PHENOMENOLOGIC STUDY OF SPOUSES’ LIVING WITH A SPOUSE WITH CHRONIC NON-MALIGNANT PAIN

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A Thesis Submitted in Partial Fulfillment of the Requirements for the Degree of

Masters of Science in Nursing

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December 2007
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DEDICATION

This thesis is dedicated to my husband Kevin,

my daughter Sarah and her husband Cory,

and my son Chris,

all of whom have supported me through my
educational journey over the past twenty four years.

I further dedicate my thesis to my parents,

Jerome and Alice Schmidt

and my grandson Jaden Riley Schmidt

whom I felt sacrificed the most by

sparing their own needs while I selfishly

continued to pursue my goals.

To God, for without his loving guidance

I would never have had the strength to complete my journey.
ACKNOWLEDGEMENTS

I would like to thank Professor Barbara Ponder, MS, RN, CCNS, for spending many evenings reviewing and making suggestions on how I could improve my chapters prior to my presenting them to the committee. Professor Ponder assured me that I would be able to complete the thesis by the deadline, which I was able to do with her persistence and guidance. I would like to thank the other committee members, Dr. Larry Reynolds and Professor Catherine Schmitt. Other Marian College faculty that I would like to thank is Dr. Gretta Kostac and Dr. Thomas Ayala. Dr. Kostac was with our class throughout the whole program and her encouragement and guidance were immeasurable.

I would further like to acknowledge my husband, Kevin, for providing me with encouragement. Kevin continuously reminded me throughout the program of how far I have come with pursuit of my goals. Without his love and support I would not have had the strength to continue. I would like to acknowledge my parents, Jerome and Alice Schmidt, who have listened to my frustrations. My mother kindly reminded me on numerous occasions that nothing comes without a price and that life is too short and I should “just tough it out.” I would also like to acknowledge family members, friends and preceptors who have helped me through this period of my life: Sarah, Cory and Jaden Schmidt, Chris Kasperek, Naomi Kasperek, Terri and Paul Meiselwitz, Linda Schiesl, Janet Gruedemann, Cheryl Habeck, Shelby DePas, Mary Connelly, Carol Keberlein, Mark Schmitz, Dr. Charles Capasso, Dr. Brian Harrison and Dr. Richard Menet. Your support has been priceless.
ABSTRACT
LIVING WITH A SPOUSE WITH CHRONIC NON-MALIGNANT PAIN
Lisa M. Kasperek
December 2007
The purpose of this phenomenologic investigation was to describe the experience of spouses’ living with a spouse with chronic pain. A convenience sample of four participants was recruited from two urban pain clinics in the Midwest. Three male and one female spouse were interviewed using an unstructured format. Data were analyzed using a constant comparative method. A core process called Everyday Life Revolves around Pain emerged from the participants’ discourse. This overall process was composed of several categories, Being a Caregiver, Financial Issues, Help and Support, Conflicting Priorities, Changes in the Marriage and Changes in Social Life. These findings indicate that chronic pain affects both the individuals with chronic pain as well as their spouses. Health care providers may improve the lives of both by addressing the needs of the spouse of the client.

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CHAPTER I

INTRODUCTION

Chronic pain is associated with disabling physical and emotional symptoms that affect the individual sufferers as well as their families. Individuals with chronic pain (ICP) are five times more likely than individuals without chronic pain to utilize health care services. ICPs report impairments of multiple quality-of-life indicators, including physical, social and psychologic well-being (Marcus, 2000). Physical impairments can include loss of strength and mobility, poor sleep quality and quantity, medication side effects and nausea or loss of appetite. Psychological impairments can include decreased enjoyment of life, increased fear and anxiety, depression, sadness or distress, loss of control over one’s life, or dependency on others. Socially, the ICPs may be unable to take part in family or social activities (Jamison & Virts, 1990; Lee, Chan, & Berven, 2007). They may also have decreased sexual function or loss of affection (Randall, 1999; Schwartz & Slater, 1991). These changes can affect the marital relationship and the spouse of the individual with chronic pain (SICP).

Acute and chronic pain differ in a variety of ways. Acute pain, for the most part, results from disease, inflammation, or injury to tissues. It is immediate and usually of a short duration. Acute pain is a normal response to injury and may be accompanied by anxiety or emotional distress. The cause of acute pain can usually be diagnosed and treated (Berger & deSwaan, 2006). Chronic pain is defined as pain that persists after the
point at which healing would be expected to be complete, or is pain associated with a
disease process in which healing does not occur (McHugh & Thoms, 2001). Literature
published as early as the 1970s and as late as the 1990s often defined chronic pain as pain
lasting for a period of six months or more. Breen (2002) states that by the end of the
1990s, the definition of chronic pain was more often described as any pain that does not
resolve as expected, or does not resolve in three months or more. For the purpose of this
study, chronic pain is that which is associated with any medical illness or condition that is
not malignant and has not resolved within six months. This is referred to as non-
malignant pain.

The ICP and SICP must contend with numerous adjustments in their lives related
to a diagnosis of chronic pain (Baanders & Heijmans, 2007). The ICP’s impairment can
include diminished function in family, occupational and social roles. As a result, the role
relationship within the family changes, particularly altering the spousal role (Rowat &
Knafl, 1985; Schwartz & Slater, 1991). While there is an abundant amount of literature
in other disciplines such as psychiatry and physiatry, few nursing studies of chronic pain
have been conducted (Breen, 2002). Little is known about the affects of living with an
ICP on the health and wellbeing of the SICP (Geisser, Cano, & Leonard, 2005; Gill-
Taylor, Lorentzen, & Blank, 1990; Rowat & Knafl, 1985). This literature review will
include how chronic pain affects the ICP, the family, the marital relationship and the
SICP.

Effects of Chronic Pain on the Individual with Chronic Pain

In order to understand the effects of the ICP’s pain on the SICP, it is necessary to
review the effects of chronic pain on the individual who is experiencing chronic pain.
Seers and Friedli (1996) conducted a qualitative study of the experience of being in chronic pain. The authors sought to describe the meaning of what it was like to experience chronic pain. The sample consisted of 75 people with chronic pain, ranging from 21-86 years of age, who were attending either a pain clinic or an outpatient clinic in England for treatment of their pain. Over 63% had pain all the time and had experienced this pain for a duration of 6 months to 47 years. Seventy-six percent were female and predominantly Caucasian (93%). More than half of the participants were diagnosed with chronic back pain. The primary theme involved the participants wanting other people to believe them when they said they were in pain. These ICPs were frustrated that the physicians treated their chronic pain as if the pain were acute and could be expected to improve. The participants did not feel the physicians were interested in why they had pain; instead, they asserted that the physicians made them think it was their fault when medical interventions did not relieve the pain. These participants with chronic pain were distraught about the fact that someone else, usually the spouse, had to take over their prior responsibilities (e.g. household chores, home maintenance, grocery shopping, etc.).

Psychological well-being is jeopardized by living with chronic pain. The goals of treatment for ICPs are to reduce the pain, improve the function, and restore the psychological health. Schofferman (2006) asserts that too often treatment ends when an ICP’s pain improves, and as a consequence, the ICP remains dysfunctional and unable to return to normal activities. Schofferman stresses that it cannot be assumed that when pain improves function will follow. Many times the ICP fears that increased activity will cause more pain, or that pain with activity is a symptom of serious pathology. Decreased activity can be a voluntary response to pain. Prolonged periods of time spent in bed, on a
couch, or in a recliner leads to further impairment of mobility. Schofferman suggests that providers should be teaching ICPs that it is safe to exercise despite pain and that there is no risk of harm. Muscles that are not used will grow weaker.

Accepting pain as part of the healing process is important. Acceptance means more than just knowing that you have pain, it means actually allowing yourself to feel the anxiety, fear, anger and grief that go with pain. Acceptance is a process which requires the ICP to acknowledge those feelings of anxiety, fear, anger and grief and move on with their life despite the pain. McCracken, Vowles and Gauntlett-Gilbert (2007) investigated acceptance and control-oriented coping in individuals with chronic pain. Participants included 120 adult patients (64.2 % women) being treated at a pain management program in the United Kingdom. Participants mean age was 44.6 years, most were married (68.3%), 13.3% were never married and 11.7% were divorced. The median length of time the participants had experienced chronic pain was eight years. The primary locations of pain were low back (50%), lower extremity (14.2%), upper extremity (11.7%), neck (10.8%), or other (13.3%). At the time of initial assessment and then again on the first day in treatment the ICP completed measures of coping, pain, disability, and pain related anxiety. McCracken et al. noted that while one would expect that attempting to control pain or seeking help when pain worsens would provide improved physical functioning, the findings indicated that physical functioning actually decreased.

Effects on the Family

The ICP is not the only person whose life changes. Every member of the family is affected and must make adjustments. These adjustments may be psychological, social, economic, or physical in nature (Jamison & Virts, 1990; Kemler & Furnee, 2002; Rowat
& Knafl, 1985; Schwartz & Slater, 1991). Children often avoid parents in chronic pain as they are no longer the loving, tender and nurturing individuals they once were. ICPs may vent their frustrations and anger on the children. The ICP may be less able or unable to tolerate noise or the presence of children (Bral, Shaughnessy, & Eisenman, 2002).

