The Meaning of Couple’s Lived Experiences of Living With Chronic Pain

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Chronic pain is a multidimensional problem that causes anguish for people who suffer from the toll taken on emotions, bodies, mind, and spirits. Chronic pain constitutes a colossal challenge for mental health professionals, physicians, insurers, employers, and families because it stretches their capabilities, finances, optimism, and not infrequently, patience. The aim of this qualitative study was to deepen the understanding of the lived experiences of families affected by chronic pain in order for clinicians to better be acquainted with and treat patients and families with chronic pain. I used qualitative methods to reveal the experiences of these families. Data was gathered from a Texas border pain management clinic. The words of the participants were presented in order to convey the emotional impact chronic pain delivers.

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Chronic pain causes misery for people who suffer from the toll it takes on their bodies, mind, and spirits. Chronic pain constitutes a colossal challenge for mental health professionals, physicians, insurers, employers, and families because it stretches their capabilities, finances, optimism, and not infrequently, patience. Today, despite the most technologically advanced health care services in our history, pain is still an elusive mystery. Even with the latest medications, skillful surgeries, and physical therapy techniques, the suffering can lead to frustration, anger, depression, anxiety, job loss, financial ruin, and marital and family disaster. The number one reason for physician office visits in the United States is to seek treatment for complaints of pain (Hazard, Haugh, Reid, Preble, & McDonald, 1996). Chronic pain is also the least understood problem facing physicians, other health-care providers, friends, and families (Bonica, 1990). Chronic pain does not respond well to traditional methods of treatment, surgical interventions, physical therapies, or medications. Chronic pain serves no purpose; it is not a means of warning the patient about danger. Often, patients’ relationships suffer the consequences of a lack of understanding from partners, children, parents, extended family, and friends (Winterwood, Beck, & Gruener, 2003). It is evident that chronic pain is a critical issue in current medical research and that its effects are felt not only by a large number of customers, but also by their families and community.

The impact of pain on the family is disturbing. It is well documented that musculoskeletal pain is associated with emotional distress for many individuals (Linton, 2000). Often, when an
individual experiences ongoing pain, s/he will stay home and remain somewhat isolated from family and friends. Spouses begin to take on the feelings of isolation and depression as these symptoms persist in loved-ones with chronic pain. Living on disability benefits, families’ income significantly decreases. When the benefits stop the stress compiles, placing even more financial and psychological strain on the individual and family. Due to the subjectivities and complexities of pain, chronic pain that has no organic etiology often results in patients being misunderstood, misdiagnosed, and labeled as somatizers and malingerers. Because of the limited amount of objective diagnoses, physicians and families frequently begin to wonder if the patient’s complaints are valid (Fishman & Carr, 1992). Mental health providers become tangled within the net of responding psychologically to the complaints by the patient about being misunderstood by the physician and family. Working within the medical paradigm of focusing on intricate symptomology and relying on diagnostics that do not find organic causes increases the complexity of these cases. In order to respond more appropriately, mental health professionals need a comprehensive approach that includes the understanding of the lived experiences of chronic pain patients within the context of the family.

The only randomized controlled trial of couple’s treatment for chronic pain was published in a series of papers by Saarijarvi, Rytokoski, & Alanen (1991). Couples ($n = 63$) were randomly assigned to groups that were to be treated with couples therapy or to a non-treatment control group. The treatment protocol called for five monthly 1-2 hour sessions. Significant differences were found between the two group conditions in psychological distress and marital satisfaction, including somatization. No differences were found on measures of pain and pain related disability. It is crucial that mental health providers begin to understand the lived experiences of this population so that effective treatment plans can be further developed.

A study by Jamison and Virts (1990) examined maladaptive behaviors of patients with chronic pain and the role family support plays. The study consisted of two groups. The first group of 275 patients endorsed problems within the family and reported a limited support system. A second group consisted of 233 patients with chronic pain who endorsed having supportive families and no disharmony at all within the family. At one year follow-up, those patients who reported having little or no support tended to be those with worker’s compensation and liability claims, depended more on pain medications, reported more pain sites and endorsed more pain descriptors. The patients who reported having supportive families reported less pain intensity, less reliance on pain medications, and higher activity levels. This group also tended to have full-time jobs and made fewer physician office visits compared to the patients who described families as non-supportive. This study provided evidence that perceived family support was an important predictor of meaningful outcome variables when a patient experienced chronic pain.

