty, Being Less than Whole, Having Intimate Knowledge,* and *Living Through Fatigue* took enormous energy and effort.

The Essence of the Phenomenon

Dancing with the Shadow: Re-Visioning Quality of Life

The essence of the phenomenon is presented in Table 11. A poem by Mae Beezwax (n.d.) seems to sum up the constant but delicate shifting in the balance of control that occurs in the participants' lives vis-a-vis their back pain.

Dancing in the rain

You may think I'm crazy
I think you're insane
Let's get together and
Dance in the rain

You spin me around
Then I'll spin you
Twirling away the pain
Just us two…

I'm crazy and I
Made you insane
Now that we're here together
Dancing in the rain

One last twist
One last twirl
The dance ends but
I'll forever be your girl

Both the major domains, *Making Normal* and *Living with the Shadow*, and their themes constructed the over-arching essence of the phenomenon, *Dancing with the*

Shadow: Re-Visioning Quality of Life. The domain *Making Norma*l included activities that showed the participants either fighting their back pain or working through several emotions to maintain their previous personal and/or professional identities and existences or to build new ones. This domain included the themes *Fighting and Denying, Being Consumed: Anger and Frustration; Surviving the Three d's (depression, devastation, and despair)*; and *Choosing, Adapting, and Accepting*. The second domain, *Living with the Shadow*, describes the process of having a long-term relationship with back pain and included the themes of *Fear and Uncertainty, Being Less Than Whole, Having Intimate Knowledge*, and *Living Through Fatigue*. The nurses seemed to be working in both domains at once, both living with the shadow and its often-changing limitations and continually attempting to make normal their abilities and their self-perceptions. Every event remotely associated with one domain had a ripple effect into the other domain. So participants were left trying to weave, bounce, and respond to their ever changing situations. The dynamic interplay among the various themes paints a compelling picture of the nurses' quality of life.

Table 11: The Essence of the Phenomenon

Dancing with the Shadow: Re-Visioning Quality of Life

"It's just that back pain is life pain and that doesn't go away with a Motrin."—Megan

For these nurses, chronic back pain was an all-encompassing part of their daily lives that went beyond physical pain. Their quality of life was affected on all fronts while they attempted to Make Normal and negotiated a delicate dance of control in order to live with the Shadow, the constant presence of something not quite right in their lives. Sometimes they led the dance; sometimes their pain led. Their quality of life was diminished by the constant shadow of chronic back pain hanging over their heads.

Back pain caused considerable distress and took enormous energy to live with. They fought to maintain a sense of normalcy while being enmeshed in a life with pain. They experienced denial, anger and frustration, and depression which not only diminished their existence, but affected those closest to them as well. They experienced losses as they added this new dimension to their lives, suffering from fear and uncertainty and the knowledge that they are now and forever less than whole. The nurses in this study wanted control over their lives and resented anything trying to wrest this control away from them. The more control over the back pain they had, the better their quality of life.

Living with chronic back pain meant re-visioning their quality of life. Re-visioning evokes a constant shifting of one's vision both on a long and a short term scale in a dynamic, multi-faceted fashion. Participants spend their days engaged in a dance of alternating hope and resignation with an entity described as the shadow. This constant dance allowed participants to re-create their self images and their constructs regarding quality of life.

Conclusions and Summary

This chapter contained the findings from my study. First I presented information from the survey returned by 11 of the RNs. The survey covered basic information such as types of treatment they had used, days of back pain a week, and Likert scale ratings for quality of life, impact of back pain, and the journal writing experience.

The two domains with their themes included *Making Normal* and *Living with the Shadow*. *Making Normal* included activities that reflected either fighting to retain a previous existence or working through grief to remake personal and/or professional self images. Included themes were *Fighting and Denying; Being Consumed: Anger and Frustration; Surviving the Three ds: depression, devastation, and despair;* and *Choosing, Adapting, and Accepting.* *Living with the Shadow* indicates existing with the constant awareness of something being not right with you…something that cannot be fixed and will never go away. Themes included in this domain were *Losses and Limitations, Being Less than Whole, Having Intimate Knowledge, and Living Through Fatigue.* The two domains with their eight themes comprised the essence of the phenomenon, *Dancing with the Shadow: Re-Visioning Quality of Life.*

In the following chapter I will discuss the relationship of this study to the current literature and present suggestions for implications in research, practice, and education.

CHAPTER FIVE

SUMMARY, IMPLICATIONS, AND OUTCOMES

The purpose of this chapter is to provide a summary of the study and a discussion of implications. A short summary of the findings is presented first, followed by a comparison of the findings to the existing body of related literature. I discuss the limitations of the study as I see them and move on to implications that arose from this project. The implications include suggestions for future research and suggested outcomes for both practice and education.

Summary of the Study

This phenomenological study investigated the lived experience of quality of life (QOL) in 15 Registered Nurses (RNs) with chronic back pain (CBP) who engaged in a structured, or prescribed, journal writing (JW) experience. The RNs were predominantly recruited through nursing school alumni directors, with one RN being recruited by a co-worker of mine. Five of the nurses participated in my first two pilot studies. The RNs all completed journals in which they were instructed to write for 20 minutes a day, three days in a row. The main idea of the JW was for the RNs to write deeply and thoughtfully about problems the back pain was causing them. They also completed a short questionnaire and had an audiotaped interview with me. I transcribed each interview and journal which became the primary source material for this study. The survey was used as a method of secondary data collection. Through the process of hermeneutic reflection and writing, I found eight themes that fit under two domains and the essence of the experience.

Survey Results

Eleven participants completed and returned surveys. All 15 participants had used over the counter medications to treat their pain, which for nine of the participants was present 6-7 days of the week (Information about the over the counter medication use came from interviews and journals in addition to the survey). More than half used prescription medications, either analgesics or muscle relaxants; physical or massage therapy; surgery, or had tried weight loss to manage their CBP. Lesser used treatments included chiropractic treatments, steroid injections, yoga, and other prescription medications. Transcutaneous Electrical Nerve Stimulation (TENS) units, dorsal root stimulators, caudal blocks, healing touch, magnet therapy, an inversion table, and the use of a DSR 9000 machine were also mentioned. In all, the 15 participants had tried a total of 122 methods to control their pain.

The majority of people followed the JW instructions completely with five following the instructions 75% of the time. Most found the writing easy to do with one exception; one participant, Anna, felt it was hard to do because it brought up too many bad memories and made her angry. The nurses had varying responses to the question of if the JW affected their QOL with most of them agreeing that it did, at least to some extent. Most also said it had at least some effect on their ability to deal with their pain. The three who did not notice a difference included Anna, another nurse who approached the JW as if it were an assignment and had no emotional disclosure in her journal at all, and one nurse who was an avid journal writer already. The majority of the nurses stated that the JW was helpful in some way, or would have been had they done it earlier in their experience with CBP. The construct that came from the JW activity was “clarity”.

Surprisingly to me, at least, eight participants rated their QOL as some variant of "good," although most qualified this with statements such as "Now that the pain is better" or "Now that I am in control of the pain." Those who viewed their QOL negatively related how restricting or limiting the pain was to them. Maintaining relationships was mentioned most often as being of vital importance to a good QOL. There were many references to physical ability impacting QOL too. The ability to have a body that works physically as they wanted was cited by several of the nurses. They related physicality to work, hobbies, caring for current or future grandchildren, and sexuality. Each participant struggled with a variety of negative psychosocial impacts including anger, depression, and effects on their families. All agreed that CBP had, or could have, a negative effect on their QOL.

Themes and Domains

In the data analysis, I found two major domains with four themes each.

