



Exploring the Needs of Parents with a Child with Chronic Pain: A Qualitative Secondary Analysis

Dominique Lefebvre¹, BScN-Hon., RN; Anne Le¹, Research Project Coordinator; Dr. Jude Spiers¹, PhD, RN, Associate Professor, BScN Honours Program Coordinator; Dr. Shannon D. Scott¹, PhD, RN, Professor, Canada Research Chair for KT in Child Health, Distinguished Researcher, Stollery Children's Hospital Foundation

¹Faculty of Nursing, University of Alberta, Edmonton Alberta, T6G 1C9, Canada

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Corresponding author: Dominique Lefebvre, BScN-Hon., RN: dllefebv@ualberta.ca

Abstract

Background: Pediatric chronic pain affects 15-39% of children and their families, yet it remains under-recognized and undertreated by clinicians. Despite increasing numbers of children diagnosed with chronic pain, few qualitative studies have explored the experiences and needs of these families. **Methods:** A secondary analysis of 13 semi-structured interviews was conducted using a qualitative descriptive approach. These interviews featured parents of children attending a large children's hospital in a major urban city in western Canada. Data was analyzed in three phases: coding, categorizing, and developing themes. **Results:** Four distinct parental needs were identified: increased awareness about pediatric chronic pain, faster access to care, validation of their child's pain, and healthcare supports throughout their journey. These themes interplayed throughout the data and shaped parents' ability to access appropriate care and supports for their child with chronic pain. **Conclusion:** Unique challenges prevent parents from accessing timely care for their child with chronic pain. Increasing awareness about pediatric chronic pain can help parents gain validation for their child's pain and result in faster access to care. Our findings highlight how parents with a child with chronic pain would benefit from additional supports to help them navigate the healthcare system.

Keywords: secondary analysis, qualitative descriptions & interviews, chronic pain, pediatrics.

Introduction

Pediatric chronic pain refers to pain that lasts longer than 3-6 months. It affects 15-39% of children and can play a detrimental role in the lives of the children and families affected (American Society of Pain, 2012; Palermo, Valrie, & Karlson, 2014). The patient population is diverse, experiencing pain as a result of an injury, a chronic disease process, or without cause (Palermo et al., 2014). Chronic pain can cause high levels of emotional distress, and can lead to impairment in physical, social, and family functioning (Jordan, Eccleston, & Osborn, 2007). Pediatric chronic pain is often under-treated by clinicians (Reid et al., 2017). Previous studies have identified that challenges exist in available resources for parents seeking information on the causes and treatments for their child's pain (Reid, Lander, Scott, & Dick, 2010). This need for evidenced-based information is due to the novelty of clinical practice in pediatric chronic pain, the lack of specialized pediatric chronic pain clinics as well as the overall shortage in resources for parents (Reid et al., 2017). As a result, the purpose of this research study was to increase public and researcher knowledge about the unique needs of parents with children with chronic pain.

Background

Pediatric chronic pain is a relatively new area of research that has gained attention in clinical care during the past decade (Noel et al., 2016). Although quantitative studies exist on the topic, they fail to capture the essence of the emotional and psychological burden experienced by parents with children living with chronic pain (Reid et al., 2017). These missing pieces warrant a needed shift towards qualitative approaches in order to map the experiences of families with children with chronic pain (Eccleston et al., 2004; Noel et al., 2016). Qualitative research in the field of pediatric chronic pain can help researchers gain a greater understanding of the experiences of families and enable them to identify gaps in knowledge, trends in emotional and psychological stressors, as well as the needed resources for these parents (Jordan et al., 2007).

Hopelessness, frustration, and disempowerment are common descriptions used by parents to illuminate their experiences (Jordan et al., 2016; Noel et al., 2016; Reid et al., 2017). Researchers have identified consistent ideas in the parents' reported emotional distress, frustration in their inability to alleviate pain, and feelings of helplessness with their child's chronic pain diagnosis (Jordan et al., 2016; Maciver, Jones & Nicol, 2010). Past research has also identified that parents are more vulnerable to feelings of stress, depression, and anxiety related to their child's chronic pain diagnosis (Noel et al., 2016). These studies also identified a significant impact on social, psychological and physical functioning of the family unit, as well as the children affected (Roth-Isigkeit, Thyen, Stöven, Schwarzenberger & Schmucker, 2005).

