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A Phenomenological Exploration of Identity Development in Adolescents with Chronic Pain

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Abstract

The aim of this study was to explore identity development in adolescents with chronic pain. Jointly, the high prevalence of chronic pain in adolescents, the importance of identity development for the wellbeing of adolescents, and the theoretical knowledge about the potentially unhelpful interactions between chronic illness and identity informed the rationale for this study. Considering the paucity of research regarding adolescents' perspectives about their identity in the context of chronic pain, this study adopted an interpretative phenomenological epistemology to understand how adolescents with chronic pain made sense of their identity. For this purpose, semi-structured interviews were conducted with seven participants aged 16 to 18. Participants included five females and two males and had varied chronic pain conditions such as fibromyalgia, arthritis and back pain. Interviews were analysed using Interpretative Phenomenological Analysis resulting in five group experiential themes: "A limited identity", "A mismatch", "Not belonging as an adolescent", "Paradoxical role of diagnosis" and "Protecting identity from pain". Each group experiential theme contained two to three sub-themes.

Novel findings of this study included participants' understanding of the sources limiting the development of their identity, the differences between participants' view of their identity versus how they thought they were viewed by others, the varied meanings linked with a diagnosis or medical explanation of pain, and the impact chronic pain had over participants' collective identity of being an adolescent. Notably, participants made efforts to retain important parts of their identity despite chronic pain, and even gained new valued parts to their identity.

Findings of this study enhance current knowledge about identity difficulties among adolescents with chronic pain. Implications for clinical practice are discussed, to support adolescents with chronic pain to manage changes and difficulties in their identity. The limitations of this study and recommendations for future research are also provided.

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Abbreviations

BPS: British Psychological Society

CoP: Counselling Psychology

CoPs: Counselling Psychologists

IASP: International Association for the Study of Pain

IPA: Interpretative Phenomenological Analysis

NHS: National Health Service

UEL: University of East London

UK: United Kingdom

USA: United States of America

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Introduction

Chapter Overview

This chapter offers an introduction to the present study. First, a background to the context of my study is provided, including a brief discussion on the relevance of my study to Counselling Psychology (CoP). An overview of my personal context for the study is presented, followed by a discussion of my positionality as a researcher.

Context of the Present Study

This sub-section provides an overview of the context and importance of my study i.e., exploring identity development in adolescents with chronic pain. A detailed understanding of the key concepts of my study (adolescence, identity and chronic pain) is offered in the Literature Review chapter.

The period of adolescence is characterised by development in several domains, including physical, cognitive and psychosocial, which can jointly facilitate adolescents to explore or make sense of their identity (Feldman, 2014). Overall, one's identity can include interconnected components such as self-definitions, social roles and group membership (Schwartz et al., 2011). Over the years, evidence has consistently suggested that a 'stable' sense of identity has been linked with better psychosocial adjustment, whereas uncertainty in identity has been associated with a higher likelihood of depressive symptoms, aggressive behaviour, substance use difficulties and loneliness (Branje et al., 2021).

Considering that one's identity can develop in the context of chronic illness such as chronic pain (Wicks et al., 2019), there appears to be a gap in current knowledge about how identity develops in adolescents who have chronic pain. Broadly, chronic pain refers to pain lasting for more than three months (Treede et al., 2019). Chronic pain has been found to be prevalent in adolescents, with approximately 44% of adolescents across countries self-reporting experiencing weekly chronic pain (Gobina et al., 2019). Studies with adults with chronic pain (e.g., Nicola et al., 2021; Smith & Osborn, 2007) suggest that chronic health conditions can have an adverse impact on one's identity. However, as adolescence is a distinct developmental stage when the process of exploring one's identity can become salient, little is known about how adolescents with chronic pain understand their identity. This is important to explore considering the potentially unhelpful outcomes that an 'uncertain' identity can have on adolescents as stated above. Further, considering that adolescents with chronic pain may experience difficulties in other contexts such as peer relationships (Forgeron et al., 2013), which can be important for identity development (Adams & Berzonsky, 2008), my study attempts to elucidate how such adolescents make sense of their identity. Increasing knowledge about this topic may potentially help Counselling Psychologists (CoPs) to tailor specific psychological support which adolescents may require.

This qualitative study focuses on the unique ways in which adolescents make sense of their identity, which resonates with CoP's underpinning of exploring the subjective experiences and meaning making processes of individuals based on their context (Milton, 2010). Thus, my study aims to provide a timely contribution to increase knowledge about an under-researched phenomenon, and the need for further research on this topic has also been suggested in a recent scoping review (Jones et al., 2021). My research also identifies and aligns with one of the roles for CoPs working with physical health, which can include provision of a psychological perspective in health research (Davies, 2016).

Personal Context

My interest in identity development and chronic pain topic arose during my postgraduate course in Health Psychology, when I studied under the guidance of paediatric chronic pain researchers, and conducted research on social and identity development in adolescents with chronic pain. The qualitative nature of my postgraduate research study helped me understand the multiple ways in which chronic pain appeared to shape adolescents' perception of themselves and their lives. As a young adult myself at that time, I felt a deep sense of empathy as I became aware of the experiences of adolescents with chronic pain. I also noticed a gap in research regarding identity development for this population, and I felt passionate about making the experiences of adolescents known.

Soon after the completion of my postgraduate qualification, I also experienced chronic pain which has now subsided. This experience furthered my interest in this area as I felt personally affected with how I perceived myself when I was in prolonged pain. I also became aware of the way that chronic pain was viewed in my social context, which in turn contributed towards the confusion I experienced in my identity of being 'too young for this'. As I was still a young adult when I experienced chronic pain, my curiosity for expanding the understanding of identity development in adolescents increased as I wondered how individuals might navigate through their identity in light of chronic pain. Specifically, considering the importance of identity development in adolescence, I sought to shed light on this experience among adolescents.

Positioning as a Researcher

This sub-section outlines the methodologies and underlying philosophical positions commonly used in the discipline of CoP, and where I situate the ontological and epistemological position of my study in relation to these.

A hallmark of CoP is the scientist-practitioner model, giving CoPs the role of both scientists and practitioners (Milton, 2010). This model emphasises evidence-based and reflective practice, and an equal focus on research and practice (Blair, 2010). ‘Evidence’ has typically been viewed from a positivist lens, with randomised controlled trials seen as most prominent and reliable (Blair, 2010). A positivist lens typically involves quantitative, systematic inquiry into a phenomenon to establish cause-effect relationships, and assumes the existence of a knowable, objective reality (Ponterotto, 2005). However, as human experience can be subjective, the positivist principles of measurement and objectivity can be critiqued (Langdridge & Hagger-Johnson, 2013) regarding what is considered as ‘evidence’ in CoP research (Woolfe, 2016). Additionally, CoP’s humanistic underpinnings uphold subjectivity, relational practice and understanding, as opposed to objectivity (Milton, 2010). These two contrasting positions contribute towards a tension, as consolidation of research and practice is a crucial part of our identity as CoPs (Milton, 2010). A need for reviewing what constitutes as ‘evidence’ was identified, leading to greater acceptance of qualitative approaches in research (Blair, 2010 & Morrow, 2007).

Qualitative approaches can be underpinned by different epistemologies and ontologies. For both research and practice, I identify my ontological position as a critical realist, as I recognise that there may be a ‘reality’, which can be experienced differently by individuals. Hence, I acknowledge chronic pain and identity as ‘real’, whilst accepting that these can be experienced differently. Epistemologically, I position myself as an interpretative phenomenologist. In the context of research, interpretative phenomenology involves layers of sense-making – participant’s interpretation of their experience, researcher’s interpretation of that, and the researcher and participant’s interaction (Cooper, 2012). Further, the researcher’s interpretations involve their own experiences and knowledge (Willig, 2013). Following my interpretative phenomenological epistemology, I believe that I am a part of the research process and cannot separate or ‘bracket’ my previous experiences and knowledge, but these can aid in understanding the data (Willig, 2013). However, considering my personal experiences with chronic pain, personal reflexivity, or recognition of how my previous knowledge can interact with research is attended to closely in this study (Kasket, 2012). Reflexivity in research is discussed throughout my study where relevant, for instance, in the Methodology chapter. Further details about my ontological and epistemological position are also presented in the Methodology chapter. Finally, I acknowledge that one methodology or epistemological approach may not be ‘superior’ to another for understanding a phenomenon. Thus, in line with my understanding of CoP’s focus on uniqueness and context, I recognise that varied methodologies can produce different and valuable findings, which can enhance our understanding of a phenomenon in a holistic manner (Milton, 2010).

Chapter Summary

This chapter provided an overview of the importance of my research study, and its relevance to CoP. An introduction to my epistemological position was presented, followed by the enhanced need of reflexivity due to my personal context regarding this research topic.

Literature Review

Chapter Overview

This chapter provides an overview of the key constructs of my study, followed by a theoretical understanding of chronic pain and identity. A review of literature on identity development in adolescents with chronic pain is then presented, followed by methodological and epistemological critique of the literature findings. Finally, a rationale for the current study and its relevance to CoP is offered.

Key Constructs

The following section offers a current and critical overview of the key constructs of my study i.e., adolescence, identity and chronic pain.