Domain One

Making Normal as a domain included activities that showed the participants either fighting their back pain or working through several emotions to maintain their previous personal and/or professional identities and existences or to build new ones. This domain included the themes of *Fighting and Denying; Being Consumed: Anger and Frustration; Surviving the Three ds: depression, devastation, and despair; and Choosing, Adapting, and Accepting.*

Fighting and Denying was an emotional theme with participants denying their back pain, refusing to seek medical attention or refusing to follow through, and stubbornly doing things they knew would cause them increased distress without thinking

it through clearly. Normalcy was important; participants wanted to be able to look and act "normal." Eventually many had to resort to taking medication or having surgery, a process they described as "giving in."

Being Consumed: Anger and Frustration was the second theme within the first domain. I have been a nurse for almost 30 years and knew that people with chronic conditions experience anger and frustration, but I was stunned at the intensity of these emotions in the participants. Anger and frustration were directed at their limitations, the on-going nature of the pain, healthcare providers who did not believe or help them, and family and friends who had a never ending supply of suggestions for them, most of which did not help. These emotions seemed to consume them and they spent enormous energy dealing with this aspect of their CBP alone. This theme seemed to affect families the most because many times loved ones became the brunt of the negative emotional outbursts. Particular hostility was reserved for the Workmen's Compensation program.

Every single participant sank into *The Three d's: depression, devastation, and despair* at some point in their experience. I chose the lowercase d to signify how these emotions made the participants feel: small. The misery they felt seemed to pen them into an ever-shrinking existence as their personal and professional identities slipped away from them. They wrote of being "crushed" and "heartbroken." One participant thought of different ways to commit suicide. Many of the participants have come to terms with their conditions and are no longer discouraged and depressed, but they could all remember this period in their lives with amazing clarity.

Finally, *Choosing, Adapting, and Accepting* have occurred for the majority of the participants. They can contemplate their overall situation and choose their priorities,

finding a way to make the important things happen. They can think rationally about things they want to do and devise better ways of accomplishing them without hurting their backs. Some of the participants went to extraordinary lengths to be able to do things that were important to them. This is *Adapting,* which is clearly different from *Accepting.* In *Accepting,* they learn to graciously cede the small battles over their back pain, often to a higher power, but in the end win the war of control as they change the way they respond to the situation. Not many of the participants have truly reached the stage of acceptance, but for those who have, it has been a liberating experience.

Domain Two

The second domain, *Living with the Shadow,* describes the process of having a long-term relationship with back pain and incorporated the themes of *Fear and Uncertainty, Being Less than Whole, Having Intimate Knowledge,* and *Living Through Fatigue.*

Fear and Uncertainty related to fear of further injury, fear of future medical treatments, and an uncertain future that could include increased disability. Many participants related wanting to participate in activities, but limited themselves due to this fear. The worry surrounding whether they would be able to continue working generated a great deal of stress. One participant was disabled and so afraid to live alone that she tolerated being in an abusive marriage. Upcoming or contemplated medical treatments generated a lot of fear, especially the fear of "what if this doesn't work"? They regarded their futures as full of uncertainty.

The ongoing nature of the losses and limitations suffered due to back pain was the core of the theme *Being Less than Whole.* Rather than generating an acute grief response,

these continuing losses led to a pervasive sense of sadness that tended to chip away at the self over time. Losses included diminished physical activity, lack of intimacy with their spouses, and the disintegration of personal freedom to name a few, and involved not only the participants but their families as well. All the participants had to give up something, either a job they loved or hobbies and activities that were meaningful to them. A few of the nurses led extremely limited lives. Many of them had regrets over lost aspirations.

Having Intimate Knowledge was the theme in which the continuous presence of the Shadow of back pain in the participants' lives was most clearly demonstrated. The exquisite detail used to describe their ubiquitous pain could rival descriptions of a lover. They were intimately connected to the pain which became part of their every moment, awake or asleep. The pain was described most often as a shadow that followed their every movement. The constant presence of the pain, or on the rare occasions they did not have pain, influenced everything they did. It was an ongoing reminder that something was very wrong with them.

Living through Fatigue was a reflection of how much the pain exhausted the participants, both because of the nature of the pain experience itself and because of the disrupted sleep most of them experienced. Some of the most detailed descriptive passages were related as participants described being in bed with their pain. Fatigue both increased and was increased by pain. The ability to function adequately was influenced by being tired, and the pervasive nature of this fatigue was nearly impossible to overcome.

Essence of the Phenomenon

The essence of the experience was *Dancing with the Shadow: Re-visioning Quality of Life.* The participants seemed to interact with their shadow in a constant dance for control. The nurses lived in both domains at once, both living with the shadow and its often-changing limitations and continually attempting to make normal their abilities and their self-perceptions. Every event remotely associated with one domain had a ripple effect into the other domain. So participants were left trying to weave, bounce, and respond to their ever changing situations. The dynamic interplay among the various themes paints a compelling picture of the nurses' quality of life. The more control they had over their pain, the better their quality of life. In the end, they had to re-make their vision of a quality life to include someone else: their back pain.

Two of the participants were clearly different from the others in the study. Mildred and Golda were older than all but one of the other nurses. Both seemed to have an inordinate ability to control their pain and plainly refused to allow it to ruin their lives. Mildred is a Healing Touch Practitioner who has remarkable control over her body, delivering two children by hypnosis and undergoing major spine surgery with only one post-operative dose of Tylenol. Golda had a total change of attitude about her back pain when a physician relative described it to her as a "headache in my back." From that point on, she stopped looking for what was wrong and how it could be corrected. While on first glance these two appeared to be contradictory cases, they fit into the essence of the phenomenon easily with its emphasis on control.

Comparison to the Literature

The information from this study fits neatly with and expands upon other research showing the impact of many types of chronic pain and chronic illnesses, including CBP, on quality of life. First and foremost, people with CBP do have a lower quality of life than do others in the general population and in those with other types of chronic illnesses (Beaulieu, et. al., 1997; Borkan, , et. al., 1995; Davis & White, 2001; Gil, 2000; Hagg, et. al., 2003; Hemmila, 2002; Lazarus & Neuman, 2001; Nickel, 2002; Norman, 2000; Patrick, et. al., 1995). Quality of life seems to be directly related to level of impairment (Kovacs, et al., 2005); certainly many of the participants in this study related the inability to do things they wanted to or the fear of being physically restricted in the future as having a major impact on their QOL. Journal writing has been shown to offer both physical and psychosocial benefit to a majority of people who engage in a structured form of this process. Using instructions developed by Pennebaker & Beale (1986), these results have been consistently demonstrated over nearly three decades of research (Frattaroli, 2006; Pennebaker & Seagal, 1999; Singer & Singer, 2006; Smyth, Hockmeyer, & Tulloch, 2008; Smyth & Pennebaker, 2008) Approximately one-third of the participants did not benefit from this process, a number similar to reports in the literature (Frattaroli, 2006).

Domain One

The first domain *Making Normal* has several consistencies with previous research. First, the emotional journey described in this domain closely mirrors the grieving process first described by Elisabeth Kubler-Ross (1967). The processes of denial and normalization have been widely reported (Asbring, 2001; Bury, 1982; Coyne,

1997; Deatrick & Knafl, 1990; Erikson & Svedlund, 2006; Gantt, 2002; Hopkins, 2004; Lazarus, 1983; Livneh, et al., 2004; Livneh & Martz, 2007; Persson, 2006; Samson & Siam, 2008; Schaefer, 1995; Telford, et al., 2006; Whittemore & Dixon, 2008) and according to Freud (1946, 1961), can be a helpful process, buying time to learn how to cope with a situation. However, denial that continues for extensive periods of time becomes maladaptive (Covic, et al., 2003; Delmar, et al., 2005; Roesch, et al., 2005; Schaefer, 1995; Stanton, et al., 2001; Wegner & Pennebaker, 1992).

