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LIVING WITH CHRONIC PAIN OF RHEUMATOID ARTHRITIS

BY

SUZETTE M. ROY ©

A THESIS

SUBMITTED TO THE FACULTY OF GRADUATE STUDIES AND RESEARCH

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DEDICATION

TO THE GENEROUS PEOPLE WHO SHARED THEIR STORIES AND GAVE WITNESS TO THE DIGNITY AND STRENGTH OF THE HUMAN SPIRIT.

ABSTRACT

Chronic pain is a pervasive problem, the prevalence of which is rising. The characteristics of chronic pain remain poorly understood. The purpose of this study was to gain an understanding of living with chronic pain of rheumatoid arthritis. Twenty participants were recruited from rheumatology clinics, the Arthritis Association, and word of mouth. Using concept mapping, ninety-two statements describing living with chronic pain were grouped into seven themes. The themes were: the impact of pain; doing less because of pain; learning to live with pain; positive ways of coping with pain; negative feelings surrounding pain; family issues related to pain; health care issues related to pain. The greatest agreement among participants was for statements regarding learning to live with pain and positive ways of coping with pain; least agreement occurred with statements regarding negative emotions surrounding pain. Insight gained into the individual's perspective of living with chronic pain provides direction for assessment, treatment, and evaluation of chronic pain.

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CHAPTER ONE

Introduction

Chronic pain has been described as pain that persists beyond the normal healing time for an acute injury or disease (Barkin, Lubenow, Bruehl, Husfeldt, Ivankovich, & Barkin,1996a; Bonica, 1990; Stacey, 1996). It has been characterized as a multidimensional condition associated with affective and behavioral changes (Bonica, 1990; Sofaer, 1992; Stacey, 1996; Whitehead & Kuhn, 1990). While authorities agree that chronic pain is more than prolonged acute pain (Bonica, 1990; Hanson & Gerber, 1990), there is no generally accepted definition for this incapacitating condition (McCaffery & Beebe, 1989; Wells, 1993).

Several categories of chronic pain are described in the literature: (1) chronic pain associated with progressive disease such as cancer (chronic malignant pain); (2) chronic pain related to chronic degenerative diseases of neurological or musculoskeletal systems (e.g., arthritis); or (3) chronic pain which persists and/or recurs intermittently without an identifiable cause (Bonica, 1990; Burckhardt, 1985; Creedon, 1991; Markenson, 1996; Turk, Meichenbaum, & Genest, 1983). The last two categories of chronic pain are sometimes referred to as chronic nonmalignant or chronic benign pain.

Effective treatment of chronic nonmalignant pain remains problematic (Lister, 1996; Rowbotham, 1995; Stacey, 1996). People experiencing this condition are often told they must learn to "live with it." Although this seems to be a less than satisfactory solution, learning to "live with" or manage pain on a day to day basis is crucial. Lorig and Holman (1993) stated that "the ability to succeed at this task commonly differentiates those who are incapacitated from those who continue to lead full and active lives in the face of equal disease severity" (p. 18).

The Incidence and Effects of Chronic Pain

The incidence of chronic pain is escalating (Turk, 1990) and it represents a major public health problem (Crombie, Davies, & McCrae, 1994). The experience of chronic pain is closely associated with the severity of disability, medication usage, and utilization of health care services (Badley, Rasooly, & Webster, 1994; Buckelew & Parker, 1989; Kazis, Meenan, & Anderson, 1983; Millar, 1996). Chronic pain not only results in an enormous economic burden to society (Bonica, 1990; Latham & Davis, 1994), but also has negative effects on the quality of life of individuals and their families (Burckhardt, 1985; Hitchcock, Ferrell, & McCaffery, 1994; Krol, Sanderman, & Suurmeijer, 1993; Markenson, 1996; Stacey, 1996).

Chronic Pain and Rheumatoid Arthritis

Chronic pain is a major feature of rheumatoid arthritis (RA) (Affleck, Tennen, Urrows, & Higgins, 1991; Davis, Cortez, & Rubin, 1990). The Arthritis Foundation (1994) defines RA as an autoimmune disease involving chronic inflammation of synovial and other joints. As with other causes of chronic pain, RA can be a debilitating condition with serious physical, emotional, and economic consequences. Pharmacological, physical, and surgical interventions have often failed to provide adequate pain relief for people with RA and so they must live with their pain on a daily basis.

Research on Chronic Pain

How well people with RA or other forms of chronic pain learn to manage their pain is affected as much by their life experiences, perceptions, and beliefs, as it is by the physiological progression of the disease. Although cognitive and behavioral perspectives on chronic pain management have stressed that these factors must be considered as integral aspects of treatment, very few studies examining chronic pain, in general, as well as pain associated with RA have actually explored the individual's personal experiences (Knish, 1994; Manne & Zautra, 1992). Rather, researchers have utilized theoretically-driven constructs and models (e.g., peripheralist pain model, social support, coping) as a means of identifying individuals' beliefs and experiences (Knish, 1994; Manne & Zautra, 1992; Turk, 1990). A universality is assumed in these models which overshadows the subjective perspective (Howell, 1994). Turk (1990) warned that failure to consider relevant patient characteristics and the patient's perspective inevitably leads to treatment failure, nonadherence, and relapse.

There are many gaps in our understanding of chronic pain and individuals experiencing rheumatoid arthritis (Turk, 1990). More knowledge is needed concerning the totality of the pain experience from the individual's perspective. Gaining a greater understanding of the individual's perspective is of vital importance for the development and provision of effective pain management and support. Many questions exist regarding the underlying dimensions of chronic pain and the effect it has on people's lives (Rose, 1994; Strong et al., 1994). More specifically, there is a lack of current information from the perspective of the person living with chronic pain due to rheumatoid arthritis.

In view of the need to clarify and further explore the dimensions underlying pain associated with a chronic condition such as rheumatoid arthritis, it is important to use a research approach that will allow the individual to freely inform the investigator. Concept mapping lends itself well to such an endeavor.

Concept Mapping

Concept mapping is a set of statistical methods that permits the clustering of qualitative data, or experiences, into underlying themes as they are reported by the participants rather than being defined by the researcher (Daughtry & Kunkel, 1991; Trochim, 1989a). This method of structured conceptualization was developed by William Trochim (1989b) and allows for the objective categorization of items along thematic lines. This method adds objectivity to the study of qualitative types of data previously analyzed using non-statistical methods (Kunkel,1991).

Concept mapping involves four basic steps: generation of ideas or statements by participants relating to the specific research question; grouping together common interrelationships between the ideas or statements expressed through the use of a card sort; carrying out a statistical analysis of card sort results to identify underlying themes; and, interpretation of the maps generated from the statistical analysis. The results of this statistical analysis are depicted in a form of a concept map (Trochim, 1989b). This type of analysis permits the investigation of the experience of living with the chronic pain of rheumatoid arthritis from the participant's perspective.

No research using the concept mapping approach has been applied to the study of individuals experiencing chronic pain associated with rheumatoid arthritis. Concept mapping was used in this study in the hope that the results will add to the understanding of chronic pain in general and more specifically chronic pain associated with rheumatoid arthritis.

Purpose of the Study

The sheer number of people affected by chronic pain and its consequences strongly suggests the importance of exploring all possible means of understanding and helping these individuals (Baptiste, 1988). Insights into the relevant dimensions of living with chronic pain must be achieved. The purpose of this study was to gain a better understanding of the dimensions underlying living with chronic pain from the perspective of the individual experiencing rheumatoid arthritis. The study was designed to answer the research question, "What are the dimensions underlying living with the chronic pain of rheumatoid arthritis?"

Significance of the Study

In order to give more supportive and empathetic care to a group of people who are often misunderstood and isolated by their chronic condition, nurses and other health care providers must know more about the individual's perspective of living with chronic pain.

The themes generated during the concept mapping process will assist in identifying the important dimensions of living with chronic pain. These themes can serve as a basis for the development of more effective assessment tools and treatment plans for people experiencing chronic pain. Themes identified can also serve as guides for program evaluation, as well as provide direction for future research in the area of chronic pain. Finally, the concept maps generated during the study, can serve as valuable communication and educational tools in the pursuit of increasing people's knowledge about this chronic condition.

CHAPTER TWO

Review of Literature

In the literature review, the background and rationale for this study on living with chronic pain associated with RA is developed. First, the prevalence and impact of chronic pain is addressed in an attempt to substantiate the importance of this debilitating condition. Next, a review of the literature describing the phenomenon of chronic pain is presented in an effort to demonstrate its complex nature and the lack of consensus which exists regarding its conceptualization and definition. Research in which the process by which people adjust to living with chronic pain is then explored. Studies, in which the effectiveness of various treatment modalities, are examined are summarized and establish the point that chronic pain remains resistant to treatment perhaps because we do not yet understand all of its underlying dimensions. In the final section, the concept mapping process is described.

Prevalence and Impact of Chronic Pain

Chronic pain has costly economic, social, and personal implications. However, data on pain are fragmented, and few accurate statistics on the prevalence of chronic pain in the general population exist (Birse 1994; Bonica, 1990). While reviewing the literature on chronic pain, Birse (1994) found that the reported prevalence rates for this condition ranged from a low of 5% to a high of 40%. He suggested that irregularities in the findings may stem from variations in: "(1) definitions of chronic or persistent pain; (2) characteristics of the population studied; and, (3) sampling methods employed in research" (p.3). In his own epidemiological study, Birse (1994) concluded that 44.3% of the population of one Western Canadian city experienced chronic pain. Included in this study were incidences of chronic pain due to malignancies.

Based on extrapolation of data from local and regional surveys done in the U.S., Bonica (1990) estimated that over one third of the American population has chronic painful conditions. Of these, 50% to 60% are partially or totally disabled for days, weeks, or months. Some, such as people with arthritis, are chronically disabled by the pain. This author suggested that up to 400 million days of work are lost and that costs in lower productivity, health care, compensation, litigation, and quackery approach $79 billion dollars per year. Latham and Davis (1994) estimated that there are as many as 5 million chronic pain sufferers in Great Britain. They state, however, that there have been few studies carried out in Great Britain's general population. In a recent Canadian study, Millar (1996) found that almost 3.9 million adults or 17% of the population aged 15 years of age and older experienced chronic pain. Of those, 70% had moderate to severe pain. This study did not include residents of institutions thereby excluding a substantial number of people who have chronic pain.

In addition to its tremendous economic and social costs, chronic pain has devastating effects on the quality of life of chronic pain suffers and their families (Markenson, 1996). Besides being disabled to varying degrees, individuals often experience anger (Fernandez & Turk, 1995), frustration and depression (Barkin, Bruehl, Husfeldt, Ivankovich, & Barkin, 1996b; Burckhardt, 1990; Creedon, 1991; Haythornwaite, Sieber, & Kerns, 1991; Fifield & Resine, 1992; Whitehead & Kuhn, 1990), strained family and spousal relationships (Manne & Zautra, 1992; Schwartz &

Slater, 1991; Snelling, 1994), a sense of personal isolation (Rose, 1994), and even suicidal thoughts (Hitchcock et al., 1994; McCaffery & Beebe, 1989).

These patterns of chronic pain and its debilitating effects are also associated with a group of musculoskeletal diseases referred to as arthritis (Burckhardt, 1985). It is the most common chronic disease in Canada, with over four million Canadians having some form of arthritis (Arthritis Society, 1996). Millar (1996) found that it was the second leading chronic condition, after back problems, associated with chronic pain. He found that an estimated 10% of Canadian men and 17% of women experienced some form of arthritis/rheumatism. In addition, arthritis is the third most common cause of disability in Canada (Badley, Rasooly, & Webster, 1994; Statistics Canada, 1986). Recent statistics show that arthritis causes 25% of all long-term disability in Canada (Arthritis Society, 1996). It is estimated that arthritis costs Canadians nearly 2 billion dollars annually. These statistics do not take into consideration the social and emotional costs of arthritis to patients and their families.

The medical, social, and economic impacts of arthritis are expected to grow dramatically as "baby boomers" age. American authorities claim that cases of arthritis and other rheumatic diseases will increase by an estimated 50% during the next 25 years, affecting 60 million United States citizens (Russell, 1995). In 1991, more than one million Canadians over age 65 had arthritis; this figure is expected to rise to more than three million by the year 2031 (Arthritis Society, 1996). Arthritis is presently a leading cause of disability in the U.S., and it is estimated that the number of Americans disabled by this condition will rise to 12 million by the year 2020 (Russell, 1995). Furthermore, as people with arthritis grow older, the proportion of them who experience pain also increases. For example, of people 15-44 years of age with arthritis/rheumatism, 40% reported chronic pain while by age 65 and over, this number rose to forty-nine percent (Millar, 1996). These facts point to the ever increasing size of the chronic pain problem.

Of the more than 100 different recognized forms of arthritis, RA is especially unpredictable and difficult to treat (Turk & Rudy, 1991). RA is the fourth most common form of arthritis after osteoarthritis, fibromyalgia, and gout. Recent statistics indicate that 274,000 Canadians have rheumatoid arthritis (Arthritis Society, 1991). This mirrors the worldwide prevalence of 1% among adults. Approximately three times as many women as men are affected by this disease (le Gallez, 1993). Although no specific statistics are available regarding the age distribution of RA patients, people 20 to 50 years of age are said to be most at risk for contracting the disease (le Gallez, 1993; McKance & Huether, 1994). The incidence of this disease is known to increase with age in both men and women (Markenson, 1991; Neuberger & Neuberger, 1984).

Chronic pain from inflamed and eroded joints is the most important consequences of RA (Affleck, Tennen, Urrows, & Higgins, 1991). Individuals with RA have indicated that their pain is present nearly 70% of the time and awakens them 40% of the time (Parker, Frank, Beck, Finan et al., 1988). They have identified pain as a major stressor (Affleck, Pfeiffer, Tennen, & Fifield, 1988) and use a variety of strategies to reduce its intensity and its psychological effects (Brown, Nicassio, & Wallston, 1989; Parker, McCrae et al., 1988). Pain from RA predicts the patient's level of health, medication usage, and subsequent physical disability (Bellamy & Bradley, 1996; Kazis, Meenan, &

Anderson, 1983; Parker, Frank Beck, Finan et al., 1988). RA patients have also ranked pain over disability as the most important symptom to be treated (McKenna & Wright, 1985). Similar to other individuals with chronic pain, individuals with rheumatoid arthritis experience depression, isolation, and strained personal and family relationships (Fifield & Reisine, 1992; Krutzen, 1983; Manne & Zautra, 1992). Finally, the treatment of pain due to RA is as complex and ineffective as that for chronic pain due to other conditions because of both the unpredictable nature of RA, and the complexity of the phenomenon of chronic pain.

Phenomenon of Chronic Pain

Pain is a highly personalized (Katz, 1996), multidimensional phenomenon comprised of neurological, physiological, behavioral, motivational, affective, spiritual, and sociocultural elements (Getto, Sorkness, & Howell, 1987; Howell, 1994; Melzack & Wall, 1982; Whitehead & Kuhn, 1990). For example, researchers have found that an individual's age, income, work status, length of illness, and educational level (Parker, Frank, Beck, Finan et al., 1988), as well as cultural background (Bates & Rankin-Hill, 1994) and perceived level of support (Affleck et al., 1988; Weinberger, Tierney, Booker, & Hiner, 1990) can affect how he or she experiences pain. Accordingly, Walding (1991) suggested that the pain experience is unique and subjective and that together with biological, psychological, social, and other factors in a person's life, creates a meaning of pain for the individual. The meaning of pain in turn affects how the individual reacts to the pain experience (Seers, 1988).

In spite of the complex nature of chronic pain, health care practitioners and patients alike still tend to ascribe to the medical or peripheralist model of pain (Hanson & Gerber, 1990; Melzack & Wall, 1987; Walker & Campbell, 1988). This model presumes that there is an organic, pathological link between pain and its cause. Thus, pain is essentially equated with peripheral nociceptive sensory input to the brain, with the spinal cord passively transmitting the messages to the "receptive" brain. In this model, it is believed that the quality and intensity of the pain is determined almost solely at the site of injury and disease (Hanson & Gerber, 1990). It follows then that pain can be eliminated by identifying and removing the cause. Although this model of pain may be applicable to acute pain, where pain signals injury or disease, it is not as relevant to chronic pain. In this case, the cause of pain often cannot be identified or the disease cannot be cured. Harding and Williams (1995, p. 682) explained that this type of pain "does not fit well with a uni-dimensional medical model where the aim is diagnosis of cause, physical or psychiatric, with treatment aimed at that cause." Hanson and Gerber (1990) also argued that when dealing with chronic pain, one must adopt models of pain which provide a much broader perspective and take into consideration not only the peripheral causes but also its complex psychological, emotional, spiritual, and sociocultural aspects. They add that conventional medical models of pain lead to conventional medical treatments. There is evidence to show that at least 50% of patients who experience chronic pain do not obtain relief from such interventions (Hitchcock et al., 1994).

Other definitions of pain exist, for which there is little consensus (Von Korff, Dworkin, & Le Resche, 1990). Some authors outline various stages of chronic pain

(Hendler, 1984; Kotarba, 1983; Empting-Koschorke, Hendler, Kolodny, & Kraus, 1990). They describe the chronic stage of pain as occurring 6 to 8 months after the onset of pain and being characterized by marked depression as the patient realizes that medical interventions have failed to relieve the pain. Others have attempted to define chronic pain in terms of the length of time a person has been experiencing it (Baptiste, 1988; Crue, 1985; McCaffery & Beebe, 1989). Although the points of division between acute and chronic pain do not appear to be based on research evidence (Birse, 1994), chronic pain has been defined as pain which persists for 6 months or more. Bonica (1990) disagreed stating that using an arbitrary time frame to define chronic pain may lead to inappropriate diagnosis and treatment. He prefers to define chronic pain as pain "which persists a month beyond the usual course of an acute disease or reasonable time for an injury to heal, or pain that recurs at intervals for months or years" (p. 180). He adds that chronic pain has no inherent value being for the most part deleterious to the patient, the family, and to society. Chronic pain is also usually associated with some degree of psychological distress, functional loss, social withdrawal, and some extent of vocational dysfunction (Barkin et al., 1996b).

Some attempts have been made in recent years to describe chronic pain from the individual's perspective. Researchers such as Howell (1994), Kodiath and Kodiath (1992), and Rose (1994) have explored the phenomenon of chronic pain in general, while others have studied chronic pain associated with specific disease conditions such as chronic low back pain (Bowman, 1994a & b; Knish, 1994; Strong, Ashton, Chant, & Cramond, 1994). Wiener (1975) specifically studied pain associated with rheumatoid arthritis. Grounded theory (Howell, 1994; Kodiath et al., 1994; Wiener, 1975), phenomenology (Bowman, 1994), focus groups (Strong et al., 1994), and concept mapping (Knish, 1994) were research methods used. Samples ranged in size from 7 to 21 subjects. All investigators included men and women in their studies, except for Howell (1994) who looked specifically at women's experiences with chronic pain.

Findings resulting from these qualitative studies point to important factors and processes pertaining to the phenomenon of chronic pain. These include the experience of physical symptoms associated with the pain itself, its intensity and unpredictability; the impact chronic pain has on family, social life, and personal relationships; altered daily performance and mobility; and the impact of chronic pain on positive and negative emotions (Bowman, 1994; Rose, 1994; Strong et al., 1994; Wiener, 1975). Additional themes emerging from Rose's study (1994) were the fear of planning ahead and being dependent on others, as well as an overwhelming sense of isolation. Strong and her colleagues (1994) identified some gender differences in terms of the importance attributed to specific factors. They stated, "It was almost as if men were experiencing greater difficulties and frustrations in coming to terms with their pain, while women were looking more at the practical, day-to-day management issues related to pain"(p. 205). Using concept mapping, Knish (1994) identified seven themes related to the beliefs held by people with chronic low back pain. These included denial/regret, self-defeating/passive, medications/pain focus, cautious realism, accepting limitations, adaptive coping, and responsibility for rehabilitation.

Adjustment to Chronic Pain

Bowman (1994a), Howell (1994), Kodiath and Kodiath (1992), as well as Wiener (1975) identified processes or phases people with chronic pain go through over time. Progression through these phases determines, in part, how well people adjust to and learn to live successfully with this condition. Although the researchers used different terminology, there were commonalties in the processes they described. The initial phase is marked by the pain taking over the patient's life. The patient seeks a diagnosis and a cure. As none is forthcoming, pain relief is sought but again none is found. At some point, the individual realizes and accepts that pain and its limitations will always be part of his or her life, and seeks ways to adjust. Finally, some individuals transcend the pain and focus on leading fulfilling lives in spite of its effects. Those who do not go through this transition often experience disability and despair.

Kodiath and Kodiath (1992) found that culture can affect how people progress through the phases of chronic pain and how they adapt. While comparing Americans to people in India, they found that many Americans do not go beyond searching for a cure and/or relief. Consequently, their lives are filled with a sense of hopelessness, isolation, and failure, as well as disability. Their Indian counterparts, on the other hand, find spiritual meaning and growth in pain and remain active in all aspects of their lives.

Qualitative findings are vital to health care workers who assist those in pain. A woman interviewed by Howell (1994) makes this point clear when she says, "they're (doctors and nurses) not letting you go through the process of whatever you have to go through emotionally. If they knew how to deal with the totality of the pain experience, it might help the physical pain" (p. 116). Identifying the factors and processes that contribute to the experience of chronic pain marks a first step in learning how to assist people. However, a major criticism of several of the above qualitative studies is that investigators obtained subjects for their research from pain clinics. Bonica (1990) and McCaffery and Beebe (1989), warned that only 3% of patients with pain attend pain clinics and that they may not be typical of the general chronic pain population. Further research focusing on other groups of people with chronic pain is therefore warranted to enhance our level of understanding and improve the effectiveness of treatment modalities.

Treatment of Chronic Pain

The treatment of chronic pain remains problematic. This may partly be due to an overreliance on the medical model of pain and the lack of consensus in defining and describing this phenomenon (Birse, 1994). Ineffective pain management increases individuals' levels of anxiety, frustration, and anger which in turn exacerbate their painful condition (Fernandez & Turk, 1995). Most strategies for the treatment of chronic pain fall within two broad categories: physiologic and cognitive-behavioral (Barkin et al., 1996a; Burckhardt, 1990). The treatment modality chosen very often reflects the pain model ascribed to by the health care professional and/or the individual who is seeking pain relief.

Rakowski and his colleagues (1988) and Conn (1990) reported that there is an overall gap in current knowledge concerning how people treat symptoms such as pain. They found that when self-care for symptoms such as pain is studied, checklists of researchers' preconceived ideas of available options were often used, thus not allowing participants to generate their own. This forced individuals into selecting predetermined responses that may not have fit their needs (Bowman, 1994), in turn limiting the acquisition of knowledge regarding what patients themselves saw as important interventions. Furthermore, there is a lack of information regarding how people decide to seek professional assistance and carry out treatment interventions (Conn, 1990) and what factors enter into their evaluation of how successful these are in helping them cope with their situations (Manne & Zautra, 1992).

Physiological Strategies

Physiological approaches for treating chronic pain include the use of heat and cold, physical therapy and exercise, the application of splints and casts, massage (Allegrante, 1996; Katz, 1996), as well as the use of nonopioid, opioid, adjuvant analgesics, and antidepressants (Barkin et al., 1996a). Although the use of opioids in the treatment of chronic nonmalignant pain is controversial (Barkin et al., 1996a; Hanson & Gerber, 1990; Stacey, 1996), some advocate that under certain conditions they are a safe and humane alternative to surgery or no treatment at all (Hazard-Vallerand, 1991; McCaffery & Beebe, 1989; Zenz, Strumpf, & Tryba, 1992). After reviewing research on the use of antidepressants in chronic pain therapy, several authors (Barkin et al., 1996a; Egbunike & Chaffee, 1990; Getto, Sorkness, & Howell, 1987; Katz, 1996; Magni, 1991; Richlin, 1991; Stacey, 1996; Zitman, Linssen, Edelbroek, & Stijnen, 1990) have concluded that antidepressants produce an analgesic effect independent of antidepressant effects in many conditions which cause chronic pain (i.e., diabetic neuropathy, chronic back pain, arthritis, headaches). However, the therapeutic effectiveness of these agents is only mild to moderate.

More invasive therapies such as trigger-point injections, nerve blocks, and surgery (i.e., neurotomies, rhizotomies) are also used (Empting-Koschorke et al., 1990; Hitchcock et al., 1994; Katz, 1996). In addition, patients are resorting to less conventional interventions such as hypnosis, acupuncture, acupressure, reflexology, therapeutic touch, and TENS (Empting-Koschorke et al., 1990; Owens & Ehrenreich, 1991). Very few controlled studies investigating the outcomes and efficacy of these physical interventions have been published (Allegrante, 1996) and reviews of existing studies have shown that their results were inconsistent (Minor & Sanford, 1993).

Physical interventions used to treat chronic pain associated with RA follow the same general pattern. Physical therapy includes application of heat and cold, exercises, TENS, and application of various ointments, to name a few (Minor & Sanford, 1993). Pharmacological interventions include the use of aspirin, nonsteroidal antiinflammatory drugs, and antidepressants for analgesia. Prednisone, gold, antimalarials, and methotrexate are used as second and third line treatments (Bellamy & Bradley, 1996; Kantor, 1991). Opioids are also recommended by some for the control of pain associated with RA, although few physicians are prescribing them due in part to physician (and patient) concerns regarding addiction or vulnerability to legal action (Bellamy & Bradley, 1996; Gonzales & Portenoy, 1993). Finally, surgical procedures such as arthrodesis and total joint replacement are also used as pain relief measures. These measures are found to be effective in not only relieving pain, but also in restoring function to the damaged joints (Bellamy & Bradley, 1996; Katz, 1996).