Adolescence

Adolescence can be viewed as the developmental period between childhood and adulthood. Prior to understanding the development that occurs during adolescence, the current debate in literature regarding the age bracket of adolescence is briefly discussed. Traditionally, adolescence has been bracketed between the ages of 10 to 19 years (World Health Organisation, n.d.). However, contemporary research has proposed extending this age bracket to 10 to 24 years, as the biological milestones marking the ‘end’ of adolescence (e.g., brain development) and social milestones marking the ‘beginning’ of adulthood (e.g., career, marriage, parenting) may extend beyond the age of 19 years (Sawyer et al., 2018). However, a critique for this wider age bracket has been offered by McDonagh (2018), which is stated as follows. First, a wider age bracket (specifically, referring to 18-24 year old individuals as adolescents) may create confusion in differentiating the healthcare services required by individuals belonging to this age group (e.g., paediatric services or adult services). Second, this debate around the age bracket may benefit from the viewpoints of those belonging within this age bracket. To manage further confusion regarding terminology considering the ongoing the debate about the 'age' of adolescents, my study uses the age range of 12 to 18 years for adolescents. The lower limit of 12 years was chosen as it is commonly used in research with adolescents with chronic pain (e.g., Jordan et al., 2018; Kashikar-Zuck et al., 2007; Sorensen & Christiansen, 2017). The upper age limit of 18 years was chosen as my study was conducted in the UK, where the healthcare system generally considers individuals up to the age of 18 as adolescents (National Health Service [NHS], 2023a, 2024).

Adolescence encompasses growth and change in several domains i.e., physical (e.g., onset of puberty, sexual maturation, and structural changes in the brain), cognitive (e.g., advancement in abstract thinking and problem solving) and psychosocial (e.g., expansion of social roles and relationships and identity development) (Backes & Bonnie, 2019). Complexity of the changes during adolescence can be understood in the context of developments in the world, for example, technological advancement can enable adolescents to broaden their social relationships (Dahl et al., 2018), Collectively, this highlights that development during adolescence can be unique for individuals (Seiffge-Krenke et al., 2010).

Identity

Although development during adolescence can be unique, it is generally believed that a key feature of adolescence is identity development, as the changes during adolescence (e.g., brain development, expansion of social relationships) facilitate adolescents to explore their sense of self or identity (Feldman, 2014; Milevsky, 2014). Nevertheless, the development of identity is not restricted to the period of adolescence, and may begin earlier in childhood and continue throughout adulthood (Kroger, 2006).

At this point, it is important to consider what is meant by ‘identity’. Over the years, ‘identity’ has been defined in several ways (Cote & Levine, 2002). Consequently, Schwartz and colleagues (2011) suggested an integrated and comprehensive definition of identity that includes personal identity (self-definitions, goals, values and beliefs), collective identity (affiliation with other individuals or groups), relational identity (social roles), and material identity (material artifacts viewed as a part of one’s self). These components are believed to form one’s identity based on the meaning one attaches to them (Schwartz et al., 2011). My study follows this comprehensive understanding of identity, as it aligns with my phenomenological epistemology that focuses on meaning making. My study also recognises interactions between internal (one’s own understanding) and external (perspectives of others) representations of identity, and how these can influence one’s identity (Barreto & Ellemers, 2003). Further, in my study, the word ‘identity’ is used synonymously with ‘self’ i.e., one’s ability to consciously think about oneself (Leary & Tangney, 2011).

A Theoretical Perspective on the Importance of Identity Development. Erikson's theory on human development (1968) suggested that adolescence involves the search for identity, and this period was consequently named as ‘identity achievement versus role confusion’. Identity development was viewed as a process occurring throughout the lifespan but gaining prominence during adolescence, as the onset of puberty, and advancement in cognitive ability and autonomy enable adolescents to explore their identity. For Erikson, identity ‘achievement’ involved integration of childhood self-identifications into the present to maintain a sense of continuity within one’s self, be able to express such self-identifications, and feel ‘at home’ with one’s body.

Consequently, an ‘achieved’ sense of identity is considered crucial for a ‘healthy personality’ (McLean & Syed, 2014), overall wellbeing, direction for the future, and connection with one’s body (Sokol, 2009). Conversely, ‘role confusion’ occurs when an adolescent is unable to ‘resolve’ the developmental task of ‘achieving’ identity – which is linked with feelings of confusion, impairment in well-being and a lack of direction for the future (Crocetti, 2017 & Milevsky, 2014).

Erikson’s perspective can be critiqued for offering a universal and positivist view of identity development on two poles of achievement versus confusion, which may undermine the unique contextual and social aspects of human experience (Alberts & Durrheim, 2018). However, my study acknowledges the core element of Erikson’s theory i.e., the importance of having a coherent sense of identity for adolescents, which has also been widely recognised in current literature. For instance, having consistency in and making sense of various aspects of identity can be crucial for adolescents as it is linked to overall wellbeing, lesser symptoms of depression and anxiety, and reduced likelihood of engaging in risky behaviours such as substance misuse, unsafe sex and violence (Schwartz and Petrova, 2018). Further, Erikson’s recognition of the body as a part of identity is also currently acknowledged in studies which highlight how individuals view their body as a core feature of their identities (Kling et al., 2018).

The Process of Identity Development. Preceding paragraphs highlight the multifaceted nature of identity, and the importance of identity development during adolescence. To reiterate, varied components can become a part one’s identity based on the meaning one attaches to them (Schwartz et al., 2011). Additionally, identity can develop in a context of one’s social relationships, economic considerations, culture, ethnicity, gender (Adams & Berzonsky, 2008), difficult life events (McLean & Syed, 2015), and chronic illness such as chronic pain (Wicks et al., 2019). In terms of identity development, having a chronic illness during adolescence can contribute towards difficulties with having a coherent and continuous sense of self (Branje, 2022; Wicks et al., 2019). This is important to consider as identity difficulties can lead to an increased likelihood of aggressive behaviour, substance use, depressive symptoms and loneliness (Branje et al., 2021).

Chronic Pain

The International Association for the Study of Pain (IASP) defines pain as "an unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue injury" (Raja et al., 2020). Pain can be classified into two groups. Acute pain is associated with a disease or an injury, and normally resolves with natural time of healing (e.g., pain following a pulled muscle) (Grichnik & Ferrante, 1991). Conversely, chronic pain can be seen as recurrent or persistent pain lasting for more than three months (Treede et al., 2019). This current view of chronic pain i.e., pain lasting for more than three months, is chosen for my study as it is currently widely accepted within healthcare systems (e.g., NHS, 2023b).

According to the IASP classification (Treede et al., 2019), chronic pain can be further divided into chronic primary and secondary pain. Primary chronic pain can be present in one or more parts of the body, cannot be better explained by another chronic pain condition, and involves a high level of emotional distress and interference with functioning. Examples include conditions such as fibromyalgia and complex regional pain syndrome (CRPS). Secondary chronic pain results from an underlying disease but can persist beyond the successful treatment of the disease, and the pain can become a problem in its own right. For example, chronic post-surgical or post-traumatic pain lasting for more than three months.

Chronic Pain in Adolescents: Prevalence and Impact. Chronic pain appears to be prevalent in adolescents, with approximately 44% of adolescents across 42 countries experiencing weekly chronic pain (Gobina et al., 2019). The same study suggested that the most prevalent type of chronic pain in adolescents was multi-site pain (headache, backache and stomach-ache). Adding to this knowledge, a recent comprehensive systematic review and meta-analysis study (Chambers et al., 2024) reviewed 119 studies to understand the prevalence of chronic pain in children and adolescents across 70 countries. Findings suggested that the prevalence was estimated to be 20.8%, which may be seen as 1 in 5 children and adolescents experiencing chronic pain worldwide. The same study further explained the potential reasons behind the varying prevalence percentages of chronic pain in children and adolescents reported across literature, which included differences in the definitions of chronic pain, pain type, age ranges and geographical locations used in other prevalence studies. Nevertheless, this study highlighted that chronic pain can continue to be seen as prevalent in children and adolescents.

Chronic pain can have an adverse impact on several areas of adolescents' lives such as on academic performance (Logan et al., 2008) and family and peer relationships (Kashikar-Zuck et al., 2007 & Lewandowski et al., 2010). In the longer term, such adolescents can have an increased likelihood of experiencing psychological difficulties like depression (Noel et al., 2016), lower educational and vocational outcomes, and difficulties in the quality of romantic relationship (Murray et al., 2020). Collectively, varied chronic pain conditions appear to be linked with common experiences in children and adolescents such as difficulty in engaging with daily activities, school absences and emotional distress (Zernikow et al., 2012).

Interestingly, in the adolescent chronic pain literature, a focus on identity development is lacking although individuals generally begin to explore their identity during adolescence

(Feldman, 2014). This can be important for research to explore, considering that chronic illnesses can have a potentially unhelpful role in forming adolescents' identity (Wicks et al., 2019). The interaction between chronic illness and identity can be illustrated through theoretical frameworks, as stated below.

Identity and Chronic Pain: A Theoretical Perspective

Self-Discrepancy Theory. As introduced by Higgins (1987), this theory suggested that the 'self' had three domains i.e., actual self (attributes you or another person believe you actually possess), ideal self (attributes you or another person would like you to have), and the ought self (attributes you or another person believe you should or must have). Self-discrepancies can occur when the attributes individuals have (actual self) differ from the ones they wish to have (ideal self) or believe they should have (ought self). Further, different kinds of self-discrepancies can contribute towards specific 'negative' emotions, for example, discrepancies between one's actual and ideal selves can lead to disappointment, whereas discrepancies between actual and 'ought' selves can be linked with guilt. Another dimension to this theory, i.e., the 'undesired' or 'feared self', was introduced by Ogilvie (1987). The feared self referred to the attributes a person does not desire for but feels scared of possibly becoming. The perception of being 'close' to one's feared self can contribute towards affective states of anxiety, guilt and depression (Heppen & Ogilvie, 2003), and a strong motivation to avoid becoming this feared self (Carver et al., 1999).

In terms of identity, research with adults with chronic pain has suggested that adults can experience discrepancies between their actual and ideal identities, and such self-discrepancies can be associated with psychological distress, depression as well as greater pain intensity (Waters et al., 2004).