Anger and frustration are often seen in chronic and disabling conditions and can motivate people to make positive changes in their lives. But left unchecked, the continuous activation of the sympathetic nervous system's flight or fight response (Selye, 1946) causes physical and emotional harm (Burns, et al., 2006; Chida & Steptoe, 2009; Duckro, et al., 1994; Slade, et al., 2009; Verbeek, et al., 2004; Yi, et al., 2008). This was evident in the participants whose lives and loved ones were negatively affected by their anger.

Depression is a common finding in illnesses that disrupt patients' lives, particularly when the person struck down is young or the condition leads to disability (Dunlop, et al., 2004; Livneh, et al., 2004; Schnitker, 2005; Schroeder, et al., 2007; Sullivan, et al., 2003). Zenker, et al. (2006), found depression occurs commonly in people with CBP. This correlates with my findings that showed 80% (12/15) nurses had experienced depression at some point.

At some point, the most helpful outcome would be for individuals with chronic conditions to come to terms with their limitations and learn to live life despite them. This leads to better physical and psychological functioning (Livneh, et al., 2004; Stanton,

et al., 2007; Zenker, et al., 2006). A few of the nurses in this study had learned to do that and they were clearly more satisfied with their lives than were the others. Part of this process is creating a new self identity, or resolving the biographical disruption that occurs when faced with a chronic condition (Bury, 1982; Corbin & Strauss, 1988; Dickson, et al., 2008; Telford, et al., 2006; Richardson, et al., 2006). Regaining this equilibrium, while advantageous, requires a great deal of energy (Whittemore & Dixon, 2008).

Domain Two

The second domain, *Living with the Shadow,* resembles the concept of chronic sorrow first articulated in 1962 by Olshansky. Chronic sorrow is a never-ending cyclical process of sadness and sorrow interspersed with periods in which people can feel normal or even happy, but where the predominant emotion is a sadness without hope of resolution (Olshansky, 1962). This concept has been explored sporadically in the literature (Ahlstrom, 2007; Eakes, et al., 1998; Hayes, 2001; Kendall, 2005; Mishel, 1990). The themes of this domain show clearly the ongoing nature of the losses leading the participants to experience chronic sorrow.

Fear and Uncertainty is a common reaction to chronic or disabling conditions and can be related to unknowns regarding both physical functioning and psychological well-being (Jarosinski, 2006; Luk, 2004; Shea, 2004; Schaefer-Schiumo & Atwood, 2009; Sullivan, et al., 2003). Glenton (2003) has described several fears specific to patients with CBP that correlated to fears mentioned in this study, specifically the fears of not being believed, of being stigmatized, and the fear of being seen as having character blemishes. Uncertainty in illness as a concept was first described in acute illness by Mischel (1988) and has been expanded upon to include those with chronic illnesses and

conditions (Brashers, et al., 2003; Mast, 1995). Uncertainty is also implicated in causing stress in family members (Bailey, et al., 2007; Barker-Collo, 2006; Brown, et al., 2006; Clayton, et al., 2006; Donovan-Kicken & Bute, 2008; Gil, et al., 2004; Gold-Spink, et al., 2000; Pelletier-Hibber & Sohi, 2001; Sammaro & Konecny, 2008; Winters, 1999). The participants expressed high levels of fear and uncertainty.

The participants in this study suffered from ongoing *Losses and Limitations,* including changes in sexuality and role functioning. Sexuality, while a basic human need (Maslow, 1954), is frequently overlooked when working with people who have either acute or chronic illnesses (Basson, 2007; Karlen, 2002; Koch, et al., 2003; Mercer, 2008; Tanyi, 2002; Taylor & Davis, 2007). I was honored that many of the participants in my study chose to share how their CBP impacted their sexuality unprompted. With chronic illness limiting a person's abilities, roles within families often change (Charmaz, 1983; Ray, 2006; Eriksson & Svedlund, 2006; Strunin & Bodin, 2004; Thoman-Touet, 1992). The participants described many ways in which their roles changed, consistent with this literature.

Participants used nearly 140 unique descriptors of pain in their journals and interviews. The level of detail in their depictions was astonishing and led me to feel that *Having Intimate Knowledge* is a requisite part of the experience of living with the ever-present Shadow of pain in their lives. I could find no literature that examined this component of the phenomenon.

Living with Fatigue is a nearly-universal component of illness that is both caused by and causes exacerbation of the original problem. It can be caused by the condition itself or from its treatment (Cella, et al., 2005; Evans & Wickstrom, 1999; Glacken, et al.,

2003; Goligher, et al., 2008; Jorgensen, 2008; Karlen, 2002; Koch, et al., 1999; Kralik, 2001; Kralik, et al., 2003; Michielsen, et al., 2004; Ricci, et al., 2007; Sharp & Wilks, 2002; Small & Lamb, 1999; Webster, 1997; Whitehead, 2009). These participants were no different; they described differing types of fatigue and the effects of their CBP on their sleep, which in turn affected both physical and psychological functioning.

The essence of the phenomenon, *Dancing with the Shadow: Re-Visioning Quality of Life,* describes a delicate dance between participant and back pain for control. Sometimes in this dance the back pain led and quality of life suffered. However, there were times when the nurses were able to lead the dance themselves. In this case, the increase in control correlated to an improved quality of life.

Limitations

This study "bucks the trend" of ongoing research into QOL. Currently QOL is measured with health care related and disease-specific tools and indeed I set out to describe QOL for people with a specific medical condition, CBP. However, I did so in the belief that QOL is a broad, individualized phenomenon and that the only authentic understanding of it comes from listening to patients' voices unencumbered by predetermined scales. I chose people with CBP because it is an interest of mine. With the prevailing thoughts regarding QOL research, my study may be dismissed as simplistic and naïve.

Another limitation relates to my skills as an interviewer. During my pilot studies I had difficulty knowing how or indeed when to redirect participants who told long stories with what I thought was only passing relevance to my questions. I had to balance my time commitments to the participants and wanting rich data related to my questions

with honoring them by understanding that this was their phenomenon and what they wanted to tell me was important to them. As I listened to and transcribed each tape, I began to recognize areas in which participants were truly straying from the topic as opposed to providing vital information in a long-winded manner. Many important insights came at the end of a long passage as the participants finally came to their point after providing what they felt was required background information.

The final limitation was revealed to me as I wrote about the themes and essence. This study was very broad, much broader than originally intended. My original intention was to understand quality of life from others' perceptions and experiences and in the end I met that goal. I have been enlightened by a full and rich appreciation of quality of life in nurses with chronic back pain. But my route was round-about; this study revealed far more about the lived experience of chronic back pain and could easily have been narrowed to this single topic. However, I feel that I would have lost a great deal of understanding had I only questioned the nurses about their back pain without reference to QOL. This study provides rich and detailed descriptions and would have been rendered an anemic version of itself had it been narrower in scope.

Implications

This study yields rich material for research, education, and practice. The mere fact that so many individuals suffer from chronic back pain offers many opportunities to expand on this work and to incorporate it into practice situations and education.

Recommendations for Future Research

This study adds to the large body of literature that encompasses such topics as back pain, chronic pain, coping with chronic illness, and journal writing, and as such is fertile territory for ongoing work.