Traditional medicine has typically focused on the use of physical interventions to treat the sensory aspect of pain, ignoring almost completely pain's other components (Barkin et al., 1996b). Several investigators have found that for a large number of patients with chronic pain, including individuals with arthritis, physiological approaches alone, provide only limited relief (Hitchcock et al., 1994; Lorig & Holman, 1993; Rowbotham, 1995; Walker, Akinsanya, Davis, & Marcer, 1990). Furthermore, as patients continue to seek different interventions to cure their pain, the experience of repeated treatment failures contributes to their growing sense of anger, depression, and hopelessness, in turn intensifying the pain (Bonica, 1990; Fernandez & Turk, 1995; Hanson & Gerber, 1990). For this reason, these authors argue that when treating chronic pain, it is essential to consider all of its contributing elements (i.e., neurologic, psychological, sociocultural, motivational, cognitive, and behavioral) and to view any of these elements as valid areas of intervention (Allegrante, 1996; Whitehead & Kuhn, 1990). Empting-Koschorke et al. (1990) stated that "the treatment of chronic pain should involve a multimodal approach that addresses emotional and psychological aspects as well as anatomic and physiologic processes (p.165). The use of multidisciplinary teams of health care professionals to carry out this approach has been supported by many in more recent publications (Allegrante, 1996; Barkin et al., 1996a; Katz, 1996; Lister, 1996; Rowbotham, 1995). Furthermore, it is argued that the treatment of chronic pain involves support and care rather than cure (Katz, 1996; Whitehead & Kuhn, 1990). Katz (1996) stressed the importance of listening, communication, and a supportive attitude while caring for people with chronic pain. Enhancing the patient's sense of control over their pain is seen as an important factor in chronic pain management, thus, assisting patients to learn techniques which help them cope with and manage their pain on a day to day basis is a more beneficial form of treatment than trying to find an ultimate cure (Hanson & Gerber, 1990). Many cognitive-behavioral interventions are aimed at assisting chronic pain patients attain this goal.

Cognitive-Behavioral Interventions

Cognitive-behavioral interventions may include such strategies as stress management, relaxation, imagery, cognitive restructuring, education, counseling, hypnosis, operant conditioning, and biofeedback (Barkin et al., 1996a; Burckhardt, 1990; Corey, Etlin, & Miller, 1987; Katz, 1996). In terms of treating chronic pain due to RA specifically, a variety of cognitive-behavioral pain management programs exist. After reviewing the literature on the topic, Parker and his colleagues (1993) found that techniques used in these programs include relaxation training, cognitive-coping strategies, goal setting, communication and assertiveness training, problem-solving, as well as training in behavior modification techniques for family members.

An abundance of research on the effectiveness of cognitive-behavioral treatment in the management of chronic pain, and factors that affect their success exists. The majority of studies in this area have been based on theoretical constructs and models such as coping, self-efficacy, perceived locus of control, helplessness, and social support. Numerous researchers have examined the effects of psychological factors such as depression (Hagglund, Haley, Reveille, & Alarcon, 1989; Hawley & Wolfe, 1988; Stein, Wallston, & Nicassio, 1988) and the use of cognitive-behavioral strategies on the perception of pain (Affleck et al., 1992; Appelbaum, Blanchard, Hickling, & Alphonse, 1988; Bradley et al., 1987; Corey et al., 1987; DeVellis, Blalock, Hahn, DeVellis, & Hochbaum, 1988; O'Leary, Shoor, Lorig, & Holman, 1988; Parker, Frank, Beck, Smarr et al, 1988; Radojevic, Nicassio, & Weisman, 1992; Slater & Good, 1991).

Most of the subjects in the above studies had RA, and sample sizes ranged from 18 to 105 people. A battery of measurement tools, questionnaires, and tests were used to measure psychological factors related to pain. Included among them were the following: the Center for Epidemiological Studies Depression Scale (CES-D), the Beck Depression Inventory (BDI), Health Locus of Control Scales, the Daily Activities Questionnaire, Pain and Arthritis Questionnaire. Physiological and physical factors were also measured using erythrocyte sedimentation rate (ESR), skin temperature, grip strength, range of motion, morning stiffness, and joint counts. Anxiety, depression, and increased perceived loss of control associated with arthritis were found to be strong psychological predictors of pain (Hagglund et al., 1989; Hawley et al., 1989; Stein et al., 1988).

Variability in observed outcomes was a noticeable feature of several studies concerned with the use of cognitive-behavioral strategies (Parker, Iverson, Smarr, & Stucky-Ropp, 1993). For example, some researchers found reduced pain following cognitive-behavioral treatment (Affleck et al., 1992; Bradley et al., 1987; Corey et al., 1987; O'Leary et al., 1988; Parker, Frank, Beck, Smarr et al., 1988) while others did not (DeVellis et al., 1988; Radojevic et al., 1992). Some investigators, but not all, found evidence of increased physical activity (Appelbaum et al., 1988; Corey et al., 1987), better psychological functioning (Appelbaum et al., 1988; Bradley et al., 1987; O'Leary et al., 1988; Parker, Frank, Beck, Smarr et al., 1988; Slater & Good, 1991), and improved joint counts (Appelbaum et al., 1988; Bradley et al., 1987; O'Leary et al., 1988). It was also found that patients with RA experience an improvement in health status (Appelbaum et al., 1988; Bradley et al., 1987; DeVellis et al., 1988; O'Leary et al., 1988) and improved coping skills (Appelbaum et al., 1988; Corey et al., 1987; Parker, Frank, Beck, et al., 1988; O'Leary et al., 1988) following cognitive-behavioral interventions. However, methodological problems limit the degree of confidence in these findings.

After reviewing several of the above studies, Parker and his colleagues (1993) concluded that two primary methodological shortcomings exist, namely high intra-subject variability and high variability of outcomes across studies. They state that the high variability of outcomes is in part due to differences in interventions being used, sample sizes, research designs, statistical analysis, and overall methodological rigor. Although high intra-subject variability is expected due the episodic nature of RA, most researchers did not use large enough samples to produce the statistical power necessary to detect treatment effect. Collection of data at infrequent time intervals may have further contributed to this problem (Parker et al., 1993). In spite of these limitations, the authors conclude that although the core element of RA pain management is optimal rheumatologic care, the results of the studies they reviewed support the usefulness of cognitive-behavioral techniques in improving the pain reports, emotional status, and activity levels of people with chronic pain due to rheumatoid arthritis. Keefe and Van Horn (1993) concurred with these conclusions but added that the improvements produced by cognitive-behavioral interventions are often not maintained over time. They found that combining cognitive-behavioral interventions with educational strategies allowed some RA patients to maintain improvements; others, however, had difficulty maintaining treatment gains in outcomes such as pain relief.

Turk and Rudy (1991) concluded that three variables may be especially important in explaining long-term outcomes of cognitive-behavioral treatment in rheumatoid arthritis. First, self-efficacy (the belief that one can successfully perform a certain behavior or task in the future) appears to be important in understanding pain and its management. Lorig and her co-investigators (1989) found that a strong association existed between increasing perceived self-efficacy and the decline of pain in subjects with arthritis who participated in a combined cognitive-behavioral/educational program. However, Keefe and Van Horn (1993) pointed out that only 14% of the subjects had rheumatoid arthritis (75% had osteoarthritis) and questioned whether these outcomes can be generalized to the RA population.

Jensen and his colleagues (1991) found that self-efficacy was strongly related to the use of a variety of coping strategies among chronic pain patients. The use of varied pain coping strategies is the second variable that may be an important mediator in maintaining positive long-term outcomes. Parker, McCrae et al. (1988) found that RA patients who used a variety of coping strategies had much better outcomes one year after completing cognitive-behavioral treatment. Finally, Parker et al. (1989) and Keefe et al. (1991) suggested that perceived control over pain may be important in explaining arthritis patients' long-term response. Using the Coping Strategies Questionnaire, they found that patients who rate their ability to control pain as being high, have lower levels of pain and disability.

Turk, Meichenbaum, and Genest (1983) stated that in order to use cognitive-behavioral approaches effectively, one must understand how individuals see their presenting problems. In order to gain a clearer understanding of the individual's perspective, investigators must put aside their preconceptions and allow the patient to inform them (Clark, Javal, & Carroll, 1989). A qualitative approach which allows an individual to describe their own perceptions of what it is like to live with chronic pain would be helpful in the development of a more comprehensive understanding of the dimensions underlying this phenomenon. Concept mapping is a relatively new research approach which permits the active involvement of participants in the generation of ideas related to the topic of study and data gathering. Although it appears that this approach has not been used to identify the dimensions underlying living with chronic pain associated with rheumatoid arthritis, it lends itself well to exploring how individuals perceive their situation and allows them to inform the investigator.

Concept Mapping

Daughtry and Kunkel (1993) stated that concept mapping is "particularly appropriate for applications in which researchers are seeking to clarify the domain, constituent elements, and underlying structure of a phenomenon as experienced within the population of interest"(p.317). Concept mapping allows for the study of constructs as they are experienced by the participants rather than as defined by the researchers (Daughtry & Kunkel, 1993). Concept mapping can add objectivity to the study of qualitative data that have typically been analyzed using non-statistical approaches (Knish, 1994; Kunkel, 1991). This process allows the data to be grouped by many sorters "thus reducing the potential for influence or subjectivity that can be present when qualitative data are sorted and grouped by an individual researcher" (Knish, 1994, p. 31). Concept mapping which combines qualitative and quantitative techniques, was used in this study to explore the dimensions underlying chronic pain associated with rheumatoid arthritis.

Concept Mapping Process

Concept mapping is a structured conceptualization process consisting of the following main four steps: (1) generation of ideas or statements about a specified research question by a specific group of subjects; (2) articulation of the interrelationships between the ideas or statements; (3) statistical analysis of the data to produce a representation of the statements in the form of a concept map which symbolizes the underlying dimensions of the phenomenon under study; and (4) interpretation of the maps (Knish, 1994; Trochim, 1989a). A description of the steps in the concept mapping process follows:

Step One: Generation of statements. In preparation for the first step of the concept mapping process, the investigator must choose the participants and establish the specific focus of the conceptualization (Trochim, 1989a). A variety of people relevant to the research question have been used to develop concept maps, from small homogeneous groups, to gaining participants by random sampling methods (Miller,1996). Although the maximum number of participants has not been established, and groups as large as 80 people have been used, the usual group size used by Trochim in his research is 10 to 20 participants (1989b). Next, the focus of the study must be defined and a single-focus question must be clearly and simply worded to avoid any confusion (Trochim,1989a). The investigator can now proceed to the first step of the concept mapping process.

The first step in concept mapping is the generation of statements or ideas about the research question. The statements are generated by the participants themselves. A variety of activities including brainstorming in a group (Trochim, 1989b), qualitative interviews (Knish, 1994; Wiener, Wiley, Huelsman, & Hilgermann, 1994), and open-ended questionnaires (Daughtry & Kunkel, 1994; Deby, 1993; Phillips, 1993) have been used.

The statements from each participant are collected, combined, and redundancies are eliminated. Statements representing unique ideas and capturing the essence of the phenomenon being studied are placed on a master list. The master list is examined more closely and any further redundancies are removed. No more than 100 statements are retained as having more than 100 statements makes the task of sorting into theme groups difficult (Trochim, 1989a). Editing of statements is kept to a minimum. However, each statement is equated for verb tense in order "to maximize the interpretability of the concept map through equating the level of abstraction and providing parallel grammatical structure for each item" (Daughtry & Kunkel, 1993, p. 318).

Step Two: Categorization of statements. Once all statements representing unique ideas have been identified and edited, information about the interrelationships between the statements is gained through the use of a card sorting procedure. For this task, each of the statements on the master list are printed on cards. A group of sorting participants is chosen which may be, but is not restricted to, the participants who generated the original statements (Miller,1996). The sorters are asked to sort the complete set of statements into groups that they perceive go together, having a common idea or theme. Although there are no restrictions regarding the size or numbers of groups (Kidder,1981;

Trochim, 1989a), several other restrictions must be imposed on this procedure. These include: (1) each statement can only be placed in one pile (i.e., a statement cannot be placed in two piles simultaneously); (2) there must be more than a single pile; and, (3) there must be more than one statement per pile (although statements which do not seem to fit in any pile may be kept separate) (Trochim, 1989a).

Step Three: Statistical analysis and representation of statements. Several steps are involved in the statistical analysis and the final representation of statements. The statistical procedure of non-metric multidimensional scaling (MDS) is performed on the card sort data to assist the investigator to determine, statistically and visually (i.e., through the production of a point map), the interrelationships between the statements. Since this technique does not categorize the statements into groups, cluster analysis is then used to group items into internally consistent clusters to assist in identifying the underlying conceptual categories (Daughtry & Kunkel, 1993; Trochim, 1989b).

Multidimensional scaling (MDS) is a multivariate analysis that enables the investigator to determine the interrelationships between individual items of data. It can be used to develop a point map of items for conceptual purposes. Non-metric multidimensional scaling is the first statistical procedure carried out on the sort data related to chronic pain. To accomplish this procedure, the card sort data of each participant are put into a space matrix with as many rows and columns as there are statements. All of the values of this matrix are either zero or one. A "1" indicates that the statements for that row and column were placed by that participant together in a pile while a "0" indicates that they were not (Trochim, 1989b). Secondly, all individual sort matrices are be added together to obtain a combined group similarity matrix. This similarity matrix is considered the relational structure of the concept domain because it gives information about how the participants grouped the statements (Trochim,1989b).

Multidimensional scaling techniques (MDS) are applied to the group similarity matrix using a non-metric two-dimensional solution. Non-metric MDS is a technique that when applied to a similarity matrix can represent any number of dimensions as distances between the original items in the matrix (Kruskal & Wish, 1978). When using MDS the investigator will determine the number of dimensions to be used. Kruskal & Wish (1978) suggested that:

> Since it is generally easier to work with two-dimensional configurations than with those involving more dimensions, ease of use considerations are also important for decisions of dimensionality. For example, when an MDS configuration is desired primarily as the foundation on which to display clustering results, then a two-dimensional configuration is far more useful than one involving three or more dimensions.(p.58)

Trochim (1989b) agreed with the above suggestion noting that "in studies where we have examined other than two-dimensional solutions, we have almost universally found the two-dimensional solution to be acceptable, especially when coupled with cluster analysis"(p. 8). This procedure results in the creation of a map of points representing the set of statements found in the similarity matrix resulting from the sorting tasks. Statements that are spaced more closely together on the map are more likely to have been sorted together more frequently and therefore are conceptually related.

The second analysis which is conducted to represent the conceptual domain under study is a hierarchical cluster analysis. With this analysis, individual statements on the point map are grouped into clusters of statements which reflect similar concepts (Trochim, 1989b). The cluster analytic technique is applied to X-Y coordinate data obtained from MDS. This has the effect of partitioning the MDS map into a number of clusters (Trochim, 1989a).

Deciding on the number of clusters to use is as essential to cluster analysis as is deciding the number of dimensions to use in MDS (Trochim, 1989a). Theoretically, hierarchical clusters analysis procedures start with as many possible cluster solutions as there are statements. In practice, the computer program automatically sets the number of clusters to about one-fifth the number of statements (Trochim, 1989a). At each step of the analysis, two clusters are combined until all of the statements form a single cluster. It is up to the investigator to decide how many clusters the statements are to be grouped into for the final solution. The investigator examines each different cluster solution and uses discretion in deciding on which makes sense for the case at hand. Each time the analysis moves from one cluster level to the next lowest, the investigator examines which statements have been grouped together at that step, and attempts to decide whether that grouping makes sense for the statements in the conceptualization (Trochim, 1989a).

Once MDS and cluster analysis have been conducted, the average ratings for each statement and/or cluster are computed. These are overlaid graphically on the point and cluster maps to produce a point rating map and a cluster rating map.

In summary, the representation of the statements involves three steps distinct steps. First, an analysis is conducted which locates each statement as an independent point on a map. This is referred to as a point map. Secondly, the statements on this point map are grouped into clusters representing conceptual groupings of the original statements.

This is the cluster map. Finally, maps are constructed that overlay the average ratings either by point or by cluster (Miller,1996; Trochim,1989a).

Step Four: Interpretation of maps. In this final step, each cluster of statements derived from the statistical analysis is visually inspected and given a label which describes the content of the grouping in question. This can be done by the original sorters or the investigator (Trochim, 1989a). Once the concepts have been identified, a concept map is constructed. The final named cluster map constitutes the conceptual framework and the basic result of the concept mapping process. This conceptual map is entirely based on the statements generated and grouped by the participants. In addition, it provides an easy to understand visual summary of the conceptualization process (Trochim, 1989a).

Trochim (1989a) maintains that the results of the concept mapping process can be used to plan or evaluate treatment programs and provide an understanding of a phenomenon from the perspective of the participant. He adds that each grouping can be viewed as a measurement construct and can thus provide direction for future research. Finally, the concept maps generated during this process, can serve as a pictorial tool used in communicating with and educating others about the topic of study.

Summary

Chronic pain is a predominant feature of rheumatoid arthritis. As indicated, chronic pain is a multifactorial syndrome with physiological, psychological, sociocultural, and spiritual elements. In spite of its increasing prevalence and devastating impact, chronic pain remains poorly understood. There is as yet no universally accepted definition for this phenomenon, and many are still ascribing to medical models of chronic pain. It is argued that the lack of understanding of all of the dimensions of chronic pain is contributing to the ineffectiveness of pain interventions of all kinds (Strong et al., 1994). Regardless of the obvious gaps in our knowledge, the majority of studies done to date have been based on theoretical constructs and models which force participants into selecting responses which may not fit their needs (Bowman, 1994a). More recent studies have attempted to explore the phenomenon of chronic pain from the participants' perspective (Bowman, 1994a & b; Howell, 1994; Knish, 1994; Kodiath & Kodiath, 1992; Rose, 1994; Strong et al., 1994). However, almost all of these studies have drawn their samples from people in the pain clinic population who may not be representative of the general chronic pain population (Bonica, 1990; McCaffery & Beebe, 1989). Although the treatment of arthritis has changed over the past 20 years, there are no qualitative studies since Wiener's research in 1975, which investigate living with chronic pain of RA from the individual's viewpoint. No studies using the concept mapping process to explore this area have been identified although this approach provides for development of knowledge from the perspective of the participant and reduces investigator bias.

Given the lack of understanding of the dimensions underlying chronic pain, the growing prevalence of chronic pain associated with RA, and the lack of recent studies in this area examining the problem from the perspective of the individual, further research is needed. It was the intent of this study to add to our body of knowledge on chronic pain associated with RA through the use of concept mapping.

CHAPTER THREE

Method

A review of the literature points to the fact that historically, research on chronic pain has overwhelmingly been of a quantitative nature, attempting to objectify and measure this phenomenon. There exists a subsequent lack of understanding of the dimensions underlying chronic pain from the individual's perspective. The goal of this research was to let the participants inform the investigator about what it is like to live with chronic pain thus gaining some insight into the dimensions underlying chronic pain. To this end, an approach which utilizes a combination of qualitative and quantitative research methods was selected for this study, allowing for maximum input from the participant who is the expert in the area of study, in view of the subjective nature of chronic pain.

Steps of the Study

Concept mapping was used to explore the dimensions underlying the chronic pain of rheumatoid arthritis. In keeping with this research approach, the study was conducted in four distinct steps: Step One: Generation of statements; Step Two: Categorization of statements; Step Three: Statistical analysis and representation of the statements in the form of maps representing the underlying dimensions of chronic pain; and, Step Four: Interpretation of the maps (Knish, 1994; Trochim, 1989a).

Sample Selection

The sample consisted of adults experiencing chronic pain of rheumatoid arthritis. Individuals were included in the study if they meet the following inclusion criteria: (1) 18 years of age or older; (2) confirmed medical diagnosis of RA for at least 6 months; and, (3) able to read and write English.

Participants were obtained by posting a notice in prominent locations in the Rheumatology Clinics at the University of Alberta Hospital and the Glenrose Rehabilitation Hospital, as well as placing an ad in the Arthritis Association of Edmonton Newsletter. Additionally, a snowball sampling technique was used and information letters were circulated by the investigator at a Rheumatoid Arthritis Public Information Forum presented at the Glenrose Rehabilitation Hospital. Although the investigator had hoped to approach people attending the Arthritis Self-Management Program in Greater Edmonton, this was not possible as no groups met during the time of the study. Instead, a cover letter along with an information sheet about the study were sent by the Director of Educational Services of the Arthritis Society, Alberta and Northwest Territory Region to former participants of the program in the Greater Edmonton Area. No participants were obtained through this method, the majority being obtained via the Newsletter and word of mouth.

People interested in taking part in the study phoned the investigator. At that time arrangements were made to go to the participant's home. Participants were informed that participation in the study was completely voluntary and that they could refuse to answer any questions or withdraw from the study at any time. The procedures for the study were explained, and written informed consent for participation in the study was obtained (Appendix A). A demographic questionnaire was then completed (Appendix B). Information collected included age, gender, ethnic background, marital status, level of education, occupation, employment status, description of general health, main source of support and the level of satisfaction with this support, length of time with RA, whether they had other medical conditions causing pain, the percentage of time they are experiencing pain due to their condition, and their typical level of pain. The first step of the study was then initiated.

Step One: Generation of Statements

An open-ended questionnaire was used to generate statements for this study (Appendix C). On the questionnaire, the participants were asked to answer, in sentence form, the question: "How has living with the pain of rheumatoid arthritis affected your life?" There are several advantages to using an open-ended questionnaire. Using this approach allows participants to freely express themselves, avoids interviewer bias, and gives participants ample time to consider their responses (Kidder, 1981). Providing ample time is an important consideration for participants who may be experiencing pain. Participants were given the option of completing the open-ended questionnaire with the investigator's assistance or to do so when it is convenient for them. Those choosing the second option, were provided with a stamped, self-addressed envelope, in which to return the completed forms. Seven of the participants opted to fill out the questionnaire on their own; one did not return the questionnaire. The remaining 14 participants chose to have the investigator assist them either because they had difficulty using their hands due to pain or deformity or, they simply wanted to expedite the process. These participants were given the option to review what the investigator had written down on the questionnaire to ensure accuracy and to add further statements if they wished. Three participants reviewed their questionnaires and mailed them in later; the remaining participants were satisfied that their statements had been accurately transcribed and did not wish to review them.

From each participant's statements, the investigator compiled a master list. A first edit was completed on the entire statement list. This process involved dividing up statements that contained more than one unique idea and combining others that had similar but complimentary meanings. Words that denoted gender (e.g., wife; husband; daughters) were replaced with more generic terms (i.e., partner; children). Verbs were changed to the present tense whenever possible. Care was taken to retain the essential meaning of the original statements during this edit. The goal of this process was to ensure that the statements were clear and concise in order to facilitate their use in other phases of the study (Miller, 1996). The list of statements of each participant was compared with that of the next and any duplicated statements or ideas were removed. The same was done with all subsequent participant listing until every statement on the original list was examined and all unique ideas were retained on the master list. No unique ideas were found after the eighteenth participant. The concept domain was therefore considered adequately sampled and it was deemed that statements had been collected to redundancy.

The reduced list of statements was reexamined more closely and any further redundancies were removed. A total of 92 statements were retained. All deletions, as well as changes to verbatim statements were reviewed by the investigator's thesis supervisor to ensure that no unique ideas had been left out or that changes had been made to the original meaning of the statement.

Step Two: Categorization of Statements

Once all statements representing unique ideas were identified and edited, the second phase of the study was conducted. The objective of this phase was to sort the statements into distinct categories. This would yield information about the interrelationships which existed between the statements and help identify existing themes. Individuals who participated in Step One of the study completed the card sorting procedure.

In preparation for the card sort, each statement on the final master list generated in Step One was printed on a 3x5 index card. Arrangements were made to have the investigator go to the participants' homes. At that time, they were given verbal and written instructions asking them to rate each statement on a scale of 1 to 5 in terms of the extent to which s/he personally agreed with what was being described in each statement (Appendix D). They were then asked to sort the cards into piles of statements that they perceived fit together (i.e., contained a common idea or theme). They were told that there was no limit on the number of piles they could have and that the number of cards per pile could vary. However, the following restrictions were imposed on the procedure: (1) each statement could only be placed in one pile (i.e., a statement could not be placed in two piles simultaneously); (2) there had to be more than a single pile; and, (3) there had to be more than one statement per pile (although statements which did not seem to fit in any pile could be kept separate) (Trochim, 1989a). Participants were given both written and verbal instructions regarding these restrictions and the card sort procedure (Appendix E). Participants were encouraged to give names to each of their piles of statements as they went along. After the card sort was completed, items in each pile were reviewed and participants were asked if they wished to make any changes in the placement of the statements or develop any new groupings. A few changes were typically made at this time but none were major.

Step Three: Statistical Analysis and Representation of Statements

Using the Concept System software (Trochim, 1989a), the card sort data from each individual sort was recorded. All individual sort matrices were then added together to obtain a combined group similarity matrix. A non-metric multidimensional scaling (MDS) procedure was performed on the similarity matrix of the participants' sorted items. A point map of the statements was thus produced. Hierarchical cluster analysis of the MDS similarity matrix was then used to group the sorted items into internally consistent clusters and a cluster map was constructed. Finally, the average ratings for each statement and cluster was computed and rating point and cluster maps were created. These maps formed the basis for further interpretation.

Step Four: Interpretation of Maps

Each cluster of statements or themes derived from the cluster analysis was visually inspected and given a label which described the content of the grouping in question (Trochim, 1989a). Once the clusters were labeled, a concept map was constructed. The final named cluster map constituted the conceptual framework and the basic result of the concept mapping process. This conceptual map was entirely based on the statements generated and grouped by the participants.

Rigor of Findings

The four criteria for assessing rigor are credibility, fittingness, auditability, and confirmability (Sandelowski, 1986). Credibility, or the faithful interpretation and representation of the participants' experiences in the research, was established in the following ways: (1) a sample of people with chronic pain was selected to ensure that participants being studied had experience and knowledge related to the purpose of the study; (2) two individuals with RA completed the questionnaire to assess the effectiveness of the research question; (3) investigator bias and influences were tracked by way of an investigator diary and memos; and, (4) the investigator's thesis supervisor and committee members were utlized as research methods experts to guide and verify procedures and interpretations at each step of the concept mapping process.

Fittingness refers to the applicability of the research findings. This criterion is met when a study's findings can "fit" into contexts outside the study situation, and when its audience recognizes them as meaningful and applicable to their own situation (Sandelowski, 1986). Fittingness was secured by the following means: (1) a selection criteria were established that ensured inclusion of participants who could illuminate the phenomenon of chronic pain; (2) participants were asked to rate each statement in terms of the degree to which they agreed with them; and, (3) content experts (i.e., a pain management specialist and rheumatology nurse specialist) were asked to review the findings to determine their fittingness in his/her area of expertise.

The investigator also ascertained that her conclusions were well grounded in the participant's statements and perspectives. The selection of unique statements and any editing of these statements for sorting were verified by the investigator's thesis supervisor to ensure that they truly reflected the original meaning of the statements and the concept domain in its entirety.

Audibility allows another researcher to follow the "decision trail" used in a particular study. Auditability was ensured by listing the original statements generated by the participants and retaining sorting matrices. As well, notes were kept regarding reasons why certain statements were discarded or editing changes made, and why specific clusters were selected or altered during data analysis. Confirmability was achieved when auditability, fittingness, and credibility were established (Sandelowski, 1986).