Chronic pain is often associated with negative impacts on the family (Kemler & Furnee, 2002; Smith & Chambers, 2006). While members of the ICP’s family attempt to maintain “normalcy” in the family unit, there is evidence of isolation among all members (Smith & Friedemann, 1999). Smith and Friedemann conducted a qualitative study to gain an understanding of the experiences of persons with chronic pain and their relationships with family members. A convenience sample was recruited from a rural Ohio chronic pain clinic. Personal visits were arranged either in the participant’s home or in the clinic. Semi-structured interviews were conducted and averaged 45-60 minutes in length. The discourse of the participants included descriptions of emotional distress such as depression, anxiety, guilt or anger. These feelings seemed to be the result of losses of function, of work, of self-worth and their inability to physically participate in activities with their children. These feelings distanced the participants from their families. The participants described their inability to share difficult feelings with other family members and acquaintances. The participant believed that others either had no understanding of what they were going through, didn’t want to hear about their pain, or didn’t believe they were in pain which contributed to the participant’s sense of isolation. The participant also described how every member of the family gave up some personal autonomy and independence to preserve the family closeness. Smith & Friedemann
concluded that there was a strong probability that spouses and children in the family may be in need of help in a situation that they too find unbearable.

Only one study of the effects of chronic pain on family functioning found that children with parents with chronic pain might not be at risk for poor functioning. Smith and Chambers (2006) explored whether children who had a parent with chronic headache pain were at greater risk for poor functioning compared to children whose parent had no pain. The study compared 52 children of parents with recurrent headaches and either low or high levels of disability compared to 23 children without parents with recurrent pain. No differences were found in the children’s self-reported psychological or family functioning. Smith and Chambers concluded that children with parents with recurrent headaches might not be at risk for poor functioning compared to the children of parents without recurrent pain.

Effects on the Marital Relationship

Chronic pain not only affects the ICP, it also contributes to the couple’s marital dissatisfaction and poor sexual adjustment. The loss of intimacy is central to a decreased quality of life (Cano & Leonard, 2006; Leonard, Cano, & Johansen, 2006; Payne & Norfleet, 1986; Schwartz & Slater, 1991). Bral et al. (2002) state that when an ICP has persistent complaints of pain, the SICP may become irritated by the constant complaining of pain from the ICP. The SICP may consequently ignore the person in pain and their request for attention, support or analgesics. As a result, SICPs have increased rates of depression, subjective stress and loneliness when compared to spouses of healthy individuals (Cano, Johansen, Leonard, & DeGroot-Hanawalt, 2005).
When pain persists over months, years, or even decades, spouses may develop frustration, anger, resentment and emotional exhaustion (Rome, 2007). These negative reactions are increased by the fact that people in pain often withdraw emotionally from the spouse and other family members. While the SICP’s negative reaction to this withdrawal is a natural response, most ICPs perceive the SICP’s negative withdrawal and negative communication about the pain as an indicator that the spouse is angry or frustrated with them. Negative responses from the SICP may positively reinforce the ICP’s pain behaviors in an attempt to obtain more desirable attention from his or her spouse (Cano, Weisberg, & Gallagher, 2000; Turk, Kerns, & Rosenberg, 1992).

In an effort to understand the SICP’s perception of the impact that chronic pain had on the SICP’s health, Rowat and Knafl (1985) conducted an exploratory descriptive study using a semi-structured interview. In addition to the interview, the SICPs completed self reported measures of pain and hopelessness. The convenience sample was recruited from a pain center in a large university teaching hospital. Forty SICP participants were interviewed. Of this sample, 21 were males and 19 were females. The SICPs aged from 33 to 71 years. The length of time their spouse was in pain ranged from 1.5 years to 16 years. The ICPs had diagnoses of chronic pain such as low back, shoulder, arm, neuralgia, incisional pain, phantom limb and rheumatoid arthritis. The ICP’s chronic pain impacted the SICP emotionally, physically and socially. The SICPs expressed emotions such as sadness, depression, fear, nervousness and irritability. The ICP’s chronic pain physically affected the SICP’s sleep, appetite, increased their blood pressure and caused frequent somatic complaints of headaches and gastro-intestinal distress. Socially the SICPs felt housebound and restricted. One participant was quoted
as saying "I didn’t get married to be alone, now I’m alone. I feel to a certain extent separated from my wife by this experience" (p. 263). Less than 50% of the SICPs made any attempt to influence the ICP’s pain through direct physical acts as they were either uncertain what to do or feared they would cause further harm. One-quarter of the SICPs attempted to control the environment with the hope that the ICP’s pain would reduce if tension levels were lowered (Rowat & Knafl, 1985).

The SICP’s response to the ICP’s pain affects the ICP’s pain threshold. Newton-John (2002) studied solicitousness and chronic pain by reviewing 27 studies that explored patient-spouse interactions in chronic pain. Encouraging the ICP to rest to decrease or eliminate pain is one example of solicitous behavior. There was evidence to suggest that patients whose spouses engaged in more frequent solicitous behavior tended to exhibit more pain behaviors. These pain behaviors included reduced activity levels, increased disability, more help-seeking behaviors and reduced coping strategies. A number of studies have demonstrated the association between ICP reports of SICP solicitous behaviors and greater levels of ICP pain intensity (Newton-John, 2002; Schwartz & Slater, 1991; Silver, 2004; Snelling, 1994; Turk et al., 1992; Weiss & Kerns, 1995).

There are high rates of depression and depressive symptoms in ICPs (Cano, Weisberg, & Gallagher, 2000; Geisser et al., 2005; Lee, Chan, & Berven, 2007; Rowat & Knafl, 1985; Schwartz & Slater, 1991). Cano et al. (2000) found that many times these depressive symptoms were associated with decreased marital satisfaction. Cano et al. investigated the relationship between marital satisfaction and pain severity to see whether there was a correlation with pain and depressive symptoms in the ICP. The study included a convenience sample of 165 married participants with chronic pain who were
evaluated for treatment at a suburban comprehensive pain and rehabilitation center in New York. The ICP participants were primarily middle-class Caucasians with a mean age of 49 years who had been married an average of 22 years. As part of the intake process, ICP participants administered self-reported measurements of pain, depression and marital adjustment. The findings suggested that negative SICP responses to the ICP's expressed pain were associated with decreased marital satisfaction and increased pain severity. An example of punishing or negative behavior was the SICP’s angry response to the ICPs for expressing pain verbally or physically. Cano et al. suggested that these negative SICP responses can result in increased depressive symptoms in the ICP.

Schneider (2004) has summarized the potential negative consequences of living with an ICP. These negative consequences were grief over the loss of one’s precious life, feelings of anger, resentment and guilt, additional responsibilities at home, unanticipated change in career (gave it up or went back to work), decreased social life and recreational activities, friendships fading away, increased isolation, decreased sex life and relationships that can change from peer-peer to parent-child.

Effects of the ICP’s Pain on the SICP

When an ICP is diagnosed with chronic pain, the burden of additional responsibilities frequently falls on the SICP (Schwartz & Slater, 1991; Paulson, Norberg, & Soderberg, 2003; Soderberg, Strand, Haapala, & Lundman, 2003). The SICP often assumes the role of family leadership in addition to caregiver to the ICP. The SICP is required to adjust to the changes in the couple’s social life due to the ICP’s condition. As a result of these changes, the SICP’s well-being is often jeopardized. Studies indicate
that spouses of ICPs have shown elevated scores on somatization, obsessive compulsive, depression, anxiety, and hostility subscales when compared with a normative sample (Gill-Taylor, Lorentzen, & Blank, 1990). Given the impairments resulting from chronic pain, it can be reasoned that roles and everyday life are altered for the spouse as well as for the chronic pain sufferer. Very often the diagnosis of chronic pain comes as a shock, leaving both the diagnosed person and the spouse unprepared and unsure of how best to move forward. SICPs are often forced to adjust their roles and responsibilities within a very short period of time.

In order to obtain a better understanding of the effects of an ICP’s pain on the family unit, Snelling (1994) conducted a grounded theory study focusing particularly on the SICP. Eighteen couples were interviewed. The interviews lasted approximately one hour and were conducted in the participant’s home setting. Social relationships and coping technique were two themes that emerged. Social relationships that were affected included the marital relationship, sexual relationship, change of family roles and change of relationship with the children, friends and family. Chronic pain changed the marital partnership from one of equality to that of a dependent-to-dominant partnership. The ICP became dependent on the partner for physical assistance. Maladaptive coping techniques were identified. These included the ICP’s non-compliance with medication regimens and closely entwined and overprotective familial relationships. The consequences of maladaptive coping techniques used by the ICP were social isolation, role tension, marital conflict and reduced sexual activity (Snelling, 1994).

Fibromyalgia is a disease characterized by symptoms of pain and fatigue. Paulson, Norberg and Soderberg (2003) conducted a phenomenological investigation of
the experience of female SICPs living with male partners with fibromyalgic pain. Fourteen couples were interviewed to obtain the meanings of their experiences. One theme that emerged was "struggling to give support and comfort." In an effort to prevent the men from becoming isolated, the spouses carried out activities that they both could do together and that the men would still enjoy.

The second theme was "struggling to keep going on." The SICPs felt exhausted as they took on most of the responsibility in the family's daily life. Paulson et al. (2003) spoke of spouses having to take the main responsibility for household duties which left them feeling exhausted and "tied down."

