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Parental experiences related to pediatric and adolescent chronic non-cancer pain: A qualitative exploration

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ABSTRACT

Purpose: To explore parental experiences in personal functioning and parenting associated with having a child experiencing chronic non-cancer pain.

Methods: Parents with children experiencing chronic pain were asked to fill out a survey prior to their initial Pediatric Pain Clinic or Pain Psychology appointment at a children's hospital in the southeastern United States. A retrospective analysis of qualitative data was conducted. Qualitative results from open-ended survey questions will be focused on within this manuscript.

Findings: A total of 288 surveys were collected in this study, with 243 participants answering at least one qualitative question. Of participants who responded to open-ended survey questions, there were 88 responses to a question related to parental change, 73 to parental impact, and 239 to goals of the visit. Through thematic analysis, five qualitative themes were identified: Pain Central: The Hub, Juggling Life, Suffering Side by Side, Unrealized Dreams, and Gettin' it Under Control.

Discussion: Parents do experience alterations in personal functioning and parenting as a result of having a child that experiences chronic non-cancer pain. Parents face struggles in many aspects of life including emotions, work, and interpersonal relationships. Theoretical considerations were discussed.

Application to practice: Understanding the experiences parents have in raising a child with chronic pain is important in helping health care providers to recognize that this population may need interventions. This also assists in informing patient treatment, improving patient and parent care outcomes, and educating clinicians on how to better support parents.

Introduction

Pediatric and adolescent chronic non-cancer pain (PCNCP) is a global problem that is estimated to impact between 11% to 38% of the pediatric population around the world (Liossi & Howard, 2016). In the pediatric population, chronic pain is defined as pain lasting longer than three months or the typical healing period that would normally be expected (Friedrichsdorf et al., 2016). PCNCP causes a variety of disruptions within a child's life that impact school, social functioning, physical activity, mood, and overall quality of life (Rostami et al., 2019). Literature examining the experience of children with PCNCP has described impact and impairment through themes including: isolation, changed self-perception, activity limitations, and fears of pain not going away or not being able to reach a future goal (Fales et al., 2018; Fisher et al., 2018; Murray et al., 2020). While research commonly highlights the effects of PCNCP on the child, PCNCP can also impact their entire family or support system (Wilson & Fales, 2015).

Parents of children dealing with PCNCP often experience changes in tasks associated with parenting due to their child's pain (Wilson & Fales, 2015). Parenting in this sense refers to the role of raising a child and does not necessarily mean a biological relation. Having a child with PCNCP often requires parents to accompany their child to appointments and visit various professionals to find pain relief for their child. This adds to the many obligations parents are already balancing. Parents may frequently take time away from work or other responsibilities to ensure their child receives the best care possible or provide additional support during pain flare-ups (Wilson & Fales, 2015). Time away from work can cause changes in income and employment status, leading to financial strain on the family. Consistent with this thought, socio-economic troubles have been commonly found in parents of children with PCNCP

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(Sieberg et al., 2017). Given these potential strains, it is understandable that PCNCP has been found to put a great emotional stress on parents (Smith et al., 2015).

All of these experiences can impact or change a parent's personal functioning. According to the Finnish Institute for Health and Welfare, personal functioning references an individual's physical, psychological, and social ability to cope and manage day-to-day life Finnish Institute for Health and Welfare (THL), Finland (2021). The numerous changes associated with PCNCP may create obstacles that could potentially alter parents' personal functioning.

When considering how parents of children with PCNCP respond to their situation, they have been found to either have a distress or resilience narrative (Noel et al., 2016). Narratives describe an individual's experience in dealing with a situation, which can create a story. In the context of PCNCP, distress narratives describe when parents experience more negative and unresolved feelings, while resilience narratives depict more positive and resolved feeling in relation to their child's pain diagnosis. Understanding these narratives in parents of children with PCNCP is important given that parents' responses can greatly influence their child's perception of pain (Wilson & Fales, 2015).