Ethical Considerations

Ethical approval for the study was obtained from the Faculty of Nursing, University of Alberta , as well as the University of Alberta Hospital and the Glenrose Rehabilitation Hospital Ethics Committee. Permission to access participants was obtained from Directors of the Arthritis Self-Management Program and the Rheumatology Clinics at the University of Alberta Hospitals and the Glenrose Rehabilitation Hospital (Appendix F).

Informed consent was obtained from all participants. This involved the provision of an information letter explaining the purpose and procedures of the study, the nature of participant's involvement, and potential risks and benefits. Participants were advised that there were no foreseeable risks or immediate benefits to be gained from participating in this study but that knowledge gained from this study might provide future benefits to people with chronic pain. It was also emphasized that participation was totally voluntary, and that they could terminate their participation at any time. They were informed that withdrawing from the study could be done by informing the investigator verbally. They were also informed that data might be used for secondary analysis but only after further ethical approval was obtained.

Protection of privacy and confidentiality of the participants during data collection was ensured by not publishing individual names or personal characteristics. Data analysis described group rather than individual information. All the data were stored in a locked cabinet, separate from consent forms which might identify the participants. Statement lists, matrices, researcher notes, and memos were stored in a locked filing cabinet when not in use.

Although there were no perceived risks for participants in this study, it was thought that writing about personal experiences of living with chronic pain could potentially evoke strong emotions. In the eventuality that this might occur, the investigator sought the names of agencies and individuals who could provide these participants with professional help.

CHAPTER FOUR

Findings

The purpose of this study was to gain a better understanding of what it is like to live with chronic pain. Themes underlying the experience of living with chronic pain were determined from the perspective of individuals with rheumatoid arthritis. Specifically, the study was designed to answer the question, "What are the dimensions underlying living with the chronic pain of rheumatoid arthritis?" Findings from each step of the concept mapping approach (Trochim, 1989a) are presented, but first, the description of the participants is summarized.

Description of the Participants

Twenty-one individuals initially volunteered to participate in this study. However, one participant did not return the pain questionnaire and was subsequently excluded from the study. The participants ranged in age from 22 to 75+ years with the majority of participants (n = 17) being 45 years or older. Four men and 16 women participated, all of whom were Caucasian. Four participants (2 males and 2 females) were never married, while 12 are presently married. One participant is divorced while the three remaining participants are widowed. They had diverse educational backgrounds ranging from elementary school (n = 2), to university degrees (n = 3). The majority of participants (n = 12) had post-secondary diplomas. The participants had been or are presently employed in a variety of occupations. In keeping with the age of this sample, 50% of the participants were retired and not working, although many stated they had stopped working prematurely due to their rheumatoid arthritis. Five other participants were not employed because they could not work due to their illness. Participants characteristics are summarized in Table 1.

Table 1

Characteristics of the Participants

Variable	Categories	Frequency	Percent
Age in years	18-24	1	5.0
	25-34	1	5.0
	35-44	1	5.0
	45-54	5	25.0
	55-64	4	20.0
	65-74	6	30.0
	75+	2	10.0
Gender	Male	4	20.0
	Female	16	80.0
Marital Status	Single, never married	4	20.0
	Married/common law	12	60.0
	Separated/divorced	1	5.0
	Widowed	3	15.0
Level of Education	Elementary School	2	10.0
	High School	3	15.0
	Post High School Diploma	12	60.0
	University Degree	3	15.0
Occupation	Occupational safety officer	1	5.0
	Advertising sales	1	5.0
	Office manager	2	10.0
	Registered nurse	6	30.0
	Housewife	4	20.0
	Secretary	2	10.0
	Clerk	2	10.0
	Parking attendant	1	5.0
	RCMP officer	1	5.0
Employment Status	Employed - Full time	4	20.0
	Employed - Part time	1	5.0
	Not employed - Retired	10	50.0
	Not employed - can't work	5	25.0

Family played an important role in providing support to the participants in this study. Although 50% of the participants claimed that their spouse or partner was their main source of support, other family members such as children, parents, and siblings were also commonly mentioned. Friends were another important source of support, especially for the single people in the sample. Several participants (n = 6) named more than one source of support. Seventy percent of the participants (n = 14) stated they were very satisfied with the support they were receiving, another 15% (n = 3) were moderately satisfied, and 15% (n = 3) were somewhat satisfied. Descriptions of the participants' sources of support and level of satisfaction with their support are summarized in Table 2.

Table 2

Participants' Sources of Support and Level of Satisfaction with Support

Variable	Categories	Frequency	Percent
Main Source of Support	Spouse or partner	10	50.0
	Children	3	15.0
	Other family members	4	20.0
	Friends	3	15.0
	Others	0	0.0
Degree of Satisfaction with Support	Very satisfied	14	70.0
	Moderately satisfied	3	15.0
	Somewhat satisfied	3	15.0
	Not at all satisfied	0	0.0

Ninety percent (n = 18) of the participants stated that rheumatoid arthritis was the only painful medical condition they had. One participant had rheumatoid arthritis and Crohn's disease and a second participant also had pain due to a spastic bowel disorder. The majority of the participants (n = 14) had lived with rheumatoid arthritis for more than 10 years. One participant was diagnosed 44 years ago and several others have had rheumatoid arthritis for more than 30 years. Two participants have been living with rheumatoid arthritis for 6-10 years, three for 1-5 years, and one for less than 1 year. Living with a chronic pain condition has affected how these individuals view their general health status. Eleven participants reported that they saw themselves as only "somewhat healthy" or "mainly unhealthy" (Table 3).

Table 3

Level of Health of Participants

Variable	Categories	Frequency	Percent
Other Painful Medical Conditions	Yes	2	10.0
	No	18	90.0
Years with Rheumatoid Arthritis	Less than 6 mo.	0	0.0
	6 mo.-1 year	1	5.0
	2-5 years	3	15.0
	6-10 years	2	10.0
	10+ years	14	70.0
General Health Status	Very healthy - No limitations	1	5.0
	Mainly healthy - Well most of the time	8	40.0
	Somewhat healthy - Often do not feel well	6	30.0
	Mainly unhealthy - Seldom feel well	5	25.0

Pain was felt 100% of the time by six of the participants, 60-79% of the time by another two, 40-59% by 2 more; and 20-39% of the time by five of the participants. The remaining five participants experienced pain 0-19% of the time (Table 4). The participants had difficulty determining their "typical level of pain." Many explained that the intensity of their pain varied greatly from one time to the next and gave a range (e.g., 6-9) rather than one specific value. When a range was given, the average value of the range was recorded. Using this approach, the mean rating of typical pain on a scale of 0 (no pain) to 10 (worst pain ever) was 6.125 (SD = 2.675); the median was 7.00; and, the mode was 8.00. These values indicate that 80% of the participants experienced moderate (4-6) to severe (7-10) pain for a significant percentage of the time. For the majority of the participants, pain has been a feature of their lives for more than a decade.

Table 4

Percentage of Time Participants Experience Pain

Variable	Categories	Frequency	Percent
Percent of Time with Pain	0-19%	5	25.0
	20-39%	5	25.0
	40-59%	2	10.0
	60-79%	2	10.0
	80-99%	0	0.0
	100%	6	30.0

Analysis of Themes

Step One: Generation of Statements

A total of 408 statements were generated by the 20 participants in response to the question, "How has living with the pain of rheumatoid arthritis affected your life?" (Appendix G). After removing redundancies, combining statements representing similar ideas, and editing, a master list of 92 statements describing what it is like to live with chronic pain was compiled. These statements are presented in Table 5 and were utilized to develop the concept map.

Step Two: Categorization of Statements

Categorization of the statements initially involved a card sort where 19 of the 20 original participants were asked to group the 92 statements into piles of "statements that go together." One of the original participant's phone number was no longer in service making it impossible to arrange to meet with this individual for the card sort. In addition to sorting the statements, participants also indicated their level of agreement with each statement on a scale of 1 (do not agree) to 5 (agree completely).

Table 5

Living with Chronic Pain Master Statement List

Living with Chronic Pain Master Statement List	
1	The mornings are the worst.
2	It is painful to get moving after being motionless for a while.
3	I've had to relearn how to do things with my hands.
4	I dread being on my feet too long as my knees, ankles, and feet get very sore and tired.
5	I have some form of pain every day.
6	I've learned to mentally block out the pain.
7	I feel useless and I'm not contributing to society.
8	I feel I've been cheated out of a career.
9	I had to stop playing sports.
10	I feel isolated at times.
11	I don't like people to feel sorry for me.
12	I had no opportunity to date, find a partner, and missed out on having children.
13	I can't do the things that other people my age do easily and take for granted.
14	I get so tired, I just want to sit and do nothing.
15	I experience depression at times and withdraw from everything.
16	I am self-conscious about my physical appearance because people ask questions and make comments.
17	I have thought about committing suicide.
18	Reading and educating myself about arthritis and how others cope helps me to go on.
19	Keeping active and doing as much as I can for myself, in order to stay as independent as possible, is important to me.
20	Support from many sources helps me cope with the pain.
21	Accepting my disease was the biggest hurdle.
22	I sometimes feel "shuffled-over" by health care professionals.
23	I am concerned about becoming addicted to pain medication.
24	I worry about the effects of the medication wearing off.
25	Medications have caused me many problems.
26	Rheumatoid Arthritis is not well understood by others and unknowingly, people say and do very insensitive things.
27	I need more sleep than many of my friends.

Living with Chronic Pain Master Statement List	
28	Rheumatoid Arthritis is associated with pain that ranges from mild to excruciating and you may experience this range in a single day.
29	When I don't have pain, it is difficult to describe how bad it can be and when I have pain, it's hard to remember what it feels like to be pain-free.
30	I have had to undergo numerous surgeries.
31	I aim for a reasonably calm attitude.
32	Travel becomes more complicated because of the pain.
33	I've had to give up living in a house.
34	The pain causes feelings of self-pity, anger, and frustration.
35	My partner and I are closer and our relationship has improved.
36	My faith has helped me cope with the pain.
37	I am fearful of falling when I go out.
38	I tend to do lots of things that are less physically demanding because of the pain.
39	I need a push from others to be more active.
40	I have found the therapists to be especially supportive.
41	My ups and downs are more pronounced because of the pain.
42	Having a painful condition makes me more aware of the good things around me.
43	I have given up social activities and hobbies little by little or changed to lessdemanding ones.
44	I find I sometimes have to make excuses or devise cover-ups for things I do or don't do.
45	Most people will help you if you ask, but it is sometimes hard to ask.
46	My partner does not understand or care about the extent of my pain.
47	It is so much better for me as a patient if the family doctors and specialists co-operate.
48	I've had to become very assertive in order to get good health care.
49	Sometimes the treatment in hospitals is demeaning.
50	Rheumatoid Arthritis pain is quite unpredictable so it's difficult to plan activitiesa few days ahead or make long-term commitments.
51	One has to get used to living with a lot of uncertainty.
52	I now hesitate to do certain things that I would have done automatically in the past.
53	I am always reminded that, in a way, I'm not the same person that I was.
54	I am much more aware of the pain other people suffer.
55	The pain causes me to reflect upon how important our health is to us.
56	I'm more careful about the my diet, my alcohol consumption, and the amountof exercise I get.
57	I have to give myself extra time to do things.
58	Physical intimacy with my partner is made difficult.

Living with Chronic Pain Master Statement List	
59	I feel much older than I am and I mourn my healthy youth.
60	I constantly feel helpless and dependent on others for doing simple tasks.
61	I can't climb many stairs.
62	There is family tension between my need for independence and my family'sconcern for me.
63	I have sleepless and restless nights because of the pain.
64	I feel jealousy towards fully-abled bodies.
65	I fear what the future holds for me.
66	Pain sucks the life out of you.
67	I have anxiety attacks.
68	Some days I feel so bad that I just stay in bed.
69	Sometimes I just want to give up because I'm just so tired of fighting.
70	A lot of guilt is involved.
71	The pain is especially stressful during holidays such as Christmas.
72	There are regrets, insecurities, and sadness at giving up what used to be taken for granted.
73	There is a financial drain due to drug costs, special footwear, adaptive devices, housekeeping services, and alternative therapies.
74	I am forced to consider all ways to alleviate pain.
75	I am especially thankful on days when the pain is less or gone.
76	I've had the opportunity to meet many individuals who share ways to cope and often I've made new friends.
77	Having a positive attitude makes all the difference.
78	Keeping busy with work and having many different interests helps you deal with the pain.
79	Having pain made it more difficult to raise children.
80	Self- care is hard at times.
81	Having to spend so much time at the doctor's is disruptive.
82	Laughter is important.
83	The disability is more of a bother than the pain.
84	My medications help to keep the pain under control.
85	When it comes to physical activity, it is a long learning process to find the balance between not hurting yourself and not babying yourself.
86	It's hard for children to understand what you're going through.
87	I notice the pain most at the beginning of a relapse.
88	I've learned to live with the pain.
89	I always fear I'm complaining about nothing.

Living with Chronic Pain Master Statement List	
90	When I have a flare-up I think "Will I have to spend the rest of my life like this?"
91	I stay hopeful that something new will be found to help.
92	When I'm feeling good I try to do a lot of things and make the most of it.

Step Three: Statistical Analysis and Representation of Statements

Once all of the card sorts were completed, they were analyzed using non-metric multidimensional scaling and cluster analysis (Trochim, 1989a). The average rating for each statement and cluster was also computed.

Non metric multidimensional scaling (MDS). The results of all of the card sorts (n = 19) were entered into the Concept System computer program (Trochim, 1989a). The MDS data analysis procedure resulted in a final stress value of 0.30. The stress value is an index of the stability of the MDS solution. It ranges from zero (perfectly stable) to one (perfectly unstable) (Daughtry & Kunkel, 1993). Stress values of 0.32 (Miller, 1996) and 0.31 (Trochim, Cook, & Setze, 1994) have been accepted in recent studies using concept mapping.

A two-dimensional point map of the 92 statements was generated. Each of the statements was indicated by a dot with the statement number next to it. The MDS procedure provided the placement of the points - the distance between points reflecting the number of times the participants sorted the items together. The more often items were sorted together by the participants, the closer together they appeared on the point map. There were several pairs of statements that fell on virtually the same area of the map. These statements should therefore be very closely related to one another. For example, on the right hand side of the map statement #5, "I have some sort of pain everyday" is located almost on top of statement #28, "Rheumatoid arthritis is associated with pain that ranges from mild to excruciating and you may experience this range in a single day." On the upper middle aspect of the map statement #77, "Having a positive attitude makes all the difference" is transposed upon statement #82, "Laughter is important." In contrast, on the lower right aspect of the map statement #15, "I experience depression at times and withdraw from everything" is obscured by statement #17, "I have had thoughts about committing suicide." The close proximity of these pairs of points is to be expected in view of their similarity in meaning. In order to identify themes underlying the similarly sorted statements, a cluster analysis was then performed on the point map produced in the MDS procedure.

Cluster analysis and rating. A hierarchical cluster analysis was conducted on the MDS solution in order to represent the dimensions underlying living with chronic pain. This data analysis groups individual statements on the basis of their similarity in meaning (Miller, 1996). At this stage, the statements are clustered into varying numbers of groups to determine the number of clusters which best represents the concept. The final solution is based both on statistical as well as conceptual considerations (Ludwig, 1996). Trochim (1989a) recommended a procedure whereby all cluster solutions from about 20 to 3 are analyzed in sequence in order to determine which grouping solution is most interpretable. Every time the analysis moves from one cluster solution to the next, statements are examined to decide whether the groupings are conceptually relevant. Trochim (1989a) noted that a key operative rule is to "maintain the integrity of the multidimensional scaling analysis, that is, try to achieve a clustering solution which does not allow any overlapping clusters" (p.9). In addition, excessive fragmentation or over-generalization of statements are to be avoided.

Computation of a "bridging index" also assists in determining the appropriate number of clusters and in the subsequent labelling of the clusters (Trochim, 1989a). The bridging index has a range of 0.0 to 1.0. The lower the bridging index value of a statement, the more likely that statement was sorted primarily with statements that are close together on the map whereas, statements with higher values are more likely "bridge" items being sorted with statements further away on the map. When trying to determine the general concept of a cluster, it is often helpful to look at the statement with the lowest bridging index since the lower the bridging, the more central the statement is to the meaning of that cluster (Trochim, 1989a).

The average bridging index for each cluster was also computed. Clusters with lower bridging values suggest a more coherent set of statements and should be easier to label. Clusters with higher bridging values are more likely to be "linking" clusters bridging between adjacent structures (Trochim, 1989a). Information related to item and bridging indices assisted in determining the most appropriate number of clusters.

Cluster solutions ranging from 18 to 4 clusters were examined. The computer program is arbitrarily set to produce a cluster solution which is one-fifth of the total number of statements (Trochim, 1989a). This resulted in an initial solution of 18 clusters. This solution, however, resulted in clusters that were too discrete (Appendix H). In many clusters, there were only a few items (e.g., clusters 3, 9, 13, 16). There also was overlap in content between several of the clusters. For example, clusters 1, 2, and 3 contained ideas related to pain and its characteristics. Clusters 16, 17, and 18 described issues related to health care.

The 16-cluster solution was examined next. The only difference between this solution and the 18-cluster solution was the combination of clusters 10 and 11 into one cluster, as well as the amalgamation of clusters 13 and 14. Although this removed some of the overlap seen in the 18-cluster solution, much of the same problems remained. As decreasing by only 2 groups did not appear to produce great differences in the cluster solutions, it was decided to decrease cluster solutions in increments of six. Next, the 10-cluster solution was examined (Appendix H). Readily apparent themes appeared to be emerging at this point. For example, cluster 2 contained items related to "being able to do less" because of the pain. Cluster 4 items suggested positive ways of coping with pain. There were still however, some areas of fragmentation. Statement #7 in cluster 5, "I feel useless and I'm not contributing to society" appeared closely related to statement #8 in cluster 6, "I feel I've been cheated out of a career." The overall underlying idea of both these clusters was one of negative feelings or emotions. Both clusters 7 and 8 had statements relating to family concerns, while clusters 9 and 10 contained statements concerning health care issues.

The 4-cluster solution (Appendix H) produced very large statement groupings yielding over-generalization and a lack of detail. Distinct themes that had been obvious in the 10-cluster solution were now grouped together. Statements dealing with family issues were now grouped with statements dealing with health care issues. Themes dealing with "being able to do less" were now grouped with items which described "characteristics of pain". Over one-half of the 92 statements were contained within clusters 1 and 4 making interpretation difficult.

As the appropriate solution appeared to be between 10 and 4 clusters, the 8-cluster solution was next analyzed (Appendix H). Here, several of the areas of fragmentation seen in the 10-cluster solution were addressed. For example, clusters 5 and 6 were both concerned with negative emotions and were now grouped into one cluster. Combining these two clusters resulted in a strong average bridging index of 0.14. Clusters 7 and 8 were also combined into one cluster dealing with family related issues. An average bridging index of 0.44 was obtained for this cluster. However, the last two clusters of this solution still appeared to be fragmented. For example, statement #22 in the new cluster 7, "I sometimes feel "shuffled-over" by health care professionals" appeared closely related to statement #48 in the new cluster 8, "I've had to become very assertive in order to get good care." These two clusters were merged in the 7-cluster solution that followed. Although the average bridging index for this cluster was high, the statements within the cluster appeared to fit together conceptually. As over-generalization of statements appeared to be a problem again in the 6 and 5-cluster solutions, it was concluded that the 7-cluster solution provided the most interpretable and concise description. The concept map of the 7-cluster solution can be seen in Figure 1 and the statements in each of the clusters along with their bridging index are found in Table 6. As a final step in the statistical analysis of the data, an average rating score for each of the seven clusters was also computed.

Step Four: Interpretation of the Maps

"Description of the concept map and individual clusters involves informed conjecture about the possible structure participants imposed on the items in their sorting" (Miller, 1996, p.89). In order to reduce the subjective nature of attaching a descriptive label to each of the clusters, this task was guided by the three-step judging procedure described by Miller (1996). Because the statement with the lowest bridging index in any cluster is most indicative of the schematic content of that cluster (Trochim, 1989a), it was the first item used to inform the labelling of that cluster. Second, less central items were systematically considered, moving from next lowest bridging index upwards. As much as possible, the label given to the cluster reflected the content of these core statements. Third, actual words found in the statements were used to label the cluster whenever possible.

Cluster 1: The impact of pain. Cluster 1, located on the far right side of the concept map, contained statements describing the characteristics and impact of the pain. It had an average bridging index of 0.35. Some of the items described what the pain was like (e.g., #28-varying intensity; #50-unpredictable) and when it was most problematic (e.g., "I notice the pain most at the beginning of a relapse"; "The mornings are the worst"; "It is painful to get moving after being motionless for a while"). Others underlined the impact of the pain (e.g., "I can't do the things that people my age do easily and take for granted"; "I have restless and sleepless nights because of the pain"; "Travel becomes complicated because of the pain"). Pain had an impact on physical (statements #4 and #5), as well as emotional (statements #41, #66, and #71) aspects of people's lives. In reviewing several of the individual card sorts, many of the

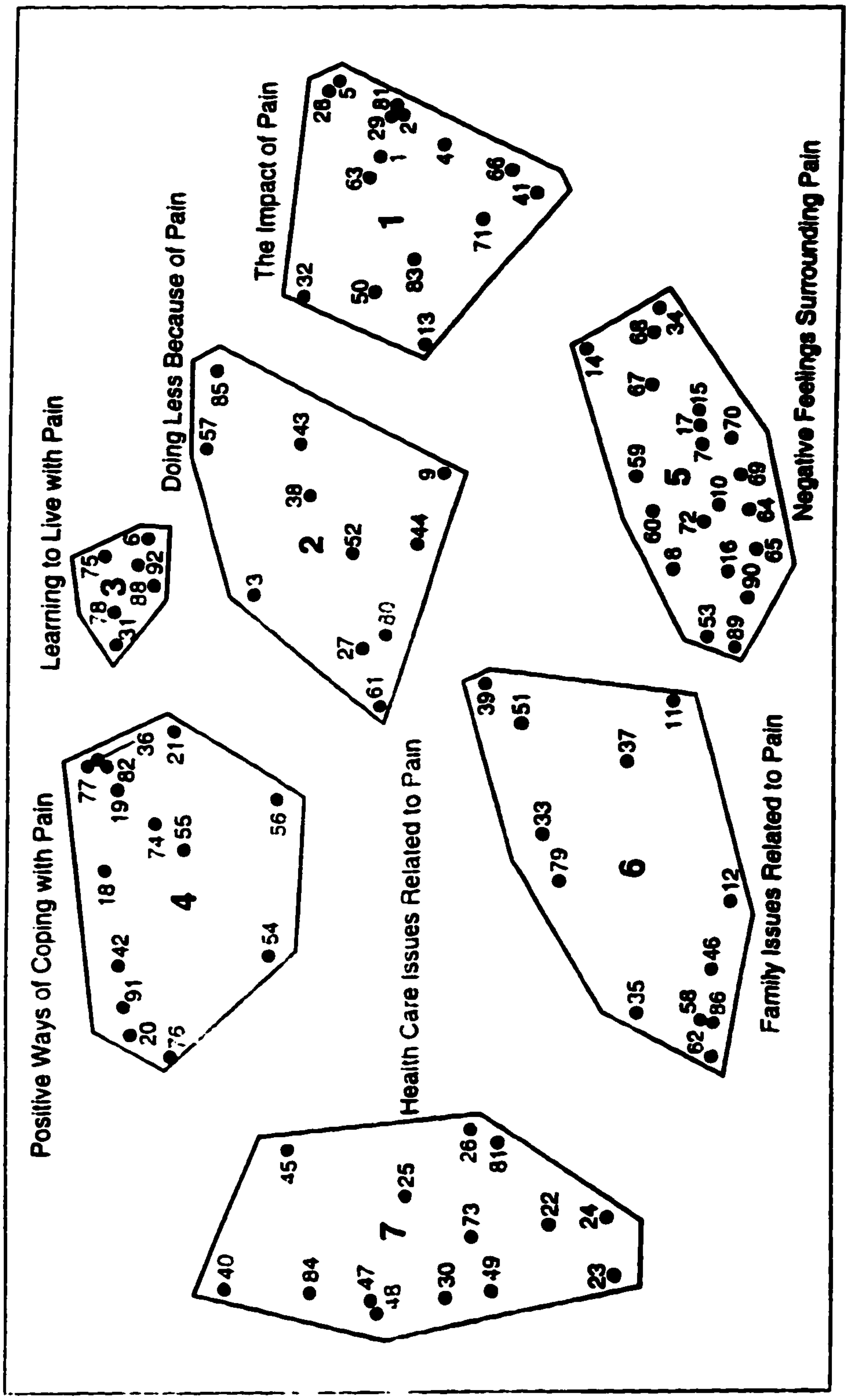

Figure 1: Concept map - 7-cluster solution

Table 6

Statements and Bridging Index for 7-Cluster Solution

	Cluster/Statements	Bridging Index
Cluster 1-The Impact of Pain		
87	I notice the pain most at the beginning of a relapse.	0.24
13	I can't do the things that other people my age do easily and take for granted.	0.25
1	The mornings are the worst.	0.27
2	It is painful to get moving after being motionless for a while.	0.27
63	I have sleepless and restless nights because of the pain.	0.29
5	I have some form of pain every day.	0.30
28	Rheumatoid Arthritis is associated with pain that ranges from mild to excruciating and you may experience this range in a single day.	0.32
50	Rheumatoid Arthritis pain is quite unpredictable so it's difficult to plan activities a few days ahead or make long-term commitments.	0.33
32	Travel becomes more complicated because of the pain.	0.33
4	I dread being on my feet too long as my knees, ankles, and feet get very sore and tired.	0.38
41	My ups and downs are more pronounced because of the pain.	0.41
71	The pain is especially stressful during holidays such as Christmas.	0.41
66	Pain sucks the life out of you.	0.42
83	The disability is more of a bother than the pain.	0.47
29	When I don't have pain, it is difficult to describe how bad it can be and when I have pain, it's hard to remember what it feels like to be pain-free.	0.58
Cluster Average		**0.35**
Cluster 2-Doing Less Because of Pain		
38	I tend to do lots of things that are less physically demanding because of the pain.	0.11
9	I had to stop playing sports.	0.17
43	I have given up social activities and hobbies little by little or changed to less demanding ones.	0.23
52	I now hesitate to do certain things that I would have done automatically in the past.	0.25
80	Self- care is hard at times.	0.26
57	I have to give myself extra time to do things.	0.27
61	I can't climb many stairs.	0.30
44	I find I sometimes have to make excuses or devise cover-ups for things I do or don't do.	0.30

