

An Art Inquiry into the Experiences of a Family of a Child Living with a Chronic Pain
Condition: A Case Study.

By

Kathryn Shea
B.A. in Child and Youth Care, Malaspina University-College, 2002

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of the Requirements for the Degree of

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ABSTRACT

Chronic pain among children is poorly understood and few studies attempt to elicit and portray the experiences of the sufferers and their families. This qualitative case study used art inquiry and narrative methodologies as a means to understand the participants' stories of chronic pain. The participating family has a child aged 6 who has been experiencing unexplained chronic pain for over 2 years. Data were gathered through five art making sessions. The first stage of analysis occurred during the art making sessions as participants and researcher worked together to understand the messages and meanings within their creations. The researcher then compiled the debriefing transcripts into stories that capture the core of these messages and meanings. Finally, the researcher pulled together themes and points of interest in terms of satisfying the purpose of this inquiry and responding to the guiding research questions.

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Chapter 1: Introduction

Childhood chronic pain is consistently identified as being underestimated, poorly understood, and lagging far behind knowledge of adult pain experiences (Bennett, Huntsman, & Lilley, 2000; Eccleston & Malleon, 2003; Schulz & Masek, 1996; Zeltzer & Blackett Schlank, 2005). Qualitative research that investigates the impact of chronic pain on children is especially limited (Salfors, Fasth, & Hallberg, 2002). Living with chronic pain has a significant impact on children's ability to participate in daily activities such as school, recreation, social interactions, and family events (Bennett et al., 2000). This inability to participate in activities can lead to feelings of isolation, fear of abandonment, and result in long-term ramifications (Schulz & Masek, 1996). Research to date also reveals that families of children with chronic pain experience significant levels of economic, emotional, and physical distress (Bennett et al., 2000; Zeltzer & Blackett Schlank, 2005) and this places an intense burden on families' abilities to cope and function (Eccleston & Malleon, 2003). As sufferers struggle to make meaning of their illness, they often internalize their anger and frustration so as not to further burden loved ones (Schulz & Masek, 1996). The meaning that children with chronic pain and their families give to their experiences in turn affects their responses to the condition and impacts their state of well-being (Schulz & Masek, 1996). As more attention is given to the issue of chronic pain in children, helping professionals are also looking for appropriate treatments and interventions that meet the needs of this population.

Art-based therapy interventions are considered an excellent tool for helping children living with chronic pain (Prager, 1993; Savins, 2002; Stronach-Buschel, 1990; Synder, 1997). Art-based interventions meet children's developmental need to make

sense of their world through play (Savins, 2002); support children's cognitive ability to understand their experience (Prager, 1993; Schulz & Masek, 1996); facilitate self awareness and expression of emotion (Synder, 1997); and assist in the externalization of subjective meaning related to experience (Carlson, 1997). "Parents can play a crucial role in helping their children manage pain" (Savins, 2002, p. 16) when they are included in creative interventions to gain insight into their child's experience and to help children to express the reality of their experiences without feeling the burden of causing parental anxiety and pain. Art-based interventions introduce families to novel ways of relating to each other and the problem and in turn, this helps them interact in ways that are not dominated by language patterns that reinforce the presenting problem (Riley, 2004). Moreover, families are often made up of individuals of various ages and developmental levels and this approach provides all members of the family an opportunity to voice their stories and have equal access to the therapist/researcher (Riley, 2004).

I came to this topic because of personal experience. As a child, I experienced unexplained chronic pain and later, as a young adult, I developed a medically recognized chronic pain condition called Complex Regional Pain Syndrome. My experiences of pain have played a dominant role in my life and yet, as a child my ability to make sense of and speak to those experiences was limited. I have always been drawn to expressive mediums such as dance, music, and art. My participation in these activities provided me with opportunities to express myself in ways that did not require language. Accordingly, as an adolescent and a young adult, I often turned to art as a means of coping with the stress, anxiety, and pain of life. Although the use of art became a major coping skill in my life, it was also an activity that I did in isolation, and thus I am curious about how my

experiences would have differed had my family joined together to communicate with each other through the medium of art.

In the process of my making sense of my life's experiences, I have developed strong values and beliefs about human nature and in turn, I decided to pursue an education that would afford me the opportunity to work with the issues that I am most passionate about. One of these passions is working with children. I believe that children's capacities and competencies are often under-recognized and under-valued. I also believe that qualitative research offers unique opportunities to engage children in a way that allows their ideas, stories, thoughts, perceptions, and emotions to be communicated in a way that adults can understand. Researchers need to ensure that the design of their inquiries allows for children to have an opportunity to speak to their own experiences and in doing so, it is possible to facilitate the emergence of data that would otherwise not be possible (Kortessluoma, Hentinen, & Nikkonen, 2003). In order for researchers to effectively interview, they must be interested in the stories of children, must have human developmental knowledge, and must acknowledge that children are vulnerable and more context dependant (Kortessluoma et al., 2003). Additionally, researchers need to take legal and ethical aspects, motivational aspects, relationship aspects, and questioning aspects into consideration.

This chapter is intended to introduce the issue of chronic pain in childhood populations as well as address how art in therapy offers significant positive contributions when working with this population and their families. The purpose of this research inquiry is identified and the researcher notes the theoretical stance from which she approached this research study. In conclusion, an overview of the thesis is presented.

Statement of the Purpose

The purpose of this case study inquiry was to understand and give voice to the experiences of a child with a chronic pain condition and his/her family. These experiences were explored through a process of art inquiry known as Symbolic Constructivism (Barry, 1996) and the meanings that emerged from the stories of experience were co-constructed among participants and researcher. The following questions served to guide this inquiry: What are the experiences of a family who has a child living with chronic pain? How does the chronic pain play out in this family's life-socially, emotionally, physically, and spiritually? What kinds of strengths and resources is the family drawing upon to fight the battle with chronic pain?

Researcher's Theoretical Stance

As a practitioner and researcher, I operate from a post-modern stance in which constructivist and narrative theories resonate most succinctly with my beliefs about the world. As such, I acknowledge that my theoretical beliefs make up part of the lens through which I view the world. This lens plays a role in the co-constructions and meanings that are created in my interactions with people and thus, I feel it is important to acknowledge some of these beliefs at this time.

Humans are unique and creative beings that, through an individualized meaning making process, construct subjective realities that are reflective of the distinctive cultural, political, and familial contexts in which they exist (Lynch, 1997b). In other words, human beings actively participate and create their personal and social realities (Lyddon, 1990) in a reciprocal relationship with their environment (Furman, Jackson, Downey, & Shears, 2003). Humans are meaning making agents and they function both individually

and collectively to co-create meaning related to their experiences in the world (Neimeyer, 2002). Human knowledge and personal identity are both socially constructed and therefore, they are impacted by the linguistic and cultural resources of any given social context (Furman et al., 2003; Lynch, 1997a, 1997b). Furthermore, Lyddon and Weill (2002) point out that different cultural and social groups have diverse ways of organizing and interpreting the world and therefore, words may not have the same meanings and definitions across cultural contexts.

Constructivists adhere to the view that individuals are cognitively proactive and humans have unconscious core ordering processes (Mahoney, 1995). Individuals are inherently self-organizing (Mahoney, 2003; Neimeyer, 1993) and our self-organizing activities are fundamental to our knowledge processes (Mahoney, 1995). In order to make sense of one's realities, individuals create narratives and stories that function as a sequential framework in which these multiple realities can be better understood (Bubbenzer, West, & Boughner, 1994; Lyddon & Weill, 2002; Lynch, 1997a). Lynch (1997a) further explains that by forming narratives, individuals are ordering experiences in a way that is reflective of their sense of self, as an intentional agent, as they move through the world. Moreover, in an interview with Donald Bubbenzer, Michael White states that "stories we have about life give meaning to experience and have real consequences in our lives...we live by the stories we have about life" (Bubbenzer et al., 1994, p. 71).

People are self protective by nature - the unconscious core ordering processes attempt to maintain a sense of coherence. As a result most individuals demonstrate some degree of resistance to changing patterns (Mahoney, 1995). Constructivists view these

challenges as developmental milestones that are crucial to major personal change (Lyddon, 1990). Kirschenbaum (2004) also suggests that clients have inherent qualities that allow them to understand their own needs and problems, as well as the ability to reorganize constructs to make constructive, positive changes. Furthermore, we are motivated by an ongoing need to survive, to reorganize, and to create meanings as we are creative, resilient life forms that are capable of surviving and adapting (Mahoney, 2003).

Problems develop when individuals feel as though they do not have the resources to deal with the presenting situation which are embedded in a social context, maintained by both internal and external factors. Within constructivism, problems are believed to arise when there is a discrepancy between a person's present capacities or categories and the presenting challenge (Lyddon, 1990; Mahoney, 2003). In other words, an individual's conceptual framework, or reality, has not yet accounted for the possibility of the presenting situation. Moreover, as one's conceptual framework presents itself through stories, a person's sense of self-identity is dependant on the content and cohesiveness of the life story. Therefore, when a situation has not yet been integrated into the life narrative, its integrity is at risk and thus, a problem occurs (Mahoney, 2003).

Language also plays a distinct role in this regard as it is an abstract framework that consists of rules. Members of a culture learn to subscribe to these rules as though they are 'truth' (Neimeyer, 1998). Problems can also become so internalized that they are incorporated into an individual's identity (Bubbenzer et al., 1994). The tendency to internalize problems is supported within a cultural context as society often attributes blame on individuals and thus, bestows narrow and unhealthy identities (Freedman & Coombs, 1996). Problems may also be maintained when families continue to use

language and tell stories that maintain the problem (Etchison & Kleist, 2000).

Chapter Summary

This chapter has provided a brief introduction into the issue of chronic pain in children. Chronic pain is a condition that affects many children and, unfortunately, the issue of chronic pain has not been sufficiently addressed in the research. At this point, research corroborates that for young chronic pain sufferers and their families, the short term and long term ramifications are potentially intense. As such, paediatric chronic pain is deserving of further attention. An introductory argument for the use of art in therapy was also provided with specific implications for use of this approach with families. I also gave an account of my personal journey of coming to the topic of using art with young chronic pain sufferers and their families. After making a statement of the purpose, I then outlined the theoretical stance from which I operated as I facilitated this study. In the next session, a brief overview of the thesis is presented.

Overview of Thesis

The following chapter includes a review of the relevant literature in the area of childhood chronic pain. The existing research highlights certain aspects of chronic pain including how it is currently defined, the prevalence of chronic pain, contributing factors, and the impact of living with the condition for the individual and their family. A developmental perspective is also highlighted. The remainder of the chapter includes a discussion of art in therapy that focuses on the topics of definition, history, major components, benefits, development in art, art with families, and art with children in pain.

Chapter Three addresses the methodological approach that was used in this study and includes the relevance of employing a qualitative approach given the issue of

paediatric pain and the specifics of its design in terms of a case study framework. The researcher discusses the use of an art inquiry data collection process and an analysis drawing upon narrative research methodology. Researcher assumptions are presented as a way of accounting for aspects of my participation and subsequent impact within the inquiry. Then the researcher notes participant requirements, the phases of the data collection and data analysis processes. Finally, issues pertaining to rigor and ethics within this qualitative inquiry are outlined.

The fourth chapter is provided as a case description to familiarize the reader with the participating family as well as to provide a detailed enough description for future researchers to be able to draw their own conclusions about any similarities that emerge as a result of their own studies of chronic pain.

Chapter Five provides an overview of the six sessions and contains the images that were created within each session. A re-storying of the debriefings of each image is presented as well as a short section on my impressions as a researcher. The presentation and format of this chapter is intended to maintain the integrity of the participants' stories by highlighting their actual words as much as possible. In presenting a separate section of my own impressions, I hoped to account for my experience without obscuring the participants' perspectives and realities.

Within Chapter Six, I respond to each of the research questions by drawing upon the stories and themes that emerged across the six sessions for the participating family. I provided examples of their actual words to highlight these themes and to emphasize the realities of the family in terms of their experience of chronic pain. Throughout the responses, I have weaved information from the existing literature to draw attention to the

consistencies and discrepancies with the current research based knowledge of chronic pain and art in therapy.

In the concluding chapter, I speak to aspects of my own journey as the researcher and I describe how certain issues arose within the process of this inquiry. I also describe some of the decisions that I made in response to the emergent issues as a further means to account for my role in the inquiry. I added this chapter as I wanted to provide a glimpse into how I as the researcher was participating and in turn, co-constructing the story of this project.

Chapter 2: Literature Review

Chronic pain represents a distressing and isolating experience for many young people in North America and the impact extends beyond the individual and affects the entire family system (Schulz & Masek, 1996; Zeltzer & Blackett Schlank, 2005). The purpose of this chapter is to present a synthesis of the present research into paediatric chronic pain including definitions, prevalence, contributing factors, and the impact of living with this condition for both the child and family and to discuss the relevance of using art in family therapy interventions.

In therapy, art provides a meaningful way of working with this population as it meets children's developmental needs (Savins, 2002) and provides families with unique opportunities to experience new ways of relating to each other (Riley, 2004). Art in therapy is loosely defined, a brief historical context is provided, and then art in therapy is discussed in terms of its major components, benefits, and its specific implications for use with families and with children in pain.

Chronic Pain

Prior to 1980, health professionals believed that young children did not experience pain with the intensity as adults and that they did not retain memory of pain and as a result many children experienced extreme levels of pain after surgeries, injuries, and illness (Lemonick, Bjerklie, & McDowell, 2005; Zeltzer & Blackett Schlank, 2005). "As late as the 1970s, infants underwent major surgery without anaesthetics while older kids were often denied powerful pain-killers, on the theory that narcotics were too addictive and dangerous to be administered to children" (Lemonick et al., 2005, ¶1). Moreover, research studies have demonstrated that early childhood pain experiences

impact the developing nervous system; cause this system to be highly sensitive to pain; and contribute to the possibility of developing chronic pain conditions (Zeltzer & Blackett Schlank, 2005). Lemonick et al. (2005) indicate that approximately twenty percent of children who experience surgery continue to experience pain long after the body has healed. Historically, chronic pain has been seen as a symptom, not as a separate condition (Zeltzer & Blackett Schlank, 2005). Fortunately, increased attention has been given to this issue and clearer definitions are emerging. It is also important to note that paediatric chronic pain must be approached from an interdisciplinary approach as it is far too complex to be understood or explained by one specific discipline (McGrath & Finley, 1999).

Definition

Chronic pain can be considered pain that is either constant or recurrent, occurring for an extended period of time, typically more than three months (Zeltzer & Blackett Schlank, 2005). Chronic pain is differentiated from short term or acute pain in that multiple factors, other than the initial cause, may be maintaining the condition (Schulz & Masek, 1996). Acute pain is considered a warning sign to indicate that action is needed; this kind of pain is brief and usually dissipates as the injury heals (Zeltzer & Blackett Schlank, 2005). However, chronic pain no longer serves as a warning signal as it is not necessarily responding to an underlying injury or disease (Zeltzer & Blackett Schlank, 2005). "Chronic pain develops when the area of the brain that has been receiving signals becomes activated and remains activated even if there are no more pain signals stimulating it" (Zeltzer & Blackett Schlank, 2005, p. 23). Chronic pain can be the result of conditions such as juvenile arthritis, fibromyalgia, cancer, or complex regional pain

syndrome. Individuals also experience chronic pain despite the lack of a known aetiology. In the event of unexplained chronic pain, there are often increased factors that play out and complicate the assessment and treatment of chronic pain as well as the impact of the experience for sufferers and their families.

Lack of physical evidence and the need for psychometrically sound measures in chronic pain often frustrate health professionals and leads to inaccurate diagnosis and misunderstandings between professionals and families (Eccleston & Maleson, 2003; Malaty et al., 2005). "If pain persists and continues to elude the search for the lesion, especially if the pain is widespread, unusual, or changing, the child will be labelled as 'pain prone' as if the pain is the child's own fault" (McGrath & Finley, 1999, p. 2). Physicians often tell parents that there is nothing physically wrong with their child and that there are no medical interventions to help relieve the pain. Zeltzer and Blackett Schlank (2005) argue that neither of those statements is true. Although more research is being conducted, presently researchers consistently state that chronic pain is poorly understood and most likely underestimated (Bennett et al., 2000; Eccleston & Maleson, 2003; Hunfeld et al., 2002; Sallfors et al., 2002; Schulz & Masek, 1996; Zeltzer & Blackett Schlank, 2005). Most importantly, it is imperative to remember that "children who develop chronic pain are not pretending to have pain, even if it seems there is no reason for it" (Zeltzer & Blackett Schlank, 2005, p. 21).

Prevalence

Chronic pain can affect a wide range of people and yet, due to the narrow focus of the existing studies on chronic pain (Schulz & Masek, 1996) and/or the lack of information defining what conditions are considered when the term chronic pain is used,

it is difficult to put together an accurate picture of the prevalence of chronic pain among children. The cited percentages across various research studies range from nine to twenty five percent of children experience chronic pain, however, due to the lack of a clear definition or the lack of defined parameters, the term 'chronic pain' is used differently across these studies. For example, Walters and Williamson (1999) cite that between nine and fourteen percent of children under the age of eighteen experience chronic pain due to a debilitating disease or disability. Bennett et al. (2000) specify that ten to fifteen percent of school aged children experience the most common types of persistent pain (headaches, abdominal pain, and limb pain). Malaty at al. (2004) indicate that ten to fifteen percent of children experience chronic pain specifically due to Recurrent Abdominal Pain (e.g., Eccleston & Malleon, 2003; Roth-Isigkeit, Thyen, Stoven, Schwarzenberger, & Schmucker, 2005; Zeltzer & Blackett Schlank, 2005). Although there appears to be some consistency in the percentages that are being reported, many studies refer to specific chronic pain conditions while other studies use chronic pain to account for multiple conditions, without specifying those that were considered in the formulation of a percentage. Regardless, it is clear that the prevalence of chronic pain in children is widespread enough for it to be considered a significant problem (McGrath & Finley, 1999).

Contributing Factors

Schulz and Masek (1996) identify four levels of pain: neural activity, conscious pain sensation, cognitive and emotional reactions to the pain, and behavioural responses to the pain. These levels suggest that pain, and especially chronic pain, is not just physiological in nature but that our psyches also plays a role in how we respond to the

experience. Other researchers agree and highlight this same dynamic by categorizing pain into the sensory component and the emotional responses to the sensory difficulty (Sallfors et al., 2002; Zeltzer & Blackett Schlank, 2005). In other words, the brain registers not only the pain sensations but also the emotional suffering of pain. Therefore, “emotions and beliefs can directly affect the nerve signaling and neurotransmitters that underlie the physiology of pain” (Zeltzer & Blackett Schlank, 2005, p. 25). Schulz and Masek (1996) indicate that in addition to any physiological causes of the persistent pain, psychological and psychosocial factors may also be contributing to the initial aetiology as well as participating in the on-going maintenance of the pain.

An important component of researchers’ attempts to understand this phenomenon better is to get a sense of what factors contribute to both the initial onset of chronic pain as well as the continuation of pain (Sallfors et al., 2002; Schulz & Masek, 1996). Unfortunately, the majority of existing studies have looked into the presence of chronic pain (Hunfeld et al., 2002) and few studies have looked beyond the actual existence of chronic pain in order to more fully understand this experience. Sallfors et al. (2002) have suggested that genetics, learning, previous pain, family functioning, developmental understanding, and ability to communicate the experience are all important factors to consider when investigating possible influences on the experience of chronic pain. Anxiety, depression, focus of attention, memories of pain, parental models, coping ability and style, age and developmental level, and learning disabilities are all factors that contribute to the experience of chronic pain (Zeltzer & Blackett Schlank, 2005). Schulz and Masek (1996) identified coping resources, social support, response of significant others, cultural values, and personality as potential influencing factors. These general

areas of possible contributing factors leave room for further investigation, yet, it is clear that regardless of the factors involved the impact of living with chronic pain is significant for both the patient and their family.

Living with Chronic Pain

Impact on the child. Although the effects of pain have been minimally researched (Hunfeld et al., 2002; Roth-Isigkeit et al., 2005; Schulz & Masek, 1996; Walters & Williamson, 1999), most studies clearly indicate that the impact for sufferers is immense (Bennett et al., 2000; Malaty et al., 2004; Sallfors et al., 2002; Schulz & Masek, 1996; Walters & Williamson, 1999; Zeltzer & Blackett Schlank, 2005). Paediatric chronic pain sufferers are at higher risk of both psychological and psychosocial maladjustment: slowed development, increased depression scores, loneliness, isolation, and difficulty expressing emotions (Walters & Williamson, 1999). Children with chronic pain often indicate their lives are guided by the pain. "The pain controlled these children's lives, everyday lives full of pain and restrictions, which prevented them from living 'normal' lives" (Sallfors et al., 2002, p. 499).

One of the most consistently reported impacts for young chronic pain sufferers is activity restriction. The lack of active engagement with friends and family leads to many secondary effects (Bennett et al., 2000; Malaty et al., 2004; Roth-Isigkeit et al., 2005; Sallfors et al., 2002; Zeltzer & Blackett Schlank, 2005). When children are not able to attend school regularly and to participate in peer or family activities, they are likely to experience feelings of isolation and abandonment (Schulz & Masek, 1996). Furthermore, they may have difficulty expressing their anger and frustration and often worry about further burdening loved ones. In Malaty et al.'s (2004) study of Recurrent Abdominal

Pain, they found that a decrease in school attendance, peer relationships, sports, and family activities led participants to experience higher levels of anxiety and depression and lower levels of self-esteem. Research suggests that chronic pain not only affects participation at school and with peers but can also impact appetite and sleep and increase use of health services (Roth-Isigkeit et al., 2005). Moreover, limiting or restricting activities does not provide ill children the same amount or quality of opportunities as typical healthy peers to master developmental tasks such as quests for autonomy and socializing with others outside of caregiver relationships (Walters & Williamson, 1999). "Children who are encouraged to participate in daily activities- activities that generally focus on social interactions with friends and quests for developmental competency- may experience less psychological distress than children who are prohibited from such activities" (Walters & Williamson, 1999, p. 47). Not only does the impact of living with chronic pain exist during the pain experience but can also affect future social, physical, and economic functioning. In time, this can have significant ramifications for families (Sallfors et al., 2002). Given the complexities of chronic pain, it is essential that health and helping professionals view chronic pain from a psychosocial orientation especially since pain alone does not account for the variability in disability or impairment (McGrath & Finley, 1999).

Schulz and Masek (1996) indicate that the type of chronic pain is not a strong predictor of the degree of impact in terms of distress and/or disability. There are multiple factors to be considered when attempting to understand the degree of disability and/or functional impairment including ability to cope, level of catastrophic thinking, family environment, and parental support (Kashikar-Zuck, 2006). The child's interpretation or

understanding of their pain experience is important to consider. In accordance with the concept that pain is a subjective experience (Sallfors et al., 2002) it is important to understand and validate each child's experience in the context of their life. Pain rating scales explain little in terms of understanding the impact of chronic pain in sufferers' lives (Kashikar-Zuck, 2006). Children will often feel stigmatized due to others' difficulty in understanding the intensity and/or characteristics of their pain and will try to convince themselves and others that their pain is real (Schulz & Masek, 1996). Regardless of aetiology, pain symptoms should not be minimized as underestimating or ignoring children's reports of pain will typically result in higher levels of distress (Kashikar-Zuck, 2006). As such, it is important to attempt to understand children's subjective experiences of pain and qualitative interviewing is one way to elicit information that might not otherwise be obtained (Kortessluoma et al., 2003). Experiences are integrated into individuals' internal worlds and when verbal children are given opportunities to talk about those experiences they are also able to communicate about their perceptions, feelings, and moods which in turn can provide professionals with a more complete picture of a sufferer's subjective experience of pain (Kortessluoma et al., 2003). Chronic pain not only affects the individual but also plays out for the entire family.