One issue with which the SICPs had to deal with was the ICP's lack of patience with family members and the individuals outside the family unit. The participants experienced a lack of understanding and support from individuals outside the family unit. The ICPs felt that society held a prejudicial view of chronic pain so the ICPs avoided talking about it. The SICPs expressed feelings that other people were not convinced that the ICP's pain was as troublesome as it was. The SICP's perception of other people's suspiciousness led the couple to live their lives in such a way that people around them would be unaware of their difficulties. The findings indicate that the invisibility of the disability was a problem in social relationships as well as in seeking help (Paulson et al., 2003).

Finally, the SICPs described a lack of support from the health care system. Paulson, et al. (2003) concluded that the SICP should be provided the necessary knowledge and information about the illness and what to anticipate with regard to the progression of that illness. If the SICP is educated with regard to the possible
complications as a result of the illness, they will be better prepared to handle stressful situations when the ICP’s illness progresses.

Soderberg, Strand, Haapala and Lundman (2003) also studied spouses of individuals with fibromyalgia, however Soderberg et al. researched the experiences of male SICPs living with female ICPs with fibromyalgia. Five men married to women with fibromyalgia were interviewed using a narrative approach. The participants ranged in ages of 50-60 years and had been married 25-40 years. The SICP participants described the impact the ICP had on their lives. This impact included increased responsibility in the home, changing of the relationship between the couple and changing of the relationship with family and friends. Prior to the ICP’s illness, the ICPs were doing the cleaning, vacuuming, dusting, laundry and shopping. After the ICPs contracted fibromyalgia, the SICPs had to take over these household chores. Fatigue associated with fibromyalgia can be a contributing factor to the changes in roles. Soderberg et al. concluded that the ICP’s illness had a great impact on the SICP’s lives. SICP’s roles can change and therefore, should be taken into consideration in care planning.

Baanders and Heijmans (2007) investigated the burden of care and how it actually changed the lives of the caregiving partner. The SICP participants were recruited from a panel of patients with chronic diseases in a longitudinal study. In 2003 a questionnaire was sent to the partner of the participant, or in the case of no partner, to someone else close to the participant. Data from 1,093 patient-partner dyads were included in the study. Baanders and Heijmans found that the most prevailing consequences were related to personal life strain and intrinsic rewards. The findings suggest that chronic disease may not necessarily lead to extensive caregiving. The researchers found that physical...
impairments in the ICP were related to higher personal life strain and financial burden for the caregiver. A chronic disease interferes with the caregiver’s life due to the unpredictability of the course of the disease. Chronic diseases in which pain was a symptom significantly affected the partner’s social relations. Of particular interest, Baanders and Heijmians found that male partners felt fewer negative consequences as caregivers than female caregivers did.

There is a preponderance of literature on spousal caregiver burden in marriages where one partner has a chronic illness. Based on the studies cited in this literature review, it is logical to conclude that chronic pain affects both the ICP and SICP in a marriage. In many cases the SICP is the ICP’s main support system. Empirical findings indicate that the needs of the SICP are overlooked in the health care delivery system (Cano & Leonard, 2006; Paulson et al., 2003; Schwartz & Slater, 1991). The SICP’s health needs must be addressed. These studies suggest that the SICP’s well-being could be jeopardized. There may also be an inability to receive support for the SICP.

Statement of the Purpose

The purpose of this qualitative study was to explore the spouse’s experience of living with a partner who has chronic pain.

Significance to Nursing

Research indicates that SICPs can be negatively affected by their spouses chronic pain (Schneider, 2004). Negative effects of chronic pain have been found to impact the marital relationship (Cano et al., 2000; Leonard et al., 2006; Payne & Norfleet, 1986; Schwartz & Slater, 1991), family relationships (Jamison & Virts, 1990; Kemler & Furnee, 2002; Rowat & Knafl, 1985; Schwartz & Slater, 1991; Smith & Friedemann,
1999) and the roles of the SICP and ICP (Paulson et al., 2003; Schneider, 2004). The SICP is the main supporter and caregiver for the ICP. Addressing the needs of the SICP will improve the lives of both. If nurse practitioners understand the meaning of what it is like to live with a spouse with chronic pain, this will allow all the dimensions of the phenomenon to be discovered. When the dimensions are uncovered, nursing care can be specific to the spouse's needs.

Qualifications

The researcher is currently working as a nurse case manager at an occupational health clinic and has been in this position for the past seven years. She has observed first-hand ICPs and the affects of their chronic pain on the SICP. The researcher pursued a graduate education to become an adult nurse practitioner with a special interest in wellness and preventive health.
CHAPTER II

METHODS

A number of studies reviewed and identified the effects of chronic illness on family members including the spouse. Few studies were found that specifically focused on the spouse. Paulson et al. (2003) and Soderberg et al. (2003) examined spouses with fibromyalgic pain. Each of these studies concluded that the ICP’s illness had a great impact on the SICP’s lives, both physically and psychologically. Chronic pain is often an invisible condition which requires no particular medical regimen. The effects of it on family members can go unnoticed by health care providers. Empirical evidence indicates that when a spouse suffers from a chronic condition, the other spouse’s quality of life suffers as well.

The current study investigated the lived experience of the spouse of an individual with chronic pain in an attempt to provide insight into the spouse’s needs for care. The research question for this study was “What is the lived experience of spouses living with a partner who has chronic pain?” In order to answer this question, a qualitative, descriptive, phenomenological method was used. According to Creswell (1994) a qualitative study is defined as an inquiry process that involves understanding a social or human problem. The understanding is based upon building a “complex, holistic picture, formed with words, reporting detailed views of informants, and conducted in a natural setting” (p. 2). The various types of experiences examined by phenomenology include
perception, imagination, thought, emotion, desire, volition and action. The participants describe their experiences and the data are systematically and rigorously examined for common themes and categories.

Phenomenology

Burns and Grove (2005) describe phenomenology as a particular qualitative method based on the philosophy of phenomenology. Phenomenology is concerned with structures of consciousness as experienced by an individual. The goal is to uncover and convey the true meaning or essence of the experience through the use of descriptive language. Through interpretation of the texts meaning can be understood of the spouse’s lived experience. The philosophers from whom phenomenology emerged include Husserl, Kierkegaard, Heidegger, Marcel, Sartre, and Merleau-Ponty (Burns & Grove, 2005).

Two ideas central to phenomenology are lifeworld and intersubjectivity. Pettersson, Berndtsson, Appelros and Ahlstrom (2005) best defined lifeworld as the world in which persons live their daily lives. It is related to “a person’s perception of the world, as well as the world in which the persons live together with others... lifeworld is to approach the question of meaning, as it is lived by the person” (p. 160).

Intersubjectivity describes how subjective awareness and understanding can be reached in a common world by two people in an in-depth interview (Gillis & Jackson, 2002). Bracketing is a necessary condition for achieving intersubjectivity. In phenomenological research, bracketing is performed by the researcher to elicit any personal biases, thoughts, and ideas on the particular research topic that may affect the research process. Gillis and Jackson (2002) define bracketing as “a cognitive process
used by researchers to set aside one’s biases and personal perspectives about the research topic” (p. 183). Researchers use bracketing to identify areas of potential bias and bracket these beliefs, attitudes and thoughts so that they do not influence the ability to hear the meaning of the informant. Through bracketing, “the researcher is made aware of when data collection and analysis reflect personal beliefs rather than those of the participants” (Gillis & Jackson, 2002, p. 183).

According to Gillis and Jackson (2002), qualitative research in general emphasizes “careful and detailed descriptions of life experiences in an attempt to understand how the participants experience and explain their own world and give meaning to it” (p. 27). With this information, nurse practitioners can provide treatment to improve the quality of life for both the chronic pain sufferer and the spouse.

**Description of Sample and Setting**

Volunteers were recruited from two outpatient pain clinics in an urban community in the Midwest. The convenience sample included three males and one female. Physicians and staff working with the ICP provided the researcher with the names and phone numbers of potential volunteers. The researcher contacted the SICPs by telephone and invited them to participate in the research project. Interested participants were selected by the researcher for inclusion in the study if they fulfilled the following criteria: (a) 18 years of age or older, (b) spouse of an individual with chronic non-malignant pain, and (c) English speaking. Participants who agreed to take part in the study were interviewed individually. The interviews were conducted at a site and time of the participant’s choosing. Interviews ranged from 15 minutes to 1 ½ hours.
Procedures for This Study

This researcher bracketed her thoughts and beliefs through journaling before the study and throughout the data collection and analysis. This was important to facilitate the participant’s telling of their stories in their own words. By recording one’s beliefs in writing, the researcher is able to see more clearly what is real for the participants and the researcher (Gillis & Jackson, 2002).