Other researchers have provided information about the negative effects experienced by the families of chronic pain patients. One study by Snelling (1994) yielded the following conclusions in relation to the effect of chronic pain on the family unit:

The aspects of social relationships affected were the marital partnership, sexual activity, contact with friends and relatives, and roles. This meant that chronic pain caused social isolation, role tension, marital conflict, reduced sexual activity and feelings of anger, anxiety, resentment and despondency among other family members (p. 543).
Smith and Friedman (1999) conducted a qualitative study in order to gain a better understanding of the experiences of persons with chronic pain and their relationships with family members. Themes derived from this study were the following: distancing from family members, emotional distress, intense mutual involvement with family members, identification with others’ problems, and an inability to share difficult feelings. The study also suggested that pain sometimes acted as an instrument regulating the distance and closeness among family members. Themes from these two studies were used in the present study to as frameworks for data collection and results conceptualization. In addition to these findings from quantitative a qualitative studies, an understanding of traditional and contemporary theoretical models informed the researcher.

**Purpose of the Study**

The purpose of this qualitative study is to gain better insight into the unique lived experiences of chronic pain patients and their spouses. The insight gained from this study will provide mental health providers information concerning chronic pain patients and their families and will allow them to have greater depth of knowledge concerning the many underlying currents and trends individuals in bi-directional relationships experience. The awareness gained will also provide mental health professionals and other healthcare providers the ability to develop a deeper therapeutic relationship, thereby decreasing the amount of anxiety, depression, anger, and feelings of isolation experienced by patients with chronic pain.

**Methodology**

As discussed earlier, chronic pain causes misery for people who suffer from the toll it takes on their bodies, mind, and spirits. Chronic pain constitutes a colossal challenge for mental health professionals, physicians, insurers, employers, and families as it stretches their capabilities, finances, optimism, and not infrequently, patience. The need for research is vital, given the critical needs of the chronic pain sufferer and his family. In this study, I used qualitative methods to explore the experiences of four married couples where the male partner suffers from chronic pain syndrome. My study’s research design was phenomenological, which is both a philosophical movement and a research method of which the main objective is to examine the described phenomena as they are continuously experienced by the person’s defined circumstances (Sandelowski, 2000). My task as a phenomenologist was to discover the lived experiences of these couples by describing as comprehensively as possible an experience from the participant’s perspective (Munhall, 2000). A basic philosophical assumption of phenomenology is that one can know only by obtaining the perceptions and meanings that awaken conscious awareness (Husseral, 1962). To achieve the goal of phenomenological research, I had to reawaken my own presuppositions and abstain from them.

**Participants**

A convenience sample included four married couples (N = 8) with one male member of the couple diagnosed by their treating physician with chronic pain syndrome. That couple member was being seen for complaints of pain at a Texas border pain management clinic. For the study, medical records served as the initial source of information. Addresses and phone
numbers were verified using internet telephone directory information. Contact was then initiated through a letter mailed from the pain management clinic, under the signature of the Clinic Director. The letter summarized my study and requested patients’ voluntary participation. The participants were selected from couples who responded to the letter. Additional inclusion criteria stipulated that one member of the couple must meet the following criteria: (a) not working due to pain for between 3 and 30 months, (b) not a candidate for lumbar surgery, (c) 18-65 years of age, and (d) reported an injury while on the job with the Texas Workers Compensation Commission. The final sample included four males and four females, all Hispanic, ranging in age from 32-55. The participants were diverse in their education. Three graduated from high school in the United States, one completed the 3rd grade in Mexico, two completed 6th grade in the United States, and two completed the 8th grade in the United States. In addition, socioeconomic status ranged from lower to middle socioeconomic income.

Procedure

After approval from the university Human Subjects Review Board, the individuals who volunteered to participate in the study were explained the study and were asked to sign informed consent forms. Confidentiality of participants was protected by not revealing their identity in any manner; a pseudonym was assigned for identification. Anonymity of participants was assured by excluding names during audio taping, transcription, and analysis. Participants were informed they had the right to refuse and/or withdraw from participation at any time during the process. I collected the data for my study over a three month period by interviewing each spouse two times, achieving data saturation when no new themes appeared. My determination in achieving saturation through repeat open-ended interviews and discussions with colleagues was documented by the number of times I was present in the clinic.

