

PATIENT PERCEPTIONS OF
TREATMENT OPTIONS FOR CHRONIC PAIN

by

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ABSTRACT

Chronic pain and pain management are frequently discussed and debated topics in American medicine today. The patients' understanding of treatment options for management of chronic pain is a less frequently discussed topic. The purpose of this study is to explore patient perceptions of chronic pain treatment options. The framework for guiding this study was Neuman's Systems Model (1995) based on the concepts of stress, client stability, and intervention. A review of the literature was completed that revealed very little information on the topic and therefore further research regarding patient perceptions of treatment options for chronic pain was warranted.

Nine patients participated in interviews and shared their experiences with treatment options and contexts or situations that influenced or affected those experiences of treatment options. Participants described their experience with chronic pain to include options available to them; the effectiveness of the methods tried; lifestyle changes associated with their pain; feelings of hopelessness for the future relative to pain resolution as well as available options; the effects of listening and understanding; and depression.

CHAPTER ONE

OVERVIEW

Introduction

The most often used definition for pain is: “an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage” (Chandra & Ozturk, 2005, p.34; Loeser & Melzack, 1999, p.1607; McHugh & Thoms, 2001, p.33). Chronic nonmalignant pain is defined as pain lasting three to six months or longer “after healing of the ostensible pain generator” (Chandra & Ozturk, 2005, p.34). A significant number of patients, who suffer from chronic pain, report that their pain is not well controlled, costs them lost days from work and interferes with activities of daily living (Gerstle, All, & Wallace, 2001). In Western Montana, there are a variety of treatment options available, including, anesthesia, physical and occupational therapy, psychology, medication management and complementary and alternative medicine. The purpose of this study was to obtain patient perceptions of chronic pain treatment options in rural Montana. Understanding patient perceptions will enhance communication between patients and providers about pain management options. Improved communication will lead to the development of improved interventions and individualized care.

Background and Significance

It is estimated that greater than 75 million Americans suffer from chronic pain (Gerstle et al., 2001). Pain is listed as the third leading cause for missing work, at a cost of over \$50 billion each year (Chandra & Ozturk, 2005). Currently, a multidisciplinary route is favored to address chronic pain with a team of professionals to include medicine, psychology, physical rehabilitation, and social support, but the majority of chronic pain patients are treated in primary care (McHugh & Thoms, 2001). Access to multidisciplinary clinics is limited by distance, funding, and awareness (McHugh & Thoms, 2001). Patient satisfaction with chronic pain management services is low to moderate with up to 50% of patients reporting poor pain control (Roper Public Affairs and Media, 2004). Although extensive research has been done regarding chronic pain management and patient perceptions of chronic pain, less is known about the lived experience of pain management and how a person perceives options for treatment. This qualitative study is designed to provide a better understanding of the process of pain management through the patient's eyes and possibly identify better ways to serve these patients.

Statement of Problem and Research Question

Exploring the lived experience of chronic pain management and perceived options for treatment will address a significant gap in chronic pain management research. This research will provide guidance that can be used to refine practice by answering the following questions: What options do patients identify and choose to use in the management of chronic pain? What factors influence those choices?

Conceptual Framework

Betty Neuman's Systems Model (1995) looks at the patient as a system made up of five variables: Physiologic, psychologic, developmental, sociocultural and spiritual. All of these variables interact and relate to each other in very specific ways unique to each individual. Surrounding the patient system, a client-client system, are a flexible line of defense, a normal line of defense, lines of resistance, and basic energy resources (Neuman, 1995). Stress will impact this client-client system in a different way with each individual system depending on each person's make-up. Chronic pain is such a stressor. When the client-client system perceives pain each component sets out to respond to it in a different and inter-related way to restore stability.

While all this is going on, the environment, which Neuman describes as any internal or external factor that affects the system, also comes into play (1995). Internal factors are interpersonal in nature; external factors are inter and extrapersonal in nature; and there is also a created environment that is intrapersonal, interpersonal, and extrapersonal in nature (Neuman, 1995). These factors can be positive or negative influences in the system. Perceptions fall into the intrapersonal category and are mediated by the client system variables of the psychologic, sociocultural, and spiritual realms.

Treatment options are evaluated using the fourth concept in Neuman's Model, nursing (1995). The objective of nursing is to assist the patient to maintain or return to, stability (Neuman, 1995). With chronic pain, primary prevention and secondary preventions have failed and tertiary prevention comes into play. Tertiary prevention involves readaptation, re-education to prevent recurrences, and maintenance of stability

(Neuman, 1995). These are the goals of chronic pain management as well. With the framework of the Neuman Systems Model (1995) and utilizing the qualitative research method of phenomenology, interviews with patients suffering from chronic pain this researcher hopes to examine the client variables, the environments and the tertiary prevention techniques used by this population of patients.

Phenomenology seeks to describe meaning for a group of individuals regarding their lived experience of a concept or phenomenon (Creswell, 2007). The purpose of phenomenological study is to collect data from individuals and then develop a composite description of the experience for all of the individuals (Creswell, 2007). The researcher assumes that human experience makes sense to those who are living it and that human experience is consciously expressed (Dukes, 1984). To accurately describe how individuals experience a phenomenon the researcher must set aside his or her own experiences and prejudgments (Creswell, 2007). Common themes derived from individual descriptions of the lived experience lead to a better understanding of that experience.

The phenomenon of interest in this study is the individual's experience with chronic pain. Common experiences of the participants will be identified and documented to better understand the patients approach to managing his or her chronic pain.

Definitions

The concepts requiring definition regarding patient perceptions of treatment options for chronic pain are: patient, treatment options and chronic pain. For the purpose of this study patient will be defined as an adult age 21 to 65 years. Treatment options are

measures identified by the patient as the methods and or strategies they use to manage their pain. Chronic pain is defined as pain lasting three to six months or longer “after healing of the ostensible pain generator” (Chandra & Ozturk, 2005, p.34).