Impact on the family. Chronic pain must be viewed in a broader social context and although studies that address the impact of living with a painful condition are limited, it is clear that the entire family is affected by this experience (Hunfeld et al., 2002; Sallfors et al., 2002; Walters & Williamson, 1999; Zeltzer & Blackett Schlank, 2005). Families often experience blame from professionals who are seeking to either understand what factors are potentially reinforcing the existence of pain within the family system, or due

to their inability to accurately diagnose, turn to the possibility that the pain is psychosomatic or imagined (Eccleston & Malleson, 2003). When chronic pain remains unexplained, families often experience frustration and distress as continuous testing and medical exploration reveals no underlying cause. As a result of these difficulties, parents are often forced to seek multiple medical opinions (Kashikar-Zuck, 2006). Families are often lacking resources in their pursuit of pain relief: multiple appointments, scheduling difficulties, childcare, missed work, and travelling expenses, to name a few (Bennett et al., 2000). Moreover, McGrath and Finley (1999) note that parents are in a difficult position. Not only does the health care system fail to recognize parents' expert knowledge but also their role in helping their child is poorly defined or under-appreciated.

Families may experience significant levels of distress including emotional, economic, and physical stress which places an intense burden on families' abilities to cope and function (Eccleston & Malleson, 2003; Zeltzer & Blackett Schlank, 2005). Some research suggests that one of the greatest impacts of living with a debilitating condition such as chronic pain is the decrease in activity of not only the individual, but also the entire family (Hunfeld et al., 2002; Walters & Williamson, 1999). Families face a difficult dilemma in wanting to safeguard their children from over-exertion while at the same time allowing them to participate in enough activities to shield them from loneliness and isolation (Walters & Williamson, 1999). Importantly, a cyclical role can occur as family functioning can impact sufferers' experience of pain (Schulz & Masek, 1996) while at the same time the condition also places tremendous burden on the ability of families to manage and cope, thus impacting their level of functioning (Sallfors et al.,

2002). Zeltzer and Blackett Schlank (2005) emphasize that families need to take control of the pain and not allow the pain to take over their lives.

Developmental Lens

Piaget's model of cognitive development has been used to investigate children's developmental understanding and ability to communicate their experience of pain (Brewster, 1982). According to Brewster, Piaget's model explains that children's ability to make sense of their experience is determined by the thought characteristics and limits that are inherent to the developmental stage in which they fall. Piaget's model includes four sequential stages: sensory motor (infant), preoperational (early childhood), concrete operational (middle and late childhood), and formal operational (adolescents and adulthood). As the focus of this inquiry is with school-aged children, a brief description of the middle stages is provided.

The preoperational stage of development is characterized by the development of language and children in this stage use symbols as a means of representing things that are not present. Children in this stage are considered egocentric as they view the world from their own perspectives and are not yet able to take others' viewpoints. Furthermore, they believe that others think in the same way that they do. Thinking at this stage also tends to be narrow as children can typically only focus on one aspect of a situation or stimulus. On the other hand, once children reach the concrete operational stage of development, there is an increase in logical thinking and an ability to understand concepts such as time and space. The concrete operational stage also differs from the previous stage in that children move out of egocentric tendencies and are able to understand and consider multiple perspectives. This is also true in terms of problem solving and children in the

concrete operational stage can account for many aspects of the problem. At this stage there are still marked limits to abstract thinking. In addition to cognitive development, young children are also developing emotional competence.

Children aged 2 to 5 years are more emotionally competent than was previously believed (Denham, 1998). As typical children advance through to their preschool years, they expand their expression and understanding of emotions. There are intrapersonal and interpersonal contributions that aid in a child's emotional development including language, self-concept, perspective taking, and parental modeling, coaching, and others' reactions (Denham, 1998). According to Denham (1998) young children demonstrate a strong understanding of emotion, yet their understanding is not complete. In the developmental process, children are not only working towards understanding more complex emotional experiences but they are also experiencing more complex emotions. By the time children reach school entry, most are capable of naming emotional expressions, identifying emotionally eliciting situations, and understanding causes and consequences (Denham, 1998). Interestingly, children most often learn to identify happy feelings followed by sad, angry, and fearful.

An integral aspect of children's emotional development is also the development of language. As toddlers develop language they use words to get their emotional needs met. Denham states, "[o]ver 75% of 3-year-old children use terms for feeling good, happy, sad, afraid, angry, loving, mean, and surprised" (p. 77). However, children do not develop emotional language in isolation and thus, the extent of their emotional vocabulary and understanding is dependant upon their experiences in their family and other social environments. Furthermore, young children's abilities to manage their

emotional arousal in social interactions are fundamental to their abilities to interact and maintain relationships with others (Denham, 1998). "It is one thing to understand that children show differing patterns of emotional competence across ages and individuals. It is quite another matter to realize that these differences have a very real impact on how children work and play together, and on their feelings of mastery" (Denham, 1998, p. 13). Cognitive and emotional development are integral components of understanding children's pain experiences and in turn, their degree of cognitive and emotional competence impacts their ability to socialize in meaningful ways. Even though human development has important implications for understanding paediatric pain sufferers' experiences, this remains an under-researched area.

Children's developmental level and subsequent ability to understand their experience of pain are contributing factors to childhood chronic pain (Sallfors et al., 2002; Zeltzer & Blackett Schlank, 2005) and yet, many aspects of this dynamic have not been explored (McGrath, 1995). For example, there is little known about children's understanding of their pain experience in terms of individual differences, for example, cognitive development, temperament, early pain experiences, family factors, ability to self-report, and ability to use cognitive and behavioural pain control strategies (McGrath, 1995). Stanford, Chambers, and Craig (2005) also noted that cognitive, linguistic, and social development are often ignored or poorly understood in pain studies. However, some studies have begun to address the issue of development in the experience of pain (Brewster, 1982; McGrath, 1995).

There appears to be a developmental progression in children's abilities to understand their pain experience in that older children have a more complex and accurate

understanding of their pain (McGrath, 1995). Brewster (1982) also noted cognitive maturity as a primary factor in children's ability to make sense of their illness. Consequently, infants and children in early stages of cognitive development have greater difficulty making sense of their pain experiences. McGrath (1995) presented general information about how children in different age ranges conceptualize pain. For example, children aged 36-60 months can give general indications about intensity of pain, begin to talk about pain with some basic descriptive terms, and attach emotions such as 'sad' and 'mad' to their experience. As children get older, approximately about age 5, they begin to distinguish and describe different levels of pain intensity more clearly and they start to implement cognitive coping strategies (McGrath, 1995). However, young children tend to think in a concrete and self-centered way (Kortessluoma et al., 2003) and consequently, abstract concepts such as cause of illness and necessity of treatment are constructs that are often beyond the developmental understanding of young children (Brewster, 1982). This dilemma is undoubtedly intensified when the aetiology of the chronic pain is unknown. If professionals cannot make sense of the pain, how is a young child expected to? Children have their own ways of making sense of their experiences and these perceptions of reality also undergo constant development (Brewster, 1982; Kortessluoma et al. 2003). Children understand the world in qualitatively different ways than adults and when conducting research with children, it is important to make certain considerations to ensure that the inquiry is designed in a developmentally appropriate way (Kortessluoma et al., 2003; McGrath, 1995). For example, a study that investigated children's abilities to verbalize their pain experiences noted that many of the self report pain assessment tools, such as face scales and pain questionnaires, rely on children's ability to comprehend the

instructions and use words to describe their pain (Stanford et al., 2005). Furthermore, these techniques are founded on unsubstantiated assumptions that children can understand and use these terms when making sense of and communicating their subjective pain experiences (Stanford et al., 2005). It is essential to develop strategies and tools that are developmentally appropriate in order to help children clearly express their understanding of pain (McGrath, 1995).

Summary

Chronic pain is not well understood in terms of how it is defined and measured; how many children are affected; what contributing factors play a role in the initial onset and on-going maintenance of the condition; and what impact this condition has on the child and his/her family. However, many groups may be included under the umbrella of chronic pain and thus, the prevalence of this condition among children is sufficient to warrant further investigation. Chronic pain appears to be best understood within physiological, psychological, and social contexts, especially in terms of the family. The implications for sufferers can be significant, especially the degree to which their participation in peer and family activities is restricted as this can lead to slowed developmental progress, isolation, depression, and anxiety. For families, the implications can include burdens in physical, emotional, and economic resources. As professionals and families strive to find ways to cope with and manage their experiences, art in therapy presents a strong argument for its therapeutic possibilities.

Art in Therapy

Definition

Art in therapy is often defined as an exploratory process that uses art media as a

tool to help individuals elicit their internal experiences in order to gain increased awareness and understanding of themselves in the world (Rubin, 1984). According to the American Art Therapy Association (n.d.), using art in therapy is a creative process in which clients engage in the use of art media and images in order to create art productions that represent reflections of who the art maker is in the world including aspects such as development, abilities, personality, interests, concerns, and conflicts.

History

Art therapy has been used within psychotherapy since the early days of psychology (Hass-Cohen, 2002). Some authors believe that it became recognized as a separate modality or formalized therapy in the nineteen-sixties (Hass-Cohen, 2002), others believe that its inception dates back as early as the nineteen-fifties (Riley, 2004), and yet the American Art Therapy Association (n.d.) cites that it emerged as a distinct profession in the nineteen-thirties. Art therapy has traditionally been reflective of different theoretical orientations including Psychoanalytic, Jungian, Humanistic, and others (Hass-Cohen, 2002). To further expand on these different orientations is beyond the scope of this paper and readers who are interested in learning more about these can consult *Approaches to Art Therapy* by Rubin (1987). However, many modern art therapists are likely to take a more eclectic approach (Hass-Cohen, 2002) and Wadeson (1987) advocates against using a specific theoretical framework as it may influence the therapist to view the picture through a narrow lens and impact what is seen. This author further argues that the goal of the art therapy is to build a bridge between the client and the therapist; therefore, the therapist must be willing to meet clients' presenting needs.

Major Components

Foundational Beliefs. Art therapy is built on the belief that there is a relationship between self-expression and emotional health (Carlson, 1997). Healing occurs during the creative process of expressing one's self (Burick & McKelvey, 2004). Since the created art products contain parts of the client's identity (Synder, 1997), it is important that this inner voice is heard and respected (Burick & McKelvey, 2004). While artistic skills are not necessary to the process of art therapy, this approach to therapy may be more appealing for those that are visual or tactile learners (Hass-Cohen, 2002). Art therapy is an exploratory process which aims to help individuals to discover their internal world of feelings, thoughts, experiences, conflicts, etc. and to come to a place of greater understanding and life-enhancement as they move toward change in their lives (Rubin, 1984).

Relationship. The relationship between the art therapist and the client is crucial to the process and must envelop trust, empathy, and safety in order to offer clients a sense of containment as they test boundaries, explore, and engage in the art making process (Arguile, 1992; Burick & McKelvey, 2004; Stronach-Buschel, 1990; Wadson, 1987). Collaboration is another key component of the therapeutic relationship as the shared experience between the client and therapist leads to a co-created conversational context (Riley, 2004). The therapist must balance between knowing when to join with the client as a way of modeling and engaging the child and not intruding on the client's creative process (Rubin, 1984; Sundaram, 1995). The therapist's role is to facilitate expression (Rubin, 1984) and stand witness to the client's experience in a non-judgmental way (Burick & McKelvey, 2004). This empathic stance allows entry into the internal and,

often times, painful world of the client (Prager, 1993).

Materials. Different art media have inherent qualities in which individuals respond to both emotionally and cognitively and art therapists need to have a sense of the inherent characteristics of each media tool (Rubin, 1984). However, people respond very differently to art media; in part due to the qualities of the material, but also because of the unique set of past experiences which the individual brings to the art making (Rubin, 1984). For example, finger paints may feel freeing to one child and overwhelming to another. Rubin suggests that the more unstructured the medium, the more the child can project upon it. Although different art materials may be threatening if they are unfamiliar, as individuals develop their skills they are able to gain control over the media and eventually learn that the art can help them to express and understand themselves (Rubin, 1984). Riley (2004) indicates that she will often go along with whatever media the client chooses as his/her choice is often indicative of what feels most comfortable.

Environment. The environment in which art therapy occurs must be supportive of the physical and emotional safety of the individual (Burick & McKelvey, 2004; Stronach-Buschel, 1990). When clients feel safe, they can engage in the process and allow their internal worlds to emerge (Farrell Fenton, 2000). Not only must clients gain trust in their therapists, they must also gain trust in the environment before they will express through their art (Stronach-Buschel, 1990). Children need to be safe in their exploration of the physical environment and therefore, the therapist should be aware of the client's developmental level and any physical limitations that may be relevant to the setting (Sundaram, 1995).

Benefits

Art therapy is based on the belief that the creative process involved in the making of art is healing and life-enhancing. Through creating art and talking about art and the process of art making with an art therapist, one can increase awareness of self, cope with symptoms, stress, and traumatic experiences, enhance cognitive abilities, and enjoy the life-affirming pleasures of artistic creativity (The American Art Therapy Association, n.d.).

Participating in art-based therapy has been found to have a significant and profound impact for many individuals. The combination of visual, auditory, kinaesthetic, and tactile modalities that are inherent to art approaches creates an interactive process that addresses problems on more than one level and are ultimately highly effective (Riley, 2004). Art in therapy is a vehicle for creativity and expression of self (Carlson, 1997; Hass-Cohen, 2002; Riley, 2004; Synder, 1997). Through the process of self-expression, individuals can learn more about their feelings and thoughts (Burick & McKelvey, 2004); internal conflicts and hidden resources (Synder, 1997); and needs and experiences (Hass-Cohen, 2002). In turn, they can create personal meaning and life-enhancing change (Synder, 1997). Being creative is in and of itself healing and it promotes a sense of joy and accomplishment in the midst of a process that may include moments of pain and anguish (Hass-Cohen, 2002). Art gives permission for individuals to express themselves through creative means in a very personal way (Carlson, 1997). Art-based therapy uses this creative process to give people the opportunity for their internal experience to find a concrete way of being in the outside world (Reynolds, 1990). Thus, art making can become the mechanism for emotional release and can give voice to one's unconscious, where words are simply not possible (Farrell Fenton, 2000). Art therapy is effective because the symbolic expression inherent to creating art allows for a release of the emotional content of the right side of the brain through the autonomic nervous system

(Tinnin, 1990).

Art-based therapy is especially useful for working with children in that it meets their developmental needs. Children use art as language before they become verbal (Hass-Cohen, 2002) and both healthy and ill children alike turn to play, including art, as a tool to cope (Sundaram, 1995). Art therapy is a way for children to engage in therapy in an effective and safe way (Hass-Cohen, 2002) while at the same time, the liberating characteristics of the art media help children lower their defences (Sundaram, 1995). Not only is art fun for children (Stronach-Buschel, 1990), it also helps facilitate the telling of their story. In turn, these images can significantly impact their relationship with the problem as well as their relationships with significant others (Carlson, 1997; Riley, 2004).

Development in Art

Children work through predictable stages of development in terms of their interactions with art materials. At the same time, the progression through the stages is a highly individualized process and is by no means linear (Rubin, 2005b). Children create images based on both internal needs and external stimuli and yet, art making behaviours are also likely explained by a combination of several different factors including neurobiological sources, preferred sensory modalities, cognitive development, appropriate growth-tasks, defence mechanisms, and external forces such as the influence of others (Rubin, 2005b). The interaction of variables is complex and although there are generalizations made about developmental stages, there is also a significant range within developmental groups. Therefore, it is important to assess and to understand developmental factors in the context of what is already known about the child.

Rubin (2005b) has created a model that identifies the different stages in which children progress. Although she provides an age guideline, she emphasizes that children develop at their own rate and may differ from the typical progression by as much as a year. The first stage (1 to 2 years) is 'manipulating' and is characterized by the sensory and motor-kinaesthetic exploration of the materials. As children near the end of this stage they begin to pay attention to not only the making process but also to the product that is being made. At age 2 to 3, in the 'forming' stage, children gain more control and skill in their use of art mediums and in turn, begin to act with the materials in a deliberate way. They experiment and explore with the shapes and designs that they can create - initially repeating movements and then creating separate and distinct shapes. The third stage is known as 'naming' (3 to 4 years) and in accordance with typical language development, children will begin to name their creations as real things, despite the fact that the objects they name do not yet resemble the actual object. "Their identity often shifts to a fluid fashion because it is not fixed in any quality of the creation, but rather in the child's association to the form at a particular moment" (Rubin, 2005b, p.38). Eventually, children begin to create images that are representational of the characteristics of the things they represent. This stage is called 'representing' and typically occurs from age 4 to 6 when children create things based on what they know. Typically the characteristics that are depicted in a creation are representational of what is important to the child creator at the time it is being made. The fifth stage is 'consolidating' (6 to 9 years) and "[t]hey begin to find preferred ways of saying things pictorially and tend to repeat them, rather than to go on as before, trying out different ways" (Rubin, 2005b, p. 40). Although the creations are not yet naturalistic, they make sense to the child creator based on their

view of the world. As children shift from this egocentric point of view, their images also reflect a broader scope and begin to incorporate other objects beyond their self and their family. The 'naturalizing' stage (9 to 12 years) is characterized by the increasingly realistic, proportionate, and accurate detailing of representations. Additionally, children in this stage become increasingly concerned about their ability to depict representations well. Finally, those individuals who continue to engage in art making during adolescence have the potential to create very naturalistic creations. Their creations often reflect their struggle with identity formation as they personalize their work and explore with different styles of art making.

Art with Families

Family art therapy has been credited to Kwiatkowska (Donnelly, 1992) when she stumbled into this idea by accident while working in a hospital setting (Kwiatkowska, 2001). Art has traditionally been used in individual therapy; however, after Kwiatkowska noticed the significant impact on visiting family members when they were asked to join the session, she became curious about how art therapy could be used with entire families. Family art therapy differs from other group therapies in that members are not only linked by a common problem but family members have also been operating as a group for many years and thus, have developed distinct patterns of interaction (Kwiatkowska, 2001).

Families present a distinctive challenge in that members are often of varying ages, developmental levels, and differing world views (Riley, 2004). In family art therapy, Riley indicates that by asking each family member to create an image, it provides the opportunity for each family member, regardless of age, to represent their story and have equal access to the therapist. As such, art therapy within the family context can often

increase the participation of young children and give them equal opportunity to express their thoughts and feelings and have those heard by the rest of the family and the therapist (Donnelly, 1992).

Moreover, art in family therapy offers opportunities to enhance the therapeutic process as the combination of verbal and visual aspects provides different lenses to explore and observe the family system by the therapist and the family (Riley, 2004). It provides unique possibilities to gain clarity and insight into family dynamics, roles and rules, and interactional patterns; as well as creating an environment in which families share experiences of relating to each other in new and different ways (Hass-Cohen, 2002; Riley, 2004). Art tasks provide families opportunities to view their family system from a place of distance. This stance often stimulates conversation and can help the family gain new insight into the problems and in turn, help them incorporate new perspectives into their stories (Riley, 2004). The use of art is integral to this possibility as words may not be enough to shift rigid patterns of behaviour (Riley, 2004).

The created images are often laden with symbols and metaphors. In exploration of these messages, the family and therapist can gain understanding into the uniqueness of each person's narrative and commence a journey to discovering alternate endings (Riley, 2004). Often within the process of exploration of each person's story, perceptions and misperceptions are revealed and the communication system becomes more overt (Riley, 2004). Kwiatkowska (2001) suggests that when families' communication systems are not troubled by their usual defences, strong feelings can be shared without resulting in the experience of guilt. Families are eventually able to shift old patterns of interaction and communication to more workable views thus moving into a new phase of change. "When

the family was released from the stereotypes they had assigned to each other, they were able to move from an outmoded stage of development to a new one” (Riley, 2004, p. 109).

Family therapy presents unique challenges and thus, demands more creativity and skill than other types of therapy (Carson, 1999). According to Taibbi (1996), family therapy “requires a flexibility, a creativity, an ability to fly by the seat of your pants that exponentially increases with the number of people in the room and their level of distress and conflict” (p. 3). Riley (2004) suggests that family art therapists can contribute to family therapy by meeting this need for creativity and innovation. “When families begin telling their stories, imagining new endings, finding new truths, they are becoming creative” (Riley, 2004, p. 35). The images evoke discussion of meaning and thus, encourage creativity and add excitement to the therapeutic engagement (Riley, 2004).

Art Therapy with Children in Pain

Art can be an integral component of working with children in exceptional circumstances such as chronic pain, trauma, and illness. Not only is it difficult for traumatized children to put their feelings into words (Savins, 2002), it may be easier for traumatized children to regain their visual modes of communication before verbal modes (Stronach-Buschel, 1990). Even when verbal skills appear to be in place, there may be some feelings that are too difficult to talk about. Children may also lack the sophisticated language needed to describe complex feelings and yet, they can find form through paintings, drawings, sculptures, or other symbols (Farrell Fenton, 2000). Furthermore, dependent upon their cognitive level, children have different abilities to understand their conditions and the related implications. According to Prager (1993), “It is evident that

there is a progressive development in the cognition of illness, in which tools for comprehension do not become fully available until adolescence” (¶3). As such, children may not only have difficulty putting words to their experience, they may also have limited understanding of what their experience means.

Play is an integral component of children’s learning and development and research suggests that traumatized children are often negatively impacted in their ability to play. Thus, their abilities to make sense of both their positive and negative experiences are hindered (Savins, 2002). Rubin (1984) also indicates that children’s development does not proceed in the same way as typical healthy peers when they face an inability to cope with the demands of their situation. Children’s drawings can deliver a healing power and by opening their creativity and imagination, children are better able to cope with their overwhelming situation (Sundaram, 1995). In art-based therapy, children find expressive ways of organizing and externalizing confusing and poorly understood emotions and as result they can gain clarity and healing over the experience (Prager, 1993; Savins, 2002). In addition to using art media to express internal dilemmas, children experience a sense of control over the media being used and they gain an increased feeling of empowerment in their lives (Farrell Fenton, 2000).

Conclusion

Art-based therapy provides a venue for exploration and self-expression. Through the use of art media, children can find creative means to express their internal subjective experience while increasing their abilities to cope with and manage chronic pain. As families play such an integral part in their children’s responses to chronic pain and since families have their own struggles in relation to this debilitating condition, family art

therapy offers unique opportunities to explore the interactional behaviour and communication patterns of families. As family members have opportunities to tell their unique stories and have those stories heard, they can begin to imagine new alternatives and experience new ways of relating to each other. They learn about each others' experiences and perceptions of chronic pain. As the issues become clearer within the family communication system then family members begin to respond and interact in healthier ways (Riley 2004).

