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Socio-developmental challenges faced by young people with chronic pain: A scoping review

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Abstract

Objective – Map the current literature investigating autonomy development, identity development, and peer relationships in young people aged 10-24 years with chronic pain.

Methods – A scoping review method was used to systematically search four databases (APA PsycNET, PubMed, Web of Science, and Cinahl) for peer reviewed articles. Search results were screened against inclusion and exclusion criteria to ensure they met the objective. Eligible papers were assessed for quality, their data relating to the objective were extracted, and results synthesized.

Results – Searches returned 3815 papers after removal of duplicates, with 42 papers included in the full review. The majority of papers investigated peer relationships (86%). Fewer papers investigated autonomy (43%) and identity (21%) development. Included papers were mostly quantitative (64%), with fewer qualitative (34%) and mixed-methods papers (2%). Overall, we found bi-directional relationships between chronic pain in young people, their social development, and a range of functional outcomes. However, the mechanisms underlying these relationships remain relatively unexplored.

Conclusions – Review results are mapped onto the model proposed by Palermo et al. (2014). Guided by this model, clinical treatment for young people with chronic pain should consider social development. The model also sets out a future research agenda focused on exploring: 1) identity development, 2) the mechanisms underlying the relationships between social developmental domains, pain, and outcomes, 3) a variety of participants and populations, and 4) a variety of methods, including longitudinal study designs.

1. Introduction

The World Health Organization (WHO) defines young people as those age 10-24 years old (World Health Organisation, 2014). This developmentally crucial time marks the transition from childhood to adulthood, and encompasses three key social developmental domains; the development of autonomy, personal identity, and changes in the dynamics and importance of peer relationships (Kroger, 2015; Smetana, 2017; Wrzus et al., 2013). Autonomy concerns the ability to make choices and exercise control over one's life (Grolnick et al., 2017), and is developed through the transfer of responsibility from parent to young person (Tilton-Weaver & Marshall, 2017). Personal identity can be defined as a unified sense of self (Kroger, 2015). Peer relationships have a greater influence on the behavior and attitudes of young people than at any other time of life (Smith et al., 2013; Wrzus et al., 2013). These developmental domains are important in their own right, but also interact and influence each other (Daddis, 2011).

Beyond normative social development, some young people face additional challenges posed by living with long term health conditions (O'Donohue & Tolle, 2009), such as chronic pain. Chronic pain is defined as pain that lasts for more than three months and can be classified as either primary or secondary pain (Treede et al., 2015). Chronic pain conditions are commonly reported by young people (Gobina et al., 2019), and they report judging themselves to be developmentally behind their peers in many areas, and ahead in other areas (e.g. Eccleston et al., 2008). Specifically, chronic pain appears to be related to developmental delay in educational achievement (Logan et al, 2017; Logan et al, 2008), autonomy (Eccleston et al., 2008), and peer relationships (Forgeron et al., 2010), compared to developmental enhancement in problem-solving (Eccleston et al., 2008) and emotional

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maturity (Jordan et al., 2018). These negatively perceived developmental outcomes appear to be associated with long term consequences (Murray et al., 2020). However, there are no reviews which synthesize the literature on the social development of young people who have chronic pain. Therefore, a review of the literature which explores the autonomy, identity, and peer relationships of young people who have chronic pain is needed to provide a clear overview of the current evidence, and identify gaps for future research.

In this scoping review we aim to identify what is known about the development and maintenance of autonomy, identity, and peer relationships in young people who experience chronic pain across qualitative and quantitative research approaches, including cross-sectional, longitudinal, and interventional designs. The protocol for this review was uploaded to Open Science Framework prior to starting the search and is available here: <https://osf.io/6sz82/>. Cancer pain will not be included in this review due to a differential in the literature which represents cancer pain's unique presentation and associated challenges. Romantic relationships will not be addressed in this review as they are explored in detail in a separate ongoing scoping review (see <https://osf.io/7bkvm/>).