The lack of qualitative literature creates a gap in the understanding of the parent experience. There is a need to gather parent narratives to understand the experience of raising a child with chronic pain, to discover the patients and families' needs from the healthcare team, and to help close the gaps in their care. Understanding their needs can inform current practice and enable further improvement in family-centered approaches in supporting families with children living with chronic pain.

Methods

This study was a secondary analysis of a larger dataset. The Evidence in Child Health to enhance Outcomes (ECHO) research team collected data from 13 parent interviews to create an e-book for parents, exploring the experiences of parents who have children with chronic pain (Reid et al., 2017; Le, Dick, Spiers, Reid, & Scott, 2019). This e-book described parent experiences, increased public knowledge about pediatric chronic pain, and gave pertinent information for the management of pediatric chronic pain to affected parents and families (Reid et al., 2017). Two manuscripts were developed from this dataset. While Le et al. (2019) explored the emotional journey for the parents, the effect of chronic pain on the entire family function, as well as the exceptional need for social supports, this article focuses on the overall needs of parents with children with chronic pain.

Qualitative secondary analyses allow for both a cost and a time-effective approach to further explore the experience of participants by drawing new findings from existing qualitative datasets (Ziebland & Hunt, 2014; Tate & Happ, 2018). Practical advantages to conducting secondary data analyses include maximizing the use of existing data and decreasing the burden of additional requests on research participants (Long-Sutehall, Sque, & Addington-Hall, 2012; LoBindo-Wood, Haber, & Singh, 2013; Tate & Happ, 2018). Additionally, secondary data can increase scientific integrity through the repeated analytical process (Davis-Kean, Jager, & Maslowsky, 2015). Several strategies were used to surmount the challenges of secondary analysis. We worked directly with the research team from the primary study, which reduced the risk of potential conflict over data ownership and interpretation (Parry & Maunthner 2005; Heaton, 2008; Tate & Happ, 2018). Additionally, personal identifiers from the study participants were removed during the transcription process of the primary study, therefore confidentiality of the participants continued to be protected. Finally, our dataset was composed of semi-structured interviews which provided flexibility to re-use the data to examine a new research question (Heaton, 2008).

Sample & Setting

Parents of children with chronic pain were recruited from a Chronic Pain Clinic at a large children's hospital for the primary study over an 11-month period. Recruitment strategies included posters in waiting room areas and information letters handed out by the clinic staff. The inclusion criteria included the ability to speak English and having a child under the age of 18 with chronic pain. The primary study's interviews took place at the children's hospital where participants were recruited (Reid et al., 2017). Please note that the parents recruited in this study were part of a larger sample. The 13 parents included in this study are coded in the findings using numbers which do not correspond to the total number of included participants, but simply to their assigned study number. For example, Parent 17 is included as a participant as one of the 13 total participants in the sample.

Data Collection

Data were collected from 13 semi-structured qualitative interviews conducted by the ECHO research team. The domains explored in the original interviews included: the effects of having a child with chronic pain on family life, social life/vacations, work schedules; feelings regarding the diagnosis; expenses associated with having a child with chronic pain; experiences with the chronic pain clinic/health professionals involved; and parents' hopes or wishes (Reid et

al., 2017). All identifiers were removed during the verbatim transcription process, and the interviews were cleaned prior to the first set of coding (Reid et al., 2017). NVIVO 12 (QSR International Pty Ltd. Version 11, 2015) was used to manage data analysis.

Data Analysis

Qualitative description was chosen as an appropriate method because it facilitates a flexible, multi-faceted, and low inference analysis which is suitable to holistically explore the phenomenon of chronic pain for children and their families (Kim, Sack, & Brad way, 2017; Sandelowski, 2010). The thematic data analysis process followed three phases: coding, categorizing, and developing themes (Hsieh & Shannon, 2005). Interview data were coded using a key word that reflected the content. Iteratively, these codes were combined into categories. Theoretical properties of these emerging categories were provisionally defined in order to differentiate them within broader themes. NVIVO 12's capacity to compare data was used to code, retrieve, and analyze interview excerpts using identified categories, and the analyst created themes, which provided a holistic view of the dataset.