Loss of Self. This theoretical framework proposed by Charmaz (1983) suggested how individuals with chronic illnesses can lose valued parts of their self or identity. This loss can stem from various interconnected sources. For example, difficulties in engaging with valued activities and relationships important to one's identity; seeing oneself as a burden on others due to increased dependency on others; and experiencing stigma or misunderstanding from others due to chronic illness which may lead individuals to question their identity. Consequently, the reduced frequency of engaging with valued experiences that created individuals' former 'positive' identity can make it difficult for them to develop new valued parts of identity.

Among adults, chronic pain has been linked to a sense of loss in social, relational, and occupational roles, and loss of personal attributes related to such roles (e.g., being responsible); which in turn can be associated with depression (Harris et al., 2013). In contrast, some adults with chronic pain appeared to have gained valued traits within their identity such as empathy and gratitude (Voorhees, 2023).

Summary. The aforementioned theoretical approaches were chosen for my study as they provide a helpful framework for understanding how chronic illness may interact with the identity of individuals. Overall, studies highlighted how chronic pain can interfere with the identity of adults, which in turn can have unhelpful consequences such as depression (Harris et al., 2013; Waters et al., 2004). However, the study conducted by Voorhees (2023) suggested that chronic pain added valued aspects to individuals' identity. Hence, individuals can have a unique understanding of their identity in relation to chronic pain. Consequently, it may be helpful for research to explore 'identity' from a subjective, first-person perspective which may be facilitated by approaches such as a phenomenological approach.

Literature Review Findings

Search Strategy

Relevant literature was identified through electronic databases such as Google Scholar and APA PsycArticles, and this process was carried out between 2021 and 2024 to remain updated about recent developments in literature. For searching literature from peer-reviewed journals, combinations of several search terms were included i.e., ‘adolescent’, ‘adolescence’, ‘identity’, ‘self’, ‘identity development’, ‘self-perception’, ‘chronic pain’, ‘fibromyalgia’, ‘juvenile idiopathic arthritis’, and ‘complex regional pain syndrome’. Due to the lack of literature on identity development in adolescents with chronic pain, other search terms such as ‘social development’, ‘lived experiences’ and ‘social relationships’ were also used as articles containing these terms contained some specific findings about identity. Some relevant articles were also identified from the reference lists of other articles or scoping review studies on adolescents with chronic pain.

Structure of Literature Review

According to my knowledge, few studies have directly explored how identity develops in adolescents with chronic pain. Hence, the current literature review first outlines briefly how chronic pain may interact with identity in adults with chronic pain. This is followed by findings from the wider adolescent chronic pain literature that reports specific results about identity development. Finally, the few studies which have focused directly on identity in adolescents with chronic pain are presented.

Chronic Pain and Identity in Adults

Overall, findings from studies with adults have suggested that chronic pain may play a disruptive role in adults’ identity. For example, adults have discussed a sense of loss or change in their gender roles (Ojala et al., 2015), activities and social roles (e.g., being a parent) that they considered important to their identity, and a difficulty in fulfilling such roles may contribute towards feelings of anger, shame and guilt (Nicola et al., 2021). Some adults experienced the development of a new and unwelcome ‘self with pain’ (e.g., seeing themselves as ‘mean’) which was in contrast with the previous ‘good self’ (Smith & Osborn, 2007).

Research with adults provides an insight into the potentially unhelpful role of chronic pain in shaping one’s identity. However, it is important to explore this topic with adolescents who have chronic pain, as adolescence can be seen as a separate developmental phase when making sense of identity can become salient (Feldman, 2014). To reiterate, difficulties with identity development during adolescence have consistently been linked with unhelpful outcomes such as depressive symptoms (Branje et al., 2021). Thus, it is crucial to understand adolescents’ unique perspective on their identity in light of significant life changes such as having a long-term condition like chronic pain. Further, as adolescents can have a different way of coping with difficulties compared to adults (Zimmer-Gembeck & Skinner, 2008), increasing knowledge about how identity develops in adolescents with chronic pain can help tailor specific support for this age group.

Chronic Pain and Identity in Adolescents: Findings from Wider Literature

Within the wider literature on adolescents with chronic pain, 11 studies were found that focused on varied topics (e.g., overall social development), but still contained relevant findings about identity. From these 11 studies, two adopted a quantitative design and are discussed first, and the remaining nine followed varied qualitative methods and are discussed thereafter.

Quantitative Studies. Eccleston et al. (2008) conducted a study to understand the impact of chronic pain on adolescents' social development, and how adolescents with chronic pain perceived their social development in comparison with their peers. Several areas of social development were considered in this study, such as independence, identity development and social relationships. Data was collected through the Bath Adolescent Pain Questionnaire (BAPQ; Eccleston et al., 2005), which can be seen as a reliable and valid questionnaire for understanding the development of adolescents with chronic pain (Gagnon et al., 2011). Findings suggested that adolescents with chronic pain perceived themselves as developmentally 'similar' to their peers in terms of identity formation. However, the findings also suggested that a higher intensity of chronic pain led adolescents to perceive their identity as less developed compared to peers. These mixed findings may be explained by the use of questions relating to identity within the BAPQ which are quite broad (e.g., 'the development of my own sense of identity as compared to my peers'). Such questions may be unable to capture the complexity of adolescents' identity, considering that identity can be multifaceted and unique. Thus, these results were unclear in elucidating which aspects of adolescents' identity were considered as 'similar' to their peers, 'how' the intensity of chronic pain led adolescents to view their identity as less developed, and what a 'less developed' identity meant for adolescents.

Kashikar-Zuck and colleagues (2007) examined peer relationships and social functioning in a school setting with adolescents with juvenile primary fibromyalgia syndrome (JPFS) in comparison with peers who did not have a chronic illness. Data was collected through a rating scale called Revised Class Play, which is considered reliable and consistent for measuring dimensions of social reputation (e.g., popularity, aggression and sensitivity) (Masten et al., 1985). During data collection, the rating scale was completed by adolescents with JPFS, their peers, and teachers. Results suggested that adolescents with JPFS were viewed or rated as sensitive/isolated (compared to healthy peers) by themselves, their peers as well as their teachers. Although this study provided an insight into how adolescents with JPFS perceived themselves in a school context and the social difficulties they experienced, the quantitative methodology used did not allow for exploration of the individual reasons these adolescents may have had about perceiving themselves as sensitive or isolated. Further, these results did not shed light on what it meant for adolescents with JPFS to be perceived (by themselves and peers) as ‘sensitive’ or ‘isolated’. Understanding such meanings behind identity can be important to explore further as peer networks facilitate adolescents to understand their identity, and a coherent sense of identity is helpful for psychosocial adjustment (Branje, 2022).

Collectively, findings from studies by Eccleston et al. (2008) and Kashikar-Zuck et al. (2007) provided an insight into the potentially unhelpful impact of chronic pain on different aspects of adolescents’ social development, including their identity. Nevertheless, a subjective understanding of adolescents’ identity difficulties was missing, which can be important considering the unhelpful psychological outcomes that identity difficulties can have on adolescents (Branje et al., 2021).

Qualitative Studies. In contrast with the findings from quantitative studies, this subsection offers a subjective understanding of ‘how’ adolescents with chronic pain may understand their identity.

Adolescents’ Overall Identity. Jordan et al. (2018) explored how adolescents made sense of their own development in light of living with chronic pain. Ten participants were included in this study, with varied chronic pain conditions like arthritis and CRPS. Interpretative Phenomenological Analysis (IPA; Smith, 1996) was used to analyse data collected through semi-structured interviews. One of the themes presented in the findings was titled as ‘an externally imposed lens on identity’, which provided a rich understanding of adolescents’ identity being ‘stolen’ by a diagnosis of chronic pain, as adolescents were viewed by themselves and others (e.g., family and friends) as a pain condition rather than someone with individual preferences. Some adolescents also experienced difficulty in engaging with activities that were important to their identity, such as being a drummer. However, other adolescents continued engaging valued activities in despite pain, which enabled them to continue seeing themselves as a ‘dancer’, rather than being seen only as a pain condition. Interestingly, some adolescents viewed themselves as more mature and better able to manage their emotions compared to their peers. Collectively, findings from this study exemplify the unique ways in which adolescents understood their identity, thus highlighting the importance of understanding adolescents’ identity from their subjective viewpoint. These findings also suggest the extent to which chronic pain may interfere with the identity of adolescents (e.g., identity being ‘stolen’ by pain). Further, the inclusion of multiple chronic pain conditions in this study suggests that adolescents with varied chronic pain conditions can have a shared experience in relation to their identity. However, the primary focus of this study was on adolescents’ perceptions of their development and the interview questions for data collection were framed accordingly. Considering the subjectivity of identity, it is important for research to focus specifically on how adolescents with chronic pain make sense of their identity, which can help provide a deeper understanding of the potential identity difficulties that adolescents with chronic pain can have.

A recent study by Parsons and colleagues (2023) explored how adolescents with chronic pain perceived and experienced flourishing i.e., positive outcomes such as growth or benefit finding whilst living with chronic pain. This study included 24 adolescents who were aged 11-24 years and had varied chronic pain conditions. Data was collected using daily online diaries over a period of 14 days, and additional data was collected through follow-up semi-structured interviews with 10 of the recruited participants. Data was analysed using reflexive thematic analysis (Braun & Clarke, 2006, 2019, 2021a, 2022) following which two themes were generated. The second theme, 'becoming a better version of myself' provided findings related to participants' identity. Such findings depicted participants' sense of growth as individuals and becoming a better and stronger person due to living with pain (i.e., increased resilience and emotional maturity in comparison with peers and their own previous self). The same theme also highlighted how living with pain enabled participants to develop empathy, which in turn strengthened their social relationships, and helped them see themselves as kinder individuals. Findings from this study further demonstrate the unique ways in which adolescents with chronic pain may view their identity. Namely, adolescents may also experience positive changes in their identity, which emphasises the need to explore their identity from their subjective viewpoint. Although this study provides some knowledge about adolescents' identity in the context of chronic pain, the primary focus of this study was on experiences of flourishing. Thus, a richer understanding of adolescents' identity remains missing, which can be important for understanding the unique difficulties as well as positive developments in identity that adolescents with chronic pain may experience.