2. Methods

2.1 Scoping Review

Scoping reviews are appropriate when one aims to map the literature and provide an overview of the evidence in a given field (Munn et al., 2018). Consequently, a scoping review was deemed most appropriate for our aims. In this scoping review we were guided by Arksey and O'Malley (2005) and Peters et al. (2017) and employed a three stage-process: search strategy, paper screening, and data extraction. In addition, we conducted an

additional stage to assess the quality of included papers. As this is outside the traditional remit of a scoping review, this has been included in supplementary material 2.

2.1.1. Stage One – Database Searches

The first author (AFJ) conducted the literature searches in four databases: APA PsycNET, PubMed, Web of Science, and Cinahl. Table 1 shows the search strings used for APA PsycNET. In each database, individual searches were conducted for each developmental domain (i.e. autonomy, identity, peers). No date criteria were set when conducting the searches as previous literature did not indicate a date to use a cut off. All searches were limited to the title and abstract fields using the age and pain search strings, with then the autonomy, identity or peers string added to each search respectively. Initial searches were conducted in July 2018 and updated searches conducted in September 2019. All identified papers were uploaded to Covidence (www.covidence.org).

2.1.2. Stage Two – Paper Screening

Following database searches, 5928 papers were identified, with duplicates (n= 2,113) removed automatically through Covidence. All titles and abstracts of included papers (n=3,815) were screened by the first author (AFJ), and to ensure rigor, ALJ screened 50% of the papers in the title and abstract stage, conflicts were resolved by LC. The title and abstract screening focused on excluding papers which clearly met the following exclusion criteria. Papers were excluded if they: were review papers, editorials, letters, commentaries, books, case studies, theses, dissertations, or book chapters; focused solely on romantic relationships; did not include any exploration of autonomy, identity, or peer relationships; did not include any participants aged 10-24 years; only included participants whose pain appeared to be a secondary concern; or only included participants whose pain was due to

cancer. Papers were retained at this stage of the selection if no clear decision on meeting the exclusion criteria could be made based on the title and abstract.

Following title and abstract screening, full text of eligible papers (n=231) were subsequently all double screened by AFJ and an independent colleague SB, whose contribution is acknowledged, with conflicts resolved by LC. The full text screening focused on including those papers that met the following inclusion criteria. Papers were included in the review if they: were peer reviewed journal articles or conference abstracts (including exploratory and intervention studies); reported on original findings; reported findings which addressed issues around autonomy, identity, and/or peer relationships in young people who experience chronic pain; were written in English; had participants aged 10-24 years old, and reported the results for this age range separately if there were also participants outside of this age range in the study; had participants who experienced chronic pain as their primary concern; or had participants who did not have cancer.

As a result of the screening process, 42 papers were included in the review. These papers were all peer reviewed journal articles as no conference abstracts were returned in the searches. No authors were contacted as no additional information was required. See Figure 1 for a detailed overview of the reasons for exclusion. [Figure 1 here]

2.1.3. Stage Three – Data Extraction

Data extraction of included papers was completed by the first author (AFJ). Each paper was given a unique identifying code as show in Table 2. Data were extracted using a template extraction form (see supplementary Table 1), which included general details of the paper (i.e., authors, year of publication, and location of the study), aims (i.e., study hypotheses or research questions), methods (study design, and specific methods, measures,

analyses used), and any relevant results relating to autonomy development, identity development, and peer relationships. For intervention studies, data from all time points were extracted. For studies that included participants outside of the 10-24-year-old age range, only data from the participants within that range were extracted. Data extraction entries (one per paper included) were checked for rigor and accuracy by research assistants SB, EN, AJ, SA, and PA (see acknowledgements). This involved comparing the data entered into the extraction spreadsheet against the full text for each of the included papers. Only minor errors (such as typing errors) were identified.

