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Which passengers are on your bus? A taxonomy of the barriers adolescents with chronic pain face in achieving functional recovery

Running head: Barriers to functional recovery in adolescent chronic pain

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Statement of Significance: Explicit identification of adolescents' individual barriers towards obtaining functional recovery could be critical to enhance the adolescents' motivation to engage with and adhere to recovery intensive interdisciplinary pain treatment.

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Abstract

Background: Despite evidence that intensive interdisciplinary pain treatment (IIPT) is effective in facilitating functional recovery in adolescents with chronic pain, engagement with IIPT is suboptimal amongst adolescents. A key aspect of IIPT is to support functional recovery via (re)engagement with age-appropriate daily activities. The aim of this study was to gain a comprehensive insight into adolescents' perceptions of the barriers they need to overcome to engage with age-appropriate activities in order to achieve functional recovery.

Methods: Forty-one adolescents who were starting an IIPT program completed the 'passenger-on-the-bus metaphor', an exercise in which they identify and describe their perceived barriers (i.e., 'passengers' on their bus) that prevent them from engaging with age-appropriate activities. The responses were analysed using inductive thematic analyses to generate a taxonomy of perceived barriers to functional recovery.

Results: We generated a taxonomy of seven different barriers that participants described facing on their road to functional recovery: physical constraints, being 'fed up', low self-confidence and self-esteem, perfectionism, avoidance of engagement with pain, feelings (such as sadness, anger, guilt, anxiety), and social barriers (received from a range of sources such as parents, friends, school, and wider society).

Conclusion: The findings reveal a variety of barriers that were perceived to hinder functional recovery through reduced engagement with age-appropriate activities and thereby hamper progress within IIPT. The passenger-on-the-bus metaphor can be used to identify similar barriers faced by adolescents in an individualized treatment approach, thereby making it possible for clinicians to target their IIPT more precisely.

1. Introduction

Paediatric chronic pain is continuous or recurrent pain lasting longer than three months (American Pain Society, 2001), which can interfere significantly with daily functioning (Gauntlett-Gilbert & Eccleston, 2007; Logan et al., 2008; Long et al., 2008) and represents a significant economic burden on the healthcare system (Coffelt et al., 2013). Optimal, evidence-based treatment for paediatric chronic pain requires an Intensive Interdisciplinary Pain Treatment (IIPT) care approach, which integrates at least three disciplines (e.g., medicine, psychology, physiotherapy) (Hechler et al., 2015; Odell & Logan, 2013). IIPT has shown to be cost-effective and successful in reducing health care utilisation and functional

disability in adolescents with chronic pain (Evans et al., 2016; Hechler et al., 2015; Odell & Logan, 2013). One central goal of IIPPT is to improve physical and psychosocial functioning through stimulating adolescents' engagement with age-appropriate activities. Engagement with age-appropriate activities is considered critical to enable the adolescent to achieve functional recovery (Hechler et al., 2015).

Notwithstanding the evidence for IIPPT (Evans et al., 2016; Odell & Logan, 2013), engagement with and adherence to IIPPT is variable, especially in adolescents (Guite et al., 2014; Simons et al., 2010), thereby slowing or halting functional recovery. Recent findings illustrated that parents, more so than adolescents, attach higher value and take more initiative in seeking IIPPT (Guite et al., 2014). Gaining a better insight into adolescents' perceptions of their barriers to functional recovery is important given that their motivation is a critical factor in determining the outcome of therapies such as IIPPT which are of a high collaborative nature (O'Halloran et al., 2014; Vong et al., 2011). Adolescents' perceived barriers to (re)engaging with age-appropriate activities in their daily life is of utmost importance to explore at the start of IIPPT given the critical role it plays in obtaining functional recovery.

Although no research has explored adolescents' barriers to functional recovery directly, a small number of studies have considered the factors related to readiness to change and adhere to IIPPT. These studies revealed that lower levels of adolescents' catastrophic thoughts about their pain were related with increased readiness to change (Guite et al., 2014), while parent-reported negative attitudes towards the effectiveness of self-management techniques (e.g., exercises, hypnoses, biofeedback) acted as a barrier for adherence (Simons et al., 2010). However, our current knowledge is mostly based on parental reports and does not explore engagement with and adherence to specific aspects of IIPPT that support functional recovery, such as (re)engagement with age-appropriate activities in daily life.

Theoretical models, such as the Children's Health Belief Model (Bush & Iannotti, 1990), illustrate how children's own perceptions (e.g., health locus of control) affect their adherence to treatment. Applying this model, research not only highlighted how an increasing number of reported barriers is related to decreased treatment adherence but also revealed a need for repeated assessment of barriers due to the fluctuating character of barriers depending on an individual's disease trajectory (Favier et al., 2018). However, the model, and its applications, are limited to a narrow focus on medication adherence only. Many adolescents with chronic pain present with a strong tendency to avoid engagement in meaningful, age-appropriate activities (e.g., attending school full time, going out with friends, doing sports) to prevent further pain, with overcoming such avoidance behaviour representing an important, but

challenging, target for treatment (Wicksell et al., 2007). Adolescents' perceptions on the barriers they face to overcome such avoidance tendencies to engage with meaningful, age-appropriate activities are currently unknown.

Consequently, the aim of the current study is to gain a comprehensive understanding, from the point of view of a sample of adolescents preparing to begin IIPT, of the barriers they face towards engaging with age-appropriate activities in order to obtain functional recovery. To this end, this study uses a rich, qualitative approach to generate a taxonomy of barriers that could be used to guide identification of similar barriers in individualized clinical care. We choose to use the Passenger on the Bus metaphor to generate adolescents' barriers as this metaphor has shown to be helpful in externalising thoughts and feelings to facilitate an open discussion and realisation of the impact listening to the "passengers" has on their life (Ciarrochi & Robb, 2005).