Many of the benefits and strengths of art based approaches in therapy translate into the research realm and as such, there is a strong argument for the emergence and relevance of art based inquiries, especially with populations such as children with chronic pain and their families. In Chapter Three, the research methodology of this inquiry is presented.

Chapter Three: Research Methodology

The purpose of this chapter is to outline the research design that was used to investigate the following questions: What are the experiences of a family that has a child living with chronic pain? How does the chronic pain play out in this family's life - socially, emotionally, physically, and spiritually? What kinds of strengths and resources is the family drawing upon to fight the battle with chronic pain? The following areas will be discussed: research approach, research design, researcher assumptions, participants, data collection, data analysis, and ethical considerations.

Research Approach

The purpose of this study was to gain a rich description and an empathic and contextual understanding of the experiences of a young chronic pain sufferer and his/her family members. Therefore a qualitative paradigm was chosen. Qualitative research allows the researcher to focus on the particular phenomenon being studied and to remain flexible enough to respond to and explore the complexities of the subject as a means of providing a holistic treatment of the phenomenon (Gillham, 2000; Maxwell, 1996; Stake, 1995). Unlike quantitative designs, qualitative research approaches offer a unique opportunity to explore a range of dimensions including experiences, imaginings, processes, relationships, understandings, and meanings (Mason, 2002), dimensions that often emerge in the context of the research and can not be accounted for in advance. Mason describes qualitative research as "exploratory, fluid, flexible, data-driven, and context sensitive" (p. 24). As a result of the emergent nature of qualitative inquiry, the researcher can present persuasive arguments about how things work in his/her given context (Mason, 2002). Moreover, a qualitative approach aims to explore the multiple

realities of all participants in order to gain an experiential understanding and ultimately offer the reader a thick description that enriches the understanding of the phenomenon in question (Stake, 1995).

The perspective on events and actions held by the people involved in them is not simply their account of these events and actions, to be assessed in terms of truth or falsity; it is part of the reality that you are trying to understand. (Maxwell, 1996, p. 63)

Research Design

A multi-method approach was used to address the unique context of this inquiry and incorporated theoretical methodologies from case study, art inquiry (including approaches termed art-based education research), and narrative. The research project took place within a case study framework, while the mode of inquiry drew from the art-based approaches. The data analysis process was informed by art inquiry, specifically symbolic constructivism and narrative methodology.

Case Study

Within this research project, I drew upon the research framework of case study as I worked with a complete bounded system, a family unit (Stake, 2005; Yin, 1994). This particular approach was especially important as the phenomenon being studied, in this case a family's experience of having a child living with chronic pain, was embedded in the context and the boundaries between the phenomenon and the context were not clearly distinguishable (Yin, 1994). A case study approach allowed for the exploration of the phenomenon's complexities in a way that may not have fit within the scope of other research approaches (Gillham, 2000). This framework also afforded the advantage of coming to an understanding of the multiple realities of the participants from an inside perspective (Gillham, 2000). My goal in this case study was not to necessarily map out

the phenomenon, but was to provide an enriched understanding of the family's experience of living with a young chronic pain sufferer.

Stake (2005) describes this approach to case study research as 'instrumental' (p. 445) as the researcher's goal is to present a holistic view of the case including a thick description of the multiple experiences and processes that are integral to understanding the phenomenon in question. Although, "the whole story exceeds anyone's knowing, anyone's telling" (Stake, 2005, p. 456), the end product will provide a rich enough description that the reader vicariously experiences the phenomenon. Thus, the case study description results in an increased sense of insight, empathic understanding, and ultimately, expands the reader's own experience (Merriam, 2001). An integral part of gaining a holistic view of the phenomenon is approaching it from multiple perspectives in order to develop a more accurate and complete picture, a process often referred to as triangulation (Gillham, 2000; Maxwell, 1996; Stake, 2005).

Triangulation is traditionally accomplished by using multiple sources of data; for example, interviews, observations, artefacts, and/or visuals. The use of these multiple data sources is not only a key characteristic of case study research but is also considered a unique strength of this approach (Yin, 1994). The intention of using multiple sources is that each source has its own strengths and weaknesses and thus, using more than one can overcome the limitations that are inherent to each (Gillham, 2000; Maxwell, 1996). However, the current project relied on a different use of triangulation in that the participants explored the topic of chronic pain from multiple perspectives by engaging in five different art activities as well as debriefing the art making process to tease out the potential multiple meanings within the art products.

Art Inquiry

“When we create artistically to learn more about ourselves, we open to laughter, tears, anger, fear, excitement, and wonderment” (Barry, 1996, p. 412). Many art-based approaches are founded on the beliefs that art making acts as a catalyst in accessing individuals’ alternate forms of knowing (Barry, 1996; Riley, 2004); non-conscious or out of awareness beliefs, feelings, and experiences (Barry, 1996); and deeply emotional experiences that draw upon a level of consciousness that does not rely on language (Scott-Hoy, 2003). Art making serves as a vehicle to bring what is private into the public realm and gives form to the conceptions that emerge in the process of expression (Finley & Knowles, 1995). It is important that this form must not be chosen haphazardly, as it must emerge from the work itself (Scott-Hoy, 2003). The process of art making can help individuals to let go of logocentric tendencies, view their creations through a more interpretive lens, and begin to understand the potentiality or multiple meanings that may be constructed within their visual representations (Barry, 1996). In turn, participants reveal parts of their world that they either had not previously considered or had intentionally avoided and gain a sense of self-understanding that may not have otherwise been possible (Barry, 1996; Bochner & Ellis, 2003). Given the potentialities, it is clear that art making as a mode of inquiry adds another dimension to qualitative research methods (Blumenfeld-Jones, 2004). Yet, historically visual data has been viewed more as a mode of representation, not inquiry (Bochner & Ellis, 2003).

Visual data have a long history in both anthropology and sociology, but for the most part, visuals have been used to enhance textual data or to act as a mode of representation (Ball & Smith, 1992; Bochner & Ellis, 2003). However, this research

approach aims to use art as the mode of inquiry (Barry, 1996; Bochner & Ellis, 2003). In other words, the art making is “the interview” and as such, the images are not intended to enhance the participants’ stories - the images are the stories. The conversational exchanges that accompany the images are intended to help the researcher and participants to understand the potential and possible multiple meanings that are co-constructed within the image (Barry, 1996). Symbolic constructivism includes three styles of inquiry: eliciting, revealing, and transformation. This research project draws upon both the eliciting and revealing styles. Barry (1996) describes the ‘eliciting’ style of inquiry as a descriptive approach in which the creation of images and symbols is intended to engage participants and have them impart more than they might otherwise while the ‘revealing’ style has an interpretive characteristic in which the focus is to explore what is not being said and explore implicit or out of awareness aspects of the image.

Art becomes a process and form of inquiry. Art can be representational, but it can also be evocative. Embodied, sensual, and emotional; art can be viewed as an object or a product, but it is also an idea, a process, a way of knowing, a manner of speaking, an encounter with others; art can reveal an artist’s perceptions and feelings, but it also can be used to recognize one’s own. (Bochner & Ellis, 2003, p. 508)

Narrative

Narrative research methodology is distinct from approaches that simply include narratives in that it is based on narrative theory (Hoshmand, 2005). Narrative theory postulates that people make sense of and organize their lived experience through stories and these stories in turn shape the individual’s reality (Freedman & Combs, 1996). The stories grow out of experiences in social and cultural contexts and thus, are greatly embedded in the values of those contexts (Hoshmand, 2005). As clients explore their stories, they are able to understand the influence of these stories on their lives and take on

new language and meanings that are more adaptive (Overcash, 2004). Similarly, narrative research approaches focus on the experiences of individuals, contextual understanding, and the discussion of meaning (Creswell, 2005). "Stories are powerful research sites. They provide us with a picture of real people in real situations struggling with real problems" (Bach, 2001, ¶8). Stories are embedded in social and cultural contexts and thus, the interchange of dialogue between researcher and participant results in a co-construction of both story and meaning (Aranda & Street, 2001). Narrative research provides a common way of connecting with real life problems (Carson & Fairbairn, 2002). As such, this form of research offers a congruent way of conducting qualitative research as it entails an approach that closely resembles practice for many helping professionals, as opposed to other methodological approaches that are so far removed from what practitioners actually do (Carson & Fairbairn, 2002).

With an awareness that there is a difference between what people can show versus what they can say, verbal accounts are not the only way that stories can be elicited (Bochner & Ellis, 2003). Visual narratives provide another place for the reconstruction of meaning regarding images and stories. As Bach (1998) describes, "I wanted the girls to be the image makers of their stories, and I hoped to provide a space for them to make a textbook of their lives, a possibility to document, reflect, and imagine" (p. 14). As the participants manipulate the art media, they have opportunities to be autonomous, flexible, and unguarded (Bach, 2001). Additionally, visuals add another dimension to the story and offer a window into different aspects of the story (Bach, 2001). Bochner and Ellis highlight art as a mode of inquiry was important because of "what it awakened or evoked in the spectator, how it created meanings, how it could heal, and what it could teach,

incite, inspire, or provoke” (p. 507).

Researcher Assumptions

I was an integral part of the research as the data that emerged from the inquiry were constructed within the context of the researcher-participant relationships (Stake, 1995). Therefore, I acknowledge my beliefs, values, and assumptions in order to understand my influence on the research and my impact on the final product (Stake, 1995). I relied heavily on memos to facilitate my self reflection in order to document and understand my role in the research (Maxwell, 1996). These memos included information about my ideas, impressions, decisions, and experiences within the research context. I considered the following points as being beliefs, values, and/or assumptions that are relevant to the research inquiry:

1. Participants are the experts on their own experiences.
2. Each participant has a subjective reality; truth and falsity are irrelevant.
3. People's stories represent their truth and are often reflective of the unique environment in which they are told.
4. Knowledge is socially constructed and largely impacted by social, cultural, and political contexts.
5. Individuals cope the best way they know how.
6. Art making accesses personal knowledge centres that may not be available to language.
7. Individuals who agree to participate are willing to engage in the art activities.
8. In accordance with the research, families with young chronic pain sufferers experience some degree of one or all of the following: social, emotional, physical

and spiritual distress.

9. Families inherently have strengths, resources, and resiliencies that they are drawing upon in their battle with chronic pain.
10. Strengthening the family unit with increased coping skills and increased communication skills can result in higher levels of family functioning and well-being and in turn, families gain a sense of empowerment.
11. Researcher's own experience of chronic pain will play a role in understanding families' experiences.

Participants

Within this qualitative inquiry, a purposive sampling strategy was used (Stake, 2005) to ensure that the participating family not only met the basic criteria but they could also offer a rich opportunity for learning that may not have been possible with other choices. The family was chosen based on the criteria that a child aged 6 – 10 within the family was living with chronic pain. Family was loosely defined and could have included individuals with whom the family identified as being fundamental to the understanding of the 'case'. Chronic pain was defined as any persistent or reoccurring pain that lasted for a duration of no less than three months, with known or unknown aetiology, and that interfered with the family's level of functioning. Due to the difficulties in diagnosing chronic pain (Eccleston & Malleon, 2003), the researcher relied on family members' self-reports in relation to these criteria.

Further considerations included: number of family members who were interested and willing to participate, openness to engaging in art making; developmental levels of individual family members; availability of family, transportation and location issues; and,

recommendations from referring professionals. No artistic talent or abilities were needed as the focus was not on the aesthetic nature of the art productions.

Data Collection

Types of data

Art making and debriefing. Participants were asked to engage in an art task that was structured in the sense of offering a directive (Table 1) yet open and flexible to how individuals responded to this directive. Thus, the responses were reflective of the individuals' unique subjective experiences. Individuals had an opportunity to project their conscious and out of awareness emotions, thoughts, fears, experiences, etc. through the art media and onto the creation (Barry, 1996; Riley, 2004). These images thus became visual representations that offered a new dimension to individuals' stories (Bochner & Ellis, 2003).

The debriefing that followed the actual art making was intended to help individuals become clear about the messages that were being reflected through the images they created (Linda Lange, Registered British Columbia Art Therapist, personal communication, September 27, 2005). However, as this process occurred in the context of relationship, the meanings were inter-subjectively co-constructed among the participants and the researcher (Barry, 1996). The debriefing process was facilitated by joining with the participants in viewing the creations from a different perspective, asking open-ended questions (Appendix A) and sharing observations and curiosities with the participants in order to gain a strong level of mutual understanding (Barry, 1996). The debriefing process was audio recorded and transcribed by the researcher in order to accurately capture the words of the participants in order to create stories that gave voice

Table 1

Outline of art activities

	Session #1	Session #2	Session #3	Session #4	Session #5
Title	Representation of self	Family Picture	Body Maps	Metaphor of Pain	Collage
Materials	Paper (11X17) Felt markers Pencil crayons Wax crayons	Paper (11X17) Felt markers Pencil crayons Wax crayons Pastels	Body outlines Felt markers pastels	Paper (11X17) Tempera paints Paint brushes	Paper (11X17) Pre-cut magazine images Glue Scissors
Directive	I would like you to draw a picture of yourself. This can be a self-portrait or a thing that you identify with such as a tree or an animal	Draw a picture of your family with everybody doing something	Colour in the body outline using different colors and shapes to show where you experience feelings and sensations in your body	Imagine what the pain looks like and paint that image.	Use the images to create a collage that represents the different things or people that help you cope and feel better and give you strength.

Purpose	To gain a sense of how each member of the family views themselves	To learn about members' experiences of living with their families.	To discover the emotional experiences that each member is managing and to increase awareness about the body connection	To externalize the pain and get a sense of how each person subjectively experiences the pain.	To uncover the strengths and resiliencies of each person.
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Source	Researcher consulted with Linda Lange, BCATR	Ziffer and Shapiro (1992)	Ziffer and Shapiro (1992)	Researcher consulted with Linda Lange, BCATR	Researcher consulted with Linda Lange, BCATR
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to their experiences. This information was used to reconstruct the stories of this family for presentation in the thesis.

Memos. In narrative research and symbolic constructivism, it is crucial that researchers be able to be reflexive and account for their own perspectives (Barry, 1996; Creswell, 2005). The researcher did not come to the research as a blank slate but entered “the research scene full of hopes, aesthetic leanings, preconceptions, stereotypes, and media preferences, all of which strongly influence the research endeavour” (Barry, 1996, p. 417- 418). The process of making memos encouraged a self reflective practice as “expertise comes largely through reflective practice” (Stake, 1995, p. 50).

Memos consisted of brief marginal comments, theoretical ideas, and a field journal (Maxwell, 1996). This technique was used to document reflections and ideas; to work out problems; to make sense of a topic, setting, or study; and most importantly to attempt to understand how the researcher was participating in the research (Maxwell, 1996). Memos were an important tool as thoughts and ideas became represented in a form that allowed for further examination and manipulation (Maxwell, 1996).

Procedures

Phase One: Recruitment. Once approval from the University of Victoria’s Ethics Review Board was received, the initial step was to begin the recruitment process. I began by contacting various community agencies such as Victoria Child and Youth Mental Health, The Pain Clinic, Child and Family Counselling Association, The Boys and Girls Club, Separation and Divorce Centre, as well as private clinicians such as child psychologists, paediatricians, and child psychiatrists who work with children. Each contact was asked if he/she would be willing to receive an outline of the research inquiry

and if he/she would consider passing the information along to any clients who met the criteria and were interested in participating (Appendix B). The outline included the purpose of the project, participant criterion, participation involvement and requirements, timeline information, and contact information so that families could contact the researcher directly if they were either interested in participating or had any questions or comments (Appendix C).

Phase Two: Sampling. As the recruitment process did not result in many responses, it was not necessary to gather information from or choose from multiple potential participants. Two families decided that given their presenting situation at the time of recruitment they opted not to participate. A third family indicated an interest and after an in-depth telephone conversation with the mother and after she discussed it with her husband, the researcher was informed that they would like to participate. An initial appointment was arranged at which time the family reviewed the informed consent.

Phase Three: Preparation. Once the parents agreed to participate, a 30 minute meeting was arranged to review the research outline, to discuss and sign the consent form, and to respond to any concerns, questions, or comments that might impact the participation within this research inquiry. The family requested that the sessions would take place at their home each week. Once the participants were clear about the requirements of the study and were still willing to participate, each parent was asked to sign the Letter of Informed Consent form (Appendix D). A date and time for the subsequent session was set each week.

Phase Four: Data Collection. At the beginning of the art making phase of this research inquiry, the family was informed that creating art is not about the end result and

the art was in no way evaluated in terms of aesthetics or talent. The purpose of using art was to help facilitate the expression of ideas, to access other ways of knowing, and to add a little fun to the process. The art materials were provided by the researcher, unless participants chose to incorporate personal art media into their creation(s).

The five art making sessions included a debriefing to facilitate the co-construction of meanings. The researcher consulted with registered art therapist, Ms. Linda Lange, regarding the choice of activities, materials, order of activities, as well as sample questions. Amendments were based on her suggestions (personal communication, September 26, 2005). An outline and brief description of the art task for each of the sessions, including the title, materials, directives, and sources is provided (Table 1). Due to the emergent nature of this type of inquiry, the debriefing questions were largely dependent on the images within the creations, yet a few sample questions are provided (Appendix A).

Each session was approximately 1 – 1.5 hours; however, only the debriefing component was audio recorded. Additionally, still photos of each art piece were taken and the researcher maintained possession of all art work for the sole purpose of data analysis until the final session at which time all the art work was returned to the family in a compiled book. The participants were observed throughout each art project and the researcher interacted to differing degrees depending on the presenting situation and the individual needs of the participants. Participants were given approximately 30 minutes to complete their projects before being asked to share their images. If the participant(s) indicated they were not yet finished, they were encouraged to continue working on them after we had talked about the pictures and to participate with as much as was completed.

The debriefing process included questions about the stories, meanings, forms, colours, experiences that were contained in the image or were absent (Appendix A). Each person was given the opportunity to share anything further that would help in ending the session.

Phase Five: Closure. The final phase of the data collection procedure included a sixth session with the family to celebrate our work together and to review the artwork. At that time, each person's art work was displayed and in turn, each person was given an opportunity to reflect on his/her experiences of the art making and his/her participation in this research inquiry. The final debriefing was facilitated in order to provide an opportunity for each family member to share any final thoughts and bring closure to the experience.

Data Analysis

Data analysis was an on going process that began immediately and continued throughout until the final draft was complete (Maxwell, 1996). This research project used analyzing techniques derived from both symbolic constructivism art inquiry (Barry, 1996) and narrative research. It is important to note that in accordance with Barry, pre-established symbolic interpretations were not used as they can interfere with the developing interpretations and they contradict epistemological values. In other words, the participants meaning making processes are of interest and predetermined ideas about the meaning of different symbols could potentially undermine the participants' stories. The first two stages of data analysis occurred concurrently with the data collection and the final stage took place once all sessions had been completed and the collection of new data was finished.

Phase one: Co-construction of meaning

The first stage of analysis took place during the debriefing following the art making activities. The family members debriefed their images together. During this stage, multiple symbolic readings were taken by asking the participants to consider different questions as they viewed their images (Barry, 1996). Approximately five questions were chosen per session to ask the family members and for the most part, each person was asked the same main questions, yet clarifying or probing questions differed among participants. As the participants shared their responses and interpretations, the researcher held a reflexive stance in which attention was paid to interpretations and feelings about the images. Some of the researcher's thoughts and curiosities were disclosed with the participants in order to co-construct more comprehensive understandings, while at the same time respecting both opinions and allowing room for both opposing and shared viewpoints (Barry, 1996). This process continued until the researcher reached a "good enough" (Barry, 1996, p. 413) level of understanding that was intellectually and emotionally satisfying. This level was considered reached when participants indicated that they were satisfied with the level or degree of processing, and the researcher's expressed understanding, and when each member expressed a desire to move on. These interactions were audio-taped and transcribed for later reference and use.

Phase two: Visual images

In this stage, the researcher spent time after each session with the art creations from each week and wrote about the images, noting impressions about not only the visual stories but also the essence of their verbal stories. During this stage, narrative analysis techniques were incorporated into the research by paying attention to any themes within

each image and across all family members' art products that emerged as well as impressions that the researcher came to understand given the unique context of the family (Creswell, 2005). These memos were incorporated into the final stage of data analysis as a way of accounting for the researcher's perspectives and impressions.

Phase Three: Retelling the stories

In this stage, the focus was on giving voice to and maintaining the integrity of the participants' stories. As such, personal narratives were compiled for each creation and those stories were embedded within the larger context of this project. In order to accomplish the first part of this stage, each person's visual representations and relevant transcripts were reviewed. The transcripts were used as the basis for the re-storying process. The documents were edited with the intention of capturing the participants' voices and experiences as much as possible while allowing the stories to flow in a way that would help capture and engage the reader. The researcher was careful to maintain the integrity of the stories by including many of the participants' words and noting them with quotation marks. Researcher memos were reviewed and incorporated into a section to account for researcher impressions and ideas about the images and accompanying stories. Part two of this stage involved contextualizing the stories in the bigger picture of how the project unfolded and thus, information about how each session began and a general overview of what occurred was provided with the stories in Chapter Five.

Phase Four: Discussion

In the final stage, a discussion about the results was formulated that responded to the research questions, highlighted relevant themes and drew out points of interest. The information presented in this section was determined by the research questions, which not

only helped maintain the focus of the discussion but also helped to communicate how the purpose of this research inquiry was satisfied. In reviewing each of the research questions, the researcher was able to read through the participants' stories and generate ideas and themes about how the participants had responded to those questions.

Rigor in Qualitative Research

One of the greatest challenges that qualitative researchers face is demonstrating to critics that although research validity can not be conceptualized in the same way as in quantitative approaches, it is equally as important and valued in qualitative approaches (Krefting, 1991; Mason, 2002; Shenton, 2004). Therefore, many researchers have developed related, but distinctive terms, to discuss research validity and rigor as it relates to qualitative approaches: accuracy and authenticity (Creswell, 2005); credibility and trustworthiness (Creswell, 2005; Krefting, 1991); and, generalizability and reliability (Mason, 2002), to name a few. Furthermore, given the variety of designs within the qualitative paradigm, not all criteria have the same relevance and therefore, consideration is given to the intentions of the specific approach that is being used (Krefting, 1991).

For this project, the term trustworthiness was used to represent the intention of this research inquiry as it relates to its quality. Lincoln and Guba (1985) present a model with four constructs in qualitative work for assessing trustworthiness: credibility, transferability, dependability, and confirmability. Shenton (2004) and Krefting (1991) use this model to provide a framework for considering strategies to ensure that these constructs are met and that steps are taken to manage threats to the trustworthiness of the study. The specific strategies used within this research inquiry as they relate to Guba's model as informed by Shenton and Krefting are presented.

Credibility

Credibility represents the degree to which the findings are representative of the reality of the phenomenon being studied (Shenton, 2004). When the idea of multiple realities is fundamental to the research inquiry, the researcher must represent these multiple realities as sufficiently as possible (Krefting, 1991). The following strategies were used to help ensure that the construct of credibility was met:

1. I met with the family several times as a means to build relationship and gain trust as the research inquiry progressed.
2. I explored the topic of chronic pain from multiple directions by asking family members to engage in five different art tasks.
3. I facilitated multiple conversations about each art image as a means to elicit the possible meanings and messages within the image.
4. The family participated in the first stage of the data analysis process and I demonstrated a commitment to gain a shared understanding.
5. In the presentation of the data, I used the verbatim words of the participants as much as possible.
6. I presented a thick description of the phenomenon that attempted to account for the complexity of chronic pain.
7. I made use of researcher memos to record and account for my decisions, impressions, experiences, etc.
8. I sought support from my thesis supervisor and committee in terms of debriefing my own experience and asking for guidance regarding decisions and the overall direction of the project.