Following data extraction, a two-stage process was conducted to produce the results presented in section 3. The first stage of this process collated the data shown in section 3.1, where Table 3 gives an overview of the characteristics of included papers. These data were collected by using the extraction records to decide the most appropriate categories for each paper, such as whether the paper adopted a cross-sectional or longitudinal design. This categorization mostly reflected the original authors' description; however, in several cases this involved further interpretation of the paper. For example, a paper may not have explicitly stated that it was cross-sectional, but only gathered data at one time-point, so was categorized as cross-sectional. Although some categories were mutually exclusive (e.g. longitudinal and cross-sectional) many papers were included in multiple categories within the same area (e.g. explored both autonomy and identity). The second stage collated data for the knowledge synthesis presented in 3.2. This involved reviewing the data extraction records for each domain and identifying common findings and methodological features.

2.1.4. Stage Four – Quality Assessment

The first author (AFJ) conducted a quality assessment using the tool outlined in Alderfer et al. (2010) (see supplementary tables 2 and 3 for full criteria and results). This tool has been used in reviews (e.g. Psihogios et al., 2019) in related topics and is therefore considered appropriate for this review. However, in this review the quality assessment tool was used solely for generating further information about papers, and no papers were excluded as a result of quality ratings. Using this tool, each paper received a rating between 1 and 3 regardless of methodology, enabling direct comparisons of methodological quality across papers. These assessments were not independently rated, therefore inter-rater reliability scores are not relevant. However, each of these assessments were checked by research assistants for rigor following training with the first author (AFJ). This training involved reading the Alderfer et al. (2010) paper, and discussion of each criterion. The research assistants reported no disagreements with the quality assessment

3. Results

3.1. Overall Results

We identified 42 papers that met the inclusion criteria. As shown in Table 3, included papers were published between 2000 and 2019, and were primarily quantitative (n=27), with fewer qualitative (n=14) and mixed-methods papers (n=1). All the quantitative papers used questionnaires, with two also using vignettes (15) or diaries (20). Most of the qualitative papers used interviews (n=13), with three using them in combination with focus groups (02, 30) or a writing task (41). One paper (16) used focus groups only. Over half of the papers (n=27) explored one domain (autonomy n=6, identity n=0, peers n=21), with some (n=9) addressing 2 domains, and fewer (n=6) addressing all 3 domains.

As Table 3 illustrates, there was a dominant female focus across papers, with a mean of 68% of participants across all papers being female. Additionally, of the 14 papers which included parent report 75-100% (mean = 92%) of these were mothers, although several papers (n=5) did not provide information on the sex distribution of the parents. Most papers (n=24) explored pain conditions in general, with others focusing on specific conditions such as Juvenile Idiopathic Arthritis (JIA), although no papers explored Complex Regional Pain Syndrome (CRPS) specifically.

3.2. *Developmental Domains*

3.2.1. *Autonomy*

A total of 18 eligible papers discussed autonomy development. Half of these papers adopted quantitative methods (n= 9) with slightly fewer qualitative (n= 8) papers, and a single mixed-methods (n=1) paper. Nearly all the papers were cross-sectional (n=17), with only one paper using a longitudinal design and only three of the papers included a non-pain comparison group. All papers in the autonomy domain included young person self-report, with some (n=8) including parent reports. Eight papers explored autonomy in young people with chronic pain in general, with no specific diagnosis under investigation, with the other papers specifically looking at those with sickle cell disease (n=1), Juvenile Idiopathic Arthritis (JIA) (04, 30), fibromyalgia (n=27, 34), headache/migraine (n=07, 20, 25, 31), and back pain (11). There did not appear to be any particular differences in the findings reported across these conditions, so we collated the results and present them in an overall synthesis.

A range of definitions and descriptions of autonomy were adopted across papers, yet all included the fundamental concept of freedom to choose for oneself and control over one's life. Autonomy was included in the study aims of seven (01, 20, 26, 27, 31, 34, 40)

papers with four of these using direct measures of autonomy (01, 20, 26, 31), and three using proxy measures such as controlling family environment (27, 34, 40). These proxy measures are not validated measures of autonomy, but measure constructs which have relevance to autonomy. The remaining 11 papers did not specifically include autonomy in their aims. These papers reported results related to autonomy but their aims were to qualitatively explore participant's experiences (02, 04, 23, 25, 29, 30), explore social development in general (07, 08), explore health-related functioning (09, 11), or explore identity development (36).