Assumptions

To complete this small qualitative study in rural Montana the researcher assumed that individuals would be open and truthful about the measures they used; that the problem of chronic pain management is as significant in Montana as it is nationwide as expressed in the nursing/pain literature; patients do have opinions about treatment for their chronic pain; and the experience patients have with the management of their chronic pain has the potential to contribute valuable information to the development of future treatment modalities. The researcher also assumed that patients would be willing to share their experiences and that options may differ in rural versus urban areas.

Limitations

This study was limited by time, money and a small sample size. As it will be limited to Western Montana, results may not be applicable to other parts of the United States. A lack of time and funding limited the study to a small sample size. These issues will also be a factor in determining the length of the interviews and the number of questions asked. Data collection took place in the time span of one college semester or approximately 16 weeks.

CHAPTER TWO

REVIEW OF THE LITERATURE

Introduction

The concepts pertinent to this study are treatment options, chronic nonmalignant pain, patient perception, rural populations, Betty Neuman's Systems Theory, and Phenomenology. This literature review will focus on determining all of the relevant information regarding these concepts and the relationships between them. Discussion of the related literature will provide validation for the research proposed.

Patient perception is a widely researched topic by nursing and the general health care community with hundreds of articles listed in the databases. Narrowing the search for literature by adding the concept of treatment options yields slightly more manageable results. There is information regarding patient perceptions of treatment options for many different kinds of treatment for many different disorders, but not specifically for chronic pain. Research regarding treatment for chronic pain is extensive but those studies including patient perceptions focus on the perceptions regarding the nature of the pain itself or perceptions of treatment effectiveness, rather than perceptions of the treatment options available.

Review of the Literature

Miles, Curran, Pearce, and Allan (2005) studied the experience of people with chronic pain in an effort to develop a grounded theory to offer insight into what it is like to have chronic pain and provide a framework for future testing regarding how these

patients attempt to resolve their pain. This was a grounded theory study conducted with a convenience sample of 29 patients who were participating in an outpatient pain clinic. Miles, et al, (2005) demonstrated that the main problem for patients with chronic pain was that of constraint in body, activity and or identity. These were seen as indications of restrictions to living a normal life. This constraint affected the relationship with the body and environment, what people were able to do and what people could become. Coping with the constraints of pain was demonstrated through assimilation, accommodation, confrontation or subversion (Miles, et al, 2005). In assimilation, patients conceptualized the changes in their lives within socially accepted life changes such as growing older. Constraints of pain were accepted with a redefinition of life in accommodation. Those patients not willing to accept the pain focused their coping efforts on maintaining their pre-pain or pre-injury status and activity levels at the expense of higher levels of pain known as confrontation, or in subversion by maintaining who they were prior to the development of chronic pain at the expense of greater activity restriction (Miles, et al, 2005).

Pain-reduction strategies used by community-dwelling older persons was evaluated by Barry, Gill, Kerns, and Reid (2005) in a cross-sectional study to identify those strategies perceived as effective in reducing pain and to ascertain factors associated with their use. The researchers gathered information from 272 people age 73 years and older. Participants perceived several pain reduction strategies to be effective to include analgesic medication, activity restriction, hot and/or cold modalities and exercise. However, 60% reported continued experiences of substantial pain (Barry, et al, 2005).

Although this study focused on the elderly, it provides important information regarding perceptions of the effectiveness of pain management options. The researchers also attempted to isolate factors that might be associated with the pain management strategies but could not identify any factor to include age or gender that was independently associated with any of them (Barry, et al, 2005).

Literature regarding the combined concepts of patient perceptions and treatment options for chronic pain was practically nonexistent. However, in 2001, McHugh and Thoms explored the patient's perspective of living with chronic pain. They sampled 245 patients with chronic pain using a structured questionnaire. All participants surveyed had attended special pain services or clinics in 11 randomly selected hospitals throughout the United Kingdom. The goal of the study was to compare patient's perceptions of chronic pain management before and after treatment (McHugh & Thoms, 2001). This study revealed that patients suffering from chronic pain had tried a number of different approaches to obtain pain relief. Modern medical techniques as well as alternative and complementary treatments were utilized.

Historically this exploration of treatment options was accomplished at considerable personal expense to the patient (McHugh & Thoms, 2001). It was identified as well, that patients had to wait a long time to be seen by a pain specialist. One third of those surveyed had waited more than four months (McHugh & Thoms, 2001). Lack of information about available services for chronic pain treatment was also found to be especially relevant with only 19% receiving such information from the pain clinics attended (McHugh & Thoms, 2001). A third area of concern identified in this study was

that one third of the patients did not know or understand the cause of their pain (p.37). They expressed fear regarding possible misdiagnosis and fear of not being believed (McHugh & Thoms, 2001).

Although this study took place in the United Kingdom and not the United States, this researcher found the information valuable as the only study to have explored specifically, patient perceptions of chronic pain treatment options. It provides strong endorsement for the need for further study in this area to determine if results would be consistent and relative to American patients.

In April of 2004, the American Chronic Pain Association conducted a telephone survey of Americans living with pain. The survey was run by Roper Public Affairs and Media, with funding from Endo Pharmaceuticals. Eight hundred adults who suffered from chronic pain were randomly selected from all telephone households in the United States, listed and unlisted, participated in telephone interviews. Identification of patient perceptions and the use of various treatment options was one part of the study (Roper Public Affairs and Media, 2004). Forty seven percent of those surveyed reported that their pain was not under control (Roper Public Affairs and Media, 2004). Eighty nine percent used alternative treatments in addition to over the counter and prescription medications (Roper Public Affairs and Media, 2004). This type of survey is limited in that the participants, though randomly selected volunteered their responses and their own opinion regarding their chronic pain status. They may have had a special interest in responding that may have skewed their responses. The usefulness of these types of surveys is that they identify areas that are in need of further study. The fact that

approximately half of the respondents felt that their pain was not under control is significant.