While qualitative studies have been conducted regarding narratives of the children dealing with PCNCP (Fisher et al., 2018), there has been limited research exploring specific parental perspectives on how chronic pain affects them and their families. One qualitative study examined the experience of 13 parents of children with PCNCP and found three general themes of having an emotional journey, pain impacting the whole family, and that social support is important (Le et al., 2019). While this research provides a helpful start in understanding the experiences of parents of children with PCNCP, research using larger samples is necessary to more fully understand parent experiences, inform clinical treatment options, and develop resources for these individuals.

The current study aims to further explore the experiences of parents with a child dealing with PCNCP. Specifically, this study focuses on how having a child with PCNCP impacts a parent's own personal functioning as well as their parenting. Qualitative analysis was used to allow functional impairments and the most difficult aspects of parenting a child with PCNCP to come to light.

Methods

Participants

Two hundred eighty-eight participants completed a study survey, developed by a pediatric pain psychologist, that included both qualitative and quantitative questions. The survey was intended to better understand the experiences of parents of a child experiencing PCNCP and better identify goals for their first visit. There were 211 pre-appointment surveys collected through a Pediatric Pain clinic, while the remaining 77 were collected through a Pain Psychology office. Of the 288 participants, 243 (84%) responded to at least one of three qualitative questions. Surveys were collected over a two-year period. Parental demographics, based on the total number of survey responses, include race, marital status, gender, and insurance type (see Tables 1–4).

Table 1
Parent demographics: race.

Race	Number of Total Participants	Percentage of Total Participants
White	209	72.5%
Latino	48	16.7%
Black	25	8.9%
Middle Eastern	4	1.4%
AIANA	2	<1%

Table 2
Parent demographics: marital status.

Marital Status	Number of Total Participants	Percentage of Total Participants
Married	186	64.6%
Single/Divorced	102	35.4%

Table 3
Parent demographics: parental gender.

Parental Gender	Number of Total Participants	Percentage of Total Participants
Female	267	92.7%
Male	21	7.3%

Table 4
Parent demographics: insurance type.

Insurance Type	Number of Total Participants	Percentage of Total Participants
Private	144	50%
Public	144	50%

Measures

For this study, three open ended questions were selected from the larger survey. The larger survey contained both qualitative and quantitative questions, however only the data from the qualitative questions (243 responses) were reviewed for this study. Qualitative questions elicited written responses from parents regarding their experiences. Qualitative survey questions were written in English and included: parental change, parental impact, and goals/expectations from their first appointment. The first two asked participants to select all that apply and provided the option to elaborate, while the third question was fully open ended (See Table 5).

Procedures

Institutional Review Board approval at the hospital conducting the survey, as well as the college affiliated with the authors, was secured prior to study initiation. Survey collection was conducted in an academic children's hospital within the southeastern United States. All families scheduled for chronic pain intake evaluations at the hospital's Pediatric Pain Clinic or Pain Psychology office were asked to complete an online survey as part of routine clinical care, prior to their initial appointment. Signed consent and assent were obtained from parents and children prior to completion of the pre-appointment survey. Only completed surveys with signed consents authorizing research were included within this study. Additional inclusion criteria included, participants being able to read and write in English (due to the survey being in English) and having an appointment with a professional in Pediatric Pain Clinic or Pain Psychology office.

Data analysis

Analysis of qualitative data was conducted by a team of three researchers. The goal was to explore common themes that captured the experience and impact of parenting a child with PCNCP. Thematic analysis of qualitative data was conducted following the six steps described by Braun and Clarke (2006) (See Table 6).

Trustworthiness

The three researchers who analyzed data within this study have a background in nursing; however, were not employed at the

Table 5
Qualitative questions.