Rigor

We followed the recommendations of Ruggiano and Perry (2019) in ensuring rigor in this secondary analysis study. The research team confirmed the primary data set met the needs of the secondary data analysis study. The time between the primary study and the current study can introduce the possibility that time, or context has changed the relevance of the data, however, the primary study research team, consisting of clinicians, parents, and researchers perceived the structural conditions had not shifted in any meaningful manner. The analyst [DL] completed coding with assistance from the project coordinator, [AL] and the primary investigator, [SS] to ensure ongoing clarification of data, validation of appropriate interpretation, analytic consensus, and rigor. Records of analytic decisions, or memos and personal diaries were kept illuminating decisions and to track the analyst's personal responses to the data. Analytic team meetings ensured the primary analysts' understanding of the data was adequate and allowed for consensus building in interpretation. Rigor was further confirmed by the purposive sample of parents of children who had direct experience with chronic pain and who were able to provide thick, rich descriptions of their experiences to support the aim of the study. The goal in the current study was deeper understanding rather than transferability of findings, however, detailed description of the findings should permit readers to determine transferability to their own contexts.

Ethics

Ethics approval was gained from the relevant academic board (Pro00050891_REN3) and operational approval from the clinical agency. Permission from the participants was obtained through the primary consent form that included the possibility that the interviews could be used in the future.

Findings

The sample consisted mostly of well-educated women who were mothers of a child with chronic pain. Most parent participants were aged 41-50 years (64%) and married (79%), and their children were between the ages of 13 and 18 years. Most of their children had experienced pain for longer than two years (79%), and experienced various types of pain. Detailed demographic characteristics are presented in Table 1.

Table 1

Participant Demographics

Variable	n	%
Sex		
Female	12	92.3
Male	1	7.7
Age		
31-40 years	1	7.7
41-50 years	9	69.2
≥51 years	3	23.1
Marital status		
Married/common law	11	84.6
Single/widowed/divorced	2	15.4
Education		
Some high school	1	7.7
Postsecondary diploma	3	23.1
Postsecondary degree	6	36.2
Graduate degree	3	23.1
Age of child who has pain		
12 and under	1	7.7
13-17 years	12	92.3
On average, how often does the child have pain per week (days)		
Every day	11	84.6
5-6 days per week	1	7.7
2-4 days per week	1	7.7
1 day per week	0	0
Less than 1 day per week	0	0
Single or multiple source of pain		
Single	6	46.2
Multiple	7	53.8
Type of Pain		
Abdominal	1	7.7
Muscular	2	15.4
Pelvic	1	7.7
Nerve	1	7.7
Arthritis	1	7.7
Headache, abdominal	5	38.5
Headache, abdominal, muscular	1	7.7
Headache, muscular	1	7.7

Our analysis identified four themes relevant to the needs of parents that were prominent throughout the data. These included the need for: validation of the child's pain, healthcare system support, faster access to specialized care and services, and increased awareness about pediatric chronic pain.

Validation of the Child's Pain

Many parents experienced years of inconclusive tests and endless visits to various healthcare providers who did not have explicit education or training in pediatric chronic pain. The lack of results consequently gave parents the sense that their child's pain was not real, and that healthcare providers did not believe their child was experiencing pain. The lack of validation for their child's pain led many parents to believe that no one was listening to them. The need for validation for their child's pain became evident when these ideas were compared with the relief felt by parents when their needs were finally acknowledged by the chronic pain team at the children's hospital. Some parents received an additional sense of validation when their child received an official chronic pain diagnosis.

Some parents reported feeling that healthcare providers, friends, and even family did not believe that their child's pain was real. One parent shared their experience of disbelief with healthcare providers:

[Child] got the message loud and clear, even though people didn't say to him, that maybe this is psychological. And he said 'mum, the doctors don't believe me'. And so he – nobody ever outright said that to him, but it was implied. (Parent 2)

Prior to accessing the Chronic Pain Clinic, many parents described feeling that no one was listening to their needs. Frequently, they sought medical advice time and time again without getting to the bottom of their child's pain.

