ADOLESCENT EXPERIENCES IN AN INTENSIVE INTERDISCIPLINARY
PEDIATRIC CHRONIC PAIN REHABILITATION PROGRAM

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Abstract

Children and adolescents worldwide experience pediatric chronic non-cancer pain (PCNCP) significant enough to contribute to functional disability and negatively impact family functioning, mental health, school attendance, social activities, and sleep patterns. For some youth, an intensive interdisciplinary pain treatment (IIPT) approach is recommended to address the multifactorial complexity inherent with this condition. While these programs demonstrate a strong evidence base and are supported by experts, research is lacking to explain why such effectiveness is demonstrated or how this change occurs. A study utilizing Interpretative Phenomenological Analysis (IPA) methodology was conducted to better understand and communicate the perspectives of adolescents currently enrolled in an IIPT program. Six participants, ages 14 to 17, were interviewed. One overarching theme, leap of faith, emerged during data analysis, along with four subthemes, living miserably on the edge, diving in, buried treasure, and charting new waters. This study leads to a fuller understanding of how adolescents perceive, make sense of, and ascribe meaning to their experiences while engaged in an IIPT program for PCNCP and serves as a foundation for future research exploring mechanisms of therapeutic change in this population.
DEDICATION

This study is dedicated to my brother Glenn, and my parents James and Donna Rae Franczak. You taught me important lessons about life and love as you endured various types of pain and suffering with strength and dignity.
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Chapter 1: Introduction

Background and Significance

PCNCP is a global complex medical issue; its etiology involves the integration of biological, psychological, socio-cultural, and developmental factors (T. Palermo et al., 2012). Conditions that are commonly related to chronic pain in children and adolescents include previous physical injury, abdominal pain, reflex sympathetic dystrophy, headache, musculoskeletal pain, back pain, neuropathic pain, sickle cell disease, and juvenile rheumatoid arthritis, among others (Calvo-Munoz & Gomez-Coresa, 2013; Wober-Bingol, 2013). The American Medical Association (AMA) and Institute of Medicine (IOM) consider chronic pain a disease state in itself (Gallagher, 2011; IOM, 2011; Lippe, Brock, David, Crossno, & Gitlow, 2010).

It is estimated that up to 20-46% of children and adolescents experience PCNCP worldwide (King et al., 2011; T. M. Palermo, Lewandowski, Long, & Burant, 2008). Approximately 8% of children and adolescents experience chronic pain severe enough to negatively affect family functioning, school attendance, social activities, and sleep patterns (Perquin et al., 2000). Research indicates an overall increase in the prevalence of PCNCP over the past several decades, and adolescents with a mood or anxiety disorder have been identified to be at even higher risk (Coffelt, Bauer, & Carroll, 2013; Mangerud, Bjerkeset, Lydersen, & Indrekavik, 2013). Children and adolescents with PCNCP commonly suffer from other comorbid medical and mental health conditions, which can prove to be a challenge for health care providers attempting to differentiate between diagnoses or pain treatment strategies (Eccleston, Jordan, & Crombez, 2006; Zernikow et al., 2012).
Children and adolescents with PCNCP often experience limitations in daily functioning and psychological distress related to chronic pain symptoms (Gold et al., 2009). They seek more medical care, use more medications, miss more school, and report worse quality of life relative to their peers without pain (Huguet & Miro, 2008). Longitudinal evidence suggests that pediatric pain may continue for years and contribute to a variety of adult chronic pain conditions (Dengler-Crish, Horst, & Walker, 2011; Fearon & Hotopf, 2001; Walker, Dengler-Crish, Rippel, & Bruehl, 2010). Since it is estimated that 35% to over 70% of children and teens with PCNCP will have continued chronic pain into adulthood, it is essential to explore the long-term consequences and to identify treatment approaches that may help to prevent these troubling outcomes. Furthermore, research is necessary to estimate the financial burden with a lens that views the full trajectory of a potential lifetime with chronic pain (Fearon & Hotopf, 2001; Groenewald, Essner, Wright, Fesinmeyer, & Palermo, 2014; Walker et al., 2010).

Economic studies related to PCNCP are limited; however, there is evidence of considerable direct and indirect ramifications for families, including medical financial costs, time spent in medical appointments, parental work absences, and childcare fees for siblings (Ho, Bennett, Cox, & Poole, 2009). Data from the United States Pediatric Health Information System Database show that PCNCP accounts for substantial medical resource utilization (Coffelt et al., 2013). In a recent evaluation of economic costs among 149 adolescents presenting for interdisciplinary evaluation and treatment for PCNCP in the United States, researchers concluded that 5% of patients with the highest costs accounted for 30% of the total costs for the group. The 75% with the lowest costs represented only 34% of total group costs. Societal costs for moderate-to-severe chronic pain in adolescents are estimated to exceed 19 billion per year in the United States (Groenewald et al., 2014).
Significant events have occurred in national health policy in recent decades, which have repercussions for those experiencing PCNCP. In 1998, the American Pain Society (APS), American Academy of Pain Management (AAPM), and American Association for the Study of Headache (AASH) developed the Pain Care Coalition with goals to influence healthcare policy, research, quality management, and treatment access for individuals and families. The time period between 2001 and 2010 was identified as the Decade of Pain Control and Research by the United States Congress, and the National Pain Care Policy Act (NPCPA) was first introduced in the United States House of Representatives in 2003. In 2006, the National Institute of Health (NIH) Reform Act of 2006 called for research specific to chronic pain (IOM, 2011).

In 2010, the initiation of the Patient Protection and Affordable Care Act (PPACA) required that the United States Department of Health and Human Services (DHHS) involve the IOM in addressing pain as a public health concern. This resulted in a groundbreaking document calling for transformation of pain treatment, education, and research (IOM, 2011). Two years later, the NIH designated the National Institute of Neurological Disorders and Stroke (NINDS) as the primary research institute for pain, and a Senate hearing addressed the challenges of treating pain. Several other national agencies have developed specific initiatives related to pain, including the Agency for Health Research and Quality (AHRQ), the Health Resources and Services Administration (HRSA), Medicare, and Medicaid.

A family foundation, The Mayday Fund, was established in 1992 and is dedicated to decreasing pain-related suffering (Lewis, 2004). It was named after the birthday of Shirley Steinman Katzenback, a philanthropist with a special interest in the treatment of pain, along with the French word “m’aidez” which is translated as “help me.” This organization formed a special committee in Washington D.C. in 2009 to address pain and medical practice in Washington DC.
The panel of experts encompassed nurses, psychologists, physicians, and pharmacists. Patient advocates were also invited to add a more comprehensive perspective on the topic. Although this international foundation is not limited to a single age group experiencing pain, pediatric pain is a current funding focus.

PCNCP has received much attention from Canadian scientists and clinicians over the past several decades. In 1989 two researchers, Dr. Patrick McGrath and Dr. Allen Finley opened the Pain Research Lab in Halifax, Nova Scotia in Canada. This lab evolved into an international Center for Pediatric Pain Research located in the Izaak Walton Killam (IWK) Health Center; it focuses on pediatric pain research with a goal of positively impacting training and clinical practice for this population. The center advocates for the interdisciplinary approach and recognizes the necessity of a multifaceted perspective because of the inherent complexity involved in pediatric pain. Trainees from a variety of disciplines are mentored from undergraduate to post-doctoral educational levels. Funding sources for the center include the Canada Foundation for Innovation, the Mayday Fund, and the Canadian Institutes of Health Research (CIHR), and a multitude of local and provincial sources. The Pain in Child Health (PICH) initiative is funded by the CIHR and represents an international body of investigators and collaborators dedicated to improving outcomes in pediatric pain. Between the years of 2002-2013, the group supported over 200 trainees, which resulted in 697 peer-reviewed journal articles related to PCNCP, as well as webinars. Trainees represented over 16 disciplines and 14 countries (von Baeyer et al., 2014).

Globally, the International Association for the Study of Pain (IASP) acknowledges that PCNCP is an under-recognized problem. In 2011, representatives from 64 IASP chapters, along with members from 130 different countries, convened for the International Pain Summit (IPS) to
address pain as a worldwide issue. This landmark gathering resulted in the adoption of the Declaration of Montreal, which asserted the inadequacy of pain management for a majority of the world’s population due to lack of national policies, inadequate research and education, and decreased access to treatment (Lippe et al., 2010). Several basic human rights were also recognized, including the importance of nondiscrimination and the necessity of access to pain assessment and treatment. Chronic pain is acknowledged as a stigmatized condition. Health care systems have failed to provide the same attention to it as to other chronic diseases such as heart disease and diabetes. The IASP has illustrated their commitment to the pediatric population by developing and supporting a special interest group (SIG) specific to pain in childhood.

Finally, the World Health Organization (WHO) published a guideline related to persisting pain in children (Organization, 2012). While this particular document focuses on pharmacotherapy, it also describes pain classification and measurement systems, opioid dependence syndrome, and non-pharmacological approaches to treatment, which are applicable to PCNCP. The guideline also advocates for individualized treatment and recognizes that some clinical situations may require a holistic approach.

**Biopsychosocial Model of Pain**

The biopsychosocial model embodies a holistic approach to pain assessment and treatment. The biopsychosocial model was first introduced by G. L. Engel, a professor of psychiatry and medicine, in response to a predominant dichotomous conceptualization of patients’ problems at that time from either a psychiatric or medical perspective (Engel, 1977). The biopsychosocial model is considered both a philosophical approach and an organizational framework to guide clinical practice. Engel proposed that psychological and social factors are involved with the development and trajectory of disease processes (Westerman, 2007).
biopsychosocial model can facilitate understanding of how a clinical condition presents and is conceptualized by the individual with pain and health care providers. Engel’s foundational work resonated with caregivers in the medical professions seeking to improve the humanization of healthcare (Borrell-Carrio, Suchman, & Epstein, 2004).

Critique of the strictly biomedical model was based on a variety of observations. The etiology of a condition may result from multiple causal factors. Also, the meaning attributed to a condition and the associated experience is unique for each individual and family. The extent of an individual’s functional disability is not always in direct proportion to their physical presentation, and a person may present in an exaggerated sick role if only biomedical factors are considered. The interpersonal relationship between an individual and clinician may influence treatment outcomes and have reciprocal effects on both the patient and provider (Borrell-Carrio et al., 2004; Engel, 1977, 1980).

An early pioneer in the development and application of the biopsychosocial model to persistent pain conditions is Dr. John J. Bonica, M. D., an army physician who personally suffered from chronic shoulder pain. After experiencing disappointment and frustration in the poor physical and functional outcomes for injured soldiers, he developed the first multidisciplinary pain clinic based on the biopsychosocial model in Tacoma, Washington (Meldrum, 2003; Wordsworth, 2012). Even though his program demonstrated positive outcomes, Dr. Bonica’s cutting-edge concepts were not immediately embraced by the scientific or clinical communities (Meldrum, 2003).

The foundations for the biopsychosocial model lie in systems ideology and propose that chronic pain and other illnesses are not solely physical or psychological in nature, but involve complex interactions between a variety of physiological, psychological, developmental, and
sociological factors. These aspects are interdependent; each patient’s responses to disease processes and pain stimuli are unique. The biopsychosocial model considers the subjective experiences of the patient along with objective factors, such as diagnostic test results, to provide for a more comprehensive understanding of complex pain presentations (Borrell-Carro et al., 2004). It encompasses the biological, psychological, and sociocultural domains of a person, and each of these can involve multiple sub-domains. Not only are these spheres or domains present, they are interdependent and reciprocally influential (Drossman, 1998; Engel, 1977; Gatchel, 2004). For example, physical factors may influence social factors, or psychological factors may affect physical ones.

According to the biopsychosocial model, none of the factors is isolated or independent. The trajectory of a chronic pain disorder may be impacted by other psychological disorders, such as anxiety, depression, or substance use disorders. Peirce (1834-1914), a mathematician, theorized that each individual is an interpreter who experiences a stimulus and then assigns meaning to it through an imprinting process. The individual interpreter draws upon their own conscious and unconscious memories, interpersonal relationships, physical state, and psychological predispositions and thoughts when appraising a physical impulse (Adler, 2009). This theoretical process may help to explain how children may react and heal differently from the same medical condition, injury, or surgery (Bruns & Disorbio, 2005).

**Biological domain.** The biological domain involves the physical presentation including disease processes or mechanical injury, genetic predispositions, sleep, diet, and exercise. Pain involves the processes of transduction, transmission, modulation, and perception (Gatchel, Peng, Peters, Fuchs, & Turk, 2007). When acute non-cancer pain becomes chronic, it no longer serves adaptive functions within the human system and is often no longer directly related to structural
pathology. Chronic pain may arise from nociceptive or neuropathic conditions, and peripheral and central sensitization processes, along with reorganization of the nervous system, which may contribute to its maintenance (Aronoff, 2016).

Research findings show that when subjects are exposed to comparable noxious stimuli each can demonstrate unique sensations and perceptions of experience, which is due to modulation of sensory pathways throughout the central nervous system (Chambliss, Heggen, Copelan, & Pettignano, 2002). Hyperalgesia may be attributable to a variety of factors, including stress, illness, or repeated nociceptor reactivation leading to sensitization, even within uninjured tissues. It is imperative for clinicians to recognize the type of pain that a patient is presenting with, whether it is nociceptive, neuropathic, or arising from peripheral or central sensitization of the nervous system, as this will influence treatment options and recommendations (Aronoff, 2016). The exact pathophysiological mechanisms leading to the development and maintenance of chronic pain are still not fully understood and remain a focus of research (Fornasari, 2012).

Chronic pain may affect brain functioning. Motivation levels can be impacted due to changes in the nucleus accumbens (May, 2011). Additionally, changes may occur in the ventral prefrontal cortex, which also relates to emotional functioning. Due to the incomplete neurological maturation of children and adolescents, these effects may be even more profound (Geraghty & Buse, 2015). PCNCP does not usually respond well to classical analgesic therapy, and opioid medication is not recommended; however, some children or adolescents may obtain some relief from adjuvant medications such as antidepressants or anticonvulsants (Mathew, Kim, & Goldschneider, 2014). Approaching the chronic pain from a strictly biological model can lead to a mechanical understanding that is purely disease-focused. This may be very different from the patient’s actual experience and may even disaffirm their suffering (Monsivais, 2011).
**Psychological domain.** The psychological domain of the biopsychosocial model entails multiple factors, including temperamental predispositions and stress responses (Carter & Threlkeld, 2012; Conte, Walco, & Kimura, 2003). Affective states, such as depression, anxiety, fear, anger, or hopelessness have been identified as important variables for assessment and treatment of PCNCP (Kozlowska et al., 2008). Personality propensities, such as tendency towards introversion, dependency, or somatization may influence how chronic pain is experienced and managed (Carter & Threlkeld, 2012; Mahrer, Montano, & Gold, 2012). Developmental changes throughout childhood and adolescence are additional considerations (Yazdani & Zeltzer, 2013). Coping skills and cognitive appraisals of situations may contribute to how a child perceives and deals with chronic pain, and self-efficacy can influence perceptions and behaviors (Huguet, Eccleston, Miro, & Gauntlett-Gilbert, 2009; Libby & Glenwick, 2010; Lynch, Kashikar-Zuck, Goldschneider, & Jones, 2007). Catastrophic thinking patterns about pain may also influence the experience of pain and subsequent treatment (Carter & Threlkeld, 2012; Guite, McCue, Sherker, Sherry, & Rose, 2011).

**Sociocultural domain.** Within the context of the biopsychosocial model, socio-cultural factors include parental and sibling relationships, along with peer influences and educational variables. When a family member is unable to fulfill aspects of their roles within the family system, it may lead to increased conflict and relational stress (Carter & Threlkeld, 2012). PCNCP places additional stress on the underlying developmental tasks of the family system, and there are multiple variables involved at the individual, dyadic, and collective levels within families, which entail layers of complexity (T. M. Palermo & Chambers, 2005). Siblings of those with PCNCP report changes to various aspects of family life, including roles and responsibilities and quality of relationships. An additional socio-cultural aspect of PCNCP involves a child and
family’s relationships with the healthcare system, specifically with key healthcare providers such as nurses and physicians (Gorodzinsky et al., 2012; Monsivais, 2011).

Disparities exist in access to pain care among youth, the elderly, and minority populations (McGee, Kaylor, Emmott, & Christopher, 2011). Although well studied in adults, race and ethnicity have not been a major focus of PCNCP research and some researchers have found no significant correlations between types of PCNCP and different ethnic groups (Lynch et al., 2007; Varni et al., 1996); however, some correlations exist in the literature (McKillop & Banez, 2016). In a Canadian study, children of European descent were found to more commonly develop juvenile idiopathic arthritis (Saurenmann et al., 2007). In a sample of US adolescents (N=6072), those of American Indian descent were found to have the highest rate of recurrent headaches; those from the Asian and Pacific islands had the lowest (Rhee, 2000). Jewish children reported more headaches than those of Arab descent in a study conducted in Northern Israel, and in a sample of American children experiencing chronic, pre-surgical, and chronic pain (N=166), Hispanic youth had higher widespread pain scores when indicating pain locations on a visual diagram (Genizi, Srugo, & Kerem, 2013; Rabbitts, Holley, Groenewald, & Palermo, 2016).

**Intensive Interdisciplinary Pain Treatment**

Considering the complex and multifactorial nature of PCNCP, clinical and health policy experts recommend intensive interdisciplinary pain treatment (IIPPT) based upon the principles of the biopsychosocial model (Cunningham & Banez, 2006; Geraghty & Buse, 2015; Odell & Logan, 2013). In a recent clinical guideline, The American Academy of Child and Adolescent Psychiatry (AACAP) recommends parameters of assessment and treatment of children experiencing physical illness (DeMaso, Martini, & Cahen, 2009). The protocol stresses the importance of collaboration among health care providers, and utilization of a holistic framework
that includes medical and psychological considerations within a familial and behavioral context. Treatment effectiveness for individual therapeutic interventions such as physical therapy, pharmacology, or psychological therapies alone have been demonstrated to be less effective than those delivered within the context of IIPT (Hechler et al., 2015).