First and foremost it adds to our understanding of the lived experience of chronic back pain and its resultant effects on quality of life in nurses. Extrapolating this data and comparing the results of this study to other studies on chronic pain in general makes a compelling argument for strategies to improve treatments for chronic back pain and, perhaps more importantly, to engage people who suffer with chronic back pain in learning how to control and manage their condition. Quality of life is supposed to be the outcome yardstick--the measure against which new innovations are compared. Clearly the nurses in this study were distressed. They had less than optimal treatment options and were dissatisfied with their care. Health care has a long way to go to optimize treatment for this group of patients but the results of this study show that need distinctly.

The sample population itself also yields many ideas for research. My sample was purposefully nurses, but by coincidence they were all Caucasian and middle aged or older. Many were employed or somehow affiliated with the health system in which I work. It would be very interesting to understand the perspectives of younger nurses or nurses of color to see if generational or cultural/ethnic considerations come into play. Having participants who work in more diverse practice areas would also help increase heterogeneity. The participants were also all female. Much has been written about the influences of culture and gender in health care, and in pain specifically, so examining this phenomenon from the point of view of males would certainly add to the richness of the

findings. However, since my population was registered nurses, that did limit the diversity of the sample. In nursing, only 4.6% are African American, 1.8% are Hispanic/Latino, and 7.9% are male (Bureau of Labor Statistics, 2008-2009).

For the first time in nursing history, we have individuals from four distinct generational groups in the workforce: the Veterans, the Baby Boomers, Generation X, and the Millennials (Carver & Candela, 2008; Frandsen, 2009). There is a large body of literature on their attitudes and differences. Perhaps they would respond to back pain and its effects differently. A historical study would add valuable insight into the topic, looking at experiences, expectations, and methods of coming to terms with chronic back pain in each of these groups. Reading the journals and transcripts from Mildred and Golda certainly piqued my interest in possible generational differences.

While journal writing has been found conclusively to improve health outcomes, no fully accepted theory for how it works exists. Grounded theory could be used to expand on the body of literature related to journal writing to attempt to determine the mechanism of obtaining benefits. Grounded theory could also be used to explore the ways in which individuals come to adjust and accept their back pain.

One area that is lacking in the existing literature shows the need for a fuller understanding of the intimate nature of the relationship of pain to its sufferer. A complete and compassionate grasp of this experience might lead to earlier recognition of the reality of pain, better treatments, and improved coping methods. A second area that would yield rich information is the study of CBP and its impact on families. There are no studies that address this specifically.

Recommendations for Education

It is clear from this and other studies, that patients in pain are dissatisfied with their care and feel disbelieved and discounted. Nursing faculty members have an obligation to teach their students about the individualized nature of illness experiences, including pain. Educators need to include pain theory in nursing curricula and include not just the objective measures of pain, but also need to emphasize the personal toll untreated pain takes on a person. Students could have experiences with individuals in pain, such as clinical time in a pain center.

Nursing students are not the only health care providers who need further education on pain and its effects on their patients. Physicians need to be taught to place more emphasis on interventions that improve quality of life. They also need to understand that chronic back pain often cannot be accurately diagnosed and treated in the standard western bio-medical fashion. This does not mean that patients with chronic back pain are drug seekers; rather they have a condition that does not fit neatly into the standard model of medical care that is so often taught in medical schools.

Several nurses in this study reserved especially vitriolic comments for the workman's compensation system. One positive outcome of the data presented here is that it could be compiled into an inservice for workman's compensation employees. While not all workman's compensation systems should be stereotyped as uncaring, the callous treatment given a few participants will be remembered by them for life.

Recommendations for Practice

The results of this study can guide health care professionals in providing compassionate quality care to patients with CBP in several ways. First and foremost, the

concept of QOL is important to people with CBP. As demonstrated, participants describe aspects of their QOL in detail, implying that they spend a great deal of time thinking and talking about it. One important feature of QOL is choice; participants wanted to choose their jobs, their hobbies and leisure activities, and their treatments. Fatigue was a surprising finding; it nearly rivaled pain in its effect on the participants. Participants also demonstrated that adjusting to their injury and learning to accept it and cope with it are not done in a linear fashion. Health care providers should attempt to view QOL as their patients view it and offer practical alternatives for being able to make choices, suggestions for living with fatigue, and assurance when the process of adapting and adjusting takes a long time. Years after the injury, participants continued to bargain, hope, rage, and despair over the changes in their lives brought on by back injury. This is significant in a society that expects people to "get over" their problems and move on.

Nurses are told that pain is whatever the patient says it is; obviously many do not heed that tenet. We have made a good start by including pain as a "vital sign" and requiring it to be assessed routinely, but assessment makes no difference if patients' opinions are not valued and their pain remains undertreated. Patients in pain need thorough assessments and a care plan tailored to their particular needs, including understanding what level of pain is acceptable to them.

Health care providers also need to understand the connection between chronic pain and depression. This study and others like it demonstrate that practitioners need to be assessing patients with chronic pain for depression. This is due in large part to the ongoing nature of the losses that individuals face, especially the loss of physical functioning.

Nurses who work with patients suffering from chronic back pain, and indeed any condition that requires ongoing coping or has little chance for "cure," could begin offering journal writing as a way for patients to gain clarity and perspective on their situation. Journal writing is cheap, easy, has little chance of deleterious effects, and as a CAM practice, is within the scope of nursing practice.

Summary and Conclusions

This phenomenological study provided an in-depth look at the lived experience of RNs who live with CBP and who engaged in a prescribed JW experience. Eight themes within two domains were identified and the essence of this phenomenon was made clear to me as *Dancing with the Shadow: Re-Visioning Quality of Life.* Nurses who live with CBP have to control their pain and learn to engage in a remaking of their QOL. The results of this study offer many exciting prospects for furthering the profession of nursing and having a positive impact on patients suffering from chronic back pain. Executing any of the various implications in research, education, or practice discussed here will no doubt have promising effects on patients' quality of life. Unquestionably, the most important thing nurses can do is to learn to hear what their patients are saying and to understand the unique nature of an experience to each person experiencing it. Then nursing will truly be the holistic caring practice it was meant to be.

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Appendices

Appendix A

Alumni Directors' Letter

Dear (Alumni Association Director):

My name is Meg Blair, RN, MSN, CEN, and I am a doctoral student at the University of Nebraska-Lincoln. I am conducting research for my dissertation, Quality of Life Despite Back Pain: A Phenomenological Study.

I am writing to request your assistance in recruiting participants for my study. I would like to be able to contact them directly about my study, or alternatively, I would appreciate it if you would send an email to your alumni requesting participation.

The study will look at the experiences of RNs who have had back pain for more than 6 months. It does not matter if these nurses are working, nor does it matter what kind of treatment, if any, they have had for their pain. The study will consist of interviewing the nurses after they have completed a brief journal writing experience. Because there is an interview involved, the participants will all need to live within reasonable driving distance of Omaha.

Interested parties can contact me directly via telephone or through my email: megblair9@gmail.com

Or, if you prefer, they can contact you and you can either give them my contact information or you can forward their information on to me.

Thank you very much for whatever assistance you are willing to provide. If you have any questions or wish to discuss this further, please don't hesitate to call me.