Transferability

Due to the nature of qualitative research, the findings are often very specific to the population being studied and therefore, the intention of many qualitative inquiries is not to be able to make generalizations (Shenton, 2004). “[G]eneralization is somewhat of an illusion because every research situation is made up of a particular researcher in a particular interaction with particular informants” (Krefting, 1991, p. 216). However, some researchers argue that simply because a case is unique does not mean that it has no relevance to the larger population (Shenton, 2004). Thus, the researcher’s job in meeting the construct of transferability is to provide sufficient contextual detail to allow the reader to make the comparisons or transfers (Krefting, 1991; Shenton, 2004). As such, the researcher only knows his/her research context (Shenton, 2004) and therefore, the responsibility of making transferability inferences lies with the reader (Krefting, 1991). In this study, detailed information about the participants, sampling, data collection, data analysis, and timeline are presented to ensure that readers have the appropriate information to make transferability inferences.

Dependability

Dependability addresses the idea that it is important that research findings are somewhat consistent if the inquiry were to be replicated (Krefting, 1991). Given the dynamic nature of the phenomenon typically explored by qualitative researchers, this construct is particularly problematic (Shenton, 2004). When meeting the needs of dependability in qualitative approaches, researchers need to provide sufficient detail so that subsequent researchers can replicate the study, recognizing that they may not obtain the same results (Shenton, 2004). Additionally, the researcher needs to identify any

particular circumstances that are unique to the given inquiry in order that other researchers can account for those differences (Krefting, 1991). The proceedings of the research inquiry was outlined in sufficient detail to ensure that subsequent researchers can duplicate the study and any participant characteristics or unique circumstances that may have impacted the findings of this particular study were highlighted.

Confirmability

The concept of confirmability relates to ensuring the objectivity of the findings (Krefting, 1991; Shenton, 2004). In qualitative approaches, researchers do not attempt to eliminate bias but rather account for it (Mason, 2002). The findings are representative of the participants' experiences and ideas as opposed to being more characteristic of the researcher's interpretations (Shenton, 2004). An integral component of confirmability is the degree to which the researcher identifies and accounts for his/her own interactions in the inquiry including: ideas, impressions, decisions, perceptions, and personal process (Shenton, 2004). The following strategies were used to help to engage in researcher reflexivity: the use of researcher memos to record and account for my decisions, impressions, perspectives, and experiences as they related to the research inquiry; and in the separation of the participants' voices from my own in a visually obvious way in the presentation of the findings.

Ethical Considerations

Although the researcher did not anticipate that the research inquiry would result in any harm to any of the participants, the process of art making can sometimes bring up memories, emotions, experiences and awareness that are not anticipated and can result in heightened emotional states. The researcher was prepared to help process these potential

responses as well as help the family access community counselling services if needed. My roles with the participants were presented and although I was negotiating dual roles as counsellor and as researcher, these roles are happening simultaneously. In other words, even when I appeared to be in my therapeutic role, it was still happening in the context of research. This information was clearly written in the letter of informed consent (Appendix D).

When family members expressed interest in participating in this research inquiry, they were provided with detailed information about the purpose, time requirements, procedures, and the right to withdraw. The chosen family was asked to sign an informed consent form that indicated that they had understood what was involved in their participation and consented to such participation. Pseudonyms were used and identifying information was omitted to protect the privacy of the family. All data will be stored in a locked filing cabinet in the researcher's home for 2 years and will be destroyed at that time. The participants did not receive payment for their participation; however, in appreciation of their contributions at the conclusion of the research project, I presented them with a thank you card and a gift certificate for \$50 to use at a local craft store.

Conclusion

Within this qualitative case study approach, an art inquiry approach was used to understand the experiences of a family of a young chronic pain sufferer, the role chronic pain plays in their lives, and the resources they draw upon in their fight with chronic pain. The purpose of the study was to explore this phenomenon and provide the reader with an in-depth, rich description of the participants' experiences in a way that elicits a sense of contextual and empathic understanding. This chapter provided information regarding the

methodological approach including research approach, research design, researcher assumptions, sample, sampling, setting, data collection types, data collection procedure, data analysis, and ethical considerations. In Chapter Four, a case description is provided so that the reader can enter the world of the participating family.

Chapter Four: Case Description

The purpose of this chapter is to familiarize the reader with the participating family and to discuss the issue of chronic pain as it relates to the affected child. In providing a detailed description of the case, it is also my hope that other researchers will have enough information about this particular case to draw their own conclusions about the parallels that emerge in their own efforts to study and understand chronic pain.

Case Description

I was connected to the participating family by a child psychologist during the recruitment for this research project. The psychologist was aware of my research study and when this family contacted her about their daughter, they were informed about my study. For the protection of the family's privacy, their given names and surname have been changed. Allison and Victor Graham, the parents, agreed to have the psychologist give their phone number to me and in turn, I contacted the family by telephone. I spoke with Allison and we talked about her family's situation including her daughter Amy's experience of chronic pain. We also discussed the details of the research project. Allison indicated that she would like to discuss the opportunity with her husband, Victor, and after doing so, she contacted me to indicate that they were interested in participating. Over the course of the six sessions of this project I gathered information about the family and in particular, information relevant to the issue of chronic pain.

Allison and Victor have been married for nearly ten years and have two children together: a 6 year old daughter, Amy, and a 3 year old son, David. Victor also has a daughter, Jennifer, from a previous marriage. They are a two-income family and fit within an upper-middle socio-economic group. Allison is a professional in the health

services industry. Victor works shift work as an officer within an emergency services department and his work focuses on education. Amy turned six years old during the course of this project and attends kindergarten at a local elementary school. David is not yet school aged, but attends daycare while his parents are working. They live in a single-family home in a quiet neighbourhood in Greater Victoria, British Columbia.

The Grahams lead a very busy lifestyle and face the challenges inherent in balancing the demands of career and family life. In devising roles, Allison and Victor have found ways to share the household duties and to manage the care of their two children. Victor enjoys cooking and takes primary responsibility for preparing meals and cleaning up afterwards. Allison likes to connect with her children and takes pleasure in their night time routine of bathing and reading stories. David demonstrates a keen interest in cars and knows the names of all the different kinds of cars and trucks in his collection. Amy expresses great interest and joy in engaging in creative tasks such as arts, crafts, and dancing. Given their busy schedules, the parents expressed that they would like to spend more time together as a group.

Allison and Victor have some concerns regarding Amy's social development and presenting behaviours. According to the parents, Amy seems to have a lot of difficulty interacting appropriately with others and identified the following as worrisome: does not respond appropriately to social cues, has limited eye contact, demonstrates limited understanding of different kinds of relationships, tends to focus on older children and adults, appears extremely shy, and does not initiate play with others. Allison and Victor view Amy as being resistant to change, rigid in her thinking, and in need of predictability and consistency. In terms of early development, Allison indicated that she had a normal

pregnancy and there were no major difficulties during delivery other than a long labour. Amy reached major developmental milestones within the typical range and seemed to develop language skills at an early age. They believe that Amy has not only a strong vocabulary but that she also has high levels of language comprehension. They reported no major illnesses or traumas in Amy's history and believe that the social difficulties were present before the onset of the pain.

Allison indicated that Amy has been complaining of back pain for over 2 years, since age 3. According to Allison and Victor, Amy complains of pain daily and describes the pain as "achy." At times, Amy's pain also radiates out from her back and into her arms and legs. The pain seems to be worse at night when she goes to bed and increases when she is tired. After numerous visits to the doctor, the only explanation that was offered was the possibility of "growing pains". However, the pain continued and growing pains did not seem to be a plausible explanation for the kind of symptoms that Amy was describing. They decided to pursue further explanation.

In the beginning of 2006, Amy was referred to a paediatrician and other possibilities such as a calcium leakage or a curvature of the spine were to be explored. The family was also referred to the paediatric psychologist at the hospital in order to help further explore the issue of chronic pain. During the time frame of this project, Amy underwent different tests and x-rays and although no medical explanation had yet been determined, they were continuing to explore possibilities. As mentioned above, Amy's parents are also concerned about her social behaviours and as such, the professionals involved are also exploring the possibility of an Autism Spectrum Disorder (ASD). At the conclusion of this project, the ASD assessment had not been completed and thus, this

possibility remains unknown.

Conclusion

This chapter provides a brief description of information that is most relevant to understanding the case in terms of this study. Some information is purposely vague to help protect the confidentiality and anonymity of the participating family.

Chapter Five: Retelling the Stories

The purpose of this chapter is to provide an overview of the six sessions and to present the art creations that were generated during five of the six sessions. Along with each of the images is a re-storying of what was shared during the debriefing of the images. A section for each image titled “Researcher Impression” is also included to acknowledge my own experience of the creations and the stories that emerged during this project.

The created images and participant stories are presented in a consistent order, beginning with Amy, then Allison and lastly Victor, for each session in an attempt to increase the clarity and flow for the reader; however, the participants took turns going first each week. Furthermore, this researcher always brought enough art supplies for David to participate and he often joined the family at the table to work on his own creations. Given his age and developmental stage, David often floated in and out of the area in which we were working and did not participate in the debriefing process.

Session One

Overview

Upon arriving at the home, I was invited in to meet the family and Victor and Allison made me feel welcome. Their son David was quick to engage with me through sharing his interest in cars which involved telling me about the different cars in his collection. Amy presented as much more shy and stayed close to her mom but as the session progressed, she also took opportunities to engage with me by showing me different things such as her sewing project and her first tooth.

The purpose of the first part of the session was to review the informed consent process and to answer any questions. I began by sharing a little bit about myself and how I came to the topic of chronic pain and the use of art. We then reviewed each section of the consent form and discussed any questions or concerns. Amy was included in this discussion and I attempted to explain the process in developmentally appropriate language. I explained that I would be coming to their home for six visits and that we would be making different art projects each week, and then we would talk about the pictures to learn about ourselves and each other. I talked about chronic pain and emphasized that I was interested in learning about her experience of chronic pain as well as the family members' experiences. I asked the family members if they understood and if they had any further questions. Amy nodded and Allison and Victor indicated that they also understood. The parents then signed the informed consent. As this process took approximately 20 minutes, it made sense to move immediately into the first art activity.

The purpose of the first art task was to learn more about each of the participants and to gain a sense of how each member of the family views themselves and experiences themselves in the world. Allison, Victor, and Amy joined around the kitchen table and the atmosphere was casual. The family members were asked to create an image that was in some way a representation of themselves. I added that I was not looking for anything specific but that they were to create either a self portrait or to choose an animal, tree, or something that they think they are like in some way. Although there was some hesitancy in getting started, once they had a few lines on the paper, the images began to emerge. They worked independently but connected with each other regularly through either verbal exchange or eye contact. The family members worked on their images for approximately

twenty five minutes and when everyone was ready we gathered around to begin the debriefing process.

I hung the images, one at a time, on a large black poster board so that the images could be seen at a vertical angle and be contained (Rubin, 2005a). The participants took turns talking about their images. I chose approximately five questions from my sample question list (Appendix A) and asked each of the participants those questions. As examples, I often asked about what it was like to create the picture; what the participants were noticing about their image; and what title would capture the image. Given Amy's stage of development and in the early sessions of this project, her need for safety, it was often more helpful to ask her about the different aspects of her picture: "What is this here?" "What about the blue over here?" "Who's that?" This allowed Amy to keep the focus off of her self and gave her some concrete things to talk about. At times, I also asked clarifying or probing questions when I was not clear about what the participant was telling me.

In this first session, Amy seemed shy and uncertain about talking about her picture and her use of language to describe her picture was limited. Victor and Allison were both open to the questions and took their time to consider the questions and to respond with insightful and interesting comments. As we were debriefing, it emerged that family members were having their own reactions to and impressions of each others' images and these were communicated.

Amy

Figure 1. While sitting on mom's lap, Amy's voice was so quiet it was hard to hear. Eventually she pointed to her picture and said "corners, and swirls, and swirls."



Figure 1: "Swirls"

When asked what she would call her picture, Amy titled it “swirls”. Mom wanted to know what’s in the middle and Amy responds “swirls.” There are lots of swirls. When the researcher expressed curiosity about how Amy relates to the swirl, Amy pointed to her picture moving her hand round and round but she did not put words to the motion. She returned to Mom’s lap and hides her face. More questions are asked...shyness is in the room...the questions go unanswered. Amy is invited to say anything at all about her picture and she says, “because” and we wait...and the silence goes on...she is asked if she is finished and she nods her head. Mom looked at the pictures and indicated that, “Amy loves rainbows and so using all the colours like that. If you ever ask her what her favourite colour is, often the answer is rainbow... I can tell that’s Amy’s picture because it has lots of circles and lots of rainbows.” Dad noted his impression “it looks like she has all this stuff going on around her. The circles represent all that’s going on. There’s all this stuff going on and she’s in the middle of it...There’s lots happening around her and she doesn’t... she might be confused about what to choose.” Amy is asked if she wants to say anything now and she shakes her head, but then stands and points to the right hand corner and says “It looks like a knife.” Mom asks if it is cutting something. Amy explains “that’s cutting...that’s a knife [pointing to the markers in the right corner]...that’s up there [pointing to a smaller swirl] to the knife, and that cuts there. The knife cuts that...then it cuts open from that to that.”

Researcher Impression. Quiet...shy... a little girl who seems uncertain...in need of more time to trust in this new situation...in a new person. Swirls...when asked how she is like a swirl, she points at her picture again and moves her finger round and round...suggesting movement, the swirls are moving. There are not a lot of other words

that go with her picture...she's said all that she can for now. Her picture also depicts a face...I am curious... where is the body? Is the face turning with the movement of the swirls? What is that like...what is she telling about her experience? She eventually adds that there's a knife and it is cutting at the swirls...she pulls back. Is the knife her pain? She's not ready to reveal more about herself in the world.

Allison

Figure 2. Not knowing where to start, Allison indicates that she eventually thought of a tree "It's full, the tree had lots of things going on and has lots of different branches... it's full of apples." Allison indicated that she has many things on the go, "lots of things that I do and hold." Yet, there's a sense of strength, "I can hold it all and I don't feel like I am going to drop anything." The tree represents strength, health, fun, and family...Allison's children seem an immense part of who she is. "With the swing, I am thinking about children. The kids are happy and playing." And the bird's nest, nurturing... "it is like looking after baby birds" and as she hugs Amy she says "You're my baby bird. I am feeding you and helping you grow." When asked about what someone would not know about her from just looking at her picture, Allison acknowledges that "there are a lot of things you wouldn't know [about me]." It does not tell you that she works full time, that she owns her own business, that she enjoys reading and shopping, and nor does it tell you about who is in her family. Allison states "a tree seems more kind of solid...it's not moving, it's not going anywhere and I don't think of myself as moving or going anywhere." Allison notes that she feels a sense of being rooted here... "this is home base and we will always be here...growing here, and making it bigger and making it better, and stronger." Yet, there's also recognition that change is



Figure 3: "The Apple Tree"

inevitable...“it looks like my apples are ready to fall but I don’t think that my children are ready to leave home quite yet...[laughing] at least I hope not... You could say that the apples are... I make good money but you never know when that’s going to end... They could all drop off [laugh] and they could get diseased [laugh] then it would be a sad time.” She titled this creation, “The Apple Tree.”

Researcher Impression. A full life...an independent woman with strong opinions. She holds an incredible amount in her life...she works full time, runs her own business and is dedicated as a mother. She feels strong and healthy and connected in her home, with her children. A twinkle emerges in her eye as she envisions the future... growing here, making it better and stronger. Her presence is solid and unmoving...yet, there is a fleeting moment of vulnerability, a slight wavering as she imagines the possibility of the apples dropping from the tree. It is the story of an apple tree.

Victor

Figure 3: Victor described the process of making this picture as “interesting” and he went on to say that he has been thinking a lot about this picture, so much so that he has wanted to design a similar image to have created into a tattoo. It was inspired from “Rodin’s The Thinker”. This image represents what Victor believes goes on in the world. “So what you see is a man...he represents strength...kneeling on one knee and holding the world on his back.” Victor asks us to envision the man looking backwards “which represents the past” and “the world above is the future”. And above the world you can see representations of weather “with the sun, the lightning, the smog, and the blue sky - they represent the emotions of the world.” And “although it’s the different emotions displayed around the world, everything is bright and sunny.” The man in Victor’s picture is

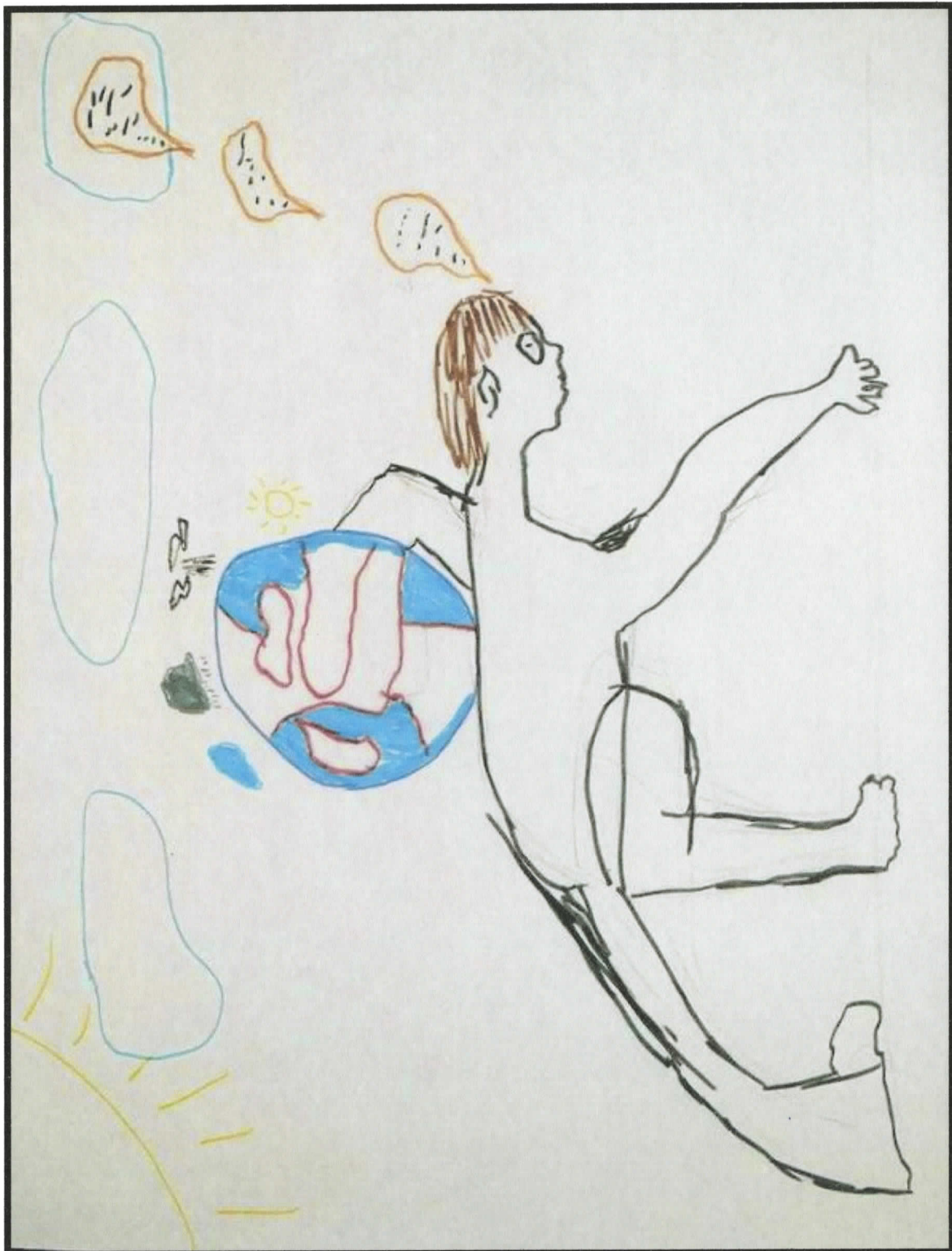


Figure 3: "Thought"

“thinking of others, thinking of all these things, all the time...thought is never ending.”

Victor discloses that he relates to this image “just thinking, always thinking about things...wondering how things work, why things happen the way they do.” However, he notes that this image does not tell us what he does for a living, or where he comes from, or what he likes to do. Victor’s wife notes that the man looks like he is carrying the weight of the world on his shoulders and Victor agrees that it represents that too. He can relate to the idea of carrying the weight of the world on his shoulders. Victor titled his creation “Thought” and believes that the message inherent in this image is “never give up.”

Researcher Impression. Strength and perseverance...a man who recognizes the range of emotions and experiences that exist in the world and above all that, he can see the goodness that prevails. A man who thinks...thinks about others...thinks about how things work...thinks about why things are the way they are. He recognizes the past and the future and yet his picture captures a moment in time, the present...a sense of carrying the weight of the world on his shoulders. And with the strength of conviction he pushes on, never giving up.

Session Two

Overview

We began the second session by having a brief check-in in which I asked the participants to share anything that they had noticed since the last session as well as anything that they wanted to say about the last session. Allison and Victor indicated that they were enjoying the opportunity to connect with each other and with Amy, especially given their hectic lifestyle. Then the family members were asked to initial the consent

form to indicate that they were freely agreeing to participate in this session. I was concerned about wanting to maintain the safety of each person; therefore, I reviewed some guidelines for commenting on the images of others and asked that participants remain curious about the images and not attempt to make their own meaning of them and to ask the person who is debriefing if it is okay to give feedback or ask questions.

As Amy had presented as quite shy in our first session, I decided to bring a lion puppet named Leon to help facilitate the process. I explained that Leon experienced chronic pain in his foot and that he found it hard to live in pain because he was supposed to be a brave lion and sometimes he did not feel very brave. Leon wanted to participate to learn more about Amy's pain so that he would not feel so alone and could learn from her how to deal with his own pain. Leon's presence seemed to help Amy engage in the process.

The purpose of the second session was to learn more about the family and to get a sense of how individual family members experience living in their family. The participants were asked to draw a picture of their family with each person doing something. I did not notice the same hesitancy as the first session and the family members seemed to focus on their own images. Once again, the atmosphere was light and as the family worked on their images they took moments to glance over at each others' images. There was laughter and teasing. Once again, when the images were complete we gathered around and took turns looking at the images and debriefing the process. Allison and Victor, once again, spoke openly about their pictures and took care to think about the questions when they were posed. Initially, Amy was quiet but she responded well to being asked specific questions about her image and in turn, became

quite engaged and revealed a significant amount of information about her perspective on her family.