The definition of rural according the United States U.S. Census Bureau (2000) is areas of open country and settlements with less than 2500 residents. Forty-six percent of Montana's population is considered rural (Montana by the Numbers,). Rural communities tend to have fewer health care resources, higher numbers of elderly people, lower levels of education, lower per capita income and a higher number of uninsured or underinsured people. Ryan-Nichols (2004) looked at rural access to healthcare and listed the following as challenges to health care access: problematic access to primary care, diagnostics and specialized services; retention of healthcare workers; limited numbers of up-to date health care facilities and travel expenses related to distance. Although this was a Canadian study these issues are fitting for rural health care access in the United States and Montana as well.

In Montana, Senate Joint Resolution 28 was passed by the legislature in 2005. As a result, the Montana Pain and Symptom Management Task Force (MPSMTF) was formed to assess pain management practices and policies in Montana and make recommendations to improve pain management practices in the state. MPSMTF completed a health care consumer survey of 239 Montana residents. The survey results were published in 2007 and indicated that pain limited activities, caused extra expenses in medication and other care and resulted in lost wages (MPSMTF, 2007). Most of the participants felt that their health care provider treated them with respect and dignity, but over a third of the participants who experienced chronic pain did not feel that their health

care providers asked good questions to learn about their pain and how that pain impacted their daily life (MPSTF, 2007). Only 53.5% of those with chronic pain felt that their healthcare providers regularly monitored their progress by asking about their pain and ability to function at each visit (MPSTF, 2007). In addition only 52.6% reported that their treatment was adjusted if their pain had not been eased or their ability to function had not significantly improved (MPSTF, 2007). Approximately one third (33.5%) of those who experienced ongoing pain reported that they had never been referred to any other provider for pain management services (MPSTF, 2007).

The Neuman Systems Model is used in educational and practice settings worldwide (Neuman, 1995). It has been used as a guide for hundreds of research projects involving many diverse areas of nursing practice.

Nurse researchers have utilized the Neuman Systems Model in qualitative and quantitative studies to explore different aspects of pain. Pain is a stressor affecting the client system. Perception is one part of the general makeup (internal factors) of the client system. There are studies that explored patient perceptions regarding various disorders and treatment modalities but none specific to treatment options for chronic pain.

In 1992, Radwinski completed a study utilizing the Neuman Systems Model, to evaluate the self medicating practices for managing chronic pain after spinal cord injury. This study looked at patient perceptions of pain and how that influenced decision making in the management of their pain (Radwinski, 1992). It did not look specifically at patient perceptions of treatment options. However, self medication could be seen as a choice made by the patient if available treatment options were perceived to be ineffective.

Radwinski discussed only briefly how she applied Neuman's Model as the theoretical framework for her study by reviewing the effects of patient behaviors on the family system (Radwinski, 1992). There is a disconnect between the purpose of the study and this discussion of family systems. Radwinski's study was limited by a small convenience sample size of 15 males and one female. The fact that the sample was predominantly male is also a hindrance as the results cannot be generalized to women.

Another study utilizing the Neuman Systems Model (1995) evaluated sleep satisfaction, perceived pain, and acute confusion in elderly clients undergoing orthopedic procedures (Bowman, 1997). Again, this study does not address directly patient perceptions of chronic pain treatment options. However, it does explore patient perceptions of pain and also provides a better outline of how Neuman's model could be applied as a framework for the study. Bowman interprets Neuman's Theory to consider "the client holistically and multidimensionally...taking into account all variables affecting an individual at any point in time" (Bowman, 1997, p.551). Bowman discussed the evaluation of internal and external stressors as outlined by Neuman and how those stressors affect the patient's ability to maintain health (Bowman, 1997). These factors were then related to the evaluation of how sleep, pain, and confusion are interrelated and how that impacts the patient (Bowman, 1997). Patient perceptions are founded in what Neuman describes as the five interrelated variables of the dynamic composite of the client system to include physiological, psychological, sociocultural, developmental, and spiritual aspects (Neuman, 1995). This study utilized qualitative interviews, pain scales

and chart review of 43 subjects hospitalized for hip surgery. It addressed chronic preoperative pain and acute postoperative pain experienced by patients (Bowman, 1997).

In 2001, Gerstle, All, and Wallace completed a study on the quality of life of patients suffering from chronic nonmalignant pain. These researchers utilized Neuman's Systems Model (1995) as the theoretical framework of their study (2001). Quality of life, chronic pain, treatment modalities and treatment goals were key concepts in this study (Gerstle et al., 2001). The researchers examined patients' perceptions of their health, functional status, socioeconomic status, psychological, spiritual and family aspects of life (Gerstle et al., 2001). Patient perceptions of treatment options were not addressed.

Gerstle et al. (2001) utilized the Neuman Systems Model with a focus on the concepts of stress and the client's reaction to stress. The five components of the client system, physiologic, developmental, sociocultural, and psychological, were reviewed and related to the study variables identified. Neuman's lines of defense and resistance were reviewed as protectors of the five basic components (Gerstle et al., 2001). The researchers provided an excellent overview of the Neuman Systems Model and how it related to their topic of study and the questions posed.