Ethical Considerations

Approval to conduct the study was obtained from the Institutional Review Board of Marian College as well as from the Institutional Review Board of the pain clinics (Appendix A and Appendix B). Before audio-taping the interview, all participants were guaranteed confidentiality and the right to withdraw from the study at any time, without penalty. Informed consents were obtained (Appendix C). Prior to beginning the interview, the participants were also guaranteed that whether they participated or not, their spouse’s care would in no way be affected. The participants were guaranteed strict confidentiality with regard to their identities and were informed that the data would be available only to the researcher who kept it in a locked fireproof container in the researcher’s home. All confidential information, including the audiotapes and transcripts, will be destroyed two years from completion of the thesis. If a participant had displayed emotional distress during the interview, the interview would have immediately been discontinued and the participant would have been given referral information as provided by the pain clinic psychologist.
Data Collection Process

Once written and verbal consent were obtained, participants were asked the grand tour question, “Tell me what it is like to live with an individual with chronic pain?” To encourage further elaboration or to clarify information, some exploratory open-ended interview questions were asked such as “Can you give me an example of that?” Data were collected from a face-to-face in-depth audio-taped interview. No participant displayed emotional distress during the interview. In fact, all seemed comfortable and interested in the topic.

This researcher transcribed the interviews verbatim. Each transcript was analyzed after each interview in a process known as constant comparative method. Each transcript was read in its entirety in order to get an overall sense of the data. Data were analyzed by the researcher and her committee’s chair who is experienced in qualitative research. Each transcript was then read line-by-line to identify significant statements. Meanings were ascribed to each statement. When disagreement occurred about the meaning or category, the coders referred to the transcripts and achieved consensus. The meanings were grouped into categories and subcategories. A full rich description of the lived experience of spouses living with an individual with chronic pain was written from the categories and subcategories. The full description was sent to each participant for verification. Each participant was asked if the description adequately described their experiences and responses concurred with the conclusion.

Qualitative research consists of strategies to ensure trustworthiness of the findings. To assess dependability (stability and trackability of changes in the data over time), an audit trail was provided of the decision-making process during data analysis.
Gillis and Jackson (2002) defined audit trail as a clear statement of “…decisions made with documented rationales so that others reading the audit can follow the decision-making process of the researcher” (p. 299). Bracketing, intersubjectivity, member checks and deep engagement occurred with all but one participant.
CHAPTER III
FINDINGS OF THE INQUIRY

This chapter presents findings from the study of the experiences of spouses living with an individual who has chronic pain. Four spouses were interviewed. They ranged in age from 28 to 67 years; three were male and one was female. Two of the males were high school graduates and one had a PhD. The female had two masters’ degrees. The years married ranged from four years to forty-five years. One of the participants was previously married. Two of the participants had children residing in the home. One of the participants was unemployed at the time; one retired; and two worked full-time. The duration of time since the diagnosis of chronic pain of the spouse ranged from just over a year to more than eight years. These data are summarized on Table 1.

The interview with each participant began with the grand tour question, “Tell me what it is like to live with an individual with chronic pain?” The audio taped interviews were 15 minutes to 1 ½ hours in duration. The audio tape of each interview was transcribed verbatim. Data were analyzed by this researcher and the chairperson of her thesis committee. Transcripts were first read in their entirety to gain an overall sense of the data. The transcripts were then read line-by-line by this researcher and the chairperson. Significant statements were identified, meanings were ascribed to the statements, and patterns of meaning were identified. The patterns of meaning were organized into categories and subcategories. When differences arose in the coding, the
Table 1.

Demographic Characteristics of the Participants

<table>
<thead>
<tr>
<th>Gender</th>
<th>Age</th>
<th>Education</th>
<th>Years Married</th>
<th>Previous Marriage</th>
<th>Dependents</th>
<th>Employed</th>
<th>PT/FT</th>
<th>Duration of Illness</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>67</td>
<td>PhD</td>
<td>45 years</td>
<td>No</td>
<td>None</td>
<td>Retired</td>
<td>N/A</td>
<td>7-8 yrs</td>
</tr>
<tr>
<td>(Joe)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>40</td>
<td>H.S.</td>
<td>18 years</td>
<td>No</td>
<td>2 (11, 17)</td>
<td>Yes</td>
<td>F.T.</td>
<td>4-5 years</td>
</tr>
<tr>
<td>(Paul)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>28</td>
<td>H.S.</td>
<td>4 years</td>
<td>No</td>
<td>None</td>
<td>Yes</td>
<td>F.T.</td>
<td>1+ years</td>
</tr>
<tr>
<td>(Sam)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>45</td>
<td>2 Masters</td>
<td>16 years</td>
<td>Yes</td>
<td>1 (10)</td>
<td>No</td>
<td>N/A</td>
<td>7+ years</td>
</tr>
<tr>
<td>(Pam)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>
transcripts were consulted and a consensus was reached. Meanings were attached to the statements. Thoughts about observations during the interviews as well as throughout the coding were kept as memos. These memos constituted an audit trail.

A core process of Everyday Life Revolves around Pain emerged from the participants' discourse. The participants were asked to validate the findings of the study. Each was provided with the final description of Everyday Life Revolves around the ICP’s Pain and asked if it accurately portrayed their experience. In addition, each was asked to comment on anything that was not correct or was missing.

The overall process of Everyday Life Revolves around the ICP’s Pain is composed of six categories: (1) Being a Caregiver; (2) Financial Issues; (3) Help and Support; (4) Conflicting Priorities; (5) Changes in the Marriage; and (6) Changes in Social Life. Being a Caregiver was further described by two subcategories of Feelings, Thoughts, and Beliefs about being a Caregiver and Activities of Caregiving. Financial Issues consisted of themes related to changes in employment and adequacy of insurance. Help and Support describe participants’ concerns of not being sure of the type of help they needed and of being unable to seek help. Conflicting Priorities describe the constant struggle between promoting the independence of the ICP and keeping pain at a manageable level. Keeping the ICP involved in family and social activities had to be balanced by the fact those activities would be affected by the ICP’s pain and fatigue. Changes in the Marriage were further described by three subcategories which include Trying to Stay Connected, Sexual Relationship and Personality Changes in the ICP. This category included the couple’s desire to stay connected mentally and physically, knowing that the ICP’s pain would make staying connected more challenging.
The subcategory, Sexual Relationship, only affected one of the participants, however, in a significant way. The third subcategory, Personality Changes, described the changes in the ICP’s attitude and interaction with the SICP. These changes affected the marital relationship. Changes in Social Life described how chronic pain isolated both the ICP and SICP socially and how chronic pain was the center of everything the couple did and did not do. Changes in Social Life also included being judged by family members and society. These judgments lead to avoiding family and friends and social isolation.

Categories and subcategories of the Core Process of Everyday Life Revolves around Pain are summarized on Table 2.

Being a Caregiver

*Feelings, Thoughts, and Beliefs about Being a Caregiver*

The role of caregiver varied among the participants. The ICPs were able to perform self-care activities of daily living, such as feeding themselves, bathing, dressing and grooming. The SICP participants noted, however, that the ICPs were easily fatigued. Pain limited the ICP’s ability to work outside the home. Tasks of the SICPs included driving the ICPs to appointments, taking over the ICP’s normal household chores, managing the finances, grocery shopping, monitoring the ICP’s pain medication, and caring for the children. Joe and Paul seemed to take on the tasks of caregiving without difficulty and without negative feelings toward caregiving. Sam and Pam, however, mentioned how the change from being a marital partner to that of being a caregiver was difficult and frustrating for them. All the participants mentioned that, at times, caregiving was stressful.
<table>
<thead>
<tr>
<th>Categories</th>
<th>Subcategories</th>
<th>Examples</th>
</tr>
</thead>
</table>
| **Being a Caregiver**     | Feelings, Thoughts and Beliefs About Being a Caregiver | "We both know that sometime or another we both are gonna need to be taken care of."
|                           |                                                    | "You can see she’s in pain but she keeps going."
|                           | Activities of Caregiving                           | "I’ll run down and do it [laundry] ... take it out of the washer, put it into the dryer, that type of stuff...Where otherwise, she’d rather do it."
|                           |                                                    | “...I’ve just plain pretty much taken over doing the stuff that needs to be done around the household.”                                                                                                                                                  |
| **Financial Issues**      | Lost Income                                        | "It is really hard on our budget because right now she has no job and I only make $7.50 an hour.”                                                                                                                                                     |
|                           | Insurance                                          | "My wife and I have probably just about the best insurance available. That was one of the things when I retired.”                                                                                                                                     |
| **Help and Support**      | Hard to know what help you need                    | "I don’t know that I need help particularly, I mean I can do it [household chores]."
|                           |                                                    | "I don’t know that I need any support group; maybe I do but (laugh)...I don’t know if they have such a thing for husbands.”                                                                                                                              |
|                           | Hard to get the help you need                      | "Maybe I need to be a little more vulnerable and ask directly for help.”                                                                                                                                                                                |
|                           |                                                    | "People do not understand... one other thing with chronic pain...for the most part it is invisible.”                                                                                                                                               |
| Conflicting Priorities | Dependence/Independence of the ICP | "It [the pain level] is the center of everything that we do and everything that we don't do."
| | | "What bothers me the most is she doesn't know when to say, O.K. I did enough."
| | Family Roles | "He (ICP) comes to maybe 25 percent of our daughter's little things at school...she's learned a lot of things like if she pours the love on with him, he might go."
| Changes In The Marriage | Trying to Stay Connected | "We gradually done less and less as a couple ..."
| | | "My life as a husband got more stressful."
| | Sexual Relationship Changes | "We do as much as we can together."
| | | "She broke her wrist and couldn't stand having me in bed because she might bang her hand against me. So I started sleeping in the other bed and that stayed."
| | Personality Changes in the ICP | "I want to be sexual; I don't want to wipe his butt."
| | | "When she is having a good day, she's in, of course, a good mood, but when she is having a bad day, she's not in such a good mood."
| | | "There are days when...she barks at me and gets so angry...not feeling so good today?"
<table>
<thead>
<tr>
<th>Changes in Social Life</th>
<th>Social Isolation</th>
<th>Being Judged By Others</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>&quot;Over the past few years she has become more and more of a recluse... In the 1970s we used to square dance together... Now her social life boils down to mostly going to church.&quot;</td>
<td>&quot;Chronic pain, it's the center of everything that we do and we don't do.&quot;</td>
</tr>
<tr>
<td></td>
<td></td>
<td>&quot;He (ICP) kind of gets the reputation of being a grumpy old man or not sociable.&quot;</td>
</tr>
</tbody>
</table>
Joe stated, “Primarily I’ve become a caregiver.” When his wife underwent her first knee replacement, Joe felt he was “pretty much just a live-in nurse.” He explained that her condition gradually worsened. Joe hoped that his spouse’s chronic pain would improve so that she would be more motivated to do things like gardening or driving again. Joe expressed this hope as well as his acceptance when he said, “I started thinking, well, maybe if I let things really go bad then she would be so motivated to get out there [gardening].” Joe mentioned how he would like her to lose weight so that she would be able to do more. Joe’s spouse recently attended a wedding which raised his hope that “she’ll start doing a little more again. But, you live with what you got.”