Amy

Figure 4. Once again, Amy did not respond to the first few questions but when Dad asked about the biggest person, she identified the biggest person as “Mom.” When asked about Dad, Amy indicated that he was “watching TV...hockey.” When questioned about Mom, Amy said she is...”dancing with me.” Amy said that David was saying, “this is my favourite car.” As Amy looked at her picture, she was holding onto her stuffed kitty and when asked what her kitty thinks of the picture, Amy pointed at her picture...at the dancer... and indicated by nodding that her kitty likes to dance, too. Amy also said that she included “the dog” Kendra and went on to say “she’s seven and she still wears diapers”...when asked why, she responded that it is because she’s a baby. Amy indicated that she would call her picture, “cat” and when asked where her kitty was in the picture she responded, “there...it’s behind the couch. That’s what the blue is on the couch...part of the cat.” She noted that when she looks at her picture, the first thing she sees is “the dancers” and although she indicated that she did not know what the dancers were feeling, she identified that when she dances she is “happy.” David is “happy...and excited.” And Dad, he and Granddad “want to watch the opposite [different television shows]” and as Amy walked us through the problem she was describing about Dad and Granddad, Dad’s feelings were identified as sad, happy, and mad at different times. Amy was asked if there was anything else she would like to say and she initially said no, but quickly changed her answer. Then Dad asked about his “tail,” Amy responded, “Because you’re a pig.” And when it is noticed that everyone has tails, she indicated that “pigs are



Figure 4: "Cat"

bad...I don't want anyone to come close to you, because you are too bad." She went on to say, "It is like a trick... they will think that you are bad, but you are really good." She is asked about who she is tricking and she said, "a giant monster with a big sword that will cut you in half...it doesn't like pig guts on its sword...so it will think it is pigs." She said that she has seen this monster and "he's bigger than this house...his sword is as big as this house...and it is two times this house." It is suggested that such a big giant monster might be scary and in a low voice Amy said, "It is very scary...up to the door scary." When asked what she does to stay safe, she indicated that "I cut him in half."

Researcher Impression. Amy is finding her voice. It seemed helpful to have her talk about the things in her picture and although at times she distracted from her picture with silliness, she was able to say many interesting things about her drawing. Most interesting was what Amy told about her picture that could not be seen...the tails are a small detail in the picture and yet represented something much larger. Amy expressed a need to protect her family from a giant monster by disguising them as pigs. I am curious...is the monster pain...is the monster anxiety? What a huge burden...to protect your family from a monster that is bigger than the house and scary, up to the door scary.

Allison

Figure 5. Allison indicated that, "it wasn't hard to figure out what everyone was doing." When asked to say more about that she described, "Victor always does the cooking. He likes to have everyone well fed and everything to be planned out. We definitely have divided roles. He cleans up the dinner and I bath the kids and get them ready for bed. Amy is always wearing some kind of costume, ballerina costume, gymnastics costume, and ballet slippers. Although I could have drawn David in ballet

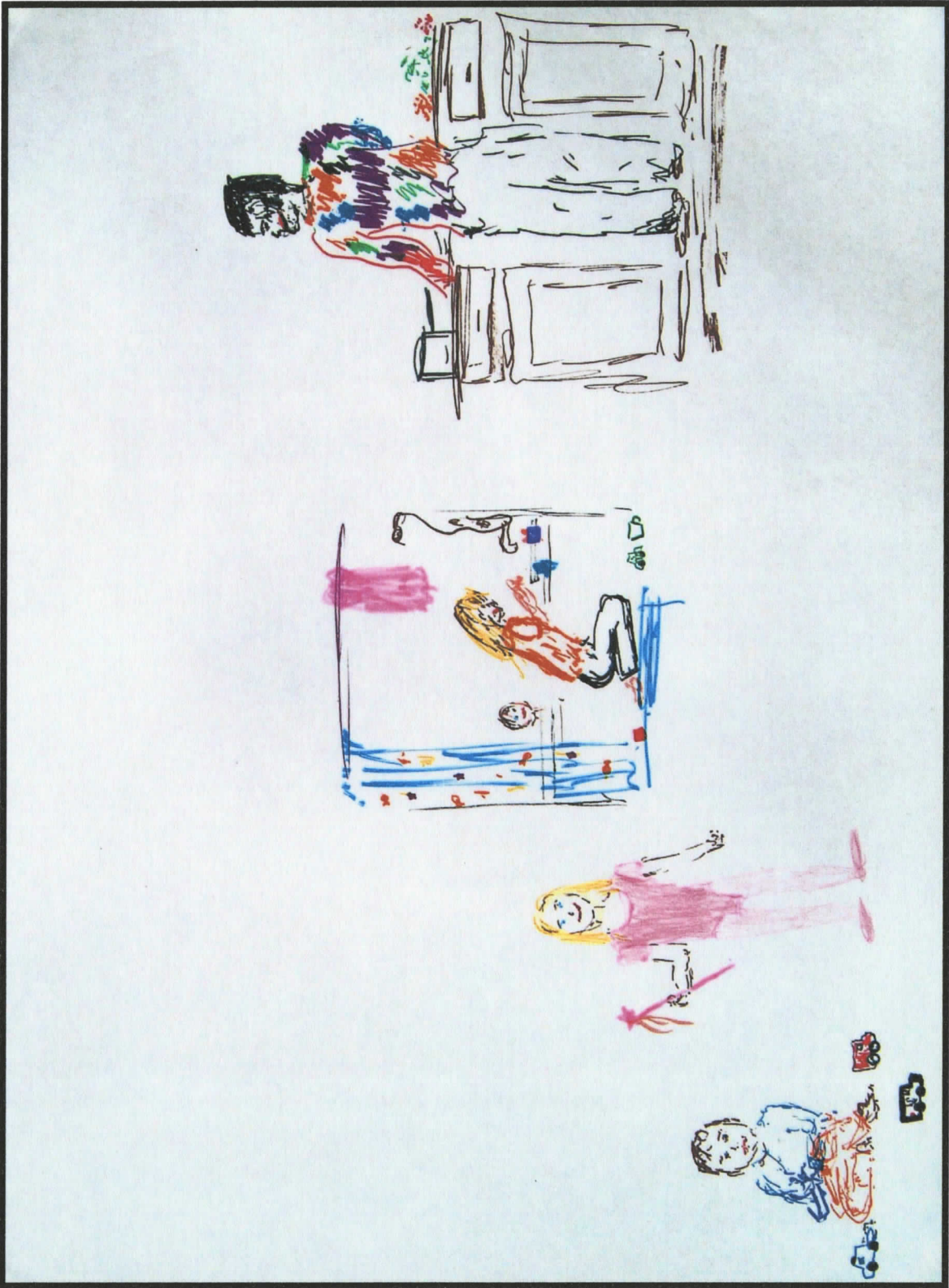


Figure 5: "The Grahams at home"

outfits too, 'cause he has already been in a ballet outfit today." David was playing with cars and Allison turned to Amy and teased, "...cause David is always playing with cars, isn't he?" And Amy agreed. Allison responded that the most obvious thing about her picture is that, "everyone's doing their own thing." And she indicated that that fits with her experience, "Usually, yeah... everyone's doing their own thing. Everyone's very busy, doing their own thing." When looking at her picture, she noticed that her eye wants to go "all over...it just goes back and forth to all the four people who are in the picture." Her sense of the picture was that "everybody's happy... we're content." Allison titled her creation "The Grahams at home" and when "everybody's busy doing their thing... they pretty much would do those things everyday. Amy has her ballet outfit on at least once a day and the kids usually get bathed just before their bedtime. I guess that's a time when we're all at home and usually, 'cause I am home from work and that's when we are all together... at dinner time...that's the time, on any particular day."

Researcher Impression. Allison's experience of her family is that they are busy...doing their own things...and everybody's happy, content. It is dinner time, the time of day when everyone is together and yet each person is doing their own thing. There seems to be a consistent routine including divided roles. They have found a way to manage their busy lives but what about connecting with each other in fun ways...ways that are not about their parent-child roles and responsibilities?

Victor

Figure 6. Victor described that it was "easy" to make this picture because "everyone has their role in the house and we've pretty much got it down to an art...well, everyone is just doing their own thing." He noted that his picture is similar to his wife's.



Figure 6: "Complete"

Victor went on to explain all the members of his family and what they are doing. "Allison is [working]...and then there's Kenny [dog] playing with a ball. And then there's me...I'm actually doing the dishes. I finished cooking and now I am doing the dishes [laugh]. And then there's Amy on the swing...cause the little ponytail sticking out of the top of her head... that's her on the swing. And that's Jennifer [Victor's daughter from previous marriage] in the middle... 'cause she dances. And that's David on the right...just playing on the floor in his bedroom" Without prompting Victor reveals that he would call this picture "complete." When asked more about this title, Victor indicated, "...just the whole dynamics of the family... and the routine. Our status in both job and house, and life... is complete. Complete and growing." Victor said that when he looks at the picture of his family, the word "busy" comes to mind. "Everyone's busy...but everyone's happy doing what they are doing...in my belief. It shows happiness. They are busy but happy." He described that when he looked at his picture his eye tended to focus on the children and that his focus "kind of starts on the left and make your way to the right... it should be more like a story, like it's a story book..." And the story is about "everyday life...in a family...in a house."

Researcher Impression. His picture consists of his wife at work, his dog playing with a ball, himself in the kitchen cleaning up after cooking dinner, Amy playing on a swing, Jennifer (his daughter from a previous marriage) dancing, and David playing on the floor of his bedroom. This is the story of their everyday life, in his family, in their house. They are doing their own things but they are happy. His story feels complete...complete but growing. Busy...everyone is busy but Victor holds onto the belief that they are happy and he notes that his picture expresses this happiness. When

Victor finished describing his picture, his wife, Allison, commented on one aspect of the picture. Her comment highlighted for this researcher that this aspect of the debriefing process had the potential to bring out family issues that are not directly relevant to the focus of chronic pain.

Session Three

Overview

Once again, we started the session by taking care of “housekeeping” issues. I took a moment to review the guidelines and emphasized the importance of safety; as such, I asked that we make a change to the debriefing process by refraining from commenting on others images and the family agreed. The purpose of this request was not only to maintain safety for each participant but also to ensure that the focus of the research remained on the exploration of chronic pain and did not verge off into working through other family issues. I also asked the family to share any thoughts on the last session or awareness that had emerged during the week and nothing of major significance was reported. After initialling the informed consent, I described the art task.

The purpose of this session’s art task was to discover the emotional experiences that each member is managing and to increase awareness about the body connection. In other words, this task was to help explore the participants’ awareness of their emotional status as well as how they experience these emotions in their body. Each participant was given an outline of a body and was asked to choose colours to represent the four feelings listed on the bottom of the page: happy, sad, angry, and worried. Then they were asked to colour in the body outline using the colours they had chosen in order to create a map of their bodies. They were encouraged to add additional colours and emotions if interested.

The family members worked hard on their maps and Amy spent extra time this day working on her body map. During the debriefing, Amy seemed to have difficulty acknowledging emotions other than happy and although she seemed to enjoy the attention of us listening to her, she engaged in many of distracting behaviours that took the attention off her body map. Eventually, she was able to take ownership of different emotions and name colours that represented those emotions. Allison seemed to have a great deal of energy in talking about her image and the impact of viewing her map appeared to be quite powerful for her. On the other hand, this activity did not seem to have the same value for Victor as he revealed that his sense of the activity was that it was more for Amy's benefit.

Amy

Figure 7. When asked about all the colours, Amy responded "rainbows". She told us that rainbows are "magical juice" and this magical juice, "it makes you turn into a fairy." When asked to tell more about fairies, Amy went to her room and brought back a small fairy to help her talk. She said "the wings are magical because they have swirls on them and the swirls are sparkly." Amy titled her picture, "Fairy Godmother" and indicated that if the picture could talk it would say "I am a fairy of gods." Amy suggested that she could not name her wish "'cause it won't come true" but indicated that if she were to tell her fairy godmother, the fairy godmother would say "I'll make it come true." Amy then informed us that "you can only tell someone who can make it come true" and that her fairy godmother is the only one who can make her wish come true because this wish needs "magic" to happen. Wondering how Amy feels about the possibility of this wish coming true...(no words come). She points to the blue strip and pink strip



Figure 7: "Fairy Godmother"

“cause those are the colours of my fairy.” As Amy talked about the other colours the only feeling word that she named was “happy.”

It seemed that it was hard to talk about difficult feelings and that one way to avoid talking about them was to distract with other behaviours. It was verbalized that everyone has sad, happy, and angry feelings and that all feelings are okay and that sometimes feelings are hard to talk about. When Amy was given some example situations, she was able to acknowledge and own other feelings. Sad is “black”; angry is “brown”; happy is “pink”. When asked about what it was like to go to the doctors, Amy indicated in a low quiet voice that she was “scared” and described that she felt “bad” about her back pain. As her pain is often worse at night, Amy was asked about her pain at that time and her response was “painless.” Through further exploration of how she becomes painless, Amy was able to shake her head, responding no, to different options. However, when asked about leaving her body and flying away, she nodded her head. At this point, Amy turned and whispered to her mom that she wanted to do something different.

Researcher Impression. Amy seems to draw upon certain things to help her cope with the range of emotions that she feels...rainbows...magic...fairies...fairy godmothers. It is hard for her to talk about difficult feelings, even just to name them. She is protective...not wanting us to know about all her feelings...only happy. But, her picture seems to show many colours...many emotions. She needs empathy...she needs reassurance that all feelings are okay and that we want to know about all her feelings. Slowly, with examples...she acknowledges that there is sadness, anger, and a yearning for magic. Interestingly, she uses the word ‘painless’ to describe a time that her parents believe is the most intensely painful for her. I am curious about how this happens and

when I ask if she turns her body off she denies this possibility. I see the fairy clutched in her hand and I ask...do you leave your body and fly away? She nods. It seems that Amy has found a creative way of coping with her pain...is this dissociation?

Allison

Figure 8. Allison indicated that “it was kind of easy - or at least I think it was - to figure out what colour to do things...if I am associating it with those feelings...I think in my body I can localize what parts feel happy and what parts I would rather chop off and trade for other.” Allison walked us through her map, “I think generally I am happy... I feel stressed and ...worried in my shoulders and in my neck and my chest.” It’s all in that area, “I have bad neck pain and shoulder pain, and I have bad heart burn and I get ulcers.” Allison also explained, “I have dermatitis and it is a constant battle, so that makes me sad and angry and those are the bits that I would trade.” Allison titled this image “Life” because “...you can’t stop living and that’s the way it is. You have to wash your hands and...that’s what happens. You’ve got to go to work and you got to learn to...battle stress of everything in life.” When asked what this image would say if it could talk, Allison found it hard to put into words, and was encouraged to think of just that moment. Then she responded, “I’ve got stuff to do...” and agreed that there was a sense of needing to keep busy, “...always got to do something...got to do this, do that, no sitting around.” If this creation needed something Allison thought that it would be, “a neck massage...and to relax a bit... not have to wash her hands all the time, just relax and have a massage. And smell the flowers.” The researcher offered that it sounds like she needs to take care of herself and Allison agreed. Allison noted that the one thing that stands out for her in the picture is the physical aspect, “I guess a lot of it seems physical...



Figure 8: "Life"

and I don't know if that was what it was supposed to be... that's the way that I interpreted it and that's the way it ended up. You know, like physical pain or feelings, I guess." She went on to say "that's the way I feel things, that's the way it comes out...I'm tired...I'm tired... and it comes out in having neck problems. If I am working more, I get more hand problems and stuff like that...physical...it takes its toll." And yet she pushes on. "I always have to keep going...it's not an option, there is no other option. That's the way it is and you just have to manage how you feel and suck it up. It's not an option to stop... I don't get to take sick days"

Allison seems pulled between all the responsibilities, "when I am at home I am with children... I am looking after them; I am looking after my house. At work I am in demand and it is not an option to just to call in one day and say...I am not feeling that great so I am just going to stay home and nurse my cold." This is hard for Allison, "I often feel resentful about it...that I am not allowed to do that and other people are." Yet she feels angry when others take advantage. And she emphasized that she is not like that...there's a sense of responsibility and a sense of perseverance, "I have always been like that." And with the suggestion that her body needs taking care of she said, "Yeah... I stress myself out. I am a stress case. [laughing]...now, now, now... more, more, more." As she talked about her experience she noticed her emotions intensify, "This is just making me ahhh ahhh ahhh." At the possibility of taking some time for herself today she seemed hesitant, "it might be [important]" and says that her husband and her often imagine, "going to go on holidays and relax... and this vision of lying on the beach in Hawaii with the children playing quietly by the side of beach." Yet, it does not seem possible in the near future as past attempts to get away have been difficult and stressful.

Researcher Impression. The theme of busy continues...and yet the hustle of this busy life may be taking its toll. The intensity of being a mother, a wife, and managing a career...there is always something or someone needing her and her sense of responsibility is so massive that there seems like no other choice but to push on. In looking at this image, it seemed that Allison saw how much her need to keep busy and her need to persevere, no matter what, was playing out in her body. The stress manifests itself in physical ways...with neck pain...shoulder pain...ulcers...and heart burn. She noticed that this is the way she feels things...in a physical way, in her body. There is a need for self care...to relax, nurture the self, to take a moment to take care of her own needs.

Victor

Figure 9. Victor started by saying, "I didn't have any idea when I was colouring this...I just coloured it to colour it. I thought the exercise was more or less for Amy." He went on to say that "to me... you have several of them, different emotions on a daily basis...on a yearly basis." In talking about feelings in his body, Victor described that "the happy could be all parts of me...when I am happy, every part of my body is happy." And in terms of sadness, "when I am sad...you probably ache a bit more." Victor acknowledged that anger surfaces in the face and hands, "when you're angry, your face gets flushed and your ears get red and you clench your teeth and sometimes, you clench your fists when you're frustrated." And, "when you're worried, your stomach bothers you or maybe your back would bother you...that's when all the aches and pains come out." Victor noted an interesting link between emotions, "I think that happy-angry emotions are kind of similar in nature...they give your body that same type of feeling...happy and



Figure 9: "Chocolates"

angry bring out those euphoric feelings.” Victor titled his picture “Chocolates... depending on the time of day, you can pick out any emotion and because of what is happening, that’s what it’s like...its like, you just never know what set of emotions is going to be on the counter any day.” Victor described that in one moment you can be “having a nice morning and then all of a sudden the kids get into the Cheerios... then there’s Cheerios all over the floor... and now you’re frustrated and angry.” “And then later in the day you’re playing with the kids at the park, and you’re having a great time...you’re looking at how angelic they are...and then at three o’clock, that three and five o’clock time when they start getting to each other and that’s when all the arguments start...so the tension in the house rises.” Laughing, Victor indicated, “that’s just daily routine, you know.” Victor expressed a recognition that happy, sad, angry, and worried are all emotions that people experience everyday. When asked what this image would say if it could talk, Victor said, “This is life.”

Researcher Impression. This particular activity did not seem to connect for Victor. His belief in the constant movement of emotions through time made it difficult to capture in a map. He described some of the things that he noticed about different emotions. In some ways, Victor seems philosophical as he contemplates happiness and anger being the similar in nature. There seems to be an acceptance of the unpredictability of emotions as he portrayed in his metaphor of chocolates and yet an ability to allow the range of emotions to flow through daily life.

Session Four

Overview

In checking in with the family members about what they had noticed since the

previous session, Allison indicated that she had been reading the book by Zeltzer and Blackett (2005) that I had lent her and was surprised to read that children with Asperger's diagnosis have a higher incidence of pain. She seemed exasperated that although professionals have been considering the possibility of Asperger's that they had not mentioned the connection to chronic pain. She also emphasized how complicated the situation has been, given that there are differing opinions and ideas about the gravity of Amy's situation. Allison noted that the pain is not debilitating but frustrating as it is playing out all the time. She also added that Amy was able to describe her pain this past week, indicating that it was like a hammer and throbbing. I also reminded the family that we would be having two more sessions and that the next session would be the final art making session and that the last session would be a chance to say goodbye and have some closure. Once we had finished checking in, they initialled the informed consent form and we began the art task.

In the previous session, Amy had talked about a fairy godmother so I used this character as a means to help with this picture. I asked the family members to imagine that Amy's fairy godmother was there and using her magic wand she was able to take the pain out of Amy's body and put it on their papers. The purpose of this art task was to help externalize the pain and explore each person's subjective experience of the pain. The family members were asked to envision that the fairy godmother had put the pain on their paper and to paint what they imagined it would look like.

Amy presented as much more grounded in this session and for the first time, she seemed able to talk about her pain and, although she began to engage in some distracting behaviour, she was easily redirected. Secondly, Allison talked about her image and

although it seemed difficult to understand what the pain might look like, she was able to explore some of her thoughts about the pain. Unfortunately, after Amy and Allison had debriefed their images, I realized that I had neglected to turn on the microphone and thus, their debriefings had not been recorded. I continued with Victor, ensuring I had turned on the microphone. Upon returning home, I wrote up a mock transcript that included the debriefings as accurately as possible and then I emailed a copy of those transcripts to the parents that same day. Allison and Victor reviewed the mock transcripts for accuracy and added a few lines that they remembered. I made changes based on their suggestions.

Amy

Figure 10. Amy began by pointing to the orange and saying “this is where my back hurts...my arms hurt...my back hurts...and my legs hurt” and pointing to the arrow, she went on to say, “it hurts in my lower back.” When asked about how the pain feels, she described it as “achy.” Wondering how often the pain is present, Amy moved away from the picture, indicating that she needed a pointer. In response to a question about the red circles on the right side, “those are the holes to make it a book.” Amy began being silly by playing with the “pointer” stick in the wet paint and then when a curiosity was expressed about whether her silliness was a way to take the attention away from her picture. She nodded her head and settled. Amy was reminded that she did not have to tell anything about her picture that she did not want to and that she decides what she tells. Amy said, “It hurts here and here...it hurts so much that it makes it hard to think” and she pointed to the arrow, “the pain is down lower” and then pointed to her back, “this is where it hurts.”

Researcher Impression. Safety is growing. Amy appeared more grounded...



Figure 10: Untitled

wanting to participate, wanting to tell the story of her pain. She shows us that her pain is real through her words. The pain is in her arms...in her back...in her legs. She describes her pain as achy. The words were hard to say...the pain is hard to talk about and she begins her distracting behaviour. I name that, I expressed my curiosity about whether the silliness was to take our attention away from the picture, and surprisingly, she makes eye contact and nods her head...she has been seen...she has been witnessed. She returns to her image and points to where it hurts and tells us, in heartbreaking words, that it hurts so much that it impacts her ability to think.

Allison

Figure 11. When asked about what it was like to make this picture, Allison struggled to put words to her experience and said, "I don't know." When she looked at her picture, she noticed that "it is kind of like I was drawing the pain out of Amy and trying to put it on my page...but, only Amy really knows what it is like, I can't even imagine..." She went on to say, "it affects everything...in so many ways... that's, I guess, what all the colours represent." All the colours represented the 'everything' that the pain affects... "it is like blah onto the paper." Allison described one example as "when she's tired...her body goes kind of limp..." If the pain could talk it would say "Mom, my back hurts" because "that's what I usually hear...Mom, my back hurts. In the picture it looks like a bubble that the words would be in." And Allison titled this creation the same phrase "Mom, my back hurts." If Allison could ask the pain one question she would have asked, "Why? Why are you there...what is causing the pain?" Allison wants answers and wants to know what is going on, "I want it fixed or at least to know what to do to help it go away." As she looks at her painting, she notices that the feeling that



Figure 11: "Mom, my back hurts"

emerges is “frustration.” Allison adds, “the pain affects all of her body and seems to radiate out from her lower back affecting how she is feeling...so the picture shows this.”

