LIVING WITH CHRONIC PAIN:
THE EXPERIENCES OF FAMILY MEMBERS

By

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ABSTRACT

Chronic Pain affects all aspects of a person's life. It can reshape his or her identity, the roles they play within the family system and it can affect their capacity to earn income, to name just a few examples. With such a wide range of changes, obviously family members are to expect some changes as well. To date, most of the research has focused on how the family can help the adjustment of the pain patient. Some research explores how the mental state of a spouse may be implicated. Very little has been done to explore how the family copes: what they see as the important changes, how they feel about and respond to having chronic pain in their lives.

In this research I spoke with six individuals who were close to someone with chronic pain. For some it was the first opportunity they have had to discuss their feelings on an issue that has been a major part of their lives for several years. Four wives and two daughters were interviewed. What came from their stories was a sense of loss that they were no longer able to participate in the same activities, in the same manner, together as they had before the onset of pain. There was a sense of loss in intimacy, shared lives, even in their dreams and expectations of the future. They reported that in some cases the ability of the pain patient to parent was undermined as the pain patient was overwhelmed by just getting through the day with their pain.

However, in each of their stories the families had learned to adjust and move forward in their lives. They found ways to make it work, even if it was not as they would have liked. Finally, they made suggestions for others who are going through similar struggles, identifying what helped and what might have helped had the support been available.

This study confirmed that the entire family system can be significantly impacted by chronic pain in one of the members of the family. It also draws attention to the constraints family members of chronic pain patients face in expressing their own experiences and frustrations – constraints that professionals in the field must challenge.

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INTRODUCTION

Chronic Pain

Chronic pain is a frequently occurring condition in Canada. The Chronic Pain Association of Canada has estimated that over 18% of Canadians are living with severe chronic pain. Other estimates suggest that the prevalence of chronic pain can be as high as 30-40 % annually in North America and Europe (Hoffman, Chatkoff, Papas & Kerns, 2007, Risdon, Eccleston, Crombez & McCracken, 2003).

Smith (2003) defined chronic pain as a "persistent or recurring pain that persists at least a month beyond the usual course of an acute disease or reasonable time for an injury to heal, and is not associated with malignant disease." The experience of pain is different for every sufferer, and the location or type of pain is also different. In some cases, the effect chronic pain has on the patient's life can be severe enough that it can be defined as a disability. For the purpose of this paper it may be helpful to define disability as the limited ability to perform major activities due to physical, mental or emotional health problems (Olkin, Abrams, Preston, & Kirshbaum, 2006). Chronic low back pain is the single largest cause of disability in our society (Osborn & Smith, 2007).

Chronic pain does not just affect the individual living with the pain; it inevitably affects all those around her/him. A significant body of research exists to suggest the role chronic pain has on all aspects of an individual's life (Soderberg, Strand, Haapala & Lundman, 2003; Romano, Turner, Jensen, Friedman, Bulcroft, Hops & Wright, 1995; Eccleston, DE C. Williams, & Stainton Rogers, 1997; Hoffman et al, 2007; Miles, Curran, Pearce & Allan, 2005; Evans and de Souza, 2008). It stands to reason that that each member of the family unit will also be impacted by the experience of pain in some way. Researchers have only started to investigate this dynamic, exploring just how the family is impacted by chronic pain. Literature studying family and the chronic pain patient focuses on three general areas (Roy, 1991); how the family affects the patient's pain behaviours, how family influences the recovery of the patient, and the consequences of chronic pain for the family. Most of the research in the latter category examines the influence of chronic pain on the mental health of the spouse (Schwartz, Slater, Birchler & Hampton Atkinson, 1990; Geisser, Cano & Leonard, 2005). Very little research is dedicated to the many other areas of the family experience. For example, their perceptions of the pain, the changes in activities they participate in as a family, or the perceptions of loss.

In order to understand the experience of the family, we must first explore how chronic pain affects the patient since ultimately, this will likely influence how the family responds.

Affects of chronic pain on the pain patient

Research indicates that there are significant changes experienced by the pain patient whether it is occupational, financial, social, psychological, medical and/or physical in nature (Miles, Curran, Pearce & Allan, 2005; Romano, Turner, Jensen, Friedman, Bulcroft, Hops & Wright, 1995; Richardson, Nio Ong and Sim, 2007). In this review, I consider sub-themes of identity and acceptance, and then discuss the broader themes that affect responses to pain: the invisibility of pain, and social norms related to work and gender.

Identity

A significant area of change for the pain patient is how their sense of self and sense of identity is affected by the pain (Werner, Widding Isaksen & Malterud, 2004; Miles, Curran, Pearce & Allan, 2005; Strunin & Boden, 2004). Because a person's life is affected in so many ways their identity is profoundly impacted (Aujoulat, Marcolongo, Bonadiman, & Deccache, 2008). Chronic pain affects an individual's sense of self, and arguably more provocative, their sense of who they might become: The latter contrasted with who they were to become prior to the onset of their pain (Harris, Morley & Barton, 2003). This can lead to feelings of grief and loss. Some individuals are forced to give up their careers, their roles within the family (i.e. breadwinner, caregiver etc), and for the first time they may be forced to depend on others for things and/or activities that they once took for granted. All these factors and the many that are not identified can have a significant impact on the patient.

Another indicator of one's sense of self relates to the fact that people tend to see themselves through the judgments of others (Miles, Curran, Pearce & Allan, 2005; Galvin, 2005). How these patients perceive their spouses' and family's beliefs about their pain will play an important role (Sharp and Nicholas, 2000) in how they cope with their pain. If those around them do not see the legitimacy of their pain this will cause unrest for the patient.

A person's parental identity is also influenced by those closest to them. Marshall and Lambert (2006) suggest that children provide a sense of relevance to their parents, and this is a fundamental dimension of parental identity. However, chronic pain can sometimes interfere with a pain patient's ability to live up to their own expectations of themselves as parents and thus, they may come to feel less relevant in the lives of those around them. This corroborates Marshall and Lambert's (2006) findings that a person's relevance is determined by their perception of the quantity and quality of attention they receive from those they deem significant others. A common behaviour for chronic pain sufferers is isolation and withdrawal from those around them, thereby reducing both the quality and quantity of attention they receive or provide to those around them.

Acceptance

Acceptance of chronic pain is a growing area of research. The literature supports that this concept of acceptance promotes a positive approach and improved functioning in chronic pain patients. Acceptance is defined as approaching life with chronic pain as a reality that requires adapting to rather than a situation that needs to be fixed or changed. In other words, it is the letting go of the ineffective coping strategies of trying to control the environment rather than adapting to the environment (Risdon, Eccleston, Crombez & McCracken, 2003).

Before a patient comes to understand the concept of acceptance they may believe that accepting chronic pain is accepting weakness. This too has a significant impact on their sense of self. They must overcome this belief of weakness (Risdon, Eccleston, Crombez & McCracken, 2003) in order to move forward.

In my professional practice with chronic pain patients I describe acceptance as a shift where patients move from a focus of what they *cannot do* with their pain to what they *can do* and how they *can do it differently* with chronic pain. For some, it is also about letting go of the search for a cure, focusing instead on what is, and moving forward.

The concept of acceptance is important as it is understood to be one of the most crucial indicators of successful adjustment to living with chronic pain (Risdon, Eccleston, Crombez & McCracken, 2003). Once a patient has accepted their pain they are more likely to improve their overall emotional and physical functioning. Behaviour is often dictated by our understanding of the world around us (Willig, 2000). Health related behaviour is no exception. If an individual feels that any active behaviour will increase pain symptoms they are more likely to avoid activities. However, if the individual feels that they can engage in enjoyable activities even though they have pain, they are more likely to experience a more enjoyable quality of life. With chronic pain, these activities may need to be done differently so as not to aggravate the individual's experiences of pain.

For some, the idea of acceptance may seem like chronic pain patients are being told to just get over it. In a lot of ways, this is true, but there is more to it than that. Acceptance is about letting go of the thinking patterns that may cause a person to repeat the same action over and over again, even though it causes them a great deal of distress. For example, someone with chronic pain may attempt to do an activity the same way they always have. Let's use cutting the grass as an example. Prior to the onset of pain an individual may have been able to cut their acre of grass using a push mower within a specified period of time. However, once they have pain this activity could cause them several days of pain and suffering if they do it the same way. The pain could cause them to feel extremely frustrated, and they may isolate in their room "recovering" for days.

However, if they were to accept that they could still do this activity if they approach it differently, they may take longer to do it, but they may not feel the same frustration and they may not require the days of recovery afterwards. Imagine what the atmosphere in the home may feel like in the first example, full of conflict, concern for the patient and possibly frustration for the other members of the household. It is important to note, that the journey to acceptance involves the grieving of losses that may have occurred as a result of the pain.

In essence, acceptance is about grieving one's old identity and embracing a new identity that reflects the changes in that person's life: This entails moving from a sick person's identity to a well person's identity. With chronic pain, it might also be the transition of living in a state of shame or self blame due to lack of medical legitimacy (as we will explore next) into a state of self-respect (Smith & Osborn, 2007). Acceptance occurs once an individual is able to redefine their identity in a positive and meaningful way while also incorporating the new limitations and restrictions as a result of the pain. Acceptance may also be understood as empowerment, as the patient comes to reject the passive sick role (Aujoulat, Marcolongo, Bonadiman & Deccache, 2007), and chooses to be more in control of his or her actions, and ultimately their pain experiences. Critical in this process is the importance of the individual to recognize that their identity is separate from the pain and their new identity can reflect the changes (altered abilities) without diminishing the person (Aujoulat et al., 2007).

Key social factors add complexity to the integration of a new identity: the invisibility of pain, and social norms related to work and gender.

Invisibility of Pain

Despite its prevalence, in our society, the ability to legitimize pain is far less common. In fact, in many cases of chronic pain, the mechanism for pain is not understood (Sperry, 2007; Rhodes, McPhillips-Tangum, Markham & Klenk, 2002). Chronic pain is an invisible condition in many ways (Richardson, Nio Ong and Sim, 2007). This invisibility of pain can make it very difficult for others to understand (Kugelmann, 1999; Soderberg, Strand, Haapala & Lundman, 2003) and appreciate the struggle that the patient is having. Most standardized medical treatments are usually unsuccessful in effectively providing sustained pain relief (Sperry, 2007). Therefore, over time professionals, even family and friends may come to doubt the legitimacy of the pain (Kleinmann, 1988 in Eccleston, DE C. Williams, & Stainton Rogers, 1997). This is only natural in a society that places the diagnostic ability of the medical profession in such high regard. If it cannot be proven, can it be real?

This issue of legitimacy can be significant when it comes to appreciating the various struggles that chronic pain sufferers may experience in their everyday lives. When those who are most significant in providing support fail to believe the pain exists, relationships become affected. Social support wanes over time (Meana, Cho, & DesMeules, 2004). Often times, there are secondary consequences to these doubts in the way of receiving proper medical care, income replacement and other benefits, and even their sense of self. Occasionally, the patient may be seen as malingering and as a result may lose benefits or risk being dismissed by medical professionals. In some cases, when medical professionals are unable to find organic signs to legitimize the pain they may turn to psychosocial explanations (Werner & Malterud, 2005, and the individual becomes responsible for his or her own suffering (Eccleston, Williams & Rogers, 1997). This may cause the patient to blame themselves intensifying feelings of guilt and shame.

Making sense of the world around us is a common tendency in North America. This need to understand remains true when it comes to one's own physical experiences. Many feel that they need to make sense of their pain symptoms and this can only be done through the discovery of the cause of their pain (Eccleston, DE C. Williams, & Stainton Rogers, 1997). Many people have a strong faith in the medical model (Rhodes, McPhillips-Tangum, Markham & Klenk, 2002), and when the medical model fails to provide answers faith dwindles. Even in the case of close family members who may be able to witness the pain and discomfort up close, patience and support toward the patient may diminish over time when they fail to see physical evidence or even successful medical intervention. People can have a hard time believing what they cannot see.

Studies have shown that spouses tend to favor physical treatment and interventions in the fight to manage pain because they believe that there must be a physical, curable basis for the pain (Sharp & Nicholas, 2000). So what happens when these physical interventions are not available or are unsuccessful as most standard medical interventions are ineffective at treating many forms of chronic pain (Sperry, 2007)? Studies have shown that how the spouse perceives the chronic pain will dictate not only how well they themselves will adjust but also how the pain patient will cope with their pain (Geisser, Cano & Leonard, 2005; Richardson, Nio Ong and Sim, 2007). Therefore, if the spouse doubts the legitimacy and severity of the pain, both the relationship and the adjustment to living with pain may be compromised.

Legitimizing pain and its consequences are a very difficult task. How successful the patient and the family are at legitimizing it will have a profound impact on how they cope and adjust to the pain. If the family has unrealistic expectations of the patient this may reflect a lack of validation (Richardson, Nio Ong and Sim, 2007), causing conflict and aggravation between the family members. The ability of the patient to accept his or her pain while still participating in daily activities will be put at risk. If he or she senses that the family is unsupportive and unbelieving they may engage in behaviours that increase their pain symptoms in order to participate, or on the opposite side of the scale they may engage in pain behaviours, like grunting, limping, moaning or crying, to give a face to this invisible condition. In the later examples the patient is exerting their energy to appear as a credible patient (Werner & Malterud, 2005) or may be using non-verbal cues to seek support or understanding (Sperry, 1999). Either way, the family and the patient are likely to be left with resentments and negative feelings.

The legitimization of the condition is also important for the patient's ability to move into a sick role (Richardson, Ong & Sim, 2007). In other words, without the legitimization of the condition the patient will not be as likely to be given exemption from participation in their traditional roles (i.e. work, household chores etc). The more difficult it is for them to participate in these activities, and the more conflict they experience as a result is likely to increase the challenge in sustaining their identity.

Social Norms regarding work

Identity is also influenced by cultural norms about work and productivity. Foucault speaks to how forces of power influence our behaviour (Foucault, 1994, in Callero, 2003). Such forces encourage individuals to maintain social norms of employment and to ensure financial contribution to society. Our self-concept is, in part, determined by our perception of ourselves as contributing members of society. This force can have negative consequences to a pain patient. To be a contributing member of society one's productive activities may include paid employment, and/or volunteer or domestic work. Individuals' perception of value in the activity as meaningful and/or contributory is fundamental. There are psychological consequences of not working and not feeling useful and productive. In some cases, the pain patient will force themselves to return to work with devastating consequences. Sometimes an early return to work or possibly engaging in work activities outside of one's restrictions can cause increased harm. As well, the effort required to get through the work day may consume all of their energy and attention, leaving very little left over for when they are at home or with their families. Either way, this pressure to work can impact how they feel when they are not at work, thereby affecting their behaviour, mood, engagement while at home and, inevitably their relationships.

Implications of Gender

It is important to consider the role that gender plays in how people adjust to chronic pain. Gender is one component of social identity, affecting the roles and responsibilities that individuals stereotypically hold in society. Obviously, chronic pain can dramatically alter these roles and responsibilities. How the individual responds to these shifts is important. The concept of hegemonic masculinity seeks to construct masculinity through the characteristics of "competition, aggression, physical strength, and stoicism" (Gray, Fitch, Fergus, Mykhalavoskiy & Church, 2002). All of these characteristics are threatened when a person becomes ill. Chronic pain prevents most men from successfully engaging in these types of behaviours without significant consequences to them through increased pain. Men are also typically the primary income earners, and when they are no longer able to provide for their families as they once did their sense of self is jeopardized. Finally, sexual performance, or more specifically, erectile difficulty, a common experience for men with chronic pain, can be the final threat to his sense of self and masculinity (Gray et al., 2002).

This is not to say that women are not also affected by chronic pain. Studies show that more women suffer from chronic pain than men, and because of the range of their responsibilities it can have more of an impact in their lives (Meana, Cho & DesMeules, 2004). It is proposed that this is because women tend to play so many roles within the family, from childcare, housekeeping, and paid work outside the home, just to name a few examples. However, as many of their responsibilities are valued differently (not economically), compensation for their responsibilities is less likely, whereas financial compensation for employment losses is more likely attainable. In addition, some studies have found that mothers typically have more difficulty with feelings of inadequacy in their role as a mother than any other area in their life (Barlow, Cullen, Foster, Harrison, & Wade, 1998). When someone has chronic pain and is unable to fulfill the roles they perceive to be important, feelings of inadequacy are likely to be magnified.

Chronic Pain and the Family

The family plays a significant role in an individual's sense of self (Soderberg, 2003). The importance of an individual's sense of self has already been established. The way in which a family provides, or does not provide support to the patient can have tremendous influence over how the patient copes with their pain (Soderberg; Sharp and Nicholas, 2000; Richardson, Nio Ong & Sim, 2007). One possible rationale to explain this significant relationship is simply based on the obvious correlation of quantity of time spent interacting with each other thus influencing the behaviour (Romano, Turner, Jensen, Friedman, Bulcroft, Hops & Wright, 1995) of those in the relationship. All of these interactions will allow the family to gain an understanding of the patient's limitations and abilities (Richardson et al., 2007). Geisser, Cano and Leonard (2005) have found that the outcomes for the patient are improved when families are involved in treatment interventions. This explains why so much of the research focuses on the family and the role families play on how the patient copes with their chronic pain. However, this is another example of how the patient's coping is the emphasis, not how family members themselves are coping.

When a member of the family is touched by chronic pain or chronic illness the family has many consequences to consider. They will be consumed by thoughts on how the condition will impact the patient, but they will also have thoughts on how the condition will impact the rest of the family (Ohman & Soderberg, 2004). They have reason to be concerned. There have been a number of studies that have shown that family members of chronic pain patients are at increased risk for developing mental or physical health problems (Ohman & Soderberg, 2004; Geisser, Cano & Leonard, 2005) or increased distress themselves (Sharp & Nicholas, 2000). One explanation for this may be that people in a care-giving type role tend to put the needs of those around them above their own health and well being (Eriksson & Svedland, 2007).

In some cases, spouses report a sense of helplessness when they are unable to play a role in aiding the patient to cope with his or her pain (Sharp and Nicholas, 2000). Sometimes the only role they can play is that of an advocate (Soderberg, 2003) and while this can be a vital role, the helplessness in relation to the pain itself may remain.

Chronic Pain and Intimate Relationships

Chronic pain can have a major impact on intimate relationships. In many studies, marital and sexual concerns were the most reported complaint (Smith, 2003). Sexual problems are very common for people living with chronic pain (Smith, 2003) or chronic illness (Soderberg, Strand, Haapala, & Lundman, 2003). Libido, performance and experiences of sex are all affected when living with pain. Often these struggles relate to side effects of medication, mood and the nature of the current relationship. Couples often report decreased emotional intimacy, and this may play a role in decreased physical intimacy.

There is a positive correlation between marital conflict and negative pain behaviours (Geisser, Cano & Leonard, 2005). Many factors play a role in this correlation. When an individual is experiencing increased pain they are likely to engage in more conflict, as they may be more irritable, less patient and communication is more strained. Increased conflict is likely to increase pain experiences. Another possible explanation is that pain behaviours may be one way that the patient asks for help or indicates difficulty, replacing effective verbal communication with less effective communication styles (Sperry, 2007).

Although research is just starting to look at how spouses cope with living with chronic pain this is a significant area of study. One study found that when women are coping effectively in their every day life, this contributes to improved self-esteem and the belief that they have more control over difficult situations (Eriksson and Svedland, 2007). This is incredibly important in the case of chronic pain where it has been found that couples may feel as though they have less control over their lives, with the illness or condition taking control instead, dictating what they can and cannot do. In some cases they are not discussing these changes or their feelings and this can lead to feelings of isolation and loneliness.

Loss experienced by spouse and family

In their study, Soderberg, Strand, Haapala & Lundman (2003) found that spouses experience many forms of loss. They have less time for meeting their own personal needs, which may include leisure activities. One explanation for this was the lack of time available to them after the shift in roles and responsibilities at home. Often these changes occur when the pain patient is less able to engage in household tasks, requiring a redistribution of tasks within the home. These may include chores such as cooking, dishes, and cleaning, but may also include parenting tasks such as carpooling, discipline and care giving. In addition, these increased responsibilities could impact their experiences of personal autonomy and independence (Smith, 2003). In many cases, financial changes occur, especially if the patient is unable to maintain previous level of employment (same job but less hours, modified job with less pay, or complete loss of job).

Studies have found that families as well as the patient can be affected by many losses, such as consequences of the condition, loss of aspirations, even a loss of freedom (Eriksson & Svedlund, 2006). This is not uncommon to those who have chronic pain. Many find they are unable to do many of the things they had been able to do before the onset of pain. As a result, occupational, recreational and financial changes may occur and these can have a domino affect on other areas. The security and vision of the future can be altered, and this can have a profound impact on not just the patient, but their immediate families as well.

Some studies have suggested that pain patients tend to be less active in their pre-existing roles in their vocation, family, recreation and social areas (Romano, Turner, Jensen, Friedman, Bulcroft, Hops & Wright, 1995). For many, there can be decreased social activities (Soderberg, Strand, Haapala & Lundman, 2003; Miles, Curran, Pearce & Allan, 2005). As a result, the spouse may feel lonely (Geisser, Cano & Leonard, 2005). These changes will have an impact on experiences of marital satisfaction (Gessier et al., 2005).

Effects on Children

When you consider the estimates of how many people are living with a chronic pain condition in North America, one must also consider how many of these adults are parents. One estimate (Mazur, 2006) suggested that as many of 21% of children under the age of 18 had a least one parent with a disability. Unfortunately, this number does not reflect the number of parents with chronic pain as the cause of the disability. In fact, there is very little research on how parental disability affects the children, and even less on chronic pain. Most of the research focuses on the situation where a child has a pain or disability, and how this affects the family. Some look at how serious or fatal forms of chronic illness of the parent affect the rest of the family, and specifically children. But the research on parental pain on children appears to be minimal.

From the research that does exist, there is evidence that children with a parent with chronic pain are more likely to experience adjustment problems. These are manifested through anxiety, depression, social or school problems, behavioural problems, as well as pain similar to their parent's pain (Evans & Keenan, 2007; Chun, Turner, & Romano, 1992; Evans & de Souza, 2008).

Some studies have looked into how the gender of the parent affects the child's adjustment. One study found that adolescent children were more affected when their father has chronic pain rather than their mother but the affects in younger children had quite the opposite result (Evans and Keenan, 2007). They suggest this is because women are more likely the primary caregivers and nurturers of younger children and the impact would be more significant as a result. Another suggestion is that perhaps in the case of a father with pain, the mother may be more of a buffer for the children, minimizing the impact on the children.

Martial conflict is believed to have a significant impact on the child's adjustment as well (Chun, Turner, & Romano, 1991). Many people with chronic pain report increased marital conflict. In addition, we cannot ignore that the financial status of the family may also be changed if a parent has chronic pain and is no longer able to maintain stable employment or the same number of hours at work. This can add to stress within the family, if their overall financial security is threatened. The children's ability to participate in extra-curricular activities may be jeopardized if the money is not available. This may potentially explain why some studies have found children are more affected by their father's condition as they get older.

The research that explored the effects of having a parent with a disability found that there were positive consequences, not just negative consequences for the children. For example, Mazur (2006) identified many positive consequences including: increased emotional closeness between family members, children learning responsibility, families being forced to re-evaluate and simplify their lives, and children learning to depend on more adults. I have heard many chronic pain patients report many of these same benefits in my own professional practice.

The values held by parents differ around the world and are influenced by culture (Bornstein, Tamis-LeMonda, Pascual, Yaynes, Painter, Galperin & Pecheux, 1996; Keller, Lamm, Abels, Yovsi, Borke, Jensen, Papaligoura, Holub, Lo, Tomiyama, Su, Wang, & Chaudhary, 2006). However, in the context of chronic pain the *values* of parenting are not as significantly altered as the *behaviours* that are valued by parents. In other words, parents with chronic pain may be unable to participate in physical activities with their children (rough housing, sports etc), they may not be able to continue with coaching or teaching of activities, or due to their mood or cognitive difficulties they may be unable to help with homework, and in some cases they are not able to physically care for their children (carry or hold them). How individuals value and perceive these changes as an individual experience are difficult to generalize. Not everyone with a back injury will mourn the loss of not being able to coach little league hockey, but for those who visualized themselves participating in their children's life in this capacity, this can be a significant blow, a tremendous loss.

Support

When considering chronic pain it can be difficult to find a way to define the role that family plays when supporting the pain patient. Once the individual has adjusted to their condition they are not as likely to require intensive care giving as some forms of chronic illness do. Therefore, standard definitions of care giving do not seem appropriate. However, they do require a form of care, more in the way of emotional care (Richardson, Nio Ong and Sim, 2007). How the family advocates, legitimizes and protects the identities of each member of the family can give great insight as to how the family adjusts to living with chronic pain in the household. Structural Family Theorists would consider how the family maintains balance when the family system is disrupted by one of its members having chronic pain (Nichols and Schwartz, 2008). This legitimizing and protecting behaviour is defined within emotional caring.

Inspiration for this study

A great deal of research identifies how chronic pain affects all areas of a person's life and by default, the lives of those around them. Even though the research supports the fact that families play a critical role in how a patient copes with their chronic pain, and they are at increased risk to develop problems themselves, there remains very little help available in the health system to address these issues (Ohman and Soderberg, 2004).

In my professional practice, chronic pain patients often express significant feelings of guilt and sadness that they are unable to be the parent they wanted to be. They are unable to engage in many activities with their children. They sometimes feel shameful that their spouses and children take on roles and responsibilities that they feel are theirs. They report increased irritability and many endorse significant periods of withdrawal and isolation from the rest of their family. In fact, it is hearing these feelings of guilt and sadness that prompted me to explore how the family perceives the impact of chronic pain in their lives. I was curious to investigate whether or not the family perceives these changes with as devastating emotional reactions as the patient. I sensed that perhaps the family was coping more positively than the patient felt they were. This is not to say that I believed the families were not impacted, but rather they were not putting in the same emotional investment into calculating the losses of missed opportunities that the patient was.

In addition, I wanted to provide an opportunity to family members to have their voices heard, while validating their experiences. There are virtually no supports available to the family members of chronic pain patients. In fact, there are very few resources available to chronic pain patients themselves outside of the medical model. Therefore, family members quickly learn that the pain is the patient's problem to live with, not theirs. I struggle with this philosophy first hand in my practice. It is difficult to encourage family members to come in for family sessions in the Chronic Pain Program. I wanted to learn more about why it was so difficult to get them engaged in a program that was attempting to offer help in an area that they might not have been offered help in before. All of these questions prompted my desire to do a study looking at the effects of chronic pain on the rest of the family. I wanted to hear their voices, their struggles and their stories.

METHODOLOGY

As noted, a gap remains in literature and practice regarding how family members interpret the impact on their own lives of living with a chronic pain patient. Through qualitative study and analysis, I have sought out to speak with family members currently living with a chronic pain patient to address this gap. The goal was to engage in a qualitative study with a small sample, interviewing them individually.

Recruitment

Initially I had gained ethics approval to recruit participants through the Chronic Pain Management Centre (CPMU), Hamilton Health Sciences. I am employed as a full time Social Worker within this agency. To address potential conflict of interest, the recruitment (and data collection) was conducted while I was on a leave of absence. As such, I had no professional contact with the chronic pain patient or the participants at any point during the course of their treatment.

Recruitment strategies included posting recruitment posters (Appendix A) throughout common areas of the CPMU. In addition, I attended weekly orientation and educational sessions to present my research study to chronic pain patients and, in some cases potential participants who would also attend such sessions. When potential participants were not present, I invited the chronic pain patient to share the recruitment poster with their family members.

After six weeks of this recruitment method, I had only recruited one participant. Therefore, after receiving additional ethics approval, I began to utilize my informal social network for seeking potential study participants. This network included colleagues, classmates, friends and family. I composed a general letter (Appendix B) asking everyone in my informal social network to pass on information of my research study to anyone who might be appropriate.

Fortunately, word-of-mouth proved a fruitful recruitment approach: I initially had nine potential candidates. Difficulty in communication to set up an interview eliminated four participants. In the end, five consented to participation in the study. I reviewed the Letter of Information (Appendix C) with each participant prior to having him or her sign the consent form. With five participants from the latter and one from the initial recruitment method, my study included six participants.

Sample

All of the participants were women; four were wives and two were daughters of a chronic pain patient. The duration of pain for the chronic pain patient ranged from 15 – 40 years (mean = 19.42). The mean age of the wives was 53.75 and the mean age of the daughters was 34.5, ages of participants were between 32 and 59 years old. Chronic pain conditions comprised various diagnoses including: back pain, shoulder pain, Reflex Synthetic Dystrophy (RSD), and knee pain. The mean age of the chronic pain patient was 57.4.

For the purpose of the study the terms "wife", "wives", "spouse", "daughter(s)" and "participants" will refer to the family member that was interviewed for this study. The term patient or chronic pain patient will refer to the individual in the family unit that has chronic pain. This study analyzes how the latter's chronic pain impacts the lives of participants.

The names referred to during the paper have in fact been changed to protect confidentiality of participants and their family.

The Interviews

I completed six semi-structured interviews. Four of the interviews were with wives of chronic pain patients, and the remaining two were with daughters.

Each interview was approximately 40 – 60 minutes in duration and followed a guide (Appendix D). Only the participant and I were present during the interview. The interviews were recorded on audiotape. All of the questions were open ended and were structured so as to probe participants to describe, from their perspectives, the effects that living with someone with chronic pain has had on their lives. In the case of the wives, they were also asked to speak to how the children may have been impacted if they felt comfortable doing so. This question was added on the suggestion of the first participant who felt that this was an important area to explore, and at the time I was unsure if children would be among those to volunteer to participate. The interviews took place in an environment that was convenient and comfortable for the participants. Five interviews took place in the participant's home, and one took place in a small room at McMaster University. Once completed, the interviews were transcribed by a third party transciptionist or by myself. In addition, participants were offered and accepted a summary of the study results once completed.

Ethics

All participants consented to participate in the study and were reassured that they could withdraw consent at any time during the study. Confidentiality was explained and referred back to, as participants were sensitive to self-disclosure. The McMaster Research and Ethics Board approved the study, including the change in recruitment.

Analysis

Following transcription of data, the interviews were read several times as suggested by Miller and Crabtree (1999). The first reading was to gain an overall understanding of the interview. The second reading was to explore how the participants spoke of themselves, the patient and others throughout the course of the interview. The third and subsequent readings were used to code themes as they presented themselves.

Some themes were predetermined by my original interest in doing the study but many more themes were identified as I reviewed each interview. In some cases, I became aware that many, if not most, of the participants spoke of similar issues and this would then become a theme. What was especially interesting was not just *what* they talked about but also *how* they talked about those issues. Originally I categorized the data into over 12 themes but found that many of the themes were closely related, so I grouped these into broader areas of discussion.

FINDINGS

The participants were asked to speak to the greatest changes in their lives since the onset of the pain condition. They spoke a great deal about changes in activities; opportunities missed, and altered intimacy. Some spoke of frustrations, while others spoke of how fortunate they were that things were not worse. All of them spoke of how their husband or mother made the decision to continue living their life even though they had pain, although how they decided to do this was different for each individual. The following themes and sub-themes emerged from the analysis: feelings of loss in the area of family life and in intimacy; the impact on parenting, the unspeakability and denial of identify for family members, as well as a look at their recommendations to other families.

The Idea of Loss

Loss is simply understood as no longer having something that once was available. The dictionary defines loss as the "failure to preserve or maintain" (dictionary.com). This is a useful definition in understanding loss as it pertains to the lives of chronic pain patients and their families. Often pain interferes with the patients' ability to participate in various activities, functions or events, thus they fail to maintain the previous lifestyle that once was shared amongst the family. Eva captures this well when she describes the greatest change in her life:

> "I guess having to change the things that I loved to do, I love to dance so he will dance but he can't dance quite as much as I can. We love to do things.... just a complete change in what I had envisioned we would be doing."

Living family life in relation to pain

The realization that many valued activities were made unbearable for the patient by pain was approached by participants in different ways.

One approach was to continue attending activities and events like they would have before, giving the patient two choices, to attend and participate (often with pain), or to attend and be an observer to the main activity. Eva demonstrates both:

> "... So we did everything, and again I think it's his personality. He certainly wasn't going to sit back or admit that there was a problem here. So he walked, even though it may have killed him."

> "When the boys were smaller we actually did go on a couple of ski holidays. I convinced him. I said lets go somewhere. *What can I do?* Not that he was whinny or anything like that, never was. Well there is a bit of a workout center where we're going, you can have supper ready for us when we got home and all that. So I would go skiing with the boys. "

Another approach was to participate in activities as a unit, involving the patient but modifying the activity, or duration, in order to minimize the discomfort to the patient:

> "Our recreation if you will was going out for a coffee and maybe going to a friends for dinner but always limited in time, we could never stay long because of his pain." (Beth)

> "So I guess it was taking a look at what are the things that we can do and it changed everything for us because what can we do? Where can we go?" (Eva)

Finally, the family member may choose to go ahead and participate without involving the pain patient. Sometimes they found other people to act in place of the patient, and this seemed to create a satisfactory experience:

> "So some friends were going to the Greek Islands and wondered if we'd like to come along. And I thought well this is perfect because if he can't do something then I've got somebody else to do something with, I don't have to just, he doesn't have to worry about me being someplace on my own." [Eva]

> "She (daughter) used to like to wrestle. When she was younger she would wrestle with her dad and it was okay but as she got older, wrestling with her dad wasn't so fun anymore because she could wrestle with the good big boys but she couldn't do it with her dad (because of his pain). And her dad and her...that was daddy's little girl. She would go to a friends house and wrestle with their dads or wrestle with me on the kitchen floor." (Caren)

In most cases, however, pursuing activities without the pain patient involved some sense of loss or struggle. Even in the quote above, for instance, while Caren was glad her daughter found other people to enjoy an activity with, it is clear that not being able to wrestle with her dad was a kind of disruption to the father-daughter bond, an erosion of her special status as 'daddy's little girl'. Other participants elaborated on the tensions and losses associated with separate activities:

> "I can't travel the way that I would like too. I would like to travel with him of course. I would like to go to Europe, I would like to do all these things that you hear all these other people doing and unfortunately, I can't. So I travel with my mom, who is getting older

> and umm, one day I'll just take off and do what I want to do. It would be nice to go with him." (Beth)
>
> "I just kinda felt guilty because we would want to, you know, maybe head out for a walk or go do something and she wouldn't be able to do that." (Michelle)
>
> "I would organize events for my social group and like a barbeque or hayride but he would not get on the hayride because it would hurt his back, right. So I'm thinking, oh God, I organized this thing and I can't even go on with my mate, he's back at the barbeque you know, cause he can't stand to do anything so that really.... holding me back and I would be there alone" (Jane)
>
> "So I am doing things alone." (Jane)
>
> "I would say the hardest part I think, is the fact that we lead two separate lives." (Beth)

Understanding this concept of "separate lives" as a loss can be confusing. One of the foundational understandings of healthy relationships is that individuals within the relationship are free to pursue their own interests. However, in the case of chronic pain, family members perceive themselves to have no choice but to pursue certain activities alone as portrayed through the comments above. Their choice has ultimately been removed due to the onset of pain and thus, making it difficult for patient participation in these activities. This lack of choice is the actual loss.

In many instances, then, families were able to find ways to continue shared activities. In some cases, however, participants in this study described giving up shared activities entirely, or pursuing these activities as individuals, and finding themselves – with a sense of loss, regret and sometimes guilt – 'living separate lives'.

Loss of Intimacy

Other significant areas of change identified by the wives in this study were changes in intimacy and sexual intercourse. Beth effectively cut to the chase summarizing her thoughts about sex and chronic pain:

> "And don't forget too that people with chronic pain, um, their sex lives are probably non existent. With his pain he is impotent."

There are multiple reasons why there might be changes in this area. For some men with pain their performance is affected, causing impotence, as Beth just points out, and for others their endurance and ability to enjoy the activity is limited as Jane discusses here:

> "Sex life, it's affected that, because endurance or whatever, or just positioning or whatever, with the pain it's been affected."

Beyond the physical limitations that are placed on the couple as a direct result of the pain, there are emotional factors as well. Even when a couple seeks medical help to overcome the physical barriers of sexual intimacy there is an emotional cost. The partner is left with a difficult choice: engage in a mutually enjoyable activity but then have to watch their lover "recover" from the experience, as Caren discusses here:

> "It was my guilt that I was going to hurt him. We went to the doctor and asked about how we could have sex with chronic back pain. It still didn't take that guilt away for me. He would tell me it's ok but afterwards he would go and take pills. And that would make me feel guilty and I would have this amount of pleasure and then have to watch him take pills. It bothers me."

Or the partners would abstain from a once mutually enjoyable activity, as Beth describes:

> "I think when you're younger that is a very important piece and then as you grow older you realize it's not that important anymore. I mean we are very close but...A lot of couples our age, that's their choice anyway. But then there are a lot of couples that it isn't their choice."

Responses to the changes in intimacy within the relationship varied among respondents. In a previous quote, Beth appears to have made peace with not having sex as a part of her marriage. As she ages, she is realizing that other aspects of the relationship are more important. However, in the case of Caren, she does not like the man he becomes when medicated, so having this as a consequence to sexual intimacy is troubling for her. Yet, they both feel that this aspect of their relationship is important enough to seek medical advice.

It is important to acknowledge that during the interview no one was asked if sexual intimacy had been impacted by the pain in his or her lives. Yet, three of the four wives volunteered this as one of the many ways their lives had been impacted. There are a range of ways of understanding their statements. First, the couple perceives this change as significant in their relationship. Or, alternatively, social expectations infer that sexual intimacy is an important element of marriage, causing tension for relationships where this might not be carried out. Ultimately, it is important for the couple to discuss their feelings regarding the role sexual intimacy will play in their relationship. For some, they will agree that having this intimacy is important, for others, they might agree that it is not as important as other elements of the relationship. It is when the couple does not share the same vision that problems will ensue.

When looking at intimacy it is important to acknowledge that pain does not just interfere with sexual intimacy but more overt aspects of intimacy as well. Often the couple no longer sleeps in the same room or shares the same bed:

> "We don't have that connection (sex) in our relationship, and that's fine, but there's not the connection that you see. For example, my aunt and uncle are almost in their 80's and they still sleep in the same bed. I don't have that, we don't have that." (Beth)

As well, common interests and activities change as a result of the pain. Many activities and moments that were once shared as a couple have been altered, they may continue to engage in these activities but there is the physical toll on the pain patient and there is likely an emotional toll on the family member. Or perhaps they abstain from these "couple" activities all together:

> "So we don't do those things (visit a friend's cottage) like that as a couple". (Beth)

Ultimately, these women clearly identify how intimacy in many different ways is affected as a direct result of the pain.

Pain and Parenting

Four wives/mothers and two daughters were interviewed and asked if the pain had any impact on the patient's parenting. Based on these interviews the pain appeared to affect the families in two ways: the emotional state of the pain patient affected the parenting partnership (wives' perspective), and the pain affected activities the patients were able to do with their children.

An interesting factor that became apparent as the participants shared their stories was their reluctance to speak of the patient in the negative. In fact, they all appeared eager to share how great the patient was. When they spoke of the patient in a less than positive light, they were quick to justify those negative issues. I'll begin to look at this tendency here, but will look more closely at this later, in the section on Unspeakability.

Influence of pain on the parenting partnership

All of the wives seem to agree that the pain influenced how the patient was able to parent. What was unique to the wives' perspective was the idea of the patient feeling overwhelmed, and therefore playing less of a role in discipline or decision-making causing the wives to feel isolated or alone as parents. Eva highlights this feeling as she reflects on her own experiences:

> "I suspect that because they are in a lot of pain, it's too much for them - like having kids is hard work and it's constant work and

> when you're not feeling well all the time, it's really difficult and I'm sure a lot of people would feel that they were doing the job alone because you know the person with the chronic pain just can't deal with that on top of the other stuff they're dealing. That puts them over the top."

It is easy to understand how someone might feel alone in their parenting if the other parent is unable to cope with the added demands of parenting to their already overloaded demands of dealing with the pain. There is a physical toll as well as an emotional toll. The changes in how the patient engages in activities within the family were discussed earlier. However, the added demands of conflict management and support contribute to the emotional toll on the spouse. This will be explored later.

If we look back at Eva's previous statement, it is interesting to note that while she is discussing her thoughts on the subject she appears reluctant to offer criticism of her partner without justifying the reasons behind it. More interestingly she starts to speak in general terms, no longer speaking of her own personal experiences or situation. She never actually says that she herself felt like she was parenting alone, rather she infers others in similar situations might. Later in the same conversation she states "But as I say, they know who's the boss in the family so to speak". This latter sentence suggests that regardless of how she might feel – or how fully she has assumed the roles of both parents – the kids know that dad is still in some way 'in charge' of the family. How the kids come to this understanding is unclear.

In the quote above, Eva considers how much work is involved in parenting and how this work is just too much for a chronic pain patient to handle when considering all of the other battles they must overcome. However, Jane is not so sure, and starts to question whether it is the pain or simply their different approaches to parenting that is causing the conflict:

> "There was just no follow through. That's what I'm saying, and I think it was because, I think a lot of it was because he just wasn't feeling up to it, maybe, or it could have been strictly his parenting, I have no idea really, knowing for sure."

Jane was able to relate how the differences in parenting caused significant conflict within the marriage.

> "I think that had a lot to do with our problems with our son, it caused disagreement in the way we thought he should be raised, but I think a lot of it too was he just wasn't feeling up to dealing with a lot of stress and he'd just kind of give in."

While Jane does consider the possibility that her husband's actions (or inactions) was simply how he parented, she seems reluctant to make him fully responsible, or even to express her own dissatisfaction in a direct way. Instead she explains the conflict as the patient being overwhelmed, taking responsibility and blame off of the patient and placing it on the pain.

Pain affecting Activities with the Children

I discussed earlier how the participants identified the lack of participation in activities as a significant loss to them. This remains true in the case of children, but perhaps not as obviously. When the participants were asked to speak to how the pain impacted on the children, or on themselves as children in the cases of the daughters, there was no consensus. In some cases they felt that the child and patient missed out because the patient was not able to participate in activities with the children. In other cases, the patient participated regardless of pain. Interestingly, there was no discussion about how the child felt having the parent participate in activities while they were in pain, or if they were even aware of the situation.

Caren was able to speak openly about how she saw her daughter and husband missing out as her daughter grew older and was able to do less with her dad.

> "The family as a whole is impacted. I find that kids are affected just as much as the parents. Our daughter had a lot of things growing up that she couldn't do with her dad because of his chronic pain."

Also, Eva briefly suggested that her kids may have missed out, but was quick to identify how this did not impact his role or identity as "the father" in the family.

> "They loved to do things so I know they would have enjoyed having dad there whether it's water skiing, snow skiing, or whatever, I think they've had a really good role model for dads. Even though he couldn't do that, he was still the center of the family and he was the man. You know they, I think they just have great respect for him. I know they do. He's the greatest."

Eva suggests, then, that while the kids may have missed their dad's involvement in specific activities, they did not 'miss out' on his fathering.

In Jane's situation, her husband ensured that the pain did not interfere with the interests he shared with his son.

> "I don't know if it was the chronic pain that impacted our son, certainly not with anything that he was doing with him, cause he was always there with the hockey and shooting the puck down the road anyway. Whether he was in pain or not."

It is possible that the pain impacted their son more indirectly through the inconsistencies in parenting and increased marital conflict that Jane described earlier. It would be interesting to explore how having the patient involved in the activities described here affected his pain levels, and, in turn, his mood and ability to handle conflict. In other words, by participating in these activities, he likely experienced an increase in pain symptoms. The increased pain was already described as having contributed to his feelings of being overwhelmed, possibly further fueling the conflict and different approaches to parenting.

In all of the interviews where the wives discussed their children, they appeared never to allege any direct feelings of loss on behalf of their children or partner. Instead, they infer that the children and their injured parent would have liked to do more. Perhaps the daughters would speak directly to their feelings? Michelle was able to identify a few moments in her life where she felt that she had missed out on an activity with her mom, but those occurred as she became an adult, not as a child. She denied ever feeling like she missed out when she was a child.

> "I don't recall like as a child (being impacted). I can think back to when she wasn't able to go for a walk in 1992 (while in university). But as a young child, no."

However, this is not to say that there were never times that Michelle did not notice that her mother was struggling with pain:

> "You could see that she would be in a lot of pain after they would jog and you could see that her knee would start giving out sometimes actually. So like on stairs and she was starting to have like falls and stuff. I would be over visiting or something then you know, I could actually see it giving out and you could actually see it swelling up sometimes too. You could see she's in pain."

There could be a couple of explanations regarding the difference between adulthood and childhood in this particular case. Although her mother had been suffering from pain since she herself was a teenager, it had really become more significant in the last 15-20 years. Another explanation may have been her mother's attitude to life "She doesn't complain, she just does". A third explanation is the reluctance to speak negatively of those closest to us, as I will explore below.

Unspeakability

While reading through the transcripts and looking specifically at how they spoke of themselves and the patient, it quickly became apparent that there was reluctance to speak of the patient negatively. I spoke of this briefly in the previous sections but will look at this in more depth here. This finding is more difficult to talk about, as it is the absence of a theme rather than the occurrence of a theme.

There appears to be general understanding in our society that it is not appropriate to speak negatively of others, especially of the sick. However, these participants seem reluctant to acknowledge any negative or unkind feeling on their part either. They avoid all talk of resentment, frustration or sadness on their own part. One could speculate that they are so used to not having anyone to talk to about this situation that they fail to recognize their own experiences, thoughts or feelings. Another potential explanation is that is just isn't polite to think ill of others, especially for women or caregivers whom comprised the subjects of this study.

Rachel highlights this conflict well. Rachel attended the interview a few moments late and was quite frazzled. As a result she was closer to immediate feelings of frustration as she felt it was her mother's fault she was late. However, throughout the interview she apologized for any suggestion of negativity. When asked whether she has a forum to talk about her feelings she responded:

> "Well no, because part of the problem is what are you going to do? I resent my poor mother who is in a great deal of pain and she had done so much for me but she is driving me crazy. What do you say?"

Her response speaks directly to the unspeakability of her situation. She feels uncomfortable speaking of her frustrations in light of the fact that it is her mother, in addition to someone who is in a great deal of pain.

How does she begin to open up about her feelings without subjecting herself to judgment by others?

Her response could give great insight and understanding as to why there is a reluctance to speak poorly of the patient. One might infer that our society would look poorly on anyone who has the courage to speak of negative feelings as it applies to a difficult situation. In all of the interviews there were many examples of opportunities lost, challenging times, and sacrifices made but participants rarely made reference to their feelings in response to these negative events. Instead, they would point out the difficult challenge the patient was faced with, almost minimizing their own experiences.

This reluctance is understandable and might not warrant further exploration had each of the participants not gone out of their way to highlight how wonderful the patient was in their eyes. This is not to suggest that the participants should feel negative, resentful or frustrated toward the pain patient. However, they seemed to almost go ‘overboard’ with praise, sometimes appearing to excuse the pain patient and erase their own frustrations at the situation. For example, the participants would occasionally offer alternative explanations for the patient’s behaviour, suggesting that maybe it was not just the pain that was to blame, as Beth does here:

> “I also think that people with chronic pain tend to become grumpier and he doesn’t have the patience. And it’s all about him, and he

> tends to fly off the handle more. How much of that is lack of testosterone and being older, and how much of that is the chronic pain – I don't know."

Yet again Beth talks about "people with chronic pain", reluctant to directly speak negatively about her husband, as we have identified other participants as doing earlier. She also explains his behaviour as being directly related to pain or other medical reasons, rather than placing it directly on the patient.

Denial of Identity

An interesting finding in this study was how rarely participants had spoken about their own experiences as family members of people with chronic pain prior to their participation in this study. Related to this, they were not at all sure that their own situation merited the attention of a researcher.

There are so few resources available specifically to the family of a pain patient. All of the resources are geared toward the patient. Families are involved only so far as to understand the patient better or to improve support to the patient. As a result, the family members do not get acknowledged as having any concerns or identity of their own. In other words, living with chronic pain does not become part of their identity even though it appears to have a profound impact on their lives. The effects of this neglect were obvious in the recruitment and interview stage of my study. For example, with most of the participants I needed to reassure them that they were appropriate participants for my study. In a couple of cases they contacted me only to suggest I speak with the pain patient or to apologize for not participating as they felt they would have nothing to add. I would have to clarify that I did not want to speak to the patient, that I was only interested in their voice. They would counter by saying they would agree to meet with me but did not know if they would be helpful. Eva summarized this well in one of our earliest interactions:

> "I'm not sure what I can add to your study, but I would be happy to meet with you."

Obviously each person I met with was helpful, but this speaks to pattern of negating his or her voice and experiences.

During the interviews the same observations were made. Some of the participants stated that it was the first time they had spoken about their experiences. Beth admitted that although she had spoken to friends, the more personal aspects of her situation had remained unspoken until now:

> "You're probably the first person I have ever really told a lot of these things too."

In some cases they explained how they would attempt to relate to peers whose spouses were going through a major health event but the uniqueness of their own experience was not acknowledged. Eva related her experiences to a friend and felt understanding:

> "I have a girlfriend whose husband has had a heart attack so she's in that same sort of boat of being very careful or very aware of his health and wanting to make sure he stays as healthy as he can. So we probably talk in those terms so she understood I think."

There can be a lot of misunderstanding or a lack of empathy when it comes to chronic pain. To the patient the pain can be all encompassing but to an outsider it is invisible, especially if the patient avoids pain related behaviour giving the misconception that they are fine. Because the pain can go on for years and is not observable to the naked eye, there may be less support and compassion offered to the patient and especially the family. If the patient themselves is not seen to have a significant or legitimate problem, then it stands to reason that the family's struggle would not be seen as legitimate either.

Michelle highlights how her mother's behaviour was often confusing to others:

> "It's very hard, I think, for some of the family members where they just didn't want to get it because she looks so healthy and she's a model of fitness and the whole bit, like she puts all of us to shame. She's so active and everything."

Eva describes her husband in a similar way:

> "He's extremely proud. So he's certainly would never let on that this is an issue. You know, he just sort of down played it."

Jane takes a slightly different approach, explaining how her husband appeared to be having a difficult time coping but continued to engage in activities. Note how she is unable to do this without placing some sort of positive explanation on it.

> "So he has continued to work right until he retired, in a lot of pain. So you know, he did what he did for the family and he never complained."

What is not talked about in any of the above situations is the consequences of the patient's attitude or approach on the rest of the family. For example, Jane highlights how he continued to do everything, like work, even though he was in pain. But in another part of the interview she discusses her frustration that he lies in bed whenever he is at home:

> "...seeing him lay down all the time and not being mobile, he's always in his room, with the blinds down and got this one beam of light on his book, and he's reading his book, and he's laying down to rest his back. That drives me crazy the most of anything. "

This is a particularly difficult situation that may contribute to the conflict of venting frustrations versus societal expectations for politeness. How can Jane reasonably complain about her frustrations when she recognizes that he is working so hard to provide for her and their son? This echoes Rachel's earlier conflict "what can I say?" Clearly her husband is working with pain and the result is that he has to come home and recover. He does this by lying down and reading a book in the dark.

In identifying these difficult situations, the family member appears reluctant to connect all of the factors together – the conflicts in parenting, missed opportunities, and loss in intimacy, being a result of potentially ineffective coping strategies of the pain patient.

Their Recommendations

One of the reasons I chose to look at how pain impacts the family is because I work with patients and their families in my everyday practice. I was interested in learning how I might better support family members through my agency. I have similar experiences getting family members involved in treatment as I did during the recruitment phase. Family members will often suggest that the pain is the patient's problem, not theirs. Those who will get involved are eager to learn how they can be more support to the patient; they are reluctant to address their own needs and experiences. As a result, I asked these women to reflect on their many years of experience living with someone with chronic pain. I asked them what might have been helpful to them.

Attend Doctors Appointments

Virtually all of the women stated that attending doctors' appointments was helpful. It allowed them to learn about the condition that was affecting their loved one, improving their own understanding and awareness.

> "I found going to the doctors appointments with him was helpful. Because I could get them to explain things in layman's terms to me." (Caren)

However, attending these appointments could also be frustrating. Doctors do not always completely understand a condition or recovery of a patient. This confusion or lack of knowledge can be frustrating for the family and patient. Eva was upfront about her frustrations with the doctor, but she also realized that she could be supportive to her husband by understanding the lack of knowledge and experience that was available to him.

> "I wanted to hear what they were saying. Most of them weren't particularly helpful, they didn't know what was what but just even to sort of be there for that."

Sometimes when the doctors knew the condition, they were unclear about the recovery or amount of help that would be needed after a treatment or surgery. Michelle was clearly frustrated by the incorrect information she was given by doctors and other medical professions in the hospital.

> "They led us to believe that she would basically come home from the hospital and be well enough to do stuff. She came home from the hospital she couldn't do anything."

It can be very difficult dealing with the medical profession. They have a lot of power. For example, they can discharge people from the hospital and this can be problematic, as Michelle highlights above. This can be an eye opener for family members. Michelle attempted to seek out help for her mother following her surgery and found that she was unable to find the help she needed. The consequences to her were quite significant.

> "I consider myself a really good advocator. Anyway, CCAC shut me down and I was, like I don't think I have ever felt silenced like that in my life."

Both Michelle's and Eva's comments reflect how easily medical professionals can fail to legitimize the patient's experience. In Eva's experience she comments on how the doctors were not helpful. This allowed her to have more insight into her husband's frustration with the medical system. However, in Michelle's experience she appears to have internalized the professionals' insensitivity and took it upon herself to find ways to help her mother cope after surgery.

Although attending doctors' appointments, or becoming involved in the medical system, can be a daunting and frustrating task, there appears to be a significant benefit to the relationship between the family member and the patient. Even in cases where the medical professionals were not helpful, an increase in understanding and awareness of the experiences of the patient was gained. This acquired understanding became a shared experience between them.

Find a listening ear

Although many of the women admitted that many of the issues they talked about during the interview had been the first time they had discussed them, they all stated that it was helpful having someone to talk to. In all but one case, they had turned to informal support networks, such as girl friends. In that one exception, she had talked with girlfriends but had also started working with a professional counselor. Often they suggested that they would turn to friends when the need to vent occurred.

> "I have some good friends. I just feel like I need to vent to someone, so I go to them, because they are my friends." (Jane)

> "Women always need to talk. They always need somebody to talk too." (Eva)

Support Groups

Once again, the wives were reluctant to identify the need for help for themselves, but many of them suggested that it might have been helpful to access some sort of support for their children, and indirectly for themselves. Beth suggested that a support group through the pain program might have been helpful for her and the kids.

> "Well I guess if there had been something when he went through the pain program, something like an Al-anon where it would help somebody learn how to deal with some of these things, or maybe a group of other wives or husbands that were going through the same thing. It might have helped the kids, if they would have gone."

Eva agrees that structured support would have been beneficial.

> "I think probably dealing with the kids or putting in some kind of supports for the kids would be helpful and valuable, and women always need to talk."

Caren had made the strong recommendation that social activities that involve the family be incorporated in to the pain program curriculum.

DISCUSSION

This study has supported what little research has already been done in the area of chronic pain and the family. Participants agreed that their lives had been affected in many ways by chronic pain; they described losses in intimacy, adjustments to activities shared within the family and difficulty in parenting. The study also supported my personal observations regarding the lack of resources that are available to family members of chronic pain patients – there just are not many, if any! In addition, this study identified gaps in the existing literature. One of the strongest themes that emerged from the interviews was the idea of loss. The spouses in the study spoke at length about the losses they felt in the area of social activities, recreation and travel. In some cases there was an awareness of missed opportunities.

The mothers identified loss on behalf of their children. Daughters, however, did not identify many concerns while they were growing up. They spoke of how their mother's attitude towards life prevented the pain from interfering in how she chose to live her life. In a recent study, Evans and de Souza (2008) learned that the mother's attitude impacted how the condition was interpreted by her children thus dictating how they responded. Considering that research has found that children are more likely to be impacted when their mother suffers from chronic pain (Evans and Keenan, 2007) it is interesting that the daughters in this study had a different experience. There are several factors to consider in relation to the findings about daughters in this study. First the daughters were adults reflecting back to childhood. Their reflections may not be as accurate as they might have been in the moment of childhood experiences. Secondly, their mother's pain worsened as she became older, possibly allowing the mother to hide her struggles more successfully from her children who were likely more independent. Finally, it may be that their mothers had accepted the chronic pain; minimizing the overall impact it had on the daughter's life. It is difficult to make any concrete linkage between the mother's attitude and the impact it had on her daughters without further exploring this situation. However, reflecting on their interviews, the daughters themselves seemed to think that their mothers had a positive attitude and approach to living with chronic pain.

An interesting trend that requires further study is the sense of loss as a result of the impaired ability to participate in physical activities with children as it is often one of the most commonly reported areas of loss for the parents. The ability to participate in children's physical activities is seen to reflect a parent's perception of being a "good" parent (Barlow, Cullen, Foster, Harrison & Wade, 1999). Not being able to live up to their expectations for themselves as parents can contribute to feelings of grief and frustration, and this area is more painful to face for chronic pain patients than any other area (Barlow et al., 1999). Caren spoke of how her daughter found a substitute adult to participate in activities that her father was unable to engage in. She infers a sense of loss for both her husband and daughter over what they can no longer share. For others involved in the study, the parent continued to participate as best they could in the regular activities with their children, but their spouse failed to discuss the consequence (if any) to doing so.

When children are asked to identify the impact the pain has had on their lives they tend to report increased responsibilities (more chores) as their primary concern (Mazure, 2006). In my own practice, the pain patient will often report guilt over this fact and this was partly the motivation in doing this research. However, the children in this study did not identify this as a concern. Interestingly, increased household responsibility was rarely mentioned by any of the participants in this study. It is possible that due to traditional family roles where women tend to do most household tasks, a father's chronic pain did not require the children to adjust their levels of responsibility. In situations where outside tasks could not be completed (more of a traditional male responsibility), the participants discussed moving (or staying) in dwellings that required less exterior maintenance. And in one case, they moved to a dwelling that provided exterior maintenance. In either case, the children appeared to be protected from increased responsibilities.

As noted, chronic pain is often associated with strain in a marriage. Marital strain impacts many areas of family life. Studies have found that the greatest indicator to how a child will cope with having a parent with chronic pain is the level of marital conflict (Chun, Turner, & Romano, 1991; Mansfield, 2005). How marital strain is played out in the parenting partnership is an important issue to explore. Many of the spouses interviewed in this study discussed how they felt their husband's parenting was somewhat influenced by the pain. They felt that perhaps their husband was too overwhelmed by the pain and other associated factors that they did not participate as equally in parenting decisions and discipline. One cannot infer that their frustrations would lead to martial conflict, but this may be an area worthy of further study.

Many of the spouses suggested that the pain patient might have felt overwhelmed by their parenting responsibilities. The idea of the pain parent feeling overwhelmed and unable to effectively parent has been identified before. The ability to participate in physical activities, increased irritability, social isolation and reduced energy and effort in the areas of discipline have been reported to impact on parenting (Evans & de Souza, 2008). Interestingly, the research in this area is minimal (Meana, Cho, & DesMeules, 2004; Evans, Shipton, & Keenan, 2005).

Previous literature suggests the loss of social activities as a significant area of concern for spouses of pain patients (Soderberg, Strand, Haapala & Lundman (2003). The spouses in this study were no different. Interestingly, findings here show that the families of the chronic pain patients adapted so that the experience of various losses was minimized. In some cases they continued to engage in activities with the pain patient, and in other cases they found someone else to do the activities with. This is not to say that there were not consequences to this: By no means did they feel that these were ideal choices. Rather, they modified as best they could, often with the pain patient being left to participate with increasing pain or to simply observe the activities, if they were included at all. In every case, the spouse stated that she would have preferred to do the activities with her husband; we can infer that this also meant without physical consequence to the patient.

The literature suggests that in situations where the pain patient is open about his or her limitations he or she might feel increased support and understanding from the family. The family will have a better understanding of what activities they can participate in as a family and they may be more sensitive to the pain patient's needs. However, in order to do this the pain patient must first accept their limitations, and this is a painful and difficult task (Barlow, Cullen, Foster, Harrison & Wade, 1999). The pain patient must first grieve the loss of their pre-pain identity, and then re-construct their identity to incorporate the multitude of changes in roles and abilities they may have experienced. In addition, the family would need to also make their peace with this new identity, potentially grieving the loss of the old roles and abilities.

What stood out from the interviews is that no one spoke of these losses or missed opportunities with resentment or frustration. Rather, they spoke of sadness that they were not able to do the activities with their loved one in the manner that they would have liked. What spoke to me through all of their interviews was the idea of acceptance once again. They seemed to have accepted the changes within their family, finding alternatives, and insisting that they continue to live their lives, and this clearly included living their lives with their husband or mother.

There is a significant body of literature that discusses the loss of sexual intimacy as a result of chronic pain (Smith, 2003). This loss can contribute to marital strain, but can also be a result of marital strain. Both are commonly experienced in marriages with the presence of chronic pain. In this study, the wives reported that there were significant changes in this area as a result of the pain. In some situations they had even spoken to medical professionals to try to overcome their struggles. It would appear that most of the couples in this study had come to find a way to accept these changes, minimizing the impact that it had on their marital relationship. For example, Beth expressed how sexual intimacy was not a necessary part of their relationship; both she and her husband had come to let go of this part of the relationship. However, Caren demonstrated how this was more difficult for her and her husband. Together they had chosen to maintain this part of the relationship, but at a significant cost (increased pain, guilt and medication use).

Marital satisfaction may be influenced by other pain-related factors as well. The perceived disability of their spouse can lead to increased conflict if it is at odds to the patient's perception of disability (Geisser, Cano & Leonard, 2005). The wives in the study all identified how attending medical appointments with their spouse was helpful in their own understanding of the pain. This may have been helpful in reducing discrepancies between their perceptions and their partner's. When the spouse appears to understand the pain and is able to provide emotional support, they are contributing to the legitimization of the condition (Richardson, On & Sim, 2007). By legitimizing the condition, the patient is able to focus on finding ways to live with the pain, rather than proving the pain exists.

This information supports the need for interventions that incorporate the family. If children are unable to participate directly in interventions, the benefit of working on the partnership is still quite significant and will ultimately be beneficial for the children, as the partnership has a profound impact on their coping and adjustment.

Support, and the (un)speakability of chronic pain

Support, specifically social support, is instrumental in helping people cope with difficult life events and situations (King, Willoughby, Specht,& Brown, 2006). Positive support is associated with improved psychological and emotional well-being, reduced stress and a sense of happiness (King et al, 2006). All of the participants in this study found that the greatest source of support for themselves was through their own informal social support networks. They felt that they could speak to friends, and sometimes family, if they needed support. However, they also noted that they were not always likely to do so. Often they reported that they just did not talk about this issue, suggesting that it had been such a part of their lives for so long that they just did not feel like they wanted to dwell on it anymore. In other cases, they suggested that they were so used to putting their needs last that they did not even recognize the need to get support for themselves until they could no longer cope on their own. One participant admitted that she did not feel comfortable reaching out for support in fear of being judged for her feelings, and this was further complicated with her resistance to even make time for herself. She expressed significant guilt at the thought of putting her needs ahead of her mother's.

Families or spouses do not typically act as caregivers to the pain patient years after the onset of the pain as the patients are functioning independently to a large extent. Occasionally they may engage in some forms of care giving behaviours but not in the same way as more debilitating conditions. Therefore, it was very difficulty to find research that was appropriate for this study. Rather than the idea of care giving, one study found it was more appropriate to look at the concept of support, or more specifically, emotional support (Richardson, Ong & Sim, 2007). It is this idea of emotional support that plays such a crucial role in legitimizing the pain condition (Richardson et al., 2007). Sometimes one of the most critical roles a spouse will play is as an advocate to others (Soderberg, Strand, Haapala & Lundman, 2003), whether it be as an advocate with medical professionals or within their social network.

It is also possible that the family compensates for the lack of support and understanding received in the pain patient's extended social network (i.e. work, friends etc) by cushioning the burden of the condition (Lonardi, 2007). This might explain the reluctance of participants to speak negatively after years of playing the role as advocate and protector. They likely recognize the difficult challenge of the pain patient to legitimize their condition, protect their identity in society, and to accept their changing self. How can the spouse or family member continue to support the pain patient in this challenging journey and face his or her own frustrations and needs at the same time? It would be much easier to deny, or ignore, personal feelings and instead focus on helping the pain patient overcome their struggles – minimizing the negative impact on the family system. It is possible that social legitimacy plays a role. This analysis is in keeping with social construction theory. Social Construction theories suggest that our interpretations are shaped by the social context in which we live (Nichols and Schwartz, 2008). If these families have learned that those outside of the family system do not believe in the legitimacy of the pain condition, they may feel pressure to "fit in" with the rest of the society, presenting their experiences as coping with minimal disruption. Thus they might minimize any negative impact or personal resentment.

In addition to these struggles there is also the reality that many people do not understand chronic pain, and discussing something that others do not understand could lead to continued feelings of frustration, possibly even loneliness and isolation. In addition, the invisibility of the condition may play a role in why those within the support networks do not offer support in the same way they might for a more "visible" or understood condition such as a heart attack, stroke or cancer.

What does not appear to be in the literature on chronic pain is the observation of unspeakability. In one study the researchers interpreted the defensiveness of a family member to speak openly as a reflection of the need to sustain legitimacy (Richardson, Ong & Sim, 2007). In that situation it appeared to reflect the cautiousness of the interviewee to speak of the issue at all, rather than the avoidance to talk negatively. In fact the only information that I could find about this reluctance to speak negatively was in suggestions of good manners. This is an interesting phenomenon. There is clearly an unwritten rule that it is not socially acceptable for a spouse or daughter to speak negatively of their family member, at least in these particular families. But does it go deeper? My observations are not based solely on the lack of negativity toward the pain patient directly but moreover, there appeared to be a reluctance to hold them accountable for certain actions or behaviours, or to even question whether they might be accountable. Are family members worried that by identifying their own frustrations that the flood gates would open? Or is this one of the ways they have come to protect the pain patient and then bolster the legitimacy of his or hers pain?

Another approach to understanding the lack of discussion regarding conflict, blame or responsibility is to consider various family theories. In structural family theory the emphasis is on how the family maintains balance when change occurs within the structure of the family system (Nichols and Schwartz, 2008). It supports the idea that change in one member of the family will impact the remaining members of the family, in this case pain is the change. Lewandowski, Morris, Draucker and Risko (2007) suggest that in order to maintain homeostasis within the family, the family may focus on the pain problem, as a way to deny any marital dysfunction. As a result the couple may present the impact of the pain and their relationship in an "idealized way". One cannot make these assumptions based on the limited information gathered during the interviews for this study. One could just as easily point out that healthy family systems accommodate changes when they occur (Nichols and Schwartz, 2008).

With a cognitive-behavioural transactional model approach to family and pain, one might conclude that this unspeakability is based on the family's belief about the pain and their ability to cope (Lewandowski, Morris, Draucker, & Risko, 2007). Based on these interviews, one might conclude that over the years of experimenting with different approaches and strategies they have found ways to cope and live with the pain. This would be an interesting issue for further study. Chronic pain has such a tremendous impact on a person's identity. How each member of the family responds to the changes that occur as a result of the pain, plays a critical role in how they will reconstruct their individual and family identity. Are they a spouse that travels without her husband? Are they supportive and understanding under prolonged and frustrating circumstances? Have their roles changed within the family system? Another interesting area for further study could be to explore how the identity of the family is affected by chronic pain.

The potential changes in the pain person's identity have been clearly defined earlier in this paper. Chronic pain has a tremendous impact on a person's sense of self. How the person responds to the impact is very significant. Feeling supported and understood by loved ones, finding a way to assimilate into society, and redefining oneself as a person with pain (but not only by their pain) can be a long and complicated journey, but it is a journey with some positive outcomes, including for their families. As a result of the shifting roles and values of the patient, they too have had to adjust their roles, and their ideas of what and how activities would be played out. The family system is a fluid system and when one part of the system is radically changed, the entire family system must find ways to adapt. Fortunately for the families in this study, they appeared to have found ways to successfully adapt although there was significant loss experienced along the way.

The idea of acceptance is vital in adjusting to chronic pain. If the family is unable to accept that there is no medical explanation or treatment then they will be unable to release the patient from owning their pain and suffering, and the resulting guilt and shame of it all. When the family accepts that there may not be treatment or explanation – it just is – then they can focus on how to live their lives together as best they can even though pain exists within the family system.

Limitations

As with all small, qualitative studies these findings are not too be generalized outside of this study. All of the participants in this study have been living with, or known, the chronic pain patient for a considerable amount of time. I suspect that findings would vary more significantly for newer relationships or more recent onset of chronic pain conditions. In addition, the spouses in this study remained married to the pain patient, many partnerships may not survive the considerable stress that is placed upon them by chronic pain.

Findings are also limited by the demographic nature of the participants. All of the participants were white, middle class, heterosexual women and most were from dual income relationships. All of the pain patients were able to maintain their regular financial income, minimizing the financial strain on their families. Research with a more diverse group of people may well lead to different findings, or a different emphasis on the findings presented here.

In addition, one cannot ignore the implications of the recruitment method. Due to the fact that informal social networks were used to recruit participants, there was the reality of social familiarity with the researcher. In some cases the researcher had direct familiarity with the participant, through shared classes or family acquaintances. The nature of these relationships could influence the participant's comfort level in disclosure, thus influencing the issues discussed, and the nature of the disclosure.

Conclusion

In summary, when working with families of chronic pain patients, identifying how they manage shared activities with the pain patient is important, as is exploring their emotional reactions to these events (or lack there of). In the event that there is a separation of lives (interests, activities, events) from the pain patient, it might be worthwhile to explore if there are any "shared" activities, and how these are managed.

Literature that highlights the significance of how the family adjusts to the chronic pain to how the pain patient is likely to adjust is plentiful (Soderberg; Sharp and Nicholas, 2000; Richardson, Nio Ong & Sim, 2007; Geisser, Cano & Leonard, 2005). In addition, there is considerable literature on the consequence to the family of living with someone who has chronic pain (Ohman & Soderberg, 2004; Geisser, Cano & Leonard, 2005; Sharp & Nicholas, 2000). The focus now has to be directed to how this information can be used to better support the pain patient and his/her family. According to this study there are a few barriers that need to be overcome in order to do this. First, the family must be given permission to step out of the legitimizing and protecting role in order to address their own concerns and frustrations. They need to recognize that they are being impacted by living with a pain patient; it is not just the pain patient's burden to face. Second, health care professionals need to come to understand the significant impact on the family and involve them in the rehabilitation process. They need to ensure the family is connected to appropriate resources earlier in the medical intervention. Finally, appropriate family interventions can be identified with funding and priority-setting for such interventions through program evaluation research. If you ask any pain patient they will confirm that their families have been significantly impacted by the pain experience, the question that remains unanswered is why so little is being done to support the family.

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Appendix A

Recruitment Poster

Do you have a family member living with chronic pain?

Do you currently live with this person?

Are you 18 or over?

If you answered yes to these questions I would appreciate being able to talk to you about your experiences as part of a research project.

I would meet with you for 60-90 minutes in order to learn more about your experiences of living with someone with chronic pain. Your privacy would be fully respected, and information that identifies you or your family member would not be included in any report from the study.

This research is not affiliated with the Chronic Pain Management Program. I am a Master of Social Work Student at McMaster University.

If you think you might be interested please contact me to find out more. I appreciate your interest.

Sincerely,
Aprile Titterson
atitterson@cogeco.ca or (905)510-5219

Appendix B
Letter to Informal Network

"As you are probably aware, I am in the process of completing a Master's Degree in Social Work at McMaster University. As part of my studies I am doing a research project on the impact of family members when someone within the home has chronic pain. I have found there is very little research from this perspective and believe that the family is an area that deserves more attention in research, services and support.

I am sending this request to you in hopes that you could forward the attached letter to anyone you might know who might be willing to participate in my research study. I am looking for any adults who live with a family member with chronic pain, preferably someone who has lived with them prior to the pain and can speak to some of the changes that might have occurred within the household over time. I would meet with any interested individuals for about 60 minutes, if the distance is too great we could arrange for a telephone interview.

Any involvement in this study would be voluntary and completely confidential. There are more details that speak to this in the attached letter of information.

I would appreciate any help you could offer in forwarding this information to appropriate people. Anyone is welcome to contact me by email or by phone if they have any questions. Thank you so much for all your help,

Aprile Titterson
atitterson@cogeco.ca
(905)336-9990"

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Appendix C

Letter of Information and Consent

March 5, 2007

Living with chronic pain: the experiences of family members

Student Investigator	Aprile Titterson Master of Social Work Candidate McMaster University Hamilton, Ontario, Canada (905) 510-5219 atitterson@cogeco.ca
Faculty Advisor:	Dr. Chris Sinding School of Social Work McMaster University Hamilton, Ontario, Canada (905) 525-9140 ext. 22740 sinding@mcmaster.ca

Purpose of the Study

I am a student at McMaster University. I am doing this study as part of the requirements for a Masters degree in Social Work.

In this study, I want to hear from family members about how their lives have been affected by living with someone suffering with chronic pain. Often, the chronic pain sufferers are asked this question, but rarely the family members directly. The family deserves to have their voice heard.

What will happen during the study?

Once you decide you would like to be involved in this study, we will arrange to meet at a time and location that suits you for an interview. If you are unable to travel, we can try to arrange a time to complete the interview over the telephone. The interview will likely take anywhere from

60 to 90 minutes. Over the course of the interview I will be asking you some questions about the chronic pain patient and the nature of the pain condition but for most of the interview I will be encouraging you to share some of your thoughts and experiences in your own words. I will ask some general questions to help start this conversation. I am interested in how your life has changed since the onset of the pain, and how these changes have affected you.

The interview will be recorded on audiotape and later transcribed into a written record by a professional transcriptionist. Your confidentiality will be protected at all times. Any personal information will not be included on the written documents. This information is being recorded so that I can understand your statements as accurately as possible. The staff at the Chronic Pain Management Program will not have access to the audiotapes or the transcriptions. In fact, they will not be made aware of your involvement in the project.

Potential Harms, Risks or Discomforts:

It is not likely that there will be any harm to you during your involvement with this study.

You may feel uncomfortable with some of the questions as they do deal with a personal and emotional topic. You do not need to answer any question that you do not wish to answer, or that makes you feel uncomfortable. You may choose to withdraw from this study at any time, no questions asked.

Potential Benefits

Your participation in this study will allow the researchers to gain a better understanding of how the family may be impacted when a family member is living with chronic pain. It is also an opportunity for you to share your story, from your perspective, which may be an opportunity you do not often have. You will not be judged, and what you share will have no impact on the treatment your family member will receive. This study is about you – and the other family members who participate in this study.

Perhaps the results of this study will provide professionals with ideas of how to better support family members.

Confidentiality:

I will do everything I can to protect your privacy and confidentiality. The information obtained will be locked in a cabinet and will be destroyed upon the completion of the study. No identifying information (your name or personal information, or that of your relative) will be included in any of the written information or in the final report.

However, individuals close to you may be able to recognize your story if they are to read the results of the study, and you should keep this in mind in what you say.

Limits of Confidentiality:

Information obtained will be kept confidential unless the law requires that confidentiality be breached. For example if you should disclose child abuse, or any serious thoughts of harming yourself.

What if I change my mind about participating in the study?

If you decide to participate, you can decide to stop at any time, even after signing the consent form. If you decide to stop participating, there will be no consequences. Any information that has been gathered will be destroyed unless you indicate otherwise.

Your participation (or lack of participation) in this study will not influence the services that you or any member of your family receives in any way.

Information About the Study Results:

If you are interested in the results of the study you can either provide your contact information and I will send you a summary of the results at the end of the study or you can contact me later to request a summary of the results. If you wish to read the full thesis, I can arrange for you to see a copy.

Additional Information about Participating:

If you have questions or require more information about the study itself, please contact Aprile Titterson.

This study has been reviewed and approved by the McMaster Research Ethics Board. If you have concerns or questions about your rights as a participant or about the way the study is conducted, you may contact:

McMaster Research Ethics Board Secretariat
Telephone: (905) 525-9140 ext. 23142
c/o Office of Research Services
E-mail: ethicsoffice@mcmaster.ca

CONSENT

I have read the information presented in the information letter about a study being conducted by Aprile Titterson, of McMaster University. I have had the opportunity to ask questions about my involvement in this study, and to receive any additional details I wanted to know about the study. I understand that I may withdraw from the study at any time, if I choose to do so, and I agree to participate in this study. I have been given a copy of this form.

____

Name of Participant

In my opinion, the person who has signed above is agreeing to participate in this study voluntarily, and understands the nature of the study and the consequences of participation in it.

____

Signature of Researcher

Appendix D

Interview Guide

I'm going to start by asking a few questions about your family member and their history with pain. As with all of my questions, you should feel free to say as much or as little as you wish.

1. Who is it in your family that has pain? [establish name and relationship to participant]

2. Can you tell me about how and when [patient] came to have pain?

    a. Probe for: duration; work or vehicle injury or other; if relevant: case resolved or still being determined

The next few questions are to learn more about your experiences. Again, please answer in as much detail as you feel comfortable sharing.

1. Do you feel that there have been changes in your life since [*patient's*] was injured? If so, can you tell me how?

2. Has your relationship with [patient] changed? Can you tell me about this?

3. Have there been financial changes within the household due to *insert patient's name*'s injury
    a. Probe for job loss/ changes, cost of medical treatments etc).

3. Often family members of people with chronic pain say that the patient doesn't really understand what it's like for the family member. What do you think or feel about this?

4. sometimes chronic pain patients say that no one understands what it is like unless they have intense chronic pain. What do you think or feel about this?

5. What has been the hardest part of the last *insert time since injury* for you?

What has helped, during the hard parts?
Probe for people, programs, social networks, beliefs, etc; opportunities to talk about your feelings, thoughts, concerns

6. are there other supports you might have wanted in the past, or would find useful now?

7. do you feel comfortable speaking to how others in the home have been impacted (children for example)?

I have a few more 'factual' questions, but first I want to ask,

8. Is there anything else you would like to say, or feel I should ask, to really understand what it's like for family members of people with pain?

OK, so finally the factual questions:

9. Can you tell me who lives at home? (i.e. number of kids, ages etc).
10. In what year were you born, if you don't mind saying? And [patient], in what year was he/ she born?
11. have you lived in Canada all of your life? If not, when did you immigrate?