Sincerely,

Meg Blair, RN, MSN, CEN
(h): 593-6097
megblair9@gmail.com

Appendix B

Institutional Review Board

UNIVERSITY OF Nebraska Lincoln	University of Nebraska-Lincoln Institutional Review Board (IRB) 312 N. 14th St., 209 Alex West Lincoln, NE 68588-0408 (402) 472-6965 Fax (402) 472-6048 irb@unl.edu	FOR OFFICE USE ONLY IRB#_____ Date Approved:_____ Date Received:_____ Code #:_____

IRB NEW PROTOCOL SUBMISSION

Project Title:	Quality of Life Despite Back Pain: A Phenomenological Study

Investigator Information:

Principal Investigator:	Meg Blair, RN, MSN, CEN	Secondary Investigator or Project Supervisor*:	Marilyn Grady, PhD
Department:	Educational Administration, Educational Leadership in Higher Education	Department:	Educational Administration, Educational Leadership in Higher Education
Department Phone:		Department Phone:	402-472-0974
Contact Phone:	402-354-7037	Contact Phone:	402-472-0974
Contact Address:	1016 Timber Drive	Contact Address:	128 TEAC, UNL
City/State/Zip:	Papillion, NE 68046	City/State/Zip:	Lincoln, NE 68588-0360
E-Mail Address:	Blair_meg@hotmail.com	E-Mail Address:	Mgrady1@unl.edu

* Student theses or dissertations must be submitted with a faculty member listed as Secondary Investigator or Project Supervisor.

Principal Investigator is:

	Faculty		Staff		Post Doctoral Student
X	Graduate Student		Undergraduate Student		Other

Type of Project:

X	Research		Demonstration		Class Project
	Independent Study		Other		

Does the research involve an outside institution/agency other than UNL*?	Yes [X] No [ ]

* Note: Research can only begin at each institution after the IRB receives the institutional approval letter

If yes, please list the institutions/agencies.	Nebraska Methodist College – Omaha, NE
Where will participation take place (e.g., UNL, at home, in a community building, etc)	At Nebraska Methodist College

Project Information:

Present/Proposed Source of Funding:	Self		
Project Start Date:	January 2008	Project End Date:	December 2011

*Please attach a copy of the funding application.

<u>Type of Review Requested:</u> Please check either exempt, expedited, or full board. Please refer to the investigator manual, accessible on our website: http://www.unl.edu/research/ReComp1/compliance.shtml, to determine which type of review is appropriate. **Final review determination will be made by the IRB.**

Please check your response to each question.

	Yes	X	No	1. Does the research involve prisoners?
	Yes	X	No	2. Does the research involve using survey or interview procedures with children (under 19 years of age) that is not conducted in an educational setting utilizing normal educational practices?
	Yes	X	No	3. Does the research involve the observation of children in settings where the investigator will participate in the activities being observed?
X	Yes		No	4. Will videotaping or audio tape recording be used?
	Yes	X	No	5. Will the participants be asked to perform physical tasks?
	Yes	X	No	6. Does the research attempt to influence or change participants' behavior, perception, or cognition?
	Yes	X	No	7. Will data collection include collecting sensitive data (illegal activities, sensitive topics such as sexual orientation or behavior, undesirable work behavior, or other data that may be painful or embarrassing to reveal)?
				8. For research using existing or archived data, documents,

	Yes	X	No	records or specimens, will any data, documents, records, or specimens be collected from subjects after the submission of this application?
	Yes	X	No	8a. Can subjects be identified, either directly or indirectly, from the data, documents, records, or specimens?

[ ] **Exempt** [x] **Expedited** [ ] **Full Board**

Description of Subjects:

Total number of participants (include 'controls'):	15

Will participants of both sexes/genders be recruited? Yes [X] No [ ]
If "No" was selected, please include justification/rationale.

Will participation be limited to certain racial or ethnic groups? Yes [ ] No [X]
If "Yes" was selected, please include justification/rationale.

What are the participants' characteristics?

Registered nurses (RNs) who have had chronic back pain for at least 6 months. All RNs are over the age of 18. RNs can participate whether or not they are currently working.

Type of Participant: (Check all appropriate blanks for participant population)

X	Adults, Non Students		Pregnant Women		Persons with Psychological Impairment
	UNL Students		Fetuses		Persons with Neurological Impairment
	Minors (under age 19)		Persons with Limited Civil Freedom		Persons with Mental Retardation
	Victims		Adults with Legal Representatives		Persons with HIV/AIDS
	Other (Explain):				

Special Considerations: Yes [X] No [ ]
If yes, please check all appropriate blanks below.

X	Audio taping		Videotaping		Archival/Secondary Data Analysis		Genetic Data/Samples
	Photography		Web-based		Biological Samples		Protected Health

			research				Information

Project Personnel List:

Please list the names of all personnel working on this project, starting with the principal investigator and the secondary investigator/project advisor. Research assistants, students, data entry staff and other research project staff should also be included. For a complete explanation of training and project staff please go to http://www.unl.edu/research/ReComp1/compliance.shtml

Name of Individual:	Project Role:	UNL Status*	Involved in Project Design/Supervision? Yes/No	Collect Data? Yes/No
Margaret B Blair	**PI**	**Graduate Student**	**Yes**	**Yes**
Marilyn Grady, PhD	**Project advisor**	**Faculty**	**Yes**	**No**

*Faculty, Staff, Graduate Student, Undergraduate Student, Unaffiliated, Other

Required Signatures:

Principal Investigator:		Date:	
Secondary Investigator/Project Advisor:		Date:	
Unit Review Committee:		Date:	

PROJECT DESCRIPTION

FOR OFFICE USE ONLY
PROTOCOL:
DATE APPROVED:

1. Describe the significance of the project.

What is the significance/purpose of the study? (Please provide a brief 1-2 paragraph explanation in lay terms.)

The purpose of this study is to explore the phenomenon of living with chronic back pain and to examine the impact of a prescribed journal writing activity on the quality of life in registered nurses (RNs) who have chronic back pain.

Back pain is a significant medical problem in the industrialized world. It is the second most common reason for physician office visits and the third most common reason for surgery. It is a leading cause of workplace disability and is seen frequently in RNs. An enormous amount of money is spent on caring for patients who have back pain, with the majority being spent on cases that become chronic, or last for more than 6 months. Unfortunately, the vast majority of people who have chronic back pain are dissatisfied with their medical care. Health care providers often find caring for patients with chronic back pain frustrating because diagnostic tests often do not reveal a specific cause that can be treated, and the pain the patients experience does not seem to correlate with physical findings. All of this leads to people with chronic back pain having much lower quality of life than do people without chronic back pain.

Journal writing, specifically a prescribed journal writing activity, has been shown to have both physical and psychological benefits for people who have a variety of medical and psychosocial problems. If a prescribed journal writing activity can improve the quality of life in people with chronic back pain, it would be a very inexpensive way to significantly improve their lives and could be directed by any health care provider, including RNs. It might also increase the satisfaction health care providers experience when working with these patients. Journal writing and interviews might reveal themes about the experience of living with chronic back pain that help health care providers understand their patients more fully and allow them to offer holistic care

2. Describe the methods and procedures.

Describe the data collection procedures and what participants will have to do.

Participants will follow a prescribed journal writing activity for three days. Each day they will write for 20 minutes about their back pain, their quality of life, any problems they are having because of the back pain, or about any other topic of their choice. After three days they will fill out a brief survey consisting of 13 items designed to assess whether or not they experienced any change in their perceived quality of life. They will return the survey and their journals to the principal investigator. They will also participate in an audio taped interview with the principal investigator.

How long will this take participants to complete?

Journal writing: 20 minutes, three times a day = 60 minutes.

Survey: 20 minutes.
Audio taped interview: 1 ½ hours.
Total time: 2 hours 50 minutes.

Will follow-ups or reminders be sent? If so, explain.
When the participants agree to take part in the study, the researcher will make an appointment for the interview with them. The researcher will ask if they wish to be called and reminded of the appointment. If a participant is a "no call, no show" for the interview, the researcher will contact him/her at that time. Otherwise, no specific follow up or reminders are planned.