Multiple Facets of Adolescents' Identity. In addition to the overall identity of adolescents, the following studies highlight the role of chronic pain in shaping different facets of adolescents' identities. A study by Sorensen & Christiansen (2017) explored adolescents' experiences of chronic pain and its impact on their daily lives. Data collected through semi-structured interviews was analysed using hermeneutic analysis (Kvale & Brinkmann, 2009;

Malterud, 2011). Findings revealed that chronic pain interfered with adolescents' engagement in sport activities (e.g., swimming, dancing, and football), which were important parts of their identity. Consequently, adolescents continued engaging in sport to preserve their valued sport identities, despite being in considerable pain. The discussion section of this study suggested how adolescents' determination to continue with activities despite pain may reflect an effort to preserve the normalcy in their collective identity of being an adolescent. However, the findings of this study provided an insight into only some aspects of adolescents' identity (sport identity and possible difficulties with the collective identity of being an adolescent). Considering the complex and multifaceted nature of identity, it can be beneficial to explore identity from a broader perspective to gain a better understanding of how chronic pain may interact with different aspects of adolescents' identities (e.g., relational identity).

A narrative study conducted by Meldrum et al. (2009) aimed to understand the impact of chronic pain on the lives of children and adolescents. Data was collected through semi-structured life history interviews, and analysed in two ways i.e., using a grounded theory approach and narrative analysis. Identity specific results from study suggested that adolescents with chronic pain perceived themselves as alone, unable to engage in enjoyable activities, and held back from their future goals. Being unable to engage in activities took over valued parts of adolescents' identities, such as being an academic achiever. Consequently, these adolescents expressed feelings of anger and frustration, as their future seemed to be different from what they had envisioned. Some adolescents, due to their chronic pain, viewed themselves as 'different' compared to their peers. Findings of this study suggest that chronic pain may interfere with adolescents' sense of belonging as an 'adolescent', and that adolescents may experience identity discrepancies (e.g., difference in actual versus 'ideal' or envisioned identity in relation to future goals). Considering that identity discrepancies in adults with chronic pain have been associated with psychological distress and depression (Waters et al., 2004), it is important to understand what identity development can look like in adolescents with chronic pain. However, the main aim of this study was to understand the impact of chronic pain on adolescents' lives and the questions asked during interviews may have been framed accordingly, but is currently unclear as the interview schedule was not reported in the text of this study. Thus, although this study provides results about identity, there is a gap in current literature for exploring adolescents' identity in light of chronic pain by including identity-specific questions in data collection methods.

A study by Jones et al. (2020) explored how adolescents with Complex Regional Pain Syndrome (CRPS) perceived and expressed their future narratives. This study included adolescents aged 14-25 years who had a diagnosis of CRPS. Data was collected using story completion (Clarke et al., 2019) with 50 participants, and follow-up semi-structured interviews were conducted with a sub-set of 10 participants. Data was analysed using inductive and deductive reflexive thematic analysis (Braun & Clarke, 2013, 2019), following which two themes were generated. In terms of identity-specific findings, the first theme, 'centrality of loss' highlighted how some participants' CRPS appeared to introduce changes and losses in their current identity (e.g., losing control over one's self), which they perceived would be a part of their future. Further, some participants experienced a loss in the non-pain parts of themselves as they perceived their pain dominated their lives, which in turn created distance between participants and their peers in terms of shared experiences and future goals. Focusing on the social aspect of adolescents' future narratives, the same theme suggested how some participants' views of how others perceived them seemed to increase the sense of loss and unhelpful feelings that participants had for themselves and their future (e.g., thinking that "people may have given up on me"). Taken together, the findings from this study highlight the losses in future identity that adolescents with chronic pain experienced. In essence, this suggests how chronic pain may have a complex interaction not only with the current but also the envisioned future identity of adolescents. However, the findings of this study are limited to understanding only one aspect of identity i.e., future identity, and it may be helpful to understand identity comprehensively, considering the multifaceted nature of identity (Schwartz et al., 2011). Further, this study included only one chronic pain condition i.e., CRPS, thus the findings of this study may apply differently to adolescents who may have other chronic pain conditions. It can thus be important to understand how adolescents with other chronic pain conditions may understand their identity (including their future identity).

To summarise, findings from studies by Christiansen and Sorensen (2017) and Meldrum et al. (2009) allude towards potential changes and loss in parts of adolescents identity due to reduced engagement in valued activities. Further, findings from the study by Jones et al. (2020) highlight the sense of loss in the imagined future identity of adolescents. Collectively, findings from these studies suggest how chronic pain may contribute towards losses multiple layers of adolescents' identity i.e., present as well as future identity. In adults with chronic pain, identity losses have been associated with depression (Harris et al., 2003), because of which it can be important for research to focus on how adolescents with chronic pain understand their identity.

Identity in the Context of Social Relationships. A study by Forgeron et al. (2013) explored the development of friendships in adolescents with chronic pain. This study included adolescents with chronic pain as well as healthy adolescents, to understand the perspective of healthy adolescents on friendships with adolescents with chronic pain. In this study, adolescents with chronic pain had varied chronic pain conditions such as headaches and musculoskeletal pain. Data was collected using semi-structured interviews including questions about adolescents' friendships, and was analysed using IPA (Smith & Osborn, 2003). Findings of this study discussed two themes. The first theme 'rethinking the self with pain' provided results about identity, and highlighted how chronic pain changed the way adolescents could engage with social and leisure activities, which in turn made them question their worth as a student, friend and person. Further, some adolescents alluded to the invisibility of pain because of which others did not believe or misunderstood them. In essence, pain seemed to have become a part of adolescents "being" as it changed the way others viewed them – instead of typical adolescents, they were viewed with scepticism in relation to their pain. These findings are suggestive of a difference in the internal and external representations of adolescents' identity. Findings from this study also suggest that adolescents with varied chronic pain conditions seemed to have some shared experiences regarding their identity. However, as this study focused primarily on friendships, the results did not provide a deeper understanding of the meaning behind the possible changes in adolescents' identity (e.g., as a friend), or how unhelpful experiences of being viewed with scepticism contributed towards their identity formation. Thus, there is a gap in research regarding the potential identity changes that adolescents with chronic pain might experience. This can be important to explore as some evidence from adults with chronic pain suggests that identity changes can have a negative impact on psychological wellbeing (April et al., 2022).

Wakefield et al. (2021) had conducted a study using content analysis (Hsieh & Shannon, 2005) to explore how adolescents with chronic pain used coping strategies (e.g., concealing pain). Findings specific to identity indicated that participants concealed their chronic pain to appear 'normal' to others, or to avoid seeing themselves like a 'burden' or 'hardship' on others like friends and family. Underlying the concealment of pain was adolescents' motivation to avoid feeling stigmatised (e.g., through social rejection or exclusion by others). These findings highlight how adolescents' identity may develop in a context of their social world that includes relationships and stigma associated with chronic pain. However, due to the primary focus of this study being on pain concealment and stigma, the findings of this study provided insight into only one aspect of identity i.e., identity associated with experiences of stigma. Specifically, the analytic codes used in this study were informed by Stigma Theory (Goffman, 1963). Thus, a more comprehensive understanding of identity in adolescents with chronic pain is currently lacking, which can be important considering the multifaceted nature of identity.

Ghio et al. (2021) aimed to understand the goals that adolescents had in trying to cope with their pain, using a theoretical model of Common-Sense Self-Regulation Theory (Leventhal et al., 1998). This study used a Framework Method Analysis (Ritchie & Spencer, 2002) to analyse data collected through interviews focusing on adolescents' experiences and perceptions of their chronic pain. Results suggested that adolescents with chronic pain viewed themselves as 'not normal', as they defined themselves through comparison with their 'healthy' peers. To 'preserve' the normalcy in their social identity, some adolescents hid their pain to avoid being seen as different. These findings highlight how adolescents wished to match their identity based on what was considered as the 'norm' for this age group. This also suggests how adolescents' identity can be shaped by what they consider as important or meaningful i.e., a sense of belongingness with other adolescents. However, the findings of this study placed more emphasis on how adolescents coped to preserve the normalcy of their identity, thus, a more subjective understanding of what it meant for adolescents perceive themselves as 'not normal' is currently lacking. Exploring such individual meanings of identity in adolescents with chronic pain can be helpful, as research suggests that perceiving oneself as having a ‘negative’ identity (e.g., identifying with negative labels) can contribute towards difficulty in healthy social engagement, and greater likelihood of unhelpful behaviours such as delinquency (Hihara et al., 2019).

A recent IPA (Smith et al., 2009) study by Corser et al. (2023) had explored the lived experiences of adolescents with varied chronic pain conditions as well as mental health symptoms (e.g., anxiety and depression). Semi-structured interviews were used for data collection with participants belonging to ages between 11-19 years. In terms of identity-specific results, the first theme, ‘a whirlwind of everything’ suggested that adolescents experienced their pain and mental health symptoms as intrusive, which left them feeling out of control. Consequently, these adolescents viewed their chronic pain and mental health symptoms as a separate external entity, because of which they experienced a disconnection between their ‘self’, body and mind. This theme also discussed how the identity of adolescents had changed as they could not engage with valued activities like horse-riding. However, the identity related results from this study were linked to adolescents’ experiences of both chronic pain and mental health symptoms, and hence it may be difficult to understand the specific role of chronic pain in shaping adolescents’ identity. Specifically, this study had an interesting result regarding adolescents’ sense of disconnection with their body. It can be important to explore this to see how adolescents with chronic pain understand different parts of their identity (including their body), as separation from one’s body in light of chronic illness can contribute towards lower self-esteem (Bode et al., 2010).

