

**From Being Othered to Moving Forward Together: Perceptions of
Adolescents with Chronic Pain About Peer Support**

by

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ABSTRACT

FROM BEING OTHERED TO MOVING FORWARD TOGETHER: PERCEPTIONS OF ADOLESCENTS WITH CHRONIC PAIN ABOUT PEER SUPPORT

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Social challenges are common for adolescents with chronic pain. Group-based peer support for adolescents with chronic pain could be a promising intervention; however, no studies have focused on the peer support needs of this population. The present study addressed this gap in the literature. Fourteen adolescents with chronic pain completed an interview and demographics questionnaire. Interviews were analyzed using reflexive thematic analysis. Adolescents with chronic pain feel misunderstood and under supported by their peers without pain leading to feeling “othered”, having to explain their pain, and not talking about their pain to their peers. Adolescents expressed that peer support would help them feel understood because of shared knowledge and experiences helping to create a feeling of belonging. Participants desire peer support and highlighted expected immediate, short-, and long-term benefits, including learning from their peers and developing friendships. Study findings suggest that adolescents with chronic pain may benefit from peer support.

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LIST OF ABBREVIATIONS

ACP	Adolescents with chronic pain
PWOP	Peers without chronic pain
PSI	Peer support intervention

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1 Introduction

Pediatric chronic pain affects 11-38% of youth and is associated with psychological, physical, and social impairments (Hunfeld et al., 2001; King et al., 2011). Low social functioning of adolescents with chronic pain (ACP) is associated with increased physical limitations, school impairment, somatic symptoms, and pain intensity (Simons et al., 2010). Social development (e.g., developing peer relationships) is an important facet of development during adolescence; however, chronic pain can hinder this development by reducing opportunities for social exposure and involvement in peer groups (Eccleston et al., 2008). Compared to their peers without chronic pain (PWOP), ACP are often less likely to be socially accepted, more likely to be victimized by their peers, tend to have fewer friends, and struggle to develop and maintain friendships because of their pain (Carter et al., 2002; Forgeron et al., 2010; Forgeron et al., 2013; Merlijn et al., 2003). Altogether, these peer relationship challenges can leave ACP feeling socially isolated and lonely because they are alienated and misunderstood by their PWOP (Forgeron et al., 2013).

Peer support, from a healthcare perspective, refers to individuals with similar conditions exchanging various types of support (e.g., informational, affirmational, emotional) which can help to decrease feelings of isolation and loneliness and promote positive psychological well-being (Dennis, 2003). A peer support intervention (PSI) occurs when those with similar health conditions spend time together and through this, provide social support. More specifically, PSIs for chronic illnesses have been implemented in groups (Cassano et al., 2008; Olsson et al., 2005) and in one-on-one formats (mentorship/coaches; Ahola Kohut et al., 2016; Matthias et al., 2016). The current study focuses on group-based peer support as this format can help to “normalize”

pain (World Health Organization, 2020), provide the opportunity to learn from and help others (Subramaniam et al., 1999), and help individuals feel that they are not alone (Lewis et al., 2016).

Group-based programs for PSIs have been implemented for adults with chronic pain (Cooper et al., 2019; Matthias et al., 2016) and for adolescents with other chronic conditions (e.g., chronic kidney disease, cancer; Nicholas et al., 2009; Cassano et al., 2008). A group-based PSI may be beneficial for ACP, given the significant role that peer relationships play in the normative development of adolescents. Stinson and colleagues (2008) identified the self-management needs of adolescents with arthritis which informed the development of a self-management intervention with peer support components (peer mentorship; Ahola Kohut et al., 2016). Studies to identify ACPs desires of a group-based peer support intervention are lacking. The current study sought to assess the peer support needs of ACP by exploring their perceptions of peer support. This is the first phase of a needs assessment that will inform the development of a group-based PSI for ACP.

2 Methods

Underpinned by an experiential orientation, which focuses on participant's meaning-making and lived experiences (Braun and Clarke, 2022), this descriptive qualitative inquiry (Sandelowski, 2000) sought to understand the peer support needs of ACP through their perceptions and beliefs using individual interviews. Additionally, the research team included a patient partner with lived experience of pediatric chronic pain to provide insight into the lives of ACP and increase research effectiveness (Duffet, 20117). The patient partner contributed to the development of research objectives and study materials, assisted with recruitment, thematic analysis, manuscript editing, and was involved in the knowledge translation of study findings.

2.1 Participants

Eligible participants were 12-17 years of age, had experienced chronic pain for ≥ 3 months, were able to understand, converse, and read in English, and were willing to keep their camera on during the virtual meeting. Those who had major developmental delays were excluded. The target sample size range was decided based on information power (Malterud et al., 2016), other studies that assessed the needs of chronic pain populations (Stinson et al., 2008; Tran et al., 2012), and pragmatic considerations (e.g., time constraints; Braun & Clarke, 2021). The final sample ($N = 14$) was determined by the richness of the data in relation to the research question (Braun & Clarke, 2021).

2.2 Measures

2.2.1 Semi-structured Interviews

To elicit the perspectives of ACP without being prescriptive, a semi-structured interview guide was developed based on existing adolescent peer support and pediatric pain literature (see Appendix A). The interview guide included open-ended questions and moved from more general to specific allowing participants to discuss their attitudes, beliefs, and desires in regard to peer support. For example, questions ranged from “*What does peer support mean to you?*” to “*If you were given the opportunity to engage in peer support (e.g., spending time with another teen who has chronic pain), would you want to take part? If yes, why; if no, why?*” and ended with the adolescent being invited to share any perceptions that were not discussed.

2.2.2 Demographic Questionnaire

A study-specific set of demographic questions were developed to capture a profile of the participants' backgrounds. Participants were asked to report their age, gender, ethnicity, pain characteristics (e.g., pain location), whether they have accessed pediatric pain services, and geographic location. Adolescents were asked to rate their average pain intensity over the past 7 days using the Numerical Rating Scale (NRS-11; von Baeyer, 2009) with scores ranging from 0 ("no pain") to 10 ("The worst pain you could ever imagine"). The NRS-11 has demonstrated convergent and discriminant validity (Ruskin et al., 2014) and has been recommended for use with youth \geq 8 years old (Castarlenas et al., 2017).

2.3 Procedures

This study received approval from the Research Ethics Board at the University of Guelph (REB#2106006) and the University of Alberta (Pro00116684). ACP were recruited through two pediatric chronic pain clinics where they were provided with the study recruitment infographic and information letter by their clinicians. Participants were also recruited through social media (i.e., Twitter, Instagram, Facebook) and pain organizations by posting or sending the study recruitment infographic which included a link to the information letter. Interested ACP had their caregiver contact D.L., and caregivers completed a screening questionnaire with D.L. The caregivers were then sent consent and assent forms for themselves and the ACP to review, respectively. Prior to the interview, verbal assent/consent were obtained and recorded. Adolescents and their caregivers were given assurances of confidentiality. The interviews were conducted by D.L. using the Zoom platform between November 2021 and April 2022 and lasted

between 58 minutes to 105 minutes. The interviews were recorded, transcribed verbatim (identifying information was removed), and field notes were taken by D.L. After the interview, the ACP verbally completed the demographic questionnaire with D.L. Adolescents were sent a \$20 electronic gift card for their participation.

2.4 Analytic Approach

Based within a critical realist ontology, inductive reflexive thematic analysis was conducted and led by D.L. following Braun & Clarke's six steps at the manifest level (Braun & Clarke, 2022) within NVivo software; (see Appendix B for analytic process). Manifest level analysis aligns with qualitative description as this level of analysis stays close to the participant's voices (Braun & Clarke, 2022; Sandelowksi, 2000). Throughout the process, strategies to ensure trustworthiness were taken such as frequent debriefing sessions among members of the research team (Shenton, 2004) and reflexive journaling by D.L. (Braun & Clarke, 2022). Descriptive and frequency statistics were used to analyze the demographic data using the software program, Statistical Package for the Social Sciences (SPSS v. 27).

3 Results

A total of 14 adolescents between 12-17 years of age ($M=15.21$, $SD= 1.72$) participated in the study. See Table 1 for demographics. Three themes and corresponding subthemes were generated (see Figure 1) which are presented below with supporting quotes from ACP.

3.1 Theme 1: Being Misunderstood

Being misunderstood emphasizes how ACP commonly feel in relation to their PWOP. The ACP shared that PWOP have an inherent lack of awareness about chronic pain as they do not experience chronic pain, and most do not attempt to understand the ACP's experiences. For the few who may attempt to understand, the participants reported that their PWOP often make superficial comments (e.g., "Oh yeah, I get that!" P14, girl, 16 years) but can never fully understand. As it is a complex chronic illness that many are unaware of, ACP believe that their PWOP struggle to understand the nuances of chronic pain such as its etiology and how it feels and manifests. Further, PWOP do not understand what having chronic pain means for ACP: how it impacts what they can and cannot do, how they manage their pain, and how it influences all aspects of their lives as identified in this quote and shared by many participants:

They just don't understand how much pain you're actually in. They don't understand what chronic pain even really is. So, they don't understand that you can be in pain constantly. Like the pain ranges in different levels, so they don't know that the pain can be really bad at times, and like how sensitive you are to touch and other stuff. They just don't understand anything about how it works. They know you have it, but they don't understand what to do with it, or they often forget because they're not- they don't have the same things going on in their life. (P11, girl, 16 years).

Some ACP described how this lack of understanding about chronic pain can lead to unnecessary concern from their PWOP. 'Over-concern' for their well-being was not something that ACP found helpful and contributed to making them feel misunderstood and different.

[PWOP will] worry- they'll ask you on a regular basis: "are you okay?" It's just like, this

is chronic, and I have it every day, it's not changing. Or if I miss a day at school or something happens, they instantly go to the pain, that's why it's happening. Then they'll be concerned about me doing any activities. I play hockey and people will just get concerned that I'm even playing hockey and it's not theirs to be concerned about. If [I'm] doing something I've consulted with my doctors, I know it's ok. They'll just worry about every movement... like hugging me. (P8, girl, 17 years)

Since their PWOP do not truly understand chronic pain, ACP voiced that they feel like they cannot speak with them about their pain experiences as they worry they would be misunderstood and treated differently. Feeling alone in their pain experience resulted in many of the participants experiencing loneliness and at times being socially isolated.

3.1.1 Theme 1: Subtheme 1: Being and Feeling Othered

A significant outcome of feeling misunderstood by their PWOP is that it often led to ACP being and feeling othered. The ACP in this study described how they felt that their PWOP viewed them as 'different' and treated them as if they are not 'normal' compared to their healthy counterparts. One of the participants summed up this experience here, which was echoed by other participants, "I think... people with pain ... get used to being treated as almost a different species like they're different and we know we're different. But, getting treated that way is kinda annoying." (P8, girl, 17 years).

Indeed, ACP voiced how being perceived as 'different' can make them feel judged and invalidated. Although participants did not appreciate the 'over-concern' that some peers exhibited towards them they also found dismissive remarks unhelpful. For example, several

participants described that when they did talk about their pain, their PWOP made comments like “just take an Advil” (P14, girl, 16 years) or PWOP would try to relate the ACP’s pain to acute pain (e.g., a brief headache). These comments were viewed by ACP as minimizing their pain experience and furthering the feeling of being ‘different’. Moreover, as PWOP lack understanding of chronic pain, they can be quick to think critically about what ACP do or how they feel. For example, P2 illustrates an all too familiar situation of the participants:

Sometimes people struggle with, you know... “why were you able to do this a week ago but you can’t do it today?” or “why aren’t you getting out of bed? Like, you’re just lazy”, when you’re not lazy, you’re just in too much pain or you just don’t have that energy. –
(P2, questioning, 17 years)

Some ACP described how the lack of understanding or misunderstanding, in some cases, about their pain cause them to be left out of activities or uninvited to gatherings or excluded from peer groups. For a few, social exclusion took the form of peer victimization (i.e., being bullied). In most cases, this rejection led to the ACP being isolated and feeling lonely as shared here:

It’s a lot of- especially misunderstanding and it’s also that- at least with teenagers, that if you talk about your inability to do something they’ll take that as you also not wanting to do it. So, I’ve found that when I do tell people about my pain, they stop inviting me places, they stop asking to hang out with me, you know, they kind of pull back because they don’t know how to treat me or place me in their lives. (P9, non-binary, 16 years)

3.1.2 Theme 1: Subtheme 2: A Pain to Explain

Since many of their PWOP do not understand chronic pain and their experiences, many participants in this study had a common experience where they found themselves having to repeatedly try to explain the complexity of their pain, which can be burdensome and a reminder of being different. Here one of the participants expresses the challenge of trying to explain chronic pain, “[My friends] don’t understand too much and it’s kind of hard to explain... just

how it feels and how it can go off and on, and how [it] can randomly appear. (P13, girl, 12 years). Even though it may be because PWOP were trying to understand, the numerous questions led to the unwanted work of having to constantly (re-) explain and answer questions. A lot of participants found this frustrating and added to the burden of living with pain as described here:

I don’t like talking about my pain to people ‘cause they usually ask so many other questions, and I don’t really wanna answer so many questions... because they usually just keep asking more questions, and then they usually forget immediately because they don’t really understand it. (P11, girl, 16 years)

3.1.3 Theme 1: Subtheme 3: The Need to Filter Out A Big Part of Your Life

A recurrent narrative from the ACP was that they felt the need to filter out a major part of their lives - their chronic pain. Since their PWOP do not fully understand their chronic pain and it is a pain to explain, ACP would rather not talk about their pain as described here, “You don’t necessarily want to tell people cause then it’s like: “oh he’s probably just looking for sympathy if he tells you.” (P4, boy, 14 years). Filtering pain out of conversations helped participants avoid being misunderstood and rejected. A few of the ACP in this study noted that sometimes, instead

of being candid with their PWOP, they say something else to avoid talking about the pain, as explained by one of the participants:

So, I don't really open [up] about [the pain] or, if I can't hang out, I usually come up with a different excuse rather than me saying "oh my head really hurts, and I can't come over"- 'cause I feel like they don't- they wouldn't get it. (P7, girl, 17 years)

However, the cost of not sharing their pain experiences with PWOP, even their close friends, was extremely isolating.

3.2 Theme 2: They Understand Me

Through spending time with other ACP, the participants perceived that they would finally feel understood- which is challenging for them to experience outside of an environment with other ACP.

It would just be nice to talk to [ACP] who understand you because I feel like every conversation you have, because pain relates to everything in your life... anything you're talking about there's always that kinda like one extra thing that people just don't understand. (P8, girl, 17 years)

Moreover, since ACP commonly feel lonely and isolated, peer support could help foster connections amongst ACP which could reduce these feelings. The youth believed that having people their age who understand what it is like to live with chronic pain would help them realize that they are not alone in their experiences.

I think [peer support] would help to- well, potentially help to prevent a lot of suffering from the isolation and just feeling... alone in everything and trying to navigate a difficult world and situations. (P5, girl, 17 years)

Through spending time with other ACP, youth would finally have people that could truly understand them. In this way, a perceived immediate and short-term benefit of peer support was that they would finally feel understood by connecting with other ACP.

3.2.1 Theme 2: Subtheme 1: Shared Knowledge and Experiences

Much of the perceived understanding between ACP was voiced as coming from shared knowledge and experiences. Through living with chronic pain, ACP have similar knowledge about its etiology, common symptoms, and impact on abilities. Participants described this as being helpful as most people, including their PWOP, are challenged to understand chronic pain. Additionally, some participants spoke about how ACP may have additional knowledge related to common comorbid conditions as well as the health system and thus could understand their challenges in managing multiple conditions and navigating the health system.

Another good thing is if you do have chronic pain, usually you have other problems too- you'd probably find people that you can relate to with other disorders you have because you might not have the same ones but you'll have similar ones or overlapping symptoms that you would also be able to talk about which is good 'cause [it's] nice to have someone to relate to with that. (P2, questioning, 17 years)

Although shared knowledge of chronic pain and other health information was described as helpful, the ACP in this study emphasized that much of the understanding would come from

shared experiences of having chronic pain as an adolescent such as challenges in navigating school and friendships. Many of the participants voiced that spending time with others who know what they are going through would be able to relate to them on many different levels which the ACP perceived as being special and novel as illustrated here:

I think there's something nice to relate to people, you know, you have the same people your age who really are going through similar things like going through school still or having trouble getting to birthday parties or having trouble doing normal kid stuff I guess without medication or without, resources or having to cancel and stuff. (P7, girl, 17 years)

Spending time with ACP who have shared knowledge and experiences could allow for a unique opportunity where ACP would not have to explain their pain, or if they did, it would be a lot easier as exemplified in the following quote, "Like if you said, "I can't do this because I have chronic pain" you wouldn't have to explain yourself and what it is, and everything cause they kind of already know." (P6, boy, 13 years). Many adolescents also mentioned that other ACP would understand if someone needed to be accommodated. For example, if plans needed to change due to pain, another ACP would understand as they may have experienced similar restrictions.

Participants spoke about how having shared experiences would allow for a deeper level of understanding and empathy among ACP but not in a way that would result in 'over-concern', as explained by P5 below and echoed by many others. This shared empathy could lead to more authentic and honest conversations and relationships.

There's just a deeper level of understanding when you're talking to someone who's also going through the same things. I think especially who can also offer you support in a way that someone who doesn't have [chronic pain] maybe can't necessarily. (P5, girl, 17 years)

3.2.2 Theme 2: Subtheme 2: A Safe Space of Belonging

Another potential immediate and short-term benefit that ACP spoke about was that spending time with others who understand them creates a safe space of belonging - a non-judgmental environment where they would not need to hide a part of themselves.

I think it would be a lot easier talking about [the pain] and I wouldn't have to worry like "Are [other ACP] gonna understand this?" or "Are they gonna say something about how it's not real?". (P12, girl, 14 years)

Additionally, participants felt that they would be accepted as they are and could be encouraged and validated by other ACP for the things that they are doing well and thus provide affirmational support. Moreover, participants spoke about how being around other ACP would make them feel more comfortable, making them feel more open to sharing their challenges as illustrated by the following quote, "Being able to just communicate and open up in a way that you cannot to other people – adults specifically, but also peers of your same age group, it's really something else." (P3, boy, 16 years).

Even though having this space would allow ACP to be more open and honest, a few ACP acknowledged that this openness could potentially lead to talking about difficult situations or experiences. Some ACP mentioned that this may be difficult as one may not know how to

respond if the topic is sensitive or negative and therefore upsetting. Moreover, some ACP also brought up the possibility of co-rumination (i.e., focusing on negative feelings and/or experiences) such as the following ACP, “[The thing that I would maybe be concerned about with spending time with ACP would be] if they’re all really negative and then feeding off of each other’s negativity and making them more sad.” (P14, girl, 16 years).

Despite some concern about co-ruminating, most participants spoke of positives about spending time with other ACPs. For example, with a shared understanding they did not worry about being othered when they spent time together. Spending time with other ACP would let them be themselves without worrying about being treated differently and, indeed, would help them feel normal. ACP could do things that typical teens do but in a group of people who understand, as P7 explained: “Sometimes chronic pain kinda doesn’t make you feel like a normal human. Whereas I feel like if you’re doing normal human stuff... with people who also experience the same thing, that’s really beneficial.” (P7, girl, 17 years)

Participants shared that making connections with other ACP would help combat loneliness as well as provide a sense of belonging, something they struggle to find. However, they acknowledged that they longed for and needed a dedicated space for these connections to form. Further, ACP in this study felt that this space would help to build and sustain a sense of community amongst them. This is eloquently expressed by P10, who speaks about a peer support group to which she belongs: “Life isn’t fair, but this community, this place we have to spend time together, this is fair.” (P10, girl, 15 years).

3.3 Theme 3: Moving Forward Together

Moving Forward Together encompasses the participant's beliefs that peer support has the potential to help them cope with their pain in a variety of ways leading to a more fulfilling life. Through sharing valuable information, providing emotional support, and companionship with the potential of developing meaningful relationships, participants viewed peer support as providing help in the long-term. There is also the potential for peer support to improve ACP's mental well-being by helping them "feel a bit more positive about everything" (P6, boy, 13 years) from knowing that others share their challenges (physically, emotionally, socially) and how this can provide hope for the future by seeing them succeed despite living with chronic pain.

You just see other [ACP] still working hard... 'cause sometimes you feel like you're alone, you're in pain, and you just can't do it. Whereas... you're not. With a group, you're not alone, you're in pain, but you see other people that are doing it, so you can too. (P7, girl, 17 years)

3.3.1 Theme 3: Subtheme 1: Learning From Each Other

One of the recurring perceptions from the participants was that spending time with other ACP would allow for the provision of informational support where ACP could share strategies for pain management and learn from others' pain journeys, as illustrated below and voiced by almost all of the participants:

[If the chronic pain has] only been there a couple of months and you're still kind of figuring it out, [peer support] would be helpful because then you'd learn a bunch of strategies and stuff. Or if you were near the end of it, like, it was getting better, then

you'd be able to be like "oh yeah these things have helped in the past for me" ... or like "this medicine has helped me and that's why I'm getting better". (P1, girl, 13 years)

As another participant describes below, the ACP in this study felt that peer support would also provide the opportunity for them and others to ask each other questions and seek advice about symptoms, healthcare professionals' suggestions, and navigating life situations (e.g., school, relationships).

[Spending time with ACP is] also good for just figuring out how to cope with things or... just being like "hey, my doctor suggested this" or "I've been thinking about trying this, how has that- like have any of you tried this? Has it helped any of you?". (P2, questioning, 17 years)

Some participants voiced how peer support in a group setting would be beneficial as it would allow for different perspectives to be shared and the opportunity to learn from multiple ACP. Of note, one ACP mentioned that it would be important not to force suggestions or advice on other ACP. The ability to support one another also extended to older adolescents in the group or even young adults who may be involved (e.g., facilitator) as they could provide informational support from a "future perspective". In this way, ACP could learn about navigating life with chronic pain as an older adolescent and/or young adult (e.g., university, transitions into adult care).

3.3.2 Theme 3: Subtheme 2: Being There For One Another

Not only would a group-based PSI provide a place to connect and learn from other ACP, most of the participants also articulated that they could be there for one another within and

beyond the PSI. The majority of ACP expressed how peer support would allow them to develop meaningful relationships that could turn into friendships. These friendships would create a network of people who understand and can provide social support into the future. Below, one of the participants describes how they perceive the development of friendships to unfold in a PSI:

I don't wanna just do this group, have fun for six months, and then go out of it. My mindset would be- I definitely want to benefit from this, in the future too. So, not necessarily putting pressure on it for like "aww, I need a lifetime friend", but I would go in it not thinking "aww temporary friend", I'd be like- yeah! I would wanna find someone who I'd be down to hang out with on the Tuesday night or whatever. (P7, girl, 17 years)

Additionally, those friendships that may be developed and sustained beyond the PSI could act as a 'safety net' for ACP as they could still receive support when needed outside of the PSI. Moreover, participants perceived that they could keep in contact with these friends during times when the PSI was not running (e.g., holidays) and/or after they may have left the group.

I'd feel a lot better to know that I've met other people that have had [chronic pain], and I can talk to them whenever. The people that you can [have] contact with- it's kind of nice to always be like "Oh well I have this person in case anything happens" and stuff like that- I feel like it would be kind of- it would be reassuring... really reassuring. (P13, girl, 12 years)

Lastly, participants spoke of how friends made from the PSI may function as a unique friend group separate from their other friends without chronic pain as explained here:

I feel like lots of people have different friend groups... they have like their school one, they have like their family, friends, then if they do any sports, they have a friend group there. I feel like it would be another one. (P14, girl, 16 years)

However, when speaking about these newly formed friendships, one ACP voiced a cautionary note about the importance of being mindful of the possibility of codependency:

I think there's a risk of... dependency? Especially if it's the first ever person who also has a chronic illness and chronic pain that you become friends with or, you know, that's your age. I feel like there might be a tendency to latch on and become really dependent on each other. (P9, non-binary, 16 years)

These meaningful relationships emerging from the PSI could help adolescents cope with their pain, as they would continue to have someone like them, as a friend in the future.

4 Discussion

This study explored the peer support needs of ACP. Through inductive reflexive thematic analysis, three themes were generated capturing ACP's perceptions of peer support: 'Being Misunderstood', 'They Understand Me', and 'Moving Forward Together'. These themes highlighted ACP's perceptions of what they are missing in terms of social support from their PWOP, as well as the immediate, short-, and long-term benefits of peer support from ACP. Altogether, the adolescents believed peer support from other ACP would be desirable, novel, and beneficial.

Consistent with the pediatric pain literature, ACP often feel like their PWOP do not understand their pain (Forgeron et al., 2013; Forgeron & McGrath, 2008; Stinson et al., 2014).

Our findings suggest that being misunderstood by their PWOP leads to a lack of social support through ACP feeling and being othered, difficulties explaining their pain, and not wanting to discuss their pain. A study exploring the friendship challenges that ACP experience found that they perceive their healthy peers as being disinterested in their pain yet wanted their peers to acknowledge their challenges in living with pain (Forgeron et al., 2013). In contrast, although a few ACP described some of their PWOP being overly concerned, none of the ACP in this study explicitly stated that they felt a lack of concern from their PWOP. Furthermore, excessive concern seemed to further ACP's feelings of being misunderstood as they felt the "concern" was not warranted. In essence, rather than disinterest and "under-concern", ACP in this study experienced 'over-concern' and being misunderstood, which they found invalidating. It may be that youth perceive this 'over-concern' as invalidating whereas appropriate validation of ACP's experiences may be acknowledging their hardships while focusing on them as a person (vs. on their pain). A key area of future research would be to explore how PWOP can appropriately validate and connect with ACP.

Adolescents also stated that it is difficult having to (re-) explain their pain to their PWOP as answering repeated questions is burdensome. Previous studies have noted this experience of ACP (Forgeron et al., 2013; Forgeron & McGrath, 2008) and our findings add to the literature by highlighting that the resistance to explain their pain stems from being misunderstood and feeling burdened by needing to explain. ACP described how they often avoid discussing their pain with their PWOP, thus filtering out a big part of their lives. This concealment has been briefly discussed in other studies (Forgeron et al., 2013; Wakefield et al., 2021) although more research focused on this specific topic is needed to understand ACP's process and reasoning behind pain

disclosure decisions to their PWOP. Due to PWOP's lack of understanding, there is a limit to the amount of fulfilling support ACP can receive from them which contributes to the loneliness and isolation ACP feel. As a result, it seems as though ACP need a different kind of social support, one that peer support from ACP could ultimately fulfill.

The participants described many potential benefits of peer support, with immediate and short-term benefits including feeling understood and connecting with others with shared experiences. ACP perceived that peer support could decrease isolation and loneliness, which is not unique to the chronic pain population (Ahola Kohut et al., 2020; Ahola Kohut et al., 2014; Letourneau et al., 2012). Loneliness is a modifiable and significant intervention target as it is associated with poor health outcomes in adulthood (Goosby et al., 2013) and a risk factor for morbidity and mortality like smoking and obesity across various health conditions (Holt-Lunstad et al., 2010). ACP expressed how many of the perceived immediate and short-term benefits of peer support were contrary to what they experience during interactions with their PWOP: it would be easier to talk about their experiences; they would not need to explain themselves; they would feel accepted, normal, and like they belong; and they would not need to hide their pain and be able to talk about their whole selves. Benefits such as these have been found in studies exploring beliefs and experiences with be-friending another ACP (Forgeron et al., 2015), peer support for adults with chronic pain (Finlay et al., 2018), and youth with other chronic illnesses (Cassano et al., 2008; Stewart et al., 2013). Further, ACP have emphasized the importance of trust, dependability, non-judgmental support, and empathy about their chronic pain as preferred characteristics in friends (Forgeron et al., 2013), which other ACP may be more suited to provide. Given the potential benefits related to emotional and affirmational support, it is

important to explore the effects of peer support on ACP's psychological and emotional well-being.

Connecting with other ACP was described as an important benefit of a PSI. Yet, some ACP felt that spending time with other ACP may lead to co-rumination. Indeed, studies have shown that co-rumination can lead to negative emotional adjustment, more significantly for girls and those with higher levels of anxiety (Rose et al., 2007). Given that adolescent girls are more likely to have chronic pain (King et al., 2011), co-rumination would be a potential risk of PSI for ACP but strategies to mitigate this risk could be integrated into a group-based PSI. For example, the ACP and facilitator(s) could be educated about co-rumination to try and deter it (Rose, 2021).

Beyond immediate and short-term benefits, participants also described long-term benefits for their journey with chronic pain. Consistent with the literature in other populations (Ahola Kohut et al., 2016; Barnfather et al., 2011), participants underscored the perceived benefit of seeking advice and asking questions about pain-related topics. This informational support has the potential to help ACP problem-solve, learn alternative ways of coping, and increase the likelihood of seeking out services they may need (Wills & Shinar, 2000). Learning from other ACP about pain-related topics may provide a level of credibility since they can provide a "lived experience" perspective. Research is needed to assess the uptake of informational support by ACP and if it is associated with improvements in functioning. Additionally, ACP noted that it would be beneficial to hear how others have managed, despite their pain and that it could provide hope for the future which aligns with other peer support findings (Ahola Kohut et al., 2016; Cassano et al., 2008). Future research would benefit from assessing the effectiveness of a PSI on ACP's hope for the future.

A noteworthy finding was that almost all the participants believed that a group-based PSI would facilitate the development of friendships with other ACP, which could provide long-term support outside of or after attending a PSI. This is promising as it could alleviate the isolation that is common for ACP and strong peer relationships have served as a protective factor for ACP (Eccleston et al., 2008). However, more research is needed to understand the long-term effects of friendships among ACP [e.g., would the frequent friendship breakups with their PWOP (see Forgeron et al., 2021) be observed for friendships among ACP?]. Furthermore, it was intriguing how ACP perceived these “peer support friends” as being different from their “other friends” which was suggested from a study that found almost all ACP who befriended another did not integrate these friends into their regular friendship network (Forgeron et al., 2015). The ACP in this study may perceive there to be different friends for different needs, with the “peer support friends” filling the need for the understanding that they are not getting from their PWOP. Future research could explore the longitudinal course of friendships while receiving peer support from ACP; perhaps having friends with chronic pain would make it easier to spend time with their PWOP as they would know they have their “peer support friends” who understand them.

Taking a patient-oriented approach, this is the first study to assess the peer support needs of ACP. However, there were four limitations to this study. First, almost all of the ACP in this study described their ethnicity as White and therefore it is unclear how these findings relate to ACP of different ethnicities and cultures. Second, this study was conducted during the COVID-19 pandemic and although ACP were encouraged to think broadly about their peer support needs, their perceptions may have been affected by their experiences during the pandemic (e.g., increased loneliness; Christ & Gray, 2022). Third, one of the recruitment strategies (social

media) may contribute to selection bias (e.g., adolescents may be wary of clicking on recruitment ads that are not from someone they know). However, study participants were recruited through clinical settings, pain organizations, as well as social media perhaps providing a cross-section of ACP and their peer support needs. Fourth, exploring the views of ACP was the focus of this study; however, the perspectives of caregivers and healthcare professionals are also valuable in understanding the components of a PSI for ACP. Our future line of work aims to engage these important stakeholders in understanding the feasibility, structure, and effectiveness of a PSI.

ACP continue to experience unmet social needs from their peers without chronic pain. They desire peer support with other ACP in a group-based PSI and viewed these relationships as being able to provide them with their unmet social support needs both in the immediate and short-term but also in the long-term and thus peer support has the potential to improve their quality of life.

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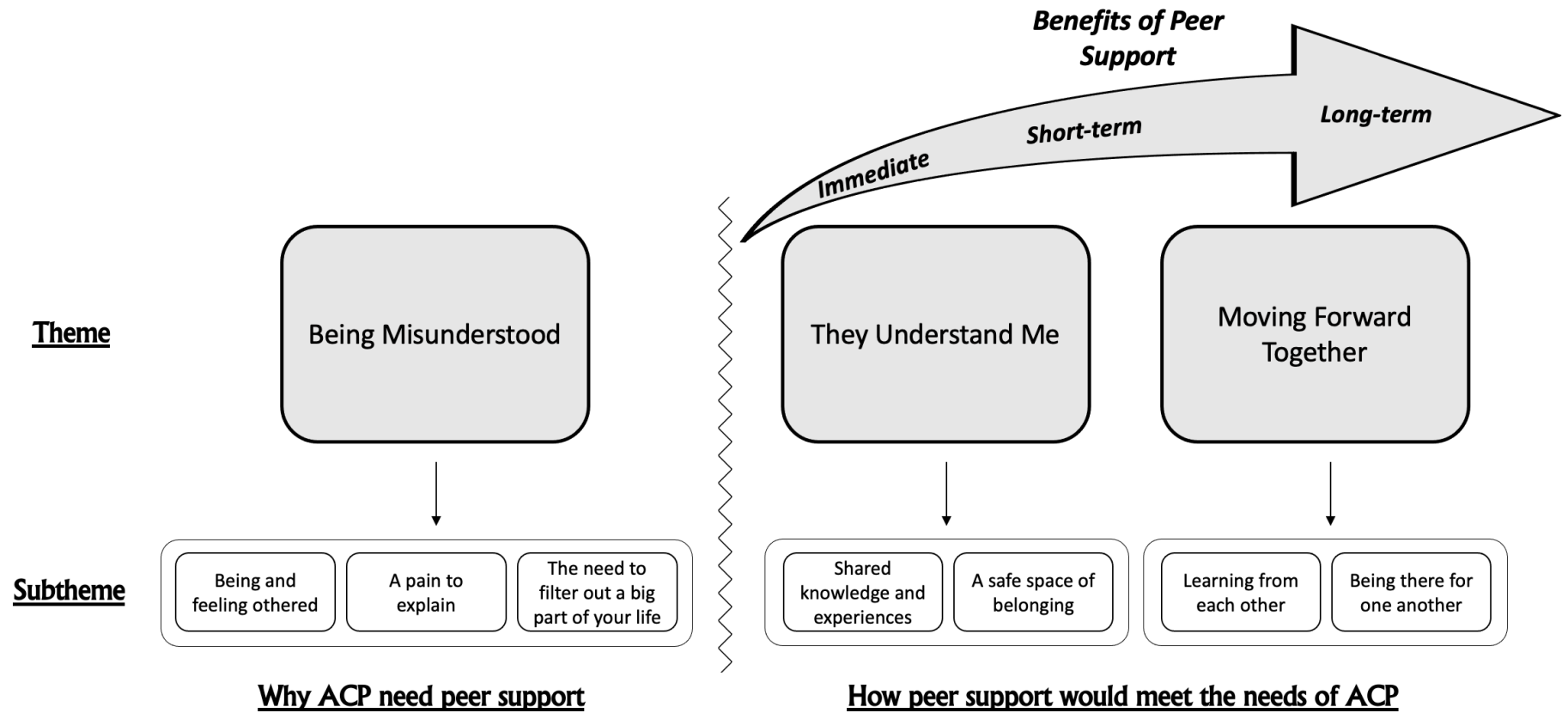
Table 1. Characteristics of Participants

Participant Characteristic	<i>N</i> = 14
Adolescent Age (<i>M</i> years, <i>SD</i>)	15.21, 1.72
Gender	
Girl	9
Boy	3
Non-binary	1
Questioning	1
Ethnicity	
White	13
Identified with multiple ethnicities	1
Pediatric Pain Services Accessed	
Pediatric pain program/clinic	12
Specialty services for chronic pain	2
Location of Pain	
Multiple areas across the body	11
Head	3
Years Living with Chronic Pain (<i>M</i> years, range)	4.00, 1- 6.5
Pain Frequency	
Constantly	9
Daily but not constantly	4
Other	1
Pain Intensity (<i>M</i> , <i>SD</i>)	6.36, 1.63
Geographic Location	
Canada	10
United States	4
Currently Knows Another ACP*	
Yes, a peer	3
Yes, from a peer support group	4
No	9
Other	1
Currently in a Peer Support Group	
Yes**	4
No	10

*Participants could provide more than one answer

**All 4 participants belonged to the same peer support group

Figure 1. Themes and Subthemes Generated From Inductive Reflexive Thematic Analysis



APPENDIX A: INTERVIEW GUIDE

N.B. Questions regarding the specifics of a potential group peer support intervention were also asked but have been removed here as they are not the focus of this thesis manuscript.

General Peer Support Perspectives and Peer Support Needs¹

1. Have you heard of peer support before?

Probes:

- a. What does it mean to you?
- b. Do you have any examples?

2. Do you know anyone else who lives with chronic pain?

Probes (if they do know someone with chronic pain):

- a. What is that like for you?
 - i. -What do you talk about/do together?
 - ii. -Do they help you or is it unhelpful?
- b. Is this someone your age or older?
- c. Do you talk to them about what it is like to live with chronic pain?
 - i. -What sorts of things do you talk about or do together?
 - ii. -Does this help you?
 1. If yes, how?

3. What do you think it would be like for you if you could spend time with other adolescents (not family members) who also live with chronic pain?

Probes:

- a. If you were to spend time with other adolescents with chronic pain, how do you think this could help you?
- b. Is there anything that you would be concerned about by spending time with other adolescents with chronic pain?

4. Can you tell me how you think spending time or talking with other people around your age with chronic pain would be different from spending time with your friends without pain?

Probes:

¹Probes were used by the interviewer (D.L.) to elicit further exploration (e.g., “can you tell me more?”) or when a topic was not freely addressed by the ACP (e.g., “can you share why you don’t say much to your friends?”).

- a. Do you find yourself not talking about your pain to your friends although things are difficult at times?
 - i. -Can you share with me why you don't say much to your friends?
 - ii. -Would this be different if they had chronic pain? How?
 - b. Do you find yourself not doing things with your friends because of your pain?
 - i. -Would this be different if they had a chronic pain? How?
-
- 1. If you were given the opportunity to engage in peer support (i.e., spending time) with other adolescents living with chronic pain, would you want to take part? Why or why not?**
- Probe:
- a. If unsure, what would you be wondering about? What would help you make your decision?
-
- 2. Is there anything that I did not ask that would be important to you about spending time with other adolescents who have chronic pain?**

APPENDIX B: FURTHER DETAILS OF THE ANALYTIC PROCESS

The research team consisted of individuals who are all interested in pediatric pain and patient-oriented research and come from a variety of backgrounds (i.e., clinical psychology, nursing, and lived experience of pediatric pain). Following the six steps of thematic analysis, D.L. first became familiar with the data by reading the transcripts and taking notes on ideas regarding the data and potential codes. Once familiar with the data, D.L. began generating initial codes by coding segments of the data that were relevant to the research question. After D.L. and C.M.M reviewed the codebook, codes were further refined, combined, or deleted. After this, D.L. and K.C.D. met to generate initial themes by clustering codes into potential themes and subthemes. Following this, D.L. checked the initial themes against the coded data and the full dataset to ensure themes were data-driven. D.L. further refined themes and subthemes and then generated initial theme and subtheme descriptions and names that were then reviewed and finalized by K.C.D, C.M.M, and P.A.F. The final stage consisted of D.L. writing the results and selecting and integrating quotations from a range of participants.