Paul voiced a feeling of empathy for his spouse’s pain. He had recently been involved in a motor vehicle accident and had sustained an injury which resulted in acute pain. His experience was reflected in his statement, “We both know that sometime or another we both are going to need to be taken care of.” Paul stated his spouse’s pain came on gradually and that “living with an individual with chronic pain varies from day-to-day.” The amount of caregiving he provided his spouse depended on how she felt on any given day.

Sam described the unpredictable nature of his wife’s condition and his frustration. He stated, “I’m trying to keep going. I don’t know how the future’s going to land because every time I think I’ve got it figured out it [the future] throws me a curve ball. I try not to look too far into the future.” He mentioned that he was frustrated because, “when we think we got her good and healthy, something else crops up.”

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Pam was struggling with the demands of being a caregiver. Pam’s situation was very different from the other participants’ situations. The ICP was her second husband. Over the past several years, Pam’s husband also developed pulmonary co-morbid health problems which resulted in frequent hospitalizations. Pam expressed her concern about the number of narcotics her spouse was taking as, “he’s been on narcotics of one type or another off and on now for seven years.” She believed that her spouse’s respiratory depression, weight gain and depression all contributed to her husband’s worsening health. Pam was the most expressive of all the participants. Pam did not want to be a caregiver to her husband. She stressed several times during the interview that she, “is trying to stay a wife and not a caregiver.” There was an incident in which Pam’s husband was being discharged from a hospital for a diagnosis other than chronic pain. At that time the ICP would require twenty-four hour care. Pam said she could see that her husband (ICP) would require a lot of care and did not wish to provide it. She informed the staff at the time of discharge that she would be unable to provide care for him. The staff wanted to know what the obstacles were. Pam felt that providing twenty-four hour care seven days a week would “be the death of my marriage.” She did not feel she would be able to “stay sane” if her spouse required such care. Pam described numerous ways in which her life had been affected by her husband’s condition. Pam said, “It is more awful for him, but it’s pretty awful for me too.” She mentioned, “Since all this happened, I have put on a huge amount of weight...I’m very ashamed about that.”
Another way that Pam’s spouse’s chronic pain has affected her is that her faith has changed:

My faith has changed in how I believe in God and my belief system has changed, and not necessarily for the better. I no longer believe things happen for a reason or God won’t give you more than you can handle.

Activities of Caregiving

All four of the participants said that their spouse’s chronic pain was more of a gradual process rather than a sudden event. Gradually, the SICPs noticed that they had to assume more household duties. Joe said:

I’ve just plain pretty much taken over doing the stuff that needs to be done around the household...I’m always the transportation...It’s been two years now that she quit driving...I do most of what needs to be done around here; things like dishes, laundry, cooking, gardening and care of the vehicles...that’s kind of my day.

Joe described in detail his caregiving duties. These included how he prepared all the meals and took them to his wife. He also took her other items like her medications and the newspaper. Paul described how the ICP tried to do household duties herself. Although he knows this was how she felt, Paul remodeled the home and installed appliances that could reduce the amount of physical activity the ICP was doing. Both he and the children were doing more housework, including the vacuuming and yard work, which previously the ICP had done. Sam described having to take over most of the household duties as his wife was in too much pain. He stated:

I help clean up and take care of the dishes...Vacuuming is solely my responsibility...She can walk around for a little bit, but as far as simple things like doing dishes or doing the laundry, bending over to tie her shoes, you can see she’s in a lot of pain.

Pam not only continued to do the housekeeping, her spouse’s chronic pain was so severe that she also had to assume responsibility for home maintenance. Pam said she was
fortunate that her husband was still able to drive and could do the grocery shopping. The two older men differed from the woman in the sample. The men began their stories with a detailed account of the tasks they took over from their ailing wives.

Financial Issues

While all of the participants mentioned financial changes resulting from the chronic pain of the spouse, little discourse was devoted to this. Three of the four participants reported little concern over finances. Joe stated, “I have probably about the best insurance available.” Paul reported having a difficult time at first, but “now I’ve got fairly decent insurance at work.” Pam mentioned, “Financially we are one of the luckier ones.” She explained her spouse was approved by SSDI the first time he applied. She was not concerned about finances “because I will secure a job that will fill our financial gap.” Pam later mentioned, though, that her husband was unable to work in the past five years and that they have supplemented their monthly income from savings. “That [saved money] is almost depleted and leaves him financially fearful about our future as he watches our resources dwindle...He is a man and can’t provide for his family.” She reminisced about a time when the couple would buy new cars and furniture without hesitation, but now had to drive older vehicles. Pam talked about as much loss of social status as she did about actual income. She stated that her parents and her spouse’s brothers would help them financially if they needed help. The youngest participant, Sam, began his story with much concern about the couple’s financial losses that resulted from his wife’s disability. Unlike the other three participants, Sam reported a great deal of anguish and hardship as a result of the ICP’s condition and her inability to earn an income.
Sam stated:

It is really hard on our budget because right now she has no job and I only make $7.50 an hour...We can’t get disability because their fighting us tooth and nail because they say she can still work...I stand on the edge of making enough money that a lot of programs don’t cover and not having any actual insurance through where I work so I am kind of between a rock and a hard place.

Help and Support

*Hard to Know What Help You Need*

The SICPs described chronic pain as a difficult condition for obtaining help. The participants mentioned that it was hard to know what type of help they needed. Joe and Paul were not sure if they needed help at all. Joe and Pam spoke of help in terms of assistance with household chores. Joe said that he hired a group of cleaning ladies that came to the home every two weeks to clean. Also, when his daughter visited with his grandchildren, she would help him. Paul mentioned that his spouse focused more on helping others than getting help for herself. He stated, “She tends to want to help other people more than worry about herself and sometimes it [the pain] gets the best of her.” Paul has told the ICP that he is alright with her helping others, but that she needs to know her limits such as realizing, “Okay, I can either do it all today or I can do a little today and tomorrow.” Sam, who was worried about finances, spoke of help in terms of financial assistance. Sam’s spouse had tried to obtain financial help. The ICP applied for disability, however, she was denied. Sam said the pain clinic assisted them with their medical bills at the time while a brother of the ICP had helped them by paying for expensive medication. Pam was the only participant who mentioned the need for social support.
Hard to Get the Help You Need

All the participants mentioned that being able to get help was related to the "invisibility" of chronic pain. Pam specifically commented, "Chronic pain, for the most part, is invisible. Sometimes I wish he (ICP) was in a wheelchair or something." Pam also mentioned her desire for help, but that she was not receiving it. While out of town in an unfamiliar area, Pam said:

Nobody offered to drive me back to the hotel. Nobody called to check to see if I was okay in this seedy hotel that we had picked out...I come off as being fairly independent...Maybe I need to be a little more vulnerable and ask directly for help, but it's hard when it's never going to end.

Pam believed that a lot of people did not understand the difficulties of their situation. She said that if they were invited to a social event and they attended, people at the event would say:

Wow, he's doing good. But what they don't know is that he spent all day resting so that he could go to the event and maybe he'll be up half the night because that [the event] was hard on him. People do not understand that pain can be invisible.

Pam felt burdened by others' advice about what she needed to do for her husband. Pam stated, "I understand it's hard to accept what his quality of life is for people who love him or care for us or me, but I can't change that for them and I'm kind of tired of holding their hands."

Conflicting Priorities

Dependence/Independence of the ICP

The SICP participants described a number of conflicting priorities in their lives with the ICP. If the ICP engaged in physical activity or attended social events, then the ICP would most likely experience pain. If the priority was for the ICP to be pain-free, then the ICP would most likely be unable to engage in the household or social activities.
All of the participants described the constant struggle between promoting the independence of the ICP and keeping pain related to those activities at a manageable level. The participants tried to keep the ICP involved in family and social activities, however, most activities were affected by the ICP’s pain and fatigue. Paul spoke proudly of his wife’s desire to be independent. He mentioned “she is into knitting and crocheting...it keeps her busy and gives her something to do to keep her sane.” Paul described how the ICP tried to do household duties herself because she would like to remain independent. Paul stated he struggled with his wife’s wanting to do activities because she says “it is her job.” Paul described a conversation he had with her:

It’s not your job; it’s just a job that’s gotta be done. She still tries to do everything that she can and would rather do it herself. I understand that’s how you feel but there’s certain stuff that you can’t do and it’s just gonna make you feel worse and hurt worse; why not let us help.