Identity Development in Adolescents with Chronic Pain: A Direct Exploration

To my knowledge, current adolescent chronic pain literature includes only three studies with a specific focus on identity (McDonagh et al., 2016; Skarstein et al., 2018; Szwimer et al., 2020). These studies adopted a qualitative approach, and their findings are presented below.

The study by McDonagh et al. (2016) focused on the relationship between identity and medication usage in adolescents with juvenile arthritis. Participants included 21 adolescents aged between 11-17 years and six parents. Data was collected through online blogs, within which participants could enter information regarding specific categories such as thoughts about identity or arthritis. Data from blog entries was analysed using content analysis (Hsieh & Shannon, 2005). Notable findings of this study suggested that the age at which participants were diagnosed made a difference to the 'normalcy' of identity. Specifically, participants diagnosed during childhood saw arthritis as a normal part of their identity, whereas those diagnosed later viewed diagnosis as a 'life changing' event as the difference in the pre and post diagnosis identity was profound. Consequently, participants tried to retain their pre-diagnosis identity, and continued engaging in age-appropriate activities despite being in pain to maintain a sense of belongingness with other adolescents. Although this study provides unique findings about the role of age and diagnosis in the identity of adolescents, only one chronic pain condition was included in this study. Thus, an understanding of how identity develops in adolescents with other chronic pain conditions is currently missing, which is important as varied chronic pain conditions can have a shared impact on the lives of children and adolescents (Zernikow et al., 2012). Further, receiving a chronic pain diagnosis for adolescents can take time (Eccleston & Malleson, 2003), and although a clear timeframe of how long it takes to diagnose adolescents in the UK is not available, data from the USA revealed that it may take approximately six and half months for adolescents to be seen for evaluation in a paediatric pain clinic (Palermo et al., 2019). Thus, it can be interesting to see how ‘being’ in prolonged pain, even without a diagnosis, can interact with adolescents’ identity. Lastly, the use of online blogs for data collection may have limited an in-depth understanding of identity as this method may not allow researchers to ask follow-up questions about interesting parts of adolescents’ blog entries. For instance, an in-depth meaning behind the ‘life changing’ experience of a diagnosis could have provided a richer insight into adolescents’ identity.

Skarstein et al. (2018) had explored how identity developed in adolescents who used medication to manage their chronic pain. This study included 16 participants i.e., eight adolescents aged between 14-16 years, and their mothers. Data was collected using semi-structured interviews which were conducted separately with adolescents and their mothers. Interview data from adolescents and mothers was combined for dyadic analysis (Brinkmann & Kvale, 2008; Eisikovits & Koren, 2010). Interestingly, the results of this study focused primarily on areas such as adolescents’ close relationship with their mothers, instead of identity development, which was the primary aim of the study. Findings about identity were presented mainly in the discussion section of the study. Such findings suggested that adolescents’ identity appeared to be based on (and sometimes restricted by) the close relationship with their mother, for example, the close relationship with mothers seemed to limit adolescents from expanding their social networks which can be important for identity development. The lack of focus on identity in this study may be explained by very broad interview questions (e.g., “Tell me about your life”). Further, the analytic method of combining adolescent–mother data may have contributed to a restricted understanding of adolescents’ unique perspectives about their identity. Since identity can be subjective (Leary & Tangney, 2011), it may have been helpful to focus more on adolescents' perspectives. Overall, a deeper understanding of adolescents' identity was lacking in the findings of this study.

Lastly, a study carried out by Szwimer et al. (2020) adopted a phenomenological epistemological approach to understand how eight female adolescents (aged between 14-17 years) with chronic pain made sense of their life and identity. Data collected through semi-structured interviews was analysed using IPA (Smith & Shinebourne, 2012). Results mainly described the "positive and negative factors of living well", such as acceptance of pain and uncertainty of pain respectively, which influenced adolescents' ability to make sense of their lives. A minor section within the results revealed that adolescents expressed worries about their future identity and the possibility of being "normal" in the future, as their chronic pain was quite unpredictable. Such results emphasised the dynamic nature of identity (McLean & Syed, 2015), and how chronic pain may disrupt adolescents' present as well as future identity. However, this study had some drawbacks which may have restricted a clearer understanding of adolescents' identity. First, the presentation of the study findings as "positive and negative factors" was more consistent with a positivist epistemology that focuses on objectivity (Ponterotto, 2005) than with the researchers' phenomenological epistemology. As identity is subjective, the use of a positivist lens in this study provided a limited insight into the subjectivity of adolescents' identity. Second, findings seemed to mainly describe participants' experiences, and lacked the interpretative approach of IPA. Thus, it was difficult to understand in-depth what it may have meant for adolescents to feel worried about being "normal" in the future. Lastly, this study lacked the perspectives of male adolescents on their identity, which can be important to understand as although chronic pain can be more prevalent amongst females, male adolescents also experience chronic pain (Gobina et al., 2019).

Epistemological and Methodological Critique

The current understanding of identity development in adolescents with chronic pain is informed by both quantitative and qualitative research. The two quantitative studies (Eccleston et al., 2008; Kashikar-Zuck et al., 2007) used quantitative questionnaires for data collection. Although these studies provided preliminary knowledge through adolescents' 'scores' on their overall identity or specific parts of their identity (e.g., self-perception in school context), these findings did not provide an understanding of what it meant for adolescents to perceive themselves as 'isolated', or the subjective understanding of 'how' adolescents developed certain self-perceptions. As the concept of identity itself can be subjective and unique (Schwartz et al., 2011), quantitative research methods following a positivist epistemology may not fully capture the unique perspectives of adolescents regarding their identity.

The qualitative studies presented in the current literature review also seemed to have certain methodological and epistemological drawbacks. For instance, some studies used a specific theory that informed data analysis (e.g., Ghio et al., 2021; Wakefield et al., 2021). Although using specific theories aligned with the primary aim of these studies (e.g., exploring adolescents' coping strategies), this may have provided a limited understanding of the uniqueness of adolescents' identity as only the theory-specific parts of identity (e.g., stigmatised identity) were focused on. As identity can be multifaceted, it may be helpful to understand adolescents' identity holistically.

Some qualitative studies used IPA (e.g., Corser et al., 2023; Forgeron et al., 2013) and hermeneutic analysis (e.g., Sorensen & Christiansen, 2017). Both analytic methods aim to highlight subjective experiences in-depth. However, the study conducted by Forgeron et al. (2013) included participants with and without chronic pain which did not appear to align with

IPA’s focus on homogeneity of experience, as the experiences of adolescents with and without chronic pain can be quite different. Thus, this may have restricted a deeper understanding of experiences of adolescents regarding their friendships and identity. In the study by Corser et al. (2023), some of the leading questions used in the interview schedule may have prompted adolescents to answer in a certain direction, which may not align with IPA’s emphasis on uniqueness and idiography. Consequently, this may have shifted the focus away from adolescents’ unique perspectives and experiences. Further, findings in the study by Sorensen & Christiansen (2017) were primarily descriptive thereby limiting the extent to which an in-depth understanding of adolescents’ identity could be gathered. However, as the primary aim of the aforementioned studies was not on exploring identity, the lack of depth in providing identity-specific insights may be explained by this.

The few studies which aimed to explore identity development in adolescents with chronic pain offered a restricted understanding of identity due to epistemological and methodological limitations. For example, the method of dyadic analysis used by Skarstein et al. (2018) shifted the focus away from adolescents’ unique perspectives about their identity to their relationship with their mothers. Conversely, the findings by Szwimer et al. (2020) aligned more with a positivist epistemology rather than the authors’ phenomenological epistemology and the findings were primarily descriptive, thus lacking the interpretative focus of IPA. Therefore, both studies did not appear to address their primary aim of providing an understanding of identity development in adolescents with chronic pain. Lastly, the use of content analysis in study by McDonagh (2016) did not facilitate an in-depth understanding of the uniqueness of adolescents’ identity, as the focus of this analytic method is organising larger quantities of data into categories (Hsieh & Shannon, 2005).

Implications of the Review and Research Gap

The presented literature review highlights the lack of in-depth, subjective, and phenomenological knowledge of how adolescents with chronic pain make sense of their identity. Overall, findings from different studies suggest that chronic pain can interfere with adolescents' identity, or parts of identity. However, a direct exploration of identity development in adolescents with chronic pain remains missing, even though identity generally begins to develop during adolescence and a coherent sense of identity can be important for overall wellbeing in adolescents (Schwartz and Petrova, 2018). The potentially unhelpful outcomes (e.g., depressive symptoms) associated with identity difficulties (Branje et al., 2021) further strengthen the need to explore adolescents' identity in the context of chronic pain.

Interestingly, findings about adolescents' identity have emerged repeatedly in qualitative studies whose original aims were varied (e.g., Forgeron et al., 2013; Wakefield et al., 2021). This may suggest that making sense of identity is important for adolescents with chronic pain. Hence, exploring this topic aims to put into action the CoP values of prioritising subjectivity, growth and empowerment (Kasket, 2016) by exploring a topic that appears to matter to the population being studied.