Across the 18 papers, a wide range of outcome measures spanning mental health, family, education, and physical areas were used. Overall, the papers consistently reported that age-appropriate autonomy was associated with positive outcomes, and lower levels of age-appropriate autonomy were associated with poor outcomes, regardless of the methods or outcomes used. One paper (26) reported this relationship after controlling for clinical factors such as pain intensity, and another (34) reported that autonomy at baseline predicted outcomes at follow-up for those with fibromyalgia but not for non-pain participants. Five papers (04, 23, 25, 29, 30) reported that participants perceived a relationship between their condition and their autonomy development. These findings suggest a possible interactional relationship between autonomy, pain and health status, and other outcome variables such as depression, anxiety, and family functioning. However, such relationships need to be explored further before further conclusions can be drawn.

Another common finding across 12 of the papers (02, 04, 07, 09, 11, 23, 26, 29, 30, 34, 36, 40) was how autonomy was related to the young person's relationship with others. In seven of these papers (07, 09, 26, 29, 30, 34, 36) autonomy was related to familial

relationships, with familial support aiding, and parental control or poor family functioning restricting, the development of age-appropriate autonomy. Other papers reported relationships between autonomy and support in general (04, 23), medical support (11), teacher support (40), and mentoring other young people who experience chronic pain (02). Three of these papers (02, 04, 23) reported overlap between the autonomy and peer relationships domains, with two papers reporting links between the autonomy and identity domains (04, 36).

3.2.2. Identity

A total of nine papers explored issues around identity, with a dominance of qualitative papers (n=8) in this domain and just one quantitative paper (n=1). Only one of the papers (36) specifically aimed to study identity, with others aiming to explore development in general (08, 23) or participants' experiences (02, 04, 13, 16, 29, 37), but nevertheless reporting specific findings relating to identity. All the papers exploring identity used a cross-sectional design, with mean ages of participants ranging from 14-20 years. Interestingly, a single paper included data from parents (36), and none of the papers included teacher or clinician reports. Just one paper included the use of a non-pain comparison group (13), and nearly all (n=8) of the papers explored chronic pain conditions in general, with only one paper (05) exploring a specific condition (JIA). Therefore, it is unclear how these identity issues change over time, or differ between different conditions and from those faced by young people without pain.

Overall, the papers in this domain suggest that chronic pain in young people has a negative impact on identity (04, 08, 13, 16, 23, 29, 36, 37), with one paper (02) suggesting the potential for the positive impact of helping others through the development of a

mentoring identity. The negative impacts on identity appear to be due to participants' internalizing their experiences of isolation and perceived stigma around their condition, and in doing so, integrating pain as a central part into their identity. In several papers (04, 13, 16, 23, 29, 37) this integration was closely linked with peer relationships. This link appears to be through three main pathways; how young people perceive themselves in comparison to peers (13, 16, 23, 37), how young people perceive that their peers view them (04, 23, 29, 37), and how pain can foster a sense of isolation from peers (13). Common throughout narratives was a sense of wishing to be, and to appear, "normal" in reaction to pain becoming a defining feature of the young person's identity (04, 16, 29, 37).

3.2.3. Peer relations

Most of the papers (n=36) included in this review explored some aspect of peer relationships, and these were mostly quantitative (n=22) with fewer qualitative (n=13) papers, and one mixed methods paper. Over half (n=20) of the papers specifically aimed to explore peer relationships. The remaining 16 papers within this domain aimed to explore social development more generally (03, 07, 08, 23, 33) or explored the experiences of young people who have chronic pain (04, 06, 09, 11, 16, 17, 25, 29, 36, 37, 41), but still reported specific findings related to peer relationships. In this domain, only two papers (22, 42) adopted a longitudinal approach, although a relatively large proportion of the papers (n=13) included a non-pain comparison group. Most papers explored pain conditions in general (n=23), with others specifically investigating sickle cell disease (17), JIA (04, 28), fibromyalgia (24, 27), headaches or migraines (07, 20, 39, 41), back pain (11, 42), and abdominal pain (19, 06). As with the autonomy domain, there did not appear to be any differences in the results across these conditions and so we present the results altogether.

Overall, the main finding across the papers included in this domain is that pain conditions in young people appear to be related to a range of specific features of peer relationships, and that this relationship is bi-directional. These specific features were reported by 22 papers, with the remaining papers (n=14) reporting more general results. The dominant results across the papers reporting general results suggest that problems with peer relationships are related to a range of negative outcomes such as anxiety and depression (03, 05, 12, 20, 25, 32, 42), and there is some evidence suggesting bidirectional and mediation relationships between depression and anxiety, peer relationships and pain (05, 42). There is also some evidence to suggest that young people who have chronic pain may interpret peer relationships and social situations differently to their peers (15, 39); benefit from contact with peers who also have pain (02, 14); be over-reliant on parents to the detriment of peer relationships (09); be able to have good friendships or show little difference to non-pain peers (11, 39); and that there may be gender differences (28).

With respect to papers within the peers domain that reported on specific features, the most common finding was that participants with pain reported a sense of difference from peers, that pain sets them apart, and a desire to be 'normal' (n=8; 04, 06, 07, 13, 16, 17, 23, 29). This was either reported as a general sense of difference (04, 17, 23), or specifically as being related to the participant's physical limitations or their peers not understanding their pain condition (06, 07, 13, 16, 29). Three papers also reported that participants limited pain-related disclosures to their peers in an attempt to appear 'normal' and reduce the perceived difference between them and their peers (13, 16, 17).

Related to this sense of difference, seven papers reported a sense of loneliness and lack of friendships in young people with pain (n=7; 06, 24, 29, 33, 36, 37, 41). There was

little variability across these papers, providing evidence that young people who have chronic pain tend to experience a lack of friendship and are at risk of loneliness. This loneliness may be connected to physical absence (33, 37, 41), although there is some evidence that it is more than a simple function of time spent with friends and is connected to the sense of difference described above (06, 29).

Another common specific finding reported was a potential relationship between pain in young people and peer victimization (n=8; 10, 18, 19, 21, 22, 35, 37, 38). For young people who have chronic pain, victimization appears to have direct (10, 19, 21, 35, 37, 38) and indirect (10, 18, 19, 22, 35) associations with a range of outcomes such as pain, functional disability, school functioning, and social functioning. Six of the papers that reported findings related to peer victimization included a control group (10, 18, 19, 21, 22, 38), however only four (18, 19, 21, 28) of these reported results suggesting that those who experience chronic pain may experience different levels of peer victimization.

Finally, three papers (08, 27, 38) reported results suggesting that positive peer relationships have an adaptive and protective function as they were associated with positive outcomes such as reduced pain and depression, and higher levels of physical functioning and mental wellbeing.

4. Discussion

This review included a total of 42 papers addressing autonomy development, identity development, and peer relationships of young people who experience chronic pain. This is the first review to provide an overview of the evidence in this area. The majority of these papers employed quantitative methods and reported results on peer relationships, with fewer reporting on autonomy development, and only a handful reporting on identity

development. Overall, there is evidence that chronic pain in young people is associated with negative social developmental outcomes, however further research is needed to explore these outcomes in detail and identify the underlying mechanisms of the associations among pain, social developmental domains, and other functional outcome measures. Included papers reported common findings across studies exploring chronic pain conditions in general, and specific conditions in which pain is a dominant feature. However, there were relatively few papers exploring each specific condition, and no studies focusing on CRPS. It is therefore important that future research explores social developmental issues both across and within conditions.