And “she knows that there are certain things that she can’t do and there are certain things she can do, but then there’s always some that didn’t hurt it this time, but next time it does.” Pam reported numerous conflicting priorities in her life. She described the conflicts between activities that she wished to do and how she had to weigh them against her husband’s condition. Pam said:

I might be mad because we’re [SICP and ICP] home alone, let’s rent a movie or get a bite to eat. See he can’t do both things. He can’t go visit his friend for an hour and sit and watch a movie with me...I’m his only window to the outside world and that really sucks because I can just tell when he’s having a bad couple of months and he can’t get out as much as he tries to, and it’s like he loses grasp.

Sam mentioned that his wife liked to walk to the neighbor’s house. “You can see she’s in pain for it but she keeps going...she tolerates it, but you can see it takes a lot out of her.” While Joe did not specifically mention any conflicting priorities, he did mention
issues with regard to his wife’s dependence on him. Due to her chronic pain, she feared being alone and he rarely left her alone. She stopped driving and he transported her to appointments. His wife’s dependence interfered with his own independence.

*Family Roles*

Chronic pain affected the relationship the ICPs had with their children. There were two participants who had children residing in the home. Paul mentioned “we used to go to the carnivals and stuff like that a lot and now she can’t go on most of the rides we used to because it’s bouncing around too much... We still go and watch the kids.” Paul described how his wife wanted to walk their son to school and she said, “I feel fine but there are times in the morning where I’ll walk him to school and get halfway back home and can’t stand the pain.” He knew that having chronic pain bothered her because she enjoyed being able to walk her son to school and do various activities with him. Pam expressed the desire for her spouse to be more involved with his daughter. In frustration she mentioned:

He [ICP] comes to maybe 25 percent of our daughter’s... little things at school... Also, it will make a difference if I can keep the house somewhat quiet and he can fall asleep, as we might get an hour of daddy time in the evening... It’s in my best interest or my daughter’s best interest if we can help daddy fall asleep during the day.

*Changes in the Marriage*

*Trying to Stay Connected*

The participants described numerous changes in their marriage with a particular interest in the desire to stay connected as a couple. Joe stated, “We gradually done less and less as a couple.” He and his spouse used to enjoy dining out. Unfortunately, over the past couple of years she would rarely leave the home. Most of the time the couple spent together was when he took the ICP to her appointments and they attended church.
together. Paul said that his wife’s chronic pain had brought the couple closer together “because you don’t want to see them in pain.” He went on to explain that his injury in an automobile accident resulted in their spending more time together. His wife had become used to having him at home more. He related what she said to him, “When you finally go back to work, I’m not going to be ready for that because now I’m used to you being here all the time and we do more things together.” Paul could see how living with an individual with chronic pain could be very difficult for some people, but overall he felt “It has probably brought us closer together.” While they were not able to enjoy some of the activities that they once enjoyed prior to the chronic pain, Paul stated, “We still try to go for a walk almost every day. We go to movies or watch them with our boys. Some physical things she can’t do anymore.”

Sam described how his marriage had changed. He stated:

We used to camp a lot. We used to walk around the block and take the dogs for walks at night. She [ICP] used to help me work out on the car and she can’t even do that anymore...I help clean up...take care of the dishes. We work together to do dishes. We’ll work together to do the laundry. Vacuuming is solely my responsibility. I’m the only person, apparently, who can operate the Kirby.

Pam felt her relationship was probably closer to her ICP husband as a result of the caregiving role, but in ways “she wouldn’t wish upon anyone.” Pam said, “I mean it’s almost like we’ve been at war together.” She reported having a strong marital relationship prior to her spouse’s chronic pain, which she perceived as a “good foundation.” Although Pam felt the relationship with her husband was closer than prior to her husband’s chronic pain, Pam described her loss resulting from her husband’s chronic pain:
A hard thing for me about being a spouse to a person with chronic pain is that there is no end in sight to grieving the on-going loss of my husband’s health and what it means to our marriage. Most people don’t experience that until they are much older and then, their friends are going through the same thing.

Sexual Relationship

Of the four SICP participants, only one talked openly and explicitly about a change in the couple’s sexual relationship as a result of chronic pain. Pam spent a great deal of time describing how her sexual needs have changed since her husband’s chronic pain began. Pam stated:

That’s [loss of sexual activity] been really sad because our sexual life has gone from good, or what was good for us, to very infrequent... We are very intimate in other ways... What I am trying to say is that we’ll try and have like tactile and... so, it’s something we talk about openly.

Pam’s husband still had the desire to be intimate, however, he was unable to fulfill her needs. She stated:

There is no spontaneity. That’s been gone for years because he really has to take care of himself, psych him up... and I mean psych him up so that he’s not in so much pain. In his mind he wants to [have sex].

Pam seemed somewhat conflicted about the change in sexual intimacy. She said she “would not change the emotional or tactile intimacy that they had,” but then went on to state:

He doesn’t like to be touched... So he’ll usually rub my back and give me... So, I wouldn’t trade all that love and everything for like a wild sex life at all, but I certainly miss it a lot.

Pam described her disappointment when her spouse planned a time that they could be intimate but could not follow through with his plan. She said:

He might say, well (daughter’s name) is going to be at a sleep over tonight, we can have a nice time, or make love or whatever, and then... I can see it in his eyes, I can hear it in his voice and I have asked him, and this has been a perfect conflict... Please don’t say that anymore. It really makes me feel bad. And I
know that it's really not about me, but I know that 99 to 100 times when he says that, I'm just going to be disappointed, so I'd rather he didn't say it.

Pam desired to remain “a wife and not a caregiver.” She stressed, “I want to be sexual, I don’t want to wipe his butt.” While Joe did not go into detail with regard to his sexual relationship, he did share that “when she [ICP] broke her wrist she couldn’t stand to have me in bed because she might bang her hand against me. So I started sleeping in the other bed and that stayed.”

**Personality Changes in the ICP**

All the participants mentioned something with regard to a change in the ICP’s personality since being diagnosed with chronic pain. While the personality changes could be dramatic, sometimes the ICP’s personality change occurred only during severe episodes of pain. Joe mentioned that his wife was more unsocial and described her as “being a recluse,” when the pain was bad.

Paul stated:

There are times where she’s on edge and it gets hard on the kids and me…The kids are like, I didn’t even do nothing and mom’s mad at me…And it’s like she’s not mad at you, she is just in a lot of pain; leave her alone, come and ask me, and I’ll take care of it.

There were times that Paul would rub his wife’s back and even that would bother her. Paul said it gets to him too because he is thinking “I’m just trying to help and now you’re mad at me because I made it worse and I wasn’t trying to make it worse.” Sam mentioned that his wife’s chronic pain had strained his relationship with her. “A lot of it stems from the money and some stems from…the pain which she doesn’t know how to express it and she doesn’t know how to deal with it right now.” He said that chronic pain has affected her mood. “It’s difficult. When she is having a good day, she’s in, of course
a good mood. But when she is having a bad day, she’s not in a good mood.”

Pam states “when he’s [ICP] really depressed, I find that harder to live with than his pain.” She described her spouse as someone who:

I could tell him anything that I wanted to remember and I didn’t have to write it down. When he got out [hospitalization after an illness] he couldn’t even read a book. I mean he’s sort of like the garbage man who reads Tolstoy. This man used to be a professor.

There were times that Pam felt her spouse was rude, but she knew it was “because he could hardly get out of bed.”

Changes in Social Life

Social Isolation

Significant changes in the social relationship of the SICP occurred due to constraints imposed by chronic pain in the spouse. Three of the four participants lived in some degree of social isolation. In one case, however, the SICP developed his own interests separate from those of his wife. Joe described how:

Over the past few years she [ICP] has become more and more of a recluse…In the 1970s we used to square dance together…Now her social live boils down to mostly going to church.

Although his spouse was not involved in many social activities, Joe was able to pursue his own social activities without his spouse. Joe described his activities:

Well my social life tends to consist of a mixture of church…I work with the Knights of Columbus and a variety of volunteer groups a little bit. There’s something called a collaboration group that meets once a month during the regular school. I’ve been going on occasion to the retired faculty dinners which are once a month during school year. I’ve been very active in the County Tobacco-Free Coalition.
Paul described how, prior to his wife's diagnosis of chronic pain, the family used to do many activities together. The family's social life has decreased as a result of his wife's chronic pain. Paul stated:

It's hard at times because it [chronic pain] affects stuff that we want to do. You know, if we want to do something as a family, there's times we cannot... We used to, a lot of times, go for a ride or just go do something... Well, a lot of times it's hard for her just to get in the car... She doesn't drive anymore unless she absolutely has to because it's that hard for her to get in and out of her car.

Sam also described the couple's social life as changed since his wife was diagnosed with chronic pain. "We have a couple friends each but as far as us being together with a particular group of people, not really."