Question #	Topic	Question	Answer Options	Total Number of Free-Text Responses
Question 1	Parent Change (Select all that apply with option to elaborate)	Have you done any of the following due to management of your child's pain?	1. Changed jobs 2. Quit jobs 3. Reduced hours at work 4. N/A (no change) 5. Please explain	88
Question 2	Parent Impact (Select all that apply with option to elaborate)	How else has management of your child's pain impacted you?	1. Change in daily schedule 2. Less time for self-care 3. Marital struggles 4. Financial difficulties 5. Less time spent with patient's siblings 6. Changes in mood 7. Please explain	73
Question 3	Goals (Open ended)	What are your goals/expectations from this first clinic visit?		239

243 participants answered at least one qualitative question of the three.

settings institution and did not provide any professional nursing care to participants in this study. Two of the researchers were Advanced Practice Registered Nurses (APRN's), who were doctorally prepared and have previous experience with conducting qualitative research. The third researcher was a BSN honors student, who worked closely alongside the APRNs. The literature was purposely not reviewed in advance of analysis to prevent unintentional influence on the findings. Final themes were confirmed via expert examination by a pain psychologist who felt each theme was applicable and relatable to the parents of patients he treats in clinical practice (Cope, 2014).

Findings

Parents who completed the survey reported having children whose ages ranged from three to twenty years old, with the mean being 13.03 years old. Of the total 288 survey responses, 243 participants answered at least one of the three qualitative questions. There were 88 responses to the open-ended question related to parental changes, 73 answers to parental impacts, and 239 descriptions of goals for their first visit.

Five themes emerged from the data that summarize the experiences parents faced in their own functioning as well as in parenting their child diagnosed with chronic pain. These were: Pain Central: The Hub, Juggling Life, Suffering Side by Side, Unrealized Dreams, and Gettin' it Under Control.

Table 6
Steps of thematic analysis according to Braun & Clarke, 2006 and actions of authors.

Phase Number	Description of Phase	Actions of Authors
1	Familiarizing yourself with your data	Each of the three researchers independently reviewed all data multiple times.
2	Generating initial codes	Each researcher independently coded all data.
3	Searching for themes	The three researchers shared and discussed their independent codes. Themes emerged based on similarities in independent coding.
4	Reviewing themes	The three researchers independently reviewed data to confirm the emerging themes and to identify any that were missed.
5	Defining and naming themes	Five encompassing themes were identified and named. Exemplar quotes were selected to reflect each of the themes.
6	Producing the Report	Themes were supported by an expert in the field and a manuscript was developed.

Pain central: The hub

Many parents described feeling that their child and their child's pain is the main focus of their lives. Everything and everyone are impacted, requiring them to revolve around the pain. As a wheel revolves around a hub, the families' lives were described as revolving around the child's pain.

There are numerous scheduled or planned tasks and events in dealing with chronic pain. Unfortunately, participants reported there are just as many, if not more, that are unexpected. For instance, parents described difficulties such as needing to be available to be with their child for multiple missed school days or the various clinical appointments they need to attend. Parents stated, "*My life revolves around her schedule of school and medical appts*" and "*My entire life is completely about helping her manage her life.*" Due to the focus on the child's pain, parents described experiencing a lack of control over their own lives.

Parents also expressed feeling that their child's pain impacts everyone in the family. One parent described this impact with her daughter's pain, stating "*When things are bad for her, they are bad for everyone because we are aware of how she suffers, and it affects us.*" Another parent explained that their child's pain required a lot of individualized attention, which lead to negative familial impacts, "*Other children feel it's unfair how they are treated differently, less time for them, and the whole family has to leave fun activities or limit activities.*"

Juggling life

The theme "juggling life" emerged, based on the idea that parents must often rearrange various aspects of daily life for their family to function. Parents explained they have work, appointments, school absences, and other family members to manage. In regard to work being impacted, a parent stated, "*At one point, I had to quit my job thus cutting our household income in half. Now, even though I am back to work, my husband can't work as much so he can be available for son's multiple appointments.*" Parents depicted that they are forced to be on edge and flexible in order to accommodate their child's needs. One participant stated, "*You are trying to juggle your children, their health, and their schooling.*" They explained the heavy burden they must carry as a result of prioritizing some tasks over other things.