The terms “multidisciplinary” and “interdisciplinary” are often used interchangeably in the literature, however “interdisciplinary” implies a more integrated approach. In a recent white paper, the APS compares the two in terms of components, attributes, and features of effective IIPT. Interdisciplinary teams are defined as having complementary roles and responsibilities, integrated problem-solving, shared accountability, and decisions are made by consensus versus individually or in a hierarchical manner (Turk et al., 2009). For purposes of this research the term “interdisciplinary” will be utilized when describing treatment approaches labeled with either term. Additionally, IIPT may be undertaken utilizing an outpatient, day treatment, or inpatient approach.

In 2012, the IASP identified IIPT as being the most clinically and cost-effective approach with the least associated negative complications (IASP, 2012). The IOM has called for this collaborative and integrative approach, encompassing both the skill and commitment of each team member, when treating chronic pain (IOM, 2011). The APS published a statement that identifies IIPT as superior and awards a Clinical Centers of Excellence designation for an exemplary interdisciplinary pediatric chronic pain program each year. It also recommends reimbursement policies to reflect the multifaceted nature of PCNCP (T. Palermo et al., 2012). The benefits to individuals, families, and society may outweigh the perceived higher economic costs that are involved with the provision of an integrated IIPT approach; however, expenditures may actually be less when considered longitudinally over the life of a child, especially when
factors such as academic achievement, unemployment, and rising medical costs are included (Evans, Benore, & Banez, 2015; Gaskin & Richard, 2012; Sleed, Eccleston, Beecham, Knapp, & Jordan, 2005).

The IIPT approach is dedicated to comprehensive treatment according to the biopsychosocial model, versus solely addressing biological disease processes. Acceptance and management of the pain condition, functional outcome improvement, and overall quality of life may become the foci. Effectiveness in meeting outcomes is measured in a variety of ways, not only pain reduction (Gatchel, Howard, & Kishino, 2011). Additional core measures (i.e., PediIMMPACT recommendations), such as physical, emotional, and role functioning are suggested for pediatric chronic pain research trials measuring treatment effectiveness (McGrath et al., 2008).

**Significance for Nursing**

The National Institutes of Nursing Research (NINR) and National League for Nursing (NLN) identify and reinforce the importance of research related to the prevention and management of symptoms, including pain. The NINR’s main research areas include self-management, promotion of personalized health strategies, and improvement of quality-of-life for individuals living with chronic illnesses. The NINR also targets areas or “spotlights” symptom science and pain research. Both organizations stress the importance of interdisciplinary management of complex chronic health conditions. Current funding opportunities include pain research, chronic illness, and family-centered self-management of chronic illness (Grady, 2014; Grady & Adams, 2015).

Pain education of nursing students and other health professionals is lacking (MacLaren, Cohen, Larking, & Shelton, 2008). Nurses report less than optimal knowledge about the
management of chronic pain, and they perceive this lack as a major obstacle in the provision of high quality patient care (Bergeron, Bourgault, & Gallagher, 2015). Nurses in primary care practices are in an ideal position to facilitate chronic pain self-management (Lukewich, Mann, VanDenKerkhof, & Tranmer, 2015). Findings in a recent systematic review of nurse-led care in both acute and chronic pain conditions show that nurses are not only involved, but play key roles in all aspects of the nursing process in the management of pain. Nurses develop therapeutic relationships with patients and families, and their beliefs and attitudes about pain management may influence those connections (Olmstead, Scott, & Austin, 2010) In addition, nurses are integral participants in interdisciplinary collaboration. Since nurses are key providers in PCNCP, an enhanced understanding of interdisciplinary treatment of these conditions would enhance patient care (Courtenay & Carey, 2008)

Children and adolescents experiencing PCNCP, along with their families often encounter multiple nurses in the search for diagnostic answers and treatment of their conditions. These may include advanced practice nurses, inpatient medical-surgical and psychiatric nurses, or nurses within other specialties. It is crucial that nurses better understand the experiences of children and adolescents living with and receiving interdisciplinary treatment for PCNCP. Better understanding can better equip nurses to provide holistic care, collaborate with other providers, and refer children to IITP earlier. Adequate pain management is considered a child’s right. Nurses must provide holistic evidence-based care, and influence clinical practices and health care policy related to PCNCP (Olmstead et al., 2010).
Chapter 2: Review of the Literature

Incidence and Prevalence of PCNCP

The incidence of PCNCP is challenging to accurately measure due to the inconsistent operational definitions utilized across research studies (Cupples, 2013). The APS describes the condition as persistent and recurrent in nature and lasting approximately 3 to 6 months in duration (T. Palermo et al., 2012; Yazdani & Zeltzer, 2013). A recent systematic review was undertaken to provide updated global prevalence rates; however, most of the studies did not meet quality criteria and findings produced significant prevalence ranges within populations (i.e. headache, 8 to 83%; abdominal pain, 4 to 53%; back pain, 14 to 24%; musculoskeletal pain, 4 to 40%; multiple pains, 4 to 49%; and other types of pain, 5 to 88%). Despite these discrepant figures, researchers conclude that overall rates are higher for females, those with lower socioeconomic status, and increased age (i.e. later adolescence) (King et al., 2011). A Dutch study included over 5400 children from a randomly selected cross-sectional population sample. One quarter reported continuous or recurrent pain lasting longer than 3 months. Half of those reporting chronic pain endorsed multiple types, and one third described it as frequent and intense. Multiple pain types and increased pain intensity and frequency were all more commonly endorsed among girls, and prevalence of chronic pain increased with age (Perquin et al., 2000).

Research findings show an increase in the prevalence of PCNCP, and this has been attributed to a combination of factors, such as improved identification, increased stress and anxiety levels for children and adolescents, along with greater public recognition which may reflect more children and adolescents presenting to health care providers for conditions that were previously considered unamenable to treatment (Landry et al., 2015).

State of the Science Related to PCNCP: Biological
Genetic predispositions. Research findings show familial and social correlates of PCNCP; however, it is unclear whether these links are genetic in nature, or if they are more strongly related to psychosocial processes such as role modeling or coping styles. In a descriptive study of over 5,000 adolescents, parental chronic pain was associated with increased chronic pain rates in adolescents, and to an even higher degree when both parents were affected (Hoftun, Romundstad, & Rygg, 2013). Fibromyalgia syndrome (FMS) and related clinical conditions such as chronic fatigue syndrome (CFS) and irritable bowel syndrome (IBS) are found to have a strong familial component, suggesting genetic contributions; however, the same researchers acknowledge that environmental factors may contribute to the manifestation of these disorders in those with genetic predisposition (Buskila, 2007).

A recent systematic review of genetic contributions to pain and acknowledge that genetic linkages have been replicated across studies (Fillingim, Wallace, Herbstman, Ribeiro-Dasilva, & Staud, 2008). A variety of interacting genes contribute to chronic pain among family members. While polymorphisms in genes specific to the serotonergic and catecholaminergic systems have been implicated, the exact genes and contributory proportions to pain conditions are still unknown. Geneticists are challenged with separating out familial linkages related to specific disease processes versus actual pain processing, which are explored by experimentally studying pain sensitivity in laboratory settings. Research involving twins concludes that genetics can account for approximately 50% of variance in chronic pain states (Fillingim et al., 2008).

Temperament. Temperament is a constitutional inborn predisposition that remains stable across time and situations (van den Boom, 1994). While certain personality traits may be associated with social factors, it is theorized that genetically determined temperamental traits exist; these temperamental traits are identified as potential contributors in the development and
maintenance of PCNCP (De Fruyt, Van De Wiele, & Van Heeringen, 2000; McKillop & Banez, 2016). Difficult infant temperaments are correlated to insecure attachment styles with primary caregivers, which may contribute to ineffective pain communication (van den Boom, 1994).

Infants who had difficulty establishing routines have higher rates of recurrent abdominal pain (RAP) in childhood, and children experiencing RAP also possess anxious, difficult or inhibited temperaments when compared with pain-free subjects (Campo et al., 2004; Davison, Faull, & Nicol, 1986; Ramchandani, Stein, Hotopf, Wiles, & Alspac Study, 2006). Children and adolescents with PCNCP have more difficult temperaments than peers; reciprocally, youth with difficult temperaments are more sensitive to pain and psychological stressors (Campo et al., 2004). While current literature suggests a relationship between temperament and PCNCP, studies are limited and additional research is needed (T. M. Palermo, Valrie, & Karlson, 2014).

**Developmental factors.** A developmental perspective is imperative when assessing or treating children and adolescents experiencing PCNCP. Physiologically, PCNCP affects the onset of puberty, growth, and physical development; this may be due to chronic stress levels related to living with PCNCP and potential side effects of medication (Geraghty & Buse, 2015; Perquin et al., 2000). Structural changes in the maturing brain, and other physical, behavioral, family, and social processes, along with cognitive and intellectual transitions, can culminate in a particularly vulnerable and sensitive course for those with PCNCP (Steinberg, 2005). There is a dearth of longitudinal research highlighting the developmental perspective of pain conditions throughout childhood and adolescence (Chambers, Corkum, & Rusak, 2008). Along with considering the individual patient’s developmental status, it is important to consider the current developmental tasks of the family of the child or adolescent experiencing PCNCP, as this could
impact assessment and appropriate intervention (T. M. Palermo & Chambers, 2005; T. M. Palermo et al., 2014).

Sleep. Quality sleep is a core research focus in PCNCP clinical studies (McGrath et al., 2008). Sleep difficulties are correlated with PCNCP, mood disturbance and functional limitations; however, it is difficult to determine the nature of the interrelationships of these variables, given that medications used to treat PCNCP may have an impact on sleep patterns (Chambers et al., 2008). While studies related to sleep and PCNCP included samples with heterogeneous pain conditions, researchers often utilized samples of younger children versus adolescents (Long, Krishnamurthy, & Palermo, 2008; Ward et al., 2008). Adolescents may develop sleep problems independent of issues with PCNCP, which may be attributable to any combination of physiological changes, caffeine intake, technological media, or stress from psychosocial pressures (Carskadon, 2004).

State of the Science Related to PCNCP: Psychological

Psychological comorbidities. Findings from a recent systematic review examining the epidemiology of PCNCP reveal that anxiety and depression are correlated with increased pain prevalence (King et al., 2011). A study estimating the co-occurrence, association, and sequence of onset of PCNCP in a representative cohort of over 6,400 adolescents found that over 25% experienced chronic pain along with a comorbid mental condition such as affective, anxiety, or behavioral disorders (Tegethoff, Belardi, Stalujanis, & Meinlschmidt, 2015). Assessment for mental health disorders was completed using the WHO Composite International Diagnostic Interview along with parental report. Mental disorders were associated with all types of PCNCP, and examination of temporal associations revealed that adolescents often experienced onset of mental health disorders before the onset of pain. More specifically, affective disorders and
anxiety often occurred before any type of chronic pain. Similarly, anxiety was found to occur approximately 3 years before comorbid abdominal pain and depression in a pediatric primary care sample (Campo et al., 2004).

Depression, anxiety, and pain co-occur within cross-sectional and longitudinal samples of those experiencing PCNCP (Lieb, Meinlschmidt, & Araya, 2007; Tran, Jastrowski Mano, Anderson Khan, Davies, & Hainsworth, 2016). These comorbid conditions share some of the same central pathways in the nervous system, and there is evidence that mental health disorders such as mood or anxiety disorders may increase pain intensity through a central pain modulation system (Bair, Robinson, Katon, & Kroenke, 2003; Mangerud et al., 2013). Other potential explanations for the co-occurrence include enhanced biological sensitivity to life stressors, increased anticipation to negative experiences of pain and emotional distress, maladaptive cognitive processes, limitations in problem solving, and behavioral manifestations such as inhibition or avoidance (Weersing, Rozenman, Maher-Bridge, & Campo, 2012).

The comorbidity of PCNCP and psychiatric disorders may make recognition and diagnosis of each more difficult, thereby potentially delaying intervention and negatively impacting prognosis and treatment (Bair et al., 2003). Investigation of pain symptoms does not always result in a clearly identifiable medical cause (Kashikar-Zuck, 2006). Psychiatric disorders are highly prevalent in children and adolescents referred for unexplained chronic pain syndromes (Knook et al., 2011). Depression, anxiety and somatic complaints, including PCNCP, are often identified as a common cluster of symptoms, a trans-diagnostic approach (i.e. focusing on common symptoms versus individual specific diagnoses) is recommended when assessing and intervening with children and adolescents presenting with this symptom cluster (Weersing et al., 2012). This is especially true within the context of IIPT programs, as even higher rates of
comorbidity are correlated with greater functional disability levels (Simons, Sieberg, & Lewis-Claar, 2012; Vetter, 2008; Zernikow et al., 2012).

**Pain catastrophizing.** Catastrophic thinking, a construct closely related to anxiety, is a focus area of psychological intervention in PCNCP. Pain catastrophizing is a preoccupation about pain along with the perception that it is beyond one’s ability to deal with and manage the pain (Martorella, Cote, & Choiniere, 2008). Others have defined pain catastrophizing as negative expectancy related to PCNCP and a strong predictor of functional disability outcomes, although, through structural equation modeling, it was identified it as a distinctly different construct than anxiety (Tran et al., 2015). Since catastrophic thinking has been inversely correlated to child-reported quality of life and physical functioning in youth with PCNCP, it is a target area for intervention (Libby & Glenwick, 2010). One study found that when PCNCP treatment focused on pain acceptance, levels of depressive symptoms, functional disability and catastrophic thinking decreased (Weiss et al., 2013). Acceptance and commitment therapy (ACT), that deemphasizes actual pain symptoms, and focuses instead on goals and positive pain coping skills, is also associated with improved functional outcomes in PCNCP (T. M. Palermo, 2009).

**Trauma.** A correlation between chronic pain and posttraumatic stress disorder (PTSD) symptoms has been found in adults, and early adverse life events such as abuse or neglect in childhood have also been associated with adult pain conditions (Asmundson, Coons, Taylor, & Katz, 2002; Asmundson, Wright, & Stein, 2004; Imbierowicz & Egle, 2003; Lang et al., 2006). A recent literature review identifies a lack of attention to the role that traumatic events may play in PCNCP, especially in regards to prevalence, risk factors, and potential trajectories (Holley, Wilson, Noel, & Palermo, 2016). As a result, a framework was proposed to include a variety of
factors (i.e., developmental, neurobiological, individual, and interpersonal) that may aid health care providers in understanding the connection between PTSD and PCNCP (Holley et al., 2016).

A recent study was conducted to compare two cohorts of adolescents, both with PCNCP (n = 95) and without (n = 100), along with their parents, using an online survey (Noel et al., 2016). Youth with PCNCP reported more stressful life events than healthy controls, both they and their parents were found to have significantly higher levels of PTSD symptomatology than peers without pain and their parents. Participants in both cohorts identified physical illness, hospitalization, and death as events causing the most distress; however, those with PCNCP more commonly reported physical and sexual abuse and death of a significant other as traumatic events. Increased levels of PTSD symptoms were found to negatively impact health-related quality of life and reduced functioning among the PCNCP cohort (Noel et al., 2016).

**State of the Science Related to PCNCP: Sociocultural**

**Familial functioning.** Findings from a systematic review of 16 studies related to family functioning and its influence on PCNCP concluded that familial interactions are complex and require further research. A family history of chronic pain, emotional distress of parents, and family interactions are both predictors and outcomes of PCNCP. An association was also found between high family functioning and lower levels of pain disability in children experiencing PCNCP. Various pain assessment, pain disability and family functioning measures were utilized across studies, which affected comparison and compilation of findings. Other limitations included the small number of studies, cross-sectional versus longitudinal designs, and limited study designs that incorporated the perspective of both parents and children (Lewandowski, Palermo, Stinson, Handley, & Chambers, 2010). Although the literature is still inconclusive,
familial variables are identified as possible targets for therapeutic intervention (Lewandowski et al., 2010).

Current theoretical conceptualizations of PCNCP within family systems are diverse. Due to the multiplicity of familial variables related to PCNCP, an organizing integrative framework has been recommended for this body of research (T. M. Palermo & Chambers, 2005). This approach involves different levels of variables that reflect the complexity of PCNCP as it occurs within a family system. Individual variables, such as parental reinforcement patterns or solicitousness of the child are contextualized within a larger level of dyadic variables that includes interactional patterns between the parent and child. These are further embedded within a more global family level, which reflects overall familial environment or functioning (T. M. Palermo & Chambers, 2005).

**Parental factors.** There is a reciprocal relationship between parental behaviors and pain coping and functioning. For example, a child learns foundational skills and behaviors within a familial context and in turn, a child’s pain condition may profoundly impact family coping and behavioral patterns (Guite, McCue, et al., 2011). Chronic parental pain has been correlated with chronic nonspecific and multisite pain in adolescents, with indications that pain modeling, environment, and family structure are significant factors (Hoftun et al., 2013). The literature examining the relationship of parental behaviors to functional outcomes in PCNCP has produced conflicting findings. Findings from some research support the link between certain parental behaviors, such as solicitousness and protectiveness, and increased disability and poorer functional outcomes (Claar, Guite, Kaczynski, & Logan, 2010; Claar, Simons, & Logan, 2008; Logan & Scharff, 2005; Peterson & Palermo, 2004). Other findings do not support a significant correlation between parental behavior and children’s disability (Logan, Guite, Sherry, & Rose,
A recent literature review examining the impact of parental and family factors on PCNCP recognizes the inconsistency of findings; it concludes that the complexity involved in parental-child relationships may not fully be appreciated and recognized in current quantitative studies (T. M. Palermo & Chambers, 2005).

A qualitative study was undertaken to observe verbal and non-verbal behaviors of parents in a clinical setting while their adolescent children with PCNCP were participating in exercise sessions (Dunford, Thompson, & Gauntlett-Gilbert, 2014). Four categories of parental behaviors were identified: monitoring, protecting, encouraging, and instructing. This research progressed beyond the utilization of traditional self-reporting by parents and identified unrecognized potentially negative ramifications of parental behaviors, which were previously perceived as positive.