The sample consisted of two groups of patients, 16 who had completed a specific pain management program and 20 who were about to enter the program (Gerstle et al., 2001). Each participant completed a quality of life index questionnaire and a demographics form (Gerstle et al., 2001). The data collected was reviewed and analyzed using Neuman's five variables (Gerstle et al., 2001). In conclusion, these researchers state, "it is the patient, not the health care professional, who determines what is

satisfactory and who knows whether the proposed goals are appropriate, desirable, or valued” (Gerstle et al., 2001, p.107). It is this statement that this researcher finds most relevant to the study of patient perceptions of treatment options for chronic pain. Gerstle and his fellow researchers were limited by the sample size and convenience of their sample. They identified the need for further study with larger samples over longer periods of time (Gerstle et al., 2001). They also identified the need for further research utilizing Neuman’s Systems Model to test and develop a theory relative to the stressor of pain (Gerstle et al., 2001).

In 2003, the American Medical Association published a series of continuing medical education regarding pain management. In these publications, chronic nonmalignant pain is referred to as “persistent” pain. This included nonmalignant or non-cancer pain – “a complex group of disorders that may be related to specific disease processes; occur following injury to bone, joint, soft tissue, viscera or nerve; or result from poorly understood psychological processes” (AMA, 2003, p.3). The AMA (2003) recognized that persistent pain had a significant impact on quality of life and was frequently accompanied by anxiety, depression and sleep disorders and all of these have the potential to complicate its management.

Summary

This literature review revealed that there is limited research information available regarding patient perceptions of treatment options for chronic nonmalignant pain; how they identify treatment options and how they choose to manage their pain, as well as what factors might influence those choices. As the problem of chronic nonmalignant pain

continues to grow, research to determine better treatment modalities will continue to be important. Addressing the problem from many different angles has already been proven to be necessary. As it is evident that current treatment methods fall short in relief of chronic pain symptoms, new questions need to be asked (McHugh & Thoms, 2001). In addition, the questions need to be addressed to the sufferers of chronic pain themselves. Only they can tell us what is missing in current treatment methods. Using Neuman's Systems Model (1995) to address patient perceptions of care provided will lead to identification of nursing interventions more appropriate to meet their needs. Analysis of the data collected utilizing Neuman's model and the five variables that make up the core of the client system will also allow more coherent interpretations of the common themes in patient perceptions of treatment options.

CHAPTER THREE

METHODS

Population and Sample

The target population for this study is individuals diagnosed with chronic pain. Sample subjects were recruited from the client base of patients who have been evaluated and received treatment at the Spine and Pain Center, St. Patrick Hospital in Missoula, Montana. Volunteers to participate in the study were taken on a first come, first serve basis. The initial goal was to interview six to eight patients. This number was subject to change to ensure adequate data for analysis, indicated by saturation of themes and categories. Ultimately, nine patients participated in this study. Volunteers were required to be adults, age 21 to 65 years of age and their pain had to meet the definition for chronic nonmalignant pain.

Six women and three men participated in this study. Ages ranged from 31 years to 65 years. Three participants were employed; one was on permanent disability; and the remainder, temporarily disabled with hopes of returning to work in the future. Three participants had college degrees; one had some college; two had high school diplomas; and three had less than a high school education. 67% of the participants were covered under workers compensation insurance, two had private health insurance through their employer, and one was on Medicare with a supplemental insurance plan. Four of the subjects lived in the city of Missoula and five lived in rural areas outside of Missoula with distance to health care services ranging from 20 to 45 miles.

All participants met the definition of chronic pain in that they had been experiencing daily pain for a minimum of six months. The actual duration of pain in this group of individuals ranged from one year to 26 years. Diagnoses included failed back surgeries; chronic low back pain; frozen shoulder; rheumatoid arthritis; chronic neck pain and headaches; and severe knee and hip injuries with multiple surgeries. All participants reported daily pain, ranging in severity from two to ten on a ten point scale.

Design

This was a qualitative study utilizing the phenomenologic approach. Phenomenological study seeks to describe meaning for a group of individuals (chronic pain patients) of their own lived experiences (perceptions) of a phenomenon (management of chronic pain) (Creswell, 2007). Through semi-structured interviews common themes were identified to describe shared experiences. Patient perceptions of treatment options were explored for commonalities and differences to paint a picture of the lived experience of pain management.

Data Collection

Data was collected through semi-structured interviews with participants in their homes or a private meeting room at St. Patrick Hospital, depending on participant preference. The interviews were tape recorded and later transcribed. Each interview took approximately one hour and no more than two hours. The researcher also took notes during the taped interviews regarding observations made. Basic demographic information was gathered from the participants, as well as information regarding the level of pain that they experienced on a daily basis.

Instrumentation

The demographic questionnaire provided the following information regarding each subject: sex, age, marital status, dependents, primary diagnosis, date of original diagnosis, education, occupation, average income, health care coverage, distance to travel to access medical services, and whether residence (rural or urban). See Appendix A. Participants were also asked to rate their level of pain using a numeric scale (0-10) and provide ratings of their best, average, and worst pain experiences. See Appendix E for the tool. The interview guide was developed based on the Neuman Systems Model and the phenomenological approach. Based on phenomenological approach participants were asked two broad, general questions (Creswell, 2007): What have you experienced in terms of treatment options for chronic pain management? What contexts or situations have influenced or affected your experiences of treatment options for chronic pain management? The interview guide is attached as Appendix B.

Rights of Human Subjects and Participant Recruitment

Human Subjects approval was received from the Joint Investigational Review Board of St. Patrick Hospital and from the Institutional Review Board of Montana State University. Subjects were recruited by placing flyers in treatment rooms at the Spine and Pain Center at St. Patrick Hospital. These flyers sought volunteers to participate in this study who would share their experiences with treatment options for chronic nonmalignant pain. Telephone tear-off strips were attached to the flyer so potential subjects could contact the researcher. Participants were assured anonymity, that participation was voluntary and that they could choose to discontinue their participation at any time. They

were informed that their participation would have no bearing on any future professional relationship with the current medical provider or the researcher. Permission was received from Dr. Randale Sechrest, Medical Director of the Spine and Pain Center, to recruit patients in this manner and it was agreed that the aggregate research results would be shared with all members of the Spine and Pain Center team and all patients who participated. The consent form is attached as Appendix C. Participants received a copy of the form for their personal records and as a reference with contact information should they have any questions or concerns regarding the research process.