Parents discussed how life is made up of many different moving parts and their child's pain adds additional challenges, impacting their lives. They described not being able to plan too far in advance due to the unexpected nature of pain. One parent wrote that one of their biggest challenges was being "*unable to plan anything.*" This inability to plan was reported to have consequences including families needing contingency plans in place and resources available in order to make unexpected adjustments if their child has a pain flare. One parent termed this struggle as having to "*piece things together*". Specifically, this parent referenced needing a combination of aides in order to care for their family (e.g., other family members, Paid Time Off (PTO), the Family Medical Leave Act (FMLA), unpaid leave, and changing or quitting jobs).

Juggling life is a mechanism that that parents described as a way to manage the changing of the priority of tasks, people, or life events as a result of PCNCP. A quote that illustrated this theme is, "*Everything and everyone gets put on the back burner while we navigate the newest hurdle.*" Parents mentioned how priorities must continuously shift and the entire family unit needs to adapt at a moment's notice.

Suffering side by side

The theme suffering side by side arose from parents' experiences of taking or wanting to take on the burden and pain their child is experiencing and how that impacted their lives. One respondent stated, "*A parent would take all the pain from their child if they could, and thus suffers side by side with the child.*" Parents are with the child daily, seeing the impact and restrictions pain has inflicted on their child.

Given this ever-present effect of pain on their child's life, participants reported they experienced both a physiological and psychological impact. Consistent with reported changes and unpredicted disruptions pain brings to the family life, one participant reported, "*It's just exhausting, not so much the pain, but everything associated with it too.*" Stress, anxiety, and worry were also concepts repeated throughout the open-ended responses. Parents reported placing pressure on themselves to provide their child the best possible life and care, which has been amplified while parenting a child with PCNCP. Parents stated, "*I ended up having a psychological breakdown… and I feel it was brought on due to the stress of her health*" and "*The increase in her pain and multiple diagnoses have caused a lot of strain on us all*", which highlight their suffering alongside their child.

Unrealized dreams

Within the responses, there were many descriptions of how parents or other family members had to put off their own dreams as a result of the child's pain. One parent wrote, "*My eldest has put off college and employment so that his brother is not left alone.*" The family unit decided what the priority had to be in this situation, ultimately impacting the older sibling's plans and goals.

Within this theme, many parents responded feeling unable to be the parent they envisioned. One parent stated, "*You second guess yourself and your choices all the time.*" Another participant described how their daughter's difficulty with PCNCP has changed how they want to be viewed as a parent, "*She thinks I have given up on her and has said so, because no one can help, and nothing shows up on tests.*" Parents reported struggling with seeing their child suffering, while feeling unable to help or be the parent who resolves the pain. One parent stated, "*There is stress with the idea of watching your child in pain and you can't do anything about it.*". Within this idea, parents also begin to consider the possibility that their child may not achieve their dreams and ultimately face emotional distress. A parent wrote, "*There is so much she tries to accomplish but her chronic pain prevents her from achieving her goals.*" Many parents reported concern about their child's future and what may be realistic or attainable goals.

Gettin' it under control

The final theme found in the data encompassed parents' desires for knowledge and definitive answers regarding the cause for their child's pain. One participant described their goal as, "*Trying to get to the bottom of the pain issues! No one we have seen has been able to give us any answers as to why she is having all these pains and episodes.*" These parents emphasized wanting new treatment options, given many had already been evaluated by several providers and attempted many treatment recommendations. Consistent with these reports, parents discussed the need for novel approaches and long-term solutions. A parent commented that they wanted, "*To create a fool-proof plan that does more than simply putting bandages over her.*"

Along with long-term solutions, parents reported longing for a sense of normalcy to return to their family. Throughout participant responses, parents communicated their need for help in fixing their children's' pain and assisting them in returning to regular activities. A parent wrote, "*I hope that someone may be able to shine some light on what the problem is and have a solution for her to get her life back.*" While parents described concerns regarding the impact of pain, they also mentioned feelings of hope, happiness, and empowerment because they were seeking new treatment. Ultimately this theme embraces parents' desire for their children to receive treatment, as well as their hope that pain can be managed, and their child can improve their quality of life in the future.

Discussion

Findings from this study highlight the experience of having a child with PCNCP and its effect on daily life. Parents depicted their own personal narratives and difficulties throughout their qualitative responses. They reported facing numerous challenges in their personal functioning, as well as parenting a child with PCNCP.

Parent responses throughout this study voiced the desire for their children and family to return to a state of normalcy, following discussion of ways life has been impacted. Goals such as having children return to school or participate in activity were often discussed. These goals for improved functioning were frequently described in parents' desires for their children and are consistent with literature describing functional improvement as the primary goal of pain management (Govenden & Serpell, 2014).

Some themes previously described in the literature regarding the experiences and impacts of PCNCP in children (Fales et al., 2018; Fisher et al., 2018; Le et al., 2019; Murray et al., 2020) appear applicable to parents as well. Specifically, data collected within this study supports the idea that themes such as changed self-perception, activity limitations, not being able to reach future goals, emotional journey, whole family impacts, and the need for social support extend to the experiences and concerns of parents. When shifting from caring for a child who had few medical concerns to having one experiencing PCNCP, parents are required to evolve and modify their own lifestyle to meet their child's changing needs. This was specifically seen in parents talking about needing to "juggle life" and having difficulty planning for the future due to the unpredictability of symptoms and prognosis. Parents have to reevaluate and must shift their priorities and goals to ensure their family unit is able to function as effectively as possible.

While not experiencing the same activity limitations as their children, parents of children with PCNCP reported difficulty continuing their own lifestyle and activities in the same capacity. Many parents discussed changes to work and social interactions as a result of needing to accommodate their child's PCNCP. Social support is a necessity in order to "juggle life" effectively. Parents described feelings that they or their loved ones may not reach a future goal, highlighting how the whole family is impacted. College, career advancements, job opportunities. and promotions were all dreams that had to be put on hold for some of these families, with no set plans for accomplishing those aspirations.

Wilson and Fales (2015) found that parents often take time away from work or other obligations for their child to receive necessary care. This idea was mentioned throughout the parental narratives in this study and the themes of Juggling Life and Suffering Side by Side emerged based upon this notion. Parents must often change or create new priorities in order to prioritize their child's care. Additionally, they may need to create plans and utilize supports and aids to balance care for their child with PCNCP with their occupation and needs of other family members. These changes parents have made are important to recognize in order to assist them in finding proper support to cope with shifts in lifestyle.

Financial struggles were found to be a prominent topic in the literature (Sieberg et al., 2017); however, within the qualitative findings of this study there were no mentions of this problem. While it is likely that finances changed due to reported changes and reductions in work due to caring for a child with PCNCP, parents in this study may have found ways to accommodate their workload that did not drastically change the family's income. They may have also felt there were more pressing issues related to their child's experience, causing their own financial struggles to be overlooked or suppressed. Another potential explanation is that parents may not have felt comfortable in sharing financial struggles within this survey.

Theoretical considerations

Theory is a valuable lens through which nurses and other interdisciplinary team members can assess, conceptualize, plan and deliver effective healthcare to patients and families. A theoretical framework was intentionally not selected in advance of this study to allow the parents' narratives to emerge without influence; however, several existing theories and models are applicable and supported by the findings.

Systems theories

Biopsychosocial model (BPM). The BPM developed out of an appreciation for the multiple factors involved in the experience of illness and encompasses much more than only the physical aspect. This model was first introduced by Engel (1977, 1980), whose training was in psychiatry and medicine. It includes the facets of biological, psychological, social, and other environmental factors that are interrelated and involved with the experience of illness, pain, and disability (Gatchel et al., 2007). The family is included within this model. Many current treatments for PCNCP are based upon the BPM and involve an approach that includes medicine, psychology, nursing, physical and occupational therapy. Intensive interdisciplinary pain rehabilitation (IIPT), where treatment is delivered within a collaborative team approach, has been found to be an effective treatment for children and adolescents with significant disability related to PCNCP (Harrison et al., 2019).

Family Systems Theory (FST). Family systems theorists view each individual family member to be interdependent. Each exists as a unique system composed of other subsystems, such as each's own internal biological and psychological makeup. While every member is an individual and possesses some wholeness and complexity in and of themselves, they are also connected to the larger family system in which the behavior of each has impact on all the others. Every family member is part of a larger whole and in turn, the family exists as a subsystem within larger systems, such as extended family, a neighborhood, place of worship, or community. Systems have the capacity to change and adapt, and typically strive for homeostasis (Bowen, 1966; Newton-John, 2022).

The BPM and FST are reflected in several of the themes expressed by the parents in this study. In Pain Central: The Hub, all members are described as interconnected to one another and to the chronic pain itself. The entire system is affected by the experiences and consequences of the child's pain. The theme of Juggling Life also captures the essence of these ideas. The family system is required to juggle schedules and priorities based on what is happening in the moment. The interdependence of the family subsystem within larger outside systems such as school and parental employment is discussed by the parents. Like a mobile, all members of the family are affected by any movement and all need to work together to adapt on a moment's notice. In addition, the themes of Suffering Side by Side and Unrealized Dreams illustrate how each family member's emotions, well-being, and even life trajectory may be affected by another's.

Chronic sorrow

The Middle-Range Nursing Theory of Chronic Sorrow describes the normal, adaptive feelings of sadness or grief associated with loss that may be the result of a single occurrence or an ongoing experience. It is different than grief, which has an identified endpoint (Eakes et al., 1998). The concept of chronic sorrow was first introduced in 1962 by Olshansky and initially described having a child with a mental disability (Olshansky, 1962). The experience of chronic sorrow has since been expanded and studied in relationship to many types of illnesses and populations. A Nursing Consortium for Research on Chronic Sorrow was formed in the early 1990s and still exists to facilitate further investigation into this important concept (Lindgren et al., 1992). Chronic sorrow may affect the individual experiencing the illness and those affected by it, such as caregivers and parents experiencing the loss of the expected or "perfect" child that they had envisioned (Batchelor & Duke, 2019; Coughlin & Sethares, 2017; Eakes et al., 1998; Lindgren et al., 1992).

In the current study, similar experiences and emotions were found in the themes of Suffering Side by Side and Unrealized Dreams. Parents described how difficult it was to recognize that their child's current life, and potentially their future, may be different than expected or hoped. In addition, all other family members' goals may not come to fruition as planned. Parents experienced stress, anxiety, and worry in relationship to parenting their child with PCNP. All these factors contribute to the experience of chronic sorrow within this population.

Adaptation models. Roy's Adaptation Model, and a later model based on Roy's work, the Middle Range Theory of the Adapting Family, have been used to research and describe the experience of individuals and families living with chronic illness (Butt, 2020; Diaz & da Cruz, 2018; Hayden & Buckner, 2014; Roy, 2009). With foundations in systems theory, these models also recognize the continuous interaction between an individual and their environment and the capacity of a system to change and adapt over time. Important concepts in these theories include focal and contextual stimuli, coping processes which include regulatory and cognitive-emotional components and four adaptive modes: physiological function, self-concept, role function, and interdependence. The goals or desired outcomes of these models include maintenance of healthy behaviors and positive adaptation to stressors that will lead to growth, coherence, and transformation within the individual or family system.

Adaptation to the child's PCNCP is reflected in the themes of Juggling Life and Gettin' It Under Control. Parents in this study described the continuous need to adapt to unexpected stimuli and to cope with both sudden and ongoing circumstances. Parents discussed the impact of the child's pain on their own self-concept and their ability to manage the various roles that they have. Ultimately, many parents described an openness and desire for new treatment approaches. They expressed hope for their child's healing and for positive influences on their child's well-being and future.