Cluster/Statements		Bridging Index
3	I've had to relearn how to do things with my hands.	0.31
85	When it comes to physical activity, it is a long learning process to find the balance between not hurting yourself and not babying yourself.	0.31
27	I need more sleep than many of my friends.	0.31
Cluster Average		**0.26**
Cluster 3-Learning to Live with Pain		
78	Keeping busy with work and having many different interests helps you deal with the pain.	0.10
88	I've learned to live with the pain.	0.21
92	When I'm feeling good I try to do a lot of things and make the most of it.	0.23
31	I aim for a reasonably calm attitude.	0.41
75	I am especially thankful on days when the pain is less or gone.	0.44
6	I've learned to mentally block out the pain.	0.51
Cluster Average		**0.32**
Cluster 4-Positive Ways of Coping with Pain		
77	Having a positive attitude makes all the difference.	0.08
19	Keeping active and doing as much as I can for myself, in order to stay as independent as possible, is important to me.	0.09
36	My faith has helped me cope with the pain.	0.16
82	Laughter is important.	0.16
18	Reading and educating myself about arthritis and how others cope helps me to go on.	0.20
91	I stay hopeful that something new will be found to help.	0.20
42	Having a painful condition makes me more aware of the good things around me.	0.30
20	Support from many sources helps me cope with the pain.	0.37
74	I am forced to consider all ways to alleviate pain.	0.38
21	Accepting my disease was the biggest hurdle.	0.41
56	I'm more careful about the my diet, my alcohol consumption, and the amount of exercise I get.	0.42
55	The pain causes me to reflect upon how important our health is to us.	0.43
76	I've had the opportunity to meet many individuals who share ways to cope and often I've made new friends.	0.49
54	I am much more aware of the pain other people suffer.	0.74
Cluster Average		**0.32**
Cluster 5-Negative Feelings Surrounding Pain		

Cluster/Statements		Bridging Index
69	Sometimes I just want to give up because I'm just so tired of fighting.	0.00
15	I experience depression at times and withdraw from everything.	0.02
17	I have thought about committing suicide.	0.05
72	There are regrets, insecurities, and sadness at giving up what used to be taken for granted.	0.06
65	I fear what the future holds for me.	0.07
64	I feel jealousy towards fully-abled bodies.	0.09
8	I feel I've been cheated out of a career.	0.10
10	I feel isolated at times.	0.12
60	I constantly feel helpless and dependent on others for doing simple tasks.	0.13
16	I am self-conscious about my physical appearance because people ask questions and make comments.	0.14
59	I feel much older than I am and I mourn my healthy youth.	0.15
7	I feel useless and I'm not contributing to society.	0.16
89	I always fear I'm complaining about nothing.	0.18
90	When I have a flare-up I think "Will I have to spend the rest of my life like this?"	0.21
53	I am always reminded that, in a way, I'm not the same person that I was.	0.21
67	I have anxiety attacks.	0.22
68	Some days I feel so bad that I just stay in bed.	0.24
70	A lot of guilt is involved.	0.30
14	I get so tired, I just want to sit and do nothing.	0.30
34	The pain causes feelings of self-pity, anger, and frustration.	0.33
Cluster Average		**0.14**
Cluster 6-Family Issues Related to Pain		
11	I don't like people to feel sorry for me.	0.04
51	One has to get used to living with a lot of uncertainty.	0.32
33	I've had to give up living in a house.	0.35
39	I need a push from others to be more active.	0.35
37	I am fearful of falling when I go out.	0.36
12	I had no opportunity to date, find a partner, and missed out on having children.	0.39
46	My partner does not understand or care about the extent of my pain.	0.44
86	It's hard for children to understand what you're going through.	0.50
79	Having pain made it more difficult to raise children.	0.52

Cluster/Statements		Bridging Index
62	There is family tension between my need for independence and my family's concern for me.	0.52
58	Physical intimacy with my partner is made difficult.	0.53
35	My partner and I are closer and our relationship has improved.	0.62
Cluster Average		**0.44**
Cluster 7-Health Care Issues Related to Pain		
40	I have found the therapists to be especially supportive.	0.48
48	I've had to become very assertive in order to get good health care.	0.52
47	It is so much better for me as a patient if the family doctors and specialists co-operate.	0.55
22	I sometimes feel "shuffled-over" by health care professionals.	0.60
81	Having to spend so much time at the doctor's is disruptive.	0.60
49	Sometimes the treatment in hospitals is demeaning.	0.60
23	I am concerned about becoming addicted to pain medication.	0.69
45	Most people will help you if you ask, but it is sometimes hard to ask.	0.70
26	Rheumatoid Arthritis is not well understood by others and unknowingly, people say and do very insensitive things.	0.72
30	I have had to undergo numerous surgeries.	0.76
73	There is a financial drain due to drug costs, special footwear, adaptive devices, housekeeping services, and alternative therapies.	0.76
25	Medications have caused me many problems.	0.83
84	My medications help to keep the pain under control.	0.98
24	I worry about the effects of the medication wearing off.	1.00
Cluster Average		**0.70**

statements found in this cluster had been sorted together into groups the participants called "pain" or "pain association" or "daily pain".

Cluster 2: Doing less because of the pain. Cluster 2 was in close proximity to cluster one. The bridging index was 0.26. Although some of the impact of pain was also described in this cluster, the overall underlying theme was one of being able to do less than what one had done in the past. The item with the lowest bridging index (0.11) was, "I tend to do a lot of things that are less physically demanding." The next two lowest items were, "I had to stop playing sports," and "I have given up social activities little by little or have changed to less demanding ones." The ideas of needing more sleep and extra time to do things were also expressed in this cluster. Statements #3, "I've had to relearn how to do things with my hands," and #85, "When it comes to physical activity, it is a long learning process to find a balance between not hurting yourself and not babying yourself," both had a higher bridging index of 0.31. Although these statements did allude to "being able to do less," there also did seem to be an underlying theme of learning, which was dominant in the next cluster.

Cluster 3: Learning to live with pain. The average bridging index for this cluster was 0.32. It was located on the upper portion of the map between clusters two and four. Although it was similar in some ways with cluster 4, in that it dealt with how one copes with the pain, it appeared to have an underlying theme of learning to live with and adjust to a life of pain. Statement #88 which had the second lowest bridging index (0.21) stated, "I've learned to live with the pain." Keeping busy (statement #78), adopting a calm attitude (statement #31), and mentally blocking out the pain (statement #6) were ways people had learned to live with the pain. They also learned to be thankful for days when the pain was less (statement #57) and made the most of days when they were feeling better (statement #92).

Cluster 4: Positive ways of coping with pain. Cluster 4 was located on the upper left side of the map. Its bridging index was 0.32. "Having a positive attitude makes all the difference," had the lowest bridging index (0.08) and seemed to reflect the general theme of positive ways of coping with pain. Coping strategies included remaining as independent as possible (statement #19), use of laughter (statement #82) and faith (statement #36), educating oneself (statement #18), remaining hopeful (statement #91) and being careful about diet and exercise (statement #56). Support form others (statement #20) and meeting new people to share ideas on coping (statement #76) were also seen as positive. The statement, "I am much more aware of the pain that other people suffer," had a high bridging index of 0.74 indicating that it was likely a bridging item that was sorted into various clusters. In reviewing where this item had been placed by individual sorters, it was observed that although it was often sorted in clusters with labels such as "positive attitude" or "coping", it was also frequently placed with groupings labelled "pain" or "pain management."

Cluster 5: Negative feelings surrounding pain. This cluster had the lowest bridging index of all the seven clusters (0.14) and was the most cohesive of the groups. Statement #69 had a bridging index of 0.00 and read, "Sometimes I just want to give up because I'm just tired of fighting." "I experience depression..."; "I have thought about committing suicide"; and, "A lot of guilt is involved," had bridging indices of 0.05 or less. Feelings of fear (statements #89 and #65), jealousy (statement #64), isolation (statement #10), and uselessness (statement #7) were also clustered within this group. Individual sorters often grouped these items under labels such as "destructive attitudes," "negative things," "depression," or "emotional effects of pain." This cluster was located in the lower right corner of the concept map at opposite extremes from cluster 4.

Cluster 6: Family issues related to pain. This cluster located in the lower left aspect of the concept map had a relatively high bridging average of 0.44. Unlike the previous five clusters which dealt with the individual's feelings and coping strategies, statements within this cluster related more to relationships with others, more specifically, those associated with family. "One has to get used to living with a lot of uncertainty," was the item with the lowest bridging index (0.32). "I've had to give up living in a house," and "I need a push from others to be more active," had the next lowest indices at 0.35. Statement #12 described how having a painful condition led to missing out on having a family. Other statements described difficulties with physical intimacy between partners (statement #58); the partner (statement #46) and children (statement #86) not understanding the person's pain; and, difficulties with raising children (statement #52). "My partner and I are closer and our relationship has improved," was the only clearly positive statement in this cluster and had a high bridging index of 0.62, again indicating that it may have been a bridging item.

Cluster 7: Health care issues related to pain. This cluster had the highest bridging average of the seven clusters (0.70). It was located alone on the far left aspect of the concept map. In spite of its high bridging index, items in this cluster appeared to consistently relate to dealing with health care workers or with health care issues. Examples of items found in this cluster were, "I have found the therapist to be especially helpful," "I've had to become very assertive in order to get good care," "It is so much better for me as a patient if the family doctor and specialist co-operate," and "I sometimes feel "shuffled-over" by health care professionals." Three items dealing with medications had the highest overall bridging indices. These include; "I worry about the effects of the medications wearing off" (1.00), "My medications help to keep the pain under control" (0.98), and "Medications have caused me many problems" (0.83). These were placed in many different groups by individual sorters including clusters they labelled "pain", "health care", "physical problems", and "concerns." Eight sorters placed these items in a separate group called "medications."

Interpretation of the map regions. In addition to interpreting and labelling the clusters, other meaningful information can be extracted by visually examining the map (Trochim, 1989a). Inspection of the cluster map reflecting the dimensions underlying living with chronic pain suggested that the experience was organized into two major dimensions: issues that related with the effects pain had on the individual, and issues related to how pain affected the individual's interactions/relationships with others, be they family members or people within the health care field. When separating the map at a diagonal angle from the upper left to the lower right corner, clusters 1, 2, 3, and 4 are grouped in the right upper corner of the concept map, while clusters 5, 6, and 7 are located in the left lower corner. Clusters grouped in the right upper corner contained items related to pain, how it affected the individual, physically and/or emotionally, as well as how the individual coped with the pain.

Clusters located in the lower left corner of the map dealt more with how the pain affected the individual's interactions with others. Pain affected family relations, be it with the individual's partner or children. It led to uncertainty (statement #51) and tension (statement #62). For the most part, the effects of pain on family relations were negative although in at least one instance, it was seen as solidifying the relationship between partners (statement #35). Having pain increased the individual's contact with the health care system (e.g., #30- numerous surgeries; #40- therapists; #49- hospitalization; and, # 81- doctors). Many of these contacts were associated with negative consequences (e.g., #22- feeling shuffled-over; #23 and #24- worries; #26- insensitivity; #73- financial drain; #81- disruption). "I found the therapists to be especially helpful," and "Most people will help if you ask..." reflected more positive experiences while, "I've had to become very assertive in order to get good care," suggested an efficient way of dealing with the people in the health care system. Generally however, the tone of clusters in this part of the concept map was more negative than that of the upper corner.

Interpretation of the rating map. In order to determine the degree of agreement which existed among the individual participants for the statements in the concept map, they were asked to rate the extent to which they agreed with each statement on a scale of 1 (not at all) to 5 (completely). The mean rating for each statement and the percentage of people who greatly or completely agreed with each statement are summarized in Table 7.

The mean agreement for all of the 92 statements was 3.37 out of 5. Fifty-nine (64%) of the 92 statements received a mean rating of 3 (moderately agree) or more. Of these, 22 statements had ratings of 4 or more. Statements #19 and #82 had the highest mean rating of 4.84, followed by statements #75 and #91 with ratings of 4.74, and statements #47, #55, and #92 whose mean ratings were 4.63. The lowest rating was 1.32 for statement #17, "I have thought about committing suicide." Statements #67 and #68 had the next lowest mean rating at 1.42, followed by statement #12, "I had no opportunity

Table 7

Average Ratings of Statements and Percent Agreeing Greatly or Completely

Cluster/Statements		Mean Rating	% Agreeing Greatly/ Completely
Cluster 1- The Impact of Pain			
1	The mornings are the worst.	3.63	52.6
63	I have sleepless and restless nights because of the pain.	3.37	32.1
2	It is painful to get moving after being motionless for a while.	3.63	57.9
29	When I don't have pain, it is difficult to describe how bad it can be and when I have pain, it's hard to remember what it feels like to be pain-free.	4.42	84.2
87	I notice the pain most at the beginning of a relapse.	4.05	79.0
4	I dread being on my feet too long as my knees, ankles, and feet get very sore and tired.	3.21	42.1
5	I have some form of pain every day.	4.11	73.7
28	Rheumatoid Arthritis is associated with pain that ranges from mild to excruciating and you may experience this range in a single day.	3.95	68.5
13	I can't do the things that other people my age do easily and take for granted.	3.58	63.1
50	Rheumatoid Arthritis pain is quite unpredictable so it's difficult to plan activities a few days ahead or make long-term commitments.	3.42	57.9
83	The disability is more of a bother than the pain.	3.21	52.7
32	Travel becomes more complicated because of the pain.	3.53	73.7
41	My ups and downs are more pronounced because of the pain.	3.59	36.8
66	Pain sucks the life out of you.	3.47	52.6
71	The pain is especially stressful during holidays such as Christmas.	3.00	36.9
Cluster Average		**3.61**	**57.7**
Cluster 2- Doing Less Because of Pain			
3	I've had to relearn how to do things with my hands.	3.42	42.1
38	I tend to do lots of things that are less physically demanding because of the pain.	4.11	73.7
43	I have given up social activities and hobbies little by little or changed to less demanding ones.	3.84	63.1

Cluster/Statements		Mean Rating	% Agreeing Greatly/ Completely
52	I now hesitate to do certain things that I would have done automatically in the past.	3.58	57.9
57	I have to give myself extra time to do things.	4.05	73.7
85	When it comes to physical activity, it is a long learning process to find the balance between not hurting yourself and not babying yourself.	3.68	57.9
9	I had to stop playing sports.	3.89	68.4
44	I find I sometimes have to make excuses or devise cover-ups for things I do or don't do.	3.00	36.8
27	I need more sleep than many of my friends.	3.74	63.1
80	Self- care is hard at times.	3.26	47.4
61	I can't climb many stairs.	3.21	47.4
Cluster Average		**3.62**	**57.4**
Cluster 3- Learning to Live with Pain			
6	I've learned to mentally block out the pain.	3.58	57.9
88	I've learned to live with the pain.	4.32	84.2
92	When I'm feeling good I try to do a lot of things and make the most of it.	4.63	94.7
75	I am especially thankful on days when the pain is less or gone.	4.74	94.7
31	I aim for a reasonably calm attitude.	4.21	89.5
78	Keeping busy with work and having many different interests helps you deal with the pain.	4.00	73.7
Cluster Average		**4.25**	**82.5**
Cluster 4- Positive Ways of Coping with Pain			
18	Reading and educating myself about arthritis and how others cope helps me to go on.	3.74	57.9
19	Keeping active and doing as much as I can for myself, in order to stay as independent as possible, is important to me.	4.84	100.0
36	My faith has helped me cope with the pain.	3.74	63.2
77	Having a positive attitude makes all the difference.	4.53	89.5
82	Laughter is important.	4.84	100.0
21	Accepting my disease was the biggest hurdle.	3.95	68.5
55	The pain causes me to reflect upon how important our health is to us.	4.63	89.4
74	I am forced to consider all ways to alleviate pain.	3.00	42.1

Cluster/Statements		Mean Rating	% Agreeing Greatly/ Completely
20	Support from many sources helps me cope with the pain.	3.63	52.7
91	I stay hopeful that something new will be found to help.	4.74	94.7
42	Having a painful condition makes me more aware of the good things around me.	4.11	73.7
76	I've had the opportunity to meet many individuals who share ways to cope and often I've made new friends.	3.00	42.1
54	I am much more aware of the pain other people suffer.	4.58	89.5
56	I'm more careful about the my diet, my alcohol consumption, and the amount of exercise I get.	4.32	84.2
Cluster Average		**4.12**	**74.8**
Cluster 5- Negative Feelings Surrounding Pain			
7	I feel useless and I'm not contributing to society.	2.21	21.0
15	I experience depression at times and withdraw from everything.	1.89	26.3
17	I have thought about committing suicide.	1.32	5.3
69	Sometimes I just want to give up because I'm just so tired of fighting.	1.74	5.3
70	A lot of guilt is involved.	2.00	15.8
59	I feel much older than I am and I mourn my healthy youth.	2.74	36.8
60	I constantly feel helpless and dependent on others for doing simple tasks.	2.42	26.4
14	I get so tired, I just want to sit and do nothing.	2.63	21.0
34	The pain causes feelings of self-pity, anger, and frustration.	2.89	36.8
68	Some days I feel so bad that I just stay in bed.	1.42	00.0
67	I have anxiety attacks.	1.42	5.3
8	I feel I've been cheated out of a career.	2.11	21.1
10	I feel isolated at times.	2.32	42.1
72	There are regrets, insecurities, and sadness at giving up what used to be taken for granted.	3.00	36.9
64	I feel jealousy towards fully-abled bodies.	2.53	11.1
65	I fear what the future holds for me.	2.84	31.6
16	I am self-conscious about my physical appearance because people ask questions and make comments.	2.16	21.1
90	When I have a flare-up I think "Will I have to spend the rest of my life like this?"	3.05	31.6

Cluster/Statements		Mean Rating	% Agreeing Greatly/ Completely
53	I am always reminded that, in a way, I'm not the same person that I was.	3.58	57.9
89	I always fear I'm complaining about nothing.	2.16	11.1
Cluster Average		2.32	23.5
Cluster 6- Family Issues Relating to Pain			
11	I don't like people to feel sorry for me.	4.32	84.3
37	I am fearful of falling when I go out.	3.37	47.4
33	I've had to give up living in a house.	2.26	31.6
79	Having pain made it more difficult to raise children.	2.63	31.6
39	I need a push from others to be more active.	1.79	26.4
51	One has to get used to living with a lot of uncertainty.	3.16	42.1
12	I had no opportunity to date, find a partner, and missed out on having children.	1.47	10.6
46	My partner does not understand or care about the extent of my pain.	1.78	26.4
58	Physical intimacy with my partner is made difficult.	2.72	21.6
86	It's hard for children to understand what you're going through.	4.05	73.7
62	There is family tension between my need for independence and my family's concern for me.	2.21	15.8
35	My partner and I are closer and our relationship has improved.	2.00	15.8
Cluster Average		2.65	32.9
Cluster 7- Health Care Issues Related to Pain			
22	I sometimes feel "shuffled-over" by health care professionals.	2.47	26.3
23	I am concerned about becoming addicted to pain medication.	2.26	26.3
24	I worry about the effects of the medication wearing off.	2.74	36.9
26	Rheumatoid Arthritis is not well understood by others and unknowingly, people say and do very insensitive things.	2.74	36.9
81	Having to spend so much time at the doctor's is disruptive.	3.05	42.1
30	I have had to undergo numerous surgeries.	3.26	63.2
49	Sometimes the treatment in hospitals is demeaning.	2.00	31.6
73	There is a financial drain due to drug costs, special footwear, adaptive devices, housekeeping services, and alternative therapies.	2.47	26.3
25	Medications have caused me many problems.	2.89	36.8

Cluster/Statements		Mean Rating	% Agreeing Greatly/ Completely
47	It is so much better for me as a patient if the family doctors and specialists co-operate.	4.63	94.7
48	I've had to become very assertive in order to get good health care.	3.26	47.4
84	My medications help to keep the pain under control.	4.11	73.6
40	I have found the therapists to be especially supportive.	3.42	52.6
45	Most people will help you if you ask, but it is sometimes hard to ask.	3.32	52.6
Cluster Average		3.05	46.2

to date, find a partner, and missed out on having children," (M = 1.47). Since most of the participants were or had been married this statement did not apply to them, thus the low degree of agreement. A percentage of great or complete agreement was evident for all of the statements except for statement #68, "Some days I feel so bad that I just stay in bed."Seventy-four percent of the participants did not agree at all with this statement, while 26% agreed only slightly or moderately. Another poorly endorsed statement was statement #67, "I have anxiety attacks." Only 5.3% of participants agreed greatly with this statement while 79% did not agree at all. In contrast, 100% of the participants agreed greatly or completely with statements #19 and #82, items describing coping strategies they felt were important to them.

Upon examining the cluster means, it was apparent that the clusters located in the right upper corner of the concept map had higher mean agreement ratings than those in the lower left corner. Of the four clusters located in this region, cluster 3, "Learning to live with pain," had the highest of all the cluster means at 4.25 as well as the highest percentage of people agreeing greatly or completely with the statements it contained

(M = 82.45%). "I am especially thankful on days when the pain is less or gone," had the second highest rating of the 92 statements and the highest rating in this cluster. This was followed closely by, "When I'm feeling good I try to do a lot of things and make the most of it," (M = 4.63).

The cluster with the next highest mean was cluster 4,"Positive ways of coping with the pain," with a mean of 4.12. The percentage of participants agreeing greatly or completely with statements in this cluster was 75%. This cluster contained the two statements with the highest agreement average of 4.84. They were, "Keeping active and doing as much as I can for myself, in order to stay as independent as possible, is important to me," and "Laughter is important." All of the participants agreed greatly or completely with these two statements. A total of eight statements (statements #19, #42, #54, #55, #56, #77, #82, and #91) in this group had mean ratings of 4 or more, with the percentage of participants agreeing greatly of completely with these statements being 100%, 74%, 90%, 89%, 84%, 90%, 100%, and 95% respectively.

Clusters 1, "The impact of pain," and 2, "Doing less because of the pain," had similar means of 3.61 and 3.62 respectively. In cluster 1 there was greatest agreement (84%) with statement #29, "When I don't have pain, it is difficult to describe how bad it can be, and when I have pain it's hard to remember what it is like to be pain-free" (M = 4.42). "I have some form of pain everyday," had the next highest mean rating of 4.11. In cluster 2, there was agreement with the statements, "I tend to do a lot of things that are less physically demanding because of the pain," (M = 4.11), and "I have to give myself extra time to do things,"(M = 4.05). Seventy-four percent of the participants agreed greatly or completely with these three statements. This high level of agreement among participants suggests that they share similar pain experiences.

There was less agreement among participants with the statements found in clusters 5, 6, and 7, located in the left lower corner of the concept map. Cluster 5, "Negative feelings surrounding pain," which had the lowest cluster bridging index on the concept map, also had the lowest mean agreement rating of 2.32. Three (statements #17, #67, and #68) of the four statements with the lowest ratings were within this cluster. Only three of the 20 statements making up this cluster had ratings of 3.00 or more. These were, "I'm always reminded that, in a way, I'm not the same person that I was," (M = 3.58); "When I have a flare-up I think, 'Will I have to spend the rest of my life like this?'" (M = 3.05); and, "There are regrets, insecurities, and sadness at giving up what used to be taken for granted," (M = 3.00). The low rating given to the items in this grouping seemed to suggest that the participants did not wish to dwell on these negative feelings. Even the participants whose personal comments were reflected in a particular item tended to not to agree highly with it. One participant labelled a grouping containing 16 of the 20 items found in this cluster, "fleeting thoughts." It is important to note however that except for statement #68, all of the statements in this cluster had some of the participants agreeing greatly or completely with what was being described. Overall, almost one quarter of the participants reported great or complete agreement with statements in this cluster.

Cluster 6, "Family issues related to pain," had the second lowest mean level of agreement of 2.65 out of 5. Although a few statements had a high level of agreement (e.g., "I don't like people to feel sorry for me," (M = 4.32); "It's hard for children to understand what you're going through," (M = 4.05)), most other statements fell in within the range of 1 (not at all) to 2 (slightly). For example, "My partner does not understand or care about the extent of my pain," had an mean rating of only 1.78. In spite of this low mean rating, 26% of participants greatly or completely agreed with this statement.

The seventh cluster, "Health care issues related to pain," had a moderate agreement rating of 3.05. Mean agreement ratings for individual statements in this cluster ranged from a low of 2.00, "Sometimes treatment in hospitals is demeaning," to a high of 4.63, "It is so much better for me as a patient if the family doctor and the specialists co-operate." Ninety-five percent of participants agreed greatly or completely with the latter statement, while 32% agreed greatly or completely with the former. Twenty-six percent of participants agreed greatly or completely that they felt "shuffled-over" by health care professionals and that they had some concerns about becoming addicted to their analgesics. Sixty-three percent greatly or completely agreed with the fact that they had undergone numerous surgeries and 73% felt that their medications helped to keep their pain under control.

Summary of Findings

Although the sample for this study consisted mostly of older Caucasian females, there were also participants from a variety of age groups, as well as educational and occupational backgrounds, who have had rheumatoid arthritis and pain for varying periods of time. Multidimensional scaling analysis yielded a point map with a stress value of 0.30. A 7-cluster solution was judged to provide the most concise and interpretable description of the themes underlying the dimensions of chronic pain. These themes were: (1) The impact of pain, (2) Doing less because of pain, (3) Learning to live with pain, (4) Positive ways of coping with pain, (5) Negative feelings surrounding pain, (6) Family issues related to pain, and (7) Health care issues related to pain. The experience of living with chronic pain was organized into two major dimensions: (1) how the pain affects the individual and (2) how it affects the individual's relationships/interactions with others. A rating of each statement demonstrated that there was a moderate level of agreement among participants for the items in the concept map. Participants had the highest level of agreement with items found in the clusters related to learning to live with the pain and positive ways of coping with pain. There was least agreement with items relating to negative emotions surrounding pain although a significant percentage of them greatly or completely endorsed the statements contained within this cluster.