Data Analysis

The interview tapes were transcribed verbatim without grammatical editing. The transcripts were triple spaced with wide margins to allow the insertion of memos, notes regarding changes in voice tone, and recollections of nonverbal behavior and emotional reactions. The transcripts were reviewed by the researcher while simultaneously listening to the tape recording to ensure their integrity and accuracy. Copies of the transcripts were made with one clean copy kept in a secure place (Norwood, 2000). Working copies were utilized for memo and note keeping in the data analysis process. All data including tapes and transcripts was maintained in a locked file cabinet and will be destroyed within three years of completion of the study. Consent forms were kept separate from the data in an alternate locked file drawer. Each interview tape and associated transcription was coded to a consent form with a separate number.

Transcribed interviews were read and reread and memos or notes were made in the margins with phrases, ideas, or key concepts identified. Using phenomenologic

principles individual experiences and the context of those experiences were identified (Creswell, 2007). Utilizing inductive analysis, specific themes were categorized into broader themes that revealed themselves. The identified themes were interpreted in the context of Neuman's Systems Model (1995) and guided by phenomenology. The five variables of Neuman's Systems Model (1995), physiologic, psychologic, developmental, sociocultural and spiritual served as guides to identify themes. Neuman's definition of tertiary prevention involves readaptation, re-education to prevent recurrences, and maintenance of stability (1995). These concepts were also considered in the review of the data and identification of common themes. The researcher was prepared to encounter themes that did not fit Neuman's Systems Model and interpreted these themes as well. In phenomenology the data was described texturally, as in what happened regarding chronic pain management and structurally, as in how the phenomenon of pain management was experienced (Creswell, 2007).

CHAPTER FOUR

RESULTS

Report of Data

Review of the transcripts and interview notes resulted in the identification of nine prominent themes. Each theme will be presented individually with supporting quotes and data extrapolated from the transcripts.

Theme 1: Limited options. Patients identified the following options as available to them: chiropractic treatment, physical therapy, medication, osteopathic manipulation, acupuncture, massage, surgery, spinal cord stimulation, implanted medication pumps, injections, “learning to live with it” and distraction. Distraction was mentioned by a 65 year old woman who has lived for 24 years with her arthritic pain. She explained how when she was younger and riding a horse, she could forget about her pain for a while. Now she turns to quilting as a distraction from her daily pain. Interestingly, psychological treatment or therapies, such as cognitive behavioral therapies were not mentioned. Those patients with less education and receiving workers compensation benefits were more likely to identify fewer options and reply, “I really don’t know what else there is to do” or make a similar statement. Alternative treatments such as acupuncture, massage, osteopathic and chiropractic manipulation may not be authorized by the workers compensation insurer, thus limiting the options available to this group of patients.

A 50 year old woman with a college education in a non-medical field stated that she didn’t know what the options were and she depended on health care professionals to

direct her care. She felt that every time she “went to a different practitioner, be it a medical doctor, an osteopath, or an acupuncturist, and it didn’t work, I walk away feeling like a fool who spent their money. I feel like a fool. And that is the worse part. Because, I am not a fool. You know, I just keep working at it”.

Four of the nine patients stated that over time the hope for a quick fix or resolution disappeared and was replaced with a feeling and a need to just learn how to live with it. “Honestly, I have been getting the notion that I am just going to have to deal with it, so I don’t really feel like I have a lot of options at this point.”

Theme 2: Influencing factors. Factors that influenced patient’s choices regarding pain management included financing, distance to care, the ability to locate good care, faith in medical providers, knowledge or the lack there of regarding options, attitude, payer source, and whether or not the treatment recommended is invasive. Financing was a big issue and especially so amongst the patients with workers compensation insurance. One 49 year old male reported that “work comp tells me what to do”. A 50 year old female injured worker stated, “Work comp dictates what I do and can’t do”.

Living for 24 years with rheumatoid arthritis, a 65 year old woman had another viewpoint on the subject, “I decided long ago, just do what they tell me to, not look outside and waste my energy chasing dreams”. This subject expressed her strong faith in her medical providers to deliver the best medical care available. She explained that she had met many people with chronic ailments, that were “always fighting the system” and she felt that generally these people did not do as well.

An opposite view is that of a 50 year old employed, college graduate with private health insurance through her employer, “the biggest influencing factor was my complete ignorance regarding chronic pain. I have bounced from provider to provider over the past two years and still have no real diagnosis. I keep trying to find better care...and answers.”

Attitude was another factor influencing choices regarding options for pain management. A 44 year young lady stated that she felt strongly the need to “take responsibility to stay strong”. She explained that in her 5 year search for resolution to her pain, core strengthening was key and she was willing to work hard on that on her own.

A 31 year old mother of two, stated, “I’m tired of physical therapy, tired of trying different medications without positive effect; I’ve become very negative about the whole thing, so my attitude is a big influence on where I am right now and what I’m willing to do”.

Theme 3: No quick fixes. Frustration, patience, and no quick fixes dominated this theme. All nine of these patients have varying levels of pain every day. None are ever completely free of it. None would agree that the methods employed to date had any lasting benefit. “It’s very, very frustrating. I’ve spent so much money and so much time, only to have it return.” This patient has suffered low back and left leg pain for five years.

Another 54 year old, female patient with low back pain following a work injury one year ago, stated, “I’m not very patient, wish I would just get better; I guess, I am slowly getting better, but wonder if it will ever end.”

After two years of hip pain, one patient reported, “I’m not feeling real good about it. I don’t feel like they have found the right plan or the right path yet. That is where I come in and try not to be negative about trying new things.”