Data Analysis

Data collection was complete when I concluded all eight interviews. I then had the interview tapes transcribed by a professional transcriptionist. When she completed transcription, I listened to the tapes while reading transcripts to verify accuracy. I read the interview transcriptions more than ten times, as open-mindedly as possible. I used no computer software in my data analysis. My goal was to turn my data into a story that captured the participants’ voices, emotions, and experiences. It was my intent to have the reader understand the lived experiences while resisting any biases I may have had. I wanted the reader to have no doubt that my data and my analysis of the data were valid, reliable, and transferable. Data analysis was an ongoing process with clusters of themes of each transcript considered concurrently as each transcript underwent analysis. Data saturation was considered achieved when no new significant statements emerged form ongoing analysis. To organize and condense the data, a matrix composed of rows and columns was constructed (Sandelowski, 2000). Content was entered into rows and themes were presented in columns.
Validity

In order to achieve validity in this qualitative study, it was necessary to ask myself whether or not I was capturing the feelings, thoughts, and actions of the participants in the context of their lives. I also had to examine my own preconceptions and assumptions (Stringer, 2004). To achieve instrument validation, I had three colleagues review the questionnaire and provide feedback.

Reliability

In order to have confidence in the observations of the researcher, reliability was obligatory (Shank, 2002). Guba (1981) provided suggestions in justifying reliability that I followed for this study. During weekly team conferences in the pain clinic, I revealed my insights with three colleagues. Two were physicians, one a board certified pain management anesthesiologist, and a psychiatrist experienced in treating people who suffer from chronic pain syndrome. The third was a licensed professional counselor experienced in treating people who suffer from chronic pain syndrome. My colleagues listened, probed, and helped me clarify insights. This was key in ensuring reliability of my study. Limitations of my study were that the population included only Hispanic couples, and only the male couple member suffered from pain in this study.

Transferability

I provided deeply detailed and rich descriptions so that the results of this study may be transferred across locations, settings, ethnicities, and couples. Nevertheless, the results of my qualitative study can only be applied to the couples in this particular study. I wanted the reader to understand what I learned while undertaking this qualitative journey. I would also prefer that the reader determine whether or not this particular study is applicable to his or her own situation.

Results

The four themes that emerged from the data and supporting quotes are presented in the text below. Broadly speaking, these themes were; feelings of emotional distress, disparity of genesis, isolation from family and community, and need for support. It was apparent that using narrative methodologies and phenomenological understanding to get to the lived experiences of the participants was vital, and the best way to understand their lives.

Feelings of Emotional Distress

All of the participants in this qualitative study discussed their feelings of anger, fear, depression, and anxiety. Wives felt a lack of understanding as to why their spouses were not better. Each participant expressed feeling as if they were the only ones who were going through
what they were experiencing. The husbands who suffered from chronic pain felt pressure to play with their children and be active again. All of the spouses discussed experiencing depression over their situation. They said things like “the doctor said he has done everything, he needs to get off his butt!”; “I don’t see no scar on him”; “It’s been almost 2 years and he still says he’s hurt”; “I am so sad, I really just want to be alone and cry all the time”; and “I just don’t know”. One husband said:

I can’t play with my kids no more, she wants me to and she gets mad at me. I can’t, I hurt so much, so I cry all the time now. I want to feel better. I can’t sleep, my stomach hurts too. I feel like crying all the time.

His wife said:

He better go to work soon or I’ll leave. I’m not going to keep my kids here like this. He has to go to work; he has to do that I tell him all the time. I don’t have no money for bills; they are going to take his truck away. I don’t know what I will do then. Oh, I’m so scared.

These personal expressions of despair and lack of hope speak to the emotional experiences of the entire family system when chronic pain is not managed effectively. One can imagine that working from the Family Adjustment and Adaptation Response model ([FAAR] Kerns, Otis & Wise, 2002) would enable a clinician to help these family members understand the process and how best to move toward positive coping and an end to the emotional crises they have expressed.

The FAAR model (2002) has shown to be particularly informative in understanding the important role the family plays in a chronic pain patient’s life. This model looks at the experience of functional loss as related to having chronic pain problems as well as lack of coping skills. Adjustments and adaptation make up the two phases of the FAAR model. Both phases are separated by family crises. Usually at onset of the problem, the family will resist change and stability remains intact. Limited coping skills create an emergence of crisis as demands begin to increase on both the family and the patient. As a family begins to develop new coping skills, homeostasis is restored and adaptation occurs. The FAAR model has had great impact on the field of pain management by specifying hypothesized constructs such as stress, coping skills, adaptation and adjustment, as well as the role of cognitive distortions. The FAAR model looks at the family system rather than the individual in clinical analysis and intervention. This new approach to understanding the adjustment and adaptation process of families has added another very important piece to mental health practitioners’ treatment of chronic pain – the family dynamic that can be a point for intervention.

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Disparity of Genesis

The participants were divided equally across gender when discussing the etiology of the pain that the husbands experienced. All four men stated that the sole cause of the pain was medically related to a physical problem. They did not feel like behaviors or emotional states were the cause of any physical pain. When discussing recent family activities, husbands said that arguments made them more irritable; nevertheless pain increased because of the injury, not because of any psychological state. On the other hand, the wives unanimously either believed or wanted to believe that the pain was a result of a medical condition that also included behavioral overlay.

One husband said:

We fight all the time now. She is mad at me. I’ll try to explain that I hurt because of my injury. Because the Doctor has not cured me yet. This ain’t in my head man. Sometimes I think everyone does think that. Then she says she does not understand why I can’t go back to work. She gets so mad at me for nothing. It makes me so mad at her I want her to shut up and listen to me. She doesn’t care I hurt, I’m sad about that. My pain isn’t because of that, it’s because of my injury.

His wife said:

He used to love his job all the time. Then his boss, you know got fired and this new one came into the plant. He was mean, yelled at everyone and fired people for stuff, like nothing. My husband said it was a power thing. He started hating going to work. He was going to quit, you know?

Here we clearly see the errors in thinking and lack of self-efficacy. The males expressed no self-efficacy in changing their experience of pain without medication or surgical intervention. The wives also experience lack of efficacy in getting their husbands to adopt positive coping strategies. The despair evident in these dialogues relate from fundamental disagreement about why the chronic pain patient is experiencing difficulties. It would seem that a cognitive behavioral approach could help these couples focus action in effective ways and find mutual goals that would ease the discomfort of both parties.

Isolation from Family and Community

The participants felt isolated from both family and community. Both spouses blamed the pain on this isolation. Couples mentioned that they once were very active with their families and in the community. They discussed going to parks, movies, out to eat with family, and many other activities before the pain problem.
One husband said:

I want to be alone all the time. I don’t want to go to the movies. I can’t, I hurt too much. Most of the time my wife is in the kitchen with my kids and I am in the bedroom. I hurt too much to go anywhere with them, I want to be in the house.

His wife said:

A big thing used to be to go to the movies, but no more, not since he hurts too much. He won’t go. We don’t even have my sisters were brothers over anymore. He most of the time is in his bedroom and me in the kids are in the house. He won’t have sex no more, because he says it hurts. It’s not like it used to be, no.

Participants reported that pain tolerance was random and they chose to stay at home instead of participating in family and social activities. The wives never mentioned doing social activities without their husbands. The isolation was interpreted as a discontinuation of activities that once were plentiful.

These dialogues regarding the theme of social isolation speak directly to the Biopsychosocial model of understanding chronic pain. It is evident how chronic pain has affected the social relationships of these families. One can also hypothesize that changes in the social environment would lead to internal changes that could help these families begin to grow past the narrative of chronic pain as a barrier to living fully.

Need for Support

The need for support was highly emphasized by both husbands and wives. Although participants discussed feelings of anger, fear, depression, and isolation, they also discussed the feeling of togetherness and support.

A husband said:

I need her to help me with things I can’t do any more like cutting the yard or working in and around the house. She gets me my medications for pain. We are close and she will help me. She helps. We are a family that helps each other. Yes, I do need her to help me.

His wife said:

When he is hurting I want to help them. My mother told me I have to help him now. Massage his back, or whatever he needs. You know? I don’t want him to hurt all the time, so I helped him. Yes, yes I get mad, I am feeling very down all the time, I need the help too from him and sometimes I get it. I do, I do.
Another husband said:

I need help from my family. I can’t work and I hurt all the time. I want to, but I need her to do it for me because I cannot. She gets my pain pills, and she gets me food. I need her to take me to the doctor visits, to wherever. I know she helps me. We are a close family.

His wife said:

I have to help. I wish he was a help like he did before. He would make sure everything was nice and I didn’t have to worry. Now that’s all I do. Worry. I do help when I know he is in pain, but I need help sometimes too and I don’t get it. But I help him.

It became apparent that the husbands with pain wanted their spouse to stay close to them so they could give the support they felt necessary. The wives felt anger and sadness, but agreed to help and felt like it was their job. They all stated that they had a desire for more support. These patterns of excessive togetherness and enmeshment are explained by Bowen (1976) as an inability to separate from the family. Pain may be the catch-all and sometimes is blamed for all problems in the family. Conversely, it is plausible that these family characteristics developed as a consequence of the pain rather than as antidotes to it (Turk et al, 1988). The narratives given by these couples about desiring support while also desiring to be freed from the demands of support mirror the theoretical debate between cognitive behaviorists. On the one hand, the husbands want support and the wives want to give it; this could lead to perceptions of support and increased health outcomes. However, the support itself could become a rewarding dynamic leading to increased pain behavior on the part of the chronic pain patient.

Discussion

By conducting this qualitative study, it was my desire to expand the discussion and clarify some of the ambiguity surrounding chronic pain, its origins, and its effects on family dynamics. It was my intent to allow the participants to speak. In their voices we heard that chronic pain was a struggle not only to the sufferer, but to the spouse and family. This was shown in four themes, feelings of emotional distress, thoughts on etiology, isolation from family and community, and need for support. The themes were entwined with one another but were separate entities reflecting the lived experiences of the participants. Listening to these people was fundamental to our understanding them, and allowed us to glance into their lived experiences in a fuller and richer way (Sandman, 1990). As researchers we must examine how to treat individuals and families with chronic pain.

While struggling with depression and other feelings of emotional distress, there was a sense of force and bravery to stay together. The families struggled on a daily basis to keep going. Struggling to keep going meant that families could no longer take normal activities for granted (Toombs, 1992). The loss of pleasure from normal life and the loss of activities previously carried out together can be seen as a threat to the family life.

The wives’ had to bearing the full responsibility for keeping the family together day in and day out. Consequently, depression and resentment replaced their self-care and compassion.
The men felt drained and isolated by their illness and perceived inability to be active. The wives felt isolated and a lack of support by the men’s illness and inability to help the family. Prominent in this study was the frustration the wives felt because of the men’s unwillingness to leave the house or give any type of support. Feelings of being angry at the men’s reluctance to give any type of support were interpreted as making partners feel isolated.

The present study elucidated wives feelings of a lack of understanding and fear. Knowing more about men’s pain syndrome would conceivably make it a little easier for them to offer support. Corbin and Strauss (1988) stated that it is equally important for the healthy partner to receive the same information as the other partner, so that the healthy partner could make sense of the illness.

Methodological Considerations

Riessman (1993) suggests that researchers should describe how interpretations were produced, and make clear what they did. I hope I have done this in this paper. Each person’s lived experience is different and cannot become another’s experience. The meaning however, can be shared (Ricoeur, 1976). It has been my main goal to adhere to the intent, meaning, and expression of the lived experiences of these chronic pain families in order to share these experiences with the mental health community.

Implications

It is my hope that the knowledge gained from this study might encourage researchers to engage in further study of families who have a member who suffer from chronic pain. I believe extension of this line of research can be accomplished by broadening the sample to various ethnic groups, income brackets, and educational levels. As in all effective qualitative study, data from each of these sample groups should be analyzed to the point of saturation in order to fully capture the lived experiences of diverse sufferers of chronic pain. Mental health professionals who treat chronic pain patients are encouraged to study the lived experiences of those individuals and their families. They are the experts, and they can give valuable insight into their worlds.
References