2. Methods

2.1 Participants

Adolescents (10-19 years) attending Clinical Psychology consultations for chronic pain as part of their IIPT at the Oxford Centre for Children and Young People in Pain (OXCYP) at the Nuffield Orthopaedic Centre, Oxford, UK were included in this study. As the qualitative data was obtained and recorded as part of routine clinical practice, ethical approval for retrospective analysis of the clinical data for this study was obtained from Oxford University Hospital NHS Foundation Trust (sponsor) and the UK National Research Ethics Service (REC reference 16/HRA/1552). Of note, we refer to the adolescents as 'participants' throughout this manuscript, in preference over the term 'patient', but acknowledge that our analysis was retrospective and thus that the adolescents were not formally consented as participants in a research study.

2.2. IIPT Program

The IIPT at OXCYP consists of daily sessions with occupational therapy, physiotherapy, and clinical psychology. Further assistance is provided by a ward assistant and a teacher. The focus is on addressing biomechanical issues, return to feared movements and activities, healthy routines (including sleep), coping with pain and psychological barriers such as anxiety and depression.

2.3. Passenger-on-the-bus metaphor

The data analysed within this study was gathered within the adolescents' first session of the intensive 2- or 3-week IIPT programme using the 'Passengers on the Bus' metaphor. Metaphors are a powerful and regularly used technique within Acceptance and Commitment

Therapy (ACT, Hayes et al., 1999), with the Passengers on the Bus metaphor aiming to discover the self-as-context (Ciarrochi & Robb, 2005). In this case, the context is the values and goals the patient has identified. For example, the patient might be asked what s/he thinks the barriers are to doing some of the things s/he is currently unable to do but would like to be able to do.

In using this metaphor, the Consultant Clinical Psychologist first explains the metaphor and acts it out using 2-3 examples. The metaphor asks the participants to imagine that they are driving a bus towards their valued direction. The passengers on the bus represent hindrances or the adolescents' thoughts and feelings that make it more difficult or prevents them from reaching their valued direction. Within this particular setting, the valued directions within the Passengers on the Bus metaphor specifically represented participants' age-appropriate activities, such as going shopping, playing sports, going to school, engaging with hobbies, and going out with friends. The example provided within this explanation concerns *"I want to go shopping, but the passengers on the bus start to shout when I turn towards the shopping centre. Examples of such passengers may be pain, tiredness or fear of making things worse."* The challenge for the adolescent, family, and the therapist is to neutralise the impact of passengers. Secondly, the Consultant Clinical Psychologist walks the participant through some steps to apply this metaphor to their own experiences in order to identify what makes it difficult or impossible to engage with age-appropriate activities. A focus on barriers to engage with age-appropriate activities was chosen as this represents an important part of making progress towards functional recovery within the IIPT approach. See Figure 1 for a visual representation of the Passengers on the Bus metaphor. This figure does not represent a visual aid used as part of data collection, but was designed for illustrative purposes for publication only.

- Insert Figure 1 about here -

2.4. Procedures

For participants younger than 16 years of age, parents were present during this session. The Consultant Clinical Psychologist leading the session had seen the participants on a number of occasions before the start of IIPT treatment and therefore had engaged with each of them sufficiently enough to build trust to have conversations about sensitive issues. All participants were seen by the same Consultant Clinical Psychologist, ensuring consistency in the approach and implementation of the metaphor. Participants were not presented with suggestions or a pre-defined list of potential barriers, but were encouraged to generate their own barriers. However, participants were offered prompts for categories to consider, by

either the consultant or their parents, if they struggled to generate ideas by themselves. The adolescents' responses were written down in a Word document by the psychologist during the first session and shared with the family as well as the rest of the multi-disciplinary team. Adolescents were free to add any other barriers they could think of by the next session. These potential additions were added to the word document, and these final documents were used within the analyses.

2.5 Data analyses

The above-described Word documents of all participants were collated, and inductive thematic analyses was applied to generate a taxonomy (i.e., a formal classification of a complex phenomenon; Bradley et al., 2006) of common barriers that participants described facing to obtain functional recovery. We followed Braun and Clarke's (2006) initial stages for data coding and collating codes into candidate themes. However, unlike Braun & Clarke's more reflexive approach to theme realization (Braun & Clarke, 2019), our final stages of thematic development aligned with other forms of thematic analysis (e.g., framework analysis; Bradley et al., 2006; Gale et al., 2013) in that we aimed to generate domain summaries representing descriptive categories of barriers, and subsequently to collate these categories into a taxonomy (Bradley et al., 2006). We generated domain summary themes (referred to as "domains" throughout the article), combined into a comprehensive taxonomy, as a pragmatic approach to qualitative data that has direct implications for treatment delivery. The resultant taxonomy of barriers to functional recovery can be readily used by clinicians applying the Passengers on the Bus metaphor to help identify different barriers within an individualised treatment approach. Although our approach is inductive, it aligns with a post-positivist theoretical standpoint that recognizes the researcher's subjectivity as an influential part of, and asset to, thematic development. Given that the data was collected by a single clinician, we also recognize this clinicians' theoretical framework as influencing the data collection process, which is particularly influenced by theory of behavioural activation, self-efficacy, cognitive therapy, acceptance and commitment /mindfulness and systemic theory.