**Sibling factors.** Research focusing on siblings of those affected by PCNCP is limited, and most has been qualitative. Youth with PCNCP and their siblings have broadly different perspectives related to family processes and responsibilities, with siblings reporting more significant changes in their relationships with the affected family member and influences of pain on the family system (i.e., increased sibling conflict or shifts in familial rules (Gorodzinsky et al., 2013). Although not specific to PCNCP, siblings of children with other chronic medical conditions report perceptions of decreased availability and attentiveness by parents, and the sense that their own lives have been interrupted (Akhtar, Kennedy, Webster, & Graham, 2012; Bellin, Bentley, & Sawin, 2009).

**School functioning.** Although PCNCP has been found to have a negative impact on school attendance, academic performance, educational completion, and future employment trajectory, these effects are highly individualized (Geraghty & Buse, 2015; Kashikar-Zuck et al., 2010;
Perquin et al., 2000). Evidence links chronic pain with disrupted cognitive function among adults; however, little is known about this relationship in children and adolescents, especially related to school functioning. This is especially significant in that school functioning may entail complex interrelated factors for the child or adolescent with PCNCP, such as absences and impaired academic achievement and social relationships (Kashikar-Zuck et al., 2010; Logan, Engle, et al., 2012). Findings in a review of 9 studies examining cognitive functioning, school attendance, and academic performance of children and adolescents with PCNCP show that school absences are a common occurrence for those experiencing PCNCP; however, methodological issues are pervasive. The specific effects of poor attendance rates remain unclear (Dick & Riddell, 2010).

**Peer relationships.** Adolescence is normally a time of greater reliance on one’s peer group and differentiation from parents with a goal of establishing a more autonomous identity; however, due to potential for increased disability and dependence on parents, adolescents with PCNCP may feel the need to differentiate even more profoundly (Geraghty & Buse, 2015). Adolescents with PCNCP may distance themselves from their peer group versus using them as a support system; this may be related to their feelings of being left out and perceptions of being different, both physically and psychologically (Martin, McGrath, Brown, & Katz, 2007). Some adolescents choose not to disclose their pain conditions to peers, which may contribute to negative social outcomes, such as when peers may misinterpret nonparticipation in activities (Geraghty & Buse, 2015).

A recent systematic review of the literature yielded 42 articles detailing peer relationships and social functioning of children and adolescents with PCNCP; however, only 9 of the studies examined peer relationships as the primary goal, while the majority included them as part of a
broader focus. As noted with other PCNCP research, there is little consistency among quantitative measures in the studies. Throughout the literature, children with PCNCP are found to be more isolated with fewer friends, considered less likeable, and more frequently victimized by peers (Forgeron, Stinson, McGrath, MacDonald, & Chambers, 2010).

**Treatment Approaches for PCNCP**

**Pharmacology.** There are limited data related to the use of pharmacology in PCNCP, and medications are often used off-label due to the lack of research (Mathew et al., 2014). Additionally, scientists must confront particularly sensitive ethical considerations when studying this vulnerable population (Berde et al., 2012). A consensus group of experts sponsored by the United States Food and Drug Administration (FDA) concluded that the primary indication for long-term opioid medication use for children and adolescents is life-limiting conditions only, and that opioids should generally not be used for PCNCP (Berde et al., 2012). Research to identify effective pharmacological approaches and to address the concerns related to potential opioid addiction from parents, health care providers, and the overall community is a high priority (Knaggs, 2006). Non-opioid medications that demonstrate some effectiveness for PCNCP include local anesthetics, anti-inflammatory drugs, anticonvulsants, antidepressants, and muscle relaxants; however, it is recommended that the pharmacological regimen be individualized as a component of a wider interdisciplinary approach (Mathew et al., 2014).

**Psychological therapies.** The benefits of psychological therapies for adults experiencing chronic pain are firmly established in the literature (Williams, Eccleston, & Morley, 2012). A recent Cochrane systematic review evaluated psychological therapies for PCNCP delivered face-to-face by a therapist including hypnosis, training in coping skills, biofeedback, relaxation, and cognitive-behavioral therapy (CBT) (Eccleston et al., 2014). Relaxation and CBT were found to
effectively decrease pain intensity in chronic headache, abdominal pain, fibromyalgia, and sickle-cell disease immediately post-treatment. These therapies also demonstrated longer lasting effects for pain reduction and disability for headache. Additional studies are recommended to further evaluate the effects of psychological therapies on depression and anxiety levels in children and adolescents experiencing PCNCP (Eccleston et al., 2014).

A meta-analysis investigating the effectiveness of psychological therapies for management of PCNCP produced similar results (Fisher et al., 2014). A total of 35 randomized controlled trials included samples of children and adolescents with different pain conditions, including headache, musculoskeletal, neuropathic, and abdominal pain. The target interventions included those delivered face-to-face, computer-based, or via the Internet; formats involved individual, group, or educational class sessions. The outcomes of interest were level of disability, pain symptoms, depression, anxiety and sleep; however, researchers discovered that none of these RCTs actually included sleep as a studied variable. CBT and other behavioral therapies demonstrated effectiveness for reducing pain levels \((ES = 0.60, p < .001)\); however, effects were time-limited at 3 to 12-month follow-up \((ES = -0.30, p < .05)\), except for headache pain, which indicated longer maintenance of therapeutic effectiveness \((RR 3.34, p < .001, NNT 2.01)\). Greater pain reduction was also correlated with higher treatment dose in headache pain post-treatment \((R^2 = .50, p < .05)\); however, not at follow-up \((R^2 = .70, p = .08)\). Effectiveness of treatment dose was not demonstrated for other pain conditions post-treatment \((R^2 = .044, p = .59)\) or at follow-up \((R^2 = .049, p = .57)\). There was minimal evidence for other psychological treatments, such as problem-solving therapy for children with PCNCP, partly because enough detail was not described within studies to differentiate specific intervention components (Fisher et al., 2014).
Another systematic review investigated only those psychological therapies delivered remotely via the Internet, computerized programs, telephone, or smartphone. (Fisher, Law, Palermo, & Eccleston, 2015). Hybrid formats blending remote with face-to-face components were also included. Remote delivery options are especially relevant in PCNCP, as pain levels and disability may preclude active participation in face-to-face treatment. Also, barriers to treatment, such as parental work absence, cost, and travel distance, could be decreased. Eight RCTs (N = 371) were identified; however, 5 of these investigated chronic headache only, and two included headache among other conditions. One study included only children with juvenile idiopathic arthritis. There was evidence of decreased post-treatment relief of headache and other mixed pain conditions; however, no effects were found for pain reduction at follow-up between 3-12 months. There were no follow-up data indicating disability outcomes. There was limited data related to intervention effects on depression and anxiety and no data available to determine if any adverse or harmful events arose as a result of treatment. Treatment satisfaction was also studied as a secondary outcome, and although mainly described positively, this was unable to be quantified due to the variety of measures utilized.

**Effectiveness of IIPT**

When children and adolescents with PCNCP do not improve or experience increasing disability or pain symptoms despite pharmacologic or psychological therapies, they may require admission to an IIPT (Evans, Benore, et al., 2015). Citing a dearth of research on IIPT for this population, a recent systematic review was undertaken to describe the nature of this form of treatment and to evaluate its effectiveness (Hechler et al., 2015). Only one randomized controlled trial (RCT) and 9 non-randomized studies (NRSs) met the following inclusion criteria: treatment occurred within either a day treatment or inpatient setting and was coordinated by 3 or more
interdisciplinary professionals; samples were larger than 10 participants all experiencing debilitating chronic pain and participant were under the age of 22; and studies were published in English. Studies were completed between 2001 and 2014, and 4 were from North America, 5 from Europe and 1 from Australia. Five domains were examined at baseline, immediately post-treatment, and at follow-up, including disability, pain intensity, school functioning, depressive symptomatology, and anxiety.

A variety of disciplines were part of the IIPT teams in the 10 studies reviewed, with more than half of the studies including 5 different types of health professionals. Physicians such as physiatrists, pediatricians or child psychiatrists typically completed diagnostic assessments, and managed medications and medical issues (Hirschfeld et al., 2013; Logan, Carpino, et al., 2012). Registered nurses monitored the milieu, completed daily assessments, facilitated goal setting, coached parents in behavioral techniques, and functioned as case managers (Hechler et al., 2009; Weiss et al., 2013). Clinical psychologists taught pain and stress coping strategies and sleep hygiene, and delivered ACT, CBT, and biofeedback (Gauntlett-Gilbert, Connell, Clinch, & McCracken, 2013; Simons, Kaczynski, Conroy, & Logan, 2012). Physical therapists worked with patients on increasing activity and improving flexibility, strength, and overall fitness, and occupational therapists helped patients to improve their self-care (Logan, Carpino, et al., 2012). One program included trained art and music therapists and another incorporated a school component (Hechler et al., 2009; Logan, Carpino, et al., 2012) Most of the studies included interventions geared towards parents, such as education, positive reinforcement, and review of parenting techniques aimed at improving child functioning (Hechler et al., 2015).

Meta-analyses were completed for pain levels, disability, and depressive symptoms; however, they were unable to be conducted for school functioning and anxiety due to substantial
differences in measures used between studies. Likewise, long-term follow-up data could not be synthesized, as only 3 out of the 10 studies reported these (Hechler et al., 2015). The single RCT showed evidence of a small effect on pain intensity immediately post-treatment ($ES = -0.38$), and the 4 NSRs showed a small, but insignificant immediate post-treatment effect ($ES = -0.32, p = .101$). A large and significant effect was found on pain intensity with both the RCT ($ES = -1.19$) and NSRs ($ES = -1.33, p = .01$) at short-term follow-up. Large effects on functional ability were found immediately post-treatment and at short-term follow-up with both the RCT ($ES = -0.80$) and 6 NSRs ($ES = -1.09, p < .001$). The RCT produced no evidence of benefit on depressive symptomatology after treatment ($ES = -0.22$), but a moderate effect was noted at short-term follow-up ($ES = -0.59$). A small positive effect on depressive symptoms was noted across 5 NSRs immediately post-treatment ($ES = -0.37, p < .001$) and at short-term follow-up ($ES = -0.40, p = .001$). Although school functioning and anxiety symptoms were not used in the meta-analysis, there was some evidence of positive benefits of IIPT on both reported in the findings of individual studies (Hechler et al., 2015). Limitations were present such as lack of control groups in the majority of studies and heterogeneous measures of outcome variables; however, the findings of this systematic review are promising related to decrease in pain, disability, and depressive symptoms and maintenance of positive treatment effects.

**Support for IIPT**

Increased numbers of IIPT programs for PCNCP are recommended, especially in light of evidence for sustained decrease in disability and distress over time (Brattberg, 2004; Hechler, Dobe, & Zernikow, 2010; Simons, Sieberg, Pielech, Conroy, & Logan, 2013). Several countries have mandated treatment with IIPT for PCNCP (Odell & Logan, 2013). A worldwide call has gone out for funding and development of additional IIPT programs for PCNCP, due to the
discrepancy between availability and need (Hechler et al., 2010). Families often have to wait extended periods of time, travel far distances, or even stay overnight for evaluation and treatment due to limited access (Peng et al., 2007).

Family members report positive perceptions of IIPT evaluation processes, specifically their perceptions of the integrated holistic approach (Schurman & Friesen, 2010). A qualitative study exploring parental satisfaction with IIPT revealed high levels of appreciation towards the comprehensive program structure, team member expertise, and perceived interest of professionals when caring for their children. These positive findings may further improve treatment adherence, resulting in positive outcomes (Gorodzinsky et al., 2012).

Although often perceived as expensive by families and insurance providers, IIPT has demonstrated cost-effectiveness by reduction of hospital stays, office visits, professional services, and missed work of parents. One study estimated health care expenses of over $61,000 in the year before admission to IIPT for a child with PCNCP, and less than $15,000 the following year. Missed parental work costs resulted in a positive difference of over $11,000. Even when adjusting for program costs, each family was estimated to have saved over $27,000 in the year following participation in IIPT (Evans, Benore, et al., 2015).

**Gaps in the Literature**

The literature related to treatment approaches for PCNCP has limitations, including small sample sizes, lack of longitudinal designs, and findings that include adult or mixed populations (Wicksell, Dahl, Magnusson, & Olsson, 2005). Often, the focus has been solely on physical pain, while other outcomes such as emotional, physical, family, or social functioning are ignored (T. Palermo, 2000; T. M. Palermo et al., 2014). Much of what is known about PCNCP is derived from findings of research using clinical samples with severe pain and functional disability.
Additional efforts to study community samples of children with mild to moderate chronic pain are needed (Huguet et al., 2009).

Despite significant positive evidence of IIPT on pain, disability, and depressive symptoms for children and adolescents with PCNCP, many unanswered questions remain. Few studies explore how these programs produce effective results, examine the processes or mechanisms by which patients experience significant therapeutic changes, or explain why this occurs (Odell & Logan, 2013; Stahlschmidt, Zernikow, & Wager, 2016). Specific factors that influence positive treatment outcomes remain unknown (Hirschfeld et al., 2013). Researchers note that while many quantitative studies related to chronic pain have been completed, the utilization of qualitative methodology may bring previously undiscovered insights to light (Dysvik, Sommerseth, & Jacobsen, 2011).

**Purpose of Study**

The purpose of the study was to explore the lived experiences of adolescents engaged in an intensive interdisciplinary pain treatment program, specifically focusing on perceptions of change during treatment in the program. Research questions were:

A) What are the lived experiences of adolescents engaged in an intensive interdisciplinary pediatric chronic pain rehabilitation program?

B) Do adolescents identify changes experienced during treatment and if so, how do they describe these changes?
Chapter 3: Methodology

The term phenomenology may reference a philosophical approach or a research method based upon this approach (Dowling & Cooney, 2012). Phenomenological methods are used to explore research questions related to essence, meaning, and insight into lived experience. No preconceived theories or frameworks about the phenomenon guide the study; rather, researchers remain open to what will be revealed in the process. Phenomenology focuses on lived experiences of participants, attempts to view phenomena with fresh eyes and to richly describe participants’ experiences, and involves a relational process that may impact both the researcher and the participant (Finlay, 2009). Nursing researchers have utilized phenomenological methods in various ways to study a multitude of clinical situations (Petrovskaya, 2014).

There are two main schools of phenomenology, descriptive and interpretive. The goal in descriptive phenomenology is to describe a phenomenon’s general characteristics, rather than describing an individual’s lived experience of that phenomenon as is the case in interpretive phenomenology (Finlay, 2009). Edmund Husserl is considered the founder of phenomenology, first introducing this philosophy at the beginning of the 20th century (Mapp, 2008). Husserl’s work guided the development of descriptive or eidetic phenomenology, in which such factors as context, culture, religion, gender, time and space are not considered, as these may detract from the pure understanding of the phenomenon under study (Tuohy, Cooney, Dowling, Murphy, & Sixmith, 2013). Interpretive phenomenology is based upon the later work of Ricouer, Heidegger, and Gadamer (Dowling & Cooney, 2012). The goals of interpretive phenomenology are to describe, understand and then to interpret significant experiences from the perspective of those who have lived through them. Because of this, contextual factors are considered not only relevant, but central in interpretive phenomenology (Tuohy et al., 2013).
Phenomenology was determined to be the best methodology to address the current gaps in the literature related to mechanisms of therapeutic change in an IIPT. Even though there is strong evidence for the effectiveness of these types of programs, it is unclear how these therapeutic changes occur. Exploring the lived experiences of a small sample of adolescents actually engaged in the IIPT program was felt to be the most foundational perspective from which to begin to explore these research questions.

**Interpretative Phenomenological Analysis**

Originating in the field of psychology in the United Kingdom, interpretative phenomenological analysis (IPA) is a recent methodology utilized by researchers in various health and social disciplines around the world (Smith, Flowers, & Larkin, 2009). IPA attempts to uncover the perspective of one who is living through a particular experience and to make sense of that person’s world through a dynamic interpretative process, or double hermeneutic. While participants attempt to make sense of what they are experiencing, the researcher further interprets and makes sense of this process, combining at the same time an empathetic yet questioning stance (Smith & Osborn, 2008). Because IPA is concerned with the idiographic nature of each participant’s lived experience, it is focused on in-depth analysis and does not attempt to make generalizations at a population level (Smith et al., 2009). There is not a single way to undertake an IPA study, however, broad guidelines provide suggestions that may be adapted according to the researcher’s style and particular topic of inquiry (Smith & Osborn, 2008).

A phenomenological study using IPA was conducted to address the gap of knowledge in the literature related to adolescent experiences in an IIPT program. This design effectively allowed the perspectives of adolescents who would soon be discharged from an IIPT program to be uncovered, and to make sense of these adolescents’ experiences of the IIPT program through
a dynamic interpretive process. This led to a fuller understanding of how adolescents perceive, make sense of, and ascribe meaning to their experiences while engaged in an IIPT program for PCNCP.

**Study Setting**

The Cleveland Clinic Children’s Hospital for Rehabilitation’s Pediatric Pain Rehabilitation Program was the setting for the study. It is the only pediatric IIPT program accredited by the Commission on Accreditation for Rehabilitation Facilities (CARF) and was recognized as a Center of Clinical Excellence by the APS in 2015. The program has been treating children and adolescents experiencing PCNCP for over 10 years, with pain conditions such as complex regional pain syndrome (CRPS), chronic headache, chronic abdominal pain, fibromyalgia, and pain associated disability syndrome (PADS). It is designed for children and teens whose lives and those of their families are significantly impacted by chronic pain and associated issues, such as functional disability, school absence, anxiety, depression, social withdrawal, sleep disturbance, and family stress.