The presented literature review also emphasises how adolescents make sense of their identity based on what seems meaningful for them, for instance, social relationships and valued activities. Consequently, an interpretative phenomenological epistemology can help to understand the subjective meaning making process behind adolescents' identity. Further, interpretative phenomenological epistemology has been recognised as an appropriate approach for understanding the complexity of identity in physical health conditions such as chronic pain (Smith, 2004 & Smith & Osborn, 2007). Therefore, I adopt an interpretative phenomenological epistemological approach in the present study to understand the uniqueness of adolescents' identity.

Rationale for the Proposed Study

Exploring identity development in adolescents with chronic pain may be useful for clinical practice in CoP and allied disciplines for several reasons. Chronic pain can impact several areas of adolescents' lives (e.g., social relationships, academics), because of which multidisciplinary treatment including psychological therapy is suggested for such adolescents (Friedrichsdorf et al., 2016 & Palermo et al., 2010). Although chronic pain is rooted in physical health, the multi-modal training of CoPs enables us to work in physical health settings (Davies, 2016) and thus with adolescents who have chronic pain.

As the field of CoP acknowledges the complexity of living with chronic health conditions, psychological interventions around identity redefinition and adaptive functioning are recommended for such individuals (Davies, 2016). However, CoPs are encouraged to be aware of and work with context-specific elements, diverse life experiences of clients (British Psychological Society [BPS], 2005) and have a child-centred or developmentally appropriate approach when working with children and adolescents (Sinitsky, 2016). Hence, my study may provide helpful and developmental knowledge for working around identity difficulties with adolescents who have chronic pain.

Further, my study aims to contribute towards the wider social science literature by adopting a comprehensive understanding or definition of 'identity', which appears to be lacking in the literature (Schwartz et al., 2011). Finally, my study may provide a unique psychological viewpoint on a physical health condition (Davies, 2016), which can inform other professionals involved in chronic pain management such as health psychologists and medical professionals.

Research Aim and Question

To conclude, my study aims to address the gap in current literature by exploring the subjectivity of how adolescents with chronic pain understand their identity. For this purpose, a qualitative, cross-sectional study with an interpretative phenomenological epistemology is proposed.

The following research question is identified: How do adolescents with chronic pain make sense of their identity?

Methodology

Chapter Overview

This chapter begins with an overview of reflexivity in qualitative research. The philosophical position adopted in my study is then discussed, followed by a rationale of the epistemological and methodological choices made in this study. Details of the research procedure such as ethical approval and data collection are then provided. Finally, a discussion regarding quality in qualitative research is offered.

Reflexivity

Considering that qualitative research focuses on subjectivity, the element of reflexivity can be seen as crucial for understanding ‘how’ a researcher’s subjectivity can interact with the research process (Olmos-Vega et al., 2023). According to Kasket (2012) CoP research can involve three kinds of reflexivity. Personal reflexivity refers to recognition of the researcher’s position and history with the research topic. Methodological reflexivity involves appraisal of the research methods used, and appropriate management of methodological issues. Epistemological reflexivity includes acknowledging that different methods can generate alternative findings. I make use of first-person language where appropriate, and my engagement with various kinds of reflexivity is stated clearly where relevant in this chapter.

Philosophical Position

A research paradigm forms the blueprint of research, and includes the concepts of ontology, epistemology, and methodology (Guba, 1990). Ontology seeks to explain the nature of reality; whereas epistemology is concerned with ‘how’ reality can be understood, and the relationship between a participant and researcher (Morrow, 2007). Methodology includes the processes and methods utilised within the research process (Ponterotto, 2005). Hence, a researcher's epistemological position about 'how' reality can be understood can subsequently inform the methodological decisions taken in the research (Willig, 2013).

Qualitative research includes different epistemologies based on how they view 'reality', for instance, some epistemological positions assume that data provides an accurate reflection of reality (realist ontology) (Cooper, 2012). Others suggest that data may not mirror reality, as reality is subjective and there can thus be as many realities as there are individuals (relativist ontology) (Levers, 2013). In between these contrasting ontologies, a critical realist ontology recognises the existence of 'true' reality, however, the knowledge about this reality can only be understood through individuals' subjective interpretations and context (Lawani, 2021). Ontologically, I position myself as a critical realist as I accept the concepts of chronic pain and identity as 'real' whilst acknowledging that these can be experienced uniquely by individuals.

I take an interpretative phenomenological epistemological position for answering my research question. Although I acknowledge the 'reality' of chronic pain and identity, I accept that I may not have 'direct access' to this knowledge or experience of participants. Following an interpretative phenomenological epistemological position, I can understand participants' 'reality' or experience through three ways – the constituents of their experience i.e., thoughts, feelings and perceptions; participants' meaning-making of that experience; and by reflecting on participants' account by interpreting it in its wider social, cultural and psychological context (Willig, 2013).

My epistemological position aligned with my research question's focus on meaning making, which is suitable for interpretative phenomenology. As such, coherence between research question, philosophical position and analytic method can be important for enhancing quality in qualitative research (Yardley, 2000), which is discussed in-depth subsequently in this chapter. An interpretative phenomenological epistemological position also appears harmonious with CoP's humanistic values of individuality and meaning making processes (Donati, 2016). Thus, my study can be beneficial to the field of CoP as it would increase our developmentally appropriate understanding about adolescents' perspectives regarding their identity in the context of chronic pain.

Methodological Decisions and Reflexivity

This sub-section highlights epistemological and methodological reflexivity as I discuss the rationale behind my methodological considerations and choices.

The Literature Review chapter of my study demonstrated that identity development can be unique and may be appropriately understood through the subjective experiences of adolescents with chronic pain. Consequently, multiple qualitative methodologies were considered for my study including Interpretative Phenomenological Analysis (IPA), Reflexive Thematic Analysis (TA), Narrative Analysis (NA) and Descriptive Phenomenology.

Reflexive TA was initially considered due to my prior experience with this methodology, and its focus on highlighting patterns of meanings in the phenomenon under question, which aligned with my research question (Harper & Thompson, 2012). Further, reflexive TA is considered 'theoretically flexible' (Braun & Clarke, 2006) and would allow understanding participants' meanings behind their chronic pain and identity from my interpretative phenomenological epistemological position. However, reflexive TA involves generation of patterns across the data set from an early analytic stage rather than analysing each case in-depth individually (Braun & Clarke, 2021b). Consequently, reflexive TA appeared unsuitable as my

Literature Review highlights the importance of understanding the uniqueness of each participant's identity and chronic pain in-depth.

Identity can also be viewed as a long-term narrative process involving assimilation of events into a life story (McLean & Syed, 2015). Consequently, NA was also considered for my study to potentially explore how adolescents integrated chronic pain into their identity. However, the gap identified in my Literature Review highlighted the unique meanings that adolescents can have about their identity in relation to chronic pain. Specifically, adolescents may not necessarily 'integrate' chronic pain into their identity. Hence, I believe the findings produced by NA would not allow to sufficiently explore the unique experiences of adolescents, as NA would focus more on integration of chronic pain into identity.

As the gap identified in my Literature Review suggested a lack of direct exploration of adolescents' unique perspectives regarding their identity, phenomenology appeared to be a suitable approach and aligned with my research question. Broadly, phenomenology aims to understand experiences (feelings, thoughts and perceptions expressed through language) from a first-person perspective (Willig, 2013). It assumes that meaning-making of an experience depends on the perceiver's context – indicating that an experience can be perceived differently by different individuals (Willig, 2013). Within phenomenology, a choice was made between descriptive phenomenology and interpretative phenomenology. Descriptive phenomenology focuses on 'describing' the lived experience exactly as it is presented by the participant, without involving any external meanings that are not a part of the original experience (e.g., the researcher's past knowledge) (Cooper, 2012). Considering my interpretative phenomenological epistemological position, I believe that my experiences are a part of my knowledge. Consequently, descriptive phenomenology did not appear appropriate as it encourages researchers to ‘bracket’ presuppositions and knowledge (Willig, 2013). Conversely, keeping in mind my previous experiences with chronic pain, I see myself as part of the research process, for example, in interpreting a participant’s experience.

Rationale for Chosen Methodology

The chosen methodology for this study was IPA (Smith et al., 2022). This sub-section provides an overview of IPA’s theoretical concepts, and the rationale for selecting this methodology.

Phenomenology

As introduced by Husserl, phenomenology refers to the study of ‘being’ or human experience, which can be understood by identifying its core structures or features (Langdridge, 2007). Phenomenology aims to uncover the ‘essence’ of experience by understanding it as it appears i.e., by suspending or ‘bracketing’ one’s previous knowledge and assumptions (Willig, 2013). Heidegger and Merleau-Ponty furthered Husserl’s work by focusing on existence itself, which is known as the existential turn in phenomenology. Heidegger suggested that phenomena or ‘being’ could not be studied in a bracketed manner, as researchers are a part of the same world they are trying to study (Langdridge, 2007). Hence, Heidegger suggested that phenomena can be understood appropriately by interpreting them in their cultural and historical context, and can be conveyed through the use of language (Langdridge, 2007). Merleau-Ponty (1962) introduced the concept of embodiment i.e., understanding and being connected with the world through our body.

Collectively, Husserl’s ideas on experience, Heidegger’s views on interpretation and Merleau-Ponty’s focus on the embodied nature of experience all contribute towards IPA’s understanding of an ‘experience’ (Smith et al., 2009). For instance, IPA explores human experiences in-depth by focusing on how individuals interpret such experiences, the language individuals use to describe the possible significance of their experience, and how such experiences may be shaped by their physical bodies (Smith et al., 2009).