3. Describe recruiting procedures.

How will the names and contact information for participants be obtained?
The principal researcher will contact alumni associations for the schools of nursing in the Omaha area and ask for assistance in disseminating a call for volunteers to participate in the study.. The researcher will also contact the State Board of Nursing to request a list of current Nebraska RNs. The researcher will also request permission to post flyers in hospitals, nursing homes, and physician offices/clinics requesting RNs to participate. The participants and volunteers not needed for two prior pilot studies, done as class projects, all agreed to be contacted again for participation in this dissertation and the researcher will contact them via telephone.

How will participants be approached about participating in the study?
Nursing school alumni will be contacted by mail or email as provided on the contact lists. Participants from two prior pilot studies will be phoned and asked if they will consent to having their data used in this study. If a former participant declines, his/her data is easily removed from the database of individual interview transcripts and journals. Volunteers who were not needed for the prior pilots studies (done as class projects) will be contacted by telephone to see if they will consent to participating in this study. If a participant nominates another nurse to be in the study, the researcher will give that nurse a flyer to give to the nurse he/she is nominating, so that nurse can then contact the researcher about participation.

****Please submit copies of recruitment flyers, ads, phone scripts, emails, etc.**

4. Describe Benefits and Risks.

Explain the benefits to participants or to others.
Benefits include a possible increase in quality of life to the participants. Benefits to others include finding a nursing-controlled intervention to help those with chronic back pain increase their quality of life.

Explain the risks to participants. What will be done to minimize the risks? If there are no known risks, this should be stated.

There is a small risk that emotional disclosure during the journal writing exercise or during the interview may produce stress. The researcher will inform the participants that if they experience distress, they may terminate their participation in the study at any time. The researcher will also have a list of mental health providers should the participants feel the need to access this service.

5. Describe Compensation. Will compensation be provided to participants?

Yes [ ] No [X]

If 'Yes', please describe amount and type of compensation, including money, gift certificates, extra credit, etc.

6. Informed Consent

How will informed consent/assent be obtained?

The principal investigator will meet with interested participants either in person or by phone. At that time, she will share information about the study to help the respondent determine if he/she is interested in participating. If the participant can meet in person with the researcher, the researcher will go over the informed consent form at the time of the initial meeting, when the journal writing and survey instructions are provided. If materials are mailed to a participant, the researcher will telephone him/her and go over the procedures and consent form over the phone. As stated above, prior participants in pilot studies will be contacted by phone and asked if their information can be used in this study. Their data can easily be separated and removed if they decline to participate. As stated above, volunteers for the prior studies who were not needed will also be contacted by phone and the researcher will use the procedure outlined for new participants. They were previously asked if they could be contacted again and all agreed.

****Please attach copies of informed consent forms, emails, and/or letters. Please refer to the last page for a checklist of the information that needs to be included in the informed consent document.**

7. Describe how confidentiality will be maintained.

How will confidentiality of records be maintained? All records will be kept at the principal investigator's home in a locked file drawer. The investigator's USB drive will also be kept in this locked drawer. Only the principal investigator has a key to this drawer. Each participant will be assigned a pseudonym that will be used on his or her survey, journals, and on their transcripts. Any identifying information (specific dates, names of workplaces, etc) will be altered. Audio recordings will be destroyed after they are transcribed and checked for accuracy. The principal investigator will do all the

transcribing herself.

Will individuals be identified? No. They will be given pseudonyms, as described above. People mentioned by name by the participant will also be given pseudonyms. Specific dates will be altered in the format of "19xx".

How long will records be kept? The compiled data and transcripts will be kept for 1 year after the project has been completed. Audiotapes will be destroyed after they have been transcribed and the transcription checked for accuracy.

Where will records be stored? At the principal investigator's home in a locked file drawer.

Who has access to the records/data? The principal investigator has the only key to the drawer where records will be kept. The project advisor will have access to the data through the principal investigator.

How will data be reported? The results of this study will be reported through a dissertation, as reports at conferences, and in journal articles.

If transcriptions are required, how will transcriptions be handled? Who is doing the transcriptions? Please attach a copy of the confidentiality agreement that transcriptionists will sign.
The principal investigator will be the only person handling the transcripts on a routine basis. The project advisor may have access to them through the principal investigator.

8. Copies of questionnaires, survey, or testing instruments.

Please list all questionnaires, surveys, and/or assessment instruments/measures used in the project.
Survey Form
Interview Protocol
Journal writing instructions

Please submit copies of all instruments/measures.

Checklist for the Informed Consent Form (cover letter, email, etc): Basic information that must be included

Project Description

	Is the project title identified?
	Is it stated that the study involves research?
	Purpose of the research?
	How long will it take to participate?
	Why participant was selected?

	Is the age of participant stated (under 19 needs parental consent)?
	Are procedures described?
	Where will it take place?
	Are experimental procedures identified? (include if applicable)

Risks, Benefits, and Alternatives

	Are risks and discomforts to participants explained? If no risks, does it say no known risks?
	If there are risks, what will be done to minimize the risks? Referrals?
	Are benefits to participants and to others that might be expected from the research explained?
	Are alternative procedures or course of treatment that might be advantageous to the participant identified?
	If the study offers course credit, are alternative ways to earn the credit explained?

Confidentiality

	Will confidentiality of records identifying participant be maintained?
	How will data be reported: scientific journal, professional meeting, aggregated data?

Compensation

	Is compensation offered?
	Are medical treatments available if injury occurs?
	Who will pay for treatments (participant or department)?
	What conditions would exclude participant from participating?

Right to Ask Questions

	Is it stated that participants have a right to ask questions and to have those questions answered?
	Are the names & phone numbers of persons to contact for answers to questions about the research provided?
	Does it state who to contact concerning questions about research participants' rights, "Sometimes study participants have questions or concerns about their rights. In that case you should call the University of Nebraska-Lincoln Institutional Review Board at (402) 472-6965."

Freedom to Withdraw

	Does it state, "You are free to decide not to participate in this study. You can also withdraw at any time without harming your relationship with the researchers or the University of Nebraska-Lincoln."
	Does it state participation is voluntary?

Appendix C

Informed Consent

Title of this research study: The title of this research study is Quality of Life Despite Back Pain: A Phenomenological Study.

Invitation to Participate: You are invited to participate in this study exploring quality of life in Registered Nurses (RNs) with chronic back pain who participate in a journal writing activity. The purpose of this study is to understand the experience of quality of life in RNs who have chronic back pain and to understand if a prescribed journal writing activity has an impact on quality of life.

Basis for Selection: You volunteered to participate in this study because you are over the age of 19, you are an RN, you have chronic back pain, and you are willing to participate in a journal writing activity.

Explanation of Procedure: The study will involve a journal writing activity. You will be asked to write for 20 minutes for three days in a row about your chronic back pain. You will be asked to participate in an interview with a student researcher that will be audio taped. The interview will last 1 1/2 hours. You may ask that the tape be turned off at any time. The researcher will also take notes during the interview. The tape will be transcribed by the interviewer and will be sent to you for review. At that time you may clarify your responses or give the researcher other information. You can complete the journal writing activity any place you chose. You will be asked to select a place with the researcher for the interview. You may also bring photographs or artwork if they help you describe your experiences.

Potential Risks and Discomforts: This research project has no direct risks to you. Depending on the nature of your experiences, writing or talking about your back pain and your quality of life may cause you some stress. If this stress places an undue burden on you, you may terminate the study or interview at any time.

Potential Benefits to the Participant: Researchers have found that when people are given the opportunity to write or to talk about their experiences, they often develop new insights related to those experiences that are personally meaningful. Thus, you may gain some personal benefit from participating in this study.

