

Living with difference: Exploring the social self of adolescents with chronic pain

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BACKGROUND: Chronic pain negatively affects an adolescent's life; however, little is known about the social impact of chronic pain for adolescents. More is known about the general peer relationships of adolescents with chronic pain than their close friendships. Close friendships begin to take on more importance during adolescence as these relationships facilitate the development of an adolescent's sense of personal identity and increasing independence from family influences. Thus, chronic pain may create friendship challenges for adolescents beyond those typically experienced during this developmental trajectory, which may negatively impact their abilities to secure social support.

OBJECTIVES: To better understand the challenges adolescents with chronic pain face with regard to their friendships.

METHODS: An interpretative phenomenological study using individual interviews was conducted.

RESULTS: Two themes emerged. 'Rethinking the self with pain' describes the intrusive nature of chronic pain, challenging the participants to rethink the way they view themselves and their place within their social network. 'Rethinking friendships' describes the interpretation of their friends' reactions to their chronic pain condition, which led to these adolescents spending more time by themselves, and feeling misunderstood and unsupported.

CONCLUSIONS: The impact of chronic pain on the adolescent as an individual as well as the responses of close friends and others within their social network resulted in the development of new friendship needs. However, the adolescents were not always able to secure these new friendship needs. Their experiences suggest factors within friendships that may be ameliorated by interventions, thus maintaining and strengthening their close friendships.

Key Words: *Adolescents/youth; Chronic pain; Interpretative methods; Social development; Social support*

Adolescents with chronic pain face many challenges. They experience a disease process that is not well understood, has an uncertain illness trajectory and is not usually accompanied by obvious physical signs. As a consequence, many teens face disbelief from friends, family and health professionals (1-3). Although the prevalence of significant chronic pain in children and adolescents is approximately 8% (4), children and adolescents with chronic pain seldom have peers with a similar chronic pain experience and, thus, often feel isolated (3).

Peer relationships, especially friendships, are important as a context in which adolescents can test and develop values and roles in the absence of adult monitoring, and refine social skills necessary to maintain peer relationships (5). These relationships appear to be instrumental in facilitating an adolescent's sense of personal identity and increasing independence from family influences (6). Friendships have been shown to ameliorate negative effects in various contexts, ranging

Vivre avec la différence : explorer le soi social des adolescents ayant des douleurs chroniques

HISTORIQUE : La douleur chronique nuit à la vie de l'adolescent, mais on ne sait pas grand-chose des répercussions sociales de la douleur chronique chez les adolescents. On en sait toutefois davantage sur les relations générales des adolescents ayant des douleurs chroniques avec leurs camarades que sur leurs amitiés proches. Les amitiés proches commencent à prendre plus d'importance pendant l'adolescence, car ces relations favorisent l'évolution de l'identité personnelle de l'adolescent et son autonomie croissante par rapport aux influences familiales. Ainsi, la douleur chronique peut créer des problèmes sur le plan de l'amitié pour les adolescents, en plus de ceux qu'ils vivent pendant leur trajectoire de développement et qui peuvent nuire à leur capacité de se doter d'un soutien social.

OBJECTIFS : Mieux comprendre les problèmes que les adolescents ayant des douleurs chroniques vivent sur le plan de l'amitié.

MÉTHODOLOGIE : Les chercheurs ont procédé à une étude phénoménologique d'interprétation au moyen d'entrevues individuelles.

RÉSULTATS : Deux thèmes ont émergé. « Repenser le soi avec la douleur » décrit la nature intrusive de la douleur chronique, mettant les participants au défi de repenser la manière dont ils se perçoivent et leur place dans leur réseau social. « Repenser ses amitiés » décrit l'interprétation des réactions de leurs amis à leur statut de douleur chronique, ce qui incitait ces adolescents à passer plus de temps seuls et à se sentir mal compris et non soutenus.

CONCLUSIONS : Les effets de la douleur chronique sur l'adolescent en tant qu'individu ainsi que les réactions des amis proches et d'autres membres de son réseau social ont donné lieu à l'apparition de nouveaux besoins sur le plan de l'amitié. Cependant, les adolescents n'étaient pas toujours en mesure de répondre à ces nouveaux besoins sur le plan de l'amitié. Leurs expériences laissent supposer que des facteurs peuvent être améliorés dans les amitiés grâce à des interventions, permettant de maintenir et de renforcer les amitiés proches.

from offsetting the negative adjustment effects for peer-victimized children (7) and buffering links between negative family environment and poor self-esteem (8), to acting as buffers against loneliness and depression in children (9). Friendships also provide individuals with affection, intimacy and reliable alliance (10). Clearly, peer relationships and friendships are crucial to the healthy development of children and adolescents.

However, the two are not the same. 'Peer relationships' is a broad category that includes classmates of the same age range, and members of sports teams and leisure activities. Research at this level typically involves a measure of peer group acceptance, a unilateral measure of an individual's popularity. 'Friends' describes a closer mutual connection and suggests a reciprocal relationship (5). Distinguishing descriptors for 'best friends', 'close friends' or simply 'friends' generally revolve around the amount of time spent with one another, shared interests, degree of intimacy and self-disclosure, and reliance on one another for

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support (5). Research measures of friendships are complex and can include self-report (one's perception of their mutual friendships and identification of their closest friend[s]) as well as measures that include reciprocal nomination to identify friends and ranking the level of one another's friendship. The majority of adolescents have at least one friend (11). During adolescence, romantic friendships start to emerge and may be classified as a type of close friendship given the degree of companionship and closeness (12).

Findings from a recent systematic review of quantitative studies suggest that children and adolescents with chronic pain conditions experience peer relationship and friendship difficulties. These children and adolescents may have fewer friends, experience higher rates of victimization and may be perceived by themselves and others as lonelier (13). The cause of these differences is not entirely known, but chronic pain does interfere with school attendance (14,15) and participation in leisure activities (15).

Previous qualitative research has described varying peer and friend experiences for children and adolescents with chronic pain. In one study, participants reported being blamed by friends for having pain (1). In other studies, participants stated that they faced disbelief from their friends but attributed this disbelief to their friends' inability to share a similar chronic pain experience, as opposed to deliberate malice or being blamed for having chronic pain (2,16). Experiences of disbelief were also expressed by adolescents with juvenile chronic arthritis; these participants did not describe reactions from their friends but expressed feeling disbelieved by classmates due to their fluctuating pain levels and needs, such as requiring crutches to walk on some days (3). Most of these studies did not solely focus on understanding friendships and, thus, little else is known about the factors that affect friendships for adolescents with chronic pain apart from missing time with peers and experiencing disbelief from others.

Friendship differences may also be attributed to factors other than missed time with peers and experiencing disbelief from others. Adults with chronic pain identify a profound change to their sense of self (17-19) resulting from the negative impact of chronic pain on physical, psychological and social health. Children and adolescents have been found to experience difficulty in integrating pain into their emerging sense of self and describe feeling different from their friends (16), suggesting that it is possible that adolescents, like adults, experience similar changes to their self-identity, which then influence their social interactions and friendships.

The purpose of the present study was twofold: first, to explore peer relationships and, particularly, close friendships of adolescents with chronic pain to understand and identify factors that affect these relationships; and second, to explore the qualities and characteristics of friendship interactions of healthy adolescents to gain a more in-depth and nuanced understanding of the impact pain has on these relationships for adolescents with chronic pain. The inclusion of healthy adolescents was determined to be necessary because no qualitative studies were found that explicitly captured supportive and nonsupportive friendship experiences from this population and/or examined the impact of a chronic illness on close friendships from the healthy adolescents' perspective.

METHOD

Interpretative phenomenology, based on Heideggerian philosophy, was used to examine friendships of adolescents with chronic pain. A study informed by Heidegger's ontological philosophical writings focuses on the meaning of 'being' as derived from the perspective of an individual's position within time and place (20) and, thus, arises through the experiences of everyday life (21). The meaning of 'being' must be considered within the context of the past and present, which influences future possibilities and is shaped in relation to, and with, others as well as with structures in the world. Therefore, 'being' is never existent in isolation but is a subjective lived experience of 'being in the world' (22). In addition, interpretative phenomenological research extends understanding by way of the hermeneutic spiral, beginning with the

participant's interpretation of their own stories in the telling, and the researchers' (re)interpretation of these experiences, which is informed by the literature (20) and their own lived experiences (23). As a result, adolescents' individual experiences with peer relationships and friendships were interpreted from the analytical lens of the principal investigator and expanded by the coinvestigators to generate meaningful insights regarding the impact of chronic pain on the social process of friendship within this participant group.

Participants

For the present study, chronic pain was defined as nonmalignant continuous and/or frequently recurrent pain that has persisted for three months or more, regardless of the location or cause of pain (24). Pain associated with diagnoses such as juvenile rheumatoid arthritis or Crohn's disease, or pain of unknown origin, exerts a cluster of common experiences for individuals; the impact of pain on adolescent friendships, and not its location or etiology, was the focus of the present study. It is unknown whether pain location or etiology impacts friendships; however, the differentiation of pain location and etiology on friendships was not the intent of the present study.

Sixteen adolescents between 14 and 18 years of age participated in the present study. Eight of the adolescents experienced chronic pain; two participants were male, one of whom experienced chronic pain. The participants with chronic pain received care through a tertiary pediatric complex pain clinic and were invited to participate. Adolescents who seek treatment from a tertiary pain clinic represent those who have a pain condition that contributes to disability or has the potential to do so, and, thus, can be considered to be more vulnerable to disruptions in friendships. Inclusion criteria for the participants with chronic pain were that they experienced ongoing or recurrent pain for a minimum of three months, regardless of etiology or location of the pain, and could converse in English. Exclusion criteria were cognitive impairment and chronic pain associated with a life-threatening illness such as cancer. Life-threatening illnesses may impact social experiences differently, and the phenomena of chronic pain and friendships was the focus of the present study. Healthy adolescents were recruited through community-wide advertisement. Inclusion criterion for this group was the ability to converse in English. Exclusion criteria for this group included cognitive impairment, receiving care for an ongoing medical condition, and the presence of ongoing pain or recurrent pain that contributed to regularly missing school and/or activities.

The adolescents with chronic pain had experienced pain for at least eight months and several had experienced pain for many years. Their pain conditions varied and included widespread chronic pain, daily headaches and musculoskeletal pain. At the time of data collection, all participants with chronic pain were experiencing daily pain. Their average pain intensity scores ranged from 4 of 10 to 8 of 10, with exacerbations as high as 9 of 10 on a 0 to 10 numerical scale, on which 0 represents 'no pain' and 10 represents 'the worst pain imaginable' (25). All of the participants were in senior high school (grades 10 through 12). The adolescents with chronic pain reported school absences that ranged from one to three days per month to a total absence for six months. The healthy adolescents reported minimal school absences; only two had missed one day of school in the current school year. This sample of 16 adolescents provided data that were rich and of sufficient depth to capture friendship experiences; thus, no additional adolescents were approached to participate. Smith and Osborn (23) suggest sample sizes of five to 18 participants for studies using interpretative phenomenological analysis.

Data collection

Data were collected using individual conversational interviews (26), which enabled participants to feel comfortable discussing their friendships without concern of how their friendships may compare with other participants. An interview guide provided a flexible approach to data collection. Questions ranged from broad questions to more specific questions as required. The following are examples of the

questions used: 'Can you tell me about yourself?' 'What do you like to do with your spare time?' 'Can you tell me what it is like for you being a student?' 'What does it mean to you to have a close friend?' 'Can you tell me about your friends?' 'Can you tell me about a time when your close friends were supportive?' 'Can you tell me about a time when your close friends were not supportive?'. In addition to these questions, the healthy adolescents were also asked the following question: 'If you or your close friend had a chronic illness, how would you want to be treated by your friends, or how would you treat your close friend?'

Interviews were conducted by the principal investigator and lasted between 45 min and 90 min; all were audiotaped and transcribed. Interviews were conducted in a location selected by the participant and ranged from a private room in a hospital to a private table at a community coffee shop. Additional data came from two broad sources (field notes and published research literature).

Data analysis

Interpretative phenomenological analysis (IPA), as described by Smith and Osborn (23), provides a semistructured guide to analysis that adheres to principles and processes advocated by others (20,27). IPA is committed to idiographic inquiry, in which each interview is examined in great detail beginning with a close interpretative read of each transcript. In the present study, this first step also included listening to the audiotapes and reviewing the field notes for each interview. As each interview was examined, initial impressions of the text (codes) were noted. The codes identified for the first four cases in each group were then used for each subsequent case, with idiographic (specific to the interview) findings in each interview being noted during the initial read of subsequent interviews. Previous interviews were also reread to ensure that any new codes that had emerged in the subsequent interviews were noted if present.

A list of larger categories was constructed for each participant. These were then used to identify themes across participants with a list of quotes that depicted the theme. Maps of the two major themes and related subthemes with descriptors were created. Refinement of the themes occurred during the writing phase and enabled the literature sources to be more formally integrated into the themes (27).

IPA advocates that at least one other researcher review the themes to ensure that they are grounded in the transcripts and represented within the data with adequate examples and quotations. The inclusion of additional researchers in the analysis process is also advocated by Conroy (20) because it enlarges the hermeneutic spiral. In the present study, the first distinctive hermeneutic cycle occurred during the adolescents' own interpretation of their peer relationships and close friendships as they relayed these experiences to the researcher through an individual interview. Ongoing hermeneutic cycles continued as a process that spiralled outward and began with the principal investigator's analysis of these collective experiences. The cycles continued as the principal investigator delved into understanding the meanings embedded in these experiences in relation to her own experience and the literature, with ongoing dialogue and brainstorming with the second author. The second author also reviewed the transcripts to ensure that the analysis was grounded in the data. The hermeneutic spiral continued outward with the coauthors' reading of the analysis, and their additional interpretations were included in the final presentation of findings.

Goodness

Goodness has been advocated for evaluating the rigour within interpretative research (28,29) and was applied during the present study. Appraisal criteria for qualitative research are not viewed along a linear trajectory but rather describe an iterative process, moving back and forth between design and implementation (30). Thus, the six criteria of goodness – foundation (philosophical stance used to guide the study), approach (methodology to provide specific ground of the study's logic), method (explicitness about data collection and management), representation of voice (ensuring no one voice is dominant), art of meaning making (interpretation and presentation of findings) and recommendations (discussion of clinical and

research implications) – were considered and reflected on throughout the study. For example, foundation and approach were adhered to because the data collection, analysis and interpretation were guided by Heidegger's philosophical stance and interpretative phenomenology. Representation of voice was balanced throughout by ensuring that at least one quote from all the adolescents with chronic pain were included and that the voices of the healthy adolescents were included but did not dominate the analysis. Interpretation of the data was primarily performed by the first author; however, the second author reviewed the transcripts and the remaining researchers reviewed the analysis and the presentation of findings to ensure that the findings were grounded in the data.

Ethical considerations

Ethics approval was obtained from the Research Ethics Board of the IWK Health Centre in Halifax, Nova Scotia. Participation in the study was voluntary. Adolescents and parents were given assurance of confidentiality. Aliases were assigned and/or selected by the participants as part of the confidentiality strategy.

RESULTS

Two major themes were identified in the analysis ('Rethinking the self with pain' and 'Rethinking friendships') and are described below. Although themes represent abstract conceptualization of participants experiences of a phenomenon (31), absolute delineation of a phenomenon into parts is artificial because it negates the integrative experience of the whole. Thus, these two themes assist in bringing forth an understanding of the friendship experiences of adolescents with chronic pain in a concise retelling; however, overlaps between and among the themes exists.

Rethinking the self with pain

For adolescents with chronic pain, pain was intrusive in their lives from its onset and became more insidious with time, challenging them to rethink the way they viewed themselves and their place in their social networks. They were no longer carefree while engaging in social activities because pain had the potential to penetrate everything they did. For participants, pain was devastating and a catalyst to questioning their worth as a person, student and friend. Joanne (16 years of age) expresses the changes brought about by pain:

It's very hard to keep close friends when you can't go out every weekend, and you can't really make friends in advance and you have to take pills all the time. And you can tell that people are kind of like, uneasy around it or they don't fully understand. They want to ask, but they don't, and sometimes I'll sort of bring it up to answer their questions. But it always kind of seems like a downer, and it's always about the pain.

Integrating pain into the self: For the participants, missing out on activities they once loved and longing to be able to engage in activities as they had before the onset of pain was the first obvious sign of pain's negative impact. Julia (16 years of age) talked of how she used to take dance lessons:

Well during the school year I dance, but the last semester of school I missed a lot of it, so I don't know, I probably won't be doing as much of it this year because of my pain.

Here Julia discloses her belief in the continuation of her pain's disruption to her leisure activities and how the uncertain nature of pain ('I don't know') limits her plans in the immediate future. An inability to plan, even for the immediate future, in terms of the types of leisure activities they would be able to engage in was echoed by most of the adolescents with chronic pain. The frustration associated with no longer being able to engage activities is voiced by Lisa (16 years of age):

[I used to do] basketball and running, and a lot of walking, and well, actually it was during school, I was trying out for cheerleading, but my knee kept giving out, and they actually told me

that, that was from my nerve. Yeah, so I had to stop going to the cheerleading try outs, so that sucked.

Given the importance of school life during adolescence, it was not surprising that many of the participants with chronic pain used academics as a way to gauge the negative impact of their pain. All of these participants acknowledged missing school due to their pain. They also reported their pain as the cause of academic difficulties due to poor concentration, comprehension and retention of course material, with their difficulties ranging from modest to extensive. Kelly (16 years of age) clearly identified her pain as the barrier to achieving higher grades:

I studied like, every night. I study for my exams for a month in advance, I tried so hard. I passed all my courses, but not with the marks that I wanted. I think if I didn't have the pain, I would have definitely had way higher marks than that.

School as a social context took on an additional importance. Many of these participants had decreased their involvement in structured leisure activities, making school their primary location for socializing. However, due to pain, not all of the social interactions that occurred in school were positive. Rather than offering opportunities to feel connected and accepted, many interactions illustrated additional dimensions of living with difference. Here Natasha (15 years of age), who had experienced pain since childhood, describes her struggles with classmates:

They [classmates] just forget or they don't care, or they don't understand really, that I gained all the weight because I was on medication [for pain] and stuff, and they just don't understand it or want to understand it, they don't care or something, they're just mean.

Natasha describes her classmates as forgetting and uncaring, which contribute to feelings of stigmatization. Conversely, the healthy adolescents who participated in the present study experienced uncertainty regarding how to respond to a classmate's health problem, stating that they would like to keep a health problem private so that they can be regarded as 'normal'. Vanessa, a healthy participant (16 years of age), talked about her approach to a classmate with diabetes, illustrating a belief that her classmate did not want to discuss her illness:

I think it's better for her when it doesn't seem like she's any different. So if we don't know a lot of detail about it, then it's easier for her to feel normal.

Unfortunately, this seemingly disinterested approach by classmates was at odds with what many of the adolescents with chronic pain expressed as desirable from classmates and, especially, close friends. The perspective of their classmates as uncaring was becoming integrated into how they viewed others in their social network.

Not only did chronic pain impact participants' views of self in relation to the influence of pain on their personal leisure and academic pursuits, it was also a catalyst for the beginnings of a change in their worldview. Some participants believed that their pain experiences helped them mature more quickly compared with some of their peers who continued to engage in what they considered immature adolescent behaviour. Here Jason (18 years of age) describes the impact of his pain on his behaviour:

I feel like I grew out of a lot of things too, yeah. Because you're not into breaking things, and stupid things like that.

Perceiving behaviours and views of their peers as immature was shared by others, as identified in the following quote by Elise (15 years of age), who for the past two years has been experiencing daily pain:

If you really listen at school, you don't really hear anything of consequence – if you listen to the conversations that people are having, they're more concerned about their clothes, and you know, what someone else said about them, and it just doesn't really seem that big of a thing.

The need to adhere to treatment was identified as another experience that necessitated a mature approach to life. However, as Natasha

explains her need to be forward thinking compared with peers, the need to be more mature added a dimension of frustration and perhaps even envy of the seemingly simple lives of peers:

Adults think I'm more mature than most people and I think that might have something to do with having to be more responsible in thinking about, well, I can't do that because that'll make that happen. I can't just go and do it, and deal with the consequences later because it's too painful. So I have to think ahead, and most people my age, they don't think ahead, they can't see this far from their face. I have to think of the consequences, I have to remember to take my pills; I have to be more responsible. So I think that I grew up a little faster.

The perceived growth in maturity was not shared by all participants with chronic pain; a few disclosed feeling socially immature as a result of their pain, as described here by Joanne:

I think it's because the pain is affecting my social growth. I think it was more the pain that kind of limited me, like in high school age, just in kind of like growing more in that way. Like in more of a socially diverse group, I think that kind of kept me back more.

Despite the challenges of living with pain, participants were able to draw on an inner strength. They spoke with pride as they talked of finding their way forward. This process developed over time and was related to strength of self as opposed to a decrease in pain intensity. Despite having to stop dancing, Julia described her experience of moving forward, an experience that was similarly expressed by other participants:

I could be handling this whole situation differently, like I could just sit at home and be very depressed. I could be very depressed about this, but I'm not, because I can't. Because if I do that, it kind of puts an end to trying to get better. I'm still trying to figure things out, and I'm still trying.

Understanding and sharing about chronic pain: All of the participants with chronic pain were challenged trying to explain their pain condition and talked about their decision making when deciding to share information with others. Although there were some individual differences that guided their decision making, all of these adolescents were protective in their disclosures. One factor that may contribute to hesitancy in disclosure is their superficial understanding of chronic pain, as shared by Julia:

I don't really know what I have because we're still trying to figure it out. Well yeah, I mean I have something, like I don't really have anything, like I've done all kinds of tests and it shows that everything's fine with my stomach, but I guess I just have super sensitive nerves, so I guess that's what I have but there's no name for it. But I don't really believe it. And that's basically it I guess, that's all I really know about it.

Complicating the superficial understanding of chronic pain by these adolescents is that the general public has limited knowledge of chronic pain, and reports of chronic pain in the public domain have not all been favourable. This lack of understanding about chronic pain results in these adolescents encountering stigmatizing situations, which reinforce their decision to be guarded in their disclosure about their pain. For example, Joanne described being subjected to overt and repeated criticism by a teacher for using the elevator at her school despite her pain condition making climbing stairs extremely difficult. Despite trying to rationalize this teachers comment, similar to other participants, Joanne internalizes this negative experience:

This one teacher calls me the elevator mafia. And it doesn't matter how many times I talk to him or that the guidance counselor talks to him, like he thinks he's being funny and like that's great and wonderful, but you have to be able to differentiate funny from mean. Like I don't want to hear it. But it's annoying to have to say that to yourself, like – I do care what people think, I do care, because kids kind of look at me, why are you on the elevator?

The invisibility of their chronic pain condition contributed to the lack of understanding about chronic pain and disbelief by others, as Elise succinctly stated:

It's like an invisible enemy that no one really sees.

Living with an 'invisible enemy' aptly describes the predicament of these adolescents. As an enemy, it takes away their ability to be a typical developing adolescent and causes them to be viewed with skepticism by others. Pain followed them everywhere; it was now an inescapable part of their being.

However, the invisibility of pain enabled participants to maintain some sense of normalcy because most people could not tell that they had a chronic pain condition. Julia liked the fact that, when she walked down the hall in school, her fellow students could not tell that she had a chronic pain condition; her secret was not 'out'. Nevertheless, pain invisibility had the potential to create tension within close friendships, as she shares here:

Like the biggest thing that I wish is just that I could just show them [closest friends] what it's like, just make them realize what's happening to me every day. It's every day, like it's all the time. So it's really starting to take over my life and I don't even know if they realize that.

Explaining chronic pain to others was not necessarily helpful, especially when they were faced with disbelief. Kelly (16 years of age) exemplified the common experience of trying to explain her chronic pain condition, highlighting the negative side to its invisibility. Interestingly, these adolescents did not voice how their own superficial understanding of pain may contribute to their friend's difficulty in understanding:

Like if I had a cast on or something, they'd be like, okay, yeah, we understand. But when I don't have anything, it's like, I'm in pain, I don't expect you to understand a hundred percent, but I expect you to at least understand what I'm saying to you when I tell you like 50 times.

For adolescents with chronic pain, it was not only the repeat questions that affected their decision making when determining whether they should disclose or remain private. Lisa (16 years of age) spoke about her reasons for keeping her pain private in her discussions with her classmates for fear of even further stigmatization:

I don't really explain about the pain, I'd rather not put it out there, and then – because people change things around and they'd probably make up weird stories about me. I don't really like to talk to them about it, because I don't know, I kind of have the fear that if I do they're going to treat me different. And I don't want that.

For two of the participants privacy was paramount. They did not like to reveal their pain condition to anyone and tried to hide their suffering from teachers, peers and even family members. This preference for privacy demonstrates that living with pain is as individual as the pain experience itself. It may also reflect attempts to pass as normal and minimize being stigmatized by others. Jason spoke of keeping his feelings about his pain private, but with a cost:

A lot of times I hold in anger and stuff, like when I feel angry [about the pain], I hold it in and not show people that I'm angry, I'd be happy and joke around. It's all bottled in. I know that it's not healthy.

Rethinking friendship

Adolescents with chronic pain experienced changes to their friendships after the onset of pain, making them, at times, feel different from their friends during social interactions. To counter these feelings of difference, most adolescents with chronic pain placed limits on engagement with close friends. These changes in time spent with friends contributed to adolescents with chronic pain rethinking who their close friends were and the characteristics they desired in close

friendships. As a result of the impact of chronic pain in their lives and the reactions/responses they received from close friends and others within their social network, new friendship needs emerged.

Distancing the self: Pain initially interfered with participants' being able to join in sports and other leisure activities and attend school. Thus, avoiding these situations began as a need to retreat from regular activities until their pain had resolved. However, for these adolescents with chronic pain, avoiding activities took on a different meaning as they spoke of purposefully avoiding specific activities to guard against friends trying to push them beyond their abilities. Lisa talked of spending lots of time with her close friends but she never attended dances despite enjoying this activity "because they'd [friends] all drag me out to dance", which was something she felt unable to do. Participants with chronic pain expressed concern that they would not be able to deal with an increase in their pain brought on by physical activity, especially in the presence of others, leading to a public display of being different. Julia's comments capture this fear and its distancing implications in her life:

I get those [episodes of escalations in pain intensity] a lot, but that's why it's all so scary because it's just the worst situation to be in if you're not at your house. If you're somewhere else and you're having like 10 [out of 10] pain, like it's bad, so I always want to be at home if that's going to happen. I just kind of want to get out of wherever I am. I wish I could, and I'd love to be that type of person, like just do whatever, but I'm very close to my house a lot.

Distancing was also used as to protect against ridicule and put-downs that occurred when out with friends. As pointed out by Natasha:

Yeah, they just think we're like weak or something, and have low pain tolerance and they just think you're a wuss [weak].

The need to protect against suspicion and ridicule was evident when declining social invitations. For Kelly and others, making excuses became an effective distancing strategy:

I'll call them and I'll say, I'll make an excuse as to like, my mom said I can't go out tonight, or like I'll make an excuse as to why I couldn't go, Yeah, like, no, I just don't want to do it, so I would rather say that [instead of my pain].

The need to socially distance themselves from close friends and their greater social networks was not expressed by any of the healthy participants in the present study. Quite the contrary, healthy participants spoke of planning events, socializing and working with others. Spending time with close friends was described as being central to their adolescent lives. Yet, due to the high demands of their increasing social lives (organized leisure and sport activities, work commitments, time for romantic partners), much of the daily close friendship interactions for the healthy adolescents occurred during the school day. The following quote from one of the healthy participants, Beth (17 years of age), illustrated that even when they believe they are always together, this togetherness occurs predominately during school:

Oh yeah, we hang out all the time, we're always together. Not really [after school] that often, we're just more together all the time at school.

Participants with chronic pain understood that their close friends may have other plans, but as Natasha describes here, the unavailability of their close friends when they were ready to re-engage was frustrating and it contributed to further self-isolation at times.

I call them but then, since I haven't talked to them for a long time, they're busy and they can't do anything, and then I just kind of separate. So I'm kind of like by myself, and then I try to call them. I actually called some of them last night and they couldn't do anything, but it's kind of annoying because then you get to the point where you don't want to do anything, and you don't want to call anybody, and you don't want to do a thing but watch TV. And you just get in like a rut, and you don't want to do a thing.

The result of continuing to distance oneself from social interactions had detrimental effects because distancing led to isolation. Joanne discloses how she feels when she stays home:

Now I'm usually alone with me, myself and I. And usually I just end up completely internalizing everything there's no way to get any frustrations out. So usually I'm just like with myself. But it's when I'm by myself is when I'm the saddest.

Self-distancing was not a uniform experience. Two of the eight adolescents with chronic pain (Sherry and Jason) fought to remain engaged with their friends. Although they missed activities and school due to their pain and related appointments, they did not acknowledge engaging in protective distancing in close friendships. Sherry decided that she would rather endure pain and push herself to engage with friends, rather than be alone or feel different as a result of not spending time with friends and participating in activities with them.

Well it [pain] has [prevented engagement] before, but I try my best not to let it do that because I don't want to miss out on anything just because of pain. I'm like, whatever, just do it anyways, who cares if it hurts.

Jason also talked about the importance of staying connected with his friends but he acknowledged that this was not always easy. He talked of hiding his feelings on bad days so that even his close friends did not know the amount of pain he was experiencing.

If I was having a bad day, nobody would know because I like to hold it in. Sometimes when I want to blow up, I'll just think that they don't deserve me to treat them like that, and it feels bad, I shouldn't beat them up for it [being in pain], so I'll just end up saying a joke or something, calm myself down, go driving around with someone. Yeah, I like to be around lots of friends.

For participants with chronic pain who were also involved in romantic friendships, pain produced anxiety because it resulted in questioning whether their romantic friend would accept them if he or she knew about their pain condition. Some adolescents managed their fears of rejection by placing limits on their honesty about pain and by not spending time with their romantic friend when their pain was intense or might become intense in the social context. The following quote from Julia, who wished that her close friends would acknowledge the challenges she lives with, reflects the added vulnerability she experienced in relation to having a boyfriend.

I have a boyfriend now, which is kind of difficult but at the same time it's good. Like when I know I'm going to have a bad day, I won't hang out with him. Well because I just don't want him to know. It's just embarrassing.

Romantically isolating oneself can be understood as a protective strategy to help participants avoid rejection and judgment. Elise, who had been rejected by close same-sex friends in the past, described and defended her decision to isolate herself from romantic friendships:

I'm interested in guys, but I'm like, I don't really want to deal with that right now, and so I'd like to think that I'm getting better before any of it happens. How would someone like that react to it?

Joanne has decided to isolate herself from romantic friendship experiences and expressed concern to protect a potential romantic friend:

I don't feel right making a relationship about my pain or having that, like for a teen boy, he doesn't have to worry about my illness all the time. And there's time for that.

Like Elise, same-sex close friends had overtly rejected Joanne after the onset of pain. It may be that these earlier rejections from close friends contributed to their protective practices in romantic friendships. However, not all participants with chronic pain avoided romantic friendship possibilities out of a concern of rejection due to their pain. Rather, similar to some of the healthy participants, they cited a lack of opportunity or interest as the reason for the absence of a romantic

relationship, versus purposefully delaying this sort of friendship due to concerns about their worthiness as a result of chronic pain.

Needing a different quality in close friendships: Pain was a pervasive presence in their friendship experiences, creating a tension between a need for 'special' considerations and balancing this need with 'normal' friendship considerations reflecting their need to rethink their social self. Changes in friendship experiences were significant and described in terms of loss. Two participants experienced extreme social loss resulting from chronic pain; one captured its devastating impact when she described experiencing a 'social death'. The stories of these two adolescents share a similarity because both described being completely shut off socially by their close/best friends with no ability to stop this social segregation. Joanne spoke about how she was discarded by her longtime friends and, although she has moved on and found new friends, the memories of this experience are raw and continue to evoke emotional distress.

Well those kids, they let me die an emotionally social death, they just skewered me. None of them talk to me, and it's still like, it irks me and it's very painful, because I've known those kids for a decade, like lived with them, danced with them, we were best friends. And there were only four of us in the class. So we were very, very close, and then I was completely alienated.

Other participants voiced changes in their close friendships that were less severe but nevertheless distressing. Kelly (16 years of age) captured these experiences of social loss:

I'd say since I've had my pain, I've probably lost a couple of friends, that I thought were my good friends, obviously aren't.

Despite facing changes to their closest friendships as a result of their chronic pain condition, adolescents also spoke of positive aspects of their experiences such as understanding who among their circle of friends was a true friend. Elise, an adolescent who had been socially excluded by her closest friends, asserted:

I think of it as I really found my friends, and that it probably wasn't worth my time if they [previous close friends] would have dropped me that quickly.

Interestingly, Jason denied experiencing any friendship changes. He described his friends as still loyal and committed:

Yeah, like [they did] not ignore me for like out for months at a time, and still being as close with them when I come back out. They'd just come over [to visit when out of school].

Friendship changes and losses as a result of their chronic pain condition added another element of complexity to the social lives of these adolescents because it forced them to rethink the characteristics they valued in quality friendships. The list of characteristics of close friendships cited by healthy participants and those with chronic pain were similar. These included shared interests, more intimate disclosure, time spent together, emotional support and companionship, all of which are described in the literature (5,32). A noted difference is that participants with chronic pain emphasized trust, dependability, non-judgmental support and empathy about their chronic pain condition over compatibility and spending time together. These characteristics are at the forefront of how Elise, who had been previously rejected by close friends, now talked about her best friend:

I think they're [close friends] there for you more, I mean, one quality is they're extremely loyal, and they just don't – if you're in need or troubled or something, they'll listen to you instead of just being there out of convenience. It's really good to have her [best friend], and it's really good to know that she's there.

For all participants, close friends were an important resource in coping with stressful life experiences (ie, romantic partner breakups, poor marks in school, family difficulties) and, for the adolescents with chronic pain, this included their daily pain coping. Interestingly, the adolescents with chronic pain were able to state what they wanted from their close friends but, for the most part, they were unable to express these needs to their close friends. Sherry (15 years of age)

found friends calling when she missed school helpful, and clearly identified that she desired to be kept informed about the social activities she had missed. These conversations enabled her to feel some degree of normalcy, provided a distraction from her pain and confirmed that she was important to her friends:

I love being called anyways, but, that just makes it 10 times better because you're like, oh look, somebody's calling me, how nice. I don't want to talk about what's wrong, I just want to talk about, what did you guys do today, what was fun, what was some funny stuff that happened?

Participants also acknowledged that close friends could be a source of stress resulting in exacerbations of their pain. Kelly explained this dual effect as:

Some days when I'm with them and I kind of like, it helps me think about other things instead of sitting there thinking about my pain, and other times when I'm stressed or arguing with one of them or something like bad [happens], then it bothers me and the pain gets worse. Like they can have a positive effect on it or a negative effect on it.

Included in the descriptions of friendship interactions was a need to sometimes discuss their pain with their friends because the angst of living with such pain became unbearable at times. This is highlighted by Elise and echoed by others:

If everything's getting to be too much, you know, we'll [close friend and Elise] go for a walk or something. I mean, I just kind of lay everything on her, and then we'll just kind of sit there and ... it helps.

Participants also wanted their close friends to acknowledge their difficulty in living with chronic pain. Julia poignantly described the conflict between understanding her close friends' behaviour and her own desire for her close friends to affirm her pain. Other participants echoed similar desires which highlights their expectations of friends to verbalize empathy and support.

There's been lots of time when I want someone to understand, it's a lot better, but it's not really their fault. You know what I mean? It's not really their fault; they don't have the pain so they don't have to worry about it. But sometimes I just want someone to come up to me and be like, I know you're having a hard time right now, but that doesn't really happen.

Julie attributed the inability of her friends to empathize with her due to a lack of experience and understanding of pain and its imposed limitations, despite not believing the explanation she herself received for her pain condition. Other participants, who voiced greater frustration, perceived their friends to be self-centred and uncaring. Kelly, who described her friends as not always understanding her pain, described a situation in which her friends were unwilling to alter lunch plans to accommodate her needs:

There's a pizza place like a seven minute walk up the road, and then there's Subway [sandwich shop], which I like a lot, but Subway is about a 15 minute walk up the road or even longer than that sometimes, and some days I'm just like, can we just go to get a piece of pizza, please? And they're just like, no, I want Subway, like I don't want pizza today. And I'm like, well I don't want pizza either but I don't want to, like, I just cannot walk today, and then they'll argue with me and they'll be like, I don't know why you have to be so stubborn Kelly. I just go and I'm in pain that night, and I'm just like, I just wish you would understand why I don't want to walk to Subway today.

The experiences of the healthy participants in the present study suggested that an understanding of chronic pain is in contrast to their own experience of acute pain. Viewing the experiences of chronic illness through the lens of an acute illness or injury may result in healthy adolescent friends displaying behaviours that do not meet the needs of

an adolescent with chronic pain. In the present study, the healthy adolescents had little illness experience, and the experiences they did have situated illness/injury along a short-lived, predictable trajectory that ended in full recovery, as noted by Susan (15 years of age):

Yeah, a couple of years ago I got kind of sick. I had a throat infection so I missed about a week of school. Yeah, it wasn't that bad. I just went back to school, and at the time I was in middle school and so, I could miss a lot more time in middle school than high school, and it's easier to make up for it. So it was pretty easy going back.

In the absence of lived experience, healthy adolescents made assumptions about what they would need or want. For example, the predominate strategy offered by the healthy participant group describing how they would like to be treated by friends if they had a chronic condition is highlighted by Anne (16 years of age):

I don't know, I think I'd like them to react as normal as they could, even if I couldn't do certain things or go certain places. I'd want them to act the same way.

Not surprisingly, healthy adolescents' knowledge and skills in providing support to a close friend with chronic pain is outside of their experiential world. They were apprehensive about their ability to understand and discuss the issues of a friend with a chronic condition. Alicia (15 years of age), one of the healthy participants, illustrates this apprehension:

I feel more comfortable talking to my friends about like, relationships and stuff like that because they're going through it as well. But health problems, that's, I don't know. I'd just feel a little embarrassed if I was talking to my [close friends] – I'm not really sure.

DISCUSSION

'Re-thinking the self with pain' and 'Re-thinking friendships' describe the effect of chronic pain on the social lives of adolescents. The present study supports previous findings that chronic pain interferes with an adolescent's ability to participate in activities and contributes to greater school absence (1,3,14), but moves beyond simple absence from activities to the disruption these consequences have on one's view of self and engagement with friends. Similar to the findings by Muldrum et al (16), the adolescents in the present study struggled as they integrated chronic pain into their emerging view of self. They were no longer able to identify themselves by the activities that helped define who they were (eg, one participant was no longer a 'dancer'). These experiences acted as a continual reminder of their difference from peers, which accompanied them into their social interactions. Furthermore, the findings from the present study provide unique insights effects of chronic pain on adolescent friendships and the effects of friendship on an adolescent's chronic pain experience.

The negative effects of pain on academic abilities have been identified (14,33). However, the present study suggests a new social dimension to the challenge of chronic pain in a student's life. Teachers and classmates were perceived as asking questions that made participants feel unsupported and judged. Examples of such questions included reasons for their absences, details about their conditions, and justification for academic or physical accommodations. The frequency of being singled out by teacher or classmates asking such questions has not been quantified; however, similar occurrences have been found by others (16), suggesting a common stigmatizing experience for adolescents with chronic pain.

The feeling of being judged, disbelieved and different extended outside of school and into their social engagements with their close friends. All but one participant described social losses – which ranged from a change in the closeness of some friendships to outright rejection by close friends. They attributed these social losses directly to limitations imposed by their pain condition and responded, in turn, by socially distancing themselves. It may also be that the negative effects

of pain on one's view of self and negative reactions of others have created a heightened sensitivity to the unsupportive reactions of their closest friends – the people they count on for support. A recent vignette study found that adolescents with chronic pain interpreted nonsupportive social situations more negatively than controls, but there were no differences in the interpretation of supportive social situations (34). Among typically developing adolescents, negative responses by friends have been identified as egregious and not offset by the benefits of supportive responses (35). Negativity within friendships has been linked to adolescent maladjustment (36). Perhaps adolescents with chronic pain have experienced situations in which friends have not provided what they perceive as supportive behaviours when they have experienced pain in public, confirming the need to be selective in their social engagements even if their friends are supportive at other times.

The same vignette study found that adolescents with chronic pain, compared with controls, would exhibit more supportive behaviours in a variety of situations to help a close friend with chronic pain (34). This finding is understandable given that, in the present study, the healthy participants discussed not being knowledgeable or comfortable listening and responding to the challenges of a friend with a chronic illness. Goffman (37) identified distancing practices as a mechanism through which the discreditable individual (someone with a stigma that is not necessarily detectable on meeting) may be obliged to divulge their difference. Thus, for most of the adolescents, staying home was clearly the 'safer route' because managing their pain as well as reactions of friends in social situations was a major worry. The desire to hide differences may also have influenced participants' decisions to distance themselves from romantic friendships. For these adolescents, deciding not to engage in romantic friendships was viewed as positive, a way to control their life.

Regardless of the reason, social distancing had a negative impact on the lives of adolescents with chronic pain because it led to feelings of loneliness. Socializing is important in the development of one's sense that they matter and in forming a collective identity (38). By removing themselves from socializing with friends, adolescents miss key opportunities to develop this sense of social connectedness. Missed opportunities may be compounded by school absences, given that school is a primary socialization site. During absences, adolescents with chronic pain may not benefit from the protective benefits of close friendships, and are at greater risk of experiencing isolation as a result of being 'out of sight, out of mind' in the increasingly busy lives of their healthy friends.

Although adolescents with chronic pain listed other friendship characteristics, such as loyalty, as taking on more importance, time spent with friends remains a defining characteristic of close friendships for healthy adolescents. Participants with chronic pain decreased the time they spend with friends, which may be in direct opposition to what their close friends desire. Exchange and equity theories of friendship propose that friendships are based on a cost benefit ratio with the continuation of mutual beneficial exchanges being necessary to maintain the friendship (39,40). Close friends of adolescents with chronic pain may find themselves requiring alternative friends to fulfill their own friendship.

Although others (16) have identified that a lack of validation by physicians of their chronic pain condition contributed to an added sense of isolation and difference from peers, our study illustrates that validation from health care professionals alone does not prevent isolation and feelings of difference. All of the adolescents with chronic pain in the present study attended a tertiary pediatric pain centre and receive assurances of belief in their pain experience. However, feeling cared about, valued and included were central to the new friendship needs of adolescents with chronic pain. When new friendship needs were not met, they felt left out and even rejected by their close friends. Yet, to attain these needs and prevent misunderstandings, the participants were challenged to communicate their pain needs to even close friends. They believed that their close friends should know what they needed, but differences in the illness/injury experience between the

adolescents with chronic pain and healthy peers suggest that this is not the case. The healthy adolescents described a short acute illness/injury experiences from which they made a full recovery, as opposed to the chronic illness experience that was shaping the lives of the adolescents with chronic pain. Thus, close friends may not appreciate the difficulties when an illness is ongoing, especially in light of the difficulty that adolescents with chronic pain have in understanding and explaining their condition.

The adolescents with chronic pain discussed their perception of their increased maturity in some aspects of their life. It was unclear what impact, if any, perceived maturity or immaturity had on their ability to engage and understand their healthy friends. Many of the adolescents with pain voiced a lack of patience with the challenges of typical adolescent development. It is possible that a change in an adolescent's perception of their development as a result of chronic pain is disruptive to friendships. Friendships are reciprocal relationships; if adolescents with chronic pain no longer identify with the interests of their peers, their acceptance, even by close friends, may be compromised.

Clinical implications

Clinicians need to explore with adolescents the changes to their close friendships since the onset of pain to assist them in identifying strategies to manage these friendships. Adolescents with chronic pain can assume a more active role in maintaining their friendships by initiating contact with their friends when they are absent from school and suggest social activities they feel capable of completing. Clinicians should also work with adolescents on concrete ways to describe their chronic pain because it may improve their ability to communicate their condition in a way close friends understand.

Finally, it may be beneficial to help them reframe what they perceive as negative behaviours by friends and classmates to positive behaviours. For example, instead of believing that their close friends or others are uncaring because they do not ask about their pain, they may have a more positive view of self if instead they understood their close friends and others were indeed trying to be caring but were unsure how best to express this. By not prying or appearing to take an interest, close friends and others may be trying to help the adolescent with chronic pain feel 'normal' in their social relationships.

Research implications

Close friendship changes and losses were identified. Research into the immediate and long-term effects of these friendship changes and losses is warranted. Only two males participated in this study (one of whom had chronic pain), and the experiences of these two males were aligned with research that suggests close friendships of adolescent girls and boys differ in some ways (41). Research that includes an analysis of sex differences in close friendships and the impact of chronic pain on these relationships is needed.

The majority of North American adolescents will have approximately four romantic friendships before leaving high school (42). For some of the participants in the present study, pain either prevented them from moving along the normal adolescent trajectory of establishing romantic friendships or added a dimension of complexity not experienced by healthy participants. Future studies should examine whether this delay in romantic friendships has a negative impact on the development of romantic relationships later in life.

Adolescents with chronic pain developed new friendship needs. Studies are needed to determine the best approach to help adolescents secure these new needs. However, it is unknown whether securing these new friendship needs will lead to improvements in social functioning, and this needs to be examined.

CONCLUSION

Adolescents with chronic pain reported a changed view of self, which accompanied them into their close friendships. Their perception of their close friends' and others' reactions to their pain contributed to the development of new friendship needs. However, in many circumstances, these adolescents were unsure about how to secure these

needs. The findings from the present study suggest that adolescents with chronic pain view close friendships through a chronic pain lens, whereas healthy adolescents may view pain conditions through an acute illness/injury lens. These different lenses offer a beginning framework for understanding the changes that occur in the close friendships of adolescents with chronic pain and provide insights into potential social interventions to mitigate negative consequences.

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