Practice implications

Findings highlight the impact of having a child diagnosed with PCNCP on parental functioning as well as challenges they faced in parenting. It is imperative to understand what parents in this situation experience in order to recognize their potential struggles and to provide them the best possible care and resources along with their child. The results of this study can guide clinicians and nursing staff in creating treatment plans to address the unmet needs of this population. Plans that focus on teaching parents effective coping strategies and providing guidance and support on their current situation may be helpful. Understanding parent narratives and their experiences with parenting a child with PCNCP can encourage practitioners to use a holistic conceptualization of the family-wide impact of PCNCP and consider how parents may be suffering along with the patient. Clinicians may also share these findings with parents of other patients they treat for PCNCP to validate and normalize their experiences. It is difficult to parent a child with chronic pain, so understanding and knowing that there are others with similar feelings may provide a sense of comfort and normalcy.

Research implications

The participants in this study were mainly represented by female, white, and married individuals. This research identified that more information is needed related to fathers, single-parents, and among more culturally diverse populations. Additional qualitative studies, based on this research, would be helpful to determine parent perceptions across different types of clinical and community settings to determine if similar parent narratives are found. Utilizing longitudinal research methodology to follow participants over several years would be beneficial to see how parental experiences and needs change over time. Further, conducting studies with a focus on the developmental stages of both the child and the family would provide more specific insight. Providers may consider generating interventions to support parents who are struggling with changes in life, difficulty coping, or overall parenting of youth with PCNCP. Narratives from this study could be incorporated in guiding topics that parent-based interventions could address. Parents of children with PCNCP deserve to have informed care, along with their child, that fits their situation and needs. This study sought to identify common feelings and experiences to inform the best care possible.

Limitations

This study assesses parent perceptions of how having a child with PCNCP has impacted their own personal functioning and what challenges they faced in parenting. This study is limited by collecting data from one hospital system and recruiting only a clinical and treatment-seeking sample, which may be representative of higher patient and family impairment. These factors may limit generalizability of the results; however, these findings still provide a glance into what parents of children with PCNCP may experience. The large sample size of participants ($n = 243$) in the qualitative aspect of this study helped to address concerns of generalizability and allowed for discovery of additional themes that support and add to those found in the literature. Additionally, the treatment-seeking nature of participants increases their likelihood of providing accurate information on the survey, given the survey's role as part of their child's clinical care. Due to the online survey format of the study, researchers were not able to engage in an in-depth exploration of narratives with the parents. To assist with this concern and improve contextual understanding, the student researcher spent two clinical days doing on-site observation of initial evaluations with the parents in the Pain Clinic, and a pain psychologist assisted with thematic development.

Conclusion

Qualitative statements collected from parental data within pre-appointment surveys identified how parenting a child with PCNCP has impacted them. Five themes emerged in this study, which highlight shared experiences including: familial strain, work and schedule impacts, physiological/psychological impacts, dream and goal impacts, and hopes of a return to normalcy. Findings reflected and supported several existing theories and models.

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Ethic approval

Study procedures were reviewed and approved by both the first and second authors' Institutional Review Board.

Consent to participate

All participants agreed to participate.

Consent for publication

The authors affirm that human research participants provided informed consent for publication.

Availability of data and material

Not applicable.

Code availability

Not applicable.

Author's contributions

Dr. Frye contributed to the conception of the work, data collection, critical revisions of the article, and final approval of the version to be published. Ms. Cole, and Drs. Risko and Hall contributed to the conception of the work, data analysis and interpretation, drafting the article, critical revisions of the article and final approval of the version to be published.

Declaration of Competing Interest

We wish to state that there are no known conflicts of interest in association with this publication and there has been no financial support for this work that could have influenced its outcome.

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