Pam described the effects of chronic pain as:

It's the center of everything that we do and we don't do. We might have gone to one movie together where he'll just tough it out because he does get pleasure from being out. The pain affects our life because we could be doing more. We used to play cards all the time with friends... go to cultural events, social things, concerts and he won't do anything like that... Going to the doctor is almost like a social event for him because he doesn't do anything else. He carries a real expensive rocker lawn chair in each of our cars. When we go somewhere, he'll take that right out into someone's house and use it to sit on.

Pam further stated that her husband is in so much pain that "he probably wouldn't leave his bedroom if he didn't have the pain pills." With regard to her social life Pam stated:

What's really weird is it's like I'm a single married person. You know if I were to be widowed or divorced, I most likely would develop my life as a single person. I would probably have some other single woman friends and I would... I'm not exactly sure what else I would do, but I would make my way a little different than I do now. But I do have a husband and it just... I'm in this like... society hasn't figured out what to do with people like me.
Being Judged by Others

Pam felt she was being judged by family members. Family members of the ICP who worked in the medical field criticized her for attending family functions and leaving the ICP at home alone. Pam stated:

Somehow he is the identified patient in the family and they feel free to bitch to me about what is happening with him...I feel very alone about it. It would seem to me that when you have a family member who is down that you rally around the person. And that did happen in the beginning...But with chronic pain, that drops away because people cannot sustain that for years and years...But I do not have a choice...My choice is to leave him, which I’m not going to do.

Pam commented about true friendships:

If you’re lucky, you’ll find new friends that will accept you as you are now, but it’s too hard for the old ones to make that transition because we don’t do the things we used to do.

Essence of the Lived Experience:

Everyday Life Revolves Around Pain

The core process revolved around the extent to which pain affected everyday life. Being a caregiver involved activity or role changes which included the SICP’s having increased household duties that were once the ICP’s responsibility. Feelings about having to be a caregiver were both positive for the ICP (empathy) and negative (bitterness). Financial issues were related to changes in the ICP’s employment which resulted in a loss of income for the couple. Financial issues were also dependent on whether or not the ICP had medical insurance. Help and support were issues because the SICP, in most cases, did not know what help they needed, nor did they know how to get the help they needed. The SICPs expressed difficulty getting help which they related to the “invisibility” of chronic pain. This invisibility made it difficult for others to
understand the needs of the couple. Conflicting priorities involved the constant struggle between the SICP's attempt to promote the ICP's independence without creating an increase in the ICP's pain. Balancing the ICP's independence within a manageable pain level helped to keep the ICP involved in family and social activities. Changes in the marriage involved a change in sexual intimacy, personality changes in the ICP, and the couple's struggle to stay connected. The ICPs and SICPs often altered their lifestyle so that the couple could spend more time together. Some of the new activities together included cooking, attending each other's medical appointments, or just staying home. Changes in social life described how chronic pain isolated both the ICP and SICP socially. Chronic pain was the center of everything the couple did and did not do. The SICPs also believed that family members and society were judging them negatively. The SICPs felt that the ICP's limited mobility, increased pain, the loss of social status from being on disability, and a reliance on the SICP for transportation were contributory factors to the couple's social isolation.
CHAPTER IV
DISCUSSION OF THE FINDINGS
AND REVIEW OF LITERATURE

This study examined the lived experience of a spouse living with a partner with chronic pain. Interviews of the spouses were used to capture the experiences of the SICPs to uncover and convey the true meaning or essence of the experience.

In the current study, three of the four participants were male. Two of the three males described their caregiver roles neutrally as though stating facts. Those two males were married considerably longer than the third male. The one female in the study had a very difficult time adjusting to the role of caregiver. One could conclude that gender and length of marriage may be related to caregiver role adjustment. This finding is consistent with Baanders and Heijmans (2007) who investigated burden of care and how it actually changed the lives of the caregiving partner. Baanders and Heijmans found that physical impairments in the ICP were related to higher personal life strain and financial burden for the caregiver. Baanders and Heijmans also found that male partners felt fewer negative consequences as caregivers than female caregivers did. This suggests that the experience may be different for female caregivers.

Financial issues were one of the themes that emerged in the discourse of these participants. Of the four participants, only one mentioned the extreme hardship he was undergoing as a result of the ICP's loss of employment. The participant had been
married only three years when his wife was diagnosed with chronic pain. The ICP’s pain was so severe that she had been unable to work. The treating physician placed very sedentary work restrictions on the ICP due to her pain. As the ICP was not considered “totally disabled” from all employment, this disqualified the ICP for disability benefits. Having significant restrictions placed on the ICP made obtaining employment more difficult. Any suitable employer would have to have been willing to be flexible to accommodate her restrictions. The couple did not qualify for medical assistance or many other benefits as the SICP made too much money based on state standards. This is consistent with Baaanders and Heijmans (2007) who found that when both individuals were able to remain employed, the caregiver was protected from increased personal life strain and financial burden. There was a significant risk of personal life strain and financial burden if the chronically ill individual was younger, as they are more likely to have a major loss of income and loss of family savings.

Discourse about conflicting priorities was prominent for all participants. The participants tried to keep the ICP involved in family and social activities, however, most activities were affected by the ICP’s pain and fatigue. Of the four participants, only one of the ICPs was able to remain somewhat independent. While Paul’s wife was unable to work due to her chronic pain, she insisted on continuing with the household chores even though it increased her pain. Based on the findings of McCracken et al. (2007), this is an acceptance and control-oriented coping technique which required the ICP to acknowledge feelings of anxiety, fear, anger and grief and to move on with her life despite the pain.

The fifth major theme identified is Changes in the Marriage. The participants reported changes in their sexual relationship, personality changes in the ICP and a desire
to stay connected as a couple. Only one of the four participants reflected a change in the sexual relationship as a result of chronic pain. While Pam described a loss of the sexual relationship, she did say that the couple found other ways to be intimate. Literature with regard to changes in marital intimacy was found to be associated with decreased quality of life (Cano & Leonard, 2006; Leonard et al., 2006; Payne & Norfleet, 1986; Schwartz & Slater, 1991). In this study, three participants described feeling closer to their spouses in other ways. The participant was female. Females may be more likely to describe intimate details than males. The one participant seemed to have a decreased quality of life as a result of loss of intimacy. One explanation for this was described by Feinauer and Steele (1992). Feinauer and Steel found that decreased sexual intimacy resulted in increased emotional intimacy, which the authors felt may be highly desirable by both the ICP and SICP.

One of the most difficult changes in the marriage that the SICPs experienced was the personality changes of the ICP. This increased irritability affected the ICP’s parenting and family roles. Paul and Pam mentioned how the personality change frustrated them and their children. Paul tried to console his children by explaining that the ICP was not directing her anger at them, but rather she was just in a lot of pain. Paul and Pam both tried to control the environment by keeping the children away from the ICP when the ICP was in pain. This finding is consistent with Bral, Shaughnessy and Eisenman (2002) who found that children often avoid parents in chronic pain as they are no longer the loving, tender and nurturing individuals they once were. Bral et al. concluded that many ICPs are less able or unable to tolerate noise or the presence of children.
The last major theme identified was Changes in Social Life. Since being diagnosed with chronic pain, the couple’s social life together was significantly reduced or was non-existent. The SICP’s noted changes in their social lives which included social isolation. The social isolation occurred usually as a result of the ICP’s diminished activity level and as a result of a lack of understanding by others of their hardship. This is consistent with research by Holloway, Sofaer-Bennett and Walker (2007) and Paulson et al. (2003). Both Holloway et al. and Paulson et al. found that ICPs were stigmatized by society. Stigmatization or fear of stigmatization emerged as a reason for the ICP’s loss of self, which lead to social isolation. Holloway et al. concluded that an important cause of their ICP’s suffering was due to the stigma of invisible and discredited illness which leads to feelings of shame. In the Paulson et al. study, the SICPs expressed feelings that other people were not convinced that the ICP’s pain was as troublesome as it was. The SICPs stated that, just because the ICPs looked healthy, did not mean they were not in pain. The SICP’s perception of other people’s suspiciousness led the couple to live their lives in such a way that people around them would be unaware of their difficulties. The couples avoided burdening other people with their problems because they did not think other people would be able to understand their situations.

Help and Support were new findings that emerged from this study. Not knowing what help the SICP’s needed or how to get the help they needed was expressed among all four participants. Joe did not know if he particularly needed help, however he did hire a cleaning service to assist with the housework. He also mentioned that he did not know whether he needed to participate in a support group. Even if Joe did need a support group, he said that he was unaware as to whether support groups were available for male
spouses of ICPs. The current study uncovered the SICP’s need for help and support as an area with little or no research documentation.

Implications for Nursing Practice

Several factors can alter a chronic pain sufferer’s treatment outcome and also adversely affect the SICP’s health. Based on the findings in this study, several factors must be addressed by healthcare providers. Advanced nurse practitioners should discuss the SICP’s feelings, thoughts and beliefs of being a caregiver. Based on the findings from Feinauer and Steele (1992), if the values, beliefs and feelings are similar to the SICPs, the nurse practitioner should determine whether it accounts for more marital satisfaction and adjustment rather than stressors of the relationship (depression, sexual limitations). It would also be helpful for the provider to determine whether the SICP is able to keep up with the demands of being a caregiver and whether the SICP’s feelings of being a caregiver are positive or negative. Secondly, it would be helpful to know whether the couple is having financial difficulty. These would include changes in employment and whether the ICP has medical insurance. Thirdly, the healthcare provider should determine if the ICP is independent in most activities or if the ICP is dependent on the SICP for household and social activities.