Researcher Impression. It is hard to talk about the pain this way. It is hard to know where to begin...it affects everything. The colours represent that ‘everything’ and they are so mixed up that it is hard to tell where one things ends and another begins. It is not neat or tidy or clear and the only person who really knows the truth about this pain is her daughter, Amy. Questions...why...what. There is frustration because Allison sees how the pain affects all of Amy’s body and she wants desperately to be able to fix it...she wants to know what to do to make it go away.

Victor

Figure 12. Victor described that making this picture was “easy” and when asked to say more about that he adds, “it was no problem...pain is about all different emotions. So it was easy to use all the different colours to represent all the emotions that we go through.” The pain is a jumble of emotions, they are all together. Victor indicated that he would title this creation “Pain” and that if the pain could talk it would say, “help.” The pain needs something.” It needs help.” And Victor talked about the image he created, “What I’ve done here is made it...it supposed to look like it is rolling. So it is rolling around and although the pain is in her back it is radiating out to her legs. It is rolling around her body looking for a way out and can’t find a way out...so that’s why it needs help.” If Victor could ask the pain a question, he indicated he would want to know, “What do I need to give you to help you?” Victor indicated that one thing that he noticed about his painting was, “it is interesting that I put blue in the background as the very first colour...because blue represents happiness and good things. And I put all the other

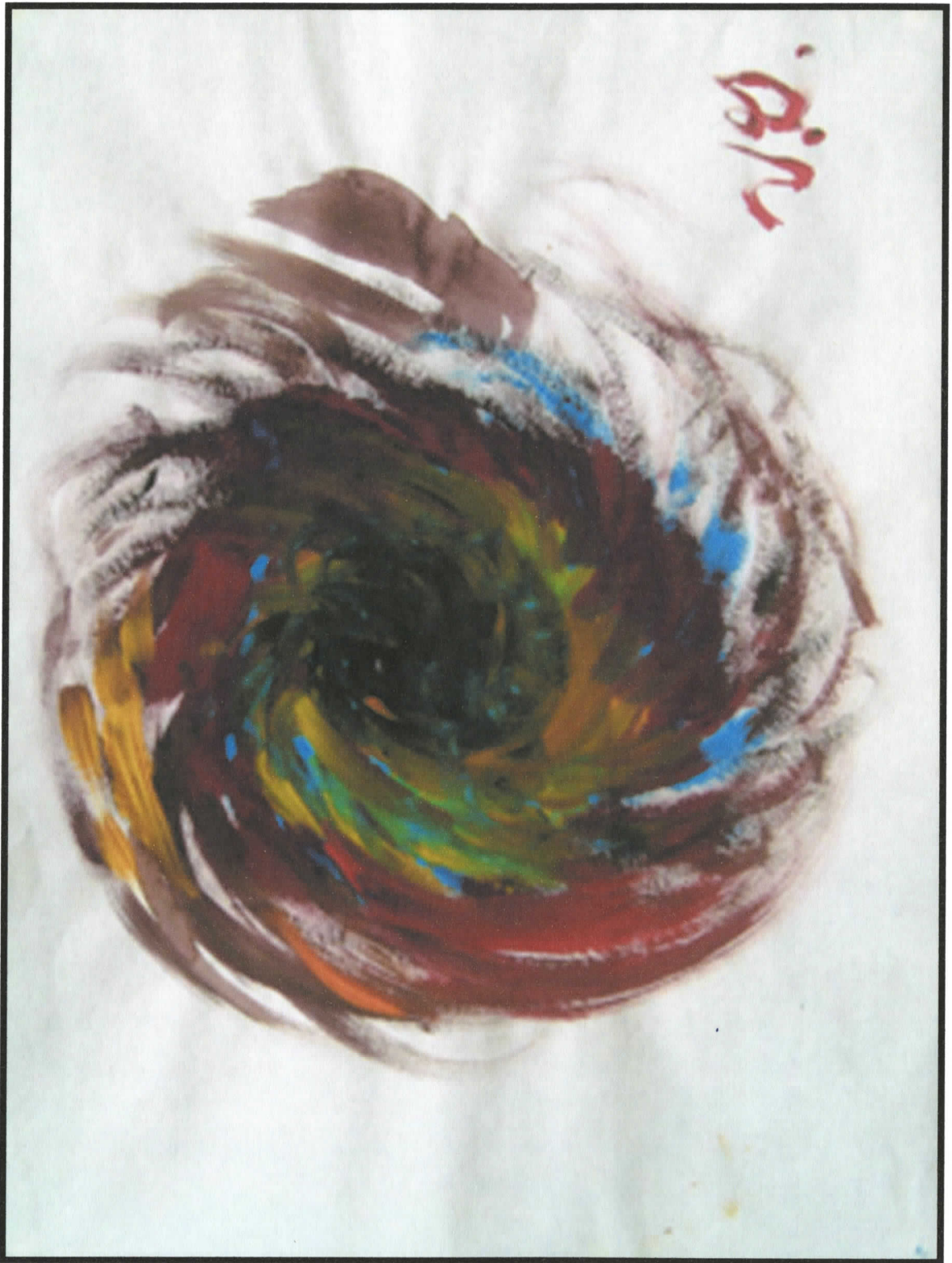


Figure 12: "Pain"

colours on top of it and so it is an indication that when the pain is gone then it is going to be happy.” Underneath the pain, “there is happiness.” When asked if Victor noticed any sensations in his body, he indicated that, “I pick up the red which is probably anger and frustration...wondering why it is there?” He described his relationship with the pain as a battle, “It’s a battle between happiness and sad and angry and all those. It’s a battle of all those emotions... and the bad, sad, and frustrating feelings are winning.” The pain is winning right now.

Researcher Impression. Pain is emotion. It seems as though Victor really understands that pain is emotional and although he previously identified himself as a thinker, he also acknowledges emotions in many ways. It is all the different emotions jumbled up together. The pain is moving through Amy’s body and is trying to find a way out...it needs help. Victor wants to know what he needs to do to help the pain find a way out. Although there is hope and happiness underneath the pain, the red of anger and frustration is dominating the battle right now. Frustration...why? The pain is winning.

Session Five

Overview

Upon arriving, I reminded the family that this session would be the final art making task and that there was one remaining session. We talked about the time since the previous session and initialled the informed consent. The family did not have anything to report other than to say that Amy had asked about me and was wondering when I was coming again.

The purpose of this art task was to explore each person’s strengths and resiliencies and the participants were asked to create a collage of images that represented

things that made them happy, that filled them up, that nurtured them and things that helped them when times were difficult. The atmosphere during this session was filled with fun and laughter. As the participants sifted through the magazine images they seemed to reconnect with happiness and nurturing that I had asked them to think about. Amy became quite fixated on looking for flower images but eventually decided to add butterflies as well. Victor and Allison both incorporated quite a range of various images. During the debriefing, Amy spoke a little about flowers but it seemed that flowers and butterflies represented much more to her than she was able to articulate. Victor and Allison talked about the different images that they had included and both expressed a sense of hope for what the future holds.

Amy

Figure 13. Amy indicated that she chose to include flowers in her picture, “because they’re pretty” and they remind her of weddings, “they look like they are having a wedding.” When asked about weddings, Amy indicated that it is when two people get married “because they have to start a family.” When questioned about how the flowers and butterflies are helpful, Amy indicated that “they [flowers] smell good... I pick them everyday.” She also talked about how her “dad held a butterfly wing...and I caught one [butterfly] in a cage.” Amy pointed to the hot pink flower in the middle of the page, indicating it was her favourite. She also identified some of the different types of flowers, “that one looks like a foxglove...those are daisies”. Amy indicated that her mom has daisies down in the garden and she wondered “Why do they grow so big?” When asked what she thought helped the flowers grow, she said, “she lets them grow.” The possibility of water was identified and she became excited “I do. I give Granny’s

flowers water.” It seemed as though Amy was sharing stories and memories about flowers and butterflies that were helpful for her and when this was verbalized, she agreed. In response to a question about what her mom and dad could do that would be helpful for her, she indicated that she would like to “pick them flowers for an anniversary.” Amy named her picture, “Butterfly Lily.” Amy was asked to share anything else that she finds helpful in her life and there was silence but when asked about her pain, she indicated that “medicine” was helpful. At this point, Amy began to act quite silly again and when asked if she was finished, she said, “I am finished.”

Researcher Impression. Amy is in many ways a typical little girl...she loves flowers and butterflies because they are pink and pretty and they smell nice. She is smart... she remembers the names of different kinds of flowers and shows pride in being able to share her knowledge. But it seems that there is more to the flowers than prettiness...there are stories and memories of being with loved ones...of sharing and connecting through the beauty of nature. She likes to talk about things that are good...and she does not want to go there when I ask about what is helpful when she is in pain. She tells us that medicine is helpful...but then she distracts and tells us she's finished.

Allison

Figure 14. Allison indicated that this picture “was fun to do. There were lots of pictures to choose from, and since you're looking for pictures that make you happy, it can't be a bad thing to do.” Allison spoke about the images, “They are all things that make me happy...things that I like to do. Flowers make me happy...I like looking at flowers and gardens. I don't like gardening but I like nice gardens...And the outdoors...

family...like children...and being a mother... and friends. I like to read and I like to take pictures and make albums. And I like to read to my kids in bed...I like to shop and I love shoes. I like to look at hummingbirds out the kitchen window. I like lightning...I like the different weather. I like the outdoors...I like going out hiking in the woods and the trees. I like my new iPod Nano to go running with” Allison said that one thing that she noticed about the collection of images was that, “maybe that I should spend more time outside...because I spend a lot of time inside, in a dark little room, all day. I do like the outside and especially the picture of the tree reminds me that I should be outside in the trees because that makes me happy and it is not something that I do very often.... And when I do it, I love it and I feel good.” She added, “It puts it in perspective...it’s free, its right there. You can’t say that you can’t afford it or you shouldn’t do it.” Allison titled her creation, “Life’s Pleasures.”

Given the stresses of daily life, Allison indicated that there are a couple of things that are really helpful in managing her stress. “I think that getting enough sleep is always a nice thing, but not always possible.” And she really emphasized making the time to do something just for herself, “taking time to do the things that make you relax and be happy in the day...even if it’s just for fifteen minutes or so. I like to read at night and even if that’s the only thing that I get to do all day that is just for me.” In conclusion, Allison indicated that one of her hopes for the future is to “visit the pyramids one day...going farther than Vancouver or Duncan...just going to go see something that is totally different.” Allison expressed hopes for the future but also a sense of contentment for the present, “For now, I am happy to be home and be with the kids and do the simple things.”

Researcher Impression. There are lots of things that Allison knows bring

happiness into her life...flowers...gardens...family...friends...reading...making albums... hummingbirds...nature. Creating this picture helped her reconnect to all of these things and put some things in perspective. In the face of stress, she knows the importance of sleep and the importance of taking time for oneself...finding even just fifteen minutes of each day just for herself. There is contentment with the present, the simple life and dreams of future adventure that stretch beyond what is known...what is familiar.

Victor

Figure 15. “It was fun...I enjoyed it,” Victor described what it was like to make this creation. As he looked at his image he noted, “these are all the things that make me happy.” Victor told us about the images in his collage, “I like going on holidays...I like to go to hot warm places. I like music and I have just started playing the guitar, so I am just learning my first songs, finally. I love the water...like scuba diving and snorkelling...there is a big beach here in this one. Of course, you have to have the blender to make the mai tai’s and strawberry daiquiris. I like family...there are some family pictures there...kids having fun in the one picture. Kids bring joy into the house, I think. Like this picture here with the man holding the baby, that’s a cool picture. And a glass of red wine is always nice with dinner. I like flying. The jaguar or leopard in the tree...I thought that was pretty cool, I always liked the jaguar or leopard kind of things. A chair for relaxing...and a camera for catching those moments. And the map signifies travel...hopefully there will be travel in the future for us, now that the kids are getting a bit older. Perhaps places like this where there is a big lake and we can have a boat and take the kids skiing and stuff like that. It is a bit of the future that I am hoping for...and

some of the present.” The collage represents not only the present but also those future dreams and goals. Victor titled his creation “Life.” In coping with the stresses of life, Victor indicated that music is an important part of his life, “I like to play the guitar when I get the chance to.” He also indicated that “relaxing” is another key to managing the stress.

Researcher Impression. Music...holidays...warm places...scuba diving...snorkelling...family...kids...travel. Victor, too, has many things in which he finds happiness and joy. The collage represents life...now in the present...and the hopes and dreams for the future. In managing his stress, he turns to his guitar...and captures those moments that invite him to relax.

Session Six

Overview

As usual, I began with a check-in and asked the participants to share anything that they had noticed from the previous week. When Amy was out of the room, Allison and Victor indicated that they were feeling really frustrated that a medical explanation had not become clear yet and as a result, they were starting to feel as though professionals were looking at them as explanations for the pain. The parents believe that Amy experiences pain and although Victor expressed some uncertainty and revealed that it is hard to figure out when there are not any answers. He described himself as a problem solver and this situation was really challenging. Allison also said that Amy was experiencing some increased difficulties at school, especially in her relationships with others. They were looking to the Autism Spectrum Disorder assessment for some answers.

The purpose of this final session was to give the participants an opportunity to reflect on the process of creating the art images and to share any thoughts they would like to about their experience of participating in the research project. In providing that opportunity, I also hoped that the participants would be able to celebrate the ending of the project and experience a sense of closure. Taking turns, each person's creations were hung on the wall in order of how they were created and each participant was encouraged to take a moment to look at the images and to share any of his/her thoughts about what he/she was noticing; anything that was standing out; what they remembered as a highlight; what they learned about themselves and others; what was the most difficult; and how chronic pain played out through the images. At the end of the session, I thanked the family members for participating and expressed my appreciation, not only for their time, but for their willingness and openness to exploring their family through the use of art. I gave a card and gift certificate to a local craft store as a token of my appreciation and they reciprocated with a card, treat, and gift certificate to a local bookstore.

Amy

Amy was encouraged to look at her pictures and share her thoughts about what it had been like to create the art work and talk about the pictures. She answered, "I don't know." She was asked specific questions about some of the different pictures and sometimes she answered with basic information and other times she answered with "[be]cause" or "I don't know." She was able to say that her favourite art task was putting the collage of "flowers" together but then she became distracted. Attempts to bring her attention back to the pictures were not successful and a curiosity of if it might be hard to talk about the pictures is shared. More questions are asked, but the silence and "I don't

know” continued. Mom said that Amy indicated yesterday that she did not understand why the project is ending, why it has to stop. The researcher reviews the project and reminds Amy that the six meetings are over and empathizes that it is hard when things change and it can be hard to say goodbye. Amy is asked if part of why she does not want to talk about her pictures is because she does not want the project to end and she nods her head in agreement. The researcher again emphasizes how hard goodbyes can be and reminds Amy that she will have the big book of all the images to keep as a reminder of the time we spent together. I then asked Amy for a favour and told Amy how much Leon really needs somebody who understands what it is like to live in pain to take care of him, someone he can talk to. Amy agreed that she can do that and takes Leon into her arms. I also told Amy that she, too, can talk to Leon about her pain as he understands.

Researcher Impression. Change is hard...and it is hard for a six year old to understand why things have to end. Amy seemed to be avoiding talking about her pictures because she did not want the project to end. It was important to empathize with her and to express that possibility with her as a means to bear witness to her experience. Amy’s willingness to take Leon into her care was an important transition in helping her hold on to the essence of what this project represented for her.

Allison

After Allison took a moment to look at her creations, she noted, “it was interesting to draw the pictures.” One thing that she noticed about the process was that she found it, “interesting to see what others draw, if you can anticipate what they were going to draw.” In terms of her own learning, the one thing that Allison indicated that she would take away from participating in this project was that “[I] have to relax more...go outside...do

some of the things that are in my happy picture...being outside and being with the kids.” She recognized that she tends to keep really busy and is often doing two things at once. She likes to keep on a schedule and she expressed curiosity that “maybe if I relax more, then maybe Amy would relax more. I wonder if some of my anxieties, not so much genetic, but just how I am rubs off on her. She knows that I am uptight about things...and that brings it out in her.” She added “especially given that anxiety plays a big role in her behaviour and I don’t want to be the cause of that or making it worse.”

Allison said that she wants to “take things easy.” One of the things that Allison expressed about participating in this project is that she enjoyed “doing stuff all together, as a family...doing something that was kind of fun.” When asked about what was difficult or challenging, Allison acknowledged that it was difficult to get “Amy to cooperate” and that the most challenging art task was, “trying to visualize Amy’s pain...that was tricky to do.” She added, “I don’t know if it was especially difficult...it was nice to sit down and take the time to share everybody’s thoughts and ideas...and how different they are between all of us.” As Allison thought about chronic pain and described how she saw it playing out in the different images she noted, “[the pain is] not present in everything, not present in my first picture... I don’t see it there so much” but “in the picture of myself [body map], I guess you could say frustration and worry... there are parts of me that hold worry and frustration and parts of that have to do with my children. Her [Amy’s] complaining or talking about that [pain] is one more thing that I can’t necessarily fix just wanting it so...that’s frustrating.”

Researcher Impression. It seemed that Allison really opened up to what the images she created were trying to tell her. She recognized how being busy and wanting to

stick to a schedule was impacting her own well-being as well as potentially modelling anxiety for her daughter. Allison was willing to be honest with herself about her own experiences and name things that she wanted to do differently.

Victor

As Victor was asked to talk about what he was noticing about his images or about the project itself, he indicated, "I thought that we would be participating to help influence others [Amy] to participate. I didn't think that we would be involved as much as we did, so that was a bit of a surprise to me." When asked how that ended up being for him, he indicated, "it was nice to sit with Allison and give Amy some one-on-one time...I enjoyed that" and he added that he would like to continue to take opportunities in the future to sit down as a family and to make art. In terms of his own learning, Victor indicated that there was not a great deal of new learning but some good awareness. "It just kind of made you think about where you are in your life" Then he added, "The pictures have told me that you have to keep a balance in your life...on a weekly, monthly, and yearly basis...time for yourself...time for your wife and yourself...time for the family unit...and there's got to be time to do the chores...time to do the housework. It's all about dividing up your time as equally as possible" As he continued he noted, "Allison and our relationship is always last... the kids seem to [come first]. I would like to...apart from wanting to understand what's happening with Amy, I would like to start putting Allison and I first a bit more. I think that's important because if we are happy and work more as a cohesive unit then I think that it will fall onto the kids." Victor indicated that he enjoyed the project and that there was not anything he did not like. He noted, "I like looking at the last one [collage] because it gives me hope, the neat things that I like

to do, as a person, as a couple, as a family...it is a happy thing to look at for me.” When asked about how the chronic pain plays out in his life, Victor pointing to the pain picture from session four indicated, “I know she [Amy] needs something but I don’t know what... so it was a sad day for me.” In conclusion, Victor said, “I am looking forward to learning more...this has been a learning process and I have learned a lot already just from our six sessions that we’ve had...It has opened some more doors. It has been helpful...in understanding Amy.”

Researcher Impression. New awareness...and important reminders of things that he already knew. It seems that Victor really enjoyed the time with his family and through the exploration of creating art, he was reminded of things that had been “put on a back shelf.” There was an expressed need for balance and recognition of how his relationship with his wife has made its way lower down the priority list...he wants that to be different, knowing the importance of their unity in the family. He holds on hard to the hope...drawing upon all the strengths he has as a person and they have as a couple and as a family. There is a sense of helplessness, wanting to fix the pain and in acknowledging that there is no easy answer, there is sadness. He demonstrates insight...caring...and thoughtfulness.

Conclusion

In this chapter a brief overview of the six sessions that made up the data collection process of this project was presented as well as the shared images and stories that emerged within the art making and debriefing times. The participating family included Amy, Allison, and Victor. The participants created five images that were intended to gradually build and explore their experiences of living with chronic pain for

Amy and having a child living with chronic pain for Allison and Victor. This chapter also presented a brief reflection piece as per the researcher's perspective for each of the images and stories. The following chapter will include a discussion of the findings of this inquiry in terms of the research questions, the use of art as an interviewing tool, the delimitations, and finally the implications for families and helping professionals.

Chapter Six: Discussion

This discussion chapter provides a brief review of the purpose of this research project. The research questions are addressed by considering the information that emerged during the sessions relevant to those questions. Throughout the responses to the research questions, the congruencies and inconsistencies of this particular case in relation to the published research are presented. Additionally, the use of art as an interviewing tool is examined by identifying benefits and challenges of this methodological approach. Finally, the chapter offers discussion about the limitations of the overall project, implications for both therapists and families, and areas for future research.

Purpose

The purpose of this case study was to explore and give voice to the experiences of family members, one of whom is a child living with a chronic pain condition. Research to date has highlighted that not only is the prevalence of chronic pain quite high for children, but the consequences for both the sufferer and the family are potentially extremely distressing (McGrath & Finley 1999; Zeltzer & Blackett Schlank, 2005). The participants were asked to engage in art making, over five sessions, as a means to explore their experiences. This methodological approach falls under the art inquiry umbrella and is specifically known as Symbolic Constructivism (Barry, 1996). The researcher worked with the participants and their images to help facilitate the exploration of meanings and thus, the stories that emerged were co-constructed. The guiding research questions for this inquiry were as follows: What are the experiences of a family who has a child living with chronic pain? How does the chronic pain play out in this family's life- socially, emotionally, physically, and spiritually? What kinds of strengths and resources are the

family drawing upon to fight the battle with chronic pain?

Findings

The findings of this research inquiry are consistent with much of the existing research, although the purpose of this research project was not to investigate contributing factors or the impact of chronic pain explicitly. Conversely, the intention of this project was to explore the family members' experiences of having a child living with a chronic pain condition and to give voice to those stories. However, many of the themes that emerged in the art making, debriefings, and check-ins mirrored those found in the present research.

What are the experiences of a family who has a child living with chronic pain?

The Grahams have been battling chronic pain for the past two years. Amy, first began to complain about back pain when she was 3 years old; however, their concerns about her pain were minimized and ignored for over two years. Only recently did the family receive referrals for specialized help and Amy finally underwent a thorough medical assessment. Yet, no plausible medical explanation has been found. Allison and Victor find themselves frustrated, angry, and helpless - not knowing what they can do to help relieve their daughter's pain and confused as to why there are no answers. They sense that because there have been no conclusive results that the professionals have turned back to them for an explanation and although they know in their hearts that Amy is in pain, they cannot help but question the situation.

The research consistently finds that due to the lack of physical evidence and psychometrically sound measures associated with chronic pain, many families are faced with inaccurate diagnosis and lack of appropriate medical responsiveness (Malaty et al.,

2005; Zeltzer & Blackett Schlank, 2005). In turn, families are forced to seek multiple medical opinions (Kashikar-Zuck, 2006). When the pain goes unexplained and undiagnosed, professionals turn to the idea that the pain is psychosomatic or imagined and, in doing so, they look to the family to attempt to understand what factors in the family are maintaining the existence of pain (Eccleston & Malleon, 2003). This is often experienced as blame by families.