Theme 4: Life changes. Patients with chronic pain often experience major life changes. These changes affect ability to work, play and perform daily activities of living. Decreased finances were common to all nine participants. The patients on workers compensation benefits suffered the most hardship, being unable to return to work in occupations that some had been doing all their lives. Even those with better insurance coverage, education, and current employment had some difficulty with treatment or medications not covered by insurance or necessary job changes to accommodate their new physical status.

A 47 year old father of two young children, decided to move to Missoula into a small apartment to be closer to medical care. Once injured at work, his income dropped from over \$100,000. a year to 33,000. a year. Given the nature of his injuries and the age of his children, two and four, his wife was not able to return to work to help support the family. The patient states, “I can’t do anything, play with my kids, camp, hike, fish. I can’t even take a walk around the block!”

Marital difficulties frequently follow these life changes. These difficulties were shared by the female participants, but not the males. “We argue more. We fight about the direction my medical care is taking, hassles with workers compensation, and sex. No man wants to hear that his wife has a headache every night.”

Another wife stated, “I’m no fun anymore.” This has effects on relationships with children as well, as there is a decreased capacity for play. One mom had to take her eleven year old son out of soccer because she could not guarantee that she would be able to get him to practice regularly.

Theme 5: Effects of increased activity. Although increasing activity is frequently recommended in the treatment plan of patients with chronic pain, all nine of the participants in this study reported that increasing activity frequently resulted in an exacerbation of pain. In spite of this, eight of the nine participants were engaged in an exercise program of some sort with four in active physical therapy treatment. Many reported that there was a need to determine a balance between rest and activity and “learning what I can and can’t do”. All were doing much less than they had prior to their diagnosis.

Theme 6: Emotional support. All nine participants depended on family and friends for emotional support. One mentioned her church and one was involved in a 12 a step program that provided “great support in all realms of my life”. Coworkers were seen as an asset for emotional support as well by a participant that works in health care. None of the nine patients interviewed was involved in any type of professional counseling.

Theme 7: Hopelessness. There was only one participant who expressed any hope regarding her future with chronic pain. The question was, where do you see yourself in five years? A 44 year old female, college graduate and employed, stated, I am going to have it all figured out. I am going to be really strong and thin. I don’t see it getting worse. I feel I am going to correct it.”

More common responses included the following: “I don’t know, it doesn’t look too good.” “I just don’t know, I wish this was over or never happened.” “Who knows where I’ll end up.” “I don’t even want to answer that question.” “In a wheelchair.” “I just don’t know what’s going to happen to me.”

Theme 8: Listening/understanding. There was general feeling of not being heard or listened to, as well as being misunderstood by their health care providers, employers, family, friends, and coworkers. This generally contributed to feelings of frustration and hopelessness. “They don’t listen and they don’t answer my questions!” This exclamation from a 50 year old educated woman, who advised, “if I had to make a strong suggestion it would be... answer the questions, just answer them. Even if the answer is that you don’t know. And then, give me options!”

One woman explained that she has tried to recognize that every person is different and she wished health care providers would do that as well. Although she felt for the most part that she had been heard over the years, there were times when she felt the need to demand it. She goes on to say, “You know there is an old saying, the difference between minor surgery and major surgery is major is when you have it and minor is when somebody else has it. And I truly believe that most people when they say, gee I am really sorry you are in pain, in their minds they are thinking, well I have pain too. You know, I think we are basically so self centered that we relate it to us rather than the other person.”

This theme is echoed by another who reported, “A lot of people don’t understand it, and I know, because when I used to be a claims adjuster for work comp and people

would have back pain and I didn't have it, I didn't understand and I thought, just deal with it and move on. So now I am much more sympathetic to people who have that."

A negative result of not listening is a delay to treatment. A 54 year old injured worker stated that it "seems like it took forever to get someone to listen to me. The neurosurgeon liked to listen to himself talk, not listen to me...he wouldn't answer my questions...when the facet injections didn't work, he just dumped me like a cold fish!"

Theme 9: Depression. Five of the nine participants discussed depression openly, all were women. One woman related feelings of depression to the frustration with a lack of resolution and the inability to do all the things she did before.

There was a concern about the "label" of depression as another stated, "It is depressing. I denied that there could be any depression involved for awhile because I didn't want to be labeled as depressed because you know I was looking at it that they were just going to label me as somebody who had depression issues instead of dealing with what was going on here. That was my fear, but it is very depressing and it is hard. It is a struggle every day."

One gentleman did mention depression in this way, "good friends are important, because without them, you know they say, are you depressed, and I'd say, no I'm not, I just realized it's tough. It is going to be tough for awhile. But that's who I am right now. I take it one day at a time. I used to look forward."

CHAPTER FIVE

DISCUSSION AND CONCLUSIONS

Evaluation of Results

In this phenomenological study, participants diagnosed with chronic nonmalignant pain described their experiences with treatment options and contexts or situations that influenced or affected those experiences of treatment options. Participants described their experience with chronic pain to include options available to them; the effectiveness of the methods tried; lifestyle changes associated with their pain; feelings of hopelessness for the future relative to pain resolution as well as available options; the effects of increased activity; emotional support; the effects of listening and understanding; and depression. The perceptions regarding influencing factors on the choices of pain management options were varied with finances being the most frequently listed influence. Other influencing factors included attitude, decisions made by the insurer or payer, level of education, distance, quality of health care services available, faith in current health care providers, and knowledge regarding options for chronic pain management.

Consistent with McHugh & Thoms (2001) study patients suffering from chronic pain have typically tried a number of treatment options to obtain pain relief that were accomplished at great expense. Delay to treatment was also an issue that was expressed in both the current study and the 2001 study. This small qualitative study also supported

McHugh & Thoms (2001) work in that there was a significant lack of knowledge regarding available services for chronic pain treatment.