Hermeneutics

Hermeneutics refer to the theory of interpretation (Willig & Rogers, 2017). Within IPA, the influence of hermeneutics can be seen as IPA aims to understand how individuals make sense of or interpret their experiences based on their social context or world (Harper & Thompson, 2012). Additionally, IPA recognises that a researcher’s interpretation of the participant’s experience is based on the researcher’s previous knowledge and experiences (Willig & Rogers, 2017). This is referred to as ‘double hermeneutic’ – as the researcher interprets the participant’s interpretation of his/her experience (Willig, 2013). Furthermore, IPA recognises that the participant’s account of their experience may also be linked to the interaction between the researcher and participant (Willig, 2013) – hence understanding of a participant’s experience can arise from an intersubjective process between the researcher and participant (Harper & Thompson, 2012).

Idiography

As experience is believed to be complex and unique, it renders itself to be studied from an individual/idiographic lens (Smith et al., 2009). IPA places emphasis on the personal meaning and significance of an experience for a participant i.e., an idiographic level of analysis (Harper & Thompson, 2012). Thus, IPA analyses individual cases in-depth before searching for themes across the data set (Braun & Clarke, 2021). Hence, IPA aims to balance individuality as well as shared features of experience in the chosen population (Willig & Rogers, 2017).

Rationale for Choosing IPA

The theoretical concepts informing IPA appeared suitable for answering my research question due to several reasons. First, IPA's phenomenological focus aligned with my research aim to explore the lived experience of adolescents with chronic pain. IPA's recognition of embodied experiences fits particularly well with my research, as pain is felt inside one's body and is generally invisible to an outsider (Ojala et al., 2015), making it important to understand this from the viewpoint of the one experiencing it. IPA acknowledges that participants' understanding of their experiences can stem from their social world (Willig, 2013). For example, IPA can help to explore how participants understand their identity uniquely in the context of being an 'adolescent'. Thus, IPA also aligns with my critical realist ontological position that assumes the existence of a 'true reality' that can be experienced by individuals uniquely (Cooper, 2012).

Second, IPA's focus on hermeneutics aligns with my interpretative phenomenological epistemological position i.e., the recognition that experiences can be understood through layers of interpretation and the interaction between researcher and participant (Cooper, 2012).

Third, IPA's idiographic focus makes it an appropriate way to understand the uniqueness of identity. Research has also suggested IPA's suitability for capturing a dynamic concept such as identity (Smith, 2004), especially in relation to chronic pain (Smith & Osborn, 2007). Thus, IPA aligns with the research gap identified in my Literature Review, specifically about the lack of a direct focus on unique ways in which adolescents with chronic pain understand their identity.

Procedure

Ethics

My study received ethical approval from the School of Psychology Ethics Committee of the University of East London (UEL) (Appendix A). The ethical considerations made due to the age range of potential participants in my study are stated below, thus demonstrating methodological reflexivity.

During the ethics application process, I obtained an Enhanced Disclosure and Barring Services (DBS) certificate as my research involved participants who may be considered as 'vulnerable' i.e., adolescents below the age of 16 years (BPS, 2021). In line with BPS (2021) research ethics and UEL's ethical guidelines, all research documents were written in an age-appropriate manner to ensure that adolescents could provide 'informed' consent. I also considered that research documents may be read by parents/guardians and hence may need to be written using appropriate language. Thus, two versions (one for adolescents and other for parent/guardian) were created for initial research documents i.e., information sheet (Appendix B) and research advertisement (Appendix C). Adolescent information sheet was piloted with a consenting 17-year-old family friend to ensure that language was age-appropriate. Based on the feedback from the pilot, language was further simplified e.g., terms such as transcription and anonymisation were explained using accessible language. To manage potential power dynamics between myself and adolescents, the information sheets encouraged adolescents to say 'no' and explained clearly that there will be no consequences if they say no for participation or choose to withdraw (BPS, 2021).

The final information sheets contained information such as explanation of the research topic, what participation may involve, confidentiality, possible risks of participation, and contact details of researcher and supervisor (UEL email address). Following research supervision, the information sheets also contained age and pain relevant contact details of support organisations for participants (e.g., Childline, Pain Concern).

The process of receiving informed consent from participants was layered. For adolescents below the age of 16 years, both written consent from parent/guardian and verbal assent from the adolescent was required for participation. Adolescents aged 16 and above are believed to have 'Gillick competence', i.e., the capacity to provide informed consent independently (BPS, 2021 & NHS, 2022). Hence, only written consent was required from adolescents aged 16 and above, but these adolescents were encouraged to discuss their research participation with their parents/guardian. Three separate, age-appropriate consent forms were created (Appendix D) – assent form for adolescents below the age of 16 years, consent form for parents of adolescents below the age of 16 years, and consent form for adolescents above the age of 16 years.

To ensure confidentiality of participants' identity and secure storage of research data (e.g., consent forms, interview transcripts), a Data Management Plan was created and approved by UEL's Research Data Management team. Consent forms were stored in my password-protected UEL OneDrive and deleted after 3 weeks of the interview. Email addresses of participants who wished to receive a summary of the results were retained in my password-protected UEL OneDrive.

Sampling

A purposive sampling approach was used for my study, to include participants based on my inclusion criteria as IPA studies aim to have a small and homogenous sample to understand in-depth the experience of a specific group on a specific topic (Langdridge, 2007). For my study, adolescents were included if they were aged between 14 – 18 years, and experienced chronic pain i.e., pain lasting for more than three months. Adolescents who experience prolonged pain due to other health conditions (e.g., cancer) were excluded. A rationale for my sampling criteria is presented below, to demonstrate methodological reflexivity.

The upper age limit of 18 years was decided as my study was conducted in the UK, where the healthcare system generally views individuals up to the age of 18 years as adolescents (NHS, 2023, 2024). The lower age limit of 14 years was determined based on the activities adolescents can engage in at this age (e.g., part-time employment) (UK Government, n.d.). As identity may develop through expanding social roles and relationships (McLean & Syed, 2015), activities such as employment may enable adolescents to explore their identity. The age range of 14-18 years also ensured homogeneity, as the prevalence of paediatric chronic pain is found to increase with age (King et al., 2011), with a peak at approximately 14 years of age (Eccleston & Malleson, 2003).

The timeframe of having experienced chronic pain for three months or more was decided based on the three-month timeframe included in the current definition of chronic pain (Treede et al., 2019), to ensure homogeneity of experience.

Adolescents were included if they experienced any type of chronic pain (e.g., fibromyalgia, arthritis, musculoskeletal pain etc.). Multiple types of chronic pain conditions were included as chronic pain can have a common impact on adolescents such as difficulties with daily activities and emotional distress (Zernikow et al., 2012). My Literature Review chapter also suggests that adolescents with varied chronic pain conditions can experience similar difficulties in their identity (e.g., Forgeron et al., 2013; Jordan et al., 2018), and to my knowledge, it is currently unknown if specific chronic pain conditions interact differently with adolescents' identity.

To ensure homogeneity, adolescents with other health conditions (e.g., cancer) were excluded as pain associated with a potentially life-threatening health condition can be experienced differently (Backryd, 2024) compared to other chronic pain conditions (e.g., fibromyalgia).

Sample Size

Professional doctorate studies using IPA are recommended to have a small, homogenous sample size between 4 to 10 participants to facilitate in-depth exploration of a complex experience (Smith et al., 2009). I initially aimed to recruit a minimum of 8 participants, to manage the possibility of drop-outs.

Recruitment

Ethics Amendments and Methodological Reflexivity. To support participant recruitment, some changes were made to the original ethics application. Three ethics amendment forms were subsequently created, and were approved (Appendix E). First, in addition to recruiting participants via chronic pain charities, a decision was made to recruit participants via online adolescent or chronic pain support groups/forums (e.g., Scope and Reddit) and their social media pages. This decision was made following research supervision, as 'patient organisations' have been considered helpful for recruiting adolescents (Kling et al., 2021). Further, recruiting adolescents through Instagram based chronic pain pages or 'influencers' was considered, as Instagram is preferred by adolescents for research recruitment (Jong et al., 2023).

Second, the wording of my inclusion criteria and research advertisement was amended. The original inclusion criteria and research advertisement stated that adolescents would be able to participate if they had been "diagnosed" with chronic pain, which was replaced with "experience" chronic pain, as pain can be a subjective experience (Wideman et al., 2019). Further, it can take time for adolescents to receive a chronic pain diagnosis (Eccleston & Malleson, 2003; Palermo et al., 2019) as stated in my Literature Review chapter. Hence, using the word "experience" appeared helpful for reaching a wider group of potential participants and aligned with my epistemological position of understanding the uniqueness of adolescents' experiences.

Third, a decision was made to offer reimbursement in the form of a £10 Amazon E-Voucher to thank adolescents for their time, as they may potentially spend an hour for the interview. This decision was made after careful consideration, research supervision and considering BPS (2021) ethical guidelines. For instance, the reimbursement was offered in the form of a voucher and not cash. The amount of the voucher was not so high that it may undermine potential participants' free decision to participate in the research. The amount was decided following BPS (2021) guidelines of keeping the National Minimum Wage as a baseline. For my study, participants could be aged between 14 – 18 years. Minimum wage for apprentices and 16-17 years old individuals is £5.28, and £7.49 for 18-20 years old individuals (U.K. Government, 2023). As the minimum wage rate is varied for my target population, the reimbursement amount was rounded off to £10. Further, the 'time' taken for participants to engage in my research is not limited to interviews only, as participants also spend some time reading information sheets. Hence, £10 may be appropriate for reimbursement. All participants were offered the same amount of reimbursement.

Recruitment Process. For recruitment, two research advertisements were created, one for adolescents and one for parents using age-appropriate language. The research advertisement contained brief information about the research topic, inclusion criteria, what participation will involve, information about reimbursement, and my contact details (UEL email address).

Some chronic pain charities (e.g., Fibromyalgia Action UK) provided permission to post my research advertisement on their website and/or social media pages (e.g., Facebook, Instagram and Twitter). For online support groups or forums (e.g., Reddit and Scope), I contacted relevant administrators for permission, after which I posted my research advertisement on these platforms.