Potential Benefits to Society: The findings of this study will help the researcher understand the meanings of quality of life and how journal writing may influence those feelings in people who have chronic back pain.

Compensation for Participation: None

Assurance of Confidentiality: Any information that could identify you will be kept strictly confidential. All participants will be assigned a code and their names will be removed from any transcription. The data will be stored in a locked file drawer and the investigator's password-protected USB drive will also be kept in the locked file drawer when not in use. Data will only be seen by the principal investigator and her advisor during the study and for 5 years after the study is complete. Audiotapes will be destroyed after transcription and verification. Data from this study will be reported in the form of a dissertation, at professional conferences, and in papers in scholarly journals.

Opportunity to ask questions: You have the right to ask questions before, during, and after the study and you have the right to have those questions answered. You may call the principal investigator at any time at home 402-593-6097 or at work 402-354-7037. You may also call the project supervisor, Dr. Marilyn Grady, at 402-472-0974. Sometimes participants have questions or concerns about their rights or wish to report a problem with the study. In that case, you should call the University of Nebraska-Lincoln Institutional Review Board at 402-472-6965.

Voluntary Participation and Withdrawal: Participation in this study is confidential. You are free to decide not to participate in this study. You are also free to withdraw from this study at any time without harming your relationship with the principal investigator, the University of Nebraska-Lincoln, your alumni association, or your place of employment. Your decision will not affect any benefits to which you are otherwise entitled.

You are voluntarily making a decision whether or not to participate in this research study. Your signature certifies that you have decided to participate having read and understood the information presented. You will be given a copy of this consent form to keep.

_____ Initial if you agree to be audio taped during the interview.

_____ _____

Signature of Participant Date

Meg Blair, RN, MSN, CEN	Principal Investigator	402-593-6097
Marilyn Grady, PhD	Project Supervisor	402-472-0974

Appendix D

Interview Protocol

1. Tell me the story of your back pain.

   a. Help me understand what it was like for you to realize this was a chronic condition.

2. Describe your quality of life for me.

   a. What is important to you when you think of quality of life?

   b. Some people describe quality of life as having different dimensions such as physical, psychological, social, and spiritual. Are any of these qualities meaningful to you?

   c. How do you describe quality of life?

3. How does the back pain enter the picture when you think of quality of life, or does it?

4. Walk me through your experience with the journal writing experience.

   a. What did the writing mean to you?

5. Did you gain anything from that experience? If yes, explain. If no, why not?

Prompts:

1. Silence
2. Repeat last question or last thought in a questioning tone
3. Re-direct to the level of a concrete example: Can you give me an example of that?

Appendix E

Journal Writing Directions

Journal Writing Activity

Directions:

In this writing activity, I would like you to write about how chronic back pain has affected your life, problems you have experienced because of your pain, and your feelings about those experiences. **I would like you to write about a specific problem the back pain has caused for you and the emotions you felt related to those problems.** If you do not have a pain-related problem to write about, then write about any other problem you may have now.

I would like you to write for 20 minutes three days in a row. Try to find a quiet place where you will not be interrupted and where you are comfortable. When you write, try to make your memories as vivid as possible, including thoughts, emotions, and bodily sensations. You may write about a different problem each day, or about the same problem each time. Do not worry about grammar, spelling, or sentence structure while you write; it is not important.

Please bring your journals when you come for your interview. Thank you.

Appendix F

Survey Tool

Quality of Life Despite Back Pain Survey

After you complete the journal writing activity, please take a few moments to fill out this survey. Please bring it with you when you come to your interview. Thank you.

Start Here:

1. As a general statement, how would you rate your quality of life? (Check one box.)

- ☐ Extremely poor
- ☐ Remarkably poor
- ☐ Poor
- ☐ So-so (average)
- ☐ Good
- ☐ Remarkably good
- ☐ Extremely good
- ☐ I am not sure

2. Overall, how satisfied with your present quality of life are you?

- ☐ Totally dissatisfied
- ☐ Dissatisfied
- ☐ Neutral
- ☐ Satisfied
- ☐ Totally satisfied
- ☐ I am not sure

3. Do you feel that your back pain affects your quality of life?

- ☐ Back pain does not affect my quality of life at all
- ☐ Back pain has some effect on my quality of life
- ☐ Back pain has a moderate effect on my quality of life
- ☐ Back pain has a lot of effect on my quality of life
- ☐ Back pain has an enormous effect on my quality of life
- ☐ I don't know

4. Over the last week, how many days did you have back pain?

- ☐ 0-1 days
- ☐ 2-3 days
- ☐ 4-5 days
- ☐ 6-7 days
- ☐ I don't remember

5. Can you describe in general terms, what the back pain was like during one episode? *Please describe the painful episode in as much detail as you can.*

6. When thinking about the prescribed journal writing exercise, did you follow the directions

- ☐ Less than 25% of the time or not at all
- ☐ 25% of the time
- ☐ 50% of the time
- ☐ 75% of the time
- ☐ 100% of the time
- ☐ I don't know

7. How difficult or easy was the prescribed journal writing exercise for you to do?

- ☐ It was very difficult
- ☐ It was somewhat difficult
- ☐ It was pretty easy
- ☐ It was extremely easy
- ☐ No opinion

8. Thinking back on the prescribed journal writing exercise, to what extent did the writing affect your quality of life?

- ☐ It had no effect on my quality of life
- ☐ It had very little effect on my quality of life
- ☐ It had some effect on my quality of life
- ☐ It had a moderate effect on my quality of life
- ☐ It had an enormous effect on my quality of life
- ☐ I don't know

9. To what extent did the prescribed journal writing activity make it easier to deal with your back pain?

- ☐ It had no effect whatsoever
- ☐ It had a little effect on my ability to deal with the pain
- ☐ It had some effect on my ability to deal with the pain
- ☐ It had a lot of effect on my ability to deal with the pain
- ☐ It had a tremendous effect on my ability to deal with the pain
- ☐ I don't know

10. Will you continue with a prescribed journal writing exercise on your own?

- ☐ I definitely will not continue
- ☐ I probably will not continue
- ☐ I may continue
- ☐ I probably will continue
- ☐ I definitely will continue
- ☐ I don't know

11. How likely are you to recommend journal writing to a person with chronic back pain as a way to improve his or her quality of life?

- ☐ I would definitely not recommend it
- ☐ I probably would not recommend it
- ☐ I probably would recommend it
- ☐ I definitely would recommend it
- ☐ I don't know

Please provide the following demographic information:
12. How long have you had back pain?

- ☐ 6 months-12 months
- ☐ 13 months-2 years
- ☐ more than 2 years, but less than 5 years
- ☐ more than 5 years, but less than 10 years
- ☐ more than 10 years, but less than 15 years
- ☐ more than 15 years, but less than 25 years
- ☐ more than 25 years

13. Which of the following treatments have you tried for your back pain? *Select as many as you wish.*

- ☐ Surgery
- ☐ Prescription muscle relaxants
- ☐ Other prescription medication
- ☐ Massage therapy
- ☐ Exercise
- ☐ Accupuncture/acupressure
- ☐ Over the counter medication
- ☐ Prescription pain medication
- ☐ Heat/cold treatments
- ☐ Physical therapy
- ☐ Weight loss
- ☐ Yoga
- ☐ Other: *please specify:*_____

14. Have you ever quit or been forced to leave a job because of your back pain?

☐ Yes ☐ No

Thank you for completing this survey. Please return it when you come to your interview. If you have any questions, please contact