Patients often present to the program after they have experienced minimal to no improvement from prior treatments or standard therapies have been exhausted. Approximately 100 patients are treated in the program annually; an estimated 70% are from out of town, and a majority are Caucasian and female adolescents. A recent review of patients admitted to this program found chronicity of pain conditions ranging from 1 to 156 months, with a mean of 27.04 months. Before admission, patients were missing an average of 3.48 days of school per week and 14.24 days per month. Parents reported evaluations of their children by an average of 2.29 providers including neurologists, pain management specialists, rheumatologists, gastroenterologists, mental health providers and psychiatrists. Prior treatments included pain
management procedures, complementary and alternative therapies, and various surgeries (Wojtowicz & Banez, 2015).

The program is led by a psychologist and staffed by an interdisciplinary team of experts, including physiatrists, a child and adolescent psychiatrist, psychologists, nurse practitioners, registered nurses, physical therapists, occupational therapist, recreational therapist, social worker, nutritionist, and certified school teacher. Treatment is highly individualized and ideally encompasses a 2-week inpatient stay followed by one week of day treatment; an estimated 2-3 patients are transitioned to day treatment each week. Some health insurance providers only approve inpatient care, while others only authorize day hospital treatment for the entire three weeks. A fourth week of programming is occasionally recommended due to a patient’s medical condition or lack of progress towards treatment goals.

The foci of treatment are functional restoration, behavioral coping skills, improved school attendance, and family functioning. The program includes a variety of interdisciplinary modalities, such as group and individual psychotherapy, mind-body skills training, family therapy, and parental support and education. Patients are involved in treatment activities 7-8 hours per day. On the first Sunday of each participant’s first week in the program, they are given an 8-hour Therapeutic Leave Day (TLD) where they can choose an activity, such as visiting a museum, the local aquarium, or shopping with friends and family. While on leave, each patient is assigned therapeutic goals and progress is reviewed afterwards with team members.

**Study Participants**

A purposive sample of 6 participants, ages 14-17, who were in the IIPT program, Wednesday through Friday of their third week, were invited to participate in the study, as they had first-hand knowledge of the phenomenon. Additional inclusion criteria included a diagnosis
of chronic pain, admission to the IIPT with an intention to complete treatment, the ability to converse in English, parental or legal guardian consent, and participant assent to participate and to be interviewed and audiotaped. Interviews were held at the end of the third week to allow participants the opportunity to engage in the full IIPT prior to sharing their experiences. One of the six participants was recommended to remain in the program for a fourth week to meet additional treatment goals. Participants were included in the study in order of expressed interest, and interviews were conducted over an 9-week period. All participants were not engaged in the IIPT program during the same 3-week time period; however, there was some overlap in their weeks of treatment.

While even single case studies have been effectively conducted utilizing IPA methodology, between 4 to 10 interviews have been recommended for a PhD dissertation study (Smith et al., 2009). Studies with samples of between one to over 15 have been published; however, due to the idiographic and detailed nature of IPA, a smaller sample was better suited for the focused attention required for in-depth analysis (Smith et al., 2009). Participants in this study were forthcoming and offered rich and expressive accounts of their experiences both before and during treatment in the IIPT program. Since the recommended sample size for dissertation studies is 4 to 10, an a priori sampling plan to interview 6 participants, analyze the transcripts, and recruit more participants if the 6-transcript analysis did not produce saturation was implemented. After detailed analysis of the 6 transcripts, it was determined that data redundancy and saturation were achieved, which is reflective of sample sizes of 3 to 6 participants in studies designed by many experienced IPA researchers (Smith et al., 2009).

**Data Collection**
Prior to recruitment and data collection, 16 hours of observation time were spent on the unit, meeting program staff, and becoming familiar with different aspects of the treatment program; this helped with contextualization of the findings (Smith et al., 2009). Observation time included observing physical and occupational therapy sessions, patient group sessions, parent support groups, individual team meetings with patients and parents, and school meetings where the treatment team reviewed patient’s progress with home school personnel. Program staff members were oriented to the study and given the opportunity to ask questions at a prescheduled monthly research meeting prior to data collection commencing. Brief research notes, devoid of patient-specific or identifiable data, were kept to assist with later data analysis (Smith et al., 2009).

**Recruitment and consent.** Recruitment fliers (Appendix A) were distributed to patients and guardians in the orientation packet upon admission to the program and those interested were given additional information. If a patient and guardian were agreeable and interested in participating, the consent and assent form were reviewed and signed by both the guardian and participant (Appendix B) and the parent, and the demographic information form was completed by the participant and/or parent Appendix C). Each parent and participant were offered a signed copy of the consent and assent forms for their reference. Completed demographic and signed consent and assent forms were stored in a locked cabinet at CCF, as required by CCF policy, and a notation that consent and assent forms were signed was made in the participant’s electronic medical record. The IIPR program director or program coordinator assisted with recruitment and consent activities.

**Interviews.** The interviews were scheduled during non-therapy hours of the IIPR program on Wednesday, Thursday, or Friday of the third week of treatment. All interviews were
conducted one-on-one with the participant in a private room that allowed for confidentiality. Data collection occurred with an in-depth semi-structured interview format using an interview schedule (Appendix D)(Smith et al., 2009). Participants were ensured of the confidentiality of their responses. They were asked before beginning the interview if they were feeling distressed; however, none of the participants endorsed this. No participant reported feeling distressed during the interview, and no interview needed to be stopped. Any significant distress or safety concerns, such as disclosure of abuse or suicidal ideation, were to be reported to the program director immediately per CCF research policy. One participant mentioned family issues that necessitated discussion with the program director; however, team members were previously aware of the situation. Participants were debriefed at the conclusion of the interviews to answer any questions or address any concerns. A $25.00 Target gift card was given to all participants who participated in the study to reimburse them for their time.

All interviews were audiotaped, transcribed verbatim and reviewed for accuracy. Two encrypted digital recorders, which met CCF research standards, were utilized to assure that data was obtained securely and was clear enough to allow for accurate transcription. All transcripts were de-identified and only a number was assigned to each participant transcript. A list identifying each participant by number, along with signed consent and assent forms were kept in a locked cabinet at CCF separate from all data such as demographic forms and transcripts. Any identifiable information such as names, city, state, or school system that participants revealed in an interview were changed to pseudonyms in the transcripts.

Transcribed interviews were stored on a secure Kent State University Blackboard Learn site. Participants, guardians, and treatment team members did not have access to interview recordings or transcripts. Following transcription, digital recordings and participants’
identification numbers and signed consents and assents were stored securely at CCF and will remain there for 7 years as indicated by CCF research policy. Following successful completion of the research, all information stored on the Kent State University Blackboard Learn site will be permanently deleted and destroyed, and the Learn site for the project will be deactivated.

**Data Analysis**

Data analysis in IPA is non-prescriptive and allows for flexibility and innovation, using an iterative and inductive cycle; however, a six-step approach is suggested for novice IPA researchers (Smith et al., 2009). Analysis initially focused on single transcripts in an idiographic, detailed manner. Each transcript was analyzed in-depth as a separate entity, and bracketing was used to prevent comparison or across-transcript analysis until Step 6. A subgroup of two dissertation committee members provided support and supervision during the data analysis process, while still allowing the PhD candidate the opportunity to develop independent research skills in interviewing, recording, transcribing, line-by-line coding, identification of emergent themes, and interpretive data analysis. This subgroup communicated via WebEx through KSU periodically throughout the analysis process to discuss progress in analyzing the data, offer guidance and provide mentoring. Completed draft manuscripts of the findings were reviewed by the subgroup, and each offered constructive feedback on the cohesiveness and clarity of the interpretation.

**Step 1- Reading and rereading.** After conducting each interview, each audiotaped interview was reviewed prior to transcription and recorded additional field notes of impressions were recorded in a research log. Transcription was completed solely by the PhD candidate, which allowed for further immersion into participants’ descriptions of experience. The transcript from Participant 5 was selected as the first transcript for review, as this interview was
particularly rich in content and also the longest. The transcript was read slowly and then re-read several times prior to documentation of any notes. The focus during this phase was on Participant 5’s account and reading slowly to absorb the nuances of the transcript (Smith et al., 2009). The subgroup did not convene during step 1.

**Step 2 – Initial noting.** During this phase, the focus was on language and identification of how Participant 5 described, verbalized, and understood her experiences in light of the specific research questions. The aim in this phase was to continue relating to the participant through the transcript, and a descriptive core set of comments emerged for the transcript. Attention was paid to staying as close to Participant 5’s description of her lived world, versus focusing on what may have been expected to find in the data. Each line of text was analyzed individually and as part of the larger transcript. Descriptive, linguistic, and conceptual comments were noted (Smith et al., 2009). Step 2 was also conducted without input from the subgroup.

**Step 3 – Development of emergent themes.** The original transcript from Participant 5 and any notes were analyzed for emergent themes. A collaborative exchange evolved between the participant’s description and the PhD candidate’s interpretation, which became more central to the process in this phase. The loose and open initial noting became clearer as the essence of Participant 5’s experience in the IIPIT program was being captured as related to the research questions (Smith et al., 2009). This was the first stage in the analysis process when a WebEx meeting was convened to discuss emergent themes. Several pages of notes were prepared by the PhD candidate that contained initial line-by-line codes, key words and phrases used by Participant 5 in the account of her IIPIT experience. While the subgroup members did not fully review each transcript, these notes served as a starting point of discussion related to the emerging themes. Appendix E contains a sample from original notes sent to the subgroup by the PhD
candidate prior to the meeting. The support and feedback from the subgroup members served as a grounding force. Encouragement by members of the subgroup was provided to the PhD candidate to remain closely connected to Participant 5’s words and account and to refrain from premature attempts to make associations between the transcript and the literature or existing theoretical frameworks.

**Step 4 – Searching for connections among emergent themes.** All emergent themes were identified in chronological order, and then related themes were clustered using emerging patterns, similarities, differences, and connections. Certain themes subsumed one another or occurred more frequently in the transcript. Again in IPA methodology, a prescriptive way is not assigned for this level of analysis to occur, and creativity is encouraged; however, notes about how this process occurred were documented and discussed within the subgroup (Smith et al., 2009).

**Step 5 – Moving to the next case.** The primacy of the individual participant account in IPA is illustrated by studies that are completed as single case studies. For this study, attention was paid to the idiographic nature of IPA. In this phase, the next transcript was explored by initially reading and re-reading and beginning the IPA process again. Since it is imperative that each case be considered individually, any themes or ideas from the earlier cases were bracketed when interpreting subsequent cases (Smith et al., 2009). Step 5 was conducted without input from the subgroup.

**Step 6 – Looking for patterns across cases.** Finally, in this stage data were examined for connections and patterns across cases. Theoretical reconfiguration was applied to understand similarities and differences among the participants’ accounts, and relabeling of themes occurred multiple times. Different levels of interpretation emerged, ranging from descriptive to quite
abstract (Smith et al., 2009). In this phase, several WebEx meetings with subgroup members were held to discuss continued emergence of the themes and to provide support. An example of notes distributed to subgroup members in advance of one meeting is contained in Appendix F. In this example, references from the literature were included that illustrate the commitment to adhering to IPA methodology in this study. As themes and subthemes were being finalized, draft versions of the findings sections of the manuscript were shared with the subgroup to assure that the written document remained true to the analysis. A final subgroup meeting was held to ensure that the research questions were answered in a way that reflects participants’ experiences.

**Validity**

The necessity of evaluation of qualitative research for quality and trustworthiness has been established across disciplines (Connelly, 2016; Pereira, 2012). Yardley’s criteria are recommended as a suitable guideline for IPA and have been utilized to assess the validity and quality of this study (Smith et al., 2009). These criteria encompass four broad principles: sensitivity to context, commitment and rigor, transparency and coherence, and impact and importance (Yardley, 2000, 2008, 2017).

Sensitivity to context was addressed throughout the planning and implementation of the study. The PhD candidate possessed familiarity with the socio-cultural milieu of the setting in which the study took place, having been employed as a nurse in an adult chronic pain rehabilitation program within the same hospital system for several years, and is a member of an international pediatric pain research training initiative and a child/adolescent psychiatric clinical nurse specialist, which enhanced her knowledge of the topic. Each member of the dissertation committee was selected due to their clinical and research experience related to pediatric chronic pain and/or phenomenology. A proposal defense meeting with all members of the committee was
held prior to implementation of the study to ensure that congruence of the design to research questions was established. Substantive changes were suggested and implemented to enhance the quality of the project.

Commitment to participants and methodological rigor were demonstrated throughout the research process. Care was taken to assure that participants were not in distress before and during data collection, and all were given to opportunity to debrief afterwards. Participants’ and parents’ rights and confidentiality were respected and protected throughout the study. Analytical claims were grounded in the data themselves, as evidenced by line-by-line coding and numerous verbatim quotations from participant illustrating each theme utilized in the findings. De-identified notes were taken and reflected upon throughout observation, data collection, and analysis phases of the research process. Each participant’s individual voice was reflected in the findings as well, demonstrating commitment to the idiographic nature of IPA. Rigor was demonstrated by the selection of a fairly homogenous purposive sample appropriately chosen to answer the research questions, and by the supervision and support provided by more experienced faculty members during select phases of data analysis. The PhD candidate’s background as a psychiatric advanced-practice nurse with over 25 years of experience was invaluable in obtaining high quality data by use of open-ended questioning and sensitive interview techniques. This professional expertise and graduate-level academic preparation enabled the PhD candidate to connect with participants in an empathetic manner, to pick up on verbal and non-verbal cues, to dig deeper when appropriate, and to bracket her own thoughts and ideas during the interviews and data analysis.

Transparency and coherence were addressed during each aspect of the study. The participants and setting were purposely selected to answer the research questions. Protocols for
the study were outlined and approved by the dissertation committee and appropriate research boards at the university and hospital. Time was spent at the study site which provided familiarity with the IIPT, and program team members were oriented to the study protocol prior to commencement of data collection. Parents and participants were given written and verbal information about the study and presented with the opportunity to ask questions or address any concerns. Data analysis was completed as a transparent process in collaboration with a subgroup composed of two dissertation committee members.

Impact and importance were demonstrated, as PCNCP has been identified as a significant global concern (T. Palermo et al., 2012). Treatment by IIPT is recommended by major stakeholders as a way to address this potentially debilitating condition affecting children and their families (Cunningham & Banez, 2006; Geraghty & Buse, 2015; Odell & Logan, 2013). A comprehensive literature review established the need for the study by revealing a gap in scientific knowledge. Research questions were developed to address this gap, and IPA was selected as the most appropriate research methodology to answer these questions from the perspective of program participants reflecting on their experience.

**Additional Ethical Considerations**

Prior to commencement, the study received approval by the Cleveland Clinic’s Pediatric Institute Research Committee (PIRC) and Institutional Review Board (IRB), and the IRB at Kent State University (KSU). Care was taken to ensure participant and guardians’ privacy and confidentiality during and after the study by de-identification of all study materials, locked storage of any PHI, and transcript storage on a secure KSU website only accessible to the research committee members.
Chapter 4: Results

The purpose of this study was to explore the lived experiences of adolescents engaged in an intensive interdisciplinary pain treatment program, specifically focusing on their perceptions of change during treatment in the program. Research questions guiding this study were:

A) What are the lived experiences of adolescents engaged in an intensive interdisciplinary pediatric chronic pain rehabilitation program?

B) Do adolescents identify changes experienced during treatment and if so, how do they describe these changes?

Demographics

The sample consisted of one male and five female participants, ranging in age from 14 years of age to 17 years of age, with an average of 15.7 (SD = 1.03) years. Reported pain conditions varied from chronic abdominal pain, musculoskeletal pain syndrome with chest and arm pain, headaches, neck pain, post-concussive syndrome, chronic regional pain syndrome (CPRS) and chronic olfactory sensitivity. One participant was African American with the remainder identifying as Caucasian. The length of time that participants experienced pain prior to entering the IIPT ranged from 4 months to 10 years, with a median length of time of 46.7 months. One participant recounted the length of time between first considering the IIPT until actual admission into the IIPT as being 4 years, during which time her condition gradually decompensated. The remaining participants considered the program for 1 to 3 months before admission, with an average timeframe of 2 months. All were interviewed within their final three days of their three-week treatment program, with the exception of one participant who remained in treatment for a fourth week as recommended by the treatment team. The interviews were conducted at the end of the third week to allow additional time for participants to be able to
reflect back on their experience. This also afforded some of them the opportunity to experience the day treatment component of the program.

**Leap of Faith**

The main overarching theme that emerged from the data was that participants took a leap of faith by not only entering the program, but choosing to immerse themselves and fully engage in treatment on many levels. A leap of faith is most commonly used to denote the act of believing or accepting something whose existence or outcome cannot be proven. The adolescents in this study accepted admission into the IIPT program even though they did not, at the time, completely believe or understand how or even if it could help. Participants did not make this commitment lightly and considered it a significant undertaking to be away from their normal routines with family, friends, and school. After admission into the IIPT program, most participants immersed themselves in various program components even though they were not sure it was right for them or would help with their pain and disability. For participants, these instances were a leap of faith also.

Participants shared background information related to their experiences before the program, which highlighted the changes experienced during treatment. This contextual data was beneficial to address the research question related to participants’ descriptions of change and served to illuminate to a greater extent the transformational process experienced during treatment. Participants described miserably enduring their pain conditions for months or years before various catalysts led them to the edge of their misery, a point in time when they chose to take the leap to dive in with all that it entailed. The overarching theme leap of faith was discernable in each of the four subthemes: living miserably on the edge, diving in, buried treasure and charting new waters.
**Living miserably on the edge.** Living miserably on the edge was selected as a subtheme; it reflected what life was like for the adolescents before IIPT, but also suggested the consequences for them if they did not succeed – that is, a life of misery would continue if the IIPT was not successful. Participants recounted increasingly challenging catalysts, such as increasing functional and emotional deterioration, that eventually led them to the edge of their suffering and allowed them to experience the decisive moment culminating in admission into the program.

For example, a 15-year-old adolescent (Participant 5) living with chronic regional pain syndrome (CRPS) described the physical, emotional, and social suffering that began after a sports injury. She was initially diagnosed with a hamstring tear for which individual physical therapy was prescribed. Her account illustrates the chronicity of her condition and unsuccessful attempts to relieve her unabating distress.

The pain was getting worse instead of better. I started having muscle spasms to the point where I’d scream because it was awful. I made my siblings scared. I made my parents scared. I couldn’t sit. I couldn’t stand. I was on crutches…couldn’t walk. I tried (brief laugh) … I tried a bunch of stuff trying to get off the crutches throughout the months.

As the months wore on, it got worse. I mean, I tried going to my softball banquet but I ended up sick. I mean, I lettered and got most improved player, but…I didn’t care. I was in so much pain because of it…it hurt (crying) …I just, I couldn’t function. To the point… I was…I was done by the time the banquet hit. I mean I was aggravated. I was frustrated. I wanted nothing more than for this to disappear. That this never happened…it was not fun…
I tried ditching the crutches three times before I came here. The pain kept getting worse, my spasms got worse, and it got to the point where some of my spasms were so bad that I lost control of my bladder just a little bit. It happened as I was coming out of school too…

A 17-year-old high school student (Participant 6) endured chronic chest and amplified musculoskeletal pain syndrome for 18 months and described a physician’s warning if she was to continue on the trajectory of inactivity and physical deconditioning. “One of my doctors told me before I came that if I kept up the way that I was, you know, just not wanting to get out of bed, not doing anything, that eventually I would be on bed rest…” A 16-year-old (Participant 3) living with chronic headaches for 9 years described the gradual decline in functioning and its consequences. The participant’s headaches became daily and increasingly debilitating, leading to “poor grades” and the inability “to do just normal teenage things.” Life before the IIPT program presented significant and ongoing challenges, resulting in role strain and physical and cognitive ramifications for another participant.

( Participant 5) “…I had to call him (father) to come get me from school because I got so…the pain got so bad. I was nauseated and vomiting at school and I couldn’t function in class. He took me home and he had to go back to work, but I stayed in bed. I couldn’t focus on anything, because…It literally kicked my butt.”

Several participants recounted feeling misunderstood, judged, and bullied by other teens who were not experiencing chronic pain. They did not feel that their experiences and suffering were comprehended by their peers, who seemed to have difficulty empathizing with them. This contributed to their miserable existence because of feeling isolated, and at times victimized.
(Participant 5) “I was on the crutches clear throughout what little school I could attend and people were just…they were rude. Just say at least. Guys tried tripping me…troublemakers tripping me…I was on the crutches and I got to the point where I wanted to hit ‘em in the man parts, but I didn’t...(laughs) because I’m a good student and I’m not going to let them get to me. But it’s frustrating because they judged me because I was still on the crutches and they called me “faker, faker” and I guess it’s hard, because they don’t know what I’m going through. Because certain movements cause electrical pains which are like cattle prod or electric fence…my leg’s on fire.”

(Participant 4) “…whenever I tell people what I have, they’re like, ‘Oh yeah. I have headaches…’ And I’m like, ‘Yeah, but…all the time…every second of every day? And they’re like, ‘Well, no…but every once in a while…And I’m like, ‘okay…that’s totally relevant…’

In addition to living miserably with the pain condition itself, sometimes the treatments prescribed to treat the pain actually contributed to additional disability and suffering.

(Participant 5) “They put me on Ketorolac, Percocet…Valium three times a day along with the Gabapentin and a bunch of other stuff. I was sedated for over a month and a half. And for me, I said, “That’s enough. I’m done.” I don’t want to take them anymore because I couldn’t function. I couldn’t do simple house chores. I couldn’t hang out with my siblings. I couldn’t…I was out of it. I was on my bed all day long. I couldn’t sleep…I was so out of my routine and everything, it was awful.”

As the participants continued to endure chronic struggles, certain catalysts led them to peer over the edge of their miserable existence to consider entering the unknown of the IIPT. Major catalysts pushing participants towards and over the edge included increasing pain levels,
previous treatment failures, functional limitations, and ramifications of their conditions on both themselves and family members. Several described a realization that previous treatment approaches, coping methods, and internal resources had proven ineffective. A 14 y/o (Participant 1) who had lived with chronic abdominal pain for 10 years described running out of options and realizing that something needed to change. “I didn’t really care what time I did it, as long as I did it, because I was kind of tired of dealing with the pain all the time and missing so much school. So…that’s what led me here, was missing a lot of school…and I was basically in my bed all day.”

While enduring their miserable circumstances, some participants described entertaining the possibility that perhaps their situations could improve, as if they were peering over the edge before taking the leap. A 16-year-old adolescent (Participant 2) who had been experiencing post-concussive headaches, neck pain, and sensitivity to smells for over 18 months reflected on the emotional reaction she experienced while walking with her mother to their car after receiving the referral to the program.

( Participant 2) We were always looking for a place where I could have all of my therapies at once, because we were always going back and forth to different doctors and stuff and trying to meet somewhere in the middle. And so we had been asking about that, and then Dr. B told us about this program…It was amazing, I remember when she told us, I just started crying. I was so like, relieved, that like there was hope…

Though tentatively hopeful, some also endorsed a more self-protective attitude due to previous disappointing treatment experiences, such as this 16-year-old (Participant 4) who had been experiencing headaches for 6 months.
(Participant 4) My parents were definitely the ones who were more enthusiastic about it. I was kind of neutral. I was kind of...I hoped it would work, but I didn’t want to get my hopes up too much, I guess. Because I’ve tried so many things that haven’t worked, and I just, you know, I don’t have that much...hope I guess.

The subtheme of living miserably on the edge provides contextual background for the leap of faith and illustrates the various types of suffering (i.e. physical, psychological, social) endured by participants prior to treatment in the IIPT program. Participants shared powerful exemplars related to their growing sense of isolation and the realization that their intense suffering might not only never improve, but could continue to worsen. The combination of unique catalysts such as increasing pain and decreasing physical functioning along with lack of progress with prescribed treatments provided prime conditions for participants to make the leap of faith into the IIPT program.

**Diving in.** Diving in was selected as a subtheme, because it captures the essence of the moments when participants made the actual leap to enter and fully engage in the IIPT. Some adolescents started the program at their parents’ insistence, while others definitely endorsed a more independent decision to discontinue ineffective therapies and to attempt this different and new interdisciplinary approach. Most of the adolescents eventually endorsed full engagement in the program with a high level of determination and willingness, although this occurred at different points in the treatment process. Some began the program with the initial mindset of being committed to fully immersing themselves right from the beginning.

(Participant 5) I came in here willing. I came in here with a positive attitude, even though I was frustrated because of this. I came in here wanting to do what they were telling me...wanting to improve. I wanted to walk. I want to run. I want to play ball, even if it is
just with my sister. And I wanted what they were willing to help me to do, and I put everything I had into this and I still am because I want my life to be back to where it was. I want to be active. I want to have fun. I want to be a normal kid. I mean, as normal as I can get with this. But to the point where I’m able to do the things I used to be able to do, and get my license…go to college.

For others, this fuller immersion occurred during the program as they became more comfortable, observant, and engaged. This adolescent shared how this process unfolded and how her attitude and orientation towards the program evolved more slowly.

(Participant 3) It was hard, I didn’t really want to go at first. It was kind of like…my mom forcing me to go, and I REALLY didn’t want to be here. But, I didn’t really feel comfortable here, because I didn’t really know anybody. So, I just kind of stuck to myself and stayed in my room the first week, week and a half…Sort of towards the Wednesday of my second week inpatient, I started to talk to the other inpatients more…sit in the common area with them more, and just hang out with them more, …I just think I just felt more comfortable with it, so…I think it might have made me work a little harder and be more involved and not as reluctant when I was doing everything after that, because I didn’t feel as if, this was like stupid and I didn’t want to be here. I felt like maybe it was working.

One of the six participants (Participant 4) never described fully diving into the experience wholeheartedly. In contrast to other participants, she described the program as an “it” or an external entity that was supposed to work “on her”, “for her”, in order to “fix her.” She put one foot in the program while keeping the other out on the edge. She described “going through the motions,” which was a contrast from the accounts of the others who described full immersion
into the program. She was one of three participants in the sample with headaches; however, she conceptualized her situation differently. “But, I…like, headaches is one of those things where…you’re expected to have it for a long time. So, you’re not going to go there and suddenly be fixed, you know…so…I just kind of felt like I was going through the motions…”

Many spoke of how the structured schedule facilitated their full engagement in all aspects of the program. This structure helped them to learn to refocus from their pain and thereby to manage it in a healthier way.

(Participant 1) They try to keep you on a schedule so that you’re more distracted, by your schedule and you can focus on that more than your pain, because if you focus on your pain… it’ll get worse and worse, because you’ll just keep focusing on it and then that’ll make you stressed out.

Another aspect of diving in was feeling challenged and “pushed” by program staff, while simultaneously recognizing and appreciating that this was done in non-overwhelming ways. This balanced approach helped most of the participants to move forward in their individual treatment programs. Participants then began to internalize this and push themselves physically, behaviorally, psychologically, and emotionally.

(Participant 4) You know, they’re good at pushing you, but not, like, I don’t know… They push you the right amount where you make progress, but you’re not like broken, you know, like. They do a really good job.

(Participant 5) We learn how to pace ourselves so we’re not overdoing it and knocking ourselves back down, off our…because they want us to climb stairs. So, we’re improving each day instead of falling backwards off a mountain.
Diving in also involved a willingness to examine previous mindsets, behaviors, and aspects of their identity. Participants agreed to follow program staffs’ recommendations, even if initially they did not agree with them, felt uncomfortable, or were uncertain of a positive outcome. The adolescents described an eventual realization that these recommendations were made for their benefit, and that they actually were quite helpful. One participant who identified as a morning person, was still willing to follow the staff’s activity and sleep recommendations despite personally disagreeing with them. The participant trusted that there was a good rationale behind the recommendation and that it was ultimately for their best interest.

(Participant 1) I’m not a morning person, so it’s hard to get up in the morning all the time… so I feel that being active for 8 hours does help…Because they say if you’re active for 8 hours, the odds are that you’re probably going to be tired, so you’ll fall asleep faster…I feel like you should have to get up at a certain time, but go to sleep whenever you want and if you go to sleep later and you’re tired in the morning, it’s your fault. That’s what I feel it should be at. It should be a thing, but, I guess it’s really up to them…they just want you to have a good sleep hygiene…

A participant lacking confidence in her artistic abilities, originally stated that she did not find certain aspects of the program as helpful because of this; however, she was willing to push past this perceived limitation to take a risk and to try new things. (Participant 5) “I mean, I started enjoying recreational therapy after I found out I didn’t have to be perfect at drawing (laughs). And plus, it got me out of algebra too.”

Diving in was not only physical and behavioral, but psychological and emotional as well. One participant spoke of trying new things by being afforded the opportunity to discuss feelings without parental presence for the very first time, which was helpful.
(Participant 1) When I do have counseling with psychologists at my hometown, they are always with my mom too. So, I’m afraid to say some of this stuff. I’d rather be one on one like this…so, I’m like more open. If my mom was in here, I wouldn’t have said any of this right now…

Others credited weekly goals set by staff and participants as being integral to their program and especially beneficial in their treatment progress as the goals provided focus and direction to their efforts. While striving towards these weekly goals and working closely with staff members, participants were encouraged to dive deeper and attempt new ways of expression and they became willing to take risks to meet their benchmarks.

(Participant 1) And another thing that kind helped me was being more open, because a lot of times, I don’t really show emotion, like happy, sad or something…I just have like a blank face most of the time. So, I’ve kind of learned to open up a little bit more, too…Basically, with my IFPs one of them was to say a positive statement every hour, which was actually kind of hard for me, because a lot of times I’m more …pessimistic… so it was really hard to do that…That was one thing that did it. Another thing was that the girl (staff member)…she comes in every week, once a week, and she’s really active and sings a lot and sings when she talks, she, dances, she plays instruments…so that kind of helped me to open up a lot too. She made me do a play of Where the Wild Things Are too, which was kind of…I didn’t like it, but I did it anyways.

The subtheme of diving in contains descriptions of moments when participants actually took the leap of faith. Participants describe an immersive process whereby they enter in to the IIPT program physically, psychologically, and socially; however, this is a unique and individualized experience for each participant. Factors contributing to the leap of faith included
the support and challenge provided by program staff, structured scheduling and goals, engagement with peers, and their own willingness to try new recommendations by the IIPT program staff.

**Buried treasure.** Buried treasure was selected as a subtheme, because it reflects a searching out and discovery of valuable riches unearthed by the participants’ efforts that may have remained hidden without immersion in treatment. The overall theme, leap of faith, suggests that participants entered the IIPT program even though they were not sure it was right for them or whether they would benefit. They were, at the time, unaware of the “buried treasure” that they would discover that would eventually help with their experience of pain and functional disability. The adolescents described various types of buried treasure that was discovered during their experiences in the IIPT. Some was found within themselves that manifested as changes experienced as a result of their engagement in treatment. One type was significant functional restoration that either helped participants to rediscover and reclaim lost parts of himself/herself or to discover new skills or perspectives. Participants described the impact of how regained function will help them to return to normal daily activities that had gradually become impossible for them over time, such as participating in school or self-care.

(Participant 5) But …I missed a bunch of school. I could only go a couple hours at a time, because I couldn’t handle sitting. I couldn’t get down on the ground, which I can now do thanks to the physical therapist…I couldn’t handle wearing socks. I couldn’t handle wearing my shoe, …keeping it tied, which I can now do…And then, I haven’t shaved my leg in over four months. And with their sensory program, it helped me shave my leg over Labor Day Weekend. It took me two razors (laughs).
(Participant 6) It’s honestly incredible, what has happened to me. I walked in unable to wash my own hair, not wanting to get out of bed, not able to do anything. This morning, I did 25 push-ups in a minute…. I can now wash my own hair…yeah. It’s been INCREDIBLE!

Several participants spoke of an overarching sense of freedom and “getting their lives back.” One participant who identified as an athlete emotionally described a powerful family moment that occurred during the program. This moment represented much more than the physical act of throwing a softball. It was symbolic of the restoration of identity, hope, family bonding, and achievement of her personal goals.

(Participant 5) And that weekend my dad brought up his glove, because I brought my softball glove up with a ball. And I sat it in my room and I said “I’m gonna get back to that. I’m gonna be better than ever. I’m gonna be stronger and fiercer…and I got to throw a softball with my dad. And it’s been four months since I had done that. And the only way that I can describe that is that I was free. I was free, I was in my happy place. And, I’m going to get choked up, because I hadn’t done it in so long…and it felt awesome (crying) and to see my mom smiling because I hadn’t moved…my dad laughing at me because my arm was so out of whack (laughs)…it felt good.

Participants described a sense of joy experienced as a result of this reclamation of lost aspects of themselves and their lives.

(Participant 5) It brought me freedom. It’s the only word I can think of, because they got me of the crutches, they got me out of bed. They’re helping me move and it’s freedom…

(Participant 6) I don’t know, I’ve just…this entire time I’ve been here, I’ve just been laughing and smiling and just full of life, because I’m finally getting it back.
Beyond restoration and reclamation of lost selves, participants discovered other types of buried treasure, such as new abilities, skills, and perspectives. Participants described specific ways that they believed they had personally changed physically, psychologically, and socially.

(Participant 2) More motivated, and feeling like I don’t have to rely on anyone else. I can rely on myself now…

(Participant 1) I have more stamina… I feel more social.

(Participant 3) Three weeks ago, I felt like I was more irritable, and just, I don’t know, just upset and just sad and… in pain all the time. But, now I just feel… I feel better and I feel more positive, and even though I still have pain, I know that I can control it a little bit to the point where I can still do the things that I need to do with my life.

(Participant 2) I used to play things over in my mind more. Now I’m more just moving forward. Because when I can’t do something, I can’t, and there’s no reason to stress about it… I used to like, “what if this, what if that… type of thing… and found that it’s not going to help anyways, and so… to think about what I actually can do.

Another type of buried treasure was a new sense of identity and valuable lessons learned about pain self-management. One adolescent realized that due to her previous identification as an athlete and “strong” person with a “really high tolerance for pain,” she was actually pushing herself too hard. Her previous mindset was not only ineffective, but ultimately detrimental to her pain management. During the program, she discovered the need for new, more effective coping and pain management strategies that allowed her to learn new ways of living while still maintaining her identity as an athlete.

(Participant 5) I tried three times – three times to get rid of those stupid crutches… but here, they taught me how to pace myself and not force myself to get rid of them, and I
think that helped. Knowing that by taking my time, I don’t have to be in front of the pack like you do in athletics. Like you don’t have to fight or compete for a spot. You have to take your time so you can re-develop and regain the muscle mass and the muscles and your bones so you can get them to the point where they are able to help work again.

This new sense of self was also reflected in several accounts where participants described rejecting the label of a hospital patient and the ramifications and stigma that come with that label. Buried treasure was found in their new-found perspective as persons living with pain versus being pain patients.

( Participant 6) A lot of my teachers haven’t been sending me work while I’m in the program. And, because they think, you know…she’s in the hospital…she needs to focus on her health. But in reality, like we have school time during the day and so I have nothing to work on here.

( Participant 2) One time I felt that it wasn’t as helpful was when we went on the field trip, because…so I think it’s really cool that we got to use it in the community…our coping skills, but all the nurses wore scrubs and stuff and we went in a hospital van, so…it kind of felt like, ‘Oh, we are the hospital kids’ and I felt like it should have been more like, ‘Oh, we’re kids with…we’re living with pain, but we’re still like everyone else.’

Another buried treasure included enhanced self-awareness. A participant with chronic headaches described increased self-awareness and how it will be beneficial for future pain self-management.

( Participant 3) I also try and think about… what type of pain I’m feeling at that moment and how I can…like what skill I can use. What coping skill I can use to ease it at the
moment instead of just thinking “I’m in pain…?” …I’m just more aware of my body and what’s going on with it, instead of just being clueless and my mind was just like…I felt like when I would go to doctor’s appointments and stuff before, and they’d ask me about my migraines and stuff, it was hard for me to describe how it felt. But now I feel it’s a little bit easier for me to say where I’m feeling my pain at and what area of my body I’m feeling my pain, and I just feel more aware of myself. …

Many participants came to the realization that they had choices related to their thinking patterns and where they focused their attention and efforts. They described a growing awareness and ability to assume greater ownership and personal responsibility for not only for their pain recovery, but also for the larger context of their life. Participants began to appreciate previously untapped potentials that they possessed in their individual situations. (Participant 2) “I remember talking in biofeedback…and, he told me, you don’t have to let the emotional tension and stuff affect your body…and we were doing the biofeedback and I was trying to…I could …I was focusing on something that was stressful for me, but trying to not let it affect my body at the same time.” One participant shared a profound moment when these connections came into focus for her and she acquired the insight that she indeed has control and choice over her thoughts and behaviors.

(Participant 6) My first day here I had to get a physical therapy evaluation and they were like, “alright…do some pushups.” And I was like “Oh, no…I can’t do pushups.” You know, for so long I’ve been so deconditioned and thinking that, “It hurts, so I can’t do it…and I WON’T do it because it hurts…” So that moment just kind of…something clicked in my brain, like “I CAN do this. It may hurt, but I can like push through it.” I was really intimidated when they told me to do the pushups. But once I started and
realized that, “You know, I am not hurting myself. It’s just my brain…” It was just really, really nice. To think that “I can get through this, I can beat this!”

Participants also developed an ability to accommodate their focus (i.e., adapt their range of view) from specific pain-related issues to “the big picture.” They began to grasp a greater comprehension of the relationship of pain to matters within a larger life context, and of the reciprocal impact of outside stressors upon their pain experience. They described a greater appreciation of the skills that they were learning and their relevance for life issues beyond management of their pain. One participant spoke of various life stressors and a growing realization of how a “rough childhood” was affecting the pain. This new perspective gave the participant insight into pain within the larger context of life experiences.

(Participant 1) A lot of that stuff is all piling on top of each other… And it’s making it really hard. And one of the skills is acceptance… they say that if you deny the fact that all the stuff is going on and you accept it, you’ll be more open to ideas and stuff like that. If you deny it, you’ll be more stressed and more, like, fatigued and stuff like that… But, it’s kind of hard to accept everything, because there’s so much happening at once.

So, I feel like, when now that I have dealt with my pain, it’s not gone, but it’s manageable now. I feel like now, I’m going to have to go to counseling for like depression and stuff like that, so I feel like that’s going to be a really big issue now. Because pain was one thing and now I don’t want to do anything because of my depression too…

Some acknowledged new awareness for others who may be privately suffering and developed the ability to empathize. They learned the important lesson of not taking people and their situations only at face value.
(Participant 5) And I guess it changes my outlook on people who have hidden illnesses because my grandfather, he’s going through stuff like that and he’s been going through that for a while…and not to judge a book by its cover.

All study participants, except for the Participant 4 who never endorsed fully diving into the IIPT program, discovered various aspects of intrapersonal buried treasure. However, even though Participant 4 did not claim to take hold of these benefits, she recognized that her peers did. She continued to refer to the program as an “it” and something that was going to either “work for” her or not…” which was a very different mindset than that expressed by the other participants.

(Participant 4) I mean, like I said…I don’t think it personally has helped me that much…but I think it has definitely helped a lot of other people. I think it’s one of those things where it’s not going to work for everybody. But, it’s definitely helped a lot of people. I’ve even… people that I’ve gone through the program with, I’ve seen it help. I think you learn a lot of good skills that help you deal with the pain you are going through, and I’ve seen a lot of people make SO much progress. I don’t think I personally have made very much progress, but I’ve seen a lot of people who I’ve become pretty close with like, start to walk!... Um, I mean, I’m happy for them. It kind of sucks to not…be doing anything, but…

In addition to the intrapersonal growth and personal changes that participants endorsed, buried treasure was discovered in the context of interpersonal relational connections and community with others. This was described to be quite profound and a major aspect of their treatment experience. The main connections identified by the adolescents were those with peers and program staff members. Several of the adolescents realized that they were not alone in
dealing with their condition, which enhanced their perspectives and helped them to reframe their experiences.

(Participant 1) The one thing that impacted me was how everyone… I thought I was the only one who has a lot these pain issues. And I found this out, and I was like, ‘Oh, man, there’s a lot of other people that have all this pain stuff…And then when we were going around the table, they told us, they told me what they’re in for, and a lot of stuff sounded almost worse than mine. But I can’t tell, because a lot of them have CRPS and they can’t move certain parts of their bodies. Like that kid named XXX, he can’t move his legs because of CRPS, and so I feel like I have it almost lucky, almost…

Most participants described benefiting from learning that their suffering was not unique and believed that this aided in the development of deep relationships with their IIPT program peers. Many of the adolescents described the contrast between peer relationships outside of the program and of those developed with peers in the IIPT program living with chronic pain. An almost universal theme or treasure throughout many participants’ accounts was a deep appreciation of being understood by their peers in the program.

(Participant 4) Last weekend, we had a TLD which is when we get to use all of our skills and stuff that we’ve learned outside of the unit. Two other girls here that I’ve been going through the program with, we all hung out in downtown and we explored for a while and then we all went to dinner together. And it was so much fun and it was just so nice, because we all went at the same pace and we all understood what each other was going through. And we were all in pain, but it didn’t stop us from like doing things, because we all understood what it meant, in that we all needed to take breaks and that we all, you know…it was different from, like hanging out with people who aren’t in chronic
pain…Yeah, they understood. It wasn’t like when you’re hanging out with someone who isn’t in pain all the time, you have to tell them when you need to stop. And that you need to take a break, and that you have to take it easy. Whereas when you’re with someone who is always in pain too, they just take it at that pace with you too, because they’re in pain too, you know? And they also understand, that like, you’re not necessarily going to feel up to things also. And they’re just, they’re just…more understanding.

(Participant 4) I think that’s probably the best thing about this experience…it’s so easy to relate with everyone here, just because…Even just the people who you are here with just for one week, because it’s their last week and your first week. You still become super-close with them, because you are with them for like five hours a day and you have so much in common and it’s just you know, I don’t know…

Others reflected on their ability to relate better one-on-one with others and to develop meaningful friendships, mutual understanding, and respect with peers in the program. Two participants spoke of significant friendships that developed during their time in the IIPT.

( Participant 5) I’ve developed some friends. I’ve got one real good friend here. She’s awesome. And she likes sports too (laughs). Even though she likes the Steelers! No, we still get along. But…because we bonded over the concept of sports and we also understand. We’ve both got the chronic pain, so it’s easier to respect each other understand when we need a pace break, we need a pace break. Or we need to take a drink of water or relax. It’s fun that way.

( Participant 6) She and I clicked the very first day that we were here together. And we’ve been here the same amount of time and, I don’t know. It’s just like finally someone understands what I’m going through and can offer me support and, um, cause, you
know…my friends at home, they’re great. They’re really understanding, but nobody really knows what it’s like to go through it, so they can’t really offer any advice. Whereas, this entire time we’ve been encouraging each other and really just there for each other.

Beyond forming peer relationships, participants benefitted greatly from making connections with the staff of the program. They described the welcoming holistic milieu environment as a “safe haven” and the treasure of feeling supported, along with a sense of belonging on many levels.

(Participant 3) I’d say this is like a safe haven…this has been a nice place just to go and take myself away from everything for three weeks and focus on, just myself, and getting better…I think it’s like everybody, like the staff too, they’re really important figures for me now, I feel, because they really helped me get back to being normal…

Several participants compared heir rehabilitation experience to the crossing the threshold into a caring family, where they were both understood and accepted.

(Participant 2) My friend was having a hard time because her grandpa died and some other stuff and it’s…the program can be really challenging at the beginning, just getting used to it. And so the girls who were outpatient and everyone met back here and threw her a little party. And it was really sweet, and just connecting with everyone is really cool, because the moment you step in everyone’s so welcoming and with chronic pain, most people are used to just being told that they are faking it…or people not believing them. So, it was really cool…everyone here you encounter is really sweet, and encouraging.
(Participant 3) I think this has just been a great experience, and sort of just like a family, sort of…because everybody just knows what you are going through. Even though we all have different chronic pain, we all know we are all dealing with pain. And that just makes it easier because when we are in the outside world nobody else understands that we’re going through pain. So, nobody is as understanding and as helpful as everybody here…

Participants described feeling like a member of a family and spoke of appreciating and valuing their experience and holding the program in high esteem as they prepared for discharge.

(Participant 1) The program’s very, very important to me because it’s helped me to deal with a lot of the pain…all I can say is that it is very important to me. Okay. It’s almost as important, as like, one of the family members or something like that. It’s VERY beneficial.

The subtheme of buried treasure consists of participants’ rediscovery and reclamation of aspects of themselves along with fresh discovery of various types of interpersonal and intrapersonal treasure. Prior to the leap of faith and immersion into the IIPT program, participants seemed unable to access intrapersonal treasure such as improved functional restoration, enhanced self-awareness, realization of untapped ability to manage their pain, and recognition of their pain experience in the larger context of their lives. Participants also discovered interpersonal buried treasure within the safe haven of the IIPT milieu. They learned that they were not alone and were able to connect with peers struggling with similar issues. Participants described feeling that they were in a safe haven and part of a larger “family” in the caring IIPT program community.

**Charting new waters.** Charting new waters captures the sense of increased hope and self-efficacy expressed by the adolescents as they incorporated changes experienced during
treatment and approached a different type of “edge” than where they began their journeys in the IIPT program. Most participants recognized feeling fortunate and expressed appreciation for the opportunity to participate in the IIPT program. Some reflected back on where they had come from in just a few weeks’ time, when they made the leap of faith to enter and dive into the program. Their comments reflected the biopsychosocial model and program’s intensive interdisciplinary treatment philosophy. Participants were unable to separate individual aspects of the program that helped make changes in their lives possible; instead, they viewed their experiences as a cohesive whole.

(Participant 3) I think everything that has happened to me in this program has been relevant to my development, because when I came here three weeks ago, I feel like I was a completely different person…I think every single thing that I’ve done here has contributed to my betterment.

(Participant 2) I really like it… I’m like so lucky to have been able to have to go here…It’s kind of like what I’ve been going to previously. But before when I was going to different doctors’ appointments…It was hard because we were trying to gather up all these different pieces of information and kind of being the main doctor and choosing what’s best and, it was hard to apply things at home. And I wanted, I don’t know… I kept saying, “it would be so nice to have a place where you just go…

As participants stood on the threshold of pending discharge from the safe haven of the IIPT program, they committed to incorporating the buried treasures experienced during the IIPT into the larger context of their life.
Participant 1) I usually just take the day by the hour...so, I just take it by the hour and I don’t really think much, because I am just going to treat like, tomorrow when I leave, I’m just going to treat it as any other day, it’s just like a regular day, that’s how I do things.

Participant 6) I feel more...valuable...like I can contribute to society more now instead of just lying in bed and feeling hopeless for myself...it has completely turned my life around... I just hope that I can continue to improve as I leave.

Participants wanted to encourage and share their newfound wisdom with other teens living with chronic pain. Some of their messages again reflected the ability that humans have to choose their thought and behavior patterns and urged others to be strong and willing to take a leap of faith as they did.

Participant 2) You can take a lot more than you think you can. So, there’s a lot more...every person can take a lot more than they think they can. People don’t usually realize how strong they can be.

Participant 5) Stay positive...there are people out there who are going through much worse. They’re losing their hair and other parts. I mean, there are people suffering in Iraq and soldiers without limbs. But, it gets better, whether you want to believe it or not. It gets better. You just have to be willing to put the effort into this program. And if you put enough effort in...if you’re just giving it your all, they will help you to the fullest...but I guess it’s the way my parents raised me too, give it your all...Keep a smile on your face. Don’t let the bullies bring you down... Just do it...

Most spoke of a renewed sense of hope and confidence as they reflected back on their programs and prepared for their short and long-term futures. They felt more confident and
possessed more self-efficacy in leaving the security of the program and taking the next leap of faith into the uncharted waters of their new lives.

(Participant 3) I feel like it’s helped me a lot…I feel way more prepared to go out into life… I’ll be okay going outside of the hospital because they’ve given me the skills that I need to just do that. And even though I still have pain, I know how to manage it now. And it’s sometimes still scary, because I don’t know if I can really manage it ALL that well, I’m still here right now, but hopefully I can. I think that I’ll be able to when I’m done with this. And, it’s made me feel better about myself.

(Participant 5) It’s amazing, because…I mean, they helped me…they’re still helping me, and I hope for what they’re giving me will help me throughout the rest of my life if I still have to deal with this.

The subtheme of charting new waters consists of participants’ anticipation of a new leap of faith as they stand on the threshold of a more hopeful future. They described incorporation of the previously elusive intrapersonal and interpersonal treasure that they discovered in the IIPT program as they approached this new edge with a renewed sense of hope and confidence.

Participants described feeling more prepared to meet the challenges of adolescence and young adulthood because of the growth that they had experienced. They reflected back on their IIPT program with a sense of gratitude while expressing hope and encouragement toward others who might be struggling with PCNCP.
Chapter 5: Discussion

Findings in Context of Biopsychosocial Model

Participants in this study endured various types of suffering that eventually culminated in taking a leap of faith and a diving into the IIPT program. Entering the IIPT program involved a commitment of their time away from family and friends, along with a sustained focus on themselves. Their willingness to set this time apart to devote to their recovery was facilitated by unique catalysts, such as increasing pain levels and functional limitations, previous treatment failures, and negative impacts on themselves and family members. Congruent with the biopsychosocial model of pain, participants engaged in their individualized treatment programs physically, psychologically, and socially, and discovered buried treasure in all three of these aspects of themselves and their lives as well. Major findings of the study will be summarized below according to the three major domains of the biopsychosocial model.

Biological. Participants described worsening and unrelenting pain and increasing functional disability prior to entering the IIPT program, despite attempts at various, usually singular, treatment modalities. While in the program, participants engaged in physical, occupational, recreational, and aquatic therapies and treatment, which was delivered by an interdisciplinary team of experts in PCNCP. Biofeedback sessions contributed to an enhanced awareness of their physical selves, which positively impacted their ability to manage pain. Learning about the importance of posture and pacing, and applying new techniques, was identified as beneficial by the participants. They described major functional restoration in physical capabilities, as well as an improvement in their sleep patterns. Sleep has been identified problematic for individuals experiencing PCNCP, although the nature of this correlation is not fully understood (Chambers et al., 2008). A participant in this study noted an improvement after
being willing to try new approaches to sleep hygiene as recommended by IIPT program staff. Physical progress throughout the IIPT program led to resumption of previously abandoned role activities due to restrictions from pain. Other areas of current PCNCP research in the biological realm involve genetics, temperament, and pharmacology, which were beyond the scope of this study (Hoftun et al., 2013; Mathew et al., 2014; McKillop & Banez, 2016).

**Psychological.** Participants engaged in individual and group psychotherapies throughout the IIPT program, some for the first time without their parents’ presence. Relaxation and CBT have been found to be effective for decreasing pain in PCNCP (Eccleston et al., 2014; Fisher et al., 2014). While participants mentioned decreases in physical pain as a result of their IIPT program, they began to think about their pain and lives differently as a result of cognitive behavioral therapy (CBT)-based interventions. Participants endorsed a willingness to challenge their previous mindsets and behaviors in relationship to their pain, which they found beneficial.

Acceptance and commitment therapy (ACT) focused on goals and positive pain coping skills has been found to be effective in improving functional outcomes in PCNCP (T. M. Palermo, 2009). This was reflected in the data, as several participants mentioned the benefits derived from collaborative goal-setting with staff members. They developed the ability to change their focus, as they learned and applied various distraction techniques. Some endorsed a growing awareness of pain in the context of their larger life and realized that they needed to begin to address emotional concerns that had long been held at bay due to the physical pain. Participants discovered that they indeed had choices in the midst of their chronic pain experience, which enhanced their internal locus of control and self-efficacy. Participants began to recognize their abilities to lead full and productive lives despite chronic pain, and were excited and hopeful about discharge from the IIPT program.
Social. Participants’ accounts in this study strongly support findings in the literature that children with PCNCP often feel more isolated, left out, different and victimized by their peers (Forgeron et al., 2010; Martin et al., 2007). The participants experienced painful situations prior to admission to the program and were targets of bullying and misunderstanding by peers who had not experienced chronic pain. Family relationships and roles were strained. By observing others in the program and engaging in groups and formal and informal social interactions, participants realized that they were not alone in their experiences of chronic pain. Connections with peers in similar circumstances were described as curative in nature. Participants felt understood, some for the first time, and developed a growing awareness that things may not always be as they appear in other peoples’ lives. Parents actively participated in treatment as well, receiving individual and family education and support. School needs were assessed and the treatment team communicated with participants’ home school staff to facilitate their post-discharge academic transition. Participants benefited from relationships developed in the program with peers and staff members, and they expressed a sense of belonging. The program was described as a “safe haven” and a place where they felt unconditional support and regard from the IIPT program “family.”

Biopsychosocial Model

Prior to admission to the IIPT program, participants had been treated according to a biomedical versus biopsychosocial model, with treatments prescribed based mainly on physical symptoms. Some attempted individual physical therapy and others took large doses of narcotic analgesics and sedative agents that often contributed to additional functional impairment. There was little communication between various healthcare professionals. While at times effective and sufficient for treatment acute pain, a strictly biomedical model does not address the complexity
of biological, psychological, familial, and social factors inherent in PCNCP (Gatchel et al., 2011; Landry et al., 2015) and the reciprocal relationships between these factors. The findings of this study show that participants developed a new and different understanding of their chronic pain experience through the lens of the biopsychosocial model. This enhanced perspective allowed participants to view their situations in a new light, which helped them increase their awareness of the whole self and afforded them options not previously explored or comprehended.

When describing their experiences of change in the IIPT program, participants were unable to partition off specific physical, psychological or social program activities as most helpful to their progress. Rather, they experienced the IIPT program as a comprehensive whole. This finding supports those of previous studies (Scascighini, Toma, Dober-Spielmann, & Sprott, 2008) that compared single treatment modalities (i.e. physiotherapy, pharmacotherapy, patient education, and ergonomic training) to multidisciplinary treatment (i.e., concurrent components such as physical exercise, relaxation training, group therapy, patient education, biofeedback and CBT). Multidisciplinary treatment demonstrated strong evidence for its use versus no treatment or standard medical treatment. There was also moderate evidence supporting inpatient over outpatient multidisciplinary programs.

While research with PCNCP populations is not yet as proliferative as with adult chronic pain, IITP programs are gaining support as effective for children and adolescents who do not respond to other treatments (Landry et al., 2015). Research findings show increased functioning, decreased depression and healthier thought patterns related to pain for children and adolescents who participate in an IIPT program (Banez et al., 2014; Hechler et al., 2014). These findings strongly endorse the biopsychosocial model of pain and systems theory, which assert that no part of a system exists in isolation, complex relationships occur between the physical, psychological
and social domains of human beings, and that the whole is often greater than the sum of its parts (Borrell-Carrio et al., 2004; Engel, 1980).

**Living Miserably on the Edge**

The potential negative impact of PCNCP on all aspects of an adolescent’s life are well documented in the literature. In this study, participants’ descriptions of experiences prior to entering the IIPT (i.e., living miserably on the edge) strongly supported this body of literature. Nervous system dysfunction and central sensitization are complex physiological processes; therefore, PCNCP is often associated with other centrally-mediated physical and psychological symptoms, such as fatigue, sleep difficulties, and problems with mood and concentration (Fornasari, 2012; T. Palermo et al., 2012). Psychological distress, anxiety, and depression are all common in children and adolescents with PCNCP. These factors, along with physical limitations and deconditioning, frequently contribute to an inability to complete activities of daily living (ADLs) and have been associated with lower health-related quality of life (Aronoff, 2016; Gold et al., 2009). In a sample of patients (N=207) referred to a tertiary pain clinic in Australia, 95% reported school absenteeism, 71% experienced sleep disruption, and 90% were unable to perform sport activities (Chalkiadis, 2001). Patients experiencing PCNCP and their families consult a variety of specialists in their search for relief of the pain and debilitating symptoms; which is often a lengthy and difficult process fraught with elusive diagnoses and ineffective treatment experiences (Brooke & Janselewitz, 2012; Wojtowicz & Banez, 2015; Zernikow et al., 2012).

**Diving In**

A current focus in PCNCP research is the concept of “readiness to change,” based upon the Transtheoretical Model of Change (TTM) developed by Prochaska and DiClemente (Prochaska, Wright, & Velicer, 2008). This concept has both similarities and differences with the
theme, “diving in,” which emerged from participants’ descriptions of experiences of change in this study. The TTM uses 5 stages to identify an individual’s readiness to change: Precontemplation, Contemplation, Preparation, Action, and Maintenance. It is theorized that the farther along one is in the stages, the more likely that individual would be to make behavioral changes aimed at enhancing their health. The TTM also includes a concept entitled Decisional Balance, whereby pros and cons of potential changes are weighed in a decision-making process prior to their implementation. Individuals in the Action stage have identified more pros associated with changing their behavior than cons. The TTM has been utilized and studied extensively in adult chronic pain populations as a potential predictor of response to treatment, and in a pediatric population to a lesser extent (Evans, Jastrowski Mano, Guite, Weisman, & Hainsworth, 2015).

The Pain Stages of Questionnaire for Adolescents (PSOCQ-A) is used to assess patients’ readiness to adopt a self-management approach to PCNCP. The PSOCQ-A includes 3 subscales. Pre-contemplation indicates little perceived personal responsibility for pain management. Contemplation identifies those considering personal behavioral change and possessing an awareness of personal responsibility for self-management. The Action/Maintenance subscale delineates individuals actively involved in learning or continuing to use self-management techniques already learned (Guite, Logan, Simons, Blood, & Kerns, 2011). Action and Maintenance are the two stages located at the farthest end of the TTM continuum, theoretically indicating a greater readiness to change.

In a recent study (Simons et al., 2018), stages of change for adolescents engaged in an IIPPT program (N=253) was used to examine trajectories of pain and functional impairment up to one year after treatment. Two groups, responders (88%) and non-responders (12%) were
identified based on level of functional disability; readiness to change was not predictive of participants in the responders group. An additional three groups were identified based on pain intensity: early treatment responders (35%), late treatment responders (38%), and non-responders (12%). Readiness to change was one of several variables discriminating non-responders from early treatment responders and late treatment responders; however, it did not distinguish early treatment responders from late treatment responders. After controlling for other factors (e.g. age, functional impairment, and patient cognitive characteristics) participants that fell into the pre-contemplative or contemplative categories versus action/maintenance category were at nine-fold greater risk of being a pain treatment non-responder. Incorporation of motivational enhancement techniques prior to admission to an IIPT program was recommended as a potential intervention to enhance treatment outcomes (Simons et al., 2018).

Another study (Logan, Conroy, Sieberg, & Simons, 2012) included children and adolescents ages 10 to 18 (N=157) enrolled in an IIPT program. Patients completed the PSOCQ-A at three time points: pretreatment, posttreatment and between 1-3 months after treatment. Willingness to self-manage pain increased for patients during treatment and was maintained at follow-up. Increases in patients’ readiness to change from pretreatment to posttreatment was correlated with decreases in depressive symptoms, functional symptoms, fear of pain, and reported use of adaptive coping techniques, which suggests that IIPT programs may positively impact patients’ readiness to change and self-manage their pain conditions, and thereby improve their emotional and physical functioning. Few associations were found between pretreatment stage of change and posttreatment outcomes.

In this study, participants described unique perspectives of their readiness to “dive in” and their experiences of change in the IIPT program. The diving in theme that emerged from
data in this study is different from the concept of readiness to change that is part of the TTM. Findings in this study do not support the decisional balance related to the TTM’s concept of readiness to change; participants did not describe consciously weighing pros and cons before deciding to take a leap of faith and dive into the IIPT program (i.e., enter the program and participate in program activities). In contrast, after enduring much suffering and living miserably, individual catalysts prompted participants to enter the program without knowing how and if it might help; once participants were admitted into the program, they described immersing themselves into treatment activities, many times without understanding or believing that the activities would be beneficial. One participant endorsed a diving in right at the beginning of treatment; however, for others this occurred at some point during the 3 weeks, and one participant never described full immersion or comprehension of the self-management approach. She continued to view the program as an external treatment designed to “fix” her. She witnessed peers making tremendous gains but was disappointed in her own progress.

**Buried Treasure**

The primary goal of this IIPT program is enhancement of daily functioning (i.e., return to school and activities) despite the presence of chronic pain. (Evans, Benore, et al., 2015). Participants attended individual PT and OT per week, along with on-land and aquatic group exercise. Buried treasure included major functional restoration, which allowed participants to return to activities that they were previously unable or unwilling to do because of their pain. These activities included brushing their hair, shaving their legs, wearing socks and shoes, sitting in the program classroom, resuming sports activities, and sleeping well. This improvement in functioning was described by participants as “incredible” and “getting their life back” and reinforced positive aspects of their identities.
An abundance of literature of the effect of PT and OT to improve functional restoration in PCNCP is available. Participation in an IIPT program for PCNCP has been correlated with decreased functional disability immediately post-treatment and longitudinally (Banez et al., 2014; Landry et al., 2015; Logan, Carpino, et al., 2012). In one study, patients ($N=95$) who completed an IIPT program at least 5 years previously reported significant pain reduction ($p < .001$) and decreased functional disability ($p < .001$) from the time of admission to follow-up. Average functional disability scores at follow-up were rated as “minimal” with 78% reporting no functional disability (Randall et al., 2018).

Participants engaged in biofeedback, a modality that targets the physical and psychological domains of the biopsychosocial model. Two different biofeedback programs are used in the CCF IIPT program. The first provides education about self-regulation of chronic pain or anxiety, and patients are provided with breathing exercises along with biological feedback about their heart rate variability (HRV). The second is a Motor Control Program with Quantitative Surface Electromyography (QSEM). This program involves activation and relaxation of certain muscle groupings (Ethan Benore, Banez, Sawchuk, & Bolek, 2014).

Much of the research involving biofeedback in the treatment of PCNCP has focused on headache. Biofeedback has been found to be efficacious in treating pediatric migraine; however, it has not demonstrated usefulness in abdominal pain or rheumatoid arthritis (Hermann & Blanchard, 2002). Of 25 studies included in a recent meta-analysis of psychological therapies for management of various types of PCNCP ($N=1247$), only 6 of the studies ($n=82$) examined the effect of biofeedback on pain levels. Biofeedback demonstrated statistically significant positive effects ($p=.0001$) with an odds ratio of 23.34. Only one study ($n=30$) investigated the relationship of biofeedback to emotional functioning, and it produced statistically insignificant
findings ($p=0.69$). None of the 25 studies explored the effect of biofeedback on disability (T. M. Palermo, Eccleston, Lewandowski, Williams, & Morley, 2010).

Cognitive behavioral therapy (CBT) is often utilized in conjunction with biofeedback and was experienced by participants as a component of the IIPT program. Goals of CBT involve increased self-awareness and development of various strategies (cognitive, emotional behavioral) designed to positively influence self-management of PCNCP by challenging negative and irrational thoughts, reinforcing healthy behavior patterns and teaching self-monitoring skills (Eccleston, N., J., H., & Sourbut, 2003; Velleman, Stallard, & Richardson, 2010). Participants in this study attributed various buried treasure to the CBT techniques that they learned, including an increased self-awareness, along with enhanced ability to self-monitor their bodies and pain symptoms. Participants endorsed learning to think differently about their pain and themselves and developing the ability to view their pain as part of a bigger picture of their life. They began to think differently about their pain and their identities as adolescents experiencing pain versus as “pain patients.” In other words, they no longer viewed themselves as pain patients. Findings from a recent review of the literature and meta-analysis related to use of computerized CBT with children and adolescents with PCNCP showed at least a 50% decrease in pain symptoms (i.e., frequency, duration, and intensity) from baseline to post-treatment and positive effects were maintained at 3 to 6-month follow-up with a statistically significant medium effect size of -0.41 ($p=0.02$). One of the four studies in the meta-analysis found a decrease in headache-related disability at 3 months and another demonstrated reduction in activity limitations; however, another study found no evidence of differences in quality of life between treatment and control groups. (Velleman et al., 2010).
The importance of peer relationships was strongly represented in the participants’ description of their experiences in the IIPT program. Adolescents are naturally drawn to peers as they serve an important role in accomplishment of developmental tasks such as identity formation, self-esteem, and individuation from family members (Akos, Hamm, Mack, & Dunaway, 2006; Aronson, 2004; Fitzgerald, 2005). Groups provide a contextual setting in which adolescents normally socialize, learn important lessons, and practice new life skills (Kulic, Horne, & Dagley, 2004). Participants in this study described curative factors as an important component of their participation in the IIPT program (Yalom, 1970). These curative factors include universality, cohesiveness, instillation of hope and identification (Sherry & Hurley, 1976). Their ability to receive and provide mutual aid in the treatment setting was also described as reciprocally therapeutic to themselves and other patients, which is reflective of the biopsychosocial model of pain and systems theory (Cicchetti & Johnson, 2015). Participants experienced the buried treasure of social support within the program as a whole; rather than attributing it to a formal actual “group therapy” setting, they discovered it in the day-to-day milieu and community activities with peers who were like them.

**Charting New Waters**

Participants expressed hope and feelings of increased self-efficacy and confidence as they were poised to take a leap of faith out of the IIPT program and into the new waters of their lives. There is not much research that explores the hopes and goals of adolescents at the point of discharge from an IIPT program or long-term outcomes. Findings from one study involving adolescents (N=95) who were engaged in an IIPT program showed that approximately one-third of them reported being pain free at follow-up five-years post-discharge, with the majority of participants endorsing significant pain reduction compared to pre-treatment (p<.001). Mean
functional disability ratings were considered minimal with significant decreases from pre-admission \((p<.001\)). Most of the participants were on track for developmentally appropriate tasks, such as high school graduation, college attendance, and independent living and high quality of life was reported across all domains: physical, emotional, social, and school functioning (Randall et al., 2018). These are promising and hopeful findings suggesting long term benefits following participation in an IIPT program.

**Limitations**

While the sample size was appropriate for an IPA study and demographic characteristics were reflective of the typical patients admitted to this particular IIPT program (i.e., majority are Caucasian adolescent females), findings may have been different if there were more male participants, those of different ethnicities, or younger ages. Participants’ accounts of their experiences in this single program may not be reflective of what other participants in other IIPT programs experience. Due to the small number of participants, it is not possible to make generalizations of the findings (i.e. patients who seem to have high readiness to change will benefit, while those who do not will not make progress); however; study findings are thought-provoking and do provide insight into individual participant experiences. Insurance coverage and provisions may have also affected participants’ descriptions of their experiences in the IIPT program; all participants were not consistently engaged in either inpatient or outpatient treatment for the same length of time, and some were only afforded a single level of care. Even though participants were interviewed the Wednesday, Thursday, or Friday of their third week of treatment, one participant was requested to stay an additional week, which may have impacted findings.

**Implications for Practice and Research**
The significant and multidimensional suffering endorsed by these study participants strongly reinforces use of the biopsychosocial model as a framework by healthcare providers for thorough assessment, treatment, and ongoing monitoring of patients experiencing any type of pain (Carter & Threlkeld, 2012; Geraghty & Buse, 2015; Kozlowska et al., 2008; Powers, Gilman, & Hershey, 2006; Rajapakse, Liossi, & Howard, 2014). It is imperative for clinicians to be sensitive to the different types and extent of suffering experienced by children and adolescents with pain. Acute pain may become chronic, and intermittent chronic pain may affect a child and family in significant ways that warrant an interdisciplinary approach. Labeling and placing strict and “arbitrary” time parameters on pain conditions may become problematic and prevent clinicians from conceptualizing each patient in a holistic and individualized manner (T. Palermo et al., 2012). Findings of this study also support the importance of viewing PCNCP as a family disease and highlight the importance of providing support and education to parents and siblings in addition to patients (E. Benore, Brenner, Banez, Wang, & Worley, 2018). This study highlights the benefits of social support experienced by participants engaged in an IIPT. Finally, findings of this study suggest that participants did not engage in a methodological decision-making process related to entering the IIPT program, as is suggested by popular change theories (i.e., TTM). Rather participants described entering treatment as a leap of faith. And the findings of this study show that once in treatment, participants immersed themselves in the treatment plan even if they did not know or believe that they would benefit. Clinicians who use assessments of patients’ readiness to change in making decisions about admissions to and participation in IIPT programs may benefit in knowing that the findings of this study revealed new concepts (i.e., leap of faith and diving in) that are similar to but different than readiness to change.
Participants in this study shared their accounts in a process-oriented manner, perhaps due to the nature of the structured 3-week IIPT program itself. They spoke of their lives “before”, “during” each week of the program, and were anticipating their lives “after” treatment. IPA methodology is described by its founder as especially useful when concerned with complexity or process, and as such, it was an ideal choice for these initial research questions related to participant experiences in an IIPT program (Smith & Osborn, 2008). This study achieved the identified purpose of exploring what being engaged in an IIPT program is like as experienced by the participants themselves. Participants shared the suffering that they endured before treatment. The expressed appreciation to be given the opportunity to enter a safe milieu environment and to learn that they were not alone or unique in their experience. This study is an important first step that provides a foundation to future research that continues to explore how therapeutic changes may occur for this population. It is a starting point for future research questions that can be studied both qualitatively and quantitatively.

Further qualitative research would be beneficial to compare and contrast experiences of those identified as responders or non-responders or at action/maintenance vs. pre-contemplative stages. Interviews or focus groups with participants who make significant progress in the stages of change while engaged in an IIPT versus those who do not may be beneficial. Identification of potential catalysts and further study of specific moments when participants decided to dive into treatment or when certain concepts “click in their brains” during treatment would be an interesting area of research. Other research questions amenable to qualitative methodology include parental experiences while their child was living miserably on the edge. Specifically, it would be interesting to explore “a leap of faith” from their perspective and decision-making processes prior to their child being evaluated for the IIPT program. This study was based on data
shared by 14 to 17-year old adolescents; future samples including children ages 10 to 13 or young adults ages 18 to 21 who are engaged in adult chronic pain rehabilitation programs would provide alternative perspectives.

Grounded theory methodology is recommended as a next step to expand on this beginning program of research to further explore questions surrounding particular mechanisms and processes of change before, during, and after participation in an IIPT program. A grounded theory study would allow for inclusion of a larger number of participants, along with parents, staff members, and informed others (e.g. outpatient healthcare providers, teachers, school counselors, or siblings) to facilitate a more comprehensive understanding of these phenomena. It would be interesting to learn more about parental experiences, including changes they have personally experienced, or what they have noticed about their children or family relationships related to the IIPT program. Parental participation is an integral aspect of this program, so research addressing their perspectives or mechanisms of change is imperative. Research focused on each family unit, including sibling perspectives, could be helpful to determine the impact of specific familial or cultural factors.

Mixed method designs combining quantitative measures of functional improvement along with qualitative data could help to discriminate how therapeutic changes may be facilitated. It would be valuable to explore perspectives of those participants who were only approved for inpatient or day treatment to compare/contrast their experiences and treatment outcomes to assess for differences. It may be beneficial to interview participants after discharge (i.e. 3 months, six months, one year) to explore integration of their program experiences into their lives or how their family relationships or interactions may have been impacted. Longitudinal research to examine long-term outcomes (e.g., ongoing physical, psychological,
and social benefits of the IIPT) and how participants apply and implement the changes made as they chart new waters would also be important to study.
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Appendix A

Adolescent Experiences in an Intensive Interdisciplinary Pediatric Chronic Pain Rehabilitation Program

You are invited to participate in this study if you are:
• An adolescent (14-17 years old)
• In day-treatment in the Cleveland Clinic Children’s Hospital Pediatric Pain Rehabilitation Program

PARTICIPATION INVOLVES:
• A 45-60 minute confidential, one-on-one interview
• Convenient interview location at the Cleveland Clinic Children’s Hospital for Rehabilitation
• Convenient interview times during your day treatment programming
• Telling your story about your experiences in the pain program

A $25.00 Target Gift Card will be offered for your time and participation

If you are interested, please contact Judy Risko at xxx.xxx.xxxx.