And it was a lot of going back, and going back, and going back, and so, I think that's where that feeling of people not understanding or listening came from, because you don't know what's going on either. But you were kinda hoping that the people that are in that helpful position – could get you to the right place. (Parent 9)

After accessing the Chronic Pain Clinic and meeting with the healthcare team, most parents spoke about the relief they experienced through feeling heard by healthcare professionals, and feeling that they listened to their child's pain experience. Validation of the child's experience was a foundation for building trust and effective teamwork between the parents, the child, and the healthcare professionals.

[pediatrician] just listened. ... [Child] truly felt heard and for me, having somebody hear my child, was just fantastic for me. ... they need to be heard. But I was being seen as his mother ...and so he just was – beautiful to have him come in here and meet the whole team in the beginning. And have him share his story and they all validated what he was saying. (Parent 2)

...it wasn't that she needed ah, a solution to the problem. I think she just needed acknowledgement that there was a problem. And there was going to be a team approach on how to get through. Not – not fix it. How to work with it. (Parent 17)

The chronic pain team offered a positive experience for all parents interviewed and mitigated the sense that the child had been imagining their pain: “...it’s validation that it’s not all in her head” (Parent 15). Another parent described the relief from having these specialist healthcare providers listen to their story: “When all those doctors are in there, and everybody’s listening to her and saying, “we believe you.” You know, “we believe you. It’s not in your head, we believe you.” That was a relief” (Parent 7). When asked about how it felt to have their child’s pain validated by healthcare professionals, one parent stated: “It makes you feel like you’re not totally crazy and that she’s not crazy or – or um, lying for attention...” (Parent 3).

For most parents, getting a chronic pain diagnosis was beneficial. Although some parents were saddened by the diagnosis of a chronic condition, most parents described getting some traction after a formal diagnosis was made: “... in hindsight now, ...we can give it a label. I – unfortunately, I think we come from a culture where we need to give it a – a label” (Parent 17). The diagnosis gave the parents a place to start to understand and learn more about the diagnosis.

...it was actually a bit of a relief to find out that you know some, there was actually something wrong with her and possibly something could be done about it even though she’s stuck with it ... I mean I’d rather she didn’t have it but I think it made her feel a bit better that you know there’s actually a name for it. (Parent 1)

Parents in our sample described the relief they felt from finally being able to label their child’s illness. Some parents also described a sense of validation from obtaining the simple acknowledgement that their child’s pain was real from the chronic pain team. This idea leads to understanding the importance of building partnerships with healthcare providers.

Healthcare Supports

During the lengthy and complex process of accessing appropriate resources for their child, parents needed additional support from the healthcare system. These included supports from healthcare professionals before and after acquiring the chronic pain diagnosis, support during emergencies and pain crisis, as well as support during the transition from the pediatric healthcare system to the adult healthcare system.

Healthcare providers. Having a child with chronic pain can be a heavy burden on parents. They identified the lack of available supports from healthcare professionals outside of the Chronic Pain Clinic at the children’s hospital, and the need for additional supports during the process of navigating the health system prior to accessing the Chronic Pain Clinic. Identified areas for support included the need for healthcare providers to value parents’ knowledge, the need for someone to coordinate the care for their child, as well as the need for available access to specialized chronic pain care.

A few parents described the need to be acknowledged as a part of the healthcare team, and to be part of the decision-making process for their child’s care. Although most parents wanted more support from healthcare providers, they also wanted to be recognized as an expert of their child. One parent explained that compared to a healthcare provider’s quick assessment, their lives with their children gave them far more credible information: “... this is my child that I spend uber amounts of time with, and you know my child from a couple of pieces of paper and a

chart and seeing him for five minutes in a clinic room” (Parent 2). Parents maintained that acceptance as part of the healthcare team and as an expert was not oriented toward self-gratification, it was because parents are the final caregiver of their child, and the parents must equally be knowledgeable and in agreement with treatment plans: “ultimately it’s us that have – that live with [child]. Not the doctor. So, we have to be able to live with what is being done, or not done” (Parent 6).