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Appendix G

Domain Sheets

Domain Sheets

Domain One: *Making Normal*		
***"Making Normal"* reflects either fighting to retain a previous existence or working through grief to remake personal and/or professional self images.**		
Included Terms	*Semantic Relationship*	*Cover Term*
Fighting & Denying		
Being Angry & Frustrated		
Surviving The Three D's (depression, despair, devastation)	is a way to	"Mak[ing] Normal"
Choosing, Adjusting, & Adapting		

Domain Two: *Living with the Shadow*		
***"Living with the Shadow"* indicates existing with the constant awareness of something being not right with you…something that cannot be fixed and will never go away.**		
Included Terms	*Semantic Relationship*	*Cover Term*
Fear and Uncertainty		
Being Less Than Whole	is a characteristic of	" Living with the Shadow"
Having Intimate Knowledge		
Living Through Fatigue		

Appendix H

My Story

My experience with chronic back pain began in 1989 when I was in my first graduate course. Sitting in a class, I felt my back "pop" and I had the sensation that I dropped in my seat an inch or so. This happened twice. There was no pain, just that odd sensation. However, when I tried to stand up, my legs would not move and my back was in screaming pain. True to the character of most nurses (at least the ones I know), I did not seek medical attention until almost six months later, when I was late to work one day because I was unable to walk from my car into work. By that time I was unable to sit for any length of time, my legs were numb, my back was in constant spasm, and I had foot drop.

I refused "emergency" surgery for what turned out to be "bulging discs" and embarked on a course of physical therapy (PT). My therapist was the only person who did not think I was crazy. My back pain far outlasted the "injury" that I was told I should get over. My medical insurance only covered six PT visits; the rest were paid for out-of-pocket, creating a major financial strain. I was written up at work for not willingly lifting heavy patients or for asking for "too much" help moving occupied stretchers…This in a profession known to have a high rate of back injuries. Eventually I gave up my dream job as a trauma nurse, being unable to work the hectic 12-hour shifts without sitting down and without muscle relaxants.

I have an ex-husband who refused to help mow the lawn or carry groceries because he thought I was lazy. Driving my manual-transmission car became nearly impossible and my ex-husband would not trade vehicles. I couldn't sit through a dinner at a restaurant or go to the movies. Visiting my elderly parents several states away was

soon became out of the question; I could not sit in either an airplane or a car that long. I was so happy when they moved back to my town and I didn't have to worry about the travel. My life consisted of working and coming home to lie down prone on my stomach for the rest of the evening. This served to isolate me from my friends and certainly aided in the demise of my marriage.

Today, 21 years later, I still have back pain, occasional numbness in my legs, footdrop, and muscle spasms. The muscle spasms affect me most of all; since it is all connected somehow, there are days when my entire body hurts. One muscle spasm leads to multiple areas being exquisitely painful. Like many of the participants in this study, I rarely even take ibuprofen for the pain. I prefer stretching, exercising, or heat and cold therapies to medication. As I look back, I can see how this has affected every aspect of my life. I was able to relate completely to the vast majority of comments from the participants in this study; certainly for me, their comments resonated clearly. I have experienced all the emotions of the Making Normal domain and have learned to live with my constant companion as articulated in the Living with the Shadow domain.

There are so many things I cannot do, or cannot do without enduring days of pain afterwards. I am amazed to reflect and realize that I nearly did not adopt my two beautiful daughters from Russia because I feared the long plane rides would incapacitate me. But beyond the physical pain, what I regret is how back pain has made me cranky and difficult to live with. My injury is "gone", but the sequelae live on and affect all those around me. I am fortunate to have a husband who believes me and pampers me and a new physician who lets me decide what treatments I need. I can control my pain far more than some of the participants in my study can. I am blessed that the pain, although

a daily presence…a true shadow…in my life, does not drive me to the despair suffered by my participants and by the outside readers whose comments appear in Appendix I. However, blessed that I am, I can agree that I am not and will never be the person I once was.

I have been dismissed, lectured, ridiculed, and isolated by others who do not think I should have pain and who do not understand the impact of living with chronic pain, including by friends, family, co-workers, and the supposedly compassionate health care professionals from whom I sought help. I hope that this study provides a voice for all who suffer from chronic pain conditions, enlightening those who come into contact with them.

Appendix I

Outside Reader Comments

The results of this study (the essence) were sent to three RNs who met the criteria for participation, but who did not take part in the study. Their comments are below.

RN 1:

I really think you did a **great** job describing how people with chronic pain deal every moment of every day with far more than physical pain. The psychological effects can be astronomical. For me, and others I have spoken to, it really does feel like a constant dance with this dark "shadow".

It is an all-out war between an agile, youthful, and determined mind with a body that is betraying its master. Good days are an amazing blessing that give just enough hope to hang on for more good days. Those same days are also overshadowed by the knowledge that they are short lived, and the pain will come back. It can be a mentality of constant mourning- the grief that health, happiness, future hopes and dreams will never exist as you had planned before the pain took control.

RN 2:

Meg, sorry it took me long to respond. Ironic that I was struggling with a back condition flair-up at the time you sent it. It actually evoked a lot of emotion when I read it because I could relate to what the study results found.

Your summary captures what I have experienced also. I can relate to what the persons in your study experience. The analogy of a shadow is very powerful and I like it. The summary is clear, easy for me to understand and captures my attention. It makes me want to read the entire study.

RN 3:

This is awesome, it's wonderful. You are right on target especially when you describe the emotions and the effect that chronic back pain has on families. I wouldn't change a thing.

Appendix J

Pain Descriptors

Pain Descriptors by Participant

Betina Like a hot button Tremendous Relentless Horrible A “tired” back	**Eliza** Really bad Ache Very deep Unbearable Burning Nagging Like a roller coaster	**Giselle** Ache
Mary Sharp Shooting Sore Nearly causes tears Aches So much pain Awful Burings Aching Electric-type Tiring Constant Wacko A terrible hurt Severe Tight Like I was falling apart	**Toni** Horrific Radiating Severe Worse than childbirth Felt horrible with it Sciatic type Numb Incredibly uncomfortable Lower back pressure Neck aches Shooting Incredibly painful Burned in Like being eaten by sharp, sharp teeth Sharp shooting pain Burning So bad it just about did me in	**Patsy** Intermittent Mild Tiring Couldn’t bear it Dull Moderate Continuous Sharp Tightness Shooting Stabbing sensation Throbs Nothing helps it Severe An irritation
Barbara Aching Makes it difficult to move Intense Incapacitating Excruciating Miserable Severe Nagging discomfort Unbearable Sharp Sensitive	**Megan** A sharp twisting kind of pain Shooting Spasms Like sitting on golf balls Aching Heaviness Relentless Pulses with pain Numb areas A “crick” Took my breath away	**Anna** Like being hit by a truck A 10# charley horse Numbness Pain Miserable Awful A numbness that hurts Stabbing Big time ache A real big ache Really strong Aching
Mildred [varies from] Insignificant to it really gets my attention!	**Sylvia** Sharp The most terrible, terrible pain Pressure-type Like a teetering tower of blocks	**Laurabelle** Stabbing A very sharp killing pain Like putting a knife in my shoulder area

Pain Descriptors by Participant, continued

Golda	**Angel**	**DeeDee**
Sharp	Arthritis-like	Feels like it's on fire
Intermittent	Stiffness	Nauseating
Ache	Soreness	Hot to touch even by others
Nagging	Chronic numbness	Burns
Discomfort	Tingling	Aches
Really sore	Chronic aching	Stabs
Annoying	Aches and pains	Feels like being beaten with a 2x4
Like "ugh"	Just always hurts	Tearing
Burning ache	A chronic, aching tightness	Awful
Burning pain		Causes anguish
Sudden		Killing
Like "sproinnnnnng"		Ripping
		It looks like a huge, jagged, pointy rock