The findings of this study indicate that SICPs are not sure what type of help they need or how to obtain the help. Healthcare providers can assist the SICPs by identifying their explicit needs. Treatment can be specifically directed toward those needs. A Community Resource Guide should be composed and available. Examples of such resources would include respite care, Unemployment and Social Security information,
Job Service, Employee Assistance Programs (EAP), support groups, volunteer groups, marriage counselors and transportation services.

Of particular importance is the need for advanced nurse practitioners to assist the SICP and ICP to better understand each other, encourage autonomy and express feelings and needs more directly. Wright and Aquilino (1998) suggested one way to do this is to provide a program with intervention strategies that will increase the well-being of the caregiver and enhance the exchange of emotional support between the SICP and ICP. Schneider (2004) suggests that the SICP and ICP seek balance through improved communication. It is also important that the SICP find outside support for themselves as well as participate in enjoyable activities with the ICP.

Strengths and Limitations of This Study

A strength of this study was the ease with which the participants told their stories of living with an ICP. Deep engagement occurred with three of the four interviewees. The participant who chose to be interviewed in the clinic (Sam) needed cues to elaborate upon his discourse. The three participants who were interviewed in their homes were more open and willing to discuss their feelings than the one individual interviewed in the clinic setting. The interviews in the participant’s homes averaged one hour in duration. The interview in the clinic setting was 15 minutes in length.

The sample was one of convenience and represented SICPs whose spouses were participating in a pain program. The participants all had what they considered to be good insurance with the exception of Sam who was uninsured.

Due to time constraints, data saturation was not achieved. This was particularly evident in the new data revealed in the one female’s discourse.
Recommendations for Further Study

Gender has been recognized in research as an important factor in marital adjustment (Paulsen et al., 2003; Soderberg et al., 2003). The current study involved only one female participant. The information obtained suggested that the experience of a female SICP may be quite different from that of a male SICP. One male SICP knew of the support group offered through the pain clinic but thought it was not for men. Future research could investigate the perceptions of both the ICP and SICP regarding effects of chronic pain on the marriage.

The current study included participants who were 18 years of age or older, a spouse of an individual with chronic non-malignant pain and English speaking. The current study was diverse with regard to variation in age and education, however, there were only four participants. Future investigators may wish to actively recruit a larger and more ethnically diverse sample. Some potentially important variables that may be considered in future research could include gender, ethnicity, age, years married, income, health insurance and access to care.

Most participants in this study believed their marriages to be good. The researcher had access to people who had some level of support to deal with their chronic pain as opposed to those who were totally isolated. Future investigators may wish to investigate the experiences of SICP and ICP individuals who are actively involved in marriage counseling.

This study identified a lack of research with regard to help and support for SICPs. SICPs are not sure what type of help they need or how to obtain the help. To provide evidence based care, further research is necessary.
References


APPENDIX A

INTERNAL REVIEW BOARD APPROVAL LETTER FROM MARIAN COLLEGE
Date: April 25, 2007

Dear Ms. Lisa Kasperek

The Institutional Review Board has approved your research project titled:

Living with a Spouse with Chronic Non-Malignant Pain

This approval is for the period of one year from the date of this notification. If you are not finished with your project in this time period, please notify the committee of your progress and request an extension.

You may proceed.

Sincerely,

James C. McCann, Ph.D., CANP, RN, IRB Chair or Divisional Representative
Dean, School of Nursing

Revised 8/15/02
APPENDIX B

INTERNAL REVIEW BOARD APPROVAL LETTER FROM AFFINITY HEALTH
June 13, 2007

Lisa M. Kasperek
525 W. Rolling Meadows Lane
Appleton, WI 54913

Dear Lisa,

On behalf of the Affinity Health System Institutional Review Board, I am pleased to inform you that your research proposal, "Living with a Spouse with Chronic Non-Malignant Pain" was approved at our meeting on May 24, 2007 pending receipt of your revised consent form giving information to study participants on how they can contact Affinity Health System if they have questions about their rights as a research subject. Your revised form was reviewed and approved as of June 11, 2007.

Enclosed is a signed copy of the AHS Request to Conduct Research Document for your files.

The IRB requests that you complete and submit a Progress Report for Continuing Review on an annual basis or at the end of your study, whichever occurs first. This form will be sent to you via e-mail.

In addition, if there are any significant changes in your submitted protocol, you will need to notify the Affinity IRB in writing with the proposed changes before implementing them.

If you have any questions, feel free to contact me at 920-236-1909 or e-mail khenke@affinityhealth.org.

Sincerely,

INSTITUTIONAL REVIEW BOARD

[Signature]

Kristen Henke, PhD
Affinity Health System
IRB Chairperson

Enclosure

cc: Wayne Winistorfer, Director Rehab Services, Affinity Health System
    Trevor Nebel, Manager Rehab Services, St. Elizabeth Hospital
Dear Sir or Ma'am,

My name is Lisa Kasperek and I am a registered nurse working as a case manager in Wisconsin. I am currently attending Marian College of Fond du Lac, where I am pursuing my master’s degree as an Adult Nurse Practitioner. You are being asked to participate in this study because you are the spouse of an individual with chronic pain. Your participation in this study is important so that nurses and other caregivers understand your needs. To conduct this study, approval has been obtained through Marian College Institutional Review Board as well as Affinity Health System.

If you chose to participate, you will be interviewed by the researcher at a time and place convenient to you. This interview will be tape recorded and may last up to one hour and a half. No names will be used in the study and only aggregate data will be reported. You will be asked to verify the researcher’s findings. This study does not involve any risk or discomfort other than the time to participate in the interview. You may withdraw from this study at anytime without any penalty to you. Your spouse’s medical care will not be affected if you do or do not participate.

The results of this study will be shared with you upon your request. This study may be of benefit to you as well as to other spouses living with a partner with chronic pain by allowing you to talk about your personal experience. There is much to be learned in regard to understanding the experience of living with persistent pain, particularly from the spouse’s perception. The information obtained may provide practitioners with strategies to improve the quality of life for both the chronic pain sufferer as well as their
spouse. The data will be available only to the researcher and kept in a locked fireproof container in the researcher’s home.

If you decide to participate in the research study, please sign the consent form. If you have any questions or concerns about this research, please contact:

Barbara Ponder, MS, RN, CCNS  
Chair Thesis Committee  
45 S. National Avenue  
Fond du Lac, WI 54935  
Phone (920) 923-8084

J. Randall Koetting, PhD  
Institutional Review Board Chair  
45 S. National Avenue  
Fond du Lac, WI 54935  
Phone (920) 923-8136

If you have any questions about your rights as a research subject at Affinity Health System, please contact Affinity Health System’s IRB Chairperson:

Robin Price, MD  
Affinity Medical Group – Family Practice  
W6981 Park View Drive  
Greenville, WI 54942  
920-882-2457

Signature of Participant ___________________________  Date ________________

Signature of Investigator ___________________________  Date ________________
APPENDIX D

DEMOGRAPHIC DATA SHEET
DEMOGRAPHIC DATA SHEET

1. Gender: Male ___ Female ___

2. Age: ___

3. Highest level of education:
   High school or less ____ Some college ____

4. Years married to current spouse: ___________________

5. Previous marriages: Yes ___ No ___

6. How many children under 18 years old live in your household:
   __________________

7. Are you currently employed: Yes ___ No ___

8. If yes, are you employed Full-time or Part-time: ________________

9. Date (year) your spouse was diagnosed with chronic pain: ________________
CURRICULUM VITAE

NAME: Lisa M. Kasperek, RN, BSN, LNC, CCM

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EDUCATION & TRAINING:

- MSN-ANP
  Marian College
  Fond du Lac, WI
  2005-2007

- Certification for Case Manager
  Commission for Case Manager Certification
  Schaumberg, IL
  2002-2012

- Legal Nurse Consultant Diploma
  Kaplan College
  Boca Raton, FL
  1999-2000

- BSN Nursing
  University of Wisconsin
  Eau Claire, WI
  1996-1998

- General Associate Degree
  University of Wisconsin
  Stevens Point, WI
  1983-1995

PROFESSIONAL EXPERIENCE:

- Affinity Occupational Health
  Nurse Case Manager – Care Coordinator
  Menasha, WI
  2006 to present
Concentra Integrated Services
Field Nurse Case Manager
St. Louis Park, MN
2000-2006

St. Elizabeth Hospital
Staff Nurse – Medical/Surgical/Oncology/Orthopedics
1998-2000

Sentry Insurance
Sr. Claims Adjuster
1982-1998

PROFESSIONAL SOCIETIES:
Marian College of Fond du Lac Nursing Honor Society
Fox Valley Health Professionals Association

PUBLICATIONS:
Commercial Driver Health Education pamphlet for Affinity
Occupational Health

INVITED PRESENTATIONS:
Effective Case Management
St. Elizabeth Hospital
Appleton, WI
September 2006

Effective Case Management
Mercy Medical Center
Oshkosh, WI
September 2006