This is a research dissertation study conducted by Judy Risko, RN, PMHCNS-BC, doctoral student at Kent State University College of Nursing. This study is supervised by Dr. Gerard Banez, PhD at the Cleveland Clinic Children’s Hospital for Rehabilitation.
Appendix B

The Cleveland Clinic Foundation
Consent to Participate in a Research Study

Parent/Guardian Consent Form and Participant’s Assent Form

Parent/Guardian Consent Form and Participant's Assent Form for participation in the research study entitled "Adolescent Experiences in an Intensive Interdisciplinary Pediatric Chronic Pain Rehabilitation Treatment Program”

Funding Source: None.

IRB protocol #: 17-746

Principal investigator:
Dr. Gerard Banez
Contact phone number: xxx-xxx-xxxx

You (representing your child in this document) are being invited to participate in a research study. A research study is designed to answer specific questions about new ways to prevent, detect, and treat disease. Being in a research study is different from being a patient. The purpose of this document is to provide a written summary of the discussion and exchange of research information you had with the research team. It is also for use as a reference during the study.

This study is being conducted by Judy Risko, PMHCNS-BC, a nurse certified in pediatric mental health, in partial fulfillment of her doctoral educational requirements at Kent State University School of Nursing.

Please note:
- You are being asked to participate in a research study
- Ask as many questions as needed so you can make an informed decision.
- Carefully consider the risks, benefits, and alternatives of the research
- Your decision to participate is completely voluntary and will have no effect on the quality of your medical care if you choose not to participate. You can also withdraw from the study at any time.

What is the research about?
You are being asked to participate in a research study to look at what it is like to participate in an intensive interdisciplinary pain treatment program. You are being asked to participate in the study because you have been admitted to the Pediatric Chronic Pain Rehabilitation Program at Cleveland Clinic Children’s Rehabilitation Hospital and might have insight into what it is like to participate in this type of a program. This research could provide helpful information to health care providers who treat adolescents with chronic pain. The study will include between 6-10 adolescents who have also participated in this program.
What will I be doing?

This research study will involve one interview of each adolescent participant that will last approximately 45-60 minutes and will be audio taped to ensure accurate depiction of the results for the researcher. The audiotapes will be transcribed and any references to people or places will be replaced with a fictional name. The tapes and transcriptions will be labeled with a number and not your name. In the event that the interview identifies safety concerns (i.e. suicidal/homicidal thoughts, or abuse/neglect) Dr. Gerard Banez, PhD, or Kristen Buchannan will be notified.

Audio recording disclosure

This research project will include audio recordings of each interview with the participants. These audio recordings will be available to be heard by Judy Risko. The recording will be transcribed by Judy Risko and will be kept for 7 years at Cleveland Clinic, after which it will be destroyed. The de-identified transcribed recordings may be viewed by other members of the study team or the dissertation committee at Kent State University.

Because your voice will be potentially identifiable by anyone who hears the recordings, confidentiality for things you say or do on the recording cannot be guaranteed, although the researcher will try to limit access to the tape as described in this paragraph.

What risks are there for you to participate in this study?

There are no physical risks associated with this study. Some of the questions asked as part of the study, may make you feel uncomfortable. You may refuse to answer any of the questions. You may become stressed, anxious, or tired during the interview. You may take a break or end the interview at any time.

There is a potential loss of confidentiality of your data. Every effort will be made to keep your information confidential through the use of the following safeguards; the recording devices are encrypted, your name will not be used to identify the recordings or the transcriptions, recordings and transcriptions will be stored in a locked office accessible only by the research team.

What good things might come about for you?

There is no direct benefit to you for your participation in this study. The information learned from this study may help develop treatments to help other adolescents who live with chronic pain in the future.

What alternatives are there to participating in this research?

You do not have to participate in this study. Participation in this study will not change the plan of care in the pediatric pain rehabilitation program. Your participation in this study will have no impact on your current or future care at the Cleveland Clinic.
Are there any costs to you if you participate in this study?

There are no costs for you to participate in this study. The cost of your care at the pediatric pain rehabilitation program will be billed to you/your insurance company.

Will I or my child get paid?

You will receive a $25.00 Target Gift Card for your time and participation.

HIPAA Authorization (Privacy and Confidentiality)

Cleveland Clinic has rules and procedures to protect information about you. Federal and State laws also protect your privacy.

The research team working on the study will collect information about you. This includes your health information, data collected for this research study and personal identifying information which may include you or your child's name, address, date of birth and other identifying information.

Generally, only people on the research team will know your identity and that you are in the research study. Program staff will be aware that you have an appointment scheduled with the researcher, so that your child’s presence will be accounted for during the treatment day. Research appointments will only be held during times when other therapies are not scheduled, so as not to interfere with treatment. Sometimes other people at Cleveland Clinic may see or give out your information. These include people who review research studies including the Institutional Review Board and Research Compliance, their staff, lawyers, or other Cleveland Clinic staff.

People outside Cleveland Clinic may need to see your information for this study. Examples include committee members at Kent State University. Cleveland Clinic will do our best to ensure your information is kept confidential and that only the health information which is minimally required to conduct the study is used or disclosed to people outside Cleveland Clinic; however, people outside Cleveland Clinic who receive your information may not be covered by this promise.

You do not have to give this permission to use and give out your information; however you will not be able to participate in this research study without providing this permission by signing this consent form. The use and disclosure of your information has no expiration date. You may cancel your permission to use and disclose your information at any time by notifying the Principal Investigator in writing, Dr. Gerard Banez, PhD, Cleveland Clinic Children's, Hospital for Rehabilitation, 2801 MLK Jr Dr, Cleveland, OH 44104. If you do cancel your permission to use and disclose your information, your participation in this study will end and no further information about you will be collected. Your cancellation would not affect information already collected in the study.
What are your rights as a research participant?

You have the right to refuse to participate or withdraw at any time. If you do withdraw your child, or your child decides not to participate, neither you nor your child will experience any penalty or loss of services that you have a right to receive. If you choose to withdraw your child, or he/she decides to leave, any information collected about your child before the date of withdrawal will be kept in the research records for 36 months from the conclusion of the study and may be used as a part of the research.

If significant new information relating to the study becomes available, which may relate to your willingness to continue to participate, this information will be provided to you by the investigator.

Who do you call if you have any questions or problems?

If any questions or concerns arise during participation in this study, please contact Judy Risko xxx-xxx-xxxx. She can be reached 24 hours per day. Alternately, please contact Dr. Gerard Banez at xxx-xxx-xxxx.

Signatures

Statement of Participant
I have read and have had verbally explained the above information to me, and I have had all my questions answered to my satisfaction. I understand that my child's participation is voluntary and that I may stop his/her participation in the study at any time. Signing this form does not waive any of my legal rights. I understand that a copy of this consent will be provided to me. By signing below, I agree for my son or daughter to take part in this research study.

Permission of Parent/Legal Guardian
You and your child have had the above research study explained to you and your child in language that you and your child can understand, and you give permission for your child’s participation.

______________________________
Parent/Guardian Signature

___________
Date

I have had the above research study explained to me in language I understand and I agree to participate.

______________________________
Printed Name of Child

______________________________
Child Signature

___________
Date
Appendix C

Participant Number ____________

Adolescent Experiences in an Intensive Interdisciplinary Pediatric Chronic Pain Rehabilitation Program

Demographic Form

Age: ___________  Gender: _______________

Ethnicity (select one):

[ ] Hispanic or Latino
[ ] Not Hispanic or Latino

Race (select all that apply):

[ ] American Indian or Alaska Native
[ ] Asian
[ ] Black or African American
[ ] Native Hawaiian or Other Pacific Islander
[ ] White

We live (circle one):  In the Cleveland area  Out of town

How long have you experienced chronic pain? ___________ months

How long have you considered admission to this program? ___________ months

What are you being treated for?

[ ] Headache  [ ] Abdominal Pain  [ ] Arthritis

[ ] Complex Regional Pain Syndrome  [ ] Sickle Cell Disease

[ ] Other: ____________________________________________________________
Appendix D

Adolescent Experiences in an Intensive Interdisciplinary Pediatric Chronic Pain Rehabilitation Program

Interview Schedule

Before the interview, explain to participant that you are interested in learning about their personal experiences. Ensure adolescent of the confidentiality of his/her responses and ask general question “Before we begin, is there anything that you are distressed about right now?” If so, reschedule interview as necessary.

Can you tell me about what led you to this program?

What was it like for you to decide to enter the program?

Could you describe what happens in the program, in your own words?

What is a typical day in the program like for you?

How do feel about the program or being in the program?

What do you think about during a day in the program?

Tell me about a time in the program that stands out in your mind.

Describe a time when you felt the program was especially helpful.

Describe a time when you felt the program was not as helpful.

How do you see yourself now as compared to when you started the program? In what ways, if any, have you personally changed?

What else, if anything, has changed for you? How would you describe these changes?

What advice do you have for other adolescents experiencing chronic pain (or entering a program like this)?

If you had to describe what the program means to you, what would you say? What words or images come to mind?

**Spend time at the end of the interview to debrief the adolescent, address any concerns, or answer any questions. Thank them for their participation.
Appendix E

Sample of notes distributed to subgroup prior to initial subgroup meeting

Initial words and codes

“Not one to cry” i.e.: not like me
Challenging to self-image and previous coping styles (“Pushing” actually may have aggravated condition)
Initial diagnoses and treatments not effective – Not responding
Medical work-up continues - Puzzling symptoms
Family responsibilities for other children – developmental needs of the family
Mother/Father role – working together to meet family and individual child needs
Father put in pool
Intensifying pain, decreasing functioning
“We/Us”
I was used to going… “to become like a couch potato for me was rough”
My mom just decided…
“They got us right in”… response and attention
Drug use and prescriptions – I couldn’t function
My brother was with us too, I felt bad for him… Family impact (scaring sibs/scaring parents)
Missing more school
I couldn’t get down to the ground – “which I can now do…”
I couldn’t handle wearing my socks… I couldn’t handle wearing my shoe, “which I can now do…”
“I was practically worthless” (another participant mentioned feeling “valuable” after program, like a contributing member of society)
I didn’t want this to define me, because I wanted to own it...
Farm work, school, decreased role function and impact on developmentally appropriate goals (school medical program, driving, etc.)
Affecting maturation process, setbacks, losses
Sedated for over a month and a half…
Sleep difficulties (other participants mentioned also)
CRISIS – Lost control of bladder at school “it got to the POINT where…” (said several times)
It kept getting worse
I was done, I was aggravated, I was frustrated… wanted nothing more than for this to disappear, that this never happened (can’t go back)
Deconditioning
Skills in my toolbox
Evaluation – good fit for the program
“We got me in here…”
Insurance
Mom had meltdown ---- we got the answer we had been looking for.
You are set up in a routine
They get you moving (joy)
Ways to help you modify (individualized focus)
Home workout plan
Functioning
Help you with school
Makes it fun too
Learn how to pace ourselves (group)
We’re not overdoing it and knocking ourselves back down
We’re improving each day…instead of falling backwards off a mountain
Athlete – needing to relearn previous ways of doing things
PT
Pool
I’m free in there
Losing the crutches (little increments one at a time – short term goals)
Love the story about throwing the softball with Dad and mom watching
Empowerment
I’m gonna get back to that…I’m gonna be BETTER THAN EVER
I’m gonna be STRONGER AND FIERCER
I was free, I was free, I was in my happy place.
Choked up
Hadn’t done it in so long
Mom smiling, felt awesome, family laughter
I’ve learned how not to force self into my pain…instead listen to my body
Spoon theory
Participant actually taught me what she had learned and applied it to herself.
Losing the crutches
Because I TRIED, TRIED three times (on own)
But here they taught me…(willingness to listen)
Reframing, appreciating small victories
Don’t need to be in the front of the pack.
RT – initially didn’t like, but later acknowledged that ok / started enjoying
Interactions
Other kids – sometimes it’s hard – everyone’s up ahead (comparing with others)
Similarities and differences with peers
I was used to going off to my bedroom (isolated from peers-teasing --- and from siblings)
It was hard, because I wanted to get in , I WANTED to have fun… (in pool at home)
Developed some friendships
It’s easier to respect each other…
We need a pace break, we need a pace break
It brought me my freedom back…to be walking on my own without fear…
More skills
Know how to calm myself down
Moving’s gotten easier…
To be able to sit right now with you… it’s amazing…
I’M HOPING THAT WHAT THEY’re giving me will help me throughout the rest of my life if I
still have to deal with this.
But it’s brought me my freedom…
Staff members – everyone’s supportive, they want to help you progress and help you further on and push you so you can do better and move and have fun
Enhanced awareness (don’t judge a book by its’ cover…
They were rude…kids at school
Tripping me, judging me, faker, faker…they don’t know what I’m going through.
I came in here willing, I came in here with a positive attitude, wanting to do what they were telling me to do…
Wanted – and willing… (said want 10 times in a short period)
I put everything I had into this…and I still am…because I want my life to be back where it was.
Able to do what I used to AND get my license, go to college…
“IT’s A WORK IN PROGRESS” -------
I’m still learning
Advice: Stay positive…people going through much worse, it gets better…you have to put effort in, give it your all…then they will help you to the fullest…
Pace yourself
Keep a smile on your face,
don’t let the bullies bring you down
Just do it…

Idea

Initially transformation – butterfly theme, (SAFE HAVEN) but not exactly
• More of a progressive downhill process (biological, psychological, social) – (some participants quick and sudden / some slow – but kept getting worse and worse ---)
• then CRISIS Stage (mother at Rheumatologist’s office) – REALIZATION
• REFERRAL and RELIEF for some (tears, etc. – described as HOPE
• Investigation/evaluation DECISION with parents (we)– then participant’s agreement to enter this intensive rehabilitation process
• Then Rehabilitation Process --- (input- throughput – output) – then healing and restoration (biological/psychological/social) (IT IS INCREDIBLE WHAT HAS HAPPENED TO ME/ FREEDOM /ETC.)
Appendix F

Sample of notes distributed to subgroup
prior to a subgroup meeting later in the analysis process


Direct Quotes: “IPA’s theoretical underpinnings stem from the phenomenology which originated with Husserl's attempts to construct a philosophical science of consciousness, with hermeneutics (the theory of interpretation), and with symbolic-interactionism, which posits that the meanings an individual ascribes to events are of central concern but are only accessible through an interpretative process… As such, it is especially suited to studies that aim to relate findings to bio-psycho-social theories that dominate current thinking within the healthcare professions” (Smith, 1996; Smith, 2004; Willig, 2001).

Contextual issues and use of IPA – “It is equally important to remember that reports about the content of the clinical encounters, from the healthcare providers’ perspectives only, frequently may not account for the perceptions or “triggers” which lead people to seek care in the first place (Veitch, 1995). These triggers, or cues to action before health consultations, relate to patients’ concerns and expectations (van Dulmen, Fennis, Mokkink, & Bleijenberg, 1996) and are commonly outside the perceptual field of the HCP.” (Biggerstaff & Thompson, 2008, pp. 215-216)

Contemplation

Context / background

Crisis --- The “final thing” – ties in with breaking point (straw that broke the camel’s back AMAZING – when doctor told them about it, she just started crying out of relief that there was hope…

Often parents initiating, researching, etc…but adolescent ultimately had to make decision

Initiation or Introduction

Safe Haven – different from the outside (almost entering into a special place)

“People understand”

Connections with friends and program staff

It’s almost as important, as like, one of the family members or something like that…It’s very beneficial.

Cumulative/additive effect of the whole…the group…

Immersion

“Buying in” maybe this WILL work…

Whole self – working hard and perseverance

Commitment to immerse SELF (not b/c of parents) – may not happen right at admission, comes a point that they independently make this decision

It was hard. I didn’t really want to go at first…mom forcing to go
I REALLY didn’t want to be here.
Questioned some of the recommendations, it’s really up to them. Willing to follow what the experts said. Different than other ways that they had previously defined self, willing to take risks
Willing to accept their reasoning and TRUST the process and the staff/experts

**Adaptation or Accommodation?**
I actually CAN learn to deal with the pain, sense of control…not only learning about pain management, but learning that I CAN learn to deal with the pain…
Take by the hour, one day at a time
Coping skills, did not really learn from staff, but I had just learned from other people describing what they were…I listened to their IFP’s
All of the actual therapies – discussed structure, mind body skills, etc.
Heard other people talking about them, vicarious learning, listening, observing
Choice of what to focus on… and what to allow to affect your body…

Layers, deeper, deeper, opening up, peeling off layers.
Big picture, expanding and taking it down to the smaller view…seeing the big picture, but also having to focus on one thing at a time…having an awareness of both simultaneously…
*My childhood was kind of roughish, really rough, and I was so focused on my pain that I didn’t really see the whole picture about my past and what’s going right now… Now that I’m kind of getting that under control and now I feel like my emotions and thoughts are the main things that are holding me back from doing the things I want…*

**Restoration**
Regaining function
Walking again / being more active, “getting their life back”
Acceptance of self and circumstances
Shaving legs (CRPS)
Playing ball
Sleeping
Etc.

**Transformation**
When I came here three weeks ago, I feel like I was a completely different person…I think that every single thing that I’ve done here has contributed to my betterment…
More motivated and feeling like – “I don’t have to rely on anyone else. I can rely on myself now…”
I used to play things over in my mind more, now I’m just moving forward. Because when I can’t do something I can’t and there’s no reason to stress about…
What if this, what if that…that’s not going to help anyways, and so to think about what I actually can do…
More stamina, more social
I’ve learned to open up a little bit more too…

Every person can take a lot more than they think they can…
People don’t usually realize how strong they can be…

**Miscellaneous thoughts/ideas**

‘Wanting to be “normal”
  - Field trip
  - School