CHAPTER FIVE

Discussion

This present study was conducted to gain a better understanding of what it is like to live with chronic pain from the perspective of the individual with rheumatoid arthritis. A review of the literature indicated that in spite of the growing prevalence of chronic pain associated with this condition, there still exists a lack of understanding of the dimensions underlying chronic pain. Furthermore, the majority of conclusions regarding chronic pain originated from studies in which theoretically-driven constructs and models were used to identify the individuals beliefs and experiences rather than exploring this condition from the individual's perspective. The concept mapping approach (Trochim, 1989a) was used to identify specific themes underlying what it was like to live with the chronic pain associated with rheumatoid arthritis. This approach resulted in the development of a concept map containing 92 statements grouped into seven themes. In this chapter, the findings of the study are discussed, the implications are presented, and recommendations for future research are made.

Concept Map

In the initial statement generation phase, 20 volunteers with rheumatoid arthritis living in two urban centres in Alberta produced 408 statements in response to the question, "How has living with the pain of rheumatoid arthritis affected your life?" These statements were edited and redundancies were removed resulting in a final list of 92 items. The editing procedure was validated by the investigator's supervisor. Nineteen of the original 20 volunteers then sorted these statements into groups which they also labelled.

The results of the card sort were analyzed using the Concept System (Trochim, 1989a) and a 7 - cluster solution was selected and labelled providing information about the themes it contained. Using the words found in participants' statements, the seven clusters were labelled: (1) The impact of pain, (2) Doing less because of pain, (3) Learning to live with pain, (4) Positive ways of coping with pain, (5) Negative feelings surrounding pain, (6) Family issues related to pain, and (7) Health care issues related to pain.

Relationship of Themes to Previous Literature

While most of the cluster themes identified in this study were consistent with results of previous research on chronic pain, the findings in this study surrounding "Health care issues related to pain," were not found in previous studies. For the most part, the themes identified in this study reiterated findings of qualitative studies on chronic pain (Bowman, 1994; Howell, 1994; Rose, 1994; Strong et al., 1994; Wiener, 1975). Findings summarized by these researchers relating to the experience of physical symptoms associated with pain itself, its intensity and unpredictability; the impact chronic pain has on family, social life, and personal relationships; altered daily performance and mobility; as well as the effect of chronic pain on emotions, fears of dependency, one's ability to plan ahead, and feelings of isolation were all reflected in the statements and themes of this present study.

"The impact of pain" theme found in cluster 1 was not only frequently found in the above mentioned research, but also supports the notions of pain being a multidimensional phenomenon associated with psychological distress and functional loss (Barkin et al, 1996b; Bonica, 1990; Getto, Sorkness, & Howell, 1987; Hitchcock, Ferrell & McCaffery, 1994; Whitehead & Kuhn, 1990). Cluster statements such as, "I have some sort of pain every day," and "Rheumatoid arthritis is associated with pain that ranges from mild to excruciating..." give credence to claims that pain is a major feature of this chronic condition (Affleck, Tenner, Urrows, & Higgins, 1991; Burckhardt, 1985; Kazis, Meenan, & Anderson, 1983; Parker, Frank, Beck, Finan et al., 1988).

"Doing less because of pain," the theme of cluster 2 was clearly recognized in the literature. Having to give up social activities, hobbies (statement #43), and sports (statement #9), as well as physical limitations such as not being able to climb many stairs (statement #61), are all factors that contribute to the sense of isolation described by Rose (1994). Having to do less physically demanding activities (statement #38), hesitating to do things (statement #52), difficulties with self-care (statement #80), and having to relearn how to do things with one's hands (statement #3) pointed to the functional loss and disability resulting from pain which was described in much of the literature (Badley, Rasooly, & Webster, 1994; Barking et al, 1996; Bonica, 1990; Hitchcock, Ferrell, & McCaffery, 1994; Russell, 1995). Wiener (1975) described how people with chronic pain, use "covering-up" as a social strategy. This was also a strategy used by participants in this study (statement #44).

The third theme, "Learning to live with pain," was supported in several studies related to the process of adjusting to chronic pain (Bowman, 1994a; Howell, 1994; Wiener, 1975). Ideas expressed in cluster 3 relate closely to the end stages of the process of adjustment described by Howell (1994) and Hendler (1984) and included: acceptance of pain and its limitations as a permanent part of life (e.g., "I've learned to live with the pain"; "Accepting my disease was the biggest hurdle,"); seeking ways to adjust (e.g., "I aim for a reasonably calm attitude"; "I've learned to mentally block out the pain"; "I'm especially thankful on days when the pain is less or gone"); and, focusing on leading a fulfilling life in spite of the pain by making the most of good days (statement #92), as well as keeping busy with work and having many different interests (statement #78). Adjusting to pain occurs over time. The fact that many of the participants in this study have lived with their painful condition for an extensive period of time may be part of the reason why statements in this cluster reflected acceptance, adjustment, and leading a fulfilling life in spite of pain.

As the fourth theme, "Positive ways of coping with pain" suggests, participants in this study were using what Manne and Zautra (1992) referred to as active coping. This type of coping involves efforts to function in spite of the pain or to distract oneself from the pain. The participants did not demonstrate the emotional, motivational, and cognitive deficits, or self-defeating behavioural patterns associated with learned helplessness reported to be associated with arthritis (Bradley, 1985). Remaining as independent as possible in spite of pain was a goal to which these individuals aspired. Some strategies described in this cluster such as information seeking (statement #18), use of one's faith (statement #36), remaining hopeful (statement #91), and keeping active (statement #19) were similar to strategies mention in several other studies (Affleck, Urrows, Tennen, & Higgins, 1992; Hagglund, Haley, Reveille, & Alarcon, 1989; Keefe, Caldwell, Martinez, Nunley, Becklam, & Williams, 1991; Manne & Zautra, 1992). Other strategies mentioned in previous research such as reinterpreting painful stimuli, giving positive self-statements, and not catastrophizing (Hagglund et al., 1989), as well as strategies used in cognitive-behavioral approaches to pain management such as use of relaxation techniques and goal setting with self-reinforcement (Parker, Iverson, Smarr, & Stucke-Ropp, 1993) were not specifically alluded to by individuals in this study. "Gaining wisdom" (Howell, 1994) was also a part of positive coping. Participants perceived that because of the pain, they had gained an awareness of the good things around them (statement #42), of the importance of their health (statement #55), and of the pain other people suffer (statement #54). This last statement was also reflected in Bowman's (1994) findings.

Many of the negative feelings expressed in cluster 5, "Negative feelings surrounding pain," have been described in previous research. This is especially true of depression associated with chronic pain (statement #15) which has been extensively studied (Fifield & Reisine, 1992; Hawley & Wolfe, 1988; Haythornwaite, Sieber, & Kerns, 1991; Hitchcock, Ferrell, & McCaffery, 1994). Along with depression, there can also be suicidal ideation as expressed in statement #17 (Bowman, 1994b; Hitchcock et al., 1994; Rose, 1994; Strong, Ashton, Chant, & Cramond, 1994; Sullivan, Reesor, Mikail, & Fisher, 1994) and feelings of guilt (statement #70) (Krutzen, 1984; Sullivan et al., 1994). Anxiety (statement #67) has also been described as being associated with the depression seen in individuals with chronic pain (Hawley & Wolfe, 1988). The negative emotions surrounding numerous losses experienced by the participants (e.g., independence - statement #60; physical and mental abilities - statements #16, #53, #59 and #64; and, meaningful work - statements #7 and #8) were supported by Howell's (1994) findings. Howell's, Bowman's (1994), as well as Rose's (1994) findings also attest to the sense of isolation (statement #10) felt by participants in this study. This isolation was found to result from being able to do less (Howell, 1994), altered interactions with others (Bowman, 1994), or a sense of not being believed by others (Rose, 1994). Participants in this study expressed similar experiences. Anger and frustration (statement #34), as well as sadness and regrets at giving up what used to be taken for granted (statement #72) have also been found to be prominent features of living with chronic pain (Fernandez & Turk, 1995; Howell, 1994; Schwartz & Slater, 1991; Strong et al., 1994).

"Family issues surrounding pain," the theme of cluster 6 has also been studied. It is generally agreed that having a family member who has chronic pain places added stress and strain on the individual's family and/or children (Bowman, 1994; Krutzen, 1984; le Gallez, 1993; Snelling, 1994; Strong, Ashton, & Cramond, 1994). Snelling (1994) found that chronic pain affected marital partnership, sexual activity, and roles within the family, leading to role conflict, decreased sexual activity, social isolation, and feelings of anger, resentment, as well as frustration in other family members. This research lends support to some of the issues raised by the participants in this study (e.g., statements #62, #58, #39, #33, and #12). As with the participants in this study, other rearchers have also found that individuals with chronic pain often feel that their pain is not understood or believed by their partner (statement #46) (Bowman, 1994; Krutzen, 1984; Strong et al. 1994). This is further supported by Schwartz and Slater's (1991) findings that spouses of individuals with chronic pain often admit to not understanding or knowing what to do about their partner's pain. Participants in this study felt strongly that it was difficult for children to understand what they were going through (statement #86). Other researchers do not fully support this notion. Both Krutzen (1984) and le Gallez (1993) found that children could understand and were extremely aware of the pain, suffering, and limitations affecting the individual. Half of the children in le Gallez's (1993) study claimed that living with a sick parent brought them closer as a family. Most of the children expressed concern and displayed a nurturing attitude towards their parent in pain. Participants in this study also agreed strongly that they did not like people to feel sorry for them (statement #11). Newman, Fitzpatrick, Lamb, and Shipley (1990) found that among individuals with chronic pain, those who were better psychologically adjusted did not seek sympathy or support from others and remained active and expressive. Finally, some of the participants felt family tension between their need for independence and their family concern for them (statement #62). Quirk and Young (1990) stated that for young individuals with chronic pain this may indeed be a problem, as some parents tend to become overprotective.

The last theme "Health care issues surrounding pain" has received less attention in this literature. Little has been written about the concerns individuals with chronic pain have surrounding their treatment regimes and/or their interactions with health care professionals. Previous investigators have focused on the patient's views of how their pain was being managed (Afilalo & Tselios, 1996; Skelton, Murphy, Murphy, & O'Dowd, 1996) and levels of patient satisfaction with interpersonal aspects of health care (Cohen, 1996; Grace, 1995a & b). Results of these studies have indicated that patients with pain had significantly lower levels of satisfaction with their care and felt that doctors did not have time to listen to them or ignored what they had to say (Cohen, 1996; Grace, 1995a & b; Rose, 1994). Similar concerns were expressed by participants in this study.

Furthermore, the need for coordination and cooperation between health care professionals caring for individuals with chronic pain (statement #47) expressed by participants, has been recognized as an issue by some health care professionals (MacLeod & Swanson, 1996). Other health care concerns expressed by participants in this study have been mentioned in the literature. For example, Wiener (1975) alluded to the individual with chronic pain's need to and difficulties with eliciting help (statement #45), while Rose's (1994) participants talked about their lives being disrupted by the need to constantly visit doctors (statement #81), or be in hospital. However, other health care issues such as concerns and problems with medications (statements #23 & 24), financial drain (statement #73), and undergoing numerous surgical procedures (statement #30) have not been addressed.

Ratings of Statements

The participants were asked to indicate the extent to which they agreed with the 92 statements on the master list. There was more agreement among participants with statements found within certain clusters than others. Statements within clusters 3 and 4, "Learning to live with pain," and "Positive ways of coping with pain," received high agreement ratings, while those in clusters 1 and 2 received moderately high agreement ratings. This would suggest that there are commonalties within the experiences of the participants in terms of the impact that pain has on their ability to do things they have done in the past and their day to day living. For example, 95% of participants agreed greatly or completely with the fact that they are thankful for (statement #75) and try to make the most of good days (statement #92) and that they remain hopeful that something new will be found to help (statement #91). Eighty-four percent of the participants agreed that they eventually learned to live with the pain and many share common strategies to help them cope positively with the pain (e.g., 95% agreed with statement #91; 89% agreed with statements #54, #55, and #77). These findings also illustrated what was most valued by these participants. All agreed greatly or completely with the desire to remain as independent as possible (statement #19) and that laughter was an important coping strategy (statement #82).

Although there are common experiences among chronic pain sufferers, there are also many differences. This is evidenced in the low agreement ratings found in clusters 5 and 6, respectively, and to a lesser extent cluster 7, "Health care issues related to pain." Statements within cluster 5, "Negative feelings surrounding pain," generally received the lowest level of agreement of all the clusters. It would appear that, although negative feelings are experienced because of pain, these feelings are not necessarily shared among the participants. The low level of agreement for statements within cluster 6, "Family issues related to pain," may in part reflect the individual's personal living arrangements. For example, items dealing with interactions with partners and/or children did not apply to those participants who were living alone while those related to not being able to find a partner and have children did not apply to those who were married and thus received a low level of agreement. It would also appear that participants have different concerns regarding health care issues depending on the quality of encounters they have had with health care workers. Although some reported negative experiences in their interactions with health care professionals (e.g., "I sometimes feel 'shuffled-over' by health care professionals," and "Sometimes treatment in hospital is demeaning"), these were not common to most of the participants and received only minimal level of agreement. It is important to note however, that 26% of the participants (n = 5) greatly or completely agreed with feeling "shuffled-over", while 32% (n = 6) reported similar levels of agreement for the statement describing demeaning treatment in the hospital.

Another factor which may have had some impact on the agreement ratings of certain statements may be the variable nature of rheumatoid arthritis itself. Referring to several of the statements describing the pain and its impact, one of the participants said, "If I had been rating these a few months ago, I would have agreed completely with these statements but I'm feeling really good right now so I can't say that I agree."

Implications of the Findings

The findings support the premise that chronic pain is multidimensional in nature. The themes illustrate that all aspect of a person's life, from their feelings and ability to function, to their relationships with family and others, are affected by pain and that chronic pain adds extra tension, uncertainty, and concerns to the lives of individuals. These findings lend support for the need to use a holistic and multidisciplinary approach in the assessment and treatment of chronic pain (Allegrante, 1996; Barkin et al., 1996a; Katz, 1996; Lister, 1996: Rowbotham, 1995; Whitehead & Kuhn, 1990). Assessment of people with chronic pain must consider not only the anatomic and physiologic processes involved in pain but also any neurologic, psychological, sociocultural, motivational, cognitive, and behavioral factor which may be contributing to the experience of pain (Bonica, 1990; Hanson & Gerber, 1990). As well, some authors suggest that assessing the patient's perspective and the meaning s/he attaches to her/his pain is helpful in the selection of appropriate treatment modalities and avoidance of long-term treatment failure (Nikolaj, 1992; Turk, 1990). Any of these elements should be viewed as potential areas of treatment intervention (Whitehead & Kuhn, 1990).

Participants strongly agreed that when receiving treatment, it was important that general practitioners and specialists cooperate. Some indicated that this was not always the case and that they were left needlessly in pain. For a multidisciplinary treatment approach to be successful, good communication, coordination, and cooperation among people working in various disciplines are paramount. Although the organizational structure of pain clinics is conducive to interdisciplinary communication and co-operation, it is important to develop innovative ways of promoting this same type of co-operation among health professionals outside of these facilities in order to meet the needs of the vast majority of people with chronic pain who do not have access to, or do not attend these highly specialized institutions.

Some of the participants in this study indicated that they felt "shuffled-over," "not well understood," and that they were subjected to "demeaning treatment." Although there was not strong agreement among participants for these comments, it is still important to recognize that these situations exist and that we must seek ways to minimize these perceptions and feelings among chronic pain patients. Health care professionals must recognize the importance of listening empathetically to individuals with chronic pain and conveying to them that their symptoms are being taken seriously. This, along with facilitating dialogue and informing individuals about treatment options and consequences, are vital components of caring for people with chronic pain (Grace, 1995b; Katz, 1996).

Findings from this study also point to areas of need for education and support of individuals experiencing chronic pain. The fact that some participants still expressed concern about becoming addicted to pain medication indicates a need to continually reinforce information regarding these medications and attempt to clarify misconceptions surrounding analgesics. Assertiveness training might also be a valuable part of cognitive-behavioural programs. Not only was it seen as important in the attainment of good health care, but it may increase a person's sense of self-efficacy which many feel contributes to successful, long-term management of chronic pain (Jensen et al., 1991; Lorig et al., 1989; Turk & Rudy, 1991). Education of children and partners of individuals with chronic pain may assist in alleviating some of the lack of understanding and tension which was perceived by participants in this study. The need for support in the form of marital and/or sexual counselling must be assessed (Schwartz & Slater, 1991). Findings also indicate that individuals have a strong desire to remain as independent as possible and value positive ways of coping with their pain. Anyone who works with people in pain should remain cognisant of this fact and provide measures that will enhance and support these individuals' independence and coping abilities.

Finally, the findings illustrate that although there are common experiences among people with chronic pain, there are also many differences. For example, individuals have different negative reactions to their pain. Their coping strategies, sources of support, and even their decisions regarding what type of support to seek were also different. Some indicated they found self-help groups very helpful, while others stated they were not "group-type" people. Health care workers must remain aware that not all people benefit or want to partake in treatment strategies that they offer. Also implied is that it would be unwise to make sweeping generalizations regarding what it is like to live with chronic pain. These findings further underline the subjective nature of pain and the importance of listening to each individual's story and assessing his/her personal perspective and situation.

As a follow-up to this study, a survey using the 92 statements on the master list, could be sent out to a large number of people with rheumatoid arthritis to see how prevalent the issues identified are among the larger population. The effects of factors such as age and length of illness on the importance attached to certain issues could be examined.

Future research using the concept mapping approach could focus on the experiences of people with other painful conditions to identify commonalties and differences in themes. The experiences of partners and children living with an individual with chronic pain could also be investigated in this manner.

Additional research relating to health care issues and concerns surrounding chronic pain could be done in view of the lack of investigation in the area. Finally, future research could focus on the resilience of people living with chronic pain. Researchers could examine how positive coping strategies identified in this study develop and what assists and/or hinders their development and use.

Limitations of Study

Since the purpose of this study was exploratory in nature, the findings are only preliminary and any interpretations must take into consideration some important limitations. First, the themes developed in this concept map are from the perspective of individuals with rheumatoid arthritis. Although it is well established that chronic pain is a prominent feature of this condition, and that the themes described in this study have been identified as applicable to individuals seen in a rheumatology rehabilitation clinic, it is not clear whether these themes would apply to people with other painful conditions such as fibromyalgia, low back pain, or migraines. In order to validate these findings, large groups of people with other forms of pain, as well as those with rheumatoid arthritis, would need to be surveyed to determine if the findings accurately describe other individuals with chronic pain.

Second, although a variety of approaches were used to recruit volunteer participants, in an attempt to reach a wide variety of people, the sample was not representative of all people with chronic pain associated with rheumatoid arthritis. As with past samples of studies relating to pain and arthritis, this sample consisted mainly of white, elderly (55+ years), women, with post-secondary education, and from middle class backgrounds. People from lower socioeconomic and educational backgrounds, ethnic minorities, and rural areas were not represented in this sample. Males and younger individuals were also under-represented. Although generalizability of findings is not an issue in an individual qualitative study, it can become so over time, if several studies on a given topic area consistently under-represent certain elements of the population.

Finally, the technique of concept mapping only provided preliminary data in this exploratory study. Additional research is needed to provide a more complete picture of issues surrounding the experience of living with chronic pain.

Conclusion

The goal of this investigation was to gain an understanding of the dimensions underlying the experience of living with chronic pain. As a result of this study, a set of 92 items describing how living with chronic pain affected people's lives were identified based on the experiences of individuals living with rheumatoid arthritis. The development and interpretation of a concept map containing these statements produced some themes previously cited in the literature as well as one theme which was not as well represented.

The rating data suggested that the participants were most unified in their agreement with statements relating to the themes of "Learning to live with pain," and "Positive ways of coping with pain." They indicated moderate levels of agreement in terms of the impact pain was having on them and their decreased functional abilities. In spite of the negative impact of pain on their lives, participants valued and used positive coping strategies and learned to live with it. As a group, they reported little agreement regarding the negative feelings brought about by chronic pain even though all mentioned some specific negative emotions when filling out their initial questionnaire. Agreement on items under the theme of family issues were dependent on whether the individual was single or had a partner and/or children. Although individual concerns were expressed surrounding health care issues, again there was only slight to moderate agreement with most of the items. However, a substantial percentage of participants agreed greatly or completely with some of these concerns. These findings have implications for practice, education, and future research.

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APPENDIX A: Information Sheet and Consent Form

Information Sheet

Study Title:	**Living with Chronic Pain of Rheumatoid Arthritis.**
Researcher:	**Suzette Roy, RN** **Masters of Nursing Candidate** **Faculty of Nursing, University of Alberta** **Phone: 438-1405**
Supervisor:	**Dr. Louise Jensen** **Associate Professor** **Faculty of Nursing, University of Alberta** **Phone: 492-6795**

****

I am a Master of Nursing student who is looking for people who would like to share their experience of what it is like to live with the pain of rheumatoid arthritis. The purpose of this study is to gain an understanding of what it is like to live with long-term pain. If you are 18 years of age or older, and have had rheumatoid arthritis for 6 months or more you can participate in this study.

Participation: There are no known risks resulting from taking part in this study. Findings from this study may help healthcare workers provide better care to people with chronic pain. Taking part in this study is completely your choice. Your participation will not be discussed with your healthcare providers. You may choose to drop out of this study at any time by simply telling the researcher. You may refuse to answer any questions. There will be no negative consequences to you or your medical care as a result.

Procedure: The study will take place in your home at two different times convenient for you. It is expected that each visit will take about 1 hour of your time.

First, you will complete a questionnaire to obtain some background information. Then, you will be asked to write as many statements as you can explaining how living with the pain of rheumatoid arthritis has affected your life. You will be given the choice of doing this with or without the researcher's help. If you choose to work on your own, a stamped, self-addressed envelope will be provided for you to return your completed statements.

Second, the researcher will contact you later to arrange to meet with you again. At this time, you will be given cards on which your statements, and those of other people taking part in the study, are written. You will be asked to sort the cards into groups of statements that you feel go together. You also will be asked to rate each statement as to how much it has impacted your life.

Confidentiality: Your identity will be kept confidential. You will not sign your name on any questionnaire. Only the researcher will know your name. All information will be kept in a locked cabinet. Your name, address, and consent form will be kept separate from other written information. The only other person who will have access to identifying information will be the researcher's thesis supervisor. Direct quotations and examples of your statements may be used in papers or presentations. However, your name will never be used. Information may be used for other studies but only after further ethical approval has been obtained.

Phone 438-1405 (after 5 p.m.) if you are interested in taking part in this study.

Consent Form

Study Title: Living with Chronic Pain of Rheumatoid Arthritis
Researcher: Suzette Roy, RN
Masters of Nursing Candidate
Faculty of Nursing, University of Alberta
Phone: 438-1405
Supervisor: Dr. Louise Jensen
Associate Professor
Faculty of Nursing, University of Alberta
Phone: 492-6795

****

Purpose of the Study: The purpose of this study is to gain an understanding of what it is like to live with the pain of rheumatoid arthritis.

Participation: There are no known risks resulting from taking part in this study. Findings from this study may help healthcare workers provide better care to people with long-term pain. Taking part in this study is completely your choice. Your participation will not be discussed with your healthcare providers. You may choose to drop out of this study at any time by simply telling the researcher. You may refuse to answer any questions. There will be no negative consequences to you or your medical care as a result. You will be free to ask questions at any time during the study.

Procedure: The study will take place in your home at two different times convenient for you. It is expected that each visit will take about 1 hour of your time.

First, you will complete a questionnaire to obtain background information. Then, you will be asked to write as many statements as you can explaining how living with the pain of rheumatoid arthritis has affected your life. You will be given the choice of doing this with or without the researcher's help. If you choose to work on your own, a stamped, self-addressed envelope will be provided for you to return your completed statements.

Second, the researcher will contact you later to arrange to meet with you again. At this time, you will be given cards on which your statements, and those of other people taking part in the study, are written. You will be asked to sort the cards into groups of statements that you feel go together. You also will be asked to rate each statement as to how much it has impacted your life.

Confidentiality: Your identity will be kept confidential. You will not sign your name on any questionnaire. Only the researcher will know your name. All information will be kept in a locked cabinet. Your name, address, and consent form will be kept separate from other written information. The only other person who will have access to identifying information will be the researcher's thesis supervisor. Direct quotations and examples of your statements may be used in papers or presentations. However, your name will never be used. Information may be used for other studies but only after further ethical approval has been obtained.

Consent: I have had the procedures for this study explained to me. I am satisfied with the answers to my questions. I understand that:

- -I can contact the researcher or her supervisor with future questions.
- -I can drop out of the study at any time.
- -I can refuse to answer any questions.
- -There are no risks or no immediate benefits from taking part in this study.
- -All records that can identify me will be kept confidential.

Participant's Statement:

I,________________________________, have read this information and agree to be in the study called "Living with Chronic Pain of Rheumatoid Arthritis." I have received a copy of this form to keep.

____________________________	_______________________
(Signature of Participant)	(Date)
____________________________	_______________________
(Signature of Researcher)	(Date)

DO YOU WISH TO RECEIVE A SUMMARY OF THE STUDY? Yes___No___

APPENDIX B: Demographic Questionnaire

ID NUMBER: __________

Please circle the right answer and fill in the blanks where appropriate.

---

1. What is your age?
    1. 18-24 years
    2. 25-34 years
    3. 35-44 years
    4. 45-54 years
    5. 55-64 years
    6. 65-74 years
    7. 75 years or older

2. Your gender is:
    1. Male
    2. Female

3. What is your ethnic background?
    1. Aboriginal
    2. African American
    3. Asian
    4. Caucasian
    5. Other ____________

4. What is your marital status?
    1. Single, never married
    2. Married or common law
    3. Separated or divorced
    4. Widowed

5. What level of education have you completed?
    1. Partial high school
    2. High school
    3. Post high school diploma/certificate
    4. Partial university (degree not completed)
    5. University degree
    6. Masters degree or higher
    7. Other

6. What was/is your occupation? ______________________________

7. What is your present employment status?
    1. Employed full time
    2. Employed part time
    3. Not employed (retired)
    4. Not employed (can't work)
    5. Not employed (can't find work)

8. How would you describe your general health?
    1. Very healthy-- no limitations
    2. Mainly healthy-- feel well most of the time
    3. Somewhat healthy-- often do not feel well
    4. Mainly unhealthy-- seldom feel well

9. Who is your main source of support?
    1. Spouse or partner
    2. Children
    3. Other family members
    4. Friends
    5. Other (minister, neighbour, rheumatologist)_____

10. How satisfied are you with your support?
    1. Very satisfied
    2. Moderately satisfied
    3. Somewhat satisfied
    4. Not at all satisfied

11. How long have you had rheumatoid arthritis?
    1. Less than 6 months
    2. 6 months to 1 year
    3. 2 to 5 years
    4. 6 to 10 years
    5. More than 10 years

12. Do you have any other medical conditions which cause you pain?
    1. Yes Specify: ____________________
    2. No

13. What percentage of the time do you experience pain due to your rheumatoid arthritis?
    1. 0-19%
    2. 20-39%
    3. 40-59%
    4. 60-79%
    5. 80-99%
    6. All of the time

14. On a scale of 0 to 10, with 0 being no pain and 10 being excruciating pain, indicate your typical level of pain.

0 1 2 3 4 5 6 7 8 9 10

No pain

Worst pain ever

APPENDIX C: Pain Questionnaire

ID NUMBER:________

Instructions:

Please write as many statements as you can about your experience of living with pain due to rheumatoid arthritis.

HOW HAS LIVING WITH THE PAIN OF RHEUMATOID ARTHRITIS AFFECTED YOUR LIFE ?

1.______________________________

____

2.______________________________

____

3.______________________________

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4.______________________________

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5.______________________________

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6.______________________________

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7.______________________________

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8.______________________________

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9.______________________________

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11.____

12.____

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14.____

15.____

16.____

17.____

18.____

19.____

20.____

APPENDIX D: Instructions for Rating Statements

The following is a list of statements describing how living with the pain of rheumatoid arthritis has affected people's lives. Read each statement and rate the extent to which you agree with what is described in that statement. Rate the statement from 1 (Not at all) to 5 (Completely) using the following scale:

Not At All	Slightly	Moderately	Greatly	Completely
1	2	3	4	5

1. The mornings are the worst. 1 2 3 4 5
2. It is painful to get moving after being motionless for a while. 1 2 3 4 5
3. I've had to relearn how to do things with my hands. 1 2 3 4 5
4. I dread being on my feet too long as my knees, ankles, and feet get very sore and tired. 1 2 3 4 5
5. I have some form of pain every day. 1 2 3 4 5
6. I've learned to mentally block out the pain. 1 2 3 4 5
7. I feel useless and I'm not contributing to society. 1 2 3 4 5
8. I feel I've been cheated out of a career. 1 2 3 4 5
9. I had to stop playing sports. 1 2 3 4 5
10. I feel isolated at times. 1 2 3 4 5
11. I don't like people to feel sorry for me. 1 2 3 4 5
12. I had no opportunity to date, find a partner, and missed out on having children. 1 2 3 4 5
13. I can't do the things that other people my age do easily and take for granted. 1 2 3 4 5
14. I get so tired, I just want to sit and do nothing. 1 2 3 4 5
15. I experience depression at times and withdraw from everything. 1 2 3 4 5
16. I am self-conscious about my physical appearance because people ask questions and make comments. 1 2 3 4 5
17. I have thought about committing suicide. 1 2 3 4 5
18. Reading and educating myself about arthritis and how others cope helps me to go on. 1 2 3 4 5
19. Keeping active and doing as much as I can for myself, in order to stay as independent as possible, is important to me. 1 2 3 4 5
20. Support from many sources helps me cope with the pain. 1 2 3 4 5
21. Accepting my disease was the biggest hurdle. 1 2 3 4 5
22. I sometimes feel "shuffled-over" by health care professionals. 1 2 3 4 5
23. I am concerned about becoming addicted to pain medication. 1 2 3 4 5
24. I worry about the effects of the medication wearing off. 1 2 3 4 5
25. Medications have caused me many problems. 1 2 3 4 5
26. Rheumatoid Arthritis is not well understood by others and unknowingly, people say and do very insensitive things. 1 2 3 4 5
27. I need more sleep than many of my friends. 1 2 3 4 5
28. Rheumatoid Arthritis is associated with pain that ranges from mild to excruciating and you may experience this range in a single day. 1 2 3 4 5
29. When I don't have pain, it is difficult to describe how bad it can be and when I have pain, it's hard to remember what it feels like to be pain-free. 1 2 3 4 5

30. I have had to undergo numerous surgeries. 1 2 3 4 5
31. I aim for a reasonably calm attitude. 1 2 3 4 5
32. Travel becomes more complicated because of the pain. 1 2 3 4 5
33. I've had to give up living in a house. 1 2 3 4 5
34. The pain causes feelings of self-pity, anger, and frustration. 1 2 3 4 5
35. My partner and I are closer and our relationship has improved. 1 2 3 4 5
36. My faith has helped me cope with the pain. 1 2 3 4 5
37. I am fearful of falling when I go out. 1 2 3 4 5
38. I tend to do lots of things that are less physically demanding because of the pain. 1 2 3 4 5
39. I need a push from others to be more active. 1 2 3 4 5
40. I have found the therapists to be especially supportive. 1 2 3 4 5
41. My ups and downs are more pronounced because of the pain. 1 2 3 4 5
42. Having a painful condition makes me more aware of the good things around me. 1 2 3 4 5
43. I have given up social activities and hobbies little by little or changed to less demanding ones. 1 2 3 4 5
44. I find I sometimes have to make excuses or devise cover-ups for things I do or don't do. 1 2 3 4 5
45. Most people will help you if you ask, but it is sometimes hard to ask. 1 2 3 4 5
46. My partner does not understand or care about the extent of my pain. 1 2 3 4 5
47. It is so much better for me as a patient if the family doctors and specialists co-operate. 1 2 3 4 5
48. I've had to become very assertive in order to get good health care. 1 2 3 4 5
49. Sometimes the treatment in hospitals is demeaning. 1 2 3 4 5
50. Rheumatoid Arthritis pain is quite unpredictable so it's difficult to plan activities a few days ahead or make long-term commitments. 1 2 3 4 5
51. One has to get used to living with a lot of uncertainty. 1 2 3 4 5
52. I now hesitate to do certain things that I would have done automatically in the past. 1 2 3 4 5
53. I am always reminded that, in a way, I'm not the same person that I was. 1 2 3 4 5
54. I am much more aware of the pain other people suffer. 1 2 3 4 5
55. The pain causes me to reflect upon how important our health is to us. 1 2 3 4 5
56. I'm more careful about the my diet, my alcohol consumption, and the amount of exercise I get. 1 2 3 4 5
57. I have to give myself extra time to do things. 1 2 3 4 5
58. Physical intimacy with my partner is made difficult. 1 2 3 4 5
59. I feel much older than I am and I mourn my healthy youth. 1 2 3 4 5

60. I constantly feel helpless and dependent on others for doing simple tasks. 1 2 3 4 5

61. I can't climb many stairs. 1 2 3 4 5

62. There is family tension between my need for independence and my family's concern for me. 1 2 3 4 5

63. I have sleepless and restless nights because of the pain. 1 2 3 4 5

64. I feel jealousy towards fully-abled bodies. 1 2 3 4 5

65. I fear what the future holds for me. 1 2 3 4 5

66. Pain sucks the life out of you. 1 2 3 4 5

67. I have anxiety attacks. 1 2 3 4 5

68. Some days I feel so bad that I just stay in bed. 1 2 3 4 5

69. Sometimes I just want to give up because I'm just so tired of fighting. 1 2 3 4 5

70. A lot of guilt is involved. 1 2 3 4 5

71. The pain is especially stressful during holidays such as Christmas. 1 2 3 4 5

72. There are regrets, insecurities, and sadness at giving up what used to be taken for granted. 1 2 3 4 5

73. There is a financial drain due to drug costs, special footwear, adaptive devices, housekeeping services, and alternative therapies. 1 2 3 4 5

74. I am forced to consider all ways to alleviate pain. 1 2 3 4 5

75. I am especially thankful on days when the pain is less or gone. 1 2 3 4 5

76. I've had the opportunity to meet many individuals who share ways to cope and often I've made new friends. 1 2 3 4 5

77. Having a positive attitude makes all the difference. 1 2 3 4 5

78. Keeping busy with work and having many different interests helps you deal with the pain. 1 2 3 4 5

79. Having pain made it more difficult to raise children. 1 2 3 4 5

80. Self- care is hard at times. 1 2 3 4 5

81. Having to spend so much time at the doctor's is disruptive. 1 2 3 4 5

82. Laughter is important. 1 2 3 4 5

83. The disability is more of a bother than the pain. 1 2 3 4 5

84. My medications help to keep the pain under control. 1 2 3 4 5

85. When it comes to physical activity, it is a long learning process to find the balance between not hurting yourself and not babying yourself. 1 2 3 4 5

86. It's hard for children to understand what you're going through. 1 2 3 4 5

87. I notice the pain most at the beginning of a relapse. 1 2 3 4 5

88. I've learned to live with the pain. 1 2 3 4 5

89. I always fear I'm complaining about nothing. 1 2 3 4 5

90. When I have a flare-up I think "Will I have to spend the rest of my life like this?" 1 2 3 4 5

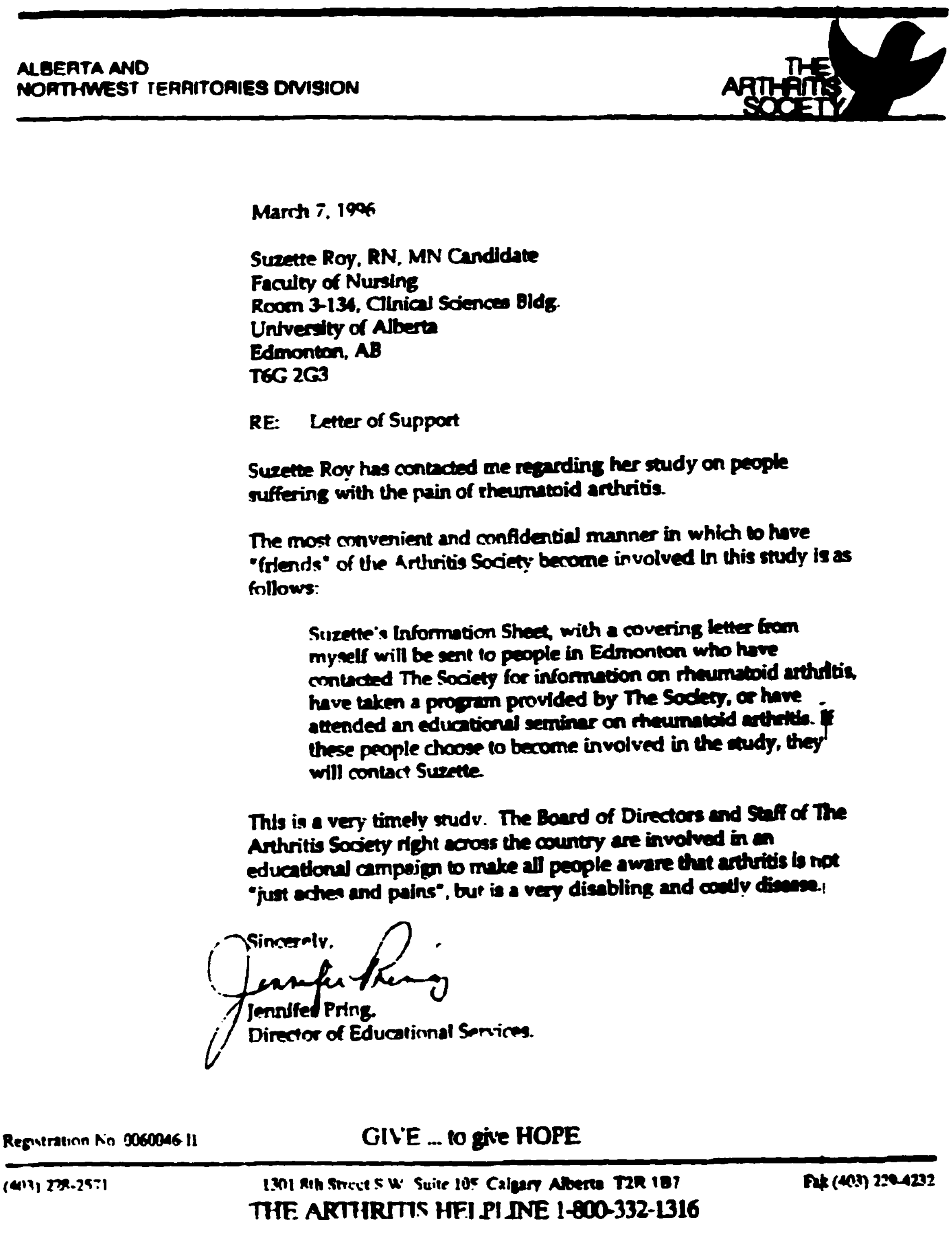
91. **I stay hopeful that something new will be found to help.** **1 2 3 4 5**

92. **When I'm feeling good I try to do a lot of things and make the most of it.** **1 2 3 4 5**

APPENDIX E: Instructions for Card Sort

Enclosed are cards with statements people with rheumatoid arthritis have made to describe what it is like to live with their pain. I am asking your help in sorting these statements into groups that go together. You can sort the statements into as many groups as you like. Each statement can only be placed into one group at a time. There has to be more than one group. Statements can be kept separate if you don't think that they fit into any group.

APPENDIX F: Permission from Institutions and Ethical Clearance



ALBERTA AND
NORTHWEST TERRITORIES DIVISION

THE ARTHRITIS SOCIETY

March 7, 1996

Suzette Roy, RN, MN Candidate
Faculty of Nursing
Room 3-134, Clinical Sciences Bldg.
University of Alberta
Edmonton, AB
T6G 2G3

RE: Letter of Support

Suzette Roy has contacted me regarding her study on people suffering with the pain of rheumatoid arthritis.

The most convenient and confidential manner in which to have "friends" of the Arthritis Society become involved in this study is as follows:

> Suzette's Information Sheet, with a covering letter from myself will be sent to people in Edmonton who have contacted The Society for information on rheumatoid arthritis, have taken a program provided by The Society, or have attended an educational seminar on rheumatoid arthritis. If these people choose to become involved in the study, they will contact Suzette.

This is a very timely study. The Board of Directors and Staff of The Arthritis Society right across the country are involved in an educational campaign to make all people aware that arthritis is not "just aches and pains", but is a very disabling and costly disease.

Sincerely,

Jennifer Pring

Jennifer Pring,
Director of Educational Services.

Registration No 0060046 11

GIVE ... to give HOPE

(403) 228-2571 1301 8th Street S.W. Suite 105 Calgary Alberta T2R 1B7 Fax (403) 229-4232

THE ARTHRITIS HELPLINE 1-800-332-1316

Anthony S Russell Professional Corporation
MA, MB, BChir, FRCP(C), FRCP Phone 492-[illegible]

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Rheumatology/Clinical Immunology
562 Heritage Medical Research Centre
University of Alberta
Edmonton, Alberta T6G 2S2

Fax 492-6055

March 8, 1996

Ms. Suzette Roy, RN
Faculty of Nursing
FAX # 492-2551

Dear Ms. Roy:

In reply to your letter of February 8th, the Edmonton Rheumatic Disease Unit approves your request for support towards your research of individuals experiencing pain due to rheumatoid arthritis. This is by way of placing a notice in the waiting area of the Department of Medicine Clinic.

Kind regards,

Yours sincerely,

P Davis, F.R.C.P.(C)

PD/vr

Arthritis Association of Edmonton

412. 10136 - 100 STREET
EDMONTON, ALBERTA T5J 0P1
PHONE: 425-8792
FAX: 425-0103

MARCH 11, 1996

MS. SUZETTE ROY, MN CANDIDATE
FACULTY OF NURSING
UNIVERSITY OF ALBERTA
T6G 2G3

Dear Suzette,

Thank you for calling us to discuss your thesis proposal: Living with the Chronic Pain of Rheumatoid Arthritis.

The Arthritis Association of Edmonton is supportive of your initiative and grants you permission to access their membership via our Newsletter.

Good Luck in your thesis work. We look forward to your results. If we can be of further assistance to you, please do not hesitate to contact us at 425-8792, Monday to Friday, 8:30 AM - 12:30 pm.

Yours truly,

Lettie Coffin, President
ARTHRITIS ASSOCIATION OF EDMONTON

BERNICE SUTHERLAND
NEWSLETTER EDITOR
ARTHRITIS ASSOCIATION
OF EDMONTON

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Faculty of Nursing

3rd Floor Clinical Sciences Building

Certification of Ethical Acceptability for Research Involving Human Subjects

---

NAME OF APPLICANT(S): Suzette Roy, MN Candidate

TITLE OF PROJECT: "Living with Chronic Pain of Rheumatoid Arthritis"

The members of the review committee, having examined the application for the above named project, consider the procedures, as outlined by the applicants, to be acceptable on ethical grounds for research involving human subjects.

Mar 28/96
Date

Janice Lander, PhD
Chair, Ethics Review Committee

ERC 96-080
5005-02-080

Capital
Health
Authority

Regional Research Administration Office
WMC 5C2.16, 492-1372

Memorandum

NOTICE OF APPROVAL FOR PROPOSED RESEARCH
UNIVERSITY HOSPITALS SITE

Project Title: Living with chronic pain of Rheumatoid Arthritis
Project No.: R-22

Investigator(s): Ms. Suzette Roy
Department: Faculty of Nursing
Division:
Address: CSB 3rd Floor
Phone/FAX: 438 1405

Supporting documents:

1)	Ethical Approval	March 1996
2)	Study Protocol	Project Summary
3)	Funds: a) Source	AARN Scholarship
	b) Type	Grant
4)	Overhead Negotiated	N/A
5)	Account #	
6)	Contract	N/A

Project Approved April 1996

By

Title

Barbara Brady-Fryer
~~*Regional Manager*~~
Research Administration
Capital Health Authority

Copies to: Dr D L Tyrrell
Department Chair
Finance

Capital
Health
Authority

REFERRAL HOSPITAL SYSTEM
Glenrose Rehabilitation Hospital Site

16 April 1996

Suzette Roy
GEO,
3rd Floor Clinical Sciences Building
Faculty of Nursing
University of Alberta
Edmonton, Alberta T6G 2G3

RE *Living with Chronic Pain of Rheumatoid Arthritis*

Dear Suzette.

The Research Ethics Committee has advised that the above-noted proposal has been reviewed and found to be ethically acceptable. On their recommendation, I am pleased to advise you that your project is approved

Approval is given for a three year period, with an automatic yearly review. Any substantial changes made subsequent to this review must be submitted to the committee for approval.

I wish you success with your project!

Sincerely,

Linda Youell
Acting Senior Operating Officer,
Glenrose Site

Enclosures

cc: K Pain

m\approval\roy

APPENDIX G: Participants' Original Statements

#	Statements	ID
1.	The mornings are the worst - lying motionless for eight hours - its hard/painful to get moving again.	A
2.	Because of the damage to my hands, I've had to learn how to hold a pen again.	A
3.	If I'm on my feet too long, they get very sore and tired.	A
4.	I have some form of pain - mostly minor- every day but I've learned to block it mentally.	A
5.	Went to the driving range today - later, my hands became very stiff and sore.	A
6.	Some days the arthritis affects my spine causing headaches.	A
7.	Feel that I'm not contributing to society.	B
8.	Had to leave work, stop playing sports.	B
9.	Friends from the office still phone but still feel isolated at times.	B
10.	I don't like people to feel sorry for me.	B
11.	First thing I think of in the morning - how much will I ache today.	B
12.	Affected personal life - started at 22 - no opportunity to date, find a mate.	B
13.	Feel I've missed out on a family life, having children, etc.	B
14.	There is a feeling of loneliness because I can't do the things that other people can do.	B
15.	Get so tired - want to sit and do nothing.	B
16.	Went into depression at one time - withdrew from everything.	B
17.	Felt a burden to friends.	B
18.	Physical appearance - isolating, self-conscious because people ask questions, make comments, etc.	B
19.	Crossed my mind to "jump off the bridge"- reading and realizing others cope helped me to go beyond this phase.	B
20.	Realized that I must do what I can for myself.	B
21.	Accepting friends have been a big help in helping me cope.	B
22.	Accepting my disease was the biggest hurdle for me.	B
23.	Feel "shuffled-over" by healthcare professionals. Specialists often say "we can't do anything for you."	B
24.	Have to take pain killers to control the pain - concerned about becoming addicted or the pain killing effect wearing off.	B
25.	Important to pace yourself - when pain gets too strong have to back off or lay down.	B
26.	Can't do much in the evenings - have had to cancel many outings because of the pain.	B
27.	Home alone a lot.	B
28.	Hard to find someone of same age with the disease to talk to and compare notes.	B

#	Statements	ID
29.	I live by myself and manage pretty well but if I can't do something it gets left.	B
30.	Sometimes when at work, had to go back the next day and apologize for snapping at people, or sit down and cool down.	B
31.	Some days feel cheated out of a career.	B
32.	Had a very supportive company who assisted me to find the work that was right for me. Was lucky to have an understanding boss.	B
33.	Made decision to quit work because I felt I was hurting myself and the company, I couldn't wait till Friday to recharge (work was put off or done in half- measure).	B
34.	Pain medications have caused me problems with my stomach and my eyes.	B
35.	Try to educate yourself and read all you can about all types of arthritis.	B
36.	I can't do many of the everyday things other people take for granted eg. open a jar first thing in the morning; sit through a two hour movie.	C
37.	RA is not well understood and unknowingly people say very insensitive things. eg. "If people going up one floor used the stairs, we wouldn't have to wait so long for the elevator."	C
38.	There are few warnings alerting you to a good day or a bad day. Changing weather usually does affect how you feel. Other times you have increased pain for no reason at all.	C
39.	Many people do not understand how you can do very active things one day and have difficulty walking up the stairs the next.	C
40.	I worry about doing things that are important to me. When I was younger I worried about doing normal things with my kids. Sometimes I couldn't put peanut butter on their toast because I couldn't hold the knife, now I worry about not being able to do the work I love. I use my back and shoulder muscles to lift and transfer patients because I can't bend at the knee.	C
41.	I pretend I'm fine sometimes when I'm not because I don't want to be treated any different.	C
42.	I need more sleep than many of my friends, chronic pain wears you down.	C
43.	I try to keep active because I don't want to lose any range of motion.	C
44.	I wear lifts in my shoes. When you have pain, you tend to walk in such a way to minimize it; this resulted in atrophy of a muscle in my legs that is corrected by the lifts. In the beginning it hurt to wear the lifts.	C
45.	As a nurse, I've seen many patients with GI bleeds due to long-term anti-inflammatory use. I've been on these meds for more than 15 years. Some years the equivalent of 3000 aspirins. I could be one of these patients one day.	C
46.	I'm fortunate in that I have very little physical deformity and therefore little functional limitation but because the cycle of exacerbation and remission is so poorly understood I worry that this might change.	C
47.	I am very frustrated by health care professionals working in this area that minimize the idea of pain. RA is associated with pain that ranges from mild to excruciating and you may experience this range in a single day.	C

#	Statements	ID
48.	I have on several occasions dreamt that I was in a car accident, when I start to wake up I realize I was just still for too long or sleeping in an awkward position. If I can straighten myself or massage the joint, the pain will lessen. Sometimes I have to wake up my husband to help me.	C
49.	Sometimes I can't wear a dress or skirt because my knees have bulging pockets of fluid.	C
50.	My medication makes me bruise easily. Goofing around with my family in particular has resulted in large bruises which they subsequently feel bad about. I have however had large bruises when I don't even recall having bumped into anything	C
51.	I was advised not to have anymore children because of the post partum hormonal shifts which frequently precipitate an exacerbation.	C
52.	When you do not have pain, it is difficult to describe where you have it or even rate how bad it can be. When you have pain, its hard to remember what it feels like not to have it.	C
53.	I sometimes wonder... If this is what 38 feels like, God help me if I live to 90!	C
54.	Orthopaedic surgery.	D
55.	Curtailed dancing, gardening.	D
56.	Try a positive attitude.	D
57.	Water exercises or showers.	D
58.	Diet - for weight control.	D
59.	Avoid alcohol.	D
60.	Gold side-effects, lungs, blood, lymph.	D
61.	Pain seems to make unsympathetic health professionals.	D
62.	Forgiven with help. (by family members)	D
63.	Aim for a reasonably calm attitude - too impatient.	D
64.	Exercise - especially range of motion	D
65.	Look for easy ways to entertain.	D
66.	Pace to avoid exhaustion.	D
67.	Avoid long trips.	D
68.	Dry eyes require medications.	D
69.	Unable to help at church activities - bake-sales, suppers.	D
70.	House and garden too much for me.	D
71.	I had to sell a Jaguar X6.	D
72.	Unable to skate, bike, and water ski because of knees.	D
73.	Set limits.	D
74.	Has affected all aspects of my life - had to give up activities such as sailing, cross country skiing and square dancing.	E

#	Statements	ID
75.	I've had to give up my house.	E
76.	Pain has caused anger and frustration which are difficult to deal with.	E
77.	Affected me mentally - gets me down and causes me to flare up du.e to frustration due to inability to do what I want to do	E
78.	Affected my wife - it was hard on her to see someone she loved be in pain.	E
79.	Whining about my condition to friends does not help - I give them the facts when they ask.	E
80.	Thankful the Lord has given me a positive outlook on life.	E
81.	My children, friends and church community are great support.	E
82.	Has brought me closer to my wife and our relationship improved.	E
83.	Has brought closer to the Lord - made me realize my dependence on him and my fallibility.	E
84.	If I go out I have to be very careful not to fall because I can't get up.	E
85.	Numerous surgeries - knees, shoulders, replacements.	E
86.	Because of the pain sometimes tend to do lots of things that are less physically demanding (computer) - my wife provides the initiative to go for walks, etc.	E
87.	Still travel by automobile but take frequent rest stops.	E
88.	Had very good experiences with people in the healthcare system - the therapists were especially supportive.	E
89.	My ups and downs are more pronounced because of the pain.	E
90.	Getting up in the morning is a constant reminder of my condition.	E
91.	Painful condition makes me more acutely aware what the good things around me - greater appreciation for nature.	E
92.	Early retirement - caused me to take theology courses and start working with older people - presently one of my most important activities - a reason to get up in the morning.	E
93.	Need a push to get involved in social activities.	E
94.	Tylenol helps me fall asleep at night - have to take them in the middle of the night.	E
95.	If I don't sleep well at night due to pain I feel worse in the morning and have to take naps - was bad when I worked but now that I'm retired I can give in to this more easily.	E
96.	Sometimes feel guilty that when I first was diagnosed I took it out on my teenage sons. Have since talked about this with them - it has not caused a rift between us.	E
97.	At first when I got RA the pain made it very hard to walk and to get up and out of bed.	F
98.	The pain was worse at night - I had to get up in the middle of the night to relieve the pain and stiffness.	F
99.	I get gold needles once a month and they control the pain well.	F
100.	I've had no problems with the needles or the Voltaren.	F

#	Statements	ID
101.	I have to pace myself when I go into the garden.	F
102.	Most of the time now I sleep well at night and have no problems with fatigue.	F
103.	Having to go to get tests and results before gold injecting is becoming more complicated as the lab is in a different place from the doctor's - lots of waiting - 2 half-days gone!	F
104.	When I first got RA, I couldn't do anything because of the pain.	F
105.	Food tasted bad at first - I lost a lot of weight - I didn't eat.	F
106.	Twice a year I saw a specialist, at first now I just see my family doctor.	F
107.	I had a carpal tunnel operation done because my fingers were numb/sleepy all the time - it helped a lot.	F
108.	The strength in my hands is not as good as it used to be.	F
109.	When my pain is bad I have a hard time getting in and out of the tub so I take showers now.	F
110.	When it first started I had to go in a wheelchair when I was on holidays.	F
111.	It took several months to see the specialist when I first got RA - the medication the family doctor gave me did not work.	F
112.	The specialist did not seem to approve of the carpal tunnel surgery.	F
113.	My husband helps me a lot around the house - there are things I cannot do.	F
114.	I can't work - my hands don't work.	G
115.	I can't play the piano, organ in church - too painful.	G
116.	I can't do any housework.	G
117.	I used to enjoy sports - basketball, bowling, skating- I've had to give these up.	G
118.	I was very involved in social activities - have given them up little by little.	G
119.	I have to always know my limitations when I start something (eg. walking) so that I know I can get back.	G
120.	I love to travel but more and more I must be careful of where I go - I like to go by myself - gives me a sense of independence but it may mean more money, more planning and pacing myself.	G
121.	I don't have the energy to do things in the evenings.	G
122.	I find I sometimes have to make excuses for not doing things with people - some understand others don't. Some people stop asking me out after a while.	G
123.	I have to go grocery shopping where someone will pack and carry groceries for me.	G
124.	Most people if you ask will help you - but it is sometimes hard to ask.	G
125.	There are a lot of misconceptions about the pain of arthritis - e.g., handicapped parking only given temporarily because my pain is variable.	G
126.	Money - I have to pay a cleaning lady, have to get my hair washed, spend money for medication/massage therapy and more pre-prepared food.	G

#	Statements	ID
127.	I expect that if my hips get worse I will have to move from my house to where there are less stairs.	G
128.	It creates problems in the family - spouse does not understand the extent of my pain and is not interested in moving.	G
129.	For about five years I was in hospital more times than out having numerous surgeries on hands, feet, etc.	G
130.	Chronic illness/pain seems to be pushed to the back burner - hard to get attention - e.g., physio - I think that it would be much better to pay attention and keep people productive.	G
131.	I've had to change my types of social activities to less active types of events - e.g., movies, theater - I don't have the energy I used to have.	G
132.	I took a long time to find a doctor who knew how to help me - they sure seem to have better treatments now.	G
133.	There seems to be some politics between the family doctor and the specialists that have placed me in awkward positions and left me in pain.	G
134.	If the family doctors and specialists co-operate, it is so much better for me as a patient.	G
135.	I've had to stop taking gold treatments because the side effects - diarrhea, rashes, etc.	G
136.	I was on prednisone - ulcer developed.	G
137.	I've had to become very assertive about my care in order to get good care.	G
138.	I was feeling very low at times - reading about others in the same situations is helpful to help you cope.	G
139.	Sometimes the treatment in rehabilitation hospitals was demeaning as we were treated like children.	G
140.	It made me realize for the first time how uncaring and unsympathetic my wife could be. This was the first time I had ever been anything but very strong and full of energy for her and her response to my pain and inability to just get around somedays was simply critical. She more or less kept denying that I could have something like RA and said, "It just takes 'willpower' to deal with it!". On many mornings, it took 'willpower' just to get out of bed, let alone function normally all day. So RA revealed something very significant to me in this way.	H
141.	RA pain is very haphazard, one day it's in a shoulder, the next day in a toe, maybe the next day nowhere at all, then the next day in a wrist or foot. It's quite unpredictable so it's difficult to plan activities a few days ahead. One has to more or less plan day by day, depending on where the pain is and it's severity. One has to get used to living with a lot of uncertainty.	H
142.	Depending on how well my medication takes each week, the extent of how much I can do and "enjoy" doing, varies. At one point, it was very difficult to sit through a two hour movie in a theater or a concert, play, etc., because of inflammation in my knees and ankles, and after the finish, have to walk at a snail's pace for the first few hundred yards, until the joint and muscle stiffness subsided somewhat. At times like that, one feels "very old" and that's psychologically difficult for someone who was very active prior to the RA.	H

#	Statements	ID
143.	I now hesitate to do certain things that would have been done automatically, like "second nature" in the past, simple things like just jumping off a short ledge of any kind, like jumping two or three feet off of our deck, because I think of what the impact might be on my ankle and knee joints. This always reminds me that I'm, in a way, not the "same person" that I was.	H
144.	On the positive side, I've met a lot of long-time sufferers of the disease, men and women of all ages, and this has made me much more aware of the pain people suffer. When you are always strong and healthy, it's difficult to empathize with those who are not. When I see someone walking or getting up very slowly now, whether it's due to RA or some other ailment they might have, I am sympathetic and don't simply ignore them as "old" as I probably did, even subconsciously, in the past.	H
145.	RA pain causes me to reflect upon how important our health is to us, it's not just a catchy phrase so often heard. As a result, I'm more conscious of other health-related aspects, like watching my weight and what I eat, lowering my wine consumption, exercising as regularly as I can etc. When you have RA, you realize you don't need any other physical drawbacks to deal with.	H
146.	Constantly feeling frustrated and helpless.	I
147.	Can't run, dance.	I
148.	Have to give myself extra time to do things.	I
149.	More prone to irritability, self-pity, anger.	I
150.	Physical intimacy with my partner is made difficult and therefore frequency decreases.	I
151.	Loss of jobs/decreased income.	I
152.	Can no longer be youthfully reckless- I feel much older than I am.	I
153.	Dependent on others for simple tasks (i.e. opening jars, moving objects).	I
154.	Can't pull my bed covers up at night.	I
155.	Can't walk for long amounts of time.	I
156.	Can't oversleep, quickly get ready, dash outside and still make it in time for an appointment, work, etc.	I
157.	Family tension between my need for complete autonomy and my family's concern for me.	I
158.	Nostalgia for my healthy youth- mourning for my healthy youth.	I
159.	Sleepless and restless nights because of pain.	I
160.	Unable to be grateful for other people's sympathy.	I
161.	Jealousy towards fully-able bodies.	I
162.	Fear of getting older.	I
163.	Do not like to think about the future.	I
164.	Fear that RA will keep me form accomplishing (career-wise) what I want to do.	I
165.	Fear of financial dependency.	I

#	Statements	ID
166.	The pain sucks the life right out of you.	K
167.	I would have committed suicide long ago had it not been that I have a son who needs me.	K
168.	It's hard on the family- they don't know how to support you- they try to understand but to no avail.	K
169.	I get frustrated when my child gets mad at me when I'm not feeling well.	K
170.	I can only handle so much pain- they tell you not to take too much medication-but I look at it this way- if I can get away from the pain for even 5 min. it is worth it for me and my family.	K
171.	I got very impacted from my medications- the doctor was very rough when he disimpacted me- I will never go to him again.	K
172.	I can't do the things with my hands that I used to do- I can't paint, wallpaper, roll cigarettes, crochet.	K
173.	I can't use my arms excessively- it causes stiffening of muscles and a burning sensation in my neck.	K
174.	The things that I like, I can't have- tea, carbonated drinks...	K
175.	I can't walk the stairs- anymore than 4 or 5 steps and I'm in pain.	K
176.	I have anxiety attacks.	K
177.	Nothing much has worked to help relieve the pain- anti-inflammatories were not much good for me.	K
178.	Doctors told me that the pain was in my head.	K
179.	Some days I feel so bad that I just stay in bed.	K
180.	The health care professionals seem frustrated because they don't know what to do.	K
181.	I have a scooter to drive- it gives me a certain amount of independence.	K
182.	I used to walk with my spouse to lose weight-now I can't anymore.	K
183.	The doctors tell you that you must exercise, you must walk- but you can only do what you can- walking from home to the drugstore and back wears me out completely.	K
184.	I'm getting worn out from not sleeping for all these years- I'm trying to get to see a doctor who specializes in sleep disorders.	K
185.	You just feel so useless- I don't have any energy to do anything- even getting dressed in the morning.	K
186.	I read articles and if sounds like what I have I'll try out what they suggest- I'm going by the books, not by the doctors , because they can't do anything-.	K
187.	Financially, I'm on ASCH- but you have to buy so many things to be able to get along.	K
188.	You can't plan to go out on a particular evening- you can be sick on that evening.	K
189.	Pain affects your friendships- they don't understand that you can't promise to do things on a definite date.	K
190.	I don't go out in the winter time except for doctor's appointments.	K

#	Statements	ID
191.	Sometimes I can't drive- the pain in my arms make it hard to turn the wheel.	K
192.	I had an episode once when my whole body seemed to lock- I couldn't move my head, my legs, nothing.	K
193.	Sometimes I just want to give up- I'm just so tired of fighting this.	K
194.	My daughter and I had a falling out- she doesn't understand what I am going through.	K
195.	Friends can't handle seeing you in pain- they don't want to talk about the pain- they don't understand.	K
196.	I feel cut off from the world.	K
197.	I can only relate with one friend because she is going through the same thing that I'm going through.	K
198.	At its worse, I didn't do laundry, I could not walk the stairs.	L
199.	I had to ask my brothers to go to the store for me or drive me to the store- I could not drive. Quite often the replies were "Do I have to?" or "I'll go later." With friends, I have to sit through all of their errands.	L
200.	Difficulties climbing onto the bus. No running to try and catch the bus. Quite often waiting for the next one.	L
201.	Glares from people wondering why I do not give up my seat to the elderly or the handicapped- I don't look sick.	L
202.	At work I use the elevator to go up one flight of stairs- listening to and having to take comments about why I'm not taking the stairs. A lot of guilt is involved. I start to try cover-ups by carrying a lot of work (binders) or transport them in carts so that is obvious why I take the elevator.	L
203.	There is a dread when I have to continuously stand up, walk to a copier and then sitting down again. It just feels lousy and hurts to bend the knee and ankle, putting weight on it. The slippery floor in the copier room- insecurities of slipping or falling down.	L
204.	My arthritis is worst Nov.-Feb.(in Vancouver)-Stress of not being able to work, can't do Christmas shopping, or groceries for baking relying on others.	L
205.	I don't feel like limping into parties. Afraid of dancing- slipping, misstepping is common (fear of falling).	L
206.	Being off work- less income and the high cost of alternative therapies.	L
207.	When the swelling was so bad I was not able to attend my martial arts class or I was limited in my ability to participate. Knowing that I can do the exercise and then can't is frustrating. Instructors wonder why I'm not working out as hard.	L
208.	The continuous explanations of why I do what I do because I am young and I look even younger. It's what one may expect of a much older individual.	L
209.	A lot of Tylenols are taken for pain- some relief achieved.	L
210.	A lot of sadness in giving up...whatever was taken for granted "Oh I can do that tomorrow" No! The time is now.	L
211.	There are regrets (should haves),depression (can't do anymore), insecurities (appearances, relationships).	L

#	Statements	ID
212.	It's only in the past 10 years that things have been positive for me- the first 30 were hell- I had to fight all the way- even to get out of bed was a battle	M
213.	I was so sore but I didn't want to show it so at first I didn't tell anyone- shaking hands was so painful it brought tears to my eyes.	M
214.	I've had numerous operations- I was self-conscious about how I looked all the time.	M
215.	It was so hard to do anything- even getting in and out of the car - my husband had to make a special handle for me to be able to open the car door.	M
216.	I appreciate so much when people notice and help you out (with doors, etc.)- most people don't though.	M
217.	I don't think that people can understand what the pain is like- they don't believe what it's really like.	M
218.	I decided to find a job just so I had a reason to get out of bed everyday; I also took correspondence courses at home to keep me busy- I had to do something.	M
219.	People at work were very helpful but it wasn't always easy- some days my husband would carry me into work and people would bring my work to me.	M
220.	My knee would hurt so much that I would spend my nights pacing the floor. Two years ago, I had a knee replacement- I had a wonderful therapist and rehabilitated very quickly. I'm very happy with the results.	M
221.	I had no social life for the first 30 years- I couldn't dress up, felt self-conscious so my husband and I went out a lot just by ourselves.	M
222.	I retired in 1975 because I felt that it wasn't fair to the people that I worked with- I was away so much, I felt guilty.	M
223.	I started walking near where I used to live when I first returned to Edmonton after my husband's death. That is how I met a lady at the Volunteer Action Center who sent me to the YWCA. The group I joined there helped me to adjust to my condition and to life without my husband and friends. Volunteering has also helped me become my own person.	M
224.	I believe that my new attitude is what is helping me deal with the pain- before, my arthritis was killing me physically and emotionally. Now, I still have the pain but I can handle it better; now, I don't let it get me down.	M
225.	I was so sick of being the 5th wheel that I decided I had to learn to do more for myself- I've joined the Elder Hostel and I've learned how to drive in the city and out on the highway.	M
226.	I have a bad spell every late winter/ early spring- I have a couple of months of "giving up", getting tired, wanting to stop fighting - but when I feel better again I forget about those times.	M
227.	I think that arthritis is caused by stress, anxiety, and unhappiness. It was so bad at first that I didn't want to live.	M
228.	I've lost the use of my fingers- the therapist was going to supply me with some aids to help me, but she never called back.	M

#	Statements	ID
229.	Therapists who deal with arthritis patients don't seem to have much caring, they seem bored (especially with older women). People are not getting the care they need. I know that looking after arthritis can become boring but these people do need help.	M
230.	When I had my knee replacement, I got super care from the therapists.	M
231.	Forced to leave employment as an RN.	N
232.	Review priorities for daily living.	N
233.	Suffer little losses along the way- e.g. no longer able to wear "nice" shoes.	N
234.	Give up tub baths.	N
235.	Withdraw from some volunteer activities.	N
236.	Seek help with housework.	N
237.	Seek help with meal preparations cutting etc. especially for dinner guests.	N
238.	Limit mobility, bus travel except "low bus" difficult.	N
239.	Seek adaptive devices and aids.	N
240.	Dressing is difficult, so mornings are very slow.	N
241.	Everything goes slower e.g. Shower, dressing, household tasks.	N
242.	Sleep is often disrupted.	N
243.	Financial drain due to drug costs, special footwear, splints.	N
244.	Travel is difficult especially by car in terms of a vacation.	N
245.	Forced to consider all ways to alleviate pain- hot, cold, prayer, alternative medicine.	N
246.	Abandoning some dreams for the future.	N
247.	Being especially thankful on days when the pain is less or gone!	N
248.	Looking at life in a different way. Letting go of coulds and shoulds.	N
249.	Relationships not always easy, as you must request help from others and its sometimes hard to do.	N
250.	Allows you to meet many individuals who share ways to cope and often make new friends.	N
251.	I've tried to live a full life in spite of the pain.	O
252.	When my hip bothered me I couldn't walk, go to the mall or walk any great length.	O
253.	I stayed home after I had my children so I was able to pace my work and rest more often when needed.	O
254.	I've always kept active in the community in spite of the pain.	O
255.	Psychologically, I didn't let the pain get me down- my mental outlook and attitude have always been positive.	O
256.	I get annoyed at times when people ask if it hurts or make comments about my hands- I wish they would mind their own business.	O

#	Statements	ID
257.	The onset of my RA seemed to have been precipitated by stress- my first daughter had just been diagnosed with epilepsy, I was devastated, stressed out to the limit.	O
258.	I've been on many different types of medications for RA- they all worked to some degree but were changed to see if other drugs would work better.	O
259.	I've experienced no real financial impact- we've always had Blue Cross to help pay for the medications.	O
260.	I'm too busy to wear splints etc.	O
261.	At one time, I was sick and tired of going for injections so I tried self- medication- hospital education was helpful in making me realize the importance of taking medications regularly.	O
262.	Though I cannot carry many bags, pain is not stopping me from travelling.	O
263.	I've always had good experiences with health care workers.	O
264.	Having a positive attitude makes all the difference- it gives you a reason to get up in the morning.	O
265.	Keeping busy (not to the point of fatigue) and having many different interests helps you deal with the pain.	O
266.	Had to give up my work- missed the social part of working at first.	P
267.	Had to sell my home.	P
268.	Had to get a cleaning lady- couldn't do housework anymore.	P
269.	It made it more difficult to raise 3 children on my own.	P
270.	Can't do many things that I liked to do- ski, sew, handwork, walking.	P
271.	Hesitate about traveling- I can't walk much anymore due to my ankles.	P
272.	Can't find shoes that fit properly any more.	P
273.	Difficult to entertain- have to even be careful about what to cook because food preparation is difficult.	P
274.	It is hard to pick up my grandchildren.	P
275.	Hard to pick up groceries- have to pick up only small amount at a time.	P
276.	Can't get a bathing suit on or off, therefore can't swim.	P
277.	Self- care can be hard at times- dressing, combing hair are painful.	P
278.	It is scary to think that every year you can do less and less, so can't think about it.	P
279.	Fear of falling- the time might come when I might need a cane but I will fight that as long as I can.	P
280.	Pain wears you down and the fatigue is very frustrating.	P
281.	I try to make plans and commitments so as to force myself to do things otherwise I might just sit in my chair all day.	P
282.	I would really like to have a week off from injections- it interferes with schedules- it's a pain in the butt.	P

#	Statements	ID
283.	It is hard to make long-term commitments such as volunteering or further studies because you don't know if you will be able to keep them.	P
284.	Managing your energy becomes very important.	P
285.	Keeping busy helps to keep your spirits up.	P
286.	Laughter is important- my upbeat friends are helpful.	P
287.	Onset of RA happened at a particularly stressful time in my life (was heading towards a divorce).	P
288.	I had some very good periods of remission for which I am grateful- it allowed me to work longer.	P
289.	Small things like buttoning clothing, putting on socks can cause great frustration.	P
290.	It is now taking longer for test results to come back from the labs- difficult coordinating medications etc.	P
291.	Developed a tolerance to a lot of pain over time.	Q
292.	I can't do things I like to do - crafts, baking, cooking, gardening	Q
293.	Disability more of a bother than the pain I think.	Q
294.	My medication - anti-inflammatories etc., help to keep the pain under control.	Q
295.	Elbows so painful at times could hardly eat.	Q
296.	Both knees replaced & joints in one hand are artificial.	Q
297.	Could hardly pick up my youngest daughter after she was born - had a major flair up during that pregnancy and spread to all my joints.	Q
298.	Methotrexate - chronic lung problem - antibiotic resisted bacteria.	Q
299.	Had to quit nursing in '87 - couldn't pass out the medications - i.e., open bottles, punch out pills.	Q
300.	Now that the children are grown and have time to do projects - I can't.	Q
301.	4 major surgeries in four years - it does wear you down.	Q
302.	Haven't driven for about 3 years - lose a lot of your independence.	Q
303.	Can't do very much - it kind of gets you down - depressing at times.	Q
304.	Can feel terrible one day - feel good the next - it fluctuates a lot.	Q
305.	Disability pension helps to deal with finances.	Q
306.	Generally good experiences with health care professionals - did feel that my former GP was tired of seeing me at times.	Q
307.	Have two little grandchildren - that keeps me going.	Q
308.	Feel RA due to physical/emotional stress, poor diet.	R
309.	Stayed off most medications - ibuprofen kept to a minimum.	R
310.	Had to interrupt holidays because knees so sore - had knees replaced.	R
311.	Was in a wheelchair for several years.	R

#	Statements	ID
312.	I worked through the pain - I put up with it.	R
313.	In 90's had to limit my activities - stairs are very much a problem.	R
314.	Do exercises daily and go to the pool three times a week.	R
315.	Use a masseuse, chiropractor.	R
316.	Can't curl, golf, dance, walk, etc. - I've had to change my lifestyle.	R
317.	Hard for the children in that even though I've tried not to let it affect them - they sometimes had to do more around the house.	R
318.	No coffee, tea, sugar, wheat flour, meat-When I hear of things that help others I try it.	R
319.	Done a lot of reading.	R
320.	Take vitamins, minerals, herbs.	R
321.	Replaced activities I can't do with other activities - swimming, playing cards, reading - go out a lot.	R
322.	Limited my piano playing.	R
323.	Don't entertain as much as we used to - when we do we keep it simple - e.g., no lunch.	R
324.	Have to learn to gage your energy and learn to say no.	R
325.	As friends grow older, they slow down too - making it easier for me.	R
326.	Rest, minimizing physical/emotional stress and eating plenty of fruits/vegetables - staying away from meat most important.	R
327.	It's been tough - husband not always as understanding - had to go on holidays no matter what - spend holiday in tent trailer.	R
328.	Unless you've actually had RA pain, can't imagine what it's like.	R
329.	Have problems with pernicious anemia due to RA - very tired and down at that time - liquid herbs have helped.	R
330.	Some doctors are more appreciative of my "free thinking" ideas - My family doctor suggests things with me but doesn't tell me what to do.	R
331.	Trying to find a balance between "Not hurting myself" and "not babying myself" when it comes to physical activity - It's a long learning process - Don't know as you are exercising if your doing too much - 24 hours later, you find out.	R
332.	Kept very private about my condition - people didn't know about it when I was not well, I'd keep to myself. (People who are well don't want to hear a whiner.)	R
333.	Notice the pain most at the beginning of a relapse then you just have to live with - you just live with it.	R
334.	Fortunate that I can live by myself.	R
335.	Cranky, more sensitive at time of pain.	R
336.	Had to stop work prematurely - couldn't work.	S
337.	First couple of years awful - raising a 3 year-old was hard - daughter had to bath her.	S
338.	Tired all the time.	S

#	Statements	ID
339.	Enlisted help of housecleaner - was wonderful.	S
340.	First 2 years were especially bad - meds did not work.	S
341.	Had side effects from medication - indocid, gold etc. or effects wore off.	S
342.	You always fear your complaining about nothing - sometimes reassuring when sed. rate is up.	S
343.	After a while, you wonder if the pain is better or whether you've learned to live with it.	S
344.	Give up activities such as square dancing etc.	S
345.	Sometimes make new friends - people with RA - friendly, supportive.	S
346.	Making the effort to keep on doing work is helpful.	S
347.	Go swimming twice a week - and spend time in the whirlpool helpful.	S
348.	Helpful to have friends to keep you active.	S
349.	When you have a flare-up you think "Will I have to spend the rest of my life like this?" But always stayed hopeful that new meds will come up to help.	S
350.	Not all health professionals are helpful - some don't have much bedside manners.	S
351.	Have tried herbs, bee stings, reflexology - some did help, others not.	S
352.	When feeling good - try to do a lot of things - make the most of it.	S
353.	The thought of flare-ups is always in the background like a sleeping giant.	S
354.	Started in my feet, then hands - at first could hardly walk.	S
355.	Took part in experimental drug studies.	S
356.	Always having to weigh benefits vs. risks when taking meds.	S
357.	Knee replacement - wondering if swimming has been responsible preventing deterioration in my other knee.	S
358.	Probably crabbier than I should have been when raising children.	S
359.	Probably affected my youngest child ð not disciplined as much as he should have been ð I did not have the energy.	S
360.	Can't wear rings, jewelry, decent clothes, or shoes.	S
361.	Not so bad now but in the beginning shoulders were so sore it was difficult to sleep.	S
362.	People have no idea how you feel - make insensitive comments.	S
363.	Look all right so people wonder why your not as active as you were, etc.	S
364.	Life - ups & downs of pain - pain I have now is from damage to my joints.	S
365.	Public transportation very difficult before my knee replacements - better now.	T
366.	Lots of surgery - knees, feet, left hand, thumb	T
367.	Still drive but not very comfortable especially now that my shoulders are sore - I don't.	T
368.	Slowed me down socially - e.g. bowling, card games, quilting.	T
369.	Still try to go places that I can tolerate - e.g. Arthritis Association, seniors group, etc.	T

#	Statements	ID
370.	Had to learn to accept the fact that there were things that I couldn't do anymore - also part of aging.	T
371.	Have given up yardwork, home, etc. - glad to be an apartment dweller now.	T
372.	Had to learn to live with it - had to learn to adjust.	T
373.	The medications have kept me going - but I don't like being more and more dependent on them.	T
374.	Fortunate I got it when my children were grown up - I couldn't even hold my grandchildren now - I don't know what I would have done.	T
375.	At first, there was really no medical help - all I could take was Aspirin for the pain, had to move from Halifax to Edmonton to get help from a rheumatologist.	T
376.	The medications all worked well at first but their effects do seem to wear off after a while - have been on many drugs (gold, penicillamine, methotrexate).	T
377.	On days you feel well you forget how it was to have pain.	T
378.	Can't turn door knob, comb my hair, etc. when it flares up.	T
379.	It's a very nagging pain that doesn't go away.	T
380.	I kept going to work to keep my mind busy - I met very good people there - I think it kept me going.	T
381.	My teenagers had a hard time at times with my being in pain - my son was/is a bit more tolerant than my daughter.	T
382.	I find that friends closer to my age understand me and my disease better - younger people don't understand - they haven't suffered as much.	T
383.	No matter what you take (drugwise) you know that the disease is still progressing - you wonder where you are going to end up.	T
384.	You learn to be so independent - if I can still do it, I like to do it by myself.	T
385.	When my knees were bad, many times I thought I would like to have life over with, but I never gave up hope.	T
386.	My faith has helped me a lot with coping with the pain.	T
387.	Used to be very active but now I'm very very limited.	U
388.	Feel I have to rest much more - I don't want to but sometimes you are forced to.	U
389.	Pain and weakness in the hands were the first symptoms I had.	U
390.	Methotrexate worked wonderfully for one year then started having side effects - dizziness, stomach upset.	U
391.	I was so miserable that I could hardly get out of bed.	U
392.	Every week had to go for blood test and needles - had to spend much time at the doctors.	U
393.	I couldn't help my children as much as I would like.	U
394.	It's hard for me to change my grandchildren's diapers.	U

#	Statements	ID
395.	I can't do as much around the house - ie - wash floor, vacuum etc. - my husband has to do this.	U
396.	Can't do any gardening.	U
397.	I'm very tough - no matter how I feel if there is something going on I do it.	U
398.	Going out with others - you talk and you feel better.	U
399.	Can't give up - you have to live with - keep pushing yourself.	U
400.	Hard for me to dress but still managing fairly well.	U
401.	Can't open jars.	U
402.	I don't go out as much.	U
403.	I don't dance anymore but I don't care - it comes with age you know.	U
404.	Knees were bad but cortisone has helped.	U
405.	I don't exercise as much as I should -it's especially hard in my hands.	U
406.	It's nice to have support from organizations.	U
407.	It's on your mind all the time - it's normal to talk about it and it helps not to keep everything to yourself.	U
408.	I think I'm doing pretty good dealing with it.	U

APPENDIX H: Cluster Solutions

18-Cluster Solution

Cluster/Statements		Bridging Index
Cluster 1		
1	The mornings are the worst.	0.27
63	I have sleepless and restless nights because of the pain.	0.29
2	It is painful to get moving after being motionless for a while.	0.27
29	When I don't have pain, it is difficult to describe how bad it can be and when I have pain, it's hard to remember what it feels like to be pain-free.	0.58
87	I notice the pain most at the beginning of a relapse.	0.24
4	I dread being on my feet too long as my knees, ankles, and feet get very sore and tired.	0.38
5	I have some form of pain every day.	0.30
28	Rheumatoid Arthritis is associated with pain that ranges from mild to excruciating and you may experience this range in a single day.	0.32
Cluster Average		**0.33**
Cluster 2		
13	I can't do the things that other people my age do easily and take for granted.	0.25
50	Rheumatoid Arthritis pain is quite unpredictable so it's difficult to plan activities a few days ahead or make long-term commitments.	0.33
83	The disability is more of a bother than the pain.	0.47
32	Travel becomes more complicated because of the pain.	0.33
Cluster Average		**0.34**
Cluster 3		
41	My ups and downs are more pronounced because of the pain.	0.41
66	Pain sucks the life out of you.	0.42
71	The pain is especially stressful during holidays such as Christmas.	0.41
Cluster Average		**0.41**
Cluster 4		
3	I've had to relearn how to do things with my hands.	0.31
38	I tend to do lots of things that are less physically demanding because of the pain.	0.11
43	I have given up social activities and hobbies little by little or changed to less demanding ones.	0.23
52	I now hesitate to do certain things that I would have done automatically in the past.	0.25

57	I have to give myself extra time to do things.	0.27
85	When it comes to physical activity, it is a long learning process to find the balance between not hurting yourself and not babying yourself.	0.31
Cluster Average		**0.25**
Cluster 5		
9	I had to stop playing sports.	0.17
44	I find I sometimes have to make excuses or devise cover-ups for things I do or don't do.	0.30
27	I need more sleep than many of my friends.	0.31
80	Self- care is hard at times.	0.26
61	I can't climb many stairs.	0.30
Cluster Average		**0.27**
Cluster 6		
6	I've learned to mentally block out the pain.	0.51
88	I've learned to live with the pain.	0.21
92	When I'm feeling good I try to do a lot of things and make the most of it.	0.23
75	I am especially thankful on days when the pain is less or gone.	0.44
31	I aim for a reasonably calm attitude.	0.41
78	Keeping busy with work and having many different interests helps you deal with the pain.	0.10
Cluster Average		**0.32**
Cluster 7		
18	Reading and educating myself about arthritis and how others cope helps me to go on.	0.20
19	Keeping active and doing as much as I can for myself, in order to stay as independent as possible, is important to me.	0.09
36	My faith has helped me cope with the pain.	0.16
77	Having a positive attitude makes all the difference.	0.08
82	Laughter is important.	0.16
21	Accepting my disease was the biggest hurdle.	0.41
55	The pain causes me to reflect upon how important our health is to us.	0.43
74	I am forced to consider all ways to alleviate pain.	0.38
Cluster Average		**0.24**
Cluster 8		
20	Support from many sources helps me cope with the pain.	0.37
91	I stay hopeful that something new will be found to help.	0.20

42	Having a painful condition makes me more aware of the good things around me.	0.30
76	I've had the opportunity to meet many individuals who share ways to cope and often I've made new friends.	0.49
Cluster Average		**0.34**
Cluster 9		
54	I am much more aware of the pain other people suffer.	0.74
56	I'm more careful about the my diet, my alcohol consumption, and the amount of exercise I get.	0.42
Cluster Average		**0.58**
Cluster 10		
7	I feel useless and I'm not contributing to society.	0.16
15	I experience depression at times and withdraw from everything.	0.02
17	I have thought about committing suicide.	0.05
69	Sometimes I just want to give up because I'm just so tired of fighting.	0.00
70	A lot of guilt is involved.	0.03
59	I feel much older than I am and I mourn my healthy youth.	0.15
60	I constantly feel helpless and dependent on others for doing simple tasks.	0.13
Cluster Average		**0.08**
Cluster 11		
14	I get so tired, I just want to sit and do nothing.	0.30
34	The pain causes feelings of self-pity, anger, and frustration.	0.33
68	Some days I feel so bad that I just stay in bed.	0.24
67	I have anxiety attacks.	0.22
Cluster Average		**0.27**
Cluster 12		
8	I feel I've been cheated out of a career.	0.10
10	I feel isolated at times.	0.12
72	There are regrets, insecurities, and sadness at giving up what used to be taken for granted.	0.06
64	I feel jealousy towards fully-abled bodies.	0.09
65	I fear what the future holds for me.	0.07
16	I am self-conscious about my physical appearance because people ask questions and make comments.	0.14
90	When I have a flare-up I think "Will I have to spend the rest of my life like this?"	0.21
53	I am always reminded that, in a way, I'm not the same person that I was.	0.21

89	I always fear I'm complaining about nothing.	0.18
Cluster Average		**0.13**
Cluster 13		
11	I don't like people to feel sorry for me.	0.40
37	I am fearful of falling when I go out.	0.36
Cluster Average		**0.38**
Cluster 14		
33	I've had to give up living in a house.	0.35
79	Having pain made it more difficult to raise children.	0.52
39	I need a push from others to be more active.	0.35
51	One has to get used to living with a lot of uncertainty.	0.32
Cluster Average		**0.39**
Cluster 15		
12	I had no opportunity to date, find a partner, and missed out on having children.	0.39
46	My partner does not understand or care about the extent of my pain.	0.44
58	Physical intimacy with my partner is made difficult.	0.53
86	It's hard for children to understand what you're going through.	0.50
62	There is family tension between my need for independence and my family's concern for me.	0.52
35	My partner and I are closer and our relationship has improved.	0.62
Cluster Average		**0.50**
Cluster 16		
22	I sometimes feel "shuffled-over" by health care professionals.	0.60
23	I am concerned about becoming addicted to pain medication.	0.69
24	I worry about the effects of the medication wearing off.	1.00
Cluster Average		**0.76**
Cluster 17		
26	Rheumatoid Arthritis is not well understood by others and unknowingly, people say and do very insensitive things.	0.72
81	Having to spend so much time at the doctor's is disruptive.	0.60
30	I have had to undergo numerous surgeries.	0.76
49	Sometimes the treatment in hospitals is demeaning.	0.60
73	There is a financial drain due to drug costs, special footwear, adaptive devices, housekeeping services, and alternative therapies.	0.76
Cluster Average		**0.69**

Cluster 18		
25	Medications have caused me many problems.	0.83
47	It is so much better for me as a patient if the family doctors and specialists co-operate.	0.55
48	I've had to become very assertive in order to get good health care.	0.52
84	My medications help to keep the pain under control.	0.98
40	I have found the therapists to be especially supportive.	0.48
45	Most people will help you if you ask, but it is sometimes hard to ask.	0.70
Cluster Average		0.68

10-Cluster Solution

Cluster/Statements		Bridging Index
Cluster 1		
1	The mornings are the worst.	0.27
63	I have sleepless and restless nights because of the pain.	0.29
2	It is painful to get moving after being motionless for a while.	0.27
29	When I don't have pain, it is difficult to describe how bad it can be and when I have pain, it's hard to remember what it feels like to be pain-free.	0.58
87	I notice the pain most at the beginning of a relapse.	0.24
4	I dread being on my feet too long as my knees, ankles, and feet get very sore and tired.	0.38
5	I have some form of pain every day.	0.30
28	Rheumatoid Arthritis is associated with pain that ranges from mild to excruciating and you may experience this range in a single day.	0.32
13	I can't do the things that other people my age do easily and take for granted.	0.25
50	Rheumatoid Arthritis pain is quite unpredictable so it's difficult to plan activities a few days ahead or make long-term commitments.	0.33
83	The disability is more of a bother than the pain.	0.47
32	Travel becomes more complicated because of the pain.	0.33
41	My ups and downs are more pronounced because of the pain.	0.41
66	Pain sucks the life out of you.	0.42
71	The pain is especially stressful during holidays such as Christmas.	0.41
Cluster Average		**0.35**
Cluster 2		
3	I've had to relearn how to do things with my hands.	0.31
38	I tend to do lots of things that are less physically demanding because of the pain.	0.11
43	I have given up social activities and hobbies little by little or changed to less demanding ones.	0.23
52	I now hesitate to do certain things that I would have done automatically in the past.	0.25
57	I have to give myself extra time to do things.	0.27
85	When it comes to physical activity, it is a long learning process to find the balance between not hurting yourself and not babying yourself.	0.31
9	I had to stop playing sports.	0.17
44	I find I sometimes have to make excuses or devise cover-ups for things I do or don't do.	0.30

27	I need more sleep than many of my friends.	0.31
80	Self- care is hard at times.	0.26
61	I can't climb many stairs.	0.30
Cluster Average		**0.26**
Cluster 3		
6	I've learned to mentally block out the pain.	0.51
88	I've learned to live with the pain.	0.21
92	When I'm feeling good I try to do a lot of things and make the most of it.	0.23
75	I am especially thankful on days when the pain is less or gone.	0.44
31	I aim for a reasonably calm attitude.	0.41
78	Keeping busy with work and having many different interests helps you deal with the pain.	1.10
Cluster Average		**0.32**
Cluster 4		
18	Reading and educating myself about arthritis and how others cope helps me to go on.	0.20
19	Keeping active and doing as much as I can for myself, in order to stay as independent as possible, is important to me.	0.09
36	My faith has helped me cope with the pain.	0.16
77	Having a positive attitude makes all the difference.	0.08
82	Laughter is important.	0.16
21	Accepting my disease was the biggest hurdle.	0.41
55	The pain causes me to reflect upon how important our health is to us.	0.43
74	I am forced to consider all ways to alleviate pain.	0.38
20	Support from many sources helps me cope with the pain.	0.37
91	I stay hopeful that something new will be found to help.	0.20
42	Having a painful condition makes me more aware of the good things around me.	0.30
76	I've had the opportunity to meet many individuals who share ways to cope and often I've made new friends.	0.49
54	I am much more aware of the pain other people suffer.	0.74
56	I'm more careful about the my diet, my alcohol consumption, and the amount of exercise I get.	0.42
Cluster Average		**0.32**
Cluster 5		
7	I feel useless and I'm not contributing to society.	0.16
15	I experience depression at times and withdraw from everything.	0.02

17	I have thought about committing suicide.	0.05
69	Sometimes I just want to give up because I'm just so tired of fighting.	0.00
70	A lot of guilt is involved.	0.03
59	I feel much older than I am and I mourn my healthy youth.	0.15
60	I constantly feel helpless and dependent on others for doing simple tasks.	0.13
14	I get so tired, I just want to sit and do nothing.	0.30
34	The pain causes feelings of self-pity, anger, and frustration.	0.33
68	Some days I feel so bad that I just stay in bed.	0.24
67	I have anxiety attacks.	0.22
Cluster Average		**0.15**
Cluster 6		
8	I feel I've been cheated out of a career.	0.10
10	I feel isolated at times.	0.12
72	There are regrets, insecurities, and sadness at giving up what used to be taken for granted.	0.06
64	I feel jealousy towards fully-abled bodies.	0.09
65	I fear what the future holds for me.	0.07
16	I am self-conscious about my physical appearance because people ask questions and make comments.	0.14
90	When I have a flare-up I think "Will I have to spend the rest of my life like this?"	0.21
53	I am always reminded that, in a way, I'm not the same person that I was.	0.21
89	I always fear I'm complaining about nothing.	0.18
Cluster Average		**0.13**
Cluster 7		
11	I don't like people to feel sorry for me.	4.40
37	I am fearful of falling when I go out.	0.36
33	I've had to give up living in a house.	0.35
79	Having pain made it more difficult to raise children.	0.52
39	I need a push from others to be more active.	0.35
51	One has to get used to living with a lot of uncertainty.	0.32
Cluster Average		**0.39**
Cluster 8		
12	I had no opportunity to date, find a partner, and missed out on having children.	0.39
46	My partner does not understand or care about the extent of my pain.	0.44

58	Physical intimacy with my partner is made difficult.	0.53
86	It's hard for children to understand what you're going through.	0.50
62	There is family tension between my need for independence and my family's concern for me.	0.52
35	My partner and I are closer and our relationship has improved.	0.62
Cluster Average		**0.50**
Cluster 9		
22	I sometimes feel "shuffled-over" by health care professionals.	0.60
23	I am concerned about becoming addicted to pain medication.	0.69
24	I worry about the effects of the medication wearing off.	1.00
26	Rheumatoid Arthritis is not well understood by others and unknowingly, people say and do very insensitive things.	0.72
81	Having to spend so much time at the doctor's is disruptive.	0.60
30	I have had to undergo numerous surgeries.	0.76
49	Sometimes the treatment in hospitals is demeaning.	0.60
73	There is a financial drain due to drug costs, special footwear, adaptive devices, housekeeping services, and alternative therapies.	0.76
Cluster Average		**0.72**
Cluster 10		
25	Medications have caused me many problems.	0.83
47	It is so much better for me as a patient if the family doctors and specialists co-operate.	0.55
48	I've had to become very assertive in order to get good health care.	0.52
84	My medications help to keep the pain under control.	0.98
40	I have found the therapists to be especially supportive.	0.48
45	Most people will help you if you ask, but it is sometimes hard to ask.	0.70
Cluster Average		**0.68**

8-Cluster Solution

Cluster/Statements		Bridging Index
Cluster 1		
1	The mornings are the worst.	0.27
63	I have sleepless and restless nights because of the pain.	0.29
2	It is painful to get moving after being motionless for a while.	0.27
29	When I don't have pain, it is difficult to describe how bad it can be and when I have pain, it's hard to remember what it feels like to be pain-free.	0.58
87	I notice the pain most at the beginning of a relapse.	0.24
4	I dread being on my feet too long as my knees, ankles, and feet get very sore and tired.	0.38
5	I have some form of pain every day.	0.30
28	Rheumatoid Arthritis is associated with pain that ranges from mild to excruciating and you may experience this range in a single day.	0.32
13	I can't do the things that other people my age do easily and take for granted.	0.25
50	Rheumatoid Arthritis pain is quite unpredictable so it's difficult to plan activities a few days ahead or make long-term commitments.	0.33
83	The disability is more of a bother than the pain.	0.47
32	Travel becomes more complicated because of the pain.	0.33
41	My ups and downs are more pronounced because of the pain.	0.41
66	Pain sucks the life out of you.	0.42
71	The pain is especially stressful during holidays such as Christmas.	0.41
Cluster Average		**0.35**
Cluster 2		
3	I've had to relearn how to do things with my hands.	0.31
38	I tend to do lots of things that are less physically demanding because of the pain.	0.11
43	I have given up social activities and hobbies little by little or changed to less demanding ones.	0.23
52	I now hesitate to do certain things that I would have done automatically in the past.	0.25
57	I have to give myself extra time to do things.	0.27
85	When it comes to physical activity, it is a long learning process to find the balance between not hurting yourself and not babying yourself.	0.31
9	I had to stop playing sports.	0.17
44	I find I sometimes have to make excuses or devise cover-ups for things I do or don't do.	0.30

27	I need more sleep than many of my friends.	0.31
80	Self- care is hard at times.	0.26
61	I can't climb many stairs.	0.30
Cluster Average		**0.26**
Cluster 3		
6	I've learned to mentally block out the pain.	0.51
88	I've learned to live with the pain.	0.21
92	When I'm feeling good I try to do a lot of things and make the most of it.	0.23
75	I am especially thankful on days when the pain is less or gone.	0.44
31	I aim for a reasonably calm attitude.	0.41
78	Keeping busy with work and having many different interests helps you deal with the pain.	0.10
Cluster Average		**0.32**
Cluster 4		
18	Reading and educating myself about arthritis and how others cope helps me to go on.	0.20
19	Keeping active and doing as much as I can for myself, in order to stay as independent as possible, is important to me.	0.09
36	My faith has helped me cope with the pain.	0.16
77	Having a positive attitude makes all the difference.	0.08
82	Laughter is important.	0.16
21	Accepting my disease was the biggest hurdle.	0.41
55	The pain causes me to reflect upon how important our health is to us.	0.43
74	I am forced to consider all ways to alleviate pain.	0.38
20	Support from many sources helps me cope with the pain.	0.37
91	I stay hopeful that something new will be found to help.	0.20
42	Having a painful condition makes me more aware of the good things around me.	0.30
76	I've had the opportunity to meet many individuals who share ways to cope and often I've made new friends.	0.49
54	I am much more aware of the pain other people suffer.	0.74
56	I'm more careful about the my diet, my alcohol consumption, and the amount of exercise I get.	0.42
Cluster Average		**0.32**
Cluster 5		
7	I feel useless and I'm not contributing to society.	0.16
15	I experience depression at times and withdraw from everything.	0.02

17	I have thought about committing suicide.	0.05
69	Sometimes I just want to give up because I'm just so tired of fighting.	0.00
70	A lot of guilt is involved.	0.03
59	I feel much older than I am and I mourn my healthy youth.	0.15
60	I constantly feel helpless and dependent on others for doing simple tasks.	0.13
14	I get so tired, I just want to sit and do nothing.	0.30
34	The pain causes feelings of self-pity, anger, and frustration.	0.33
68	Some days I feel so bad that I just stay in bed.	0.24
67	I have anxiety attacks.	0.22
8	I feel I've been cheated out of a career.	0.10
10	I feel isolated at times.	0.12
72	There are regrets, insecurities, and sadness at giving up what used to be taken for granted.	0.06
64	I feel jealousy towards fully-abled bodies.	0.09
65	I fear what the future holds for me.	0.07
16	I am self-conscious about my physical appearance because people ask questions and make comments.	0.14
90	When I have a flare-up I think "Will I have to spend the rest of my life like this?"	0.21
53	I am always reminded that, in a way, I'm not the same person that I was.	0.21
89	I always fear I'm complaining about nothing.	0.18
Cluster Average		**0.14**
Cluster 6		
11	I don't like people to feel sorry for me.	0.40
37	I am fearful of falling when I go out.	0.36
33	I've had to give up living in a house.	0.35
79	Having pain made it more difficult to raise children.	0.52
39	I need a push from others to be more active.	0.35
51	One has to get used to living with a lot of uncertainty.	0.32
12	I had no opportunity to date, find a partner, and missed out on having children.	0.39
46	My partner does not understand or care about the extent of my pain.	0.44
58	Physical intimacy with my partner is made difficult.	0.53
86	It's hard for children to understand what you're going through.	0.50
62	There is family tension between my need for independence and my family's concern for me.	0.52
35	My partner and I are closer and our relationship has improved.	0.62

Cluster Average		**0.44**
Cluster 7		
22	I sometimes feel "shuffled-over" by health care professionals.	0.60
23	I am concerned about becoming addicted to pain medication.	0.69
24	I worry about the effects of the medication wearing off.	1.00
26	Rheumatoid Arthritis is not well understood by others and unknowingly, people say and do very insensitive things.	0.72
81	Having to spend so much time at the doctor's is disruptive.	0.60
30	I have had to undergo numerous surgeries.	0.76
49	Sometimes the treatment in hospitals is demeaning.	0.60
73	There is a financial drain due to drug costs, special footwear, adaptive devices, housekeeping services, and alternative therapies.	0.76
Cluster Average		**0.72**
Cluster 8		
25	Medications have caused me many problems.	0.83
47	It is so much better for me as a patient if the family doctors and specialists co-operate.	0.55
48	I've had to become very assertive in order to get good health care.	0.52
84	My medications help to keep the pain under control.	0.98
40	I have found the therapists to be especially supportive.	0.48
45	Most people will help you if you ask, but it is sometimes hard to ask.	0.70
Cluster Average		**0.68**

4-Cluster Solution

Cluster/Statements		Bridging Index
Cluster 1		
1	The mornings are the worst.	0.27
63	I have sleepless and restless nights because of the pain.	0.29
2	It is painful to get moving after being motionless for a while.	0.27
29	When I don't have pain, it is difficult to describe how bad it can be and when I have pain, it's hard to remember what it feels like to be pain-free.	0.58
87	I notice the pain most at the beginning of a relapse.	0.24
4	I dread being on my feet too long as my knees, ankles, and feet get very sore and tired.	0.38
5	I have some form of pain every day.	0.30
28	Rheumatoid Arthritis is associated with pain that ranges from mild to excruciating and you may experience this range in a single day.	0.32
13	I can't do the things that other people my age do easily and take for granted.	0.25
50	Rheumatoid Arthritis pain is quite unpredictable so it's difficult to plan activities a few days ahead or make long-term commitments.	0.33
83	The disability is more of a bother than the pain.	0.47
32	Travel becomes more complicated because of the pain.	0.33
41	My ups and downs are more pronounced because of the pain.	0.41
66	Pain sucks the life out of you.	0.42
71	The pain is especially stressful during holidays such as Christmas.	0.41
3	I've had to relearn how to do things with my hands.	0.31
38	I tend to do lots of things that are less physically demanding because of the pain.	0.11
43	I have given up social activities and hobbies little by little or changed to less demanding ones.	0.23
52	I now hesitate to do certain things that I would have done automatically in the past.	0.25
57	I have to give myself extra time to do things.	0.27
85	When it comes to physical activity, it is a long learning process to find the balance between not hurting yourself and not babying yourself.	0.31
9	I had to stop playing sports.	0.17
44	I find I sometimes have to make excuses or devise cover-ups for things I do or don't do.	0.30
27	I need more sleep than many of my friends.	0.31
80	Self- care is hard at times.	0.26

61	I can't climb many stairs.	0.30
Cluster Average		**0.31**
Cluster 2		
6	I've learned to mentally block out the pain.	0.51
88	I've learned to live with the pain.	0.21
92	When I'm feeling good I try to do a lot of things and make the most of it.	0.23
75	I am especially thankful on days when the pain is less or gone.	0.44
31	I aim for a reasonably calm attitude.	0.41
78	Keeping busy with work and having many different interests helps you deal with the pain.	0.10
18	Reading and educating myself about arthritis and how others cope helps me to go on.	0.20
19	Keeping active and doing as much as I can for myself, in order to stay as independent as possible, is important to me.	0.09
36	My faith has helped me cope with the pain.	0.16
77	Having a positive attitude makes all the difference.	0.08
82	Laughter is important.	0.16
21	Accepting my disease was the biggest hurdle.	0.41
55	The pain causes me to reflect upon how important our health is to us.	0.43
74	I am forced to consider all ways to alleviate pain.	0.38
20	Support from many sources helps me cope with the pain.	0.37
91	I stay hopeful that something new will be found to help.	0.20
42	Having a painful condition makes me more aware of the good things around me.	0.30
76	I've had the opportunity to meet many individuals who share ways to cope and often I've made new friends.	0.49
54	I am much more aware of the pain other people suffer.	0.74
56	I'm more careful about the my diet, my alcohol consumption, and the amount of exercise I get.	0.42
Cluster Average		**0.32**
Cluster 3		
7	I feel useless and I'm not contributing to society.	0.16
15	I experience depression at times and withdraw from everything.	0.02
17	I have thought about committing suicide.	0.05
69	Sometimes I just want to give up because I'm just so tired of fighting.	0.00
70	A lot of guilt is involved.	0.03
59	I feel much older than I am and I mourn my healthy youth.	0.15

60	I constantly feel helpless and dependent on others for doing simple tasks.	0.13
14	I get so tired, I just want to sit and do nothing.	0.30
34	The pain causes feelings of self-pity, anger, and frustration.	0.33
68	Some days I feel so bad that I just stay in bed.	0.24
67	I have anxiety attacks.	0.22
8	I feel I've been cheated out of a career.	0.10
10	I feel isolated at times.	0.12
72	There are regrets, insecurities, and sadness at giving up what used to be taken for granted.	0.06
64	I feel jealousy towards fully-abled bodies.	0.09
65	I fear what the future holds for me.	0.07
16	I am self-conscious about my physical appearance because people ask questions and make comments.	0.14
90	When I have a flare-up I think "Will I have to spend the rest of my life like this?"	0.21
53	I am always reminded that, in a way, I'm not the same person that I was.	0.21
89	I always fear I'm complaining about nothing.	0.18
Cluster Average		0.14
Cluster 4		
11	I don't like people to feel sorry for me.	0.40
37	I am fearful of falling when I go out.	0.36
33	I've had to give up living in a house.	0.35
79	Having pain made it more difficult to raise children.	0.52
39	I need a push from others to be more active.	0.35
51	One has to get used to living with a lot of uncertainty.	0.32
12	I had no opportunity to date, find a partner, and missed out on having children.	0.39
46	My partner does not understand or care about the extent of my pain.	0.44
58	Physical intimacy with my partner is made difficult.	0.53
86	It's hard for children to understand what you're going through.	0.50
62	There is family tension between my need for independence and my family's concern for me.	0.52
35	My partner and I are closer and our relationship has improved.	0.62
22	I sometimes feel "shuffled-over" by health care professionals.	0.60
23	I am concerned about becoming addicted to pain medication.	0.69
24	I worry about the effects of the medication wearing off.	1.00

26	Rheumatoid Arthritis is not well understood by others and unknowingly, people say and do very insensitive things.	0.72
81	Having to spend so much time at the doctor's is disruptive.	0.60
30	I have had to undergo numerous surgeries.	0.76
49	Sometimes the treatment in hospitals is demeaning.	0.60
73	There is a financial drain due to drug costs, special footwear, adaptive devices, housekeeping services, and alternative therapies.	0.76
25	Medications have caused me many problems.	0.83
47	It is so much better for me as a patient if the family doctors and specialists co-operate.	0.55
48	I've had to become very assertive in order to get good health care.	0.52
84	My medications help to keep the pain under control.	0.98
40	I have found the therapists to be especially supportive.	0.48
45	Most people will help you if you ask, but it is sometimes hard to ask.	0.70
Cluster Average		0.58