A few parents conveyed the need to temporarily delegate the responsibility of coordinating their child’s medical care after an exhaustive journey of navigating the health system:

... I wanted somebody else to steer the boat. I wanted to just be the mom and not the social worker and the psychologist and the physician, all in one. So that’s really why I called [Health Professional] and – and got [Child] in here. And that’s been so nice, to just hand that over to somebody else. (Parent 2)

Most parents indicated the need for a strong support network of healthcare providers in order to cope with the ambiguity and unpredictability of the chronic illness. A few parents described the support they felt from the comprehensive care offered at the Chronic Pain Clinic, and from having readily available support from a healthcare provider:

[physician] has been just the greatest support to us. Because ... we can go see him any time. I can call him up, you know, in the morn – like, “Ah, I don’t know, he’s in so much pain. What do I do?” You know. And he’s really good at walking me through it – and so he’s been ... such a tremendous help to us. (Parent 9)

One parent described her gratitude towards having a continuing relationship with the Chronic Pain Clinic staff. She talked about the importance of having continuing access to specialized care:

It’s pretty impressive to be able to know that ... they’ve said how many times that she can call her [referring to Chronic Pain team] ... if she has a relapse, or she you know, stumbles – all she has to do is pick up the phone and they’re gonna go over her plan, or if it’s really bad, it sounds like she can come in for an appointment. (Parent 17)

Almost all parents felt that the chronic pain team conveyed an atmosphere of support. One parent suggested that the success of the Clinic may stem from the caring environment it provides:

They genuinely care about every kid that comes through their door. And that has gotta be exhausting for them. But they do – they’ll do whatever they can to help every one of them. I think that’s why their program is so successful. (Parent 8)

Emergency support. Many parents indicated the need for specialized care during chronic pain emergencies, which could range from acute exacerbations or new health care concerns that impacted the chronic pain experience. Their experiences relayed a lack of available supports and specialized care to treat children with chronic pain in emergency rooms, as their needs differ from children experiencing acute problems. Some of these experiences include parents’ perception that they do not belong in the pediatric emergency room, feeling that they are

a burden in the emergency room, and their difficulty to differentiate between a new health emergency versus a symptom or exacerbation of their child's chronic pain condition. One parent described her experiences with emergency room care and identified the need for a specialized place for children to go when experiencing a chronic pain crisis:

...kids with chronic pain ... don't belong in the Emergency. And so, when that's offered as your only option, it is ... our last option. ... if we could get a witch doctor to the house, we would do that before we would go to the – the Emerg. 'Cause we feel like a bed blocker. ... I mean, if [child] was having trouble breathing, we would take him. But not for much else. And we would try everything else we could, before we would do that... it's almost like they need a walk-in chronic... chronic care place, for chronic kids. 'Cause it truly is different from acute care. (Parent 6)

Another parent found it difficult to differentiate an emergency from an expected level of pain in their child's chronic pain condition, as she was not always able to differentiate whether her child's severe pain indicated a new and emergent health issue or if it was a part of their chronic pain. This provided an added challenge when making health decisions to bring the child to the emergency department: "... how do we know whether it's an emergency or not because, some days she's just got like 11 out of 10 pain and you can't ignore that, can you?" (Parent 1).

Transitional care. Several parents expressed concern over their child's transition into adulthood. Due to the complexity and multidisciplinary approach to managing their child's chronic pain, parents were concerned about the available supports for their child once they entered the adult health system. Additionally, a few parents identified the lack of relevant resources available to their child as they were in their later teenage years at the Chronic Pain Clinic.

Overall, the analysis identified a gap in available resources for children and parents through their transition into adulthood with a chronic condition.

Now that she's turned 17, it's a little bit – ah, scary. ... I am more worried, yes, I am. Because the [Large Hospital] got her in. Now, in the adult world, how fast is she gonna be in an emergency room? ... The adult world is a whole different game. (Parent 4)

One parent shared her concern with the lack of peer supports for young adults in a primarily older adult population experiencing chronic pain:

... when she turns 18, there's really nothing yet, in between pediatric and old farts. And I've already discussed it with our general practitioner – it's true. There's nothing for her age – and it's not gonna help her. Doctor ___ [doctor2] and I both agree, it's probably not gonna help her to come sit with people as old her mom. (Parent 8)

Some parents expressed their desire for more age-appropriate material for their adolescent children at the Chronic Pain Clinic. One parent explained that the material and information provided was directed towards younger patients and was not as relevant to her adolescent's needs.

I found them very pediatric based. And difficult to answer. To answer truthfully. And because – I – I personally think they should have them in more stages... Of – the pediatric ages. Right, you have your – your infant, your toddler, your child, and then your adolescents slash young teen. Because the questionnaires were so much about their sleep pattern. Their eating pattern – what time do they go to bed – and I – I said, I don't know, [chuckling] he's 16 years old. He goes to bed when he wants, he's a big boy. (Parent 10)

Lack of Social Awareness as a Barrier to Care

Most parents expressed frustration with the lack of awareness from society at large and healthcare professionals about pediatric chronic pain and the pediatric Chronic Pain Clinic. The lack of awareness created a major obstacle in their ability to access appropriate care for their child. The lack of awareness created additional obstacles for parents in their ability to receive appropriate care and supports due to the invisibility of the illness. Parent 15 explained that “... none of the physicians thought or suggested chronic pain. I didn't even know ... chronic pain existed for pediatrics.” Some parents experienced delays in obtaining referrals to the Chronic Pain Clinic, as parent 8 explained: “My doctor didn't know about it. We found out about it, because my doctor went ... back home for a few months and I had to see a different doctor.”

Likewise, none of the parents interviewed knew about the Chronic Pain Clinic prior to their referral. This meant that they had no basis from which to advocate for their child.

...we didn't know there's something called a pediatric chronic pain clinic. ... It would have been so nice, at the beginning, to know that, you know, there's this pediatric chronic pain clinic that you can go to. (Parent 9)

Some parents suggested that difficulty accessing the Chronic Pain Clinic was exacerbated by their own lack of awareness about the condition which prevented them from seeking appropriate care for their child: “... if you don't even know about it [chronic pain], then how can you advocate for it?” (Parent 7).

A few parents described the difficulties of having a child with an illness that typically is invisible. Parents stated that due to the ‘invisible’ nature of the illness, it is challenging to explain to others what their child is experiencing. Furthermore, the lack of understanding and awareness of chronic pain can often be misconstrued by parents as a lack of compassion: “...it's not a lack of compassion. It's purely a lack of knowledge. But how do you teach people what they can't see?” (Parent 8).

Timely Access to Chronic Pain Services

Almost all parents interviewed spoke about the difficult and delayed process of acquiring specialized care for their child with chronic pain. Some parents spent years reaching out to various healthcare professionals before finally being referred to the Chronic Pain Clinic. Parents experienced a slow referral process and lengthy wait times to access the Chronic Pain Clinic. “We were told ..., there was probably a two-month waiting, but it turned out to be probably five months” (Parent 12). This lengthy access process to the Chronic Pain Clinic led to increased frustration on the part of the parent, and for many, prolonged their engagement with alternative resources and services.

Most parents reported a lengthy process of trial and error through various professions of healthcare providers and alternative medicines. Parent wished for a faster access to appropriate care for their child. Parent 7 described the slow process of acquiring a referral to the Chronic Pain Clinic:

...I just think that they should recommend this sooner. Sooner. Not wait until it's – you know, like a year. ... if you're still in pain after a month and they can't figure out why, you have chronic pain. And you need to come to the clinic.

All parents interviewed were thankful to have access to appropriate care at the Chronic Pain Clinic. However, the overall satisfaction with the Clinic was matched with the frustration for the length of time it took for them to access specialized care. Most parents recognized that the services provided at the Chronic Pain Clinic were well suited to their child, however they needed access to these supports much sooner: “*We're very lucky ... but probably could have used access a long time ago...*” (Parent 6). Another parent recognized needing support from the Chronic Pain Clinic at the start of their child's pain journey: “*...this is what my kid needed at the beginning*” (Parent 4). The following quote from a parent exemplifies the frustration resulting from not knowing how to help their child while waiting to access the Chronic Pain Clinic.

... it would have made the world of difference. I don't know that she had gotten so sick. If we'd known it was here and she could have got help right away – 'cause it was down to education. I didn't know a dang thing when all this started. (Parent 8)

Parents expressed frustration with the lengthy and strenuous process to accessing specialized care for their child. The lack of timely access to care left parents and children without supports for several months to years, and lengthened the time before a child was able to start pain management programs at the Chronic Pain Clinic. Due to the long waiting process, parents looked to alternative therapies to cope with their child's pain, spending additional time and money on treatment that rendered poor results.

Discussion

We aimed to gain a greater understanding of the needs of parents with children with chronic pain while also understanding their experiences. Four themes emerged from the findings. Parents face barriers in obtaining validation for their child's pain. Parents require additional support from the healthcare system through healthcare providers, during emergencies, and during transition from the pediatric to the adult healthcare system. Parents identified the need for a timely access to care for their child, a necessity that is often impeded due to the lack of awareness about pediatric chronic pain. Parents felt that increased awareness may speed up the process of accessing care and reduce barriers to obtaining an appropriate diagnosis and treatment for their child's pain. This last finding is similar to the findings from the primary study, which discussed the potential for the knowledge translation tool (hard-copy book and e-book) to increase awareness about chronic pain and potentially reach parents who were not yet aware of the available resources at the Chronic Pain Clinic (Reid et al., 2017). Additionally, findings from the primary study saw that parents felt that the Chronic Pain book validated and mirrored their experiences, themes that were also explored in this secondary data analysis (Reid et al., 2017).

Diagnostic Relief

Pediatric chronic pain is not a normative disease, in that the diagnosis cannot be supported or disproved by diagnostic tests. Parents in our study wanted to know the cause of their child's pain. Although their children were ill, countless visits to healthcare providers and numerous tests were inconclusive, leaving parents with no answers. Diagnostic relief, a sub concept within illness uncertainty (Chaney et al, 2016), is a concept that reflects the relief experienced when a correct diagnosis is made and how the diagnosis facilitates better understanding and acceptance of the condition. This, in turn, helps patients and caregivers adapt (Midence & O'Neill, 1999). Diagnostic relief has been explored within a range of contexts, including dementia (Connell & Gallant, 1996), fibromyalgia (Undeland & Malterud, 2007), myalgic encephalomyelitis/Chronic fatigue syndrome, multiple sclerosis (Lacerda et al, 2019), bipolar disorder (Proudfoot et al, 2007) and autism (Midence & O'Neill, 1999). In our data, parents speak to these ideas by expressing the relief they felt from finally being able to label their child's condition and although they were saddened by the diagnosis of a chronic condition, they felt that it gave them necessary footing to begin adjusting their lives around the diagnosis. Although the concept of diagnostic relief was evident in Midence and O'Neill's (1999) study of parents obtaining a diagnosis of autism for their child, little literature exists on diagnostic relief in pediatric chronic pain. Obtaining a diagnosis has the potential of giving parents relief from uncertainty, a sense of control, and a place to start to understand and learn more about the diagnosis.

Supports

Access to support has been identified as one of the most important coping and adaptation tools for parents with a child with a chronic illness (Meleski, 2002). Pinquart (2017) found that caregivers of children with chronic illness report greater stress than caregivers of healthy children. Stress is associated with greater responsibility for treatment management, an issue that was directly raised in our study by parents who identified the need for someone to "*steer the boat*", and assume treatment management from the caregiver in order to reduce the burden of the disease (Chow, Otis & Simons, 2018).

We have identified strategies in the literature to support parents with children with chronic illnesses. Peer support is an effective method of parental support as it allows parents to share social identity and support one-another during their child's illness (Shilling et al., 2013). Meleski (2002) determined that strong support networks composed of "friends, family, health professionals, organizations, spiritual and religious sources" were effective tools to help parents cope with the ambiguity of their child's illness (p. 52). Despite the increasing number of children diagnosed with chronic pain, there is a no paralleled increase in available supports for parents. Although parents in our sample did not identify specific desired support programs, they described the need for greater supports from healthcare providers at the individual level, which calls for additional healthcare provider education to enhance patient centred pain management interventions, as well as to direct parents to appropriate resources. Kanstrup et al. (2016) and more recently, Sheng, Ma, Ding & Zhang (2019) found that including parents in caregiver involved psychological therapies with their child had benefits on the parent's mental health as well as overall quality of life for both children and parents.

A link has been established between parent distress and behaviour with the child's psychological functioning and disability with regard to chronic pain (Chow, Otis & Simons, 2016). Parents in our sample described the importance of developing relationship and communication between parents and healthcare providers, an idea that Heath, Farre and Shaw (2017) have identified as a partnership that allows for better patient outcomes, and also aids in the transition from the pediatric to the adult healthcare system.

Transitional Care

Transitional care, a concept that represents uninterrupted, coordinated and developmentally appropriate care for adolescents transitioning to the adult healthcare system, has increased in relevance over the past four decades as children with chronic health conditions are now surviving into adulthood (Zhou, Roberts, Dhaliwal, & Della, 2016; Hagell, Coleman & Brooks, 2013). Research by Schraeder et al. (2018) reported that 2,400 youth with chronic care needs transition into the adult health care system each year in Alberta, and they are often underprepared for this transition. Although there is no validated assessment tool or measurement to assess readiness to transition, researchers have found that readiness to transition has a significant impact on post-transition outcomes (de Saliva & Fishman, 2014; Bindels-de Heus, van Staa, van Vliet, Ewals, & Hilberink, 2013). Abraham and Kahn (2014) identified the "lack of developmental maturity, readiness and self-efficacy" as barriers to effective transition (p. 633). Additional barriers include the differences in supports and treatment available between pediatric and adult care and "parental and provider reluctance to transition" (Abraham & Kahn, 2014, p. 633). In our findings, parents identified that they feared their child's transition into the adult health care system, and that few services were in place for young adults with chronic pain. This finding is supported by Forgeron, Higginson, and Truskoski's (2016) article that found necessity and value in providing transitional care to adolescents with chronic pain in order to provide a successful transition into the adult health care system. Specifically, adolescents in our sample could benefit from transitional care by bridging the supports offered in the pediatric and adult system. Additional research on the needs of adolescents with chronic pain transitioning into the adult healthcare system would be beneficial to create appropriate transitional care services, as increasing numbers of people are being diagnosed with chronic pain in childhood and require continuity of care into adulthood.

Awareness

Parents experienced difficulties with accessing specialized care for their child with chronic pain due to the lack of awareness about pediatric chronic pain and about the Chronic Pain Clinic. These difficulties were attributed to the lack of general public awareness of the existence of pediatric chronic pain, and within healthcare practitioner circles; however, this idea was not present in current literature. This finding was raised numerous times in the interviews, yet little evidence exists on the topic in current literature. Therefore, there is the potential for future directions to improving care for parents with children with chronic pain. Parents emphasized the need for increased awareness in all aspects: disease process, diagnosis, treatment and management, schools, and healthcare settings. Since almost all parents spoke about this issue, there is a need for better strategies to educate community clinicians about the available chronic pain services. The prevalence of pediatric chronic pain justifies the need for better education and better preparation for healthcare providers to care for patients and their parents. Education about pediatric chronic pain should start in healthcare practitioner undergraduate

education. Healthcare providers should be aware of the resources available, and be able to refer parents to appropriate services.

The individuality of each case of chronic pain creates an added challenge of presenting information about pediatric chronic pain, however general information should be available to the public. Increased access to information could increase awareness for the public, parents, and healthcare practitioners, and offer links to available resources for parents seeking care. Information about specific types of chronic pain may be difficult to disseminate, as each child experiences pain in an individual way. Selective information tools could be beneficial, such as infographics that allow parents to explore treatment options based on their child's needs and symptoms.

Limitations

The study limitations include the inability to ask further questions to participants due to the secondary qualitative methodology (Ziebland & Hunt, 2014). Additionally, our study lacked a paternal perspective as our sample consisted mostly of mothers.

Conclusion

This study highlighted key needs for parents with children with chronic pain, and served to identify the gaps in the supports provided for these parents. These included the need to validate a child's pain, to increase supports from healthcare providers in emergency care and transitional care, as well as to increased awareness and timely access to care for pediatric chronic pain. We also identified the need for additional support for parents and children with chronic pain transitioning into the adult healthcare system. Some findings from the primary study were confirmed in the secondary analysis, such as the importance of disseminating knowledge about chronic pain to the greater public, and solidified the importance of validating the family's story (Reid et al., 2017). Additionally, the findings served as a reminder for nurses to take the time to listen to patient stories, and to validate pain. Finally, our findings gave an additional dimension to the experiences of parents with children with chronic pain, and identified areas where healthcare providers can improve the care for these families.

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Promissory Note

This manuscript has never been published and is free from plagiarism.

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