Interested participants contacted me via the UEL email address provided on the research advertisement. Potential participants were sent a follow-up email to ensure that they met the inclusion criteria. Using my UEL email, participants were then sent relevant information sheets, age-appropriate consent forms, and were encouraged to ask questions about the research. Once the consent forms were returned to me, participants were contacted to arrange a suitable day and time for interviews.

The Participants

Seven participants took part in this study. No participant asked to withdraw from the study. Five participants were females and two were males. Participants were aged between 16 to 18 years and had experienced chronic pain for a minimum of 1 year approximately. Demographic information of participants is presented in Table 1 and pseudonyms are used to refer to participants to ensure confidentiality. In retrospect, I believe that my sample size and variability (e.g., in chronic pain conditions) was adequate to facilitate an in-depth understanding of identity development in the context of chronic pain.

Table 1

Demographics of Participants

Participant	Age	Gender	Ethnicity (self-reported)	Type of chronic pain	Duration of pain
Amy	18	Female	Prefer not to say	Arthritis	1 year
Beth	16	Female	White-Caucasian	Ankle/foot pain (right foot)	2 years
Chloe	18	Female	White-British	Fibromyalgia, myofascial pain	> 5 years
Daisy	17	Female	African	Lower back pain	> 5 years
Ethan	17	Male	Caucasian	Muscle and joint pain, stomach-ache	> 5 years
Frank	18	Male	African American	Head pain	2 years
Georgia	16	Female	White-Other	Gastric pain	1 year

Note. The symbol > denotes a pain duration of more than 5 years.

Data Collection

My study used semi-structured interviews for data collection, including a set of non-directive, open-ended questions to guide the interview process (Langdridge & Hagger-Johnson, 2013). Semi-structured interviews used in IPA studies encourage the researcher be sensitive and empathetic, to help understand the lived experience of participants (Willig & Rogers, 2017).

Consequently, semi-structured interviews appeared appropriate for data collection to explore the experiences of adolescents from a first-person perspective. Further, the real-time interaction with adolescents in semi-structured interviews enabled me to build rapport with them, which can be crucial for research with adolescents (Castro et al., 2017).

Interview Schedule. The interview schedule is presented in Appendix F. Following the suggestion by Smith et al. (2009), questions in the interview schedule were developed by covering various topics relevant to my research question. The order of the schedule followed a broad to specific format. For instance, initial questions focused on participants' understanding of their general identity (e.g., "Can you tell me about the things that make you, 'you'?"), and descriptive questions about their chronic pain (e.g., "How did your chronic pain start and progress?"). Subsequent questions focused on more specific topics such as participants' thoughts and feelings about themselves in light of their chronic pain. Such questions included participants' past, current and future thoughts and feelings about themselves, to explore the dynamic nature of identity. For each question, a set of open-ended prompts was developed to help participants expand on their account. Particular attention was given to the use of age-appropriate language for adolescents in the interview schedule to build rapport with adolescents (Castro et al., 2017 & Rogers et al., 2021). Research supervision was used to ensure that interview questions used day-to-day language.

The process of developing the interview schedule questions was informed by the lens I adopted in this study on the concepts of identity, chronic pain and adolescence. Details of this process are described below. Questions relating to identity were prepared based on my view or lens of identity i.e., seeing it as a sense making process (Schwartz et al., 2011). However, considering that identity can be complex in nature (Schwartz et al., 2011), I ensured that questions around identity were developed using accessible language. For this purpose, I referred to the interview schedule used in Smith and Osborn's (2007) study on identity and chronic pain, to explore how questions around identity could be developed using day-to-day language. Identity-related questions in my interview schedule were developed accordingly, for instance, "how did you think or feel about yourself when you first started experiencing pain?". Such questions also aligned with my interpretative phenomenological epistemology which suggests that phenomena can be understood through the contents of experience (e.g., thoughts and feelings) (Willig, 2013). Further, the initial question about identity, "can you tell me what makes you, you?" aimed to explore the uniqueness of each participant's identity. Finally, questions and subsequent prompts were also created keeping in mind the multifaceted nature of identity, to explore how adolescents made sense of different parts of their identity (e.g., related to valued activities, social relationships etc.). For example, questions and prompts relating to activities included "can you tell me what each day is like for you (in light of your pain)?" and questions about social relationships included "how do you feel around others (friends/peers/family)?". Such questions also ensured that age-relevant areas such as daily activities and friendships were focused on during the interview.

Questions relating to chronic pain were developed considering the subjective nature of pain (Wideman et al., 2019). For example, "can you tell me about your chronic pain / or [name of chronic pain condition] if known?". Additionally, such questions about pain ensured that the adolescent's terminology regarding their pain was used, to improve communication and gain an understanding of how the adolescent viewed their condition (Rogers et al., 2021).

Pilot Interview. The interview schedule was initially piloted with a consenting fellow trainee CoP for receiving feedback on the order and wording of questions. I merged some similar questions together, based on the feedback received. I also noted my reflections after the completion of the pilot interview, which helped me identify some leading questions that were based on my previous research knowledge about adolescents' experiences of living with chronic pain. The interview schedule was further revised following a discussion with a group of fellow trainee CoPs during a research workshop. Consequently, certain leading questions were identified and revised. For example, the question "how does your pain affect your day-to-day activities?" was revised to "can you tell me what each day is like for you?".

The first interview with a participant meeting my study's inclusion criteria was considered as a pilot. This was included in the final sample as the interview questions appeared appropriate in helping the participant discuss her experience in depth, and the participant thanked me for listening after the completion of the interview.

Conducting the Interviews. Interviews were conducted online on Microsoft Teams (video-call), between November 2023 March 2024. Interviews were audio-recorded and lasted between 25-58 minutes. Considering the chronic pain of participants, online interviews were conducted with the aim of ensuring participants' comfort as it would enable them to participate from home.

Before starting the interview, I confirmed with the participant if they had read the information sheet. The participant's consent for participating was renewed, confidentiality of data was reiterated and an opportunity for asking questions was provided. Participants were also reminded that there were no right or wrong answers, they could say 'no' for answering any question, ask me clarifying questions at any time, and that we could take breaks if required. All participants were sent a debrief sheet (Appendix G) after the completion of the interview. The debrief sheet contained age and pain appropriate contact details of support organisations (e.g., Childline, Samaritans, Pain Concern). Participants were also sent a £10 Amazon E-Voucher after the completion of the interview, to thank them for their time. This was sent on the participant's preferred email address.

In initial interviews I felt some conflict in my role as a researcher and trainee CoP as I heard participants discuss their emotional experience of living with chronic pain. As I was aware of this during initial interviews, I ensured that I used the interview schedule as a 'guide', whilst also following the participant's account as participants can be seen as the 'expert' of their experience (Smith & Shinebourne, 2012). After completing each interview, I noted in my reflexive journal my personal responses and feelings in relation to the interview, to ensure that I could be aware of these during the analysis stage.

Data Preparation. Interviews were audio-recorded on an external device, and the transcription feature of Microsoft Teams was used. Audio-recorded interviews were transferred from an external recording device to my UEL password-protected OneDrive after the completion of the interview, for secure storage. The transcript created by Microsoft Teams was exported to Microsoft Word on my UEL password-protected OneDrive. Transcripts were checked multiple times by listening to the original recording and making relevant amendments for accuracy i.e., adding missing words, amending incorrect words, and checking punctuation. Interview audio recordings were deleted after completion of transcription. Transcripts were checked thoroughly and all identifiable information (participant's name, names of other people, and names of places) was changed and participants were given pseudonyms. During transcription, non-verbal communication such as pauses were noted in brackets (Smith et al., 2009). For clarity and format, each line in the transcript was numbered for later stages of analysis.

Analytic Process

Interviews were analysed following the guidelines of IPA as suggested by Smith et al. (2022). As a beginner in this methodology, these guidelines were closely followed. Before starting the data analysis process for each transcript, I engaged in a reflexive writing exercise to immerse myself into a participant's account. This was done through a timed-writing process of noting down my thoughts and feelings in relation to the interview. The following steps highlight my reflexivity in engaging with the analysis, and add to the transparency of my research.

Stage 1: Reading and Re-reading. I started this stage by reading and re-reading the transcript to facilitate the process of the participant becoming the focus of analysis. I tried recalling the participant's voice during the interview as I was reading the transcript to immerse myself into the data. Recalling the participant's voice enabled me to engage with the data further, as I was able to notice my own responses in relation to the participant's account. For instance, I experienced intense happiness for a participant as I read (and recalled the participant's tone of voice) about her personal growth despite the difficulties of living with chronic pain. This differed from my presupposition that living with chronic pain would mainly involve difficulties. I noted such responses in my reflexive journal, which helped me ground the analysis in my participant's account, and be aware of my presuppositions.

Stage 2: Exploratory Noting. I entered this stage by creating a 3-column table on Microsoft Word. The transcript was placed in the middle column, and the exploratory notes in the right-hand side column alongside the participant's account. I colour-coded interesting elements of the transcript and matched these colours with the specific exploratory notes in the right-side column. Following the process outlined by Smith et al. (2022), I made notes on the description of participants' experience; language (e.g., word repetitions, powerful phrases such as 'invisible disability'); and the meaning that certain experiences had for participants (e.g., the importance of friendships for identity). I also made notes on shifts in a participants' account to understanding the meaning behind these (e.g., feeling frustrated with pain and then accepting pain). A University-based research workshop helped me reflect on the conciseness in my conceptual notes about psychological processes (e.g., writing 'uncertainty' instead of 'uncertainty of pain limits engagement with social activities, which seem important for her identity'), specifically, how very concise notes did not demonstrate how I interