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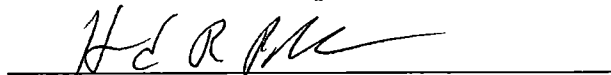
I am submitting herewith a dissertation written by Dianne E. Briscoe entitled "The Experience of Coping with Chronic Pain: A Phenomenological Investigation". I have examined the final copy of this dissertation for form and content and recommend that it be accepted in partial fulfillment of the requirement for the degree of Doctor of Philosophy with a major in Education.

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The Experience of Coping with Chronic Pain:
A Phenomenological Investigation

A Dissertation
Presented for the
Doctor of Philosophy Degree
The University of Tennessee, Knoxville

Dianne E. Briscoe

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This dissertation is dedicated to
the twelve participants
who shared the stories of their experience
of chronic pain with me.

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ABSTRACT

The goal of this investigation was to describe the thematic structure of how people experience and cope with chronic pain. To accomplish this task, phenomenological interviews were conducted with twelve different participants who had chronic pain for at least six months duration. Participants responded to a research question which asked them to describe how they coped with chronic pain.

All interviews were audio taped and then transcribed. Following this, individual protocols were interpreted within the context of a phenomenological research group. In this group, an attempt is made to describe the thematic structure of the experience of coping with chronic pain as articulated by participants. On the basis of these procedures, a two-part thematic structure emerged: one describing the experience of chronic pain and the second describing how participants coped with the pain. Four themes described the experience of chronic pain itself: (1) Invisibility to others, (2) Limitations, (3) Out of control, and (4) Separation. Five themes emerged to describe the ways in which participants reported coping with each of these various themes Characterizing the experience of chronic pain: (1) Hiding/Revealing, (2) Accepting/Denying,

(3) Enduring/Managing, (4) Connecting/Withdrawing, and (5) Monitoring/Evaluating/Deciding. Taken together, these themes formed the structure of coping with chronic pain for participants in this study.

Each of these themes was inextricably connected with one another despite the fact that all emerged as figural within the context of a changed way of life for participants. The themes of coping were derived from the themes of the experience of pain and represented a method by which participants sought to modulate the experience of chronic pain. In describing one theme, it was necessary to include aspects of the other themes.

The findings of the current study are related to the existing literature in the field of counseling psychology and to that of medicine. Suggestions for researchers, therapists, and health care providers are offered; implications for the treatment of chronic pain also were discussed. These suggestions and implications are derived from the current investigation, which emphasizes the interrelatedness of all aspects of the experience of coping with chronic pain.

TABLE OF CONTENTS

Chapter

I.	INTRODUCTION.....	1
	Problem Statement.....	8
	Research Question.....	9
II.	REVIEW OF THE LITERATURE.....	11
	Overview of Chronic Pain.....	12
	Theories of Pain Perception.....	15
	Assessment of Chronic Pain.....	23
	Living with Chronic Pain.....	33
	Coping with Chronic Pain.....	40
	Treatment of Chronic Pain.....	47
III.	METHOD.....	52
	Rationale for Choice of Method.....	52
	Relevant Concepts in Existential Phenomenology..	54
	Data Collection and Analysis.....	59
	Analysis of Interviews.....	65
	Issues.....	67
IV.	RESULTS.....	69
	Narrative Trajectory.....	72
	Invisibility to Others.....	75
	Hiding/Revealing.....	77
	Limitations.....	79

Accepting/Denying.....	83
Out of Control.....	85
Enduring/Managing.....	89
Separation.....	93
Connecting/Withdrawing.....	95
Monitoring/Evaluating/Deciding.....	98
Summary.....	100
V. DISCUSSION.....	101
Invisibility to Others.....	105
Coping Strategy: Hiding or Revealing.....	106
Limitations.....	114
Coping Strategy: Accepting or Denying.....	115
Out of Control.....	120
Coping Strategy: Enduring and Managing.....	123
Separation.....	130
Coping Strategy: Connecting and Withdrawing....	131
Coping Strategy:Monitoring/Evaluating/Deciding.	134
Methodology.....	136
LIST OF REFERENCES.....	140
APPENDICES.....	154
APPENDIX A. Informed Consent Form.....	155

Appendix B. Participant Narrative	158
Appendix C. Consent for Narrative	172
VITA.....	174

Chapter I

INTRODUCTION

Chronic pain has been referred to as a mystery (Morris, 1991) and as a puzzle (Melzack, 1973). Even though pain is one of the most universal experiences of human life, it presents conceptual and practical difficulties in terms of definition. The International Association of Pain (IASP) (1986) attempted to deal with the complexity of pain phenomena and defined pain as "an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage" (p. S217). Chronic pain is pain that persists longer than the expected normal time of healing and fails to respond to relevant types of biomedical intervention. The point of division between chronic and acute pain is usually set at three months (Bates, Edwards, & Anderson (1993); IASP, (1986).

Both the prevalence and cost of chronic pain are a serious social, medical, and financial problem facing the twenty-first century. Approximately 75 million Americans are currently suffering handicapping chronic pain (Seitz, 1993). Pain is responsible for the disability of 50 million people

and it results in the loss of 700 million work days annually (Bettencourt, 1991). The problem will continue to grow as people continue to live longer and as more people become ill or injured every year (National Institute of Health, 1994)

Living longer has been described in the literature as not necessarily living better as acute diseases have been replaced with chronic illnesses such as cancer, diabetes, heart disease, AIDS, as well as injuries due to automobile and work-related injuries. Preceded only by heart disease, arthritis and orthopedic impairment are the second and third most common pain conditions in the United States, and 60% to 80% of the population will be affected by low back pain at some time in their lives (Lister, 1996). Chronic pain with its accompanying disability has become a health care problem of considerable significance in America (NIH, 1994). The cost of health care and lost productivity due to chronic pain is over \$70 billion a year (Turk, 1994) and growing. When the cost of litigation is factored in, the figure rises to \$100 billion dollars a year (Weintraub, 1995).

The cost of chronic pain is also considerable in terms of human suffering. Chronic pain compromises all aspects of the life of the sufferer and requires a considerable amount of emotional resilience. Not only does it deplete the emotional resources of the person in pain, but also taxes

the coping capacity of family, friends, co-workers, employers and the health-care system (Turk, 1994). The psychosocial effects may disrupt family roles and relationships, end careers, and result with the individual with chronic pain withdrawing into personal isolation. The isolation can create a further sense of hopelessness and helplessness which results in increasingly impaired psychological functioning. Thus the person in chronic pain is faced with severe physical, economic, social, and emotional consequences (Altmaier & Johnson, 1992; Roy, 1992; Sieppert, 1996; Turk & Rudy, 1989).

The problem of understanding, assessing, and treating chronic pain has spurred professional interest increasingly in the last decade. There is a proliferation of research, articles, and books on the topic in the medical, the psychological, and the sociological literature concerning the need for data and further knowledge on this phenomenon.

Studies in the medical literature have focused on the problems and effects of surgical interventions (Katz, 1994); pharmacological interventions (Davis, J., 1997; Haddox, 1997; Kouyanou, Pither, & Wessely, 1997; Lister, J., 1996); Sayer & Britt, 1997); attitudes of health care providers toward chronic pain patients (Cassell, 1976; Chibnall, Tait, & Ross, 1997; Shapiro & Miller, 1994; Tait & Chibnall, 1997); and

physiological aspects of chronic pain (Katz, 1994; Markenson, 1996; Swanson, 1984). In 1996, The American Journal of Medicine issued a special edition devoted to examining current problems in the management of chronic pain. The conclusion of the authors of this issue was that there are no easy answers to the management and treatment of chronic pain. Invasive treatments and pharmacologic treatments have serious drawbacks (cost and potential iatrogenic complications). Although health care providers (physicians, nurses, and psychiatrists) attempt to keep abreast of current developments in treatment, there appears to be no single answer that works for everyone. Therefore, it is easy for physicians to become frustrated with chronic pain patients because they do not get better.

According to Katz (1996), there are no reliable ways to assess pain accurately because pain is subjective. He discussed the need for the physicians to listen to the pain patient, respect the importance of pain as symptom, and to give a priority to patients in pain. Health care providers are becoming increasingly open to alternative therapies in conjunction with traditional treatment methods and call for additional research, especially from the field of psychology as it relates to the areas of understanding, assessing and treating chronic pain (Allegrante, 1996).

The psychological literature has focused on theory (Melzack and Wall, 1965; Fordyce, 1976; and Turk, Meichenbaum, & Genest, 1983); how anxiety and depression exacerbate the expression and effect of chronic pain (Chapman, 1995; Crisson & Keefe, 1988; McCracken & Gross, 1993); how to measure/assess chronic pain (Bradley, Haile, & Jaworski, 1992; Melzack, 1975; Millon, Green, & Meagher, 1982; Rosentiel & Keefe, 1983 Turk & Melzack, 1992; Turk & Rudy, 1985; Turkat & Pettegrew,); and how to treat chronic pain from a psychological viewpoint (Bradley, 1996; Gatchel & Turk, 1996; Sternbach, 1987; Turk & Rudy, 1989; Weisenberg, 1987). According to Beutler (1986) "the entry of psychology into the field of medical disorders has been gained through the portal of chronic pain" (p.751).

The sociological literature has focused on the effects of gender/culture on chronic pain (Cademenos, 1981; Kotarba, 1980; Sieppert, 1996). Kortarba (1980) investigated the chronic pain experience of male athletes and male blue collar workers within a cultural context. Cademenos (1981) explored the social dimensions of chronic pain within a cultural context.

The void that remains to be filled in the literature is research on how and why some people cope with chronic pain

better than do others. For the purpose of this study, coping is defined as the specific thoughts, and behaviors that people use to manage their pain or their emotional reactions to their pain. There are several important questions in considering coping with chronic pain: Why are some people with chronic pain able to continue to function productively while others become totally incapacitated? Why do people with the same diagnosis experience and cope with pain in very different ways? What is the structure of coping with chronic pain? What does it look like and how do people cope with pain that lasts forever?

Turner, Clancy, & Vitaliano (1987) called attention to the paucity of data and lack of research that has considered patient differences in coping styles pointing out that little is known about how patients appraise and cope with their pain, physical limitations, family pressures, and other stressors. Bombardier, D'Amico, & Jordon (1990) discussed the limited research available which investigates the role of appraisal and coping in adjustment to chronic medical conditions. Turk(1996) called for research to determine which factors account for the very different individual expressions of subjective experience and behavioral responses in relation to the phenomena of chronic pain.

According to Pollio (1991), one way to approach an understanding of a situation of interest is to ask the people who are involved in that situation. Some researchers have used qualitative methods to ask and discover what the experience of chronic pain is like for the individual sufferers. For example, Erdmann (1987) used an existential/phenomenological approach to examine the experience of chronic low back pain and described the more immediate bodily and emotional concomitants of the pain experience, some attempts at how participants dealt with pain, and some of the long term effects of chronic pain. Cademenos (1981) used a phenomenological approach to investigate the social and psychological implications of the divergences between scientific medical definitions of chronic pain and patient experience of chronic pain. He analyzed how the implicit assumptions underlying the medical model in conjunction with the divergence of the patient's actual experience governed the behavior patterns of patients and physicians toward each other which often resulted in misunderstandings and distrust of one another. Newshan (1996) also used a phenomenological approach to understand the experience of chronic pain as it is lived in hospitalized patients with AIDS, and discussed the idea that

doctors and patients live in different experiential worlds, leaving room for miscommunication and misunderstandings. She emphasized the need to listen to the pain patient.

Phenomenological methods of investigation are best suited for listening to the pain patient and for exploring the lived experience of the person coping with chronic pain. According to Pellegrino (1979), professionals are obligated to seek an understanding of the existential lifeworld of the pain patient in order to be able to give competent medical care that is congruent with the patient's needs. According to Merleau-Ponty (1964), lived experience is the origin of all science. The phenomenological interview explores the lived experience of the chronic pain patient to provide data to further inform science by eliciting the lived experience of coping with chronic pain from the person doing it.

Problem Statement

Turk and Rudy (1986) have stated that the use of phenomenological research is the best way to understand the world of the chronic pain patients and thus to examine how they cope with pain on a daily basis. However, no research has yet been done using the existential/ phenomenological

method to focus specifically on how people with chronic pain cope with their pain and how they describe their experience of coping with chronic pain.

Research Question

The yet unanswered question is whether the above mentioned studies as well as other studies have provided a complete understanding of the phenomenon of how people cope with chronic pain in order to provide adequate treatment as Turk (1996) has suggested is needed. Therefore, the purpose of this current research is to fill that void. More specifically, the goal of the current investigation is to describe the essential structure of how people cope with chronic pain. Following phenomenological guidelines, no hypotheses are stated or tested. The only question guiding this research is how do people report coping with chronic pain? In answering this question within a phenomenological framework, the researcher attempts to describe those themes which capture the experience of coping with chronic pain. The individuals interviewed are viewed as the experts of their experience.

A review of the literature on coping with chronic pain is presented in Chapter II. Theoretical support for the use of a phenomenological method as well as a description of the

specific procedures used for the research in this study are outlined in Chapter III. Descriptions of the experience of coping with chronic pain from the perspective of the participants involved in this research are presented in Chapter IV. A discussion of the results and the implications for the field of counseling psychology in regard to the consideration, assessment, and treatment of people suffering with chronic pain is presented in Chapter V.

Chapter II

REVIEW OF THE LITERATURE

The one thing that all writers, researchers, and investigators seem to agree on is the complexity of the pain phenomenon. In a review of the literature related to the experience of chronic pain and its treatment, physicians, philosophers, and psychologists have tried to define the nature of pain. Many definitions for pain can be found in the literature, although no one definition is universally agreed upon. Cademenos (1981) observed a key problem to a clear definition of pain is that as attempts are made to define pain operationally, statements are produced that are both true and contradictory at the same time. While pain is an "ally" that warns of tissue damage, it is also an "enemy" producing intense human suffering and debilitation. The problem of paradox is also presented as one attempts to distinguish between pain as normal and abnormal because according to Leriche (1979), all pain has to appear normal and abnormal at the same time since it is the normal signal for the abnormal.

Overview of Chronic Pain

Defining Chronic Pain

The International Association for the Study of Pain (IASP) (1979, p. 250) has defined pain as "an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage". Chronic pain has been defined by the IASP as pain that persists longer than the expected normal time of healing and that fails to respond to the normal types of biomedical intervention. The point of division between chronic pain and acute pain is three months (Bates, Edwards, and Anderson, 1993). Perhaps, one of the best definitions of pain is that put forth by McCaffery (1979, p.11). Pain is "whatever the experiencing person says it is, existing whenever he (or she) says it does".

Katz, Ritvo, Irvine, and Jackson (1996) describe chronic pain as an intractable condition that interferes with all aspects of living. Chronic pain impairs concentration, demands attention, and drains the individual of energy. The person becomes preoccupied with finding relief and with finding a meaning for the pain. According to Katz et al. (1996) coping with chronic pain is defined as "the thoughts and actions people engage in their efforts to manage pain on a daily basis" (p. 253). These actions can

be as diverse as implementing self-management pain programs to specific individual strategies such as hoping and praying.

The History of Chronic Pain

Early psychologists and philosophers attempted to define the experience of pain in terms of sensation, feeling, and suffering. Husserl (1931) discussed the importance of distinguishing between pain sensations and suffering where suffering was seen as an intentional act and as referring to the person in pain. This is opposed to the sensation of pain which is able to continue independently of the acts (feelings and /or behaviors) which it causes.

Scheler referred to pain as a state with sensory feelings referring to self and therefore defined pain as a sensation of feeling (Buytendijk, 1961). The term pain is derived from the Latin word 'poena' which meant punishment and Kleinman (1988) described pain as the expression of helplessness which comes home to man in the form of suffering. Plessner described the experience of pain as being thrown back on one's self without a means of defense with the painful part of the body becoming the only existence of which we are aware. Gebattel described the experience of pain as the "destruction of self in the body

of agony" as he sought to understand the purposefulness of pain and the intimate relationship between suffering and personal life (Buytendijk, 1961).

Medical science originally attempted to define the pain experience in terms of a sensory experience involving stimulus-response terminology. From this view, pain was considered a response to tissue damage on the basis of responses which indicated its presence. These responses included blood pressure changes, behavioral withdrawal, or expressions of hurt.

Willis (1995) described pain in terms of physiological experience such that the sensation of pain depends on the activation of a set of neurons that comprise a pain system comparable to other sensory systems such as the auditory system. He describes nociception as involving primary afferent fibers that selectively respond to a stimulus which threatens or causes damage. As the activity from these nerve fibers become increased, sensations of pain are produced. Medical interventions are designed to correct organic dysfunction or pathology. Unfortunately, pain is more than the end product of a direct pathway that transmits neural impulses from peripheral receptors to a pain center in the brain.

Chronic pain is also often reported in the absence of an identifiable stimulus (Chapman, 1995). Physiological explanations so far have not been sufficient to account for the discrepancies in identified physical pathology and severity of reported pain and disability. According to Turk (1996), the main question to be answered is to determine what factors account for the very different individual expressions of subjective experience and behavioral responses in relation to pain. He criticizes the biomedical model for failing to take into account both physical and psychological factors as well as their dynamic interaction over time. He addresses the need for a biopsychosocial perspective which focuses on the interaction between biomedical, psychosocial, and behavioral factors which seem to evolve and change over time in the chronic pain experience.

Theories of Pain Perception

Specificity Theory

Descartes was the first to describe a scientific theory of pain in 1644 in his Traite de l'homme (Melzack, 1993). His concept of pain was based on a theory of physiology whereby tissue injury such as a burn to the skin activated specific pain receptors which followed a pathway that

directly connected the skin to the brain. This theory spurred a major revolution in scientific thought and proposed that the human body works like a machine that can be studied using experimental methods such as those proposed by Galileo and others (Melzack, 1993). Thus Descartes set the stage for the body to be treated as object and for the mind/body split.

This simplistic concept of pain as a distinct activity of the sensory system was treated as a fact and was left unquestioned for the next 250 years when Von Frey developed Descartes' ideas into the specificity theory of pain in 1894 (Melzack, 1973). Von Frey proposed the idea of specific pain receptors that produce pain when stimulated; he further argued that there existed a unique set of peripheral nerves with a direct pathway to the brain..

The impact of Descartes and the specificity theory sparked a search for specific pain fibers and pathways and a specific pain center in the brain. This notion has guided medical research and the history of experiments on the anatomy and physiology of pain for the past century and has determined the course of therapy for pain (Melzack, 1993). In fact, the specificity theory of pain continues to be taught in most medical schools and is sometimes presented as the only theory of pain as well as being the basis for most

discussions of pain in medical textbooks (Melzack, 1973). This theory allows for only two types of medical treatment: surgical and chemical (Kotarba, 1980) and both serve to stop the sensation of pain by severing or blocking the pain pathway. In the case of chemical agents such as analgesics, the central nervous system is depressed at the thalamus and cerebral cortex. In the case of surgical options, how surgical techniques are used to sever the nerve itself can carry a high risk of paralysis (Kotarba, 1980).

Pattern Theory

Some clinical observers in the twentieth century became increasingly aware that not all pain experience could be held to be proportional to peripheral injury. Patients complained of pain for which no direct organic link could be determined. The search for a new theory began and these attempts resulted in what was termed as "pattern theory" although there were actually several different pattern theories (Melzack, 1993). Goldcheider in 1894 proposed that stimulus intensity and central summation were the critical determinants of pain and that pain resulted from the stimulation of receptors in the skin when the total electrical output of cells exceeded a certain level in the nervous system (Cademenos, 1981):

Livingston proposed the central summation theory (1943) after observing patients with phantom limb pain where there could be no pathway between a nonexistent limb and the brain. This theory proposed that after peripheral nerve damage, stimulation of sensory nerves could initiate activity in reverberatory circuits of neuron pools in the spinal cord which could be interpreted as pain. Something as simple as friction with clothing could trigger this impulse. Pattern theories were generally considered too vague and inadequate to explain the involvement of the brain except as the role of passive receiver of impulse messages. According to Melzack (1993), these theories did set the stage for looking into the spinal cord and away from peripheral sites as the answer for pain perception.

The Gate Control Theory

Since 1960, three models of pain have emerged which have had a major impact on the current treatments of pain. Melzack and Wall used some of the theoretical concepts of pattern theory and saw both the need to integrate brain processes into a theory which allowed for feedback and feed-forward transmissions and the need for a new spinal cord mechanism which would be a strong enough theory to challenge the specificity theory (Melzack, 1993). They combined

physiological and psychological theories of pain with the Gate Control Model of Pain (1965). This theory expanded the conceptualization of pain to a multidimensional model that integrates sensory-physiological components of pain with motivational-affective components and cognitive-evaluative components. The model included psychological factors as an integral aspect of the pain experience and it demonstrated the importance of the modulation of psychological variables in pain perception. By emphasizing central nervous system mechanisms involved in the pain experience, it provided a physiological basis for the role of psychological factors in chronic pain (Turk, 1996).

Specifically, the Gate Control Theory proposed that there is a gating mechanism located in the dorsal horn which modulates the transmission of nerve impulses from afferent fibers to spinal cord transmission cells. Impulses coming from large fibers close the gate by inhibiting transmission while impulses from small fibers open the gate and facilitate transmission. The gating mechanism is also influenced by nerve impulses descending from the brain providing feedback and feed-forward transmission. There is a specialized system of large diameter fibres which activate selective cognitive process that modulate the gating mechanism through descending fibres. As the output of the

spinal cord transmissions cells passes a critical level, the Action System is activated and the subsequent patterns of behavior and experience characteristic of pain emerge (Melzack & Wall, 1965).

Operant Theory

In 1976, Fordyce developed an operant conditioning model based on the idea of reinforced pain behaviors. Fordyce said that since pain is not directly observable, all that can be known about pain is based on verbal and non-verbal communications from the patient. These communications are behavioral manifestations which are observable and capable of eliciting reinforceable responses which may increase these behaviors even in the absence of nociception. This theory differs from the Gate Control Model because it ignores cognitive, affective, and even sensory components of the pain experience (Turk & Rudy, 1986). Braden (1991) provides some support to this model in her discussion of learned responses to chronic illness in terms of disability payments acting as reinforcers to "pain behaviors".

Cognitive-Behavioral Theory

The cognitive-behavioral transaction model of pain was developed by Turk et al. (1983) and is based on the interaction of sensory, affective, cognitive, and behavioral factors in the experience and treatment of pain. It affords importance to the patient's perspective of the pain experience and focuses on the attitudes and beliefs of the patient and describes pain as a complex, multidimensional, perceptual phenomenon that is also a dynamic, interpretive process. The model also takes into account the idea that the patient's behavior elicits responses from others that can reinforce adaptive and maladaptive thoughts, feelings and behaviors (Turk & Rudy, 1986). Much research has been conducted to assess the effectiveness of cognitive strategies used to help patients modify the experience of pain. Turk performed a meta-analysis (1989) of 46 laboratory studies and found that subjects trained to use one or more cognitive coping strategies appeared better off than 80% of the subjects not provided with specific coping strategies.

Neuromatrix Theory

In 1993, Melzack proposed a new theory of pain perception. Convinced that the future of pain research lay

in understanding the brain, he proposed the idea of a body-self neuromatrix. After studying phantom limb pain, he became aware that the "body-self" was still present in experience even when input from that part of the body was gone. Pain continued to exist without the presence of defined neuroceptors (Melzack, 1989). In other words, the brain not only detects and analyzes input, it is also able to generate perceptual experience even when no external input occurs (Melzack, 1993).

The neuromatrix theory is based on the idea that "the neural networks for perceiving the body and its parts are built into the brain" (Melzack, 1993, p.628). Specifically, Melzack (1993) proposes that a neuromatrix is the result of the anatomical substrate of the body-self as a large and widespread network of neurons which are made up of a series of loops located between the thalamus and cortex and between the cortex and limbic systems. This network of neurons generates patterns through a cyclical processing and synthesis of nerve impulses. As it processes the information that flows through it, it results in producing the pattern that is felt or experienced as the whole body. The neuromatrix acts as a psychologically meaningful unit that is influenced both by heredity and learning and it results in a whole, unified entity. Melzack combines physiology and

experience by identifying physiological substrates for pain as well as identifying conscious awareness resulting in the individual experience of pain (Melzack, 1993). It will be interesting to see what impact this theory will have on the treatment of phantom limb pain and other chronic pain in the future.

Assessment of Chronic Pain

The assessment of chronic pain is inherently difficult because pain is a perception that is experienced by an individual and thus is a subjective experience (Turk & Melzack, 1992). The definition of pain put forth by the International Association for the Study of Pain (IASP, 1979) acknowledges both the sensory and emotional components of pain. To understand and treat pain, it is necessary to measure it.

A comprehensive review of the literature suggests that a multidimensional assessment process be used rather than a unidimensional assessment. Many facets of pain must be measured in order to arrive at an accurate assessment of chronic pain (Chapman, 1995; Derogatis, 1986; Keefe & Gil, 1986; Turk & Melzack, 1992; Turk & Rudy, 1986; Turk & Rudy, 1987; Vlaeyen, Eek, Groenman, & Schuerman, 1987; Williams & Thorn, 1989). This type of assessment takes into account

the physical and psychological factors involved in the experience of chronic pain. Since people with the same medical diagnosis respond differently to the same treatment, there is an acknowledgment of, and empirical support for, the importance of psychological factors in the assessment of chronic pain (Turk & Melzack, 1992). The present review focuses primarily on instruments which take into account the psychological factors of chronic pain and discusses those instruments most often used in the assessment of chronic pain.

Perhaps the most widely used pain assessment instrument is the McGill Pain Questionnaire (MPQ) (Melzack, 1975). This instrument is conceptually related to the Gate Control Model and was designed to separate and quantify three related yet separate components of pain: cognitive-evaluative, sensory-discriminative, and motivational-affective (Turk & Rudy, 1986). Over 100 words frequently used by patients to describe pain sensations were put into 20 sets of pain descriptors with each set containing up to six words in an empirically determined ascending order of pain intensity. The pain patient is asked to choose the word in each set that best describes his experience of pain within the three conceptual domains listed above. The premise is that each kind of pain is characterized by a distinct constellation of

words (Melzack & Katz, 1992). The advantages of this instrument include short administration time and rapid scoring. It can be administered verbally in about five minutes or it can be administered as a paper and pencil test (Melzack & Katz, 1992). In 1983, the instrument was combined with a self-report inventory complimented by a semi-structured interview that was used to clarify responses to the inventory and investigate subjective variables making the instrument more comprehensive in scope. It is useful in understanding the experience of the individual, but it has been criticized for being more time consuming and difficult to score (Turk & Melzack, 1992). The disadvantage to the MPQ is the mixed findings concerning the discriminative validity of the instrument between the three components of pain that it is designed to measure. Several studies have found that the instrument actually measures only one construct, pain intensity (Clark, Fletcher, Janal, & Carroll, 1995; Turk and Rudy, 1987).

The West Haven-Yale Multidimensional Pain Inventory (WHYMPI) (MPI) is a self-report instrument with a multi factor base. Designed to assess psychosocial variables in the chronic pain experience, it is theoretically linked to a cognitive-behavioral perspective (Kerns, Turk, & Rudy, 1985). The WHYMPI is a 52-item, 12- scale inventory

designed to provide a comprehensive assessment of the pain experience. It is divided into three parts: Part I evaluates the dimensions of chronic pain such as pain severity and affective distress, Part II evaluates the patient's perceptions of the response of others to his/her pain complaint, and Part III measures patient reports of their participation in common daily activities such as household activities and social activities. The advantages of this measure include its brevity and easy scoring as well as demonstrated reliability and validity (Kerns and Jacob, 1992). A spouse version of this inventory has been developed which could be a useful check on both the validity of the patient report and the perceived impact of pain on the significant other. The disadvantage to this instrument is that, since the test is relatively new, psychometric properties have yet to be established and caution is advised in its use (Kerns & Jacob, 1992).

The Illness Behavior Inventory (IBI) (Turkat & Pettegrew, 1983) is a 20-item self-report developed from a behavioral perspective that considers two factors; Work Related Illness Behavior and Social Illness Behavior. The advantages of this measure are that it is easy to use and that it is psychometrically sound based on initial findings. Test-retest reliability is high as well as discriminant

validity and concurrent validity (Kerns & Jacob, 1992). The newness of the test is the only mentioned disadvantage. Suggestions have been made to substitute the word pain for illness in this inventory to address the chronic pain population indicating the self-observed behaviors could help in the education of pain patients concerning the development of a chronic pain mind set in the expression and maintenance of pain.

The Sickness Impact Profile (SIP) (Bergner, Bobbitt, Carter, & Gilson, 1981) was designed to measure perceived health status and to do so with enough sensitivity to detect changes within groups (and over time) no matter what demographic, cultural, or medical variables were involved. It is a 136-item test with 12 scales divided into three categories, independent categories, physical categories, and psychosocial categories. It can be administered by an interviewer or self-administered in 20-30 minutes (Kerns & Jacob, 1992). The advantages to this measure include its sound psychometric properties demonstrated through comprehensive testing and its provision of a variety of information for work with the chronic pain population (Williams, 1989). Individual scales of interest can be administered without compromising reliability or construct validity. The disadvantage is that it is a long test and

cumbersome to score (Kerns & Jacob, 1992).

The Coping Strategies Questionnaire (CSQ) (Rosenstiel & Keefe, 1983) was designed to measure six cognitive and two behavioral coping strategies which include coping self-statements, catastrophizing, and increasing pain behaviors. This questionnaire also includes two items that ask the patient to report perceived control over pain and perceived ability to control pain. It is a 50-item self-report instrument which has been researched to test its ability to predict treatment outcome studies, to compare patient subgroups, and to test the ability to make factor analysis of dimensions of coping (DeGood & Shutty, 1992). Advantages of this test include clinical utility in comparing reported use of coping strategies to patient functioning and treatment outcomes. Two relationships have been reported between CSQ factors and adjustment to chronic pain: (1) patients with low back pain who endorse items such as reinterpreting pain sensations, praying and hoping, and attention diversion have greater pain and disability levels indicating ineffective coping strategies for coping; (2) patients who use catastrophizing styles and feel themselves to be ineffectual at controlling pain appear to be more disabled and suffer more depression. The disadvantage of this measure is that there appear to be some weaknesses in

the interpretation of factors in reliable dimensions of coping strategies (Degood & Shutty, Jr., 1992).

The Minnesota Multiphasic Personality Inventory (MMPI) (Hathaway, McKinley, Butcher, Dahlstrom, Graham, Tellegen & Kaemmer) is the most commonly used instrument to evaluate the psychological health of chronic pain patients (Bradley, Haile, & Jaworski, 1992; Costello, Hulsey, Schoenfeld, & Ramamurthy, 1987; Turk & Rudy, 1987). The MMPI-2 includes the same number of clinical and validity scales. The primary difference between the original and revised versions is that the MMPI-2 is more representative of the U.S. population (Bradley et al, 1992). The original and revised versions are currently used to evaluate chronic pain patients. The original test consisted of 566 items and the revised version has 567. There are 10 clinical scales and three validity scales with a true/false format. Computer scoring is most often used. Investigators use the MMPI to obtain hierarchical clustering of scores to identify profile patterns that are produced most frequently by chronic pain patients. A factor analysis performed by Deardorff, Chino, & Scott (1993) yielded four interpretable factors: (1) Psychological Dysfunction indicated by elevations on scales F, 7, 4, 8, 6, and 2; (2) Interpersonal Isolation indicated by negative loading on Hy-2 and Hy-1 and

positive loading on scale 0; (3) Psychomotor Retardation indicated by elevation on scale 9 and negative loading on Hy-5; (4) Physical Dysfunction indicated by elevations on scale 1,3, Hy-3 and Hy-4.

Costello et al. (1987) derived a four-cluster topology for chronic pain with each of the various types labeled P,A,I, and N. Type A was considered the most pathological profile, with elevations on most of the clinical scales. Type P was described as the most likely to seek health care, but show the least amount of improvement as a result of treatment. Type A is the least differentiated type and is defined by a conversion V on the 'neurotic' triad scales. This type has no consistent correlates attributed to it. Type I shows marked elevations on scale 1,2,3 and elevations on scale 7,8. This type appears to be the most infirm with multiple surgeries and the least physical improvement. Type N was characterized as extreme in endorsing items in the direction of health. This type has the least amount of pain duration, least restrictions socially, emotionally, and vocationally and responds well to treatment.

Keller and Butcher (1991) had similar findings and encouraged the use of the MMPI and MMPI-2 as a tool to tailor treatment to individual pain patients rather than to groups of patients. The advantage to using this instrument

is that the MMPI-2 provides a clear profile of the pain patient in terms of the clinical scales and there is a history of clinical trials which show that the MMPI does indeed reflect differences in some patient profiles especially back pain patients before and after treatment (Bradley et al, 1992). The biggest drawback of using this instrument is that it was not normed for profile interpretation with chronic pain patients and so there is contamination of items with physical symptoms. In addition, there is some criticism that it does not reflect consistent changes before and after treatment in all cases. Finally the test is lengthy and time consuming for the patient to take.

The Millon Behavioral Health Inventory (MBHI) (Millon, Green, & Meagher, 1982) is a 150 item self-report measure designed to evaluate the psychological functioning of a medical population. Its scales measure major psychosocial stressors, various ways patients relate to health care providers as well as responses to illness and treatment. It, too, is a true/false format. The advantages of this instrument include fewer items than the MMPI where these items are not contaminated by symptoms of physical illness. It was normed on a population of patients with various medical problems. Construct validity and

reliability have been found to be good as a result of several studies conducted by the test author. The major disadvantage is that results have not been consistent in confirming that the instrument is able to predict treatment outcomes with a variety of chronic pain complaints. Therefore caution has been advised in its use to predict outcomes (Bradley et al., 1992; Murphy, Speer & Speer, 1986).

There are a vast number of assessment instruments that have been proposed in addition to the above for use in the study of chronic pain. Many of these have not had adequate testing for soundness of psychometric properties. Reliability and validity have not yet been adequately determined for them.

Assessment instruments have been helpful in designing treatment and in understanding pain. However, most instruments are true/false, yes/no, Likert scale, or multiple choice questionnaires which limit patient responses in describing pain and the impact pain has on their lives. This ipsitive factor also limits understanding of the pain experience. What is missing is a phenomenological approach which uses the patient's own words to give a full description of the pain experience.

Living with Chronic Pain

When an individual lives with chronic pain on a daily basis, the experts agree that the experience of living with pain is ultimately a private subjective experience or perception(Craig, 1984; Frankl, 1959; Hubner, 1984; Seitz, 1993; Turk & Rudy, 1986;). Hubner(1984) discussed the meaning of pain to the individual as posing "the ultimate question of meaning" (p.446) and described the experience of pain as "being ripped away from something else, of being separated, or being alone" (447). Seitz (1993) discussing the personal fear associated with pain wrote "most people fear death less than they fear continuing pain" (p.64).

According to Turk and Rudy (1986), "chronic pain is a complex, subjective phenomenon that is uniquely experienced by each patient...patients' perceptions of their life circumstances and the personal meaning of pain are likely to influence their communications with significant others and with health care professionals" (p. 766). LeShan (1964) discussed the patients' need for meaning and the need to find the cause or reason for the pain. Frankl (1959) addressed the need to find meaning especially when people are suffering through unbearable pain. It would appear that how the meaning of pain is interpreted is an important part of how one copes with pain.

Impact on Daily Life

Erdmann (1987) and Martin (1989) using a phenomenological method did research on people living with chronic low back pain. Both found that the chronic low back pain affected every facet of the individual's daily life. The presence of pain dominated their lives on a daily basis and each person spent time trying to find a way to deal with the pain and spent time seeking medical help.

People also found their lives limited in many ways since it was no longer possible to do their normal daily activities. These activities ranged from needing help bathing and dressing to not being able to maintain employment. Some participants found the pain all consuming whereas others were able to continue functioning within limitations. Many felt a sense of helplessness, with the pain being in control of their lives: other people found some value in their suffering.

Research findings with these two populations also indicated that people with chronic low back pain became isolated from others largely because of the difficulty in dealing with others while experiencing pain. Some participants experienced frustration with others, some received comfort from others, still others felt lonely. All participants reported disruptions in their daily lives

on a physical basis, psychological basis, and a social basis. Being in pain seemed to bring about a change in all these areas of life (Erdmann, 1987; Martin, 1989).

Social and Family Interactions

Although several researchers (Murphy, 1993; Roy, 1992; & Seville, 1993)have discussed the issue of social and family interactions in the context of chronic pain, there is still little known regarding the interpersonal issues that affect the pain patient, the spouse, and the children. No outcome studies were found which described the effectiveness of family therapy for treating families with a chronic pain patient. The clinical literature also does not offer any outcome studies or assessment of the role of informal networks or social support even though patients often describe the benefits of supportive relationships (Roy, 1992).

Murphy (1993) looked at spousal influence in relation to the pain patient's report of pain severity in sixty couples. He found that if a pain patient feels highly regarded by his spouse, then he perceives himself to be more in control of his pain. Seville (1993) studied perceived available support in sixty-six chronic pain patients. Her results indicated that while perceived available social

support was associated with higher pain reports and affective distress, it was also associated with higher levels of daily activity. This relationship was not consistent across genders and across indices of disability, however indicating a need for further research.

Health Care Attitudes

A study by Tait and Chibnall (1997) indicated that social context influenced physician judgements of patients with chronic pain. The results suggested that medical judgments were influenced by the patient, the situation, and by the interaction/relationship between the physician and patient. Findings suggest that physicians rated pain and disability lower when patients reported high levels of pain and that physicians tended to inflate ratings for patients who reported low levels of pain. Physicians also rated pain and disability lower for patients without supporting medical evidence. Patients with negative affect were rated as having more distress, higher somatic preoccupation and greater disability. Physicians also tended to discount reported levels of pain, and to give lower disability ratings to patients with whom they had a negative relationship.

In another study by Chibnall, Tait, and Ross (1997) medical students were asked to judge symptoms of

hypothetical low back pain patients. Again, findings indicated similar biasing variables in the assessment of pain. While there was no physician-patient interaction, medical students tended to rate patients according to medical evidence: Patients with reported high levels of pain tended to be discounted if pathology was ambiguous or inconclusive where patients with reported moderate or low intensity of pain were rated accurately or augmented when medical evidence was present. According to Chibnall et al., these findings suggest a tendency "to overweight medical findings in clinical decision-making for chronic pain patients" (p.268). The authors stated the need for future research to assess the independent and interactive effects of other situational variables on physician judgments. These variables include communication styles, patient litigation status, and patient characteristics of gender and ethnicity.

Sieppert (1996) studied medical social workers' attitudes toward the management of chronic pain and medical social workers' knowledge of chronic pain. Two hundred and twelve social work departments in hospitals and related facilities across Canada participated in the study. The researcher found that while medical social workers recognize the importance of the treatment of chronic pain in their

basic items from the pain management literature. According to the author, the implication is that "if medical social workers from health care settings are unfamiliar with chronic pain and its effects, then one can expect even less knowledge from those in non-health settings" (p.128). There is a concern that a significant proportion of chronic pain patients in medical and non-medical settings are unlikely to have their chronic pain adequately assessed and treated.

Chronic Pain and Suicide

Hitchcock, Ferrell, & McCaffery (1994) surveyed 204 persons with chronic pain. Of these respondents, 50% reported having considered suicide because of feelings of hopelessness associated with their pain. Depression was also identified as one of the worst problems caused by their chronic pain. This study illustrated the tremendous impact of chronic pain and adds to the evidence that chronic pain can be life-threatening. Fishbain (1996), Kotarba (1983), and Livengood and Parris (1989) have all stressed the importance of early detection of suicide ideation in this population.

Pentinen (1995), Fishbain (1995), and Stenager (1995) have studied suicide ideation and suicide completion within the chronic pain population. Stenager (1994) and Breslau,

Davis, & Andreski (1991) have pointed out that migraine headache sufferers as well as others whose pain is unresponsive to treatment do commit suicide. The conclusion was that these attempts were related to pain, and were independent of major depression or any other disorder.

The current research data on chronic pain and suicide also indicate that the longer the duration of pain, the greater the likelihood of suicide ideation (Hinkley & Jaremko, 1994). According to Fishbain (1996), current data indicate that chronic pain patients are at risk for suicidal ideation and suicide completion at a higher rate than individuals without pain in the general population.

Kotarba (1983) became interested in the prevalence of suicide in chronic pain patients when two of his pain patients committed suicide. He said that people attempt suicide when they give up hope for a cure and when they feel that they cannot "live" with the pain. In essence, they lose cognitive control over their pain and see suicide as the ultimate pain control. They begin to see positive value in terminating existence, the cessation of pain.

Wolf (1977, p.54) poignantly stated:

The pain person wistfully clings to an inadequate, but heartfelt, conviction that all pain should be short term. Our word choices, then, betray the terrible truth that we simply do not know what to do about persistent pain. As the lady said,

cancer would, on the whole, seem preferable. The prospect of there being no end to the experience is so devastating that all but the most determined personality can be reduced to a whine and a whimper...Yes, some pain persons do kill themselves, either in a single act or by degrees, with an overdose or with alcohol.

In recent years, there has been a growing debate regarding euthanasia and doctor assisted suicide in ending the suffering of terminally ill patients. Jack Kevorkian, M.D. has challenged the current laws regarding euthanasia by assisting patient suicides to put a final end to the suffering of several of his patients. In a recent court case, he was convicted of murder (Grace, 1999 and McGinn, 1999). It is not known what effect this recent controversy and legal decision will have on chronic pain patients contemplating suicide. It is not known whether this will act as a deterrent to suicide in chronic pain patients.

Coping with Chronic Pain

How people actually cope with chronic pain has become an important question in the study of chronic pain. Turner, Clancy, & Vitaliano (1987) point out how little is known about how chronic pain patients appraise and cope with the various stressors included in the chronic pain experience. The experience includes not only the pain, but financial

pressures, physical limitations, and stress in interpersonal relationships. Other researchers in the area of chronic pain have emphasized the importance of gaining more knowledge concerning how people cope with chronic pain (Bombardier, Amico, & Jordan, 1990; Brown & Nicassio, 1987; Chapman, 1992; Dolce, 1987; Gatchel & Turk, 1996; Kores, Murphy, Rosenthal, Elias, & North, 1990; Philips, 1987, Turk & Melzack, 1992; Turner, Clancy, & Vitaliano, 1987; Weisenberg, 1987).

Stress Models

Several researchers have used the stress model proposed by Lazarus (1969) to study how chronic pain patients cope (Bombardier et al., 1990; Turner et al., 1987). According to Lazarus (1969 p.172), " stress always has the implication of an event that in some way harms or threatens to harm the person because it is perceived to exceed his resources to cope with it". He termed psychological stress as "demands made upon a person which tax him to the limits of his resources or beyond" which can be perceived as threats to the maintenance of life or to the avoidance of pain (Lazarus, 1961). In 1984, Lazarus and Folkman proposed a model for the appraisal process involved in coping with stressful events. An appraisal of a stimulus as threatening

or benign (primary appraisal) occurs between stimulus presentation and stress reaction. Primary appraisal depends on two classes of antecedent conditions: (1) The perceived features of the stimulus situation and (2) The psychological structure of the individual. Some of the factors affecting primary appraisal are the imminence of harmful confrontation, the intensity and duration of the stimulus, and the potential controllability of the stimulus. Personal factors that affect individuals appraisal would include their beliefs about themselves and the environment, the pattern and strength of their values, and their personality dispositions.

When a stimulus has been appraised as requiring a coping response, individuals evaluate their resources in order to determine whether they can cope with the situation by eliminating the effects of the stressful stimulus. This is secondary coping. These coping responses may involve actions designed to alter the threatening conditions (flight or fight) or thoughts and/or actions whose goals are to relieve the emotional stress response (body or psychological responses) (Lazarus & Folkman, 1984). In this model, coping derives from the appraisal process because the judgements made concerning the ability to change or control the stimulus, or the judgements made concerning the limits of

the individual's adaptive ability, determine which forms of coping will be used. There are basically two kinds of coping strategies: (1) problem-focused coping (attempts at managing the external aspects of a stressor-seeking information) and (2) emotion-focused coping (attempts to regulate the internal affective consequences of a stressor such as self blame or wishful thinking) (Bombardier et al, 1990).

In a study by Turner et al. (1987), chronic pain patients were asked to identify the primary current stressor in their life and to identify how they appraised and determined a strategy to cope with that stressor. They found that appraisal of one's pain was significantly associated with how one copes with pain. Those patients who accepted their pain and did not believe that the pain required them to restrict their activities, used more problem-focused coping and sought less social support. Those patients who believed their pain held them back, used more emotion-focused coping and were more likely to blame themselves and feel guilty because they could not manage normal responsibilities. These patients showed more avoidance tendencies.

Cognitive and Behavioral Strategies

Fernandez (1986) categorized coping strategies as cognitive or behavioral. Examples of cognitive strategies are distraction, imagery, or counting whereas behavioral strategies include actions taken to manage pain such as resting or taking pain medication. Within this system of classification, coping strategies can be further classified to reflect an active or passive style. Active coping styles are often associated with adaptive coping strategies, whereas passive coping strategies are associated with maladaptive coping strategies. Caution is advised by Katz et al., (1996) when interpreting the chronic pain literature as it relates to active and passive styles because these terms have been defined differently depending on which questionnaires have been used and whether the questionnaire defines a particular strategy as cognitive or behavioral. These two terms do not seem to be clear cut in the chronic pain literature and they seem to overlap quite a bit. In other words, it might be difficult to determine in some cases if the individual is using an active or passive coping style.

Maladaptive Coping Strategies

Maladaptive coping styles are identified as those which lead to increased pain, functional disability, and poorer psychosocial adaptation. Two of the main strategies falling in this category are catastrophizing and avoidance. According to Keefe, Brown, Wallston, & Caldwell (1989), catastrophizing is defined as the patient's unrealistic belief that the current situation will lead to the worst possible outcome. This coping strategy has been associated with increased depression, (Sullivan & D'Eon, 1990), psychosocial dysfunction (Jensen, Turner, & Romano, 1989), and increased pain intensity (Flor & Turk, 1988).

According to Philips (1987) avoidant behavior, which can begin as an adaptive response to pain to allow for tissue healing, becomes maladaptive in chronic pain patients as the behavior becomes prominent and extensive over time. He found avoidance to be the most prominent component of pain behavior and identified six types of avoidance: social avoidance, housework, daily mobility, activities, exercise, and stimulation. He found avoidance behavior to be persistent and linked to the belief that pain may be prevented by withdrawal or avoidance. This strategy leads to a paradoxical element in coping with chronic pain. It seems that whereas withdrawal from activity negatively

reinforces the belief that increases in pain have been prevented, pain severity remains the same. In other words, people did not reduce pain by withdrawing from normal activities. The pain level remained the same.

Adaptive Coping Strategies

Adaptive strategies used to cope with chronic pain are linked with self efficacy beliefs and perceived control (Crisson & Keefe, 1988; Dolce, 1987; Kores et al., 1990; Partridge & Johnson, 1989). Researchers have investigated the relationship between perceived control and adaptive coping strategies with chronic pain based on Bandura's (1977) self-efficacy theory in which a self-efficacy belief is defined as a personal conviction that an individual can successfully perform certain behaviors in a given situation. Bandura believed that actual performance accomplishments were the most effective way of raising self-efficacy expectations. Researchers have found that exercise quota systems can effectively raise these beliefs for exercise among chronic pain patients (Dolce, 1987; Kores et al, 1990).

Adaptive strategies include distraction and attention-diversion techniques to focus the patient's thoughts on other activities, objects, or events. Direct approaches

would include relaxation and imagery. Indirect approaches would include reading and socializing (Katz et al, 1996).

Katz et al. (1996) have proposed a risk-adaptation model to cope with chronic pain. This model was developed to help people clarify their decision making processes as they attempt to cope with chronic pain. Judgments of beliefs are balanced with judgments of consequences. For example, if patients need to make decisions about returning to work after an injury, they are helped to clarify the risks involved (will returning to work make the condition worse?), his beliefs regarding the decision (returning to work may or may not affect the amount of pain), and consequences of these decisions (reduced family income or the need for further medical evaluation). The model involves redirection and support for the patients as they engage in functional attention-regulation and helps them to make decisions based on rational consideration of modifiability-consequentiality problems with realistic optimism regarding outcome.

Treatment of Chronic Pain

Treatment goals for chronic pain involve reducing pain perceptions, reducing pain behaviors, and increasing self-efficacy in the management of daily life activities.

Different treatment protocols place emphasis on different aspects of these goals separately and in combination. Traditional medical models have emphasized pain reduction through surgical and pharmacological methods with varying success rates (Flor & Birbaumer, 1993). Psychological treatment plans focus on operant, behavioral methods; psychodynamic methods; cognitive-behavioral methods; group therapy methods; and family therapy methods (Gatchel & Turk, 1996). Multidisciplinary pain management centers focus on combinations of these treatments.

Operant Methods

Operant interventions are discussed because such methods form the basis of many current treatments. Fordyce (1976) pioneered much of the early work in the area of chronic pain management by developing comprehensive behaviorally oriented procedures for pain management based on applied learning theory. He emphasized the importance of learned pain behaviors such as complaining, grimacing, inactivity and further demonstrated how these behaviors come to be reinforced through conditioning responses from the patient's environment, medical community, friends, and family. Prolonged use of medication, and inactivity also reinforce pain behaviors according to this model.

The major task of pain management in his view was helping the patient stop engaging in undesirable pain behaviors and to begin engaging in adaptive or well behaviors. His operant methods involved three components: (1) the identification and elimination of reinforcers for pain behaviors, (2) the gradual decrease of pain medications, and (3) the gradual increase in social and physical activities. What is missing from this approach was the study and management of cognitive, affective, and physiological components of the chronic pain experience.

Cognitive-Behavioral Methods

Cognitive-behavioral approaches to the treatment of chronic pain incorporate operant methods with cognitive methods to take into account individual beliefs, expectations, evaluative, and affective factors. The premise of Cognitive-Behavioral Therapy (CBT) is that effective interventions for chronic pain must work with the emotional, cognitive, and behavioral dimensions of pain as well as help patients to become active participants in their management of pain (Bradley, 1996). There are five primary assumptions involved in CBT: (1) Individual behaviors are influenced by the patient's expectations and by the perceived consequences of their actions; (2) The patient's

thoughts both may alter his or her behavior; (3) the patient's behaviors can be influenced by the environment and can also shape environmental events; (4) to be effective, treatment interventions must address the cognitive, emotional, and behavioral dimensions of the patient's problems; and (5) patients must become active participants in their treatment to learn adaptive methods of responding (Turk & Rudy, 1989). The goal of CBT then is to help patients develop expectations that they can learn to manage their pain and associated problems and then to provide them with the skills they need to be able to respond effectively with both current problems and with problems that may arise after treatment is terminated. Many different cognitive-behavioral interventions have been used with a variety of chronic pain problems including relaxation, biofeedback, and hypnosis (Bradley, 1996).

The individual experiences of chronic pain taken together show a tremendous impact on the United States economy in terms of lost wages and strain on the health care system. Not only is there room for further research to gain more knowledge in the area of chronic pain and thus more treatment alternatives, but there is a demand for more research in the area of chronic pain. This section ends with the words of Weisenberg (1987, p. 310), "There are

still many limitations to the effective treatment of pain. Many patients are never treated successfully. It is now necessary to proceed to the next stage, whereby we extend these limits". Extending these limits through an existential-phenomenological method of study is called for to increase the understanding of both the experience of chronic pain and how one copes with that pain from the perspective of the chronic pain patient.

Chapter III

Method

The purpose of this study was to describe the essential structure of how people cope with chronic pain. First a rationale for using existential-phenomenological methods is discussed followed by a brief explanation of relevant concepts in the application of this methodology. Finally, the specific procedures used in this study will be described.

Rationale for Choice of Method

The area of chronic pain has been studied extensively using predominately quantitative methods. The result has been an extensive contribution to the body of knowledge concerning chronic pain in terms of objective data. Many assessment instruments have been developed to assess different aspects of chronic pain and a variety of treatment methods have been proposed and utilized in its treatment. Unfortunately, according to this literature, chronic pain is becoming an ever larger societal problem, and currently used treatment methods show a significant number of patients who

show little or no improvement (Turk & Melzack, 1992;). Many questions remain regarding what is the best treatment for each patient and quantitative studies force the participants to adapt to the researcher's model and the instrumentation being used. Because of this, the data seem somewhat restricted in quality and quantity since much of the personal experience of the patient is lost. Using an existential-phenomenological method, the opposite thing is believed to happen; that is, such methods are adapted to individual patient's style of communication and expression.

According to Turk and Rudy (1986), phenomenological research methods are perhaps the best way to study chronic pain in order to understand the world and experience of the chronic pain patient. Turk and Melzack (1992) studied the complexities of the phenomena of chronic pain and discussed its impact in terms of many factors including cultural, economic, social, environmental, and psychological factors in addition to physical pathology and personal history. Philips (1989) investigated the need for information on the cognitive reactions of pain sufferers and the need for clarity on the nature and changes in chronic pain cognitions. All of these conditions suggest that a phenomenological approach to pain may provide a rich yield of new information concerning its nature and meaning to the

suffering individual. One major advantage of the phenomenological method in the study of chronic pain is that by allowing the chronic pain patient to teach us about the pain, new information may be gained that may lead to different ways of looking at the problem and different and more effective ways of treating the problem of chronic pain.

Further support of the phenomenological method in the study of chronic pain is given by Good, Kleinman, and Brodwin (1992) who say that the study of the experience of chronic pain begs for a critical phenomenology. Personal narratives have the potential to offer insights into the nature of illness and the illness experience. Even though the experience of pain is created in the body, it is also constituted in the body's relationships to society. Support for the phenomenological method in the study of chronic pain also comes from Roy (1992) who emphasizes the social context in which the chronic pain patient lives.

Relevant Concepts in Existential Phenomenology

Existential Phenomenology and Human Experience

Existential-phenomenology is a combination of two philosophies, phenomenology and existentialism. Both share a common interest in human experiences in the world of everyday human life with a focus on experience as the

relationship between the individual and his or her world. Both phenomenology and existentialism seek "a rigorous description of human life as it is lived in all of its first-person concreteness, urgency and ambiguity. For existential-phenomenology, the world is to be lived and described, not explained". (Pollio, Henley, and Thompson, 1997 p.5).

In this context, description has a very specific meaning, and it is important to understand what is included and what is excluded (Ihde, 1986). Whatever is not directly related to the experience is excluded. These exclusions include any attempts at explanation, theory, hypotheses, as well as any attempt to link cause and effect. What is included is anything within the experience as Heidegger (1962) put it, "that which shows itself in itself...". Included here would be the person's encounters with other people, places, objects, and all kinds of events that are significant to the person. According to Polkinghorne (1989), experience is the meeting of person with world. If experience is defined by these encounters, and if existence results from the interaction between world and person, then existence and experience are inseparable (Henderson, 1992). Heidegger (1962) defined existence as person-who-is-in-the-world; with this understanding in mind, the life-world of

the person becomes the cornerstone of existential phenomenological inquiry (Valle, King, and Halling, 1989).

Existentialism had its beginning in the middle of the 1900s with Kirkegaard, and was concerned with questions of human existence. Phenomenology began in the late 1900s with Husserl and was concerned with developing a methodology to study human existence.. Heidegger is credited with bringing the two together although Merleau-Ponty, in the mid-twentieth century, laid the groundwork for existential-phenomenology to be used as a qualitative approach to the study of psychological issues. He used empirical methodology to study human existence from a psychological point of view, and gained much of his direction from some of the early Gestalt psychologists such as Wertheimier and Kohler(Pollio, et al.,1997).

Perhaps Merleau-Ponty's greatest contribution lies in his description of the "lived body", in which he attempts to capture man's dialectic interaction with the world. Merleau-Ponty noted that bodily behavior is not dependent on causal explanation, such as stimulus and response sets, but instead on the perceptions of the person which must be understood from the point of view of the person who is experiencing his or her body in relation to his/her world. This dialectic was expressed in terms describing the

differences between the "body object" and the "body subject" (Merleau-Ponty, 1962). Sartre discussed these concepts in terms of the "body as it is for others" and the "body as it is for me" (1956). This way of thinking about the human body was meant to bridge the mind-body split and to overcome Cartesian dualism so that human experience could be considered in the first person perspective rather than from the third person perspective and could be considered without the boundaries imposed by a third person object only stance.

Intentionality.

According to Pollio et al. (1997), Intentionality is "a basic structure of human existence that captures the fact that human beings are fundamentally related to the context in which they live...that all being is to be understood as "being-in-the-world" (p.7). Both Husserl and Ihde (1986) define intentionality as the directional shape of experience. Both Husserl and Merleau-Ponty consider intentionality in terms of human action/motility/behavior from a first person perspective of direct involvement with the world (Merleau-Ponty, 1962; Pollio et al., 1997).

The activity of this consciousness gives rise to meaning. The idea that no fact enters experience without receiving a significance is one of the fundamental insights

of phenomenological description (Husserl, 1931; Merleau-Ponty, 1962). Husserl speaks of the intentionality of consciousness noting that consciousness is not a passive receiver of experience, but is an action -- a human performance that bestows meaning. Without this bestowing of meaning, no act is conscious (Husserl, 1931). Therefore, one can only talk about concrete experiences in terms of the subjective concept of meaning or, as Husserl states, "perceptive consciousness is the universal and sole medium of 'access' to reality in whatever sense this term is understood" (1931, p.47). This is true whether the reality at the moment is that of the environment or of some bodily state.

Phenomenology describes the human being as meaning-creating existence because everything appears to man as meaning. The way in which reality becomes meaning depends on the way in which man meets with reality (Cademenos, 1981). However, man is not alone in his world and it is through his interactions with others or through his culture that meaning is made manifest. Nature is apprehended through culture and man gives meaning "to nature through the perspective of his sociocultural situation in which his own biographical situation is located" (Cademenos, 1981, p.49). To understand the meaning of an experience, one must

describe the intentional stance of an event from the perspective of the person experiencing it from within the framework or cultural background where the event takes place.

Lebenswelt/Life World.

Husserl's "Lebenswelt" or "life world" and Pollio's "everyday life" can be discussed in terms of how the lived body is the origin of all spatial relationships. The life world is the world in which the individual eats, sleeps, works, feels pain, and interacts with others. It is where he locates himself as a body. It is the center and origin of all space. The place the individual occupies within the world, his "here" is the beginning point from which he takes his bearing in space and which makes intelligible ideas such as far and near, beside, above, and below. The knowledge one possesses always depends upon his physical placement in the world (Cademenos, 1982).

Data Collection and Analysis

Polkinghorne gave some general guidelines for performing existential-phenomenology research. Henderson (1992) summarized three steps:

1. Gather descriptions from people who are

having or have had the experience of interest;

2. Analyze these descriptions so that the researcher may grasp the common elements that make the experience what it is;
3. Write a report that gives a clear, accurate description of the elements. The reader of the report should come away with thinking that "I understand better what it is like for someone to experience that" p.71.

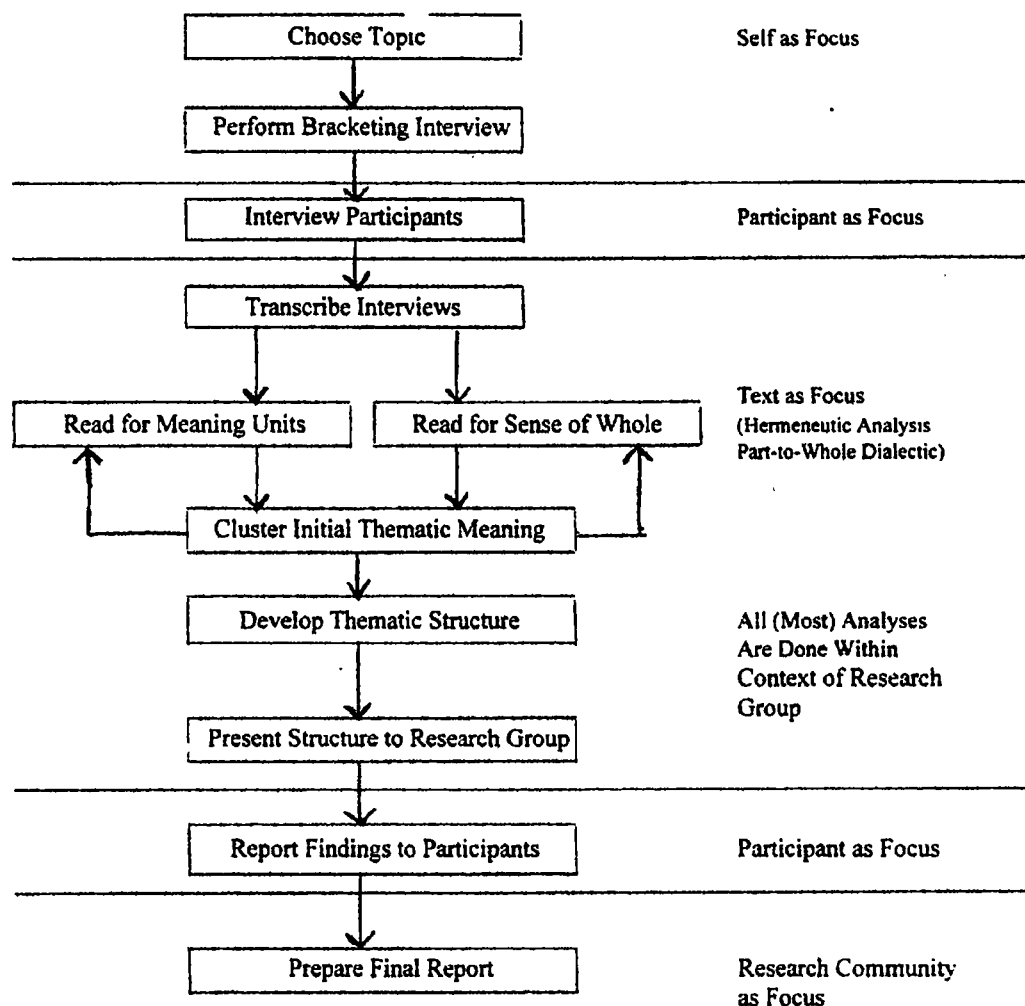
The focus of the present research is on obtaining a clear description of the lived experience of coping with chronic pain. The specific flow of procedures for doing this type research are described next including Figure 1 which is derived from Pollio et al. (1997) and outlines each step.

Participants

Participants in phenomenological research are selected because they have knowledge about the phenomenon in question. Participants are considered the experts, as they describe and teach the researcher about the experience being studied, and the reader, hopefully comes away with a clearer understanding of what it is like for someone to have had that particular experience (Polkinghorne, 1989).

Twelve participants volunteered for this study; seven men and five women who had a variety of chronic pain problems. The criteria for chronic pain was six months

METHOD



Steps in phenomenological research.

Figure 1

Source: Polio, H. R., Henley, T., & Thompson, C. B., (1997). The phenomenon of everyday life. New York: Cambridge University Press.

duration. Participants had a range of chronic pain from 6-33 years and their ages ranged from 45-54 years. All participants volunteered for the project, and were given no incentive. The first seven participants were recruited from a flyer posted on the University of Tennessee Campus. The last five participants were recruited from a pain clinic. Each participant signed an informed consent form (Appendix A) which explained the confidential and voluntary nature of the project.

The Interview

The phenomenological interview allows the patient to give a full description of his/her experience with chronic pain, and allows for the most salient or figural aspects of that experience to emerge for further analysis and interpretation. Kremer, Atkinson, & Kremer (1983) studied the importance of the language of pain and the affective descriptors of pain. The phenomenological interview method depends on and utilizes the language of the interviewee for the description of the phenomena under investigation.

A unique aspect of the phenomenological method is that the structure of the experience of the interviewee (person with chronic pain) is not preconceived, i.e. there is no null hypothesis to disprove. In addition, the

phenomenological interview provides a first-person description of a specific domain of experience and the participant sets the course of the dialogue as he or she responds to the opening question. The interviewer keeps the description at the level of the interviewee's lived experience (Thompson, Locander, & Pollio, 1989). To this end, the interviewer asks open-ended questions and repeats the individual's words and phrases to elicit further descriptions. The interviewer seeks to create a climate in which the interviewee is comfortable and can respond honestly and comprehensively as suggested by Moustakas (1994): According to Polkinghorne (1991, p. 188), "positive interviewer effects are those that encourage subjects to overcome the propensity to give guarded and socially desired descriptions".

According to Sauerbruch and Wenke (1963) who approach the problem of chronic pain from both a medical and a philosophical position, how a chronic pain patient supports his/her pain and how he copes with the pain experience depends on his/her attitude. His or her attitude and experiences are fundamentally different from those of the physician hearing the pain complaint. The phenomenological interview is designed to elicit the pain experience for further study and analysis and through interpretation to

allow for a better understanding of the phenomena for those who will help treat the chronic pain patient.

The opening statement for this project was "tell me about a time when you were aware of having chronic pain". The statement was slightly changed in wording for the last six participants and asked participants to "tell me about a time when you were aware of coping with chronic pain". Each participant was interviewed for approximately an hour, and each interview was audio taped and then transcribed verbatim. All identifying information was changed to protect confidentiality. The interviewer asked open-ended questions and repeated the individual's words and phrases to elicit further descriptions.

Bracketing

The process of bracketing which is a method of looking at one's own preconceived notions and expectations is a fundamental component of phenomenological analysis. When the researcher is aware of his/her own preconceived thoughts and ideas, the potential for distortion in data collection and description are reduced. The expectations of the researcher are made explicit in a bracketing interview (Hunt, 1992). Although a complete bracketing of one's previous knowledge and experience is impossible and

unnecessary. What is important is to have a conscious awareness of one's own preconceived ideas about the phenomenon under study. "When bracketing, the researcher relates to respondent reflections in a non-dogmatic fashion and attempts to grasp, rather than impose, meanings emerging from the dialogue" (Thompson, Locander, & Pollio, 1989, p 141.).

A bracketing interview was conducted in which the researcher described her experiences of chronic pain. The interview was conducted by a member of the interpretive research group and this interview was analyzed by the research group before participant interviews took place.

Analysis of the Interviews

Interpretive Group

An established phenomenological research group including the researcher read and interpreted interview protocols. Members of the group were from the areas of psychology, education, nursing, and religious studies and included both senior faculty and doctoral students.

The interpretive group serves several functions in phenomenological research. It maintains bracketing by conscientiously questioning the assumptions of its members during analysis. The group keeps interpretation at the

level of the subject's lived experience and makes sure that all interpretation evolves from and is supported by the subjects' own words. The group makes sure that passages are taken in their proper context and attempts to avoid theoretical explanation and abstraction. The group also makes sure that support for proposed themes are available in all transcripts as outlined by Thompson, Locander, and Pollio (1989).

Thematization

Data was analyzed according to methods outlined by Polkinghorne (1991). The transcribed interview was read aloud by a reader in the interpretive group. The reading was done in units, with each unit being a specific response made by the subject to the interviewer. Group members then decided which words, phrases or sentences from the text represented the meaning of the unit. Passages or units were then related to the overall content of the transcript. Using this procedure, group members were able to identify emerging themes for each individual protocol. Individual themes were then clustered into more general themes which were common to all protocols. In this way, patterns common to all the participants began to emerge as figural aspects common to their experience of coping with chronic pain.

Issues

Reliability

The issue of reliability in phenomenological methods has been addressed by Goodrich (1988) who says that if the themes derived from interpretations by the research group show a clear consistency across people in time, then the results can be considered reliable. When a theme is identified in each protocol of a study, then the criterion is met.

Validity

Validity means that a method of study measures what it claims to measure. According to Polkinghorne (1989) who takes a more general perspective on this issue, the degree of validity of the research depends on whether the person reading the presentation experiences the description as significant. The reader should be able to see that the description provides a coherent picture of the common features, and that structural connections become apparent in the examples collected. The interpretive group can guard against threats to validity by maintaining bracketing, making sure transcriptions are accurate, making sure that alternatives are considered before conclusions are reached, making sure that the contents and connections in the

transcripts provide the evidence for the structural descriptions, and connecting specific experiences across situations when identifying across protocol themes (Henderson, 1992).

Chapter IV

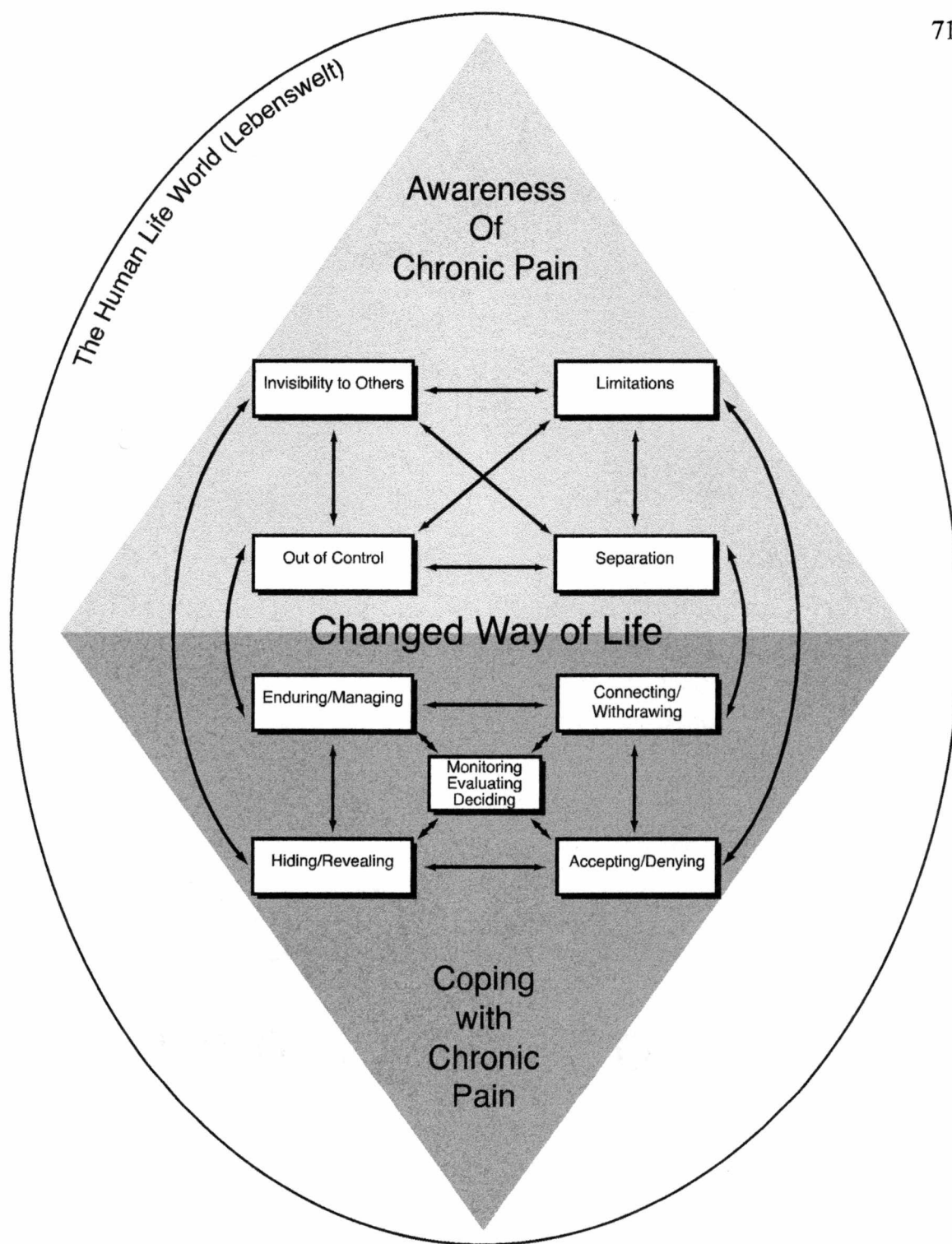
Results

The goal of this study was to learn how people cope with chronic pain and to describe the thematic structure of coping with chronic pain. The analysis of participant interviews revealed a two part thematic structure: one describing the experience of chronic pain and the second describing the experience of coping with chronic pain. Four themes in the description of the experience of chronic pain were identified: (1) Invisibility to Others, (2) Limitations, (3) Out of Control, (4) Separation. Five themes were identified in the experience of coping with chronic pain: (1) Hiding/Revealing, (2) Accepting/Denying, (3) Enduring/Managing, (4) Connecting/Withdrawing, (5) Monitoring/Evaluating/Deciding. These themes were identified as participants first explained what it was like to have this experience, and then went on to describe how they experienced coping with chronic pain.

Each narrative followed the same course. Participants did not spend much time talking about prepain although some participants did give a brief description of what life was like before having chronic pain; often this description would occur later in the text. Most participants described

how the pain felt, how it came to be in their life, and how they became filled with uncertainty about what had happened to them. Finally each participant reported being aware that the condition was chronic, and would always be with them. Each spoke of how their life was irrevocably changed and each then began to speak of how he/she coped with the pain on a daily basis.

A diagram illustrating the cyclical, two-part experience, including major themes and their interrelationships, is presented in Figure 2. The top half of the diagram contains the themes of the experience of chronic pain. In all cases the descriptions of these themes preceded a description of the themes of coping. The bottom half of the diagram illustrates the major themes of coping with chronic pain. In the following sections, descriptions of the narrative trajectory which show how these themes were developed also provide descriptions of the themes with relevant subthemes. Excerpts from participant protocols are used to explain these themes as well as to provide concrete examples of each theme. Participants in this investigation gave both rich and colorful descriptions of their experience of chronic pain.



Specific Themes in the Awareness Of
and Coping with Chronic Pain

Figure 2

The remainder of this chapter will use participants' own words to provide the structure of coping with chronic pain as it emerged in these descriptions. Their words will also show how the themes are interrelated and how the participant's focus moved back and forth across themes. A geometric figure is perhaps the best way to illustrate the overall structure of the total experience because it at once reveals how one aspect of the experience is sometimes figural and how it is sometimes in the background though always present in the everyday world of the chronic pain patient.

Narrative Trajectory

Even though none of the participants knew one another, each described his/her experience of coping with chronic pain in much the same way. A description of the pain would be given followed by how the pain came to be a part of their lives.

It feels like a knife is stabbing through my back into the front. It's like describing a knife inside of me. It's under the shoulder blades, across the back and through the chest. And then if I turn over at night, under the rib cage in the front, it's like somebody is ripping you open.

I was on my route in a car accident. A lady run into me and I was taken to the

hospital in an ambulance. I couldn't move and I was pretty well paralyzed from the neck down and they thought my neck was broken and it was about 5 hours before I could walk. Well they called it walk.

Participants described the sense of disruption caused by the advent of the pain in their lives.

It's just like you're living to die. There's nothing left. You wonder if you're coming to the end of your rope because you can't handle it no more. I always come out of it and I get over it but it's just indescribable how it makes you feel to know that you can't live without pain much less be able to do anything that you want to do. It just takes everything out of you. I mean I know God don't put anything on you you can't handle, but there are still times you wonder how much longer you can handle it.

The pain is really bad. All you are really aware of is the pain. The pain just takes over. You know you're there in the world and you've got things to do and you don't want to respond. You don't want to get up. You don't want to take a bath. You just want the pain to go away...

In the beginning the pain was focal, participants then became aware of the temporal aspect of the pain. Chronicity became equally significant at this point and changed their experience of the pain. Participants also began to see pain as never-ending and to realize a situation in which they must deal with both things simultaneously.

I believed that there was going to be a cure for what was wrong with me. After about 3 to 9 months, it began to seep in that there might possibly be no end to this. That's when I became aware of chronic and pain. Prior to that I think I just viewed it as pain from the accident. At that date, I began to entertain the thought that this might be chronic and how was I going to deal with it?

...nothing seemed to get rid of my pain no matter what they did. When I came to the point of doing work hardening and I couldn't do that without pain, then I mean I didn't know it was chronic pain or considered chronic pain. But I was getting the idea that I was going to be in pain for the rest of my life.

Intense to me is just more the degree of the pain that I have. Chronic just means that it doesn't have a beginning and an end that is something that is there over a long period of time.

After participants became aware that the pain would be with them indefinitely, then they described the following themes that defined the experience of that pain. Once participants described themselves as aware of each of these themes, coping then became, first of all, an awareness of the various aspects of pain about which participants could do something. Following this, coping became the activity of actually doing something about each theme. After each theme of the experience of chronic pain was described, participants described how they experienced meeting the demands of their life with the awareness of each theme.

Invisibility to Others

One of the first things participants talked about was the invisibility of their pain to others. Chronic pain is not something others can see, and others have no way of knowing when the person is in pain unless it is communicated. Two participants described the experience in the following excerpts.

I know that people can't see the pain that I'm in. When I ask for help, they look at me like what's wrong with you, you know?

I said, "Look at me. Can you tell that there is anything wrong with me?" She said no. I said, "Right, you would not know it unless you knew me so don't judge." She said, "Well, I'm sorry. My husband is the same way. You would not know there is a thing wrong with him but he goes on dialysis machine and he has to have it too. But looking at him you wouldn't know nothing.". I mean until they have to deal with it, they can't see it.

Most participants found that having a diagnosis helped to make the pain visible. Before a diagnosis was made, however, participants reported going from doctor to doctor in an attempt to find out what was wrong with them and to find "a good doctor".

The bottom line is I want it to be better. I don't want to be like this. So I kept going to doctor after doctor.

I even went as far as going to a doctor that's in Memphis. I really was looking to try and get better.

A particular aspect of the invisibility of pain is that it is also invisible from a medical standpoint.

Participants experienced frustration and anger when their pain was not acknowledged or defined by the medical profession. Three participants described it this way:

If you have something that isn't run of the mill, if there aren't a hundred like units, of this kind of either injury or illness or disease, then the doctor is going to become rather frustrated with his diagnosis and inadvertently, you become the object of his frustration. If they can't find anything right away or if it's marginal what's wrong, then they're going to say, you know, are you sure this isn't some sort of emotional problem that you're dealing with as opposed to a physical problem?... I find it very frustrating.

You're hoping that that person is going to tell you what it is because you know that you're not crazy. You know that you're not dreaming this. You know that you're not laying there and your body jerking for no reason at all. You know that this isn't happening for no reason, but they try to convince you that it ain't happening. Yeah, and that is the worse part and I think everybody that I have spoke to in the group and stuff, all have experienced it with the doctor. And it's all because it was chronic pain.

That was really frustrating and I felt very angry about that because my life had changed and I couldn't seem to do

anything about it at the time and the anger just grew. Until I was properly diagnosed and then got on the road to recovery, it was very frustrating.

When a diagnosis was given, participants experienced relief at having a concrete label to make the pain visible. They also felt that they were no longer considered "crazy", "the pain was all in their head", or that they were "lazy".

So me myself, that has been -- my road back has been making sure -- knowing that I have the doctors that are going to listen and not think that I'm crazy, you know.

Hiding/Revealing

Once participants labeled what was wrong, they said that they began the coping process by deciding when to hide their pain from others and when to reveal it. Participants noted that making the pain visible could have both positive and negative consequences. Some participants found that revealing the pain could prevent them from getting a job or could jeopardize continuing employment. Two participants described the consequences of revealing their pain.

Absolutely nothing was going to keep me from interviewing for that job. The fact is I think that he felt that was going to be a continuing problem and that's one of the reasons why I didn't get the job...there's no way to see through and perhaps that's the reason why maybe you do conceal pain...

I don't want competitors or customers to be too aware of my problems. I could lose my business.

For others it was critical to reveal the pain and extent of disability in order to receive disability income:

I'm afraid that sometimes I'm overly defensive about convincing somebody that I really do feel bad and that probably also stems from having to go through getting disability income and you know proving it and then making sure I'm not faking it or malingering or anything. I think I overcompensate there sometimes. I think you're always going to be a little concerned about your own contributions to society when you're damaged.

Participants also described the consequences of hiding and revealing their pain to family and friends.

If you were to feel poorly and, if you were to have an injury and you were to make something of it, people would think less of you because it's unmarime to make an issue out of something you really ought to be working through.

I went on vacation right before I had my shoulder surgery and I think people thought I was being kind of wimpy, truthfully. Cause I walked around with a large blue ice bag on my shoulder most of the time. Especially while I was on vacation. The real issue was I think some of them couldn't figure out why I was acting strange. You know. Somebody said to my wife later, "Boy, he must have been in a lot of pain. I didn't think he was." You know, you get used to not showing pain, but you got this

big blue ice thing on your shoulder. It looks kind of strange all the time. It's pretty visible.

Finally, participants described the conflict between the struggle to appear stoic and the need for understanding and support as they became aware of limitations.

Limitations

Participants found that chronic pain not only put limitations on the body but also on relationships and on expectations of themselves. The world became full of barriers. Time became limited to the here and now or to the near future.

Participants described the experience of limitations on their bodies and the things they could no longer do in the following excerpts.

It's just limiting in various areas of life. You know lots of things I can't do... There are things that I would like to do, but I probably shouldn't do it. I'm aware that one of my worst back spasms comes from reaching up to move the rear view mirror and so I'm aware and cautious of things like that. Anything that has a twist to it or a kind of twist and a forward motion at the same time, I'm very aware of. At other levels, I'm very aware of -- I used to play racquetball and I can't do that. Just can't do that anymore. I tried and was out for about a week.

It's not only physically painful, but it's mentally painful to have to know that a point through your life you were always strong and you were healthy. Nothing could stop you. You know you could do anything. You could lift anything, go anywhere, do anything and then all of a sudden you're not able to do that anymore. You can't even sit at a picnic table and get comfortable. You hope that if you take a hot bath that it will ease your pain and you do that and you get out and you're still the same. You hope every time that you take your medicine that it will help that pain ease. It doesn't. It's sometimes more than you can deal with.

When I get up in the morning, I am extremely in pain. I can't just sit straight up, I have to roll over onto the side and get my legs off the bed and come up and I typically limp for the first 5-7 minutes when I get up.

Another important aspect of limitations is an awareness of the cost of doing an activity in spite of the limitation. One participant described the cost as a penalty.

The conscious issue--here is the limitation on what you can do cause if you do this, you will pay for it for quite awhile. I guess that's the awareness cause you're not going to pay for it for a day or two, but you're going to pay for it for a couple of weeks.

Participants described how they became aware of limitations in their relationships with family and friends.

If it was just me, I might be able to deal with it. It's everyone around me. It's everyone I'm involved with... You

and another couple go to a movie and half way through it, you have to get up and go walk around. That really makes you popular with everybody. You try to get there 15-20 minutes early so you can get in without stumbling over people. It's not just my immediate family that's affected by it, it's all my close friends and everything else. I was a bad one to deal on what I had to give up. I was real active up until the accident. I was a square dancer and a two step and round dancing and on and on. I can't do that now.

My sex life is practically nonexistent for 4 years and as bad as it is on me, I can't imagine what it's like on my wife so that's another thing indirectly that the pain problem has.

Those days that I was flared, I was dealing with it and the kids they don't understand pain. My youngest one has got a bad thing of pulling my arm down and then there you are you know and you'll bark at them and then it hurts their feelings and then they are upset.

Participants described suddenly experiencing a world full of barriers.

Cause if I sit in the wrong type of chair, my back will go.

...like being out shopping and step off a curb the wrong way and twist and there you are in the car the rest of the time.

When you fall on the ice, and you land on your back and you get up and you get that white hot sheet of pain...

Participants also reported becoming aware of limits on time and expectations of themselves:

I knew that one of the things that was very, very important to me prior to this car accident, well still is (but I've had to learn to live with it) is to be reliable. If I told you that I would do something or that I would be somewhere, that you could count on me being there and with this kind of illness, it just rises up right out of the blue and you just can't know from day to day what kind of day you're going to have and I think that's created probably one of the top three problems for me psychologically is not being able to count on myself and feeling such horrible anguish when I have to call somebody and tell them that I'm not going to make it or I don't meet a deadline that I set for myself.

I feel like I deal with a lot less time than other people do because I lose so much of my time. I might get to live a week as far as accomplishments go whereas other people have that whole month to accomplish things. I find that frustrating.

At this point, participants became aware that there had been a radical and dramatic change in their style of life and in their very existence. The person in chronic pain had to take into account that the ground conditions of existence had changed. Participants said they had two coping choices to the experience of limitations. They could choose either to accept or to deny their limitations.

Accepting/Denying

Participants said that attempts at denial were ineffective because pain could not be denied. Most denial centered on the issue of chronicity or the fact that the pain could not be cured and they found it hard to accept the permanence of limitations. One participant expressed it in terms of wishfulness.

If you -- you just wish that there was a time when somebody would say "we can fix you". I wished for that for a long time, but nobody has got any way of doing it.

Denial is probably appropriate in some areas of human endeavor, but when it comes to your physical and mental well being, denial cannot be a part of life. You can become an absolute basket case if you don't know.

Another participant tried to explain the difference between denial and acceptance.

I think to say that you deny it would be to try to then do something that you know you can't do. Uh if you accept it and you acknowledge it and you live within the constraints imposed by it, then you live with it and I think there is a fundamental difference. That's the way I see it.

Diagnosis was another important aspect of participants being able to accept limitations. Another participant talked about the importance of the diagnosis in acceptance.

I really don't dwell on it a whole lot. I accepted it. They showed it to me on x-rays and stuff. They showed me what it was and why it was going to be like that and what they were going to have to do when it came to that point. And I just figured there is nothing I can so about it. I mean I can go home and rant and rave and cry and scream and go crazy and go to the hospital, but it's still not going to change a thing. So with that in mind and with this pain management program behind me, I think I was able to handle it a lot better. I've always been strong about stuff like that.

Participants discussed coming to an acceptance of their limitations through the process of grieving and of dealing with their fear of the painfulness of their pain and with the fear of the foreverness of the pain.

There is some grieving at not being able to do some things...It's like grieving anything else...That whole piece of my life is gone.

You know, fear to do things. Fear to experience it. Fear of what it means. When the pain is no longer connected to danger or uncertainty, it's not as bad.

The fear of the chronic pain experience was a part of the experience of feeling out of control as well as the realization of the participants that many parts of the experience were out of their control.

Out of Control

All participants talked about feeling out of control, being out of control, and trying to find a way to regain control in their lives. One participant put it this way:

It just took over - just took over. You didn't feel like you had any control over it. You couldn't talk yourself out of it. You couldn't ignore it. You couldn't divert your attention from it. It was just there. It was incapacitating, but it was all--it took over. The incapacitation took over.

There are several important subthemes within this theme. These subthemes include the importance of knowing/not knowing, predictable/unpredictable, winning/losing, and the issue of death. Each of the subthemes will be discussed within the context of control.

Participants described the subtheme of knowing/not knowing as being critical to a sense of control. Once they knew what was wrong with them (having a diagnosis), they were able to begin to cope with a new way of life.

But after I went to someone who looked at the x-rays and said, "yes there's things wrong. Here they are. The reason you can't do anything is because of this and this. Then, I think that's when I got to the point where I think I started. It wasn't a miraculous, over night thing, but I think I started being able to accept it then and start to get over it.

He saw things that the other doctor didn't tell me about and he told me about on the x-rays, and on the MRI, and on the myelogram, and stuff. Just having someone in your corner helped.

So, if you know what it is, you can deal it. To the extent that your information approaches near perfect, you'd have the basis for making some sort of conclusion or arriving at some sort of conclusion about what the problem is at hand. If you're in the dark, then it becomes extremely worrisome.

Not knowing led to the strongest sense of being out of control:

Everything starts falling apart and that's scary. That really is. At the same time, I started to have other things that I didn't understand. What was happening to me?

I didn't know what was wrong with me. I just knew that I was hurt. I kept trying to ignore it and then just go on about my daily routine and I couldn't do that and so I felt very out of control.

Part of feeling out of control was the unpredictability of the pain. All participants described good and bad days. A bad day was often when the pain was unpredictably worse and the participant was incapacitated. Often the participants felt undependable as a result:

I can't always plan for when it's going to happen. Over the years, I know definitely some things that's going to make it increase and some things that definitely will make it decrease. But

some times, I don't know. And then I have to make excuses why I can't do something.

I feel sorry for the people around me because I just can't be depended on anymore to do things like I used to be able to. I never imagined myself at 37 years old in constant pain and not being able to do what I like to do most and that was helping others.

Chronic pain was an "It" for participants and they often described feeling as if they were locked in mortal combat with the pain. They all spoke about "fighting the pain" and "winning the battle". The following excerpt describes one participant's experience:

The pain for me is--I'm not managing it. I'm battling it. And I think if I give up the battle, I'll give up more than-- I'll just give up completely and turn into a couch potato. I don't want to do that. I need to battle it. It's like a fight with me. I mean I'm not going to give up the fight.... Overall I think thinking that I will eventually win the battle is what's keeping me going more than anything else.

The issue of death was an important subtheme for participants. Every protocol addressed this issue in some way. Some participants spoke of making the decision to live or survive, others spoke about suicidal ideation and choosing death as the means to control the pain. Participants in this study said they had chosen to live, but several participants described how they had planned to kill

themselves before making that decision; and some participants also noted that they continued to have suicidal ideation from time to time. One participant said that "suicide is not an option" four times. The term, chronic pain, sometimes became a metaphor for death as participants spoke about specific parts of their life coming to an end through their limitations.

The following excerpts describe some of the struggle with thoughts of death that participants described:

I have a rough time with it and I think if it wasn't for the love of my family and belief in God, I would just leave this world. There are some points in pain where I'm sure a bullet would have been a lot better than the pain, you know what I'm saying? Just ending it. I mean after 24 hours of pain, you're just over it.

But they don't realize I'm fixing to go out back and blow my brains out for relief. I mean you can only take so much if you're a human being you know... I've thought it. I've grabbed my pistol. I've went out and sat on a brick and you know it's just--if it wasn't in my religion and it wasn't for my family, I wouldn't be here.

I wish somebody had killed me to be honest with you. I asked them to.

It's just--you know--you're looking for any way out of the pain and uh sometimes you come up with some pretty unreasonable thoughts. I mean I haven't thought about killing myself or anything like that. I want to live. I pray for

the day, maybe one day they'll figure
out how to keep me from being in pain.

According to the participant interviews, once the participant made the decision to survive the chronic pain experience, they began to cope by enduring and managing.

Enduring/Managing

Enduring was described as an active choice to be inactive involving the cognitive actions of letting time pass and living through the worst of times which were the experience of chronic pain at its worst. Participants described enduring as having a quality of acceptance, of redefinition of who they were, and of integrating experience and coping. Managing was described as being accomplished on the basis of active manipulation of feelings, attitudes, thoughts, and the corporeal body.

Participants described enduring the pain in the following excerpts:

All of these things work together to make it something you endure alone. You survive it alone...you survive the pain. There's an achievement in surviving.

There are times when I just have to go to bed not only because of the pain but to hopefully sleep and get my mind off of it for awhile cause I need that mental break as well as that physical break. Then you wake back up and if you're lucky, then you will come out of

that state of mind and you'll go on about whatever if it's making phone call to the doctor. You just go on. I won't ever give up.

Probably the primary thing is to stop, stop whatever you're doing. You can't do anything anymore. You have to lie down, sit down, lay down, whatever. It's this humongous, giant stop sign that says stop functioning in the normal way. I can't handle it. I being the body saying, "I can't handle life the way you're trying to live right now."

You acquire a new standard of living or a new standard of what feels normal to you...when you injure yourself, you end up finding something especially if it's going to be an enduring injury, one that's going to cause you pain, you end up finding a way either a biomechanical change in the way you do business or a change in the business that you do.

Participants described active ways of managing chronic pain in the following excerpts:

That's one of the ways that I'm managing, that I'm looking for positives instead of negatives.

I try to minimize the stress level as much as I have any control over it...I try not to get overly tired. I know that's deadly for me...I don't get into large crowds of people very often. I have to minimize the amount of projects that I am involved in, but not eliminate. There must be some sort of gratification in life.

And so I have to, even from a self talk level, almost be very tender and caring toward my body - give myself permission to lie down, give myself permission to

withdraw from activities that the members of the rest of the family is involved in or permission to withdraw from a chore I'm involved in. Give myself permission to do it without the guilt and without beating up on myself and that's not easy. You must sit down, lie down, rest. And the thing is, I'm discovering that I really do a much quicker recovery if I'll do it that way.

I think the whole key is day to day. Just get up and do what you can today and then wait till tomorrow. Get up and do what you can tomorrow. If you can't do nothing, don't do anything. The bottom line is that's how I'm doing it. Look at long term hoping we get a medical breakthrough and the short term just do what you can when you can.

Managing also included "rules to live by". Every participant created his/her own personal set of rules for daily living:

If you have an injury like my knee, you adapt to that injury in a fashion that that adaptation becomes you. If you take two steps at a time and hyper-extend your knee, you don't take two steps at a time. If you bound up the steps and hyper extend your knee, you don't bound up steps. You take them one at a time because that and pretty soon you just never even think about bounding up steps or taking steps two at a time.

I don't jump. I don't step hard downstairs. I have to make myself not lift things. I have a tendency to lift things not thinking about it.

I do not do things that I know make me hurt. I no longer jog or run. I simply walk. During the day, I may change

shoes several times, changing the height of the heel, changing the composition of the material in it. I might change shoes 3 times in a day.

If it hurts, move it. Just--you have to take control of your own life. Course it might hurt. I hurt everyday. Well you take that responsibility yourself. That's just what I have to do. I mean if I hurt everyday, that's what I do. But I don't let it stop me.

Take it day by day. Never lose hope. Do your best to try whatever it is that you're trying to do. Don't ever give up. Don't ever give up. Always try to find a way around whatever it is that's bothering you at the time.

You got to take one day at a time and you got to take care of yourself, you know. That's the key. Knowing your limitations and not being stubborn, and not letting it be known that's as far as you can go. No matter what it is, you know your limitations. You're the only one knowing what you're feeling. Nobody else feels the same and so if you don't open your mouth and take care of yourself, nobody else is going to.

Becoming separated from the world around the participant was often an important rule as well as an unavoidable state.

Separation

The theme of separation was described by participants as separation from one's own body and also from the world.

In the case of own's own body, participants reported:

You almost have to separate yourself from your body and care for your body like it was something separate from you.

In terms of separation from others, participants reported:

When I ruptured that disc, I didn't want anybody near me--anybody. I didn't want anybody to touch me. I didn't want anybody to talk to me. I didn't want anybody--especially did not want anybody to ask me how it was. I wanted to deal with it.

In terms of separation from the world, participants reported:

When I really hurt, I become very quiet. My wife likens it to an animal crawling off into the woods to die very quietly.

Again, I don't want to be disturbed. I don't want to uh I don't want anybody to talk to me. And it happens often.

Participants described separation in terms of breaks in communication with others, being stigmatized, and needing to be alone. The following excerpts offer descriptions of ways in which participants experienced separation.

Participants described breaks in communication most often with family members and with the medical profession.

One day my wife and I were driving down the road and something happened, something stupid. I don't even remember what it was-- tells you how important it was. And I got on her over it. I don't even know if it was her fault. Well, she pulled over to the side of the road

and said, " You can either drive or walk, but you're not going to keep on me like this"... and I realized that I had been a real bear on her because she couldn't do anything right. But a lot of it had to do with if somebody pulls over in front of you, you have to hit your brakes. That's not her fault and I got mad over that cause it hurt.

The first doctors I went to, they weren't listening to what I was saying. One of them about killed me. I got ulcers and I told him. He gave me medicine that you can't give to nobody with ulcers. It almost killed me. I mean this is a doctor that give me medicine. He didn't read my chart. They are just not listening. A lot of doctors are there for the money I guess. I don't know. Whatever, I think doctors should listen more to relax the patient to where they won't be nervous. There are people that are more outspoken than what I am. I am more outspoken now then before I got hurt. I think doctors should be listening to the patients more and reassure them. "Is there anything else you need to tell me?" I'm not a doctor, but I know what I think they should do.

Another participant described being stigmatized in the following excerpt:

I think the association--because one of my problems is the Workman's Comp because I was hurt on the job so automatically every time you walk in to see someone, you are faking your injury or that's the impression they give you. You're out for what you can get. You're out for how much money you can get or whatever. You don't want to work. That's the impression that a lot of the doctors gave me when it first started

and that really played on me and that was really tough to deal with....always ---like I was telling my wife--- he always looked at me like I was something on the bottom of his shoe (laugh) like something he had stepped in on his way to work and why I don't know. I didn't go in there wanting to be taken off work or anything else.

Participants coped with separation by choosing to connect with others or by choosing to withdraw from them.

Connecting/Withdrawing

Some participants chose to connect with others through providing education about chronic pain. One participant wrote articles for a newsletter; another became active giving public lectures on chronic pain. Another participant resolved to become a millionaire to prove to others that he could overcome his limitations.

I've set certain things what I have to do. And I know what I want out of life and know what I'm going to get. I've told myself that by the time I reach age 50, I'd be a millionaire and I will. I'm over half way there.

Still another participant chose to wear his injuries as a badge of courage selectively letting others know of how he earned his badges.

It became sort of a red badge of courage... Look what I have endured. Could you have done the same? I know there are people in the Marine Corps who

are absolutely blown away by the fact that I'm even alive through some of the shoot downs I was involved in. Uh there are some people after that helicopter explosion fire in 1967, uh that they are surprised that that didn't drive me away from aviation. On the contrary, I still love to fly.

Another participant uses his experience to work therapeutically with people in pain.

Being a therapist who in part deals with people in chronic pain, I have had to stop and analyze what that means to me in a way that I don't think most people have. I think you only focus on your own experience of pain for the most part and uh to explain it to somebody else over the years and to talk to people about their pain is to bring some form and structure to it...The issue becomes fundamentally does pain become your life or do you live your life? Do you go on with your life?

Participants also connected with others in order to get help for pain.

There comes a point when you hurt so badly that you have to reveal it... My wife has acquired the ability to sleep through all that. If it goes on too long, she will get up and commiserate with me. She never tells me to knock it off. She never tells me to go to another room. She never tells me any of those things. She's just very supportive.

No matter how open participants were with other people regarding their pain, at times each described feeling the

need to withdraw and to deal with their pain in private.

Being alone was one of the subthemes of withdrawing.

Participants described withdrawing from others and being alone in the following excerpts:

When I ruptured that disc, I didn't want anybody near me--anybody. I didn't want anybody to touch me. I didn't want anybody to talk to me. I didn't want anybody--especially did not want anybody to ask me how it was. I wanted to deal with it.

I was trying to curl up inside myself because I hate to keep making an issue - it's got to be horrible for someone who is healthy to live with someone who isn't. As tired as I get of having bad days, can you imagine how tiring it must be from the other person's point of view? At any rate, I didn't even want him to look at me. I just wanted the whole world to go away and leave me alone.

It's almost like you have to go down deep within a hole or something in order to block out everybody's everything whether it's their thought, their opinion, their need, even their conversation. I desperately want to be left alone at a time like that. I think that is because I need every single resource that I have in order to cope and I can't share those resources at all at that point.

Each participant also described connection to other pain sufferers by expressing the hope that participation in this research study would in some way help others who were experiencing chronic pain. Most participants stated that

this was the reason they chose to volunteer to participate in this research.

The last theme of coping was described by the participants as the method they used to determine how they would cope with their pain on a daily basis or at times on a minute by minute basis. This was accomplished by constantly monitoring, evaluating, and deciding.

Monitoring/Evaluating/Deciding

Participants described monitoring their bodies, their environment, and the reactions of others to them. They evaluated this information and decided how to respond to their world. These three activities were a constant in their lives determining how they would react and how they would choose to cope with the other themes of their experience. This theme moved across and back and forth between all the other themes of coping.

Participants were constantly monitoring, evaluating, and deciding about the unreliability of their bodies; the separation they were experiencing from others or the separation they wanted from others; the need to hide or reveal the pain; how to control pain; and how to deal with limitations. This theme appeared at the center of all the other themes of coping as an ongoing cognitive process.

One participant described monitoring, evaluating, and deciding in term of differentiating the pain.

You also learn to differentiate things. Pain is not one thing. There is dull, throbbing pain and there's sharp, shooting pain. And then there's that kind of white hot flash of pain. Irritation. There's soreness and they are all very different and there's probably other stuff that I haven't named and some of them are things you pay attention to and some of them aren't... If you wanted to differentiate what's going on, you want to differentiate things that are damaged based and the long term versus things that just hurt and you kind of ignore the things that just hurt unless they are that kind of white hot pain. And you can't ignore that.

Other participants described monitoring their environment:

This condition I have is very, very heavily influenced by barometric pressure and any kind of low fronts that move through. So by checking the weather channel later that day and the next day, I was aware that a front had begun to move through this area as this day progressed, but I wasn't aware of it at the time because we were watching movies...I know that's a warning signal.

I've learned that I have to be able to manage my environment a little bit. Now, I make sure if I have to do any work, I have a high back chair. As I have gotten stronger, I can work for many hours now and its not a problem. Just learning what I needed and making sure I had those things.

Summary

To summarize present results: all participants gave a description of a two phase process in which the first phase described their awareness of the experience of chronic pain in terms of the invisibility of the pain to others, their limitations, separation and being out of control. In the second phase of their narrative, Participants described how they coped with those experiences by hiding and revealing the pain, by accepting and denying their limitations, by connecting and withdrawing from others, by enduring and managing their pain, and finally by monitoring, evaluating and deciding how and when to do each of these activities.

Chapter V

Discussion

The purpose of this investigation was to describe the thematic structure of how people cope with chronic pain. Participants responded to the research question by describing how they coped with the pain within the context of a personal experience of chronic pain. In their answers, all participants identified a two part process; first they described an awareness of the themes of chronic pain against a background of painful existence. This was followed by a description of how they became aware that their lives had irrevocably changed and what the experience of coping with their pain was like.

An interesting result was that participants told the same story even when the research statement was altered. The first six participants were told that the researcher was interested in how people coped with chronic pain and then asked to talk about a time when they were aware of having chronic pain. The second six participants were also told of the researcher's interest in how people coped with chronic pain and were then asked to talk about a time when they were aware of coping with chronic pain.

In all cases, the participant narratives followed the same trajectory: first they described how they came to have the pain, how they experienced that pain, and then how they coped with it. Each described the perception of pain and the awareness of that perception. Thus, the first finding was that participants seemed to feel that before there could be an understanding of coping with pain, there had to be an understanding of one's experience with pain.

These findings echo those of Erdmann(1987) who noted similar themes and subthemes in the experience of chronic pain. The participants in that study also spoke about the problems they experienced with the invisibility of their pain, feeling out of control, sensing limitations, and expressing separation from others. Martin (1989) and Cademenos (1981) using phenomenological methodology reported similar themes in the experience of participants with chronic pain. They also described participant experience of separation, limitations, and some of the problems of the invisibility of the pain.

Participants in this study were quite clear in communicating the importance of verbalizing the experience of pain. The most often voiced complaint of participants was that no one wanted to listen to them talk about their pain. All participants verbalized the thought that no one

was interested in hearing about how much they hurt, how their life had changed, or about how they were searching for a way to cope with the pain. Newshan (1996) found that participants in her study on hospitalized patients with chronic pain due to AIDS felt that no one was listening to them or taking their pain seriously within the hospital setting. Kleinman (1992) and Lunde (1993) found that physicians had little understanding of the world of their patients, and that doctors and patients often live in different conceptual worlds. Jackson (1992) reported that patients coming into treatment at the Commonwealth Pain Center in New England felt confused about how to describe their pain to the medical staff because of the fear of not being believed that the pain was "real".

These findings emphasize the importance to participants of listening to and taking the word of the chronic pain patient regarding their personal experiences of pain. The issue to participants became a matter of believing what the chronic pain patient said and of then validating such concerns. Researchers such as Cademenos (1981), Frank (1997), and Martin (1989) all found a major problem for chronic pain patients was that of not feeling believed by family, friends, and the medical profession. This particular issue offers an example of the ways in which

themes of the experience of chronic pain are interrelated. People with chronic pain find that others have difficulty believing them because the pain is not readily visible. Such pain, however, is real to the patient, and the person in pain describes his life against a background of pain involving limitations, feeling out of control, and as well as feeling separated from others because no one can understand his experience. He finds himself alone against a background of silence regarding his pain.

Several researchers (Beutler et al., 1986, Passchier et al., 1996; Turk & Okifuji, 1996) have discussed the depression and anxiety experienced by people who suffer from chronic pain. Not feeling heard, understood or believed appear to be one source of that depression and anxiety. People in pain say they think no one wants to listen and so they become alone with their pain. Without a sense of social support for an experience that "takes over the world", the chronic pain patient is a candidate for depression. According to participants, the phenomenological interview used in this study gave voice to the their experience of chronic pain and allowed them to feel heard.

Themes in the experience of chronic pain are important to understand because they are found not only in this study but throughout the literature (Erdmann, 1987; Cademenos,

1981; Kortaba, 1980; Martin, 1989). It is hoped that health care providers who work with this population will find an understanding of these themes useful in working with individuals having chronic pain. The themes describing the experience of chronic pain will be presented individually, and the experiential structure of coping will be discussed within the context of each of these themes.

Invisibility to Others

The theme of invisibility uncovered in this study is similar to the issue of invisibility described by Fernandez (1992) in a study focusing on patients with lupus. Women with lupus were thought to be malingering, or to be lazy, because the complex symptom pattern made the disease difficult to diagnose. Patients expressed relief at finally receiving a diagnosis and becoming validated in their social context as having a 'real' disease. The importance of validating the reality of chronic pain was discussed by Howell (1994); the women in her study did not make a transition to an effective coping pattern until their pain had been diagnosed and thereby validated. Diagnosis served to make the pain visible.

According to the Braden (1991), the issue of secondary gain is a major concern of health care

professionals and is often an important factor in the diagnosis and treatment of chronic pain. The invisibility of chronic pain serves to further complicate this issue. Because pain is invisible to others, others can not know with any degree of certainty when one is suffering or when one is malingering. Proof of disability requires proof that one is not malingering. In this case, the pain must be made visible in some manner.

One female participant in the current study said that she often wished that she was paralyzed and in a wheel chair instead of being saddled with chronic pain. She thought that if she were confined to a wheelchair, her pain would be visible. Paralysis would be public and others could see it. If she were paralyzed, she thought that she would not have to ask for help; others would give help automatically.

The issue of the invisibility of the pain was problematic for all the participants in this study. Participants were concerned about others' perception of them and this affected how each person sought to make the pain visible or sought to conceal it from others.

Coping Strategy: Hiding or Revealing

All participants in this study spoke about the invisibility to others of their pain and the necessity of

hiding or revealing it. Each person described the decision making process of when to hide or reveal pain, the context of those decisions, and the consequences of the decision to hide or reveal pain.

Participants said they had to reveal the pain in order to ask for help from family, friends, and the medical profession. One participant said he had to ask his wife to tie his shoes. Another said he could not get out of bed unassisted.

The common framework was that family members were not able to anticipate the chronic pain patient's need for help and the person in pain had to say he was hurting and needed help. Making the decision to hide or reveal the pain was problematic in several ways. Participants said that when they revealed the pain in the context of needing help, they felt vulnerable because sometimes they were labeled "wimpy" or as one woman put it, "He looked at me like oh no, here we go again". The experience of negative reactions from family and friends and the fear/anticipation of negative reactions from family and friends sometimes kept the person from revealing pain and asking for help.

Several participants described times they suffered in silence rather than "making an issue". At these times they chose to hide the pain and to withdraw from others. Two

participants described instances in which they received support from their spouse when they revealed the pain and asked for help. A general finding was that participants did not think they could receive compassion, empathy, or nurturance from others so they did not ask. Even the two participants that described instances of receiving support did not make a habit of asking for help. They prefaced that they only asked when they felt there was no other choice.

Overall, participants said that there was a risk of rejection when they revealed their pain and often they were not willing to take that risk and chose to hide the pain. One participant said that at the times when he hid the pain, he knew that his children thought he was mad at them and he said he knew that they just "couldn't understand". People in this study noted that they did not want to appear weak, undependable, whiny, or to have others think less of them and so they often chose to hide the pain.

This finding leads to the conclusion that there seems to be a catch-22 quality to revealing chronic pain especially to intimate others. This situation encompasses both the person in pain and significant others. The person with chronic pain wants and needs help, but does not want to appear weak or whiny. If he hides the pain and appears stoic, he gets no help, sympathy, or support. If he asks

for help often, or talks about the pain often, he becomes a whiner and he feels that the other will get tired of hearing about the pain. The result is that the chronic pain patient is left with the belief that there are negative consequences for asking for help and negative consequences for not asking for help.

There is also a catch-22 for the other person in that he or she cannot see the pain and cannot understand the pain from the point of view of the person in pain. It is not possible for the other to consistently mirror the experience of the person in pain. According to participants, even when others want to help, they can not do it as often as the person-in-pain needs it and if they try to give help as often as it is needed, then the other person will neglect himself/herself and becomes impatient with the person in pain. No matter how helpful the other tries to be, he or she cannot change the essential experience of chronic pain. Finally, this situation begins to resonate with the other's own mortality. One participant said, " As hard as it is on me to be in pain, I can't imagine how hard it must be to live with someone in chronic pain". This appears to be an essentially no-win situation for both the person in pain and for their intimate others. This finding addresses the need for continued research on the effect of chronic pain on the

family and the need for outcome studies regarding treatment within a family systems approach.

Two participants described their difficulty with others in using handicapped parking. Because both appeared to be healthy, the pain was not visible to others. Both reported feeling victimized by negative comments from strangers when using handicapped slots.

All participants talked about the need to make the pain visible to health care providers and each of the narratives spoke about "good" and "bad" doctors. A "good" doctor was described as one who listened when the pain patient tried to make the pain visible. Even when the physician did not have a cure, he was still considered a good doctor if he or she listened. Having a cure or giving direct help to deal with pain was not as important as listening. One participant described his doctor giving him the news that he would eventually become confined to a wheelchair. The participant continued to see him as the good doctor because he felt that the physician cared about him. A "bad" doctor was described as one who did not listen and who did not believe the participant because he could not see the pain.

Four participants described a good physical therapist. Five of the participants had been referred by their doctor to a pain clinic and each of these participants described

having a good experience with the staff psychologist. Again, the differentiating characteristic was that the psychologist listened to the participant, validated their pain, and recommended interventions based on the participant's specific complaint. Two participants had sought the services of a psychologist on their own and two participants had consulted a psychiatrist. The nine participants who had seen a psychologist or a psychiatrist described having had a positive experience and of having received help. Again, the most important factor seemed to be listening on the part of the health care provider: listening makes the pain visible.

An additional finding was that all nine of these participants also reported having learned relaxation or self hypnosis techniques while receiving therapy. They also reported finding these useful interventions in coping with chronic pain. Each person also reported continuing using these skills after terminating work with the psychologist or psychiatrist.

These findings illustrate the dilemma faced by both the chronic pain patient and the health care provider regarding the invisibility of the pain. The participants were afraid to make the pain visible and the physicians were not able to "fix" what they could not see. These finding can be used to

address the issue of physician judgements described in the study by Tait and Chibnall (1997). In this study, physicians relied heavily on physical findings and tended to rate both pain and disability lower when physical damage was not readily visible and/or when they had a negative relationship with the patient.

Counseling psychologists can help prevent misunderstanding between physicians and patients by facilitating communication between them. Patients can be helped to articulate the pain problem to the physician and can be helped to make pain visible in a way that establishes a positive relationship with the physician. The counseling psychologist can communicate to the physician the difficulty that chronic pain patients face in communicating pain, including their need for validation and support through listening. In this study listening appeared to be more important than fixing. Such information can be most helpful when shared.

According to participants in this investigation, part of the distrust between patient and physician concerns the issue of pain medication. Health care providers are concerned with substance abuse and this is an important issue for them. Participants supported the physician's need to be careful in prescribing pain medication; in this study,

however, participants were adamant that they took little to no pain medication. They described waiting until the pain was intolerable before seeking relief through medication. One participant denied any use of pain medication no matter how severe the pain because of being accused of drug seeking behavior when visiting a physician. Medication was not a focus of this investigation, although the results do point toward a need for further phenomenological investigation of how pain patients actually use medications.

Aronoff, Wagner, & Spangler (1986), Haddox (1997), and Kouyanou, Pither, & Wesley (1997) have discussed the varying positions within the medical community regarding the prescribing of medication for chronic pain. Kouyanou et al. (1997) studied drug misuse, abuse, and dependence and issued cautionary statements in prescribing pain medications with emphasis on patient education. Aronoff et al. (1986) reviewed the different properties and pharmacological effects of pain medications. These included analgesics, narcotics, and antidepressants. They cited the need for psychologists to assess depression, anxiety, and psychosocial distress when medication is prescribed. Haddox (1997) discussed increased quality of life with appropriately prescribed medication. He cautioned against denying patients needed medication.

Limitations

All participants described being aware of limitations. These limitations were described as continuously present and as a part of everyday life for the person in chronic pain. Limitations were described, more specifically, as being both chronic and changing. Participants described limitations on their physical abilities, expectations of themselves, use of their time, relationships with others, and their experiences of the world.

Participants described their awareness of limitations as changing the nature and meaning of their existence. Heidegger called such a condition a "thrownness of life" (1962). In his description of personal existence (Dasein), Heidegger referred to "being thrown" as the way one finds oneself in the world. Chronic pain patients find their existence in the world to be quite different following an illness or injury. The awareness of limitations against a ground of pain can be compared to Heidegger's description of existential dread which is a "relation to the world that encompasses being in all its aspects but without the familiar feeling of being at home in the world" (Pollio et al., 1997). And so it seems to be for the chronic pain patient as he faces limitations. There is no longer a feeling of familiarity, of being at home in one's world; the

world has become forever changed. At this juncture, participants described a redefinition of the self as a self-living-with-pain. Also at this point, they stopped speaking about their life before pain. Accepting the limitations with chronic pain seemed to negate the importance of their history before pain and began to focus them on the present or near future.

Coping Strategy: Accepting or Denying

Participants described denial as something that happened early in their awareness of limitations. Denial could take the form of not believing the pain was chronic and a part of one's daily life. In such cases, the participant would go from doctor to doctor looking for a cure or he or she would withdraw from normal activities and wait for a cure. At this point, some participants described waiting to get back to being their "old selves" and to putting their lives "on hold". Participants said that the pain itself could not be denied. Some participants described trying to ignore the pain, but this was different from denying its existence. Therefore ignoring was considered a type of coping strategy that had more to do with the theme of control and its relation to the theme of monitoring/evaluating/deciding.

Participants also described what helped them accept the limitations imposed upon them by chronic pain. The two events that stood out were getting a diagnosis and going through a grieving process. Diagnosis was important in removing some of the limits of the pain and the fear of the pain. A diagnosis made the pain more visible and therefore easier to accept. The importance of getting a diagnosis was repeated across themes.

The grieving process seemed to help participants accept their limitations by grieving their losses. These findings coincide with that of other researchers (Erdmann, 1987 and Howell, 1994) who have discussed stages of chronic pain that are similar to the grieving process and the stages of grief as described by Kubler-Ross(1969). One participant spoke eloquently of grieving in regard to his specific losses and limitations. Limitations encompass losses, and grieving those losses appeared to be part of the adaptation process. When explaining chronic pain in terms of the stages of grief, denial would be the first stage in the process. The grieving process does not follow a linear path. Instead, an individual moves through the stages in a back and forth manner. Acceptance of chronic pain is somewhat similar in that the individual does not make a single adaptation to limitations. Participants described the

process as dynamic; just as one adapted to and accepted one change, he would become aware of yet another limitation connected to the pain.

Making the decision to adapt to a changed way of life and accepting its limitations was an important part of coping with limitations. An example is provided by one of the participants who described having to accept the limitations imposed by headaches and dizziness following a head injury. She described accepting the limitations on her expectations of herself. She noticed that some days would be worse than others and that she could not depend on herself to fulfill obligations to herself and others on bad days. Not only did she learn to accept that her limitations were unpredictable in occurrence, but that they were also unpredictable in their severity. She accepted that at times she was unable to walk unassisted. Acceptance meant not only accepting this change in her circumstances by using a walker, but also to plan activities differently.

She discovered that she had to adapt to and accept limitations on both her time and energy level. The pain left her with less energy thereby placing a limit on her time, and she discovered that everything she did now required more time. She also accepted that the world had new barriers; for example, she noted that going to the mall, or

another place that was crowded, increased her difficulties with balance and dizziness because of the constant movement of others. She also discovered that it was more difficult to use her walker in crowded areas and that she no longer felt safe in places that were once easy and familiar. She reported that others became impatient with her because she had to move slowly to keep her balance. She reported accepting that some friends no longer wanted to go places with her because she couldn't keep up with them. This description of the participant's acceptance of her limitations also demonstrates how coping with one part of her experience moved across all the other themes of the experience of chronic pain.

Psychologists can facilitate the adaptation process by helping the pain patient understand the diagnostic information and by helping the patient progress through the grieving process in order to accept loss. It is important to help the patient to understand the dynamic process of limitations. Psychologists can also focus on treating the whole person and, when acting as part of a treatment team, could help keep the focus on the person not just on their injury. It is easy under an ordinary medical way of looking at illness not to think in terms of the whole person being changed by the illness or accident. For the chronic pain

patient, the world is now lived in an ill way rather than by a "me" who lives the same way as before but who happens to be ill. For example, having a cold does not radically change who the person is after the cold has passed; but having a chronic illness does, however, change the person. While there may be an inclination to treat a spinal injury, it is more appropriate to treat the person who has a spinal injury. In doing so, it is important to discover what meaning the chronic pain has for this person before we can design appropriate treatment.

Appropriate tools to enable the pain patient would be things that incorporate a sense of control over one's daily life. Processing the meaning of a changed way of life with chronic pain should be an early and ongoing part of treatment. This meaning could be quite different for each individual. For example, if the person was injured in a senseless accident, then he probably is taking a victim stance and the damage extends to his sense of self and the way in which he now perceives himself. Interventions which empower would be appropriate for pain patients in the victim stance.

It is interesting to note that one thing that was not found in this investigation was the use of humor as a coping strategy. One participant made brief mention of using "black

humor" to cope with pain. A recommendation for further research is to explore the use of humor as a coping strategy for chronic pain.

Out of Control

The theme of control was perhaps the most obvious aspect of the experience of chronic pain. Each participant described feeling out of control as well as being out of control and making attempts to gain control of the pain. Being out of control was associated with being incompetent, being diminished in the eyes of others, being alone in a pejorative sense, and "living to die". Bradley(1996) in describing cognitive-behavioral methods to treat chronic pain said that effective adaption of living with chronic pain was linked to the amount of perceived control of the pain.

An example of feeling out of control, being out of control, and making attempts to regain control was described by a male participant as he recalled an out of control experience in which he suffered humiliation. He reported being with his wife and children in a department store when he lost control of both his legs and his bowels due to the unpredictable flare-up of a previous spinal injury. He was not able to stand because his legs had become temporarily

numb and he could not get to his feet. He described lying helplessly on the floor trying to explain his situation to the store personnel and asking for help to get to the door. Not only did the management refuse to help him, but intimated that he had staged "a slip and fall" in order to file a lawsuit. He tearfully related this story insisting that all he wanted was for someone to help his wife get him to his car so that he could leave. Being out of control left him, and other participants, feeling helpless and "degraded".

All participants took steps to regain control and to minimize their pain. All participants began the process of regaining control by trying to obtain an appropriate diagnosis for the pain. Again, the importance of obtaining a proper diagnosis was central to any kind of progress. Not knowing was described as an out of control experience when knowing brought about a sense of control. The issue of getting an appropriate diagnosis which validated the pain was repeated over and over throughout the protocols and across themes.

The unpredictability discussed previously in the section regarding the acceptance of limitations was also figural in an out of control experience. Not being able to predict flare-ups of pain and being caught off guard as in

the situation described above kept participants off balance and contributed to feelings of fear, anxiety, and depression. Attempts to regain control meant accepting unpredictability as an aspect of their changed way of life and of taking that into account when making plans. Other researchers (Kortarba, 1983; Martin, 1989; Turk et al., 1983) have discussed similar findings regarding the unpredictability of chronic pain and the concomitant increase in the feelings of fear, anxiety, and depression associated with it.

Participants often described their chronic pain as an "it" that they had to "battle" for control. This finding is consistent with Cassell (1976) who studied the language used in doctor-patient interactions. He found that disease or even symptoms of disease were seen as a separate entity in order for the person to gain distance from the symptom. Winning or losing the battle with the pain ("it") was figural in gaining or losing control.

Along with the issue of battling the pain was the issue of death. All participants spoke about the issue of death in relation to issues of control. For some participants death was a metaphor for the pain. Choosing to live with pain or choosing to die appeared to be the ultimate solution to the issue of control. Once the decision was made to live

with the pain and accepting its limitations on them, participants dealt with issues of control in everyday life through enduring and managing.

Coping Strategy: Enduring and Managing

An important finding was that participants made a conscious/existential decision to accept limitations and to continue living; to endure. Several participants described serious consideration of suicide as an option and of then making the decision to endure. Thoughts of suicide were described in depth by three participants. This finding is consistent with research done by Fishbain (1996) and Kotarba (1983) who described suicidal ideation and the rate of completed suicides among the chronic pain population. Both researchers advised assessing chronic pain patients for suicidal ideation and stressed the importance of early detection. Approximately 50% of respondents surveyed by Hitchcock et al. (1994) reported having considered suicide because of the feelings of hopelessness associated with their pain.

Accepting limitations and making the decision to live with the pain made participants aware of their mortality in a way similar to Heidegger's (1962) view of the experience of Angst or the dread of possible nothingness (death).

According to Pollio et al. (1997), the dread of nonbeing allows the person to confront the patterns of his life with both its changes and its continuities in a way that he is able to continue his life in a more authentic way. The chronic pain patients included in this investigation appeared to confront the possibility of death and through this confrontation made the decision to live within the limitations on life associated with chronic pain. With this decision came a redefinition of the self which was the cornerstone of enduring.

Merleau-Ponty (1962) would perhaps have described the phenomenon of redefining the self in chronic pain in terms of continuity and change within the present moment. Change would imply what is figural and continuity would imply the ongoing situation of one's life. His description of this phenomenon would have taken the form of the intentional relatedness of the person to his present situation (being in pain) and the acceptance of a life with pain would appear as the intentional relatedness to what has been and to what is still to come. This would appear as a constantly redefining of the self in pain according to whatever is the present situation since adaptation to pain is a dynamic process. In fact, this is what most of the participants described as happening. The chronic pain patient does not appear to make

one change in accepting his limitations with chronic pain but rather change and adaptation appear to be a continual process due to the unpredictability of the pain that required continual reevaluation, acceptance, and redefinition.

Enduring was the coping strategy that allowed this process to occur, and participants described enduring as a cognitive process that enabled them to "survive the pain" or to "get through the pain". Enduring had a quality of acceptance which allowed participants to transcend the pain by not fighting it but rather by adopting a stance that allowed time to pass. Enduring meant living with a new definition of self; the me-with-pain. In this new definition, enduring was concerned with being whereas managing was concerned with doing.

Participants described the strategy of managing as the active manipulation of feelings, attitudes, thoughts, and the body. These coping strategies generally fell into three categories which included (1)cognitive managing (thinking), (2)behavioral managing(doen), and (3)affective managing(feeling). Turk (1996) discussed coping strategies in terms of behavioral managing; however, cognitive and affective factors were described as responses to pain instead of coping mechanisms. It is interesting to note

that no studies were found that discussed cognitive and affective factors in terms of strengths on the part of the chronic pain patient.

Affective coping was the least frequently mentioned and was associated more with being depressed, anxious, frustrated, angry, or scared. It seemed to be a catalyst, however, for managing through thinking and doing in order to gain relief. The ability to manage feelings through affective coping seemed most salient after the person in pain had gained some sense of control through enduring.

Feelings of fear and helplessness were managed by participants gaining control of the unknown through acquiring knowledge about their pain. All participants described ways they sought information about pain; these ranged from seeking information from professionals to sophisticated searches through research. One female participant described the motivation to cope with the fear, and even though she had little "book learnin'", she now spoke with authority on the facts of her pain condition. She had returned to school and had begun to give speeches to interested groups on the issue of chronic pain.

The most frequently mentioned strategies used in managing by participants were thinking and doing. Thinking consisted of finding meaning for the pain, mental distancing

techniques, synthesizing information and knowledge about the condition, and reflective activity in planning coping strategies such as rules to live by. "Knowing" was a key factor in this type of coping and it was often used in reducing the emotional pain of "not knowing".

Finding meaning for the pain was figural for participants. The way the self was defined in the changed way of life appeared to depend on whether the pain was the result of a meaningful or meaningless event. If the pain was the result of a meaningful activity -- such as in the case of an army test pilot with three purple hearts -- the pain could be experienced as meaningful and the self seen as valuable and heroic. On the other hand, pain resulting from a meaningless and senseless accident led to a different type of meaning for the self. There was a big difference between being a hero and being a victim. One participant who had been injured in a "senseless" accident, in trying to find meaning for his affliction said, "I must have done something wrong" and he described experiencing a great deal of guilt. The pain for him was a retribution for past sins. There was a need for participants to be able to make some kind of sense out their pain. Another participant described the meaning of pain gotten senselessly as "sinful", another described the meaning of his pain as a test.

One female participant spoke at length about finding meaning and choosing her attitude toward dealing with her pain. Her descriptions were reminiscent of Viktor Frankl (1959) who said that when he was imprisoned in a Nazi concentration camp during World War II, he discovered that he was free to choose his attitude toward his circumstances when all other freedom was gone. He was influenced by Nietzsche's ideas of suffering -- such as how pain separates -- and the idea of that which does not kill one, makes one stronger (Crane, 1965). The importance of meaning cannot be ignored. In designing treatment plans for chronic pain patients who have been involved in senseless accidents, it might be quite important to help people reframe the experience in a way that the meaning of the pain becomes helpful rather than damaging to the person.

Doing was described as the way a person in pain took action to minimize pain and to take control of his or her life instead. "Doing" was important to all participants. It was interesting to note that a "good day" was described in terms of what was achieved and not by how well the person felt. Participants tended to measure themselves by what they could or could not do. Several participants said that not being able "to do" was more debilitating than the pain itself.

Tailoring one's activities was a core method of managing and gaining control by doing. Each participant described ways of managing one's environment. Participants described designing personal rules and rituals to gain and maintain control. These rules and rituals included such things as when to change one's shoes, how to put one's foot down, how to get out of bed, "taking it day by day", etc. These "rules to live by" served to maintain awareness and thereby prevent exacerbation of pain. The rules and rituals also gave a measure of structure and control to the management of chronic pain.

Since chronic pain patients place such a great emphasis on doing, psychologists can help the pain patient reframe what doing means. Instead of experiencing failure because he cannot do the same amount of work as he could do before the illness or injury, the pain patient can be helped to focus on current strengths and ways of building upon them. It would seem important to define "doing" in a new way in which the pain patient can find a renewed sense of self-efficacy. This may start with the learning of self-care and with learning the importance of self-care and how that can affect one's ability to regain a sense of control in their life. Psychologists could also help chronic pain patients to become aware of the power to actively choose their attitude

toward their chronic pain instead of becoming helpless victims of it.

Some patients in this study described learning relaxation skills as serving this type of function. These participants were able to experience a sense of efficacy in being able to relax themselves and thereby to experience hope as they relaxed and could think about their future. This technique appeared to help them to begin to think of things they could do to change the future. A sense of agency can make the difference between depression and hope. The benefit of relaxation techniques for chronic pain patients have been described at length by Arena & Blanchard (1996).

Separation

The theme of separation as described by participants involved separation from their own bodies, separation from others, and separation from the world. Sometimes participants chose to separate themselves from others and the world and sometimes they reported that others and the world became separate from them when they couldn't keep up their former pace of life. The separation from others was often recognized through breaks in communication, being stigmatized and needing to be alone.

Hunt (1992) described how women with cancer felt separate from others and as a consequence began setting up barriers to control their fears of isolation from others and/or to control the threat of being taken over by the needs of others. The women in that study felt it necessary to take "time out" as a way of coping much like the woman in the present study who said that at the moment of extreme pain she could not share her resources with anyone. In Erdmann's study (1988), of low back pain patients, reported that participants experienced emotional consequences of chronic pain when they were alone. When they described situations in which they were cut off from other people, they reported feelings of depression and self pity. Parks (1987) in a study on emotional pain described withdrawal as a method of gaining strength, decreasing vulnerability, and escaping from being too overwhelmed by too much stimulation. "People with chronic pain are generally withdrawn from others and the world due to the private nature of the pain" (Erdmann, 1988, p. 179).

Coping Strategy: Connecting and Withdrawing

Participants coped with separation by connecting or withdrawing from the self, others, and the world. There was

a paradoxical quality to this particular coping strategy. And participants said there were both positive and negative consequences to connecting and withdrawing. At times all participants said that they tried to distance themselves from their body. It appeared that this "mind from body" split or distancing technique was the only power a person felt in the moment of extreme pain. The pain was seen as an intrusive object instead of as a part of themselves. The pain was described most often as an "it" rather than as something belonging to "me". As mentioned previously, Cassell (1976) discussed patients' use of language as a functional way of psychologically manipulating illness in order to distance it from the self. It is interesting that no other studies were found that have investigated the importance of the pain patient's language in coping with pain.

Several participants in this study described the pain as an "it", an alien sort of thing that came into their bodies and "took over". They each described themselves as being isolated and being in mortal combat with the pain as with an opponent within their body of whom they would never be free. The struggle preempted any thought of connection with the self or with others. Battling the pain became the only thought and winning the battle the only goal.

All participants described withdrawing and connecting with family members. One man said that he had to be by himself in moments of intolerable pain and when he withdrew to take care of himself, he was concerned for his wife and children because they thought he was mad at them. The concern he showed for his family and his not wanting to worry them or to "bring them down" was illustrative of all the other participants who described worrying about the effect on others of their withdrawal and of their need to be alone.

Being alone with pain was full of paradoxical feelings for participants. At times, being alone brought solace. At times being alone was painful. Being alone sometimes meant the person in pain could think only of himself/herself and could take care of his/her needs whereas at other times it meant being lonely. Participants described using time alone to escape through sleep or through distractions. Two women in the study described how they got a "mental break" from the pain by changing their state of consciousness through sleep. Time alone was also spent "enduring the pain", being alone in pain and being alone with the pain.

One participant described how being alone in his pain separated from his family as being as painful as having the chronic pain. All participants were alert to interpersonal

relationships as well as to how the act of withdrawing affected others. They also were quite sensitive to the other's attributions about them sometimes experiencing guilt, sometimes anger, and sometimes blame for their withdrawal.

The "Catch-22" situation described earlier in this chapter is also relevant here. There is a basic misunderstanding of the person in pain and a basic miscommunication with the person in pain because the other person cannot possibly know what it is like to have the experience and the person in pain cannot make his experience understood without becoming a "hermit" or a "whiner". For example, if the person in pain tried to be stoic and retreat with his pain, he could be seen as not wanting to be with his family. On the other hand, if he tried to explain the depth of his pain, he could be perceived as weak, or even worse, he might not be believed.

Coping Strategy: Monitoring/Evaluating/Deciding

Descriptions of this coping strategy filled the narratives told by all participants. This theme appeared at the center of all the other themes of coping as an ongoing cognitive process. Each participant monitored his/her body, evaluated what he/she could or could not do, and decided

when to connect or withdraw; when to accept or deny limitations; when to hide or reveal the pain; and how to endure and manage at any given time. Participants described putting a great deal of time and energy into this activity because it required constant awareness. Participants described differentiating the levels of pain, deciding what it was safe to ignore and deciding which pain signaled danger to the system.

Knowledge of this theme is important in the assessment of cognitive distortions. These distortions can affect how each of the other themes is dealt with by chronic pain patients at any given moment. Interventions made in this domain can enhance coping ability in all other domains. In developing a treatment model of chronic pain based on the findings of this investigation, this particular theme could serve as a gateway for interventions to enhance coping decisions. Here is where one can begin to investigate the role of appraisal in coping. Additional research was called for by Bombardier et al. (1990) specifically in this area.

These recommendations support Lazarus' work (1969) on the role of appraisal and the evaluation of helplessness in coping. According to Lazarus, the amount of threat someone feels depends on the extent that a person feels himself capable of mastering danger. When an individual acquires

tools that enable him to feel capable of dealing with difficult life situations (such as chronic pain), those situations can become ordinary. Thus when the threat of chronic pain is reduced through knowledge; monitoring, evaluating, and deciding can become more adaptively, rather than maladaptively focused and coping skills can be enhanced.

Methodology

This investigation accomplished the goal of describing how people cope with chronic pain. Participants in this study gave descriptions of the experience of chronic pain which supports the work of other researchers mentioned in the above text. The unique contribution of this research has been the description of the experience of coping with chronic pain which explains the process of how people cope with chronic pain. The existential-phenomenological method has been an effective research methodology to gain this particular understanding of the coping process.

Interviews using the existential-phenomenological method allowed the researcher to gain a first person description of how chronic pain patients coped with their chronic pain. From these interviews emerged the essential

structure of how participants in the present investigation experienced and coped with their pain.

Each of the participants was interested in giving the interviewer a description of the lived experience of the pain and in explaining coping strategies used to deal with it. These participants told the interviewer about the social context of pain, how and why breaks in communication occur between significant others and between pain patients and their physicians. The interviews revealed how the pain was monitored and evaluated on a moment to moment basis and how decisions were made regarding when to use a particular coping strategy. Participants described how they determined their particular "rules to live by".

The interviews revealed the importance of meaning in the definition of the pain and in the definition of the self in pain. The meaning of the pain to the individual determined how the person was redefined when he or she realized the pain would be chronic. The personal meaning of pain was figural in their redefinition progressing either to an adapted self or to a self that progresses toward increasing illness, damage and despair as described by Howell (1994) or Kotarba (1983). Finally, the interviews illustrated the impact of the invisibility of the chronic pain and the impact of limitations.

Participants in this investigation also expressed an appreciation for the research method. Some commented on the benefits of the method by saying how talking about the experience helped them to see things in a different light, to gain relief by feeling heard, and to put the experience into "its proper perspective". Participants expressed a desire to help others by sharing their stories. They also expressed the hope that more knowledge would be gained about the personal difficulties of chronic pain and that more effective treatments would be found.

A particular advantage to this methodology is that by allowing the data to come directly from the individual, instead of by being the result of forced choices into a predetermined category, the knowledge gained is likely to be more accurate. The method also allows for clarification of the data by the participants at the time of the interview which helps the researcher to avoid improper inferences and assumptions.

Future researchers in the area of chronic pain might consider the development of a questionnaire based on this method which could be designed to rule out malingering or drug seeking behavior. Such an assessment interview might enable physicians to give the legitimate sufferer appropriate treatment and prevent future patients from

having the experience of "feeling like something on the bottom of his shoe (the physician)". Finally, interview techniques arising from qualitative assessment which allows for the personal expression of the chronic pain experience seem to lead to a better understanding of the unique experience of each patient and seem to be an effective aid in discovering the best way to tailor individual treatment for the individual in chronic pain.

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APPENDICES

APPENDIX A
INFORMED CONSENT FORM

INFORMED CONSENT FORM

Research Purpose and Procedures:

The purpose of this research is to find out how people cope with chronic pain. To do this, the researcher, Dianne Briscoe, would like to sit down with you in a quiet place and listen to you describe your experience of coping with chronic pain. This interview will probably take sixty to ninety minutes to complete and it will be recorded with a cassette tape recorder. The second step of the procedure is the completion of a short questionnaire which should take about ten minutes. You may be contacted for a follow up interview for the final stage of the research. You will be asked to indicate whether you agree or disagree with what seem to be the major themes in your experience of coping with chronic pain. The information collected will be used primarily to complete the requirements for a doctoral dissertation, but may also be used for educational purposes or in a reputable publication(s) in a manner consistent with the stated purpose of the research.

The risk involved in this research is minimal, and only requires you to be thoughtful and open in your discussion of coping with chronic pain. The benefits are also minimal, and extend no further than your satisfaction in helping to improve the understanding of how people cope with chronic pain.

Your identity will be kept confidential at all times. This form will be filed separately from the questionnaire which will be kept in 108 Claxton Education available only to the principle researchers and maintained there for 3 years past this study. Your responses will be typed before they are analyzed. Personal or particular place references will be deleted or coded. Analysis will be conducted to discover themes of the experience which emerge and to develop a thematic structure. Only group results will be reported.

A research group will help with the interview analysis. Each group member will sign a statement to keep information in strict confidence. Their signed statement will be kept on file with the informed consent forms and the interviews will be kept in U.T.'s CECP office. The research group will not have access to your identity.

Your help with this project is appreciated. Your participation is voluntary and you are under no obligation to participate. If you have any further questions about this research contact Dianne Briscoe at 974-5131.

Statement of Consent and Agreement

I consent to participate in a program of research being conducted by Dianne Briscoe. I understand the purposes and

procedures as they are described above, and I accept the statement that both risks and benefits are minimal. I understand that no compensation will be awarded for my participation.

I understand that I am free to withdraw my consent and to discontinue my participation on the project at any time without penalty. If I become uncomfortable at any time during the interview process, I may end my participation.

I have had the study described to me to my complete satisfaction and I have read the summary of the research project. I have also had the opportunity to ask questions and obtain any additional information.

Participant's Name(print): _____

Participant's Signature: _____

Date: _____

APPENDIX B
PARTICIPANT NARRATIVE

Chronic Pain Research
Interview 1

I: We're here today to talk about your experience of coping with chronic pain. Please tell me about a time when you were aware coping with chronic pain.

B: I was involved in an automobile accident a number of years ago. In the beginning, there was so much uncertainty about what had even occurred and so my first goal was to get this diagnosed. Like all good Americans, I believed that there was going to be a cure for what was wrong with me. After about 3 to 9 months, it began to seep in that there might possibly be no end to this. That's when I became aware of chronic and pain. Prior to that I think I just viewed it as pain from the accident. At that date, I began to entertain the thought that this might be chronic and how was I going to deal with it?

I: Tell me about the nature of the chronic pain.

B: The pain varies from time to time. In the early years the pain was very much headache pain. I have since had some surgery that has helped alleviate that to some degree. Uh the pain that I experience now is very much intertwined with being sick. In other words, I have a lot of nausea uh achiness and because of the chronic nausea, then it flips over into horrific stomach cramping and pain there because I have vomited quite a bit over the last number of years and so when these attacks come and they're attacks of vertigo, so obviously there's going to be a lot of sickness that goes with the vertigo. But when you have chronic vertigo, it gets into a pain situation which can involve muscle aches, backaches, neck aches, stomach pain uh just a general overall feeling pretty awful. Malaise is often described as a part of vestibular dysfunction and that along with malaise, you're going to feel real ache.

I: You're saying that it has been diagnosed as a vestibular dysfunction?

B: That's correct, which is pretty encompassing. It has also been described as Meunier's Disease and involves some tissue damage.

I: What is a bad day like for you?

B: A bad day normally uh starts out with a tremendous ringing in my ears, a lot of pressure in my ears, often... often that pressure is accompanied by an earache uh vertigo, normally the first symptom that I am aware of as I try to get out of bed and face the day. Uh it doesn't take long for the vertigo to feel like you're going to vomit. Uh it influences your balance so naturally you're groping for the walls and countertops and things like that just trying to get into the bathroom. Uh because I have been at this for such a long, long time, when I have

that kind of morning, I know to just turn around and go back and get in bed. Once I'm in bed and I'm flat of my back, the symptoms tend to stabilize except for the pain and the pain can continue even though I'm in bed all day. And it will entail some headaches, some earaches, uh muscle pain... general I mean I've had several other vestibular patient's that I've talked to describe it as feeling like the flu.

I: Tell me about the muscle pain.

B: Uh because you maintain your balance by using your eyes, your inner ear, and your muscles, because the inner ear isn't functioning properly, you're gonna overuse your eyes and your muscles. My eyes also don't function completely properly so I'm really over using my muscles so the muscle is associated with an eventual cramping around joints. From tightening up to maintain my balance, I tend to take my toes and dig them into the floor unconsciously through my shoes and socks so you're gonna have some pain radiating up from the bottom. But by far the neck and back pain is the worst and of course I assume that's from trying to maintain my balance through hunching my shoulders and along my spinal column.

I: Tell me more about the neck and back pain.

B: Well we've tried a number of approaches with the neck and back pain that have been fairly unsuccessful. I don't seem to tolerate any kind of medication very well so the general muscle relaxers or Xanax type drugs uh have not been especially effective for me. Uh therefore, I have to lie down. It seems to be the only way, to apply heat or ice and lie down a lot. Uh seems to be the only way I can even bear it. Recently, I have started I often uh use chiropractic care and that certainly has helped me manage my pain probably more than any other thing. And then recently, by consulting with my chiropractor, we elected to try a new program of muscle reeducation, muscle therapy in short muscle massage. I'm doing that once a week with a specially trained muscle therapist who is familiar with vestibular dysfunction. I don't get a uh a massage in the way you would go to a health spa and get a massage. She described it as you come there with your muscles all fired up. I'm going to translate that into saying that they're all tight and knotted up from trying to maintain your balance. It is so painful that any kind of kneading just produces more pain and anxiety for the patient so she smooths it out. She uses a lot of real soothing, smoothing out strokes. And that has been very beneficial. Of course, I would love to do it every day and that doesn't-- it isn't feasible so once a week isn't really enough. I'm usually by the time of the next appointment, I'm in a lot of pain again and I'm real anxious for the appointment to hurry and get here.

I: So you find that helpful in reducing the pain?

B: Right. It's made it a lot more bearable. Actually, it's made me a lot more mobile. I've been able to do more things in the last 3 or 4 months than I have been previously.

I: What is a good day like for you?

B: A good day is a day that you wake up and your brain seems to be clear. You're thinking quickly. I know the difference between sluggish thinking and quickly being able to process thoughts and those days are like the days that occurred prior to the accident. You can explain something to me and I understand it right away or you can ask me a question and I'm able to dig into my, you know, my past events and bring out an answer for you very quickly. Whereas on a day that is not as good, I muddle around and sometimes it may be the next day before I can even remember the real answer to what you have asked me. I find it very, very difficult to think on a bad day but on a good day, that is the number one symptom. If I wake up and I can think, I know I'm going to have a good day or let me say I can process my thoughts quickly. Then I know that's a good day. It means that my balance is good. It means that my color is good. It means that the aching has subsided some.

I: When you're talking about being able to process your thoughts, is that like less confusion than on a bad day?

B: Yeah, that's a good way to put it. Yeah.

I: Tell me more about the confusion.

B: Well, I like symbolism so I'm afraid I may describe things like that, but it's my way of making sense to myself. A bad day feels to me like a lot of storm clouds have moved into my brain. It's very hazy. You can't see clearly and there's a lot of uh uh static in the atmosphere so it isn't processing clearly. It's almost like an electrical thing where the uh if you were comparing it to a computer where the signal wouldn't be getting to the right program.

I: And so you feel confused at those times?

B: Right. The thing about it is I know that I'm confused. It's not like you're unaware that you're not doing this. You're real aware that you're doing it and there's a great deal of frustration because you know that you can think faster. You know you're smarter than that. You know that you know the answer to that and you just can't get to it.

I: So on a bad day, it's really hard to think.

B: In addition to the pain that's involved and the sickness that's involved with that kind of day.

I: And the sickness is when you experience vomiting?

B: Right.

I: You said that you had two surgeries ?

B: The first surgery was performed at Vanderbilt Hospital uh it's called vascular loop syndrome and the surgery, well they uh they chip out part of your skull in order to lift your brain up to go deep down into your head and once there getting toward the inner ear, once there, they discovered that I had a damaged nerve that was pressing on a blood vessel in that area. Now they take this nerve out. They don't remove it, but they pull it out in order to scrape it. The surgeon described it as a frayed electrical wire and he's unable to repair it or replace it, but he can scrape it to minimize the amount of fraying. So once he did that, he put it back with a piece of Teflon between that nerve and a blood vessel going into my brain. That was real beneficial. That helped but it didn't obviously take everything away. Then they close you up and afterwards, uh due to an error they made in prescribing some drugs, there was some drug overdose and I consequently wound right back up in the hospital with a uh diagnosis of chemical meningitis which was pretty darn painful. I came off of all medications there and that's also made me real leery of using medication for chronic pain, you know, to this day. The second surgery occurred 18 months after the first surgery and was much more minor surgery than the first time. Uh they went in and took my left ear completely off in the back and flipped it forward. The flap, completely turned it forward and went in and just explored everything in my ear. Uh sort of looking for a hole in the ear drum that sort of thing. What he found was that every single blood vessel behind my ear was compressed so he decompressed it. And that resulted in the worst case of vertigo I've ever experienced in my entire life. I mean I think that's the one time you could die from vertigo if it didn't go away. It lasted for almost a week. Uh I still have a great deal of difficulty getting over that surgery. I was very, very aware that I was very, very ill but everyone around me was telling me that I was-- that I had enough time to be over it, to get up and to stir around-- that was part of my problem. As it turned out though, I had developed an ear infection from that surgery and consequently lost a small portion of hearing in that ear. Some years after that, they put tubes in my ears which some people consider surgery, some don't. Anyway, there is a little incision made there. I think the tubes have helped more than anything else.

I: You feel like the surgery has reduced some of the pain?

B: The first surgery reduces some of the haziness in my brain. The second surgery was a wash. As far as I'm concerned the only thing I got out of the second surgery was that yeah every time they open me up, they do find something wrong so there is some affirmation that it's not a psychological chronic pain, you know, and loss of some hearing. I have since developed or have overcome the loss of hearing, but for probably 6 months after the first loss of hearing you know just a minimal loss of hearing, I didn't understand how much we hear in stereo and it was just maddening to me because I heard different levels of sound in the two ears and it took a while for my body to compensate for that.

I: Sounds like you had a tough time with it.

B: I perceived it as such.

I: What did you mean by psychological chronic pain? Could you tell me about that?

B: Yeah, I think it probably is universal. If you have something that isn't run of the mill, if there aren't a hundred like units, of this kind of either injury or illness or disease, then the doctor is going to become rather frustrated with his diagnosis and inadvertently, you become the object of his frustration. If they can't find anything right away or if it's marginal what's wrong, then they're going to say, you know, are you sure this isn't some sort of emotional problem that you're dealing with as opposed to a physical problem?

I: It sounds as if you've had to deal with that.

B: Several times. I find it very frustrating.

I: Tell me about the frustration.

B: Well, I mean I'm sure other people have experienced some doubts about that kind of thing. I personally have. But when I try to think it through and become real logical with it, I always go back to the fact that prior to Jan. 11, I didn't experience these symptoms. I had the car accident on Jan. 11th and since then, for nine years now, I have experienced these problems. It doesn't sound to me like you would have an emotional or psychological problem resulting from a blow to the head, not the way I understand psychological problems. I do think you have psychological problems from dealing from chronic pain for nine years.

I: What are those like?

B: I'm afraid that sometimes I'm over defensive about convincing somebody that I really do feel bad and that probably also stems from having to go through getting disability income and you know proving it and them making sure I'm not faking it or malingering or anything. I think I overcompensate there sometimes. I think you're always going to be a little concerned about your own contributions to society when you're damaged. I knew that one of the things that was very, very important to me prior to this car accident, well still is (but I've had to learn to live with it) is to be reliable. If I told you that I would do something or that I would be somewhere, that you could count on me being there and with this kind of illness, it just rises up right out of the blue and you just can't know from day to day what kind of day you're going to have and I think that's created probably one of the top three problems for me psychologically is not being able to count on myself and feeling such horrible anguish when I have to call somebody and tell them that I'm not going to make it or I don't meet a deadline that I set for myself because I wasn't able to work toward that project 3 out of the last 4 days. Obviously, you're going to fall behind. I feel like I deal with a lot less time than other people do because I lose so much of my time. In a month period, I might get to live a week as far as accomplishments go whereas other people have that

whole month to accomplish things. I find that frustrating.

I: You said the top three psychological problems that you felt that you have. Tell me about the other two.

B: Well, the first one I meant was being defensive about it. I wish I would let go of that uh and then the . . . I don't know that I can just right off the top of my head right now say ok this is the most difficult and this is the second most difficult and this is the third most difficult, but I just know out of, in a vague sort of way, out of all the things that are tough, that would probably be in one of the top three. I'm probably not going to be able to be more specific than that right at the moment.

I: Can you tell me about a specific day in your life when you are experiencing chronic pain?

B: Well uh my days can be rated on a scale of 1 to 10 and a bad day being 10 and a good day being a 1, I can have 4s, 5s and 6s, but I guess about a week or two ago my husband was home from work one day and we had decided it was going to be a laid back, relaxed kind of day and we all - with the pets, we have two dogs. My husband and I and the two dogs curled up on the sofa. I knew it was going to be a relaxed, calm type of day so I was pretty comfortable with that. I didn't have to symbolically take my temperature that morning. I didn't wake up and listen to hear if my ears were ringing or whatever. I just thought of all I have to do is put on my comfortable sweats and go get on the sofa. I was really looking forward to this day. So we got in there and we were watching the movies, dozed a couple of times and was just thoroughly enjoying it. For some reason in the early afternoon, my husband asked me to do something for him and I don't recall what it was. I remember as the day progressed, I began to feel worse and worse and let me stop and explain too that this condition I have is very, very heavily influenced by barometric pressure and any kind of low fronts that move through. So by checking the weather channel later that day and the next day, I was aware that a front had begun to move through this area as this day progressed, but I wasn't aware of it at the time because we were watching movies. Anyway, he asked me to do something for him and everything in me didn't want to do it. Probably something like go to the kitchen and get a glass of water. It wasn't a big deal. It was a small thing. So I know that once someone has asked me to do something that is real simple that I would have no objection to do at any other time, but I feel a reluctance inside me, I know that's a warning signal. I looked at him and thought, "Oh, I don't want to do that." And then I thought I know it isn't going to make any sense for me to tell him that I don't want to do that. He's going to feel like I'm being less than supportive cause he's really good to get me a drink of water of whatever. So I thought, "I'll push and I'll do that." I attempted to stand up. I lost my balance. I nearly passed out. I don't know why. My knees buckled out from under me and I start going down and I grabbed on to the furniture and he looked at me like, "Oh no, here we go again." I think, if I remember correctly, I did manage to do whatever it was that he had asked and get right back on the sofa. He kept giving me odd looks and I was trying to curl up inside myself because I hate to keep making an issue - it's got to be

horrible for someone who is healthy to live with someone who isn't. As tired as I get of having bad days, can you imagine how tiring it must be from the other person's point of view? At any rate, I didn't even want him to look at me. I just wanted the whole world to go away and leave me alone. Within 15 or 20 minutes, I was frantically trying to find my, we keep a number of these throughout the house, pans that I have to throw up in. I grabbed my pan. I threw up. A couple of minutes later, I threw up again. Ten minutes later, I threw up again. I was so miserable. It isn't just that you throw up, you feel sick in order for this to occur, so I think I threw up maybe five times and then I just laid my head over and just curled within myself. I know that when I do that, that it's not only physical, it's emotional.

I: Tell me about how it's emotional.

B: I just am not up to dealing with anyone else's needs. I'm not up to even dealing with anyone else's opinions at that point. I need. . . I need total peace and quiet that supersedes even a peaceful evening with a family member. It's almost like you have to go down deep within a hole or something in order to block out everybody's everything whether it's their thought, their opinion, their need, even their conversation. It's too much of a challenge to even comprehend what the words mean within a sentence. I desperately want to be left alone at a time like that. I think that is because I need every single resource that I have in order to cope and I can't share those resources at all at that point.

I: Can you explain a little bit further how you cope with your pain at these times?

B: Aside from uh withdrawing, I've learned the vomiting can become an out of control thing for me and I've been hospitalized many times for dehydration. So I've learned that if that vomiting had not stopped after five or six times, then it's mandatory that I get some kind of medication in me. I don't typically like to take the medicine because I don't care for the side effects that I'm going to get, but I would then get-- if I could not stop the vomiting enough to hold down the pills, then I would have to use suppositories, otherwise I have some prescription drugs that I have to take just to try and control the nausea. I also know that I must be very still, that movement is going to aggravate the vomiting. I also know to do a few things if I don't get too bad off. I can do a few things for myself such as a warm heating pad on my neck and shoulders will sometimes help with the pain and when I'm vomiting, oftentimes I hurt everywhere. I mean every symptom flares up all at the same time. So I'll deal with that. I'll take a anti-inflammatory, an ibuprofen, typically it's a prescription strength, but I can take that drug if I can keep it down. Sometimes that will take the edge off the pain especially if it is an earache, then that is fairly effective for that. Sleep is always welcomed, a great way to deal with pain. If I can take the medicine and get to sleep and sometimes I'm even able- if the nausea is not too bad, I'm able to drink a soothing herb tea. Anything like that can get me past that jagged edge and over into sleep can normally get me to the point where things are calm enough when I wake up, I can deal with them better. And you're refreshed a little bit, your body's been able to uh focus, fixing what's wrong with you as opposed to coping with life and then you're a tiny bit stronger once you wake up. You're

rested you know. And then sometimes when I wake up the front has moved off far enough that I can ease off some too. Probably the primary thing is to stop, stop whatever you're doing. You can't do anything anymore. You have to lie down, sit down, lay down, whatever. It's this humongous, giant stop sign that says stop functioning in the normal way. I can't handle it. I being the body saying, "I can't handle life the way you're trying to live right now."

I: What are some of the things that you did to maybe prevent a bad day?

B: I try to minimize the stress level as much as I have any control over it. My theory behind that is that the inner ear nerve is swelling. That's not a theory. My inner ear nerve is damaged, but the theory being that since that is a nerve and this damaged nerve is obviously going to react to stress because all nerves do, that I try to keep the stress down. I try to minimize the amount of salt that I take in my diet because any fluid kept on the ear, is going to aggravate the ear. Those are some of the obvious things. I try not to get overly tired. I know that's deadly for me. I guess the other thing is and I don't think I mentioned this earlier, because my eyes are damaged - I did mention that my eyes are damaged but I didn't tell you how. They are damaged and I think if I understand this correctly, a lot of chaos of my environment now and chaos can mean people, but it can also mean colors or patterns, anything that's real disruptive to me will cause me to be ill, so I avoid malls at all costs. I don't get into large crowds of people very often, just the fluttering movement of light and color, people's hands, their clothing. I'm very uncomfortable with someone who has on a loud, patterned dress or jacket or something. So I try to avoid those things. Stay home. If it's a marginal day, I need to stay home because I have a lot of calm, serene colors in my home. That helps me not to have as bad an attack as I would if I just threw myself back into the world as fast as it is.

I: Can you tell me a little bit more about the colors and patterns and how that affects you?

B: I don't tolerate a lot of real heavy light uh it gives me a tremendous headache. The uh certain colors make me feel more nauseous than others. But, primarily, it's patterns - geometric patterns, plaids. I'm not sure I understand why, but they certainly make me feel very bad. They're very chaotic, very disruptive. One time I went to the dentist and he had plaid wall paper and I had a seizure by the time I left because the plaid wallpaper was making me violently ill.

I: Tell me about the seizure.

B: I have stress seizures. At one point, we had investigated them being epileptic seizures. But they have since decided that they are stress seizures. That if I get overly stressed, and you know again, I'll go back to patterns, colors, and movement stresses me uh police car lights just sends me into orbit. Any kind of piercing light, any light that's moving.

I: What happens when you go into orbit? What does that mean?

B: OK, this is going to sound really strange, but I feel like I'm falling into a dark hole, a dark pit and I'm frantically trying to get back out of it. That's what the piercing light does to me and what I do is like shut my eyes or put my hands against my temples and I feel like I'm doing this major back pedaling thing trying to keep from going over the edge and maybe having a seizure. I have had seizures from light before too so they are very frightening. I don't want to do them.

I: Are there things you find that you can do to prevent the seizures?

B: It's going to sound redundant. Lie down, be still and minimize the amount of activity in your environment and mute colors or light.

I: I'm curious about what you said about the colors. Can certain colors bring on seizures? What colors do find most disruptive?

B: I don't know that I know which. I'm doing a lot of investigating right now just to find some printed material on the subject. Sometimes I'm not really aware of exactly what has triggered something. I just know that I have just got to get away from it and it's only after years of doing this that I am becoming aware that there is a pattern to that.

I: It sounds like you're trying to figure out what the patterns are?

B: Right and I know for a fact geometric patterns and plaids and some paisleys and things like that bug me, but I'm not quite sure which colors are bad colors. I just know which colors are good colors. Now, I know that pastels are good. I really enjoy an apricot kind of a peach and a pink together. For some reason, that makes me feel very good. It's not only soothing and calm, it feels pretty to me so that's a good color. I've been able to tolerate a real muted gold color in my bedroom, some yellow but not your bright sunshine yellow, that I don't do real well with, but more of a muted sand yellow with some gold in it. That seems to work fairly well for me. I don't care for some brilliant royal blue. I don't care for bright, bright purples and these are probably not good color for that, because even just to look at them, I kind of turn my head and pull back. It's almost like a physical reaction to the color and that's how I'm discovering what doesn't work well for me - just trying to pay attention how I am reacting to colors. But I haven't gotten it all figured out yet.

I: Can you tell me some other things you do to cope with the pain?

B: I have to do a lot of self talk. You have to tell yourself that it isn't going to last forever. You have to tell yourself that even though it feels like as unto death, it isn't. You have to tell yourself that you're an ok person. You almost have to separate yourself from your body and care for your body like it was something separate from you. In other words, if my body

were my child and my child were going through what I'm going through right now, I would be very solicitous and comforting and caring. And so I have to, even from a self talk level, almost be very tender and caring toward my body - give myself permission to lie down, give myself permission to withdraw from activities that the members of the rest of the family is involved in or permission to withdraw from a chore I'm involved in. Give myself permission to do it without the guilt and without beating up on myself and that's not easy. I must get the laundry done. I must get the dinner prepared. You know, do away with that kind of self talk and say uh oh, you don't feel good. You must sit down, lie down, rest. And the thing is, I'm discovering that I really do a much quicker recovery if I'll do it that way.

I: That sounds like you've really struggled finding how to deal with this. If you were going to tell someone else who was having chronic pain for the first time how to deal with their pain, what would you share with them?

B: Well, to sound redundant, I really think the first thing I would say to that person would be to be kind to themselves you know. I guess it depends on the personality of the person. Some people, you hear people talking about other people, "Oh they just give into the pain and they give into this and they're just a big baby about it or whatever." From my own personal struggle with it and fights with it, I think that the guilt that's associated with it is just awful. It's a physical pain too so I would say to be kind to themselves. I would say try to find something that distracts you from your pain if at all possible. I would tell them to try to find, to explore ways to get beyond the pain so that they can fall asleep because when the pain is really at a high ebb, there's no way you're going fall asleep, but if you can just keep searching for a way to get the pain under control so that you can get the sleep, I think that would be beneficial. You know, I think I would also encourage someone to research the origin of their pain if they had any idea of what the origin would be in order to share that knowledge with an interested outsider. Now typically you would say family, family would understand what you're going through. Sometimes your family, either they have dealt with it for so long, they don't care what you're going through anymore. But it helps me sometimes even when I just share it with someone who's not close to me. So evidently just getting it outside yourself verbally and even though nobody solved anything, just getting it outside of yourself can be helpful.

I: Being able to talk to another person about it?

B: Right. And maybe explain it to them, explain what's happening, what's going on. Sometimes that doesn't work, but sometimes it does.

I: What's that like when it works?

B: I think it's kind of like any other kind of sharing of problems. You just got it out there and 'whew', it's a load off. For some reason it's kind of a heavy trunk you're carrying on your back and you get it off your back for a little while. I don't know whatever the

psychological reason for people talking about their problems is, but it applies to that too.

I: You mentioned distraction. What are some of the things you use for distraction?

B: Well in the beginning of my illness, I was able to read a lot and that was very helpful because even before the accident, I was this major bookworm so being able to pick up a book and get into a book, but because the visual disturbances became worse as time progressed, I'm not able to track anymore very easily. If I'm having vertigo, then reading is pretty much out of the question. I was devastated when the disease got that bad where I lost my major coping skill. Since then, I have turned to the television a lot. I'd say that probably my number one distraction right now is television. Fortunately, cable TV has improved a lot. I do find some channels that offer educational or informative programs about some projects I'm real interested in. I found myself getting interested in sewing and things like that I didn't before. Not major projects, but smaller projects for good days and then crafts and things like that, things that are on a smaller level. I don't do real well with a project that's going to be a two or three week project, because I have so many down days during that period of time, it stretches out like an eternity for me and then I have to deal with that old problem of either disappointing someone else or disappointing myself because I haven't reached the goals that I set for myself by having this ready on Friday or Thursday or the 15th or whatever. I have to be careful that I don't become my own worst enemy by setting myself up for a great deal of frustration.

I: You still have problems with frustration. Is that what you're saying?

B: Right. Being frustrated with yourself for being sick is I would assume, well I guess I am assuming. Maybe everyone doesn't have - I'm very frustrated with myself for being sick. There are so many things that I want to do. I want to be able to live my life. There are so many things out there to do that are fun. There are great things to do. I want to go do them. I can't.

I: So how do you cope with the frustration?

B: Well, I have to do some self talk here. I have to minimize the amount of projects that I am involved in, but not eliminate. There must be some sort of gratification in life. I mean you have got to feel like you can manage to do something so you've just got to keep that balance there of not having too many projects there but having a project or a couple of projects so you have something to look forward to on a good day. If I were to wake up and have a good day and I didn't have anything already planned, I might waste my one good day and then the next day would be a bad day and to me that would be a horrible shame. So if I've got some things going and I wake up and I have a good day it's like 'oh boy, oh boy'. I just go bounding in there and I just tackle that project that day and that's the things that carry you over with frustrating times you know. I guess I hadn't thought about it before right this very minute, but I guess that's a pretty good thing about the crafts because it is gratifying

on a bad day because if you see something that you've done, sitting on a shelf or something, then you can say, "But I had a good day and I did that and I'll have another good day and I can do another one."

I: You also mentioned talking with someone about the pain making a difference. I'm curious about what it has been like for you to talk about it here today.

B: Well, I think it's been very enlightening even as I hear myself expressing these thoughts or relating how something has occurred. It seems to have gotten a little clearer. There's something about thinking it, saying it, hearing it that is rewarding. It's more gratifying once it's gone through all three processes as opposed to just thinking about it internalizing it and sometimes I suppose you could become a little more muddled. For me, it's been clearer just because I've gotten it out and heard myself saying it.

I: So you feel like the whole thing has become clearer to you?

B: For the moment. I know I've had this for nine years. I know that it's an ongoing battle. If I let myself think that I've solved it, I would only set myself up for a major disappointment which leads to a major frustration. I know that I'll have bad days again and I know that I will become confused about how to cope with all this again. Now, typically I can recover fairly quickly from that, but I know it will come again. I don't want it to. I know that it will.

I: Is there anything else you'd like to add to what you've already said?

B: Simply that being the victim of a disease or an injury, we've put so many labels on it that it's kind of confusing, uh I think it's just one more straw on the camel's back. I have a great deal of empathy for everyone who deals with chronic pain, but I know that some chronic pain generates instant compassion from people because they can understand it whereas one that doesn't show and one that very few people have, presents an extra burden over and above the level of chronic pain.

I: Are you describing your experience here?

B: Absolutely. I can't tell you how many people don't even know what vestibular means. But that's ok. I didn't know either until I had it. I don't mean that I'm upset with them. I just wish that we knew more about it, we as a society as a whole. The point again was just that just makes it that much tougher because so little is known about it so therefore so few people know about it. The only support group that has been available for this is a Middle Tennessee support group and then a national one that's out of Oregon. Both of them are completely unavailable to me because of distance. I'm not a good traveler because of this inner ear problem.

Therefore my only contact with them has been through the newsletters and an article or two

that I've written myself that helps you feel like you're a little bit part of it. If it were something where more people had it, then we'd have one in East Tennessee and I could attend on a regular basis. It seems like that would be helpful.

I: You said that you had written articles for a newsletter?

B: I mean it's not any big deal, but yeah for Middle Tennessee Vestibular Dysfunction. They have a newsletter and the girl who prints that, had written to me and asked if I would write an article about being a member of this as a far away member. In other words, there are an awful lot of people in this group who were too ill to attend the meetings that she wanted everyone to feel like we were all part of a larger group and so she asked me to write my feelings about that. So I did.

I: What was that experience like for you?

B: It was really good in that again by getting it out there, thinking it, saying it, listening to it and then writing it down on a piece of paper and reading it again, it helped. It's an unloading. It's an unburdening.

I: Tell me about that.

B: It made me feel a little more useful. Sometimes when you have a chronic illness and you're removed from the everyday flow of things you feel rather useless at times.

I: Is there is anything else you'd like to add?

B: No, this is probably a good place to end.

APPENDIX C
CONSENT FOR Narrative

INFORMATION AND CONSENT FORM: NARRATIVE

I am interested in using all or part of the narrative of your interview in my dissertation. Excerpts from the interview may be used in the body of the text to illustrate the way the experience of coping with chronic pain has been described. The full narrative might be included in the appendix to give the reader access to the data of the dissertation.

You have a summary of the results of the data and a description of the findings. Please tell me if this summary appears to be an accurate description of your experience of coping with chronic pain. It is important that this summary is an accurate description of your experience.

If you agree that I may publish part or all of your interview, please sign this permission slip. I will be happy to discuss any questions that you may have.

Thank you for being a participant in this research project.

I have read the above Information and Consent Form. I agree to the reproduction of part or all of my interview with Dianne Briscoe regarding my experience of coping with chronic pain.

Signature: _____

Date: _____

VITA

Dianne E. Briscoe was born in Knoxville, Tennessee on January 5, 1948. After graduation from Holston High School in 1966, she attended the University of Tennessee, Knoxville where she earned the Bachelor of Science degree in Psychology in June, 1971.

In 1994, she was awarded the Master of Science degree in Community Agency Counseling at the University of Tennessee. In that same year she was admitted to the doctoral program in the College of Education and Counseling Psychology at the University of Tennessee, Knoxville.

She will receive the Doctor of Philosophy degree with a major in education and a concentration in Counseling Psychology in 1999. Currently, she is completing an internship at the University of Tennessee Student Counseling Services Center, Knoxville.