The findings of this review suggest that there are complex relationships between chronic pain and social development in young people. The model proposed by Palermo, Valrie, and Karlson (2014) provides a useful framework to understand the mechanisms underpinning these relationships. This model integrates previous models of chronic pain in young people and suggests bi-directional relationships between the young person, parent, and family level variables. Each of these levels can be further subdivided; young person level variables for example include biological factors, emotional state, functional disability, and individual perceptions and responses to pain. Finally, the model incorporates a developmental perspective which highlights how the relationships between these variables differ, and change over time, with age and developmental stage of the young person. Figure 2 shows how the results of this review map onto this model, providing a structure to develop our understanding of the mechanisms driving the relationships. However, Figure 2 also shows the results from this review which are currently unable to be mapped onto the model. For instance, although this model can be applied to the peer relationships domain,

the overall results from this review provide substantial evidence that peer level variables are highly influential in other areas of social development. Therefore, in addition to the young person, parent, and family level variables, an amended model including peer level variables may provide a more nuanced and detailed explanation of chronic pain in young people. Such a model would help to move the literature forward and begin to build more detailed models and theories for each of these social developmental domains. [Figure 2 here]

The methods used by the included papers were mostly questionnaires and interviews, therefore there is a need for a greater variety of methods. For example, to ensure that the literature explores each of these domains comprehensively, it would be useful for future research to use creative methods such as story completion (see Clarke et al., 2019). This review did not include an examination of the psychometric properties of the measures used in the included papers. However, there is an identified need for a measurement-related review to provide a detailed examination of measures used to assess social development in adolescents who experience chronic pain. In addition, future research would benefit from the inclusion and comparison of multiple perspectives. As perhaps to be expected, all the papers in this review included self-report; however relatively few included parent, teacher, or clinician reports, precluding any comparisons of similarities or differences in perspectives. Across the papers included in this review, the participant samples had an overall mean of 69% females, with participant samples 95% female in some papers, potentially creating a sex bias within the literature. However, the sex balance of the papers may simply be a reflection of the population under investigation (Gobina et al., 2019). Nevertheless, there may be sex differences which are under-studied and may be of particular importance when in the context of the development of young people, where sex

differences in social development have been well documented (e.g. Gyberg & Frisé, 2017; Molloy et al., 2014; Poulin & Chan, 2010). Furthermore, the majority of the papers included in this review were conducted in the USA (n=18), Europe (n=17), or Canada (n=6), we have limited knowledge about how chronic pain affects young people across different populations. Finally, future research needs to include more longitudinal and high-powered studies. Nearly all the papers included adopted a cross-sectional design and although this is often the more achievable option, it is problematic when exploring developmental issues because such designs do not allow temporal study. Additionally, there was a lack of high-powered quantitative papers in this area. Overall, these suggestions for future research build on recommendations from previous reviews which identified a need for more research to adopt a developmental perspective and longitudinal approach (Palermo et al., 2014), and exploring familial influences in the development of young people with chronic pain (Schinkel et al., 2017).

Clinically, the review suggests that autonomy, identity, and peer relationships are related to pain and other targets of treatment such as school functioning, anxiety, depression, and disability. This review also suggests that for young people, these social-developmental domains have an important role in their quality of life. Incorporating these developmental domains into clinical assessment and interventions could help to individualize treatment and enhance treatment outcomes. School appears to be an important social as well as educational context, and peers may play an important role in both developmental tasks and treatment outcomes. Additionally, it is well known that parents can have a substantial impact on the clinical outcomes of young people who have chronic pain (e.g. Eccleston et al., 2012). Any clinical intervention supporting a young

person's autonomy development would also need to include parents as they have a key role in this developmental process. The model in Figure 2 could help to guide such interventions as it provides a structure for how developmental and clinical outcomes may be interconnected. The model also includes recognition of the importance of the age and developmental stage of the young person. However, as none of the included papers explored these social developmental domains in the context of treatment, further research is needed in this area.

In conclusion, although there are many papers included in this review, the current literature around the social development of young people with chronic pain is somewhat limited. There is, however, a consistent picture emerging that pain is related to unwelcome changes in the developmental domains of autonomy, identity, and peer relationships. There are clear directions for future research, specifically a need for a variety of methods, a review of measures, and the inclusion of a wider variety of participants and cultures. Additionally, there is a need for a focus on identity development, clinical research, and use of models to guide research exploring the mechanisms underpinning relationships between social development and chronic pain. As the social context within which young people are developing is continually evolving, research should also evolve to stay relevant.

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