Allison and Victor both work full-time and although they have found ways to balance the intense demands of career, household, and family duties, there is also a sense of being stretched. Allison identifies herself as a strong woman who is solid and unmoving like a tree. In the face of stress, she is determined and persistent to push through and on the other hand, she recognizes that the stress does not go away; it manifests itself in her body. She also worries about how her own stress and anxieties are being modelled to her daughter. Victor describes himself as a thinker and as a problem solver and although he communicates a sense of acceptance around the fluidity of emotion, he does not know how to help his daughter and this saddens him. He holds out for hope and yet the picture he created of the present conveys a much bigger burden - he is carrying the weight of the world on his back.

Families of young chronic pain sufferers often live in a busy environment and in their attempts to attend multiple appointments, overcome scheduling difficulties, make-up for missed work, manage a household, and care for children, they are often tapped of resources (Bennett et al., 2000). Moreover, a family's ability to cope and manage these stresses is reflected in their members' levels of functioning which in turn, impacts the sufferer's experience of pain (Schulz & Masek, 1996). The family environment is an

important factor to explore when attempting to understand the experiences of young chronic pain sufferers as parents are constantly teaching them about how to manage their emotional experiences. “Children learn about how to react to pain by watching how their parents react, not only to the child’s pain but also to their own pain” (Zeltzer & Blackett Schlank, 2005, p.109). When children notice their parents become anxious, they too may become anxious (Zeltzer& Blackett Schlank, 2005). Furthermore, parents’ modeling, coaching, and reactions to children’s emotions play a role in how children develop emotional expressiveness, understand emotions, and cope with their own emotions as well as those of others (Denham, 1998).

Although Amy initially presented as shy and quiet, she engaged willingly and worked hard on each of her creations. Yet, when it came time to look at her pictures, the words were often hard to find or too difficult to talk about. She seemed unfocused and distractible in the face of such big feelings and difficult topics. Amy had more difficulty talking about her ‘negative’ feelings, especially about her pain. According to Denham (1998) most typically developing children aged 5 to 6 are able to identify, understand, and use basic feeling words. In McGrath’s (1995) study, he found that children as young as 36 months were able to talk about their pain experience by providing a general idea of intensity and by describing their pain using some descriptive terms and basic emotions. However, research consistently finds that pain can impede children’s abilities to talk about their emotional experiences (Savins, 2002; Stronach-Buschel, 1990). It is also important to acknowledge that children often increase their use of display rules in the presence of new individuals, especially adults in authority-type positions such as teachers, therapists, and even researchers (Zeman & Garber, 1996). Display rules are the

social and cultural norms that emerge regarding what are acceptable emotional displays and children learn at a young age that 'negative' emotions are typically responded to less positively (Zeman & Garber, 1996).

When Amy could talk about her pictures, she often revealed profound details and illustrative metaphors. The process of art making allows children to express their experiences without relying on language; however, in the process, children often learn about their feelings and thoughts (Burick & McKelvey, 2004). When children experience art making as liberating, their defences lower and their stories emerge. In turn, they often develop a new relationship with the problem (Carlson, 1997; Stronach-Buschel, 1990; Sundaram, 1995). The image also provides children at this developmental stage something concrete to talk about and often sets children at ease (Kortessluoma et al., 2003). Amy was able to tell us, through her images, that she feels a need to protect her family from a giant monster. She tells us that she has wishes that only her fairy godmother can grant because of her magic. This type of theme is consistent with Amy's developmental age as the pre-operational developmental stage often includes fantasy play. The concept of young sufferers wanting to protect their families and avoid burdening them further is documented in the existing research. When children worry about causing their families further anxiety, they tend to internalize the pain leading to increased anxiety and/or depression (Savins, 2002).

Although it is often difficult to get a sense of the intensity of a child's pain (Zeltzer & Blackett Schlank, 2005), Amy was able to reveal, through her painting (Figure 10) and story, that sometimes the pain is so intense that it makes it hard for her to think. She also said that at night, when the pain is at its worse, she feels "painless". She leaves

her body and flies away. Once again, Amy is drawing on the world of fantasy and her love of fairies provides her with a creative way of coping with the intensity of her pain. Dissociation, as a response to intense pain, is not specifically named in the body of paediatric chronic pain research. It is a feasible possibility given “[d]issociation is often viewed as an adaptive initial survival strategy in the face of overwhelming stress” (Banyard, Williams, & Siegel, 2001, 29). Individuals can experience varying degrees of dissociation dependent upon the severity of the trauma experience (Banyard et al., 2001). Furthermore, dissociation is believed to be a more prevalent coping strategy or defensive mechanism in childhood (Banyard et al., 2001).

Amy talked about special memories of times with her family and yet she did not mention any friends. Her mom and dad indicate that she seems to be really struggling socially and has a difficult time interacting and responding appropriately in peer relationships. It seems that Amy may not be facing just chronic pain; she is being assessed for an Autism Spectrum Disorder (ASD). Social maladjustment is not only identified as being a consequence of chronic pain but it is also a marked characteristic of ASD (Zeltzer & Blackett Schlank, 2005). This leads to the issue of co-morbidity. Zeltzer and Blackett Schlank identify a high percentage of children with ASD who also have chronic pain. This suggests the possibility that children with ASD are further affected by their experience of chronic pain when it comes to social maladjustment. Moreover, there are other characteristics and symptoms that are identified as being difficult for chronic pain sufferers and children with ASD such as difficulty reading and expressing emotions (Tantam, Monaghan, Nicholson, & Stirling, 1989; Zeltzer & Blackett Schlank, 2005). It is important to note that a diagnosis of ASD does not discount the existence of pain nor

suggest that the pain is imagined (Zeltzer & Blackett Schlank, 2005).

How does the chronic pain play out in this family's life?

Chronic pain plays out in families' lives and influences their experiences within several realms: socially, emotionally, physically, and spiritually. The experiences are often different for family members and are reflective of their own subjective experiences. The following points represent themes and key points of interest that emerged for the participating family.

Socially. The social aspect beyond the family and extended family did not emerge as a major explicit theme within this project; however, the theme of being "busy" was consistent and prominent within the parents' debriefings. The lack of a social theme could possibly be more telling in its absence and be reflective of the degree of its presence in the participants' lives. Nonetheless, it is difficult to speculate as to whether their hectic lifestyle is such that there is limited time for friends or whether it simply did not emerge given the selected art tasks and subsequent conversations.

Allison and Victor both described their family as busy but their social lives beyond the routine of daily life were not highlighted. Allison noted that she often feels pulled between the responsibilities of her career and her family and as a result her own self care is often sacrificed. Victor also recognized that their marital relationship is often the last to be nurtured. The idea of 'busy' is not uncommon to many families in this day and age especially as many families now have two working parents (Halpern, 2005). Although it has been believed that the influx of women into the workforce has had a detrimental impact on family functioning, Halpern (2005) points out other family factors are far more significant including quality of childcare, marital status, consistency of

employment, poverty, poor health, and other significant stressors. The concept of “busy” is important to understand within the context of this family as many of the responsibilities and obligations that were named, such as balancing the demands of both career and home life, are not a direct result of chronic pain. However, given the intense demands of managing a home with two full-time working parents, the extra stress of attending medical appointments and parenting a child with chronic pain would undoubtedly intensify an already busy lifestyle.

Additionally, I did not hear Amy talk about friends or talk about playing with peers. Her parents indicated that Amy struggles socially and has a difficult time understanding and acting appropriately in peer relationships as outlined in the case description. However, many of their concerns about her social behaviour emerged before the onset of the pain and thus, her delay in social development is not likely explained solely by chronic pain. As mentioned above, social maladjustment is a major concern for this family, especially as Amy faces the possibility of an ASD diagnosis.

Emotionally. Chronic pain clearly plays out emotionally for this family as the participants communicated, either verbally or through their art creations, ways in which their emotional selves are affected directly or indirectly by chronic pain.

For the parents, one theme that emerged was a sense of anger, frustration, and helplessness in not understanding the cause of Amy’s pain or what to do to address the pain. The issue of pain is present everyday in this family’s life, and “the pain is not debilitating but frustrating as it is playing out all the time.” Moreover, the situation is complicated as the professionals not only do not know what is causing the pain but they also have different opinions about the severity of the issue. The theme of frustration and

anger on the part of parents is commonly reported in the existing research and is especially prevalent when the pain is unexplained (Eccleston & Malleon, 2003; Kashikar-Zuck, 2006; Zeltzer & Blackett Schlank, 2005). In the absence of a feasible medical explanation, there are often misunderstandings between families and professionals (Eccleston & Malleon, 2003). Other than the anger, frustration, and helplessness, I did not get a sense of either Allison or Victor's internal emotional state as it was not explicitly discussed. Nevertheless, in session three, Allison came to the realization that she experiences her emotions in very physical ways and experiences high levels of stress. Victor copes with his experiences as a "thinker." Talking about emotions and expressing emotions did not appear to be a norm within this family.

Amy was able to communicate about her emotional experiences through the art images and at times, these images helped her to put language to her experiences. For example, when Amy told us about her family drawing (Figure 4), she indicated that she had disguised her family members as a way of protecting them from a giant monster. It is difficult to know what the monster represents. Possibly it is a metaphor for her pain or anxiety. Regardless, Amy communicated that she experiences fear in the face of this monster and she feels responsible for protecting her family from it. Children in the pre-operational stage of development think in very concrete terms and operate from an egocentric point of view. Asking Amy to focus on the details of her picture enabled her to talk about aspects of her experience that were beyond what was portrayed in the image itself and, in turn, this provided a glimpse into her emotional experience (Kortelnuoma et al., 2003). Through the image making, Amy's internal experience became concrete in the world (Reynolds, 1990). Furthermore, the creating of the image provided an opportunity

for Amy to metaphorically make sense of an experience that is more complex than her developmental level enables her to understand (Rubin, 2005b). “[T]heir work is a condensed form of symbolization, showing what they are able to, about that which *interests* them” (Rubin, 2005b, p. 39).

In session three, during the debriefing of the body mapping exercise, Amy would only acknowledge “happy” as an emotion that she experiences. However, the image itself communicates a different picture. Although Amy was eventually able to acknowledge other feelings, it was often difficult for Amy to talk about her ‘negative’ emotional experiences. This difficulty manifested itself in several ways during the course of the project as Amy often became fidgety and unfocused. She would engage in a variety of distracting behaviours in order to avoid talking about aspects of her images. When children are developing emotional competence, they typically recognize happy emotions first but this stage is typically reached before children enter school (Denham 1998). Eventually, Amy was able to talk about emotions other than ‘happy’ and as previously mentioned, her reluctance to express ‘negative’ feelings may be explained by situational factors in that children tend to use display rules in the face of newer adults (Zeman & Garber, 1996). On the other hand, it may also have been that the emotions were simply too difficult to talk about (Farrell Fenton, 2000).

Physically. Evidently, the physical aspect of chronic pain is more pronounced for the sufferer, Amy. Surprising physical discomfort also emerged as a theme for Allison. Victor did not verbalize any symptoms of physical distress other than in his representation of self when he used the metaphor of carrying the weight of the world on his back.

Amy's parents reported that she complains of her pain on a daily basis and that she seems to experience more intense pain in the evenings at bedtime. Although Allison and Victor will provide Amy with pain medication, they are concerned that she will come to rely on it and not develop alternate coping strategies. She often tells her mother that her back is hurting but according to her parents she also describes that the pain radiates into her arms and legs. Although Amy typically had a difficult time acknowledging 'negative' experiences, she was able to talk about her experience of pain after she painted her pain in session four. Amy was able to give us a true glimpse of the intensity of her pain and described that at times, the pain is so intense that it is hard to think. Children who live in pain often indicate that their lives are controlled by pain (Sallfors et al., 2002). Children who live in pain are at higher risk for psychological and psychosocial maladjustment (Walters & Williamson, 1999). As the type of chronic pain is not indicative of the intensity of pain, it is important to honour the child's subjective pain experience (Schulz & Masek, 1996).

During the body map exercise in session three, Allison communicated a sense of feeling overwhelmed in trying to meet the demands of her busy life and recognized that she often experiences her emotions in very physical ways. She indicated that although she is generally happy she also experiences stress and the stress manifests itself in her body. Moreover, Allison expressed a belief that no matter how stressed it is not an option to stop and it is not okay to take sick days. The tone that Allison expressed as she talked about her body map suggested a sense of being weighed down. As previously mentioned, modeling is an important factor to consider and Allison clearly expressed her belief that one should push on and be persistent regardless of the amount of stress. The potential for

Amy to internalize that message and in turn, have difficulty expressing her true experiences of stress and anxiety is high. Parents who have children with chronic pain tend to focus their attention on their child to the point that they neglect their own well-being and self-care (Zeltzer & Blackett Schlank, 2005). This emerged as a concern for the parents. Importantly, parents also model for their children appropriate ways of managing stress and Allison and Victor also have valuable resources such as a engaging in hobbies, accessing support from loved ones, and taking time to nurture themselves (Denham, 1998; Zeltzer & Blackett Schlank, 2005).

Spiritually. Although the participating family did not identify any particular spiritual or religious beliefs or values, they communicated a sense of spirituality in their connection with one another. However, as this area did not emerge as a major focus of discussion, it is difficult to further comment in this area.

What kinds of strengths and resources is the family drawing upon to fight the battle with chronic pain?

Despite the tremendous amount of stress and struggles that they have encountered in their battle with chronic pain, the family members have been able to draw upon many strengths, coping skills, and resources. Although they each have their own individual strengths and resources, the themes of the importance of relationships, having interests and hobbies, and holding onto hope emerged.

Relationships. The participants touched on the idea that their relationships with each other and their relationship as a family are important and help them move forward during stressful and difficult times. Amy highlighted how the flowers and butterflies in her collage help her to feel happy and to gain strength. Notably, her stories about flowers

and butterflies were connected to special memories of spending time with her mother, father, and grandmother. Allison also highlighted her relationship with others, for example, in her collage she identified resources as family and friends. Similarly, when Victor debriefed his collage, he talked about family and how children are a source of joy within the house. Family functioning is an important factor to consider when examining the experience of chronic pain for families and an integral component of functioning is the cohesiveness and sense of support within the family system. Families that are characterized by positive interactions, cohesion, and less conflict experience better adjustment in the face of difficulties (Barnum, Snyder, Rapoff, Mani, & Thompson, 1998).

Interests and hobbies. Interests and hobbies was also a prominent theme for each of the participants and remarkably, each participant seemed to have a broad range of interests and hobbies. Amy enjoys creative tasks such as art, playing, and dancing. Other themes that emerged included rainbows, swirls, fairies, magic, ballet, flowers, and butterflies. According to her parents, these are themes that are consistent in her life and appear in her art, her stories, and her play. Allison also identified many interests and hobbies: taking pictures and making albums, shopping, hiking and being outdoors, running, and reading. She noted that the most important thing for her is to do at least one thing each day that is just for herself. Victor also noted a variety of hobbies and interests including learning to play the guitar, scuba diving and snorkelling, enjoying wine, flying, travel, and relaxing. Interests and hobbies are often important resources for individuals as they can provide a distraction from the problem as well as provide activities that individuals can look forward to (Juniper, 2005). Distraction is a key strategy in managing

chronic pain because when attention is not focused on the pain, then the nerve impulses that are causing the pain are likely to weaken (Zeltzer & Blackett Schlank, 2005). As such, it makes sense that when individuals can name interests, hobbies, and activities that they enjoy engaging in that these should be considered personal resources.

Hope. Although not always explicitly stated, a thread of hope seemed to travel through the weeks and emerge at different times, for each participant. In the first session, Allison talked about feeling rooted and as she imagined the future, she expressed a sense of hope for her future in her home. In the first session, Victor also alluded to hope in his description of the world. He talked about that despite difficult times, good remains and prevails in the world. Victor noted a similar theme in session four when he noticed that underneath the mixture of colours, he could see the colour blue showing through, realizing that underneath the pain there is happiness. The collage exercise also evoked a sense of hope for Allison and Victor as they both said that aspects of their collage did not represent the present but symbolized hopes, goals, and dreams for the future.

Amy also seemed to draw upon the resource of hope although her conceptualizations of hope were markedly different from that of her parents. She talked about having magic that could turn her into a fairy and making wishes to her fairy godmother. Amy revealed that she had a special wish but she could not share it with us as it would not come true, adding that her fairy godmother is the only one capable of granting her wish. When asked about what her fairy godmother would say about this wish, Amy responded that her fairy godmother would make it come true. This represents hope as she believes that things can be different, that someone is able to help her in her struggles.

The construct of hope is believed to be an important factor in predicting psychosocial adjustment in both children and adults (Barnum et al., 1998). Although hope has been minimally researched with special populations such as those with chronic conditions, research findings suggest that there is some utility (Barnum et al., 1998). Those with higher levels of hope are able to find new and different ways to accomplish their goals and they maintain their sense of drive towards these goals even in the face of challenges and barriers (Barnum et al., 1998). Accordingly, they are more likely to overcome these difficulties and in turn, they experience greater degrees of psychological adjustment (Barnum et al., 1998).

It is important to help families identify strengths and resources as these tools are fundamental to their ability to maintain a sufficient level of functioning (Zeltzer & Blackett Schlank, 2005). It is also imperative that professionals engage in a hope engendering process and at the same time, this can be optimized if the sufferer has access to family and other social supports (Barnum et al., 1998). Unfortunately, the childhood chronic pain research in the area of family resources is limited; one of the unique outcomes of this research is the identification of informal sources of personal strengths.

Art as an interviewing tool

Although art therapy has been a founded discipline for decades (Hass-Cohen, 2002), art inquiry as a methodological approach is now emerging in research for many of the same reasons. Art, as an interviewing tool, proved to be an effective approach in this research project. There were many benefits with this approach but, as with most approaches, there are always some inherent challenges.

Benefits

By asking family members to follow basic directives and engage in art making, they were able to engage creatively and make sense of the task in a personally meaningful way (Riley, 2004). They were able to explore and talk about aspects that were most relevant to their present and lived experiences. As a result, I gained a rich and in-depth picture of not only each individual but also the interactions, roles, and rules within their family (Hass-Cohen, 2002). I learned information about the family members and the family unit that I would never have been able to anticipate in advance; thus, I would not have been able to ask questions that would have elicited the same information (Kwiatkowska, 2001). Furthermore, this approach was particularly useful given Amy's shy personality and developmental level. She was able to communicate her experiences through the art creations without having to rely on language and linguistic skills. Each family member was able to participate equally in the art making component of this inquiry.

When the art images were complete and we gathered to talk about them, the creations played a crucial role. Firstly, the images provided something concrete to talk about and helped participants to make sense of their experience as well as communicate that experience more clearly to the others (Riley, 2004). When Amy had difficulty answering questions, by referring to her pictures, she was often able to reveal more about her beliefs, perceptions, and experiences. Moreover, the visual aspect often revealed new information and provided opportunities for new awareness for participants, especially when they were encouraged to consider what the image was trying to communicate (Riley 2004). Finally, based on participant feedback, it seemed that the art making and

debriefing was a rewarding experience for the participants and the researcher.

Using art with families is therapeutic in that the exploration process often results in the family members' gaining new perspectives and new relationships with the problem (Riley, 2004). In constructivist approaches to family therapy "changing family members' cognitive views, or constructions, of the presenting problems should be a primary focus of treatment (Coulehan, Friedlander, & Heatherington, 1998, p. 17). When family members describe their art work and explore the meanings of their creations, communication opens to new possibilities and alternate resolutions of the problem (Riley, 2004). Then, families are able to incorporate more flexible and adaptive stories into the dominant stories (Coulehan et al., 1998). The parents highlighted new awareness regarding their relationship to the problem and were able to name specific shifts in understanding that had come as a result of engaging in this study. They indicated that these changes were positive and helped them to re-evaluate their situation.

Challenges

The most significant limitation of an art inquiry approach is the amount of time involved. Not only is it important to have enough time for participants to create their images, it is also imperative that each person has time to view, explore, contemplate, and share his/her image. Given the time consuming nature of this type of approach, one risk is that participants are asked to attend to the activities beyond what is reasonable given their developmental age (Kortessluoma et al., 2003). Furthermore, this type of approach is most effective over the course of several sessions as this provides opportunities to build safety and rapport. Without these relationship qualities, participants are not as likely to reveal deeper aspects of their experiences or feel safe enough to talk about those experiences

with the researcher (Burick & McKelvey, 2004; Stronach-Buschel, 1990; Wadeson, 1987).

Because the art tasks are open for participants to project their experience onto, the results do not always respond to the research questions as clearly as asking several direct questions in an actual interview. In other words, it is difficult to know whether the absence of a theme is due to lack of relevancy for the participant or if the art tasks simply did not elicit that information. Furthermore, art making can be an intimidating prospect for many people and it can be challenging to convince participants that you are not interested in the aesthetic value of their images. Individuals also have a tendency to interpret and judge images and thus, it is also important to encourage participants to remain curious about other's images and refrain from interpreting them for meaning. This can be particularly challenging when working with families as they have additional information about each other and sometimes, family members may not want the researcher to be privy to that information. Thus, if a family member reveals information about another, the safety of that individual is at risk.

Implications

For therapists

For therapists who work with childhood chronic pain populations, it is imperative that the condition be viewed through a psychosocial lens as pain is far too complex to be explained or understood by one phenomenon (McGrath & Finley, 1999). A multi-disciplinary approach is often necessary in order to address the multiple factors that could potentially be creating or maintaining the existence of pain (Zeltzer & Blackett Schlank 2005). Accordingly, the family needs to be assessed in terms of discovering possible

factors within the family system that could be contributing to the ongoing pain and they also need to be recognized for the role they play in helping their child adjust to and manage their experiences of chronic pain (McGrath, 1995).

Therapists need to have a strong foundation in human developmental psychology processes in order to educate parents and others about how children make sense of pain, express pain, and manage pain (Zeltzer & Blackett Schlank 2005). When therapists can assist important others in the child's life to understand the complexity of pain for a particular child at a particular developmental stage, the child is more likely to receive the support and understanding that he/she needs. A strong developmental foundation will also help therapists to create appropriate assessments and interventions that allow for sufferers to express their experiences of pain in ways that meet their developmental needs (McGrath, 1995), for example, art and play therapies.

For families

One of the most valuable strategies that parents can implement in order to help their suffering children is to create an open atmosphere where children are encouraged to talk about their pain experiences and the emotions that accompany them. An integral component of creating this kind of atmosphere is modelling healthy ways of expressing and managing difficult emotions for children (Zeltzer & Blackett Schlank 2005). Parents and other family members need to honour the suffering child's experience with empathy and not question whether the pain is real. It can be extremely frustrating to have unexplained chronic pain; however, there are many possibilities for why the aetiology of the pain has yet to be discovered (McGrath, 1995). When children do not feel heard or understood in their pain they are likely to internalize their pain which can lead to

increased psychological maladjustment (Zeltzer & Blackett Schlank, 2005).

As the experience of chronic pain can have an intense impact on the entire family, parents need to engage in self care (Zeltzer & Blackett Schlank, 2005). When parents are able to take time to nurture themselves and engage in activities that are personally rewarding then they are better prepared to cope with the stress and difficulties that come with parenting a child with chronic pain. At the same time, parents are modeling healthy and appropriate coping strategies for their children (Denham, 1998; Zeltzer & Blackett Schlank 2005). Finally, parents need to act as advocates for their children and trust their instincts as they know their children better than others. Advocacy may include seeking second opinions, consulting with professionals with different areas of expertise, and actively participating in finding ways to minimize the impact of living with chronic pain (Zeltzer & Blackett Schlank 2005).