As previously stated, Gerstle et al. (2001) reported on the quality of life of patients suffering from chronic pain. The authors (Gerstle et al., 2001) reported that chronic pain affected all aspects of an individual's life, causing stress to the individual in the physiologic, sociocultural, developmental and spiritual health components identified in Neuman's Systems Model. In the current study, the two themes of effects of increased activity and effectiveness of pain management methods fall within Neuman's (1995) physiologic realm. The sociocultural realm is apparent in the themes of available options, influencing factors, lifestyle changes, support, hopelessness, listening/understanding, and depression. The psychologic realm is present in influencing factors, effectiveness of pain management methods, support, hopelessness, listening/understanding, and depression. Developmental issues may also exist in the influencing factors theme.

The theme of effects of increased activity identified in this study supports the work of Miles et al. (2005) in that increased activity frequently resulted in exacerbation of pain and each participant responded to this in a different way. Some accepted this as a part of growing older; some worked hard to maintain a level of activity consistent with pre-pain days regardless of the pain; some restricted activity but made attempts to maintain who they were prior to developing chronic pain; and accept their pain and redefine their life. Even these responses are consistent with the idea of Neuman's Systems Model (1995), as there is an ongoing effort to return to or maintain stability.

As discussed earlier, Neuman's Systems Model (1995) views the patient as a system composed of the physiologic, psychologic, developmental, sociocultural and spiritual realms. This study supports Neuman's theory in that all these variables seem to interact and relate to each other in specific ways that are unique to each individual. The nine themes identified can be seen to interact similarly within the patient system. Patients have a general knowledge of the treatment options available to them based on their primary diagnosis, their perception of their own pain levels, the care providers they have seen, the information provided by these care providers, the effects of increased activity, finances and payer source, level of education, the success or lack, thereof, of treatment provided to date, and distance to travel to obtain services.

Themes identified as part of the psychologic realm in Neuman's theory can be seen to have an effect on the perception of the overall effectiveness of the treatment methods employed. Lifestyle changes necessary as a result of chronic pain perpetuate the cycle of hopelessness, depression and the staying power of long term support systems, such as care giver fatigue and interpersonal stresses. Any one of these themes if perceived as unstable in any way can disrupt the overall patient system thus impacting each and every other component of the system.

Neuman (1995) states the goal of the system is to maintain stability. In this group of participants with chronic pain multiple attempts to restore and maintain stability have been tried without long term success. Participants/patients wait to be told what the next available option is. They determine affordability. They are told by the insurer whether or not the treatment option will be covered. If it is determined that the option is a viable one,

a new cycle of restoring stability is begun. If not, the person may find themselves in a situation with little or no hope for stability.

Neuman (1995) evaluates the success of treatment options for chronic pain using the concept of tertiary prevention. This involves readaptation, re-education to prevent recurrences, and maintenance of stability. In the patients interviewed for this study this is a never ending and seemingly life long process.

Participants in this study continue to search for effective methods of pain relief that is consistent and long lasting. Methods utilized currently provide temporary relief, but each participant experienced daily pain. As in previous studies resolution of chronic pain is an illusive outcome. Barry et al. (2005), 60% reported continued experiences of substantial pain. Roper (2004) reported that 47% of participants surveyed indicated that their pain was not under control.

Study Limitations

In this small qualitative study nine patients who have either been evaluated and/or treated at an outpatient pain management program in Missoula, Montana were interviewed. Similar studies at different pain clinics around the country may support the results of this study or dispute them. A strength is that the sample did contain patients with a number of diagnoses, chronic pain lasting from one year to 24 years, a range in age from 31 years to 65 years and a range of pain level from patients able to work and function to those that were totally disabled as a result of their pain. A limitation other than the small sample size is the fact that six of the nine participants were female.

Previous studies have shown a difference in level of pain and dysfunction between men and women.

Implications

Patients in need of chronic pain management services continue to struggle to find answers to their questions and resolution of their situation. The results of this qualitative study support the need for ongoing research, specifically addressing the patient's perceptions regarding all realms of the patient system. Education of the public, primary health care providers and other health care professionals regarding chronic pain management continues to be an issue, as these patients describe their difficulties with obtaining information regarding available options. This study identified as well the need to continue to develop the art of listening and empathy. Nurses have typically been seen as care providers willing and capable of listening and displaying empathy. It has been seen as the heart and soul of nursing. What continues to be lacking however, is the ability for nurses to communicate what they have heard to other care providers responsible for directing the care of patients with chronic pain.

If we, as care providers, as Neuman explains in her Systems Theory (1995), can identify in our patients the psychologic, sociocultural, developmental, physiologic, and/or spiritual factors influencing the ability to restore or maintain system stability in chronic pain patients, we are one step closer to achieving comprehensive and standardized treatment methods for persons suffering from chronic pain.

Recommendations

Medical care providers directing the care of patients with chronic pain need to be aware of the multiple factors that may impact how this population of patients perceived options available to them and the effectiveness of those options tried. Assessment questions should include those directed to gather information regarding sociocultural, psychological and spiritual stressors. A simple question such as “what’s going on in your life these days?” should open the door to explore the presence of these stressors. Care providers must recognize the multifactoral nature of chronic pain to provide quality pain management.

Education regarding chronic pain management options was identified in this study as a need for care providers as well as the patient population. We, as care providers, must seek out current information regarding pain management options available and current practice standards regarding pain management. We need to be aware of when a referral to comprehensive pain management services is warranted, as patients clearly benefit from receiving treatment promptly. It would be helpful to provide patients with educational materials and a list of options that provide treatment to address physiological, psychological, sociocultural, and spiritual aspects of chronic pain. This recommendation is supported by the work of Glenton, Nilsen, and Carlsen (2006), who studied the lay perceptions of evidence-based information on a website targeting chronic back pain sufferers. Glenton et al, (2006) found that participants in their qualitative study appreciated finding different types of information all in one place. Many participants however, complained that information about complementary or alternative treatments

was missing (Glenton, et al, 2006). To prevent the large amount of information from becoming daunting to the lay person the researchers suggested providing a short overview of all available treatments for each condition (Glenton, et al, 2006). Participants in this study also indicated that they place a high emphasis on experience based information from others who have been through what they have. Participants stated that given the choice between evidence based information and experience based information they would be more likely to accept as truth, the experience based information. Glenton, et al, (2006), therefore recommended that treatment information provided to patients include both evidence based and experience based sources of information. The authors concluded that the provision of information about treatment options and their expected outcomes can lead to better decision making (Glenton, et al, 2006).

Finally, it was apparent in the statements of participants in this study that care providers work to develop the skill of listening. We all appreciate it when we feel heard. In busy medical practice offices with limited time to see each patient we need to remind ourselves to take a deep breath before entering the room and direct our attention to the person sitting there, waiting for our services.

From the standpoint of future research, this study provided information regarding patient perceptions of, and experience with, chronic pain treatment options for nine patients who have received care in and around the community of Missoula, Montana. Replication of this type of study in different communities across the country would be interesting to determine whether or not the results would be consistent and applicable to all patients diagnosed with chronic pain.

Factors influencing patient perceptions of chronic pain and the treatment options available included effectiveness and quality of treatment provided; lifestyle changes; financing/payer sources; hopelessness, depression, listening/understanding, attitude, education, and distance. Each of these factors warrants specific research in its own right. Efforts to increase our knowledge base and understanding in these areas will lead to higher levels of care for patients suffering from chronic pain.

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APPENDICES

APPENDIX A
DEMOGRAPHIC SHEET

APPENDIX A

Demographic Information

Age: _____ **Sex:** male _____ female _____

Marital status: Single ____ Married ____ Separated ____ Divorce ____

Widowed ____

of children and ages _____

Your education: Less than 12 years ____ High School ____ Some College ____

4-yr. graduate ____ Graduate ____

Occupation: _____

Average household yearly income: _____

Healthcare coverage: Employer or self-paid insurance/PPO ____ HMO ____

Medicare/disability ____ Medicaid ____ Worker's comp ____ Self-pay ____

Place of residence: _____

Primary diagnosis and date of diagnosis: _____

Distance to travel (miles) to obtain pain management services: _____

emergency services _____ routine medical care _____

APPENDIX B

INTERVIEW GUIDE

APPENDIX B

Interview Guide

Description of typical day – cues: before pain management program and after

What makes pain better or worse

What is your understanding of current options available for pain management

What factors influence your choices regarding pain management – cues: finances, distance, access

Current methods utilized to manage pain

Perception of effectiveness of current methods

How do current methods compare to what was learned in pain program

Life changes/adjustments related to chronic pain

Information regarding primary caregiver in relation to pain management

Sources of emotional support

Where do you see yourself in 5 years, 10 years – cues: hopeful vs. no hope; expectations regarding medical advances

Any other comments

Thank you

APPENDIX C

CONSENT FORM

APPENDIX C

SUBJECT CONSENT FORM

FOR

PARTICIPATION IN HUMAN RESEARCH AT

MONTANA STATE UNIVERSITY

“Patient Perceptions of Treatment Options for Chronic Pain”

Thank you for responding to my flier posted at the Spine Center at St. Patrick Hospital and volunteering to participate in a study regarding chronic pain management. The purpose of this study is to understand patient perceptions regarding treatment options for chronic pain so that we in nursing and health care can better understand your needs and develop ways to help people like you manage pain. The following information is provided for you to decide whether you wish to participate in the current study. You are free to decide not to participate or to withdraw at any time without affecting your relationship with St. Patrick Hospital Spine Center, myself, or the College of Nursing at Montana State University.

The study will consist of completion of a demographic form, a pain rating scale and an hour long interview. The interview will be tape recorded and later transcribed. I will be sharing the aggregate results with the members of the Spine Center; however, no participant will be identified in any presentation or report.

Please do not hesitate to ask any questions about the study before participating or during the time you are participating. I will be happy to share a summary of findings

with you after the study is completed. Your name will not be associated with the research findings in any way and your identity as a participant will be known only to me.

The only risk associated with this study is that you may recall unpleasant or difficult personal experiences or situations; however, you may chose not to answer the question or to stop the interview at any time. The expected benefit associated with your participation is the opportunity to share your experiences with chronic pain treatment in the hope that the data gathered will lead to improved treatment options in the future.

Additional questions about the rights of human subjects can be answered by the Chairman of the Institutional Review Board, Mark Quinn, at 406-994-5721.

AUTHORIZATION: I have read the above and understand of the nature and purpose of this study. I, _____, agree to participate in this research. I understand that I may later refuse to participate, and that I may withdraw from the study at any time. I have received a copy of this consent for my own records.

Signed: _____

Witness: _____

Investigator: _____

Date: _____

Researcher: Valerie Benzschawel

Phone number: 406-240-8167

Research Supervisor: Elizabeth Nichols, DNS, RN, FAAN

Phone Number: 406-994-3784

APPENDIX D

REQUEST FOR COPY

APPENDIX D

Request for copy of the results summary

Please fill out this form if you would like to receive a copy of the summary of results of the study “Patient Perceptions of Treatment Options for Chronic Pain”.

Name: _____

Mailing address: _____

This information will remain confidential and will not be included in the study information.

APPENDIX E

NUMERIC RATING PAIN SCALE

APPENDIX E

Numeric Rating Pain Scale

0 _____ No pain

1 _____

2 _____

3 _____

4 _____

5 _____ Moderate pain

6 _____

7 _____

8 _____

9 _____

10 _____ Unbearable pain