AS and LC independently engaged in the initial coding stages of inductive thematic analyses, with generated domains being reviewed and discussed collaboratively between AS and LC in consecutive cycles. In line with a post-positivist qualitative framework, this collaborative approach to data analysis was used to gain a rich and nuanced understanding of the data rather than to reach shared consensus or reliability (Braun & Clarke, 2019). Specifically, after engaging with data immersion, AS and LC initiated the coding phase. A

total of 24 codes reflecting relevant, distinct features of the data were created. After linking all responses to at least 1 code, the content of codes was then reviewed for clarity and revised if needed. This code revision included merging codes, renaming codes and creating new codes, which led to a refined set of 14 codes. The final set of codes was discussed by AS, LC and KJ and collated into domain summary themes that represented a comprehensive taxonomy of the barriers that the participants described. Several of Braun & Clarke's criteria for demonstrating the quality of thematic analysis were met (Braun & Clarke, 2013). This included the following: 1) equal attention was given to each data item in the coding process, 2) we provided a balance between data (i.e., quotations) and analytic narrative, 3) most participants were represented with one quotation; no participants were represented with more than four quotations, and 4) the researcher was positioned as active in the research process.

3. Results

The sample consisted of 41 adolescents ($M_{\text{age}} = 14$ years, range: 10 – 19 years; 80% girls). Adolescents reported a wide range of chronic pain symptoms, including widespread musculoskeletal pain (54.2%), localized musculoskeletal pain or CRPS (37.5%) and abdominal pain (8.3%). We generated seven domains representing different categories of barriers adolescents with chronic pain face to engage with daily age-appropriate activities. These domains are as follows: 'Physical constraints', 'Being fed up', 'Low self-confidence/self-esteem', 'Perfectionism', 'Avoidance of engagement with pain', 'Social barriers', and 'Feelings' (with four subdomains within the domain 'Feelings').

Physical constraints

Unanimously, participants described their physical symptoms, such as pain and tiredness, as the biggest constraint which get in the way of engaging in the activities they used to enjoy. As illustrated in the participants' quotes, pain symptoms, such as "*feeling dizzy from being in pain*" or "*emotionally and physically drained*" have the tendency to halt adolescents as they are "too tired to do it" and pain makes them "stop what you are doing and sit down and rest.". Fatigue tends to prevent adolescents from starting activities as they do "*not [have] as much energy as I had before*".

Being fed up

A large proportion of participants reported a general feeling of being fed up and having had "*enough of picking myself up again and again!*", which prevented them from engaging in any activities. For most participants, this viewpoint of hopeless and wanting to give up hope of recovery did not make a specific reference to what exactly they were fed up about. However, some participants did provide more specific details on what they were fed up

about, which revealed that they were particularly *“fed up to go to hospital appointments; not being 100% fit, not being ‘normal’ and having to explain to people but they cannot understand it”*. While adolescence is a developmental stage where peers are becoming more influential and being accepted by their peers is of increasing importance, these participants express being fed up by how their experience of chronic pain seems to create an uncontrollable rift between themselves and their peers. This experience of others not understanding their chronic pain experiences overlaps with the central organising concept of the “social constraints” domain (see below). However, the experience of being fed can be distinguished from such social constraints, as others not understanding their experience is just one of many reasons that can lead to adolescents being fed up.

The participants’ quotes reflect how the key aspect of being fed up is the learned helplessness due to the unpredictability of their chronic pain, which has made the adolescents believe that no matter what they do, it will not help them control their pain and will not make a difference. For some participants the continued stream of setbacks made them lose enjoyment in and motivation to engage with activities, an experience that for some lead to thoughts such as *“you might as well give up, it is never going to get better”* and *“better to not to try, I will be disappointed anyway”*. Such deep expressions of being fed up can lead to and are closely associated with feelings of sadness, such as *“what is the point of doing something if I am not going to enjoy it and will drag everyone down”*. Nevertheless, the domain of ‘Being fed up’ can be distinguished from the ‘Sadness’ domain (see details below), which reflects participants’ more general expressions or feelings of sadness that could be related to any aspect of their chronic pain experiences. Being fed up on the other hand reflects the very specific, particular experience of hopelessness and giving up.

Low self-confidence and self-esteem

Low confidence in their own abilities, for a wide variety of reasons, was a common barrier for participants to engage with age-appropriate activities, as part of their road to functional recovery within IIPT. For some participants, this low self-confidence was specifically linked to their pain experiences in the sense that they believed that *“you can’t do it anyway so you might as well not bother and if you do try you will feel pain”*. However, for the majority of participants the low self-confidence was a general feeling being *“weak – you can’t do it!”* and not being capable of engaging with the valued activities as their *“low self-confidence stops me from overcoming obstacles; I will automatically think I cannot do it or that I am not good.”*

It was not always clear whether this low self-confidence preceded the start of the chronic pain experiences or not. What was clear though, in these expressions, was how low self-confidence and self-esteem had a direct influence on each other. Indeed, participants quotes revealed how low confidence in their abilities has the tendency to become integrated within their subjective evaluations of their own worth or respect for themselves, such as *“feeling worthless or useless”* or *“I do not always like myself – makes me feel that I cannot do things, that I am not good, that they are better and that I do not deserve to get better”*.

Irrespective of the link between chronic pain experiences and low self-confidence and self-esteem, this barrier identifies a direct link in adolescents between thinking they cannot do something and not doing the activity, not even trying. Consequently, not engaging in the valued activity also prevents adolescents from finding out that they can actually do it and a potential opportunity to change their low confidence and self-esteem attitudes.

Perfectionism

For some of the participants, low self-confidence took on a very specific form of only wanting to engage in activities when they were certain they could do them well or even perfectly, which reflects the central organising component of the domain ‘perfectionism’. This ‘perfectionism’ domain reflects how participants experience thoughts such as *“if you cannot do things right, you might as well not do it at all as otherwise you have failed”* and *“I would rather not do something than do it badly”*. However, due to pain symptoms and associated disability, some participants felt that they could not engage in the activities anymore up to the high, perfectionistic, standards they expected from themselves and hence decided not to, to avoid repeated confrontations with failures. This need to achieve perfection also links back to self-esteem, as the participants seem to have adopted an attitude of *“unless I do it perfectly, I’m not good enough”*. This need to ensure perfection before being willing to engage into an activity reflects a pattern of black and white thinking in these adolescents with chronic pain, without a grey area that allows some flexibility of engagement or involvement that is not perfect.

Avoidance of engagement with pain

Within the context of their chronic pain, a specific age-appropriate activity that is relevant is seeking help (for example, engaging with IIPT). A common barrier expressed by the participants, which prevented them from engaging with this activity, was avoidance. This avoidance was demonstrated in a variety of ways and went beyond fear avoidance to prevent injury or pain. In particular, a clear distinction can be made between responses reflecting cognitive avoidance and emotional avoidance. Cognitive avoidance reflect adolescents’

tendency to not wanting to think about pain such as *“Pretend that things are not happening – it means I do not do what I am supposed to do (e.g. pacing) AND I don’t confront the problems.”* . On the other hand, emotional avoidance reflects adolescents’ tendency to not wanting to get in touch with the feelings pain and associated disabilities evoke. As examples of such emotional avoidance participants revealed how they *“don’t always want to talk about how I feel”* or perceive themselves as *“an emotionally guarded person, I do not like to open up”*. However, at the same time, they express insight into the consequence of such emotional avoidance, such as *“if you are not willing to tell people you are struggling it is more difficult to get help”* or *“then it all builds up and I feel confused and angry”*.

Beyond the distinction between cognitive and emotional avoidance, for some participants, this tendency to avoid seeking help was a reflection of their growing sense of independence about their life and associated responsibility to make their own decisions: *“It is my life not yours, [doctors] do not tell me what to do”*. This growing sense of independence was also reflected in expressions of stubbornness, such as *“I do not want to ask for help”*, and feelings of pride to accept any help, as they *“do not want people to think of me as the kind of person who needs help/can’t do anything.”*

However, when adolescents avoid, they do not engage with the problem, including solutions to the problem. In this sense, avoidance can act as a barrier towards re-engaging with normal activities.

Feelings

The domain of ‘Feelings’ encompasses a wide range of general emotional experiences, such as sadness, anger, guilt and anxiety, described by the participants as substantial barriers to engage in age-appropriate and valued activities. For each of these feelings, we describe below how they can be experienced as a barrier to engage in activities.

Sadness: A very common feeling expressed by participants, which prevented them from engaging with activities, was a general feeling of sadness which was not necessarily directly related to their chronic pain symptoms and associated disabilities. An important observation made within these expressions was the direct link between feeling sad and either withdrawing from a specific valued action, such as *“if I feel down, I won’t do my homework and go to bed or cry or both”* or withdrawing from valued activities altogether as they do not so the point of *“why try to be happy when I am not?”*. Such withdrawal behaviour is a key component of depressive symptomatology and hence could be an important diagnostic marker for clinicians to note during these interactions.

Anger and frustration: Several participants expressed feelings of anger and frustration about the unfairness of their pain condition and how this gets in the way of engaging in typical age-appropriate activities as well as chronic-pain specific activities, such as seeking help to get better. These expressions of anger varied widely with respect to the content of the anger. For instance, some participants experienced their pain as *“why me? It’s unfair!”*, thereby reflecting injustice of not being able to *“live the way others do; including friends, school works, activities; it’s not fair!!!”*. However, other participants expressed how the fear of showing their anger towards others makes them avoid such situations, with one participant sharing that *“when I go out with my friends, I always get angry, so it is better to stay on my own”*.

Guilt: The above described feelings of anger were closely related to the guilt adolescents felt in relation to their condition and associated consequences. These guilt feelings were complex and included feeling that they should *“stop enjoying yourself”* when they did enjoy an activity despite being in pain as well as anticipated guilt of having to rely on others and what others might think about them if they ask for help. This anticipated guilt towards others revealed how participants *“don’t want to bother/burden people”* and *“don’t want my family to think that I am attention seeking”*. Feeling like they may be a burden often acts as a barrier to engaging in activities with others, in that adolescents may decide not to go out in order to save others (peers, family members) from not being able to do the things they want to do.

However, for some participants these feelings of guilt went a step further and seemed to result in blaming themselves for their current situation. Such self-blame was expressed in statements ranging from *“it is my fault that it has all happened”* to feeling they *“may deserve to be where I am today because of who I am or something I have done”*. However, while many participants looked for someone or something to blame for their current condition and associated inability to engage in activities, not all expressed self-blame and associated guilt. Indeed, several participants blamed others for the disability related to their chronic pain, such as their school because *“they made me do PE when I said that my back was hurting”* or expressed being *“angry with parents of what happened”*. *Anxiety:* A large variety of anxious thoughts and feelings were expressed as a reason for not engaging in typical age-appropriate activities or activities related to their chronic pain experience, such as engaging with IIPT. These can be split up into a) anxiety about being judged, b) anxious about making things worse, and b) anxiety about change.

a) Anxiety about being judged included participants’ feelings of *“anxiety of being judged by someone”* as well as thoughts such as *“what will people think of me? (being*

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in pain)”, which reflect a confirmation of adolescents’ growing awareness of and importance they attach to other people’s opinion, especially the opinion of their peers and their wish to fit in and be like everyone else. This anxiety of being judged can also be seen as one particular way in which adolescents express their experience of low confidence and being perceived different by others (see above). While some participants did report negative experiences of other’s judgements, such as *“I will be mocked; that has happened in the past”*, it was not always clear in participant’s stories whether the anxiety to be judged reflected actual experiences or their own perception of how others see them. For instance, some quotes, such as *“What if...I get an anxiety attack” (in front of others)”*, revealed how this anxiety around judgements can have more of an anticipatory character.

b) Anxious about making things worse reflects the common anxiety participants shared of a specific consequence of engaging in age-appropriate activities. Indeed, many participants avoided activities due to *“anxiety that things will get worse”* and even *“anxiety of permanent damage”* by doing the activity. Some adolescents highlighted how this anxiety stemmed from their low self-confidence to deal with the pain, such as *“anxiety that I won’t be able to cope”* or *“not able to overcome the pain.”*

Anxiety about change was specifically related to the potential change their engagement with treatment-related activities or seeking help might introduce. In particular, adolescents expressed feeling familiar and even comfortable with their current life, even if it is not an ideal life. Engaging with treatment-related activities induced in many an *“anxiety of new things/change in routine”* because of *“not liking change and expecting bad things to happen”*. This specific expression of anxiety reflects that for these adolescents, engaging with treatment and the potential associated change is a stressor in which they react to with a “better safe than sorry”, sometimes seen as a ‘freezing’ response. Several responses revealed how such treatment-related change might be associated with uncertainty about their future and potential disappointment and is therefore perceived as a stressor. For instance, some participants revealed how *“it is easier to stay on crutches to avoid questions, teasing and bullying”*, thereby reflecting how their current disability has made the pain visible to others, resulting in increased understanding and acceptance of their condition by others. It is understandable that for these adolescents the anticipation of getting better, which involves taking away this important level of visibility, is anxiety-provoking.

Social barriers

All of the participants described one or more forms of social constraint(s) that held them back from leading the life they want or seeking help for their pain symptoms. These social constraints come from their immediate family (parents and siblings), friends, school environment, as well as the widespread common misunderstandings about chronic pain within society. The common underlying concept of these various social barriers in the adolescents' life, was how *"nobody understands what it is like"*, which has the potential to lead to thoughts such as *"people will think I am faking it"*.

Adolescent's relation with their immediate family and perspective on their involvement with their pain condition was varied. Some adolescents expressed wanting to protect their family from the real burden as showcased in behaviours such as *"not show them [friends and family] how much pain I am in – it is better to hide/withdraw on those occasions"*. Others however felt that their family's response acted as a barrier because *"parents' level of focus to monitor/do the things that need to be done to support me has not always been optimal"*.

With respect to engaging with friends and peers, adolescents reported that this is quite difficult as their friends are not necessarily loyal to them. Especially if the adolescent misses out on a lot of school, they expressed how *"people have moved on without me"* or even how *"friends forgot about me"*, which leads to feelings of isolation and loneliness. As stated very eloquently by one of the participants, missing out on friendships and associated loneliness, was strongly related to their feelings of being perceived as different from others: *"You are always lonely and you always are going to be lonely; you will be quite different, so leave it; why go through the pain if you are going to be different?"*. Such perceptions of being different included both their own views that others see them as different as well as the adolescents' personal belief of being different from their peers. The experience of being viewed as different by others was most frequently induced by the adolescent's perception of *"the way people stare at you"*. Participants revealed how they experience that *"they look at me like I am an idiot; it is difficult to be friends with people who look at me like I am an idiot; difficult to trust them"*. Adolescents' own inner belief of *"I am different from other teenagers"* seemed mostly induced by making a comparison with what their peers are being able to do and thereby noticing that *"they [peers] do things that they like to do and I can't"*.

Engaging with the school environment despite their chronic pain was expressed as a challenge for these adolescents and thus acted as a barrier towards attending. While some of the school-related challenges were tied to their pain experiences such as school *"do not understand"* or *"do not make an effort"*, other challenges seemed to already be in place

before the pain symptoms started and making it difficult for adolescents to go to school in the first place. These pre-existing challenges varied from common, general barriers such as wanting “*to be good at things at school and more generally; pressure not to make mistakes*” to being able to pinpoint specific turning points in their school experiences, such as starting secondary school: “*In secondary school people looked at me more which made me feel more embarrassed and upset that people don’t see me as one of them; so my self-confidence went down quite a lot when I went to secondary school*”.

4. Discussion

The aim of this study was to gain a comprehensive insight into adolescents’ perspectives on the barriers they face to achieving functional recovery. To this end, we performed a retrospective analysis of clinical data from adolescents who were preparing to start IPPT, who completed the ‘Passengers on the Bus’ metaphor in which they identified barriers they perceive in engaging with age-appropriate activities. Using inductive thematic analysis, we generated a taxonomy of seven different barriers to obtaining functional recovery: 1) Physical constraints, such as pain and fatigue, 2) Being fed up, 3) Low self-confidence and self-esteem, 4) Perfectionism, 5) Avoidance of engagement with pain, 6) Social barriers from a range of sources such as parents, friends, school, and wider society, and 7) Feelings such as sadness, anger, guilt, and anxiety.

The identified barriers related to avoidance and feelings provide support for the role of child pain-related anxiety as outlined in the Interpersonal Fear Avoidance Model (IFAM; Goubert & Simons, 2013) by stimulating avoidance of age-appropriate activities and thereby contributing to pain-related disability. Our data highlights how avoidance of activities is not only induced by fear or anxiety, but also by other emotions such as sadness, anger, and guilt. Furthermore the anxiety expressed was not limited to anxiety about the pain getting worse, but also reflected a social component, for example anxiety around being judged. Taken together, our findings indicate that adolescents experience an array of complex inter- and intra-personal emotions which can make the road to functional recovery difficult. Beyond the role of emotions, our findings illustrate how other internal characteristics, such as perfectionism, being fed up and low self-confidence, can act as barriers for adolescents in their road to functional recovery. In support of clinical observations and a recent theoretical framework on perfectionism in pediatric chronic pain (Randall et al., 2018), our findings highlight how perfectionism can exacerbate the impact of chronic pain and be a barrier for adolescents to get better. Underlying mechanisms of how perfectionism contributes to pain-related disability need further investigations but are theorised to be related to the mismatch

between the cognitive rigidity and pride associated with perfectionism on the one hand and the unpredictability of and need to accept help in managing chronic pain on the other hand (Dignon et al., 2006; Gonzalez et al., 2015). Although evidence is accumulating on how high levels of perfectionism could reduce the adolescents' motivation to engage with activities, there is a paucity of literature and hence little consensus on how to approach perfectionism.

The identified external, social barriers further confirm previous literature (Forgeron et al., 2013; Meldrum et al., 2009) by reflecting how the invisibility of pain is a challenge for others to understand what the adolescent is going through and how the adolescents perceive themselves, or feel perceived by others, as different. The challenge of 'feeling different' is assumed to be of particular importance for adolescents given how their social world shifts dramatically characterised by a reduced reliance on parents and increasing preference for friendships (Guassi Moreira et al., 2018). As highlighted in the barrier of being fed up, many of these adolescents have engaged in multiple attempts to defend their pain experiences in an attempt to fit in with peers and feel less different. However, due to these attempts not being successful, adolescents lost motivation and gave up trying to engage with age-appropriate activities (Forgeron et al., 2013; Meldrum et al., 2009). As adolescents have less control over these external, social barriers, it will be of importance, in both future research and clinical practice, to gain a better understanding of how these external social barriers interact with the adolescents' internal barriers to recovery.

Beyond the IFAM, our findings also align with extant models of barriers to treatment adherence more broadly. For example, drawing from the Children's Health Belief Model (Bush & Iannotti, 1990), Moffit and colleague have noted that identifying the child's perceived barriers to recovery, particularly through interviews, may increase adherence to their overall treatment regimen and thus should form a core part of pediatric medical care (Rapoff, 2010). This model has been used as a framework to study barriers to adherence across multiple pediatric populations, including Juvenile Idiopathic Arthritis (JIA). The most commonly reported barriers for youth with JIA include pain and embarrassment (Favier et al., 2018), which align with the 'physical constraints' and 'feelings' domains in this study. Importantly, the majority of previous research applying models such as the Children's Health Belief Model to pediatrics have focused on adherence to medications (Rapoff, 2010); this study provides some of the first in-depth exploration of barriers to adherence towards behavioral treatment for youth with chronic pain. Interestingly, in one previous study Simons et al (2010) described that parents' perceived barriers to their child engaging in IIPT focused more around issues of access and finances, although negative attitude and beliefs were the

most commonly identified barrier. Taken together with our findings, these studies indicate that parents and children may perceive different barriers to IIPT engagement and thus both should be considered in attempts to improve treatment engagement.

From a clinical perspective, our findings reveal the relevance of exploring adolescents' barriers to functional recovery through engagement with age-appropriate activities at the start of treatment, in order to formulate an individualised plan for treatment that is more precisely targeted at the individual's emotions and cognitions. Furthermore, engaging in such an exercise to identify barriers to functional recovery allows the clinician to explicitly illustrate to the adolescents the direct link between their individual barriers and the impact of these barriers on their daily lives. Future research on the effectiveness of such a barrier-focused approach to increase motivation to recovery is needed as improved adolescents' motivation could have important implications for the adolescents' adherence to and effectiveness of IIPT. Indeed, while to our knowledge no such research is available in the context of pediatric chronic pain, evidence in the context of cognitive behavioural therapy (CBT) for pediatric anxiety disorders shows the important role of pre-treatment child motivation (Wergeland et al., 2016) and motivation enhancement therapy (Buckner, 2009; Buckner & Schmidt, 2009) in determining treatment success.

Interestingly, the adolescents' narratives revealed a close connection between the experience of negative emotions and reducing engagement with age-appropriate activities, especially social activities. This pattern showcases how adolescents with chronic pain may regulate their emotions by avoiding activities. Consequently, a focus on developing more adaptive emotion regulation skills, such as reappraisal to reframe the pain or avoided situations in a positive way, should be an important early component of IIPT to provide adolescents with the appropriate tools to attenuate stressful situations (Jenkins et al., 2018). Furthermore, the findings also further support the central role of gradual exposure to age-appropriate situations and activities within IIPT, to increase the adolescents' confidence in their skills to engage in such age-appropriate activities without increasing or inducing uncontrollable pain (Lalouni et al., 2016; Simons et al., 2015).

These findings should be interpreted in the light of the several limitations and considerations based on our methodological approach. First, the study was conducted in a single hospital setting, so further research is needed to establish the generalisability of the identified barriers to functional recovery across settings, cultures and countries. Second and relatedly, the data was collected by a single Consultant Clinical Psychologist. This ensured that the procedure was consistently implemented across participants. However, additional

barriers may result from application of the Passengers on the Bus metaphor by individual clinicians who bring their own theoretical and clinical frameworks to their treatment sessions. For example, the data did not indicate pain memories as an identified barrier, but this may be in part due to the clinician's unawareness of the importance of pain memories at the time of data collection and thus not guiding adolescents to consider these memories as potential barriers. Third, the Passenger on the Bus exercise was conducted at the beginning of treatment. Although the Consultant Clinical Psychologist had established rapport with the adolescents before starting the treatment, trust was likely still building in the therapeutic relationship. Consequently, some of the more subtle barriers or barriers that are more based in the adolescents' core beliefs might not have been expressed at this early stage in treatment. For instance, later on in treatment the Consultant Clinical Psychologist observed how various adolescents expressed a 'fear of getting better'. Future research looking at how the barriers to engage with IIPPT evolves throughout the treatment process would be able to shed more light on the dynamic nature of the barriers. Lastly, for some adolescents, parents were present while engaging with the Passengers on the Bus metaphor, which might have influenced their response, especially with respect to adolescents' perspectives on the helpfulness of parental responses towards their pain.

This study revealed a variety of barriers that can hinder adolescents' functional recovery through reduced engagement with age-appropriate activities, thereby hampering progress within IIPPT. The Passenger on the Bus metaphor can be used by clinicians to identify similar barriers faced by adolescents to further individualize the IIPPT approach, thereby improving precision in pediatric chronic pain care.

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Author Contributions

K.J. gathered all the data, contributed to the analyses and the write up of entire manuscript. A.S. conducted the inductive, reflective thematic analyses and contributed to the write up of the findings. L.H. took charge of the ethical approvals for the study and contributed to the write up of the entire manuscript. L.C. conducted the inductive, reflective thematic analyses and took the lead on writing up the manuscript. All authors discussed the results and commented on the manuscript.

Figure legend

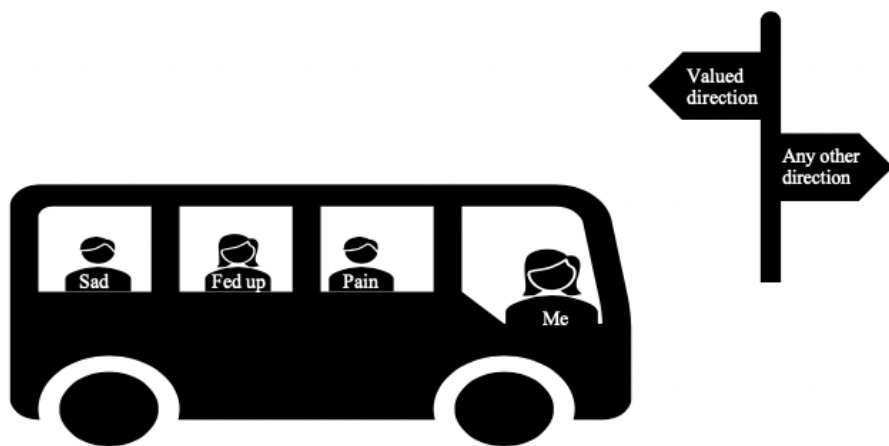
Figure 1: Visual representation of the Passengers on the Bus metaphor.

References

- American Pain Society (2001). *Pediatric chronic pain*. Glenview: American Pain Society.
- Bradley, E. H., Curry, L. A., & Devers, K. J. (2007). Qualitative data analysis for health services research: developing taxonomy, themes, and theory. *Health Services Research*, 42(4), 1758-1772.
- Braun, V. & Clarke, V. (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3, 77-101.
- Braun, V., & Clarke, V. (2013). Successful qualitative research: A practical guide for beginners. sage.
- Braun, V., & Clarke, V. (2019). Reflecting on reflexive thematic analysis. *Qualitative Research in Sport, Exercise and Health*, 11(4), 589-597.
- Buckner, J. D. (2009). Motivation enhancement therapy can increase utilization of cognitive- behavioral therapy: The case of social anxiety disorder. *Journal of Clinical Psychology*, 65(11), 1195-1206.
- Buckner, J. D., & Schmidt, N. B. (2009). A randomized pilot study of motivation enhancement therapy to increase utilization of cognitive-behavioral therapy for social anxiety. *Behaviour Research and Therapy*, 47(8), 710-715.
- Bush, P. J., & Iannotti, R. J. (1990). A children's Health Belief Model. *Medical Care*, 28(1), 69-86.
- Ciarrochi, J., & Robb, H. (2005). Letting a little nonverbal air into the room: Insights from acceptance and commitment therapy Part 2: Applications. *Journal of Rational-Emotive and Cognitive-Behavior Therapy*, 23(2), 107-130.
- Coffelt, T. A., Bauer, B. D., & Carroll, A. E. (2013). Inpatient characteristics of the child admitted with chronic pain. *Pediatrics*, 132(2), e422-e429.
- Dignon, A., Beardsmore, A., Spain, S., & Kuan, A. (2006). 'Why I Won't Eat' Patient Testimony from 15 Anorexics Concerning the Causes of Their Disorder. *Journal of health psychology*, 11(6), 942-956.
- Evans, J. R., Benore, E., & Banez, G. A. (2015). The cost-effectiveness of intensive interdisciplinary pediatric chronic pain rehabilitation. *Journal of Pediatric Psychology*, 41(8), 849-856.
- Favier, L. A., Taylor, J., Rich, K. L., Jones, K. B., Vora, S. S., Harris, J. G., ... & Kohlheim, M. (2018). Barriers to adherence in juvenile idiopathic arthritis: a multicenter collaborative experience and preliminary results. *The Journal of Rheumatology*, 45(5), 690-696.

- Forgeron, P. A., Evans, J., McGrath, P. J., Stevens, B., & Finley, G. A. (2013). Living with difference: Exploring the social self of adolescents with chronic pain. *Pain Research and Management*, 18(6), e115-e123.
- Gale, N. K., Heath, G., Cameron, E., Rashid, S., & Redwood, S. (2013). Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC Medical Research Methodology*, 13(1), 117-125.
- Gauntlett-Gilbert, J., & Eccleston, C. (2007). Disability in adolescents with chronic pain: Patterns and predictors across different domains of functioning. *Pain*, 131, 132-141.
- Gonzalez, B., Baptista, T. M., & Branco, J. C. (2015). Life history of women with fibromyalgia: beyond the illness. *The Qualitative Report*, 20(5), 526-540.
- Goubert, L., & Simons, L. E. (2013). Cognitive styles and processes in paediatric pain. *Oxford Textbook of Paediatric Pain*, 95-101.
- Guassi Moreira, J. F., Tashjian, S. M., Galván, A., & Silvers, J. A. (2018). Parents Versus Peers: Assessing the Impact of Social Agents on Decision Making in Young Adults. *Psychological science*, 0956797618778497.
- Guite, J.W., Kim, S., Chen, C.P., Sherker, J.L., Sherry, D.D., Rose, J.B., & Hwang, W.T. (2014). Pain beliefs and readiness to change among adolescents with chronic musculoskeletal pain and their parents before an initial pain clinic evaluation. *Clinical Journal of Pain*, 30, 27–35.
- Hayes, S. C., Strosahl, K. D., & Wilson, K. G. (1999). *Acceptance and commitment therapy: An experiential approach to behavior change* (Vol. xvi, 304 pp.). New York, NY, US: The Guilford Press.
- Hechler, T., Kanstrup, M., Holley, A. L., Simons, L. E., Wicksell, R., Hirschfeld, G., & Zernikow, B. (2015). Systematic review on intensive interdisciplinary pain treatment of children with chronic pain. *Pediatrics*, 136(1), 115-127.
- Jenkins, B. N., Granger, D. A., Roemer, R. J., Martinez, A., Torres, T. K., & Fortier, M. A. (2018). Emotion regulation and positive affect in the context of salivary alpha- amylase response to pain in children with cancer. *Pediatric Blood & Cancer*, 65(6), e26973.
- Lalouni, M., Olén, O., Bonnert, M., Hedman, E., Serlachius, E., & Ljótsson, B. (2016). Exposure-based cognitive behavior therapy for children with abdominal pain: a pilot trial. *PloS one*, 11(10), e0164647.
- Logan, D.E., Simons, L.E., Stein, M.J., & Chastain, L. (2008). School impairment in adolescents with chronic pain. *The Journal of Pain*, 9(5), 407-416.

- Long, A.C., Krishnamurthy, V., & Palermo, T.M. (2008). Sleep disturbances in school-age children with chronic pain. *Journal of Pediatric Psychology*, 33(3), 258–268.
- Meldrum, M.L., Taso, J.C.-I., & Zelter, L.K. (2009). “I can’t be what I want to be”: Children’s narratives of chronic pain experiences and treatment outcomes. *Pain Medicine*, 10, 1018-34.
- Odell, S. & Logan, D.E. (2013). Pediatric pain management: the multidisciplinary approach. *Journal of Pain Research*, 6, 785–790.
- O’Halloran, P. D., Blackstock, F., Shields, N., Holland, A., Iles, R., Kingsley, M., ... & Taylor, N. F. (2014). Motivational interviewing to increase physical activity in people with chronic health conditions: a systematic review and meta-analysis. *Clinical Rehabilitation*, 28(12), 1159-1171.
- Randall, E. T., Smith, K. R., Kronman, C. A., Conroy, C., Smith, A. M., & Simons, L. E. (2018). Feeling the pressure to be perfect: Effect on pain-related distress and dysfunction in youth with chronic pain. *The Journal of Pain*, 19(4), 418-429.
- Rapoff, M. A. (1999). Adherence Theories: Review, Critique, and Clinical Implications. *Adherence to Pediatric Medical Regimens*, 23-45.
- Simons, L.E., Logan, D.E., Chastain, L., & Cerullo, M. (2010). Engagement in Multidisciplinary interventions for pediatric chronic pain: parental expectations, barriers, and child outcomes. *Clinical Journal of Pain*, 26, 291–299.
- Simons, L., Smith, A., Hogan, M., Norton, A., Hung, E., Beebe, J., ... & Basch, M. (2015). (526) Exposure treatment of pain-related fear for children with chronic pain. *The Journal of Pain*, 16(4), S107.
- Vlaeyen, J.W.S., & Linton, S.J. (2000). Fear-avoidance and its consequences in chronic musculoskeletal pain: a state of the art. *Pain*, 85,317–32.
- Vong, S. K., Cheing, G. L., Chan, F., So, E. M., & Chan, C. C. (2011). Motivational enhancement therapy in addition to physical therapy improves motivational factors and treatment outcomes in people with low back pain: a randomized controlled trial. *Archives of Physical Medicine and Rehabilitation*, 92(2), 176-183.
- Wergeland, G. J. H., Fjermestad, K. W., Marin, C. E., Bjelland, I., Haugland, B. S. M., Silverman, W. K., ... & Heiervang, E. R. (2016). Predictors of treatment outcome in an effectiveness trial of cognitive behavioral therapy for children with anxiety disorders. *Behaviour research and therapy*, 76, 1-12.



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