Limitations

The purpose of this case study is not to generalize to other cases or to the general population of young chronic pain sufferers and their families but to explore the experiences of one family in order to give voice to those who live in the world of chronic pain and to highlight areas for future research.

This case study revealed one of the most difficult aspects of studying childhood chronic pain. The experience is so embedded in the family context that it is not possible to tease out exactly how the presence of chronic pain relates to all the experiences identified by the child and family. As with most things, chronic pain does not happen in isolation. Although the themes that emerged within this project are consistent with the existing research, they may not all be sole results of the existence of chronic pain. For

example, Amy clearly experienced some social difficulties and even though the research suggests that chronic pain sufferers may experience psychosocial maladjustment, Amy was also being assessed for an Autism Spectrum Disorder. As such, there are potentially multiple factors playing out. Although it is probable that chronic pain either contributes to or intensifies different issues, it may not be the sole explanation.

Directions for Future Research

As childhood chronic pain research remains limited, there are many areas and directions that are in need of future research. Much of the research to date has highlighted areas of concern (Hunfeld et al., 2002; Malaty et al., 2004; Roth-Isigkeit et al., 2005; Sallfors et al., 2002; Schulz & Masek, 1996; Walters & Williamson, 1999; Zeltzer & Blackett Schlank, 2005). More in-depth inquiries are needed in order to increase our understanding of how certain factors contribute to the occurrence of chronic pain and, most importantly, how we can intervene to minimize the impact for sufferers and their families.

As the familial context plays such an integral role in childhood chronic pain, research in this area would be extremely beneficial. Future research needs to explore how families can support their children's adjustment to and management of their chronic pain. Implications for researchers include taking an active role in not only coming to an understanding of which factors and dynamics hinder and which factors and dynamics help but researchers also need to provide practical and reasonable strategies that families can implement. Hence, researchers need to continue to explore different approaches in family therapies, such as art in family therapy. The strengths and limitations of each of these approaches needs to be ascertained so that therapists and families alike can make

informed choices about what is most suitable for their families.

Other areas that are in need of future research include increasing our understanding of how children understand and make sense of their experience of chronic pain; developing a protocol for responding to childhood chronic pain that incorporates an inter-disciplinary approach; and pursuing information about childhood chronic pain sufferers who also experience other mental health issues.

Conclusion

Within this chapter, I briefly reviewed the purpose of this research project. I then responded to the research questions by highlighting the related ideas that emerged within the project including the congruencies and inconsistencies of this particular case in relation to the existing research. For the most part, the findings of this research project are consistent with the published research. I also examined the use of art as an interviewing tool by identifying benefits and challenges. Next, I presented the research limitations and finally, I offered implications for both therapists and families and highlighted areas for future research. In chapter seven, I write about my own journey as the researcher in order to highlight some of the strengths and challenges that I encountered along the way.

Chapter Seven: Researcher's Journey

I feel very fortunate to have had the opportunity to facilitate this research project as it has been tremendously rewarding to journey through the process of having an initial idea evolve into a reality. From the moment of conception, I have held this project near to my heart and through all the hard work and challenges I have felt the fire of my passion hold steady. This chapter is an opportunity to share with the readers aspects of my journey that highlight some of the issues that emerged for me during the process. One of my intentions in sharing my personal perspectives is to account for them and to be transparent in how I believe they played out in the research.

Personal experiences of chronic pain

As I mentioned in Chapter One, one of my motivations for conducting this research was that I have my own experiences of living with chronic pain. As a child and adolescent, I experienced a variety of painful illnesses and injuries including recurrent episodic pain in terms of sore throats, pneumonia, sprained joints, damaged ligaments, lower abdominal pain, and more. It felt as though I was constantly seeing the doctor. In retrospect, I remember the anguish and shame that I felt when the doctor questioned the degree or existence of my pain and when my parents expressed exasperation that I was complaining of pain, yet again. I started to question my own experience and wondered if there was something wrong with me. Then, as a young adult, I developed a recognized chronic pain condition known as Complex Regional Pain Syndrome and have experienced two major episodes of this intensely painful condition. Although the pain condition was medically recognized, the experience still came with experiences of stigmatization and frustration. Yet, when I read the literature on paediatric chronic pain, I

began to feel validation in my experiences of pain and recognized that given the prevalence, many other children are facing the difficulties inherent to chronic pain. Thus, I wanted to learn more about these experiences and provide an opportunity for sufferers and their families to voice these experiences.

In terms of the research, I believe that my own experiences of living with chronic pain helped me remain, as a researcher, in a non-judgemental stance of wanting to learn about Amy's experience of pain without attempting to make judgements about its truth or falsity. As I listened to Amy's stories, I wanted to communicate a genuine curiosity as well as an acceptance of her subjective reality. I also noticed that I felt drawn to a role of advocate and chose to provide reading materials and research based information about the complicated issues of chronic pain in children as a means of helping Amy's parents remain open to and accepting of what Amy was telling us about her experiences.

It is really working!

Throughout this project I often felt exhilarated and excited and, although I came to the project believing in the power of art, it was really rewarding and exciting to see how the art making and debriefing of images were eliciting and revealing information that I would never have been able to anticipate. Moreover, the research design allowed me to spend enough time with the family, in their home, to be able to gain insight into the family's interactions and individual ways of being. As the weeks progressed, I became more and more certain that art as an interviewing tool was not only an effective way of learning about issues but that this type of approach had a depth of inquiry not available in many other approaches. I was also fortunate to have participants who were courageous enough to open their minds to the possibilities of art and to take the risk of revealing, not

only to the researcher but to themselves, their inner most thoughts, feelings, beliefs, values, and experiences. As I sat with the participants, week after week, I felt honoured to be a part of the journey and exploration process. Yet, no experiences are without challenges.

Putting Expectations Aside

One of the greatest challenges I faced was to put my own expectations aside about what the process would look like and how it would unfold. I had to buy into the idea of trusting in the process and allowing the research to unfold, knowing that it would reveal what it needed to. This challenge became clear to me during the first session when Amy's participation did not fit with what I had imagined. I was expecting that Amy would not only be willing to talk about her pictures but that she would be eager to reveal many things. Yet, it was often difficult for Amy to talk about her images and she often became unfocused and distractible during the debriefings. After the first session, I became aware that Amy was in fact communicating. Her behaviours were letting us know that it was hard and uncomfortable to talk about her experiences of pain. Moreover, I realized that when Amy was creating the art, she was focused and task oriented. The reasons that I had initially identified for using art were validated. I was then able to let go of my own expectations and allow Amy to participate in whatever way made sense to her. Although it was often difficult for Amy to talk about her experiences, she was communicating through her images and in turn, she was eventually able to put words to those experiences. Amy's parents also had expectations about how she should participate. I was able to provide information that I hoped would help them to understand Amy's behaviour in a new light and thus, allowed them to be open to her way of participating.

Tension between Researcher and Practitioner

Another challenge inherent to this approach was managing the dual role of researcher and therapist. Although my primary role was researcher, it was also not possible to disengage completely from the part of me that is trained as a therapist. My therapist part has become an integrated part of who I am as a person. Although, I can step out of my role as therapist, the way I perceive the world and interact within it is influenced by my therapist lens. Furthermore, even if it were possible, I am not sure if I would have made a different choice. One of the values of this project is that it closely resembles what practitioners actually do and I believe enhanced the process. My skills as a therapist helped me to make sense of the dynamics that were playing out in the research setting and to respond to these dynamics in order to establish and maintain safety for the participants. As a result, the participants were able to engage more deeply in the research process and uncover aspects of themselves that they might otherwise not have. For example, when Amy was engaging in her distracting behaviours, I was able to make sense of these behaviours and provide her with empathic statements that helped her re-engage in the process and talk about her pictures. On the other hand, I also had to make decisions that helped the family and me stay within the realm of research and not engage in actual treatment.

In order to stay within the realm of research, I had to continually remind myself that the primary purpose of this research project was to elicit and explore the experiences of the participating family in relation to either living with chronic pain or having a child living with chronic pain. As such, I had to remain in an inquiry stance and although I could be curious about their experiences as a means to better understand them, I had to

avoid going to the place of actually processing events, emotions, or experiences that the participants were naming. I also had to pay attention to issues that were emerging that could have potentially taken us off track and away from the issue of chronic pain. The one decision that stands out for me in regards to this dilemma was when I asked participants to no longer express their thoughts, ideas, and perspectives about each others' art images. This had emerged quite spontaneously within the first session and although I was curious about how sharing these ideas would deepen the contextual understanding, I was also concerned about the emotional safety of each participant. Therefore, I attempted to set some boundaries and guidelines to help the participants note their own experience of seeing the image, without interpreting the meanings of others' images. Issues unrelated to the research project were emerging that may have potentially needed more therapeutic type conversations to process and thus, I made the decision to discontinue that component of the debriefing process.

Conclusion

As the researcher within this project, I too had my own journey and experiences of participating. I wanted to highlight a few of the experiences that emerged as a way of accounting for my role in the project. I wrote about how my own experiences of chronic pain played out for me as I worked with this family and about my excitement and enthusiasm as I witnessed the project take shape and evolve. I then addressed some of the challenges including putting my own expectations aside and managing the tension between the roles of researcher and therapist. Overall, this was an amazing experience and one that I am very proud to have been a part of.

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Appendix A

Sample Questions

Questions either taken from or inspired from Weiser (1993)

- What are the most obvious things about your creation?
- How would you describe your creation to someone who was unable to see it?
- What would you title your creation?
- What is the message of this creation?
- What feelings does this creation give you?
- What changes would you make to this creation?
- If your creation could talk what would it say?
- What are three things I would not know about you from this creation?
- What is the first word or phrase that pops into your head when you look at this creation?
- If this creation was trying to tell you something what might that be?
- If you were this creation, what would you say?
- Tell me a short story about what is happening in your picture.
- What do you see differently when you look at your picture upside down?
- What does this picture remind you of?
- What three needs that this image has or might want?
- What are some questions that your creation is asking you?
- In what ways does this creation remind you of yourself?

Appendix B

Recruitment Telephone Script

Hello! My name is Kate Shea and I am a graduate student in the Counselling Psychology Department at the University of Victoria. I am currently recruiting participants for a research project that I am undertaking in partial requirement of my Master's degree. I am calling to inquire if you would be willing to receive an outline of my research inquiry in order to inform potential participants of this opportunity. Briefly, this opportunity is for one family who has a child living with a chronic pain condition and will involve asking all family members to engage in art making tasks as a means to explore the family's experience of chronic pain. The research outline will provide you and potential families with information about the nature of the research inquiry, research purpose, participant criteria, participation involvement, timeline, and contact information. You may choose to pass on the information to families in whatever way makes sense for you. However, the research outline, should you pass a copy directly to the families, highlights that you are passing the information to them, on my behalf, and no personal information has been given to me. If the family is interested in participating, they are to contact this researcher directly.

Would you be willing to receive a copy of my research outline and pass the information along to any families that you think may interested in participating?

Thank you very much for your time, it is greatly appreciated.

Thank you.

Appendix C

Research Outline

Research Project Title: An Art Inquiry into the Experiences of a Family of a Child Living with a Chronic Pain Condition: A Case Study.

Investigator:

Kate Shea
Graduate Student
Counselling Psychology Program
University of Victoria
370-9439
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University Supervisor:

Dr. Blythe Shepard
Assistant Professor, Department of Educational Psychology and Leadership Studies
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THE INVESTIGATOR IS A GRADUATE STUDENT IN THE EDUCATIONAL PSYCHOLOGY DEPARTMENT AT THE UNIVERSITY OF VICTORIA AND THIS RESEARCH PROJECT IS A PARTIAL REQUIREMENT FOR A MASTER OF ARTS DEGREE.

Funding: Social Sciences and Research Council of Canada (SSHRC)

Research Purpose:

The purpose of this research project is to work with a child living with chronic pain and his or her family and to give voice to their experiences of coping with this condition. These experiences will be explored through a process of art making and the researcher and participants will work together to come to an understanding of the meaning within the art creations. The following questions will serve to guide this inquiry: What are the experiences of a family who has a child living with chronic pain? How does the chronic pain play out in this family's life- socially, emotionally, physically, and spiritually? What kinds of strengths and resources is the family drawing upon to fight the battle with chronic pain?

Participant Criteria:

The main criterion for participation is that a child (aged 6-10) in the family is living with a chronic pain condition. Chronic pain is defined as any persistent or reoccurring pain that lasts for a duration of no less than six months, with known or unknown aetiology, and is interfering with the family's level of functioning. Due to the difficulties in diagnosing chronic pain, the researcher will rely on family self-reports in relation to the

above listed criteria. Further considerations include: number of family members who are interested and willing to participate; openness to engaging in art making; developmental levels of individual family members; availability of family; transportation and location issues; and recommendations from referring professionals. It is important to note that no artistic talent or abilities are needed as the focus is not on the aesthetic nature of the art productions.

Participation Involvement:

The participating family will be asked to meet for six 60 to 90 minute sessions, the first five will involve participating in an art activity and debriefing and the final session will be a review of the art work and closing celebration.

	Initial Meeting	Session #1	Session #2	Session #3	Session #4	Session #5	Session #6
Participants	Parent(s)	Parent(s) and children	Parent(s) and children	Parent(s) and children	Parent(s) and children	Parent(s) and children	Parent(s) and children
Activities	Sign Consent Forms	Representation of self	Family Drawing	Body Map	Pain metaphor	Collage	Review all art work
Directives	N/A	I would like you to draw a representation of yourself. This can be a self-portrait or a thing that you identify with such as a tree or an animal	Draw a picture of your family with everybody doing something	Take turns tracing each other's bodies and then make a map using different colors and shapes to show where you experience feelings and sensations in your body	Imagine what the pain looks like and paint that image.	Use the images to create a collage that represents the different things or people that help you cope and feel better and give you strength.	Spend time looking at your art work and reflect on what you have noticed, learned, and/or experienced
Purpose	Review informed consent information and clarify any questions or concerns.	To gain a sense of how each member of the family views themselves	To learn about member's experiences of living with their families.	To discover the emotional experiences that each member is managing and to increase awareness about the body	To externalize the pain and get a sense of how each person subjectively experiences the pain	To uncover the strengths and resiliencies of each person.	Review and reflect on experience of research project

				connection			
Estimated time needed	30 minutes	60 to 90 minutes	60 to 90 minutes	60 to 90 minutes	60 to 90 minutes	60 to 90 minutes	60 to 90 minutes
Recording device	N/A	Audio taped and still photos of artwork	Audio taped and still photos of artwork	Audio taped and still photos of artwork	Audio taped and still photos of artwork	Audio taped and still photos of artwork	Still photos of art work

Time Line:

The research data collection will occur over a two month period, February and March 2006, and the participants' involvement will involve six weekly sessions. Other arrangements, within the two month period, can be made to suit individual family needs.

Location:

The participant can choose to participate in this research project at their home or on the campus of the University of Victoria.

THIS LETTER IS BEING SENT TO YOU BY THIS ORGANIZATION ON BEHALF OF THE INVESTIGATOR AND NO PERSONAL INFORMATION HAS BEEN PROVIDED TO THE INVESTIGATOR.

If your family is interested in participating in this research project, please contact the investigator, Kate Shea, directly.

Kate Shea
 GRADUATE STUDENT
 Counselling Psychology PROGRAM
 University of Victoria
 370-9439
 kshea@uvic.ca

Appendix D

Participation Consent Form

Research Project Title: An Art Inquiry into the Experiences of a Family of a Child Living with a Chronic Pain Condition: A Case Study.

Investigator:

Kate Shea
 Master of Arts in Counselling Psychology student
 University of Victoria
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University Supervisor:

Dr. Blythe Shepard
 Assistant Professor, Department of Educational Psychology and Leadership Studies
 University of Victoria
 721-7772
blythes@uvic.ca

Funding: Social Sciences and Research Council of Canada (SSHRC)

*This consent form is intended to provide you with important details and information about the research project that you are being invited to participate in. If you have any questions about the information included herein or questions about information that is not included in this form, please do not hesitate to ask. Your questions are important and I will do my best to provide you with the answers. **It is very important that you read through this consent form thoroughly and that you understand and agree to all the information.***

THE INVESTIGATOR IS A GRADUATE STUDENT IN THE EDUCATIONAL PSYCHOLOGY DEPARTMENT AT THE UNIVERSITY OF VICTORIA AND THIS RESEARCH PROJECT IS A PARTIAL REQUIREMENT FOR A MASTER OF ARTS DEGREE.

Research Purpose: The purpose of this research project is to work with a child living with chronic pain and his or her family and to give voice to their experiences of coping with this condition. These experiences will be explored through a process of art making and the researcher and participants will work together to come to an understanding of the meaning within the art creations. The following questions will serve to guide this inquiry: What are the experiences of a family who has a child living with chronic pain? How does the chronic pain play out in this family's life- socially, emotionally, physically, and

spiritually? What kinds of strengths and resources is the family drawing upon to fight the battle with chronic pain?

Criteria: You are being asked to participate in this research project because there is a child, aged 6 -10, in your family that has been suffering from a chronic pain condition and your family has shown interest in participating in this research inquiry. Chronic pain is being defined as any persistent or reoccurring pain that lasts for a duration of no less than six months and is interfering with the family's level of functioning. The cause of pain may or may not be known.

Participation: Your participation in this research project is completely voluntary and your family may choose to withdraw consent to participate at any time. I will ask you to initial this consent form at the beginning of every session to confirm that you are providing continual consent.

If your family or an individual family member chooses to withdraw, they can decide whether they would like their data included in the study or not. If the withdrawing party or parties would like their data to be included in the study, they will be asked to sign a consent (see Appendix F).

If your family voluntarily agrees to participate in this research inquiry, you will be asked to meet with the investigator on several occasions and to engage in different activities. See table below for details:

	Initial Meeting	Session #1	Session #2	Session #3	Session #4	Session #5	Session #6
Participants	Parent(s)	Parent(s) and children	Parent(s) and children	Parent(s) and children	Parent(s) and children	Parent(s) and children	Parent(s) and children
Activities	Sign Consent Forms	Representation of self	Family Drawing	Body Map	Pain metaphor	Collage	Review all art work
Directives	N/A	I would like you to draw a representation of yourself. This can be a self-portrait or a thing that you identify with such as a tree or an animal	Draw a picture of your family with everybody doing something	Take turns tracing each other's bodies and then make a map using different colors and shapes to show where you experience feelings and sensations	Imagine what the pain looks like and paint that image.	Use the images to create a collage that represents the different things or people that help you cope and feel better and give you strength.	Spend time looking at your art work and reflect on what you have noticed, learned, and/or experienced

				in your body			
Purpose	Review informed consent information and clarify any questions or concerns.	To gain a sense of how each member of the family views themselves	To learn about member's experiences of living with their families.	To discover the emotional experiences that each member is managing and to increase awareness about the body connection	To externalize the pain and get a sense of how each person subjectively experiences the pain	To uncover the strengths and resiliencies of each person.	Review and reflect on experience of research project
Estimated time needed	30 minutes	60 to 90 minutes	60 to 90 minutes	60 to 90 minutes	60 to 90 minutes	60 to 90 minutes	60 to 90 minutes
Recording device	N/A	Audio taped and still photos of artwork	Audio taped and still photos of artwork	Audio taped and still photos of artwork	Audio taped and still photos of artwork	Audio taped and still photos of artwork	Still photos of art work

The researcher will provide all art media materials needed each session.

Anonymity:

Although I, the principal researcher, will be aware of your identity you can decide whether you would like me to use your legal names in the presentation of the case study or have your anonymity protected by using fictitious names and removing all identifying information from text and visuals.

Please check one of the following:

- We would like our legal names used in the presentation of the case study and we are aware that this means that our names, first and surnames, may be published in one or more of the following: Master's thesis, academic journal(s), book(s), conference(s), and brochures/pamphlets.

Or

- We would like our anonymity protected beyond our relationship with the researcher and thus, fictitious names should be used and all identifying information should be removed from text and visual representations.

Confidentiality:

Participant confidentiality is of utmost importance within this research project, thus the researcher will not discuss any of the information that is shared during the

inquiry (with exception of circumstances listed below) and anonymity will be maintained by using fictitious names and removing all identifying information from text and visuals.

1) In accordance with the law, there are a few circumstances in which all persons, including the researcher of this project, are required to report to the proper authorities.

These exceptions include:

- If a child is in need of protection because of emotional, physical, and/or sexual abuse.
- If anyone indicates an intent to harm oneself or another person.
- If the researcher were to receive a court order requesting either documentation or an appearance in court.

2) As the researcher is a student and under direct supervision from the University of Victoria, the privileged relationship also extends to the supervisory relationship. This means that the researcher will share with her supervisor the minimal amount of information necessary for the purpose of gaining support in the progress of this research project.

Dual Roles:

Within this research project, the researcher is playing a dual role as counsellor and researcher. It is important that you understand that these two roles are happening simultaneously. In other words, when the inquirer is working with the family as a counsellor, this is also happening in the context of research; however it is important to understand that the main role is that of researcher. As such, the researcher will help the family process any difficulties that arise within context of the research time frame and in the event that one or more family members is in need of extra support, the researcher will help those family members to access additional support within the community. The role of the researcher is not to provide counselling services.

Benefits:

As a result of participating in this project, members of your family may experience:

- an increased level understanding of self and others
- an increased sense of empathy for the experiences of self and others
- a new way of relating to the problem and each other
- new awareness about self, others, and the problem

Risks:

As a result of participating in this project, members of your family may also experience:

- emotions, memories, experiences, and awareness that were not anticipated
- heightened emotional states
- fatigue and/or increased experience of pain
- delayed responses to art making
- resistance to engaging in the art making

Contributions: This research project is an important contribution to chronic pain research as much of the existing literature does not address the experiences of those who live with this debilitating condition and their families. This project is an important step

towards giving voice to families and offers unique contributions in terms of research design. It is important that the focus of this project is not only to meet the researcher's academic obligations but that it also contributes to the wider knowledge of chronic pain. As such, the researcher will attempt to share the results of this research in as many of the following forums as possible:

- Academic journals in counselling, psychology, education, and research methodology
- Professional Conferences such as Canadian Counselling Association Annual Conference, Montreal 2006
- Potentially a published book
- Other publications and presentations: handouts and/or brochures for helping professionals and families, informational sessions with community agencies, consultations with helping professionals.

Ethical Approval:

This research project has been approved by the University of Victoria Human Ethics Board and confirmation of this approval can be obtained and provided, if necessary. IF YOU HAVE ANY CONCERNS OR QUESTIONS ABOUT THIS RESEARCH PROJECT PLEASE CONTACT THE ASSOCIATE VICE PRESIDENT OF RESEARCH AT (250) 472-4545.

Important Reminders:

I/We acknowledge that

- All sessions will be audio taped _____ (Initial(s))
- All art work will be photographed _____
- Our participation is completely voluntary _____
- We may withdraw from the research project at any time _____
- The findings of this research will be shared in several contexts including but not limited to a thesis, journal articles, and conference presentations _____
- Anonymity will be protected by having all identifying information changed or concealed, if chosen by the family _____

Signatures:

Family Member	Age	Relationship to child with chronic pain	Signature

Continuing Consent:

Date:

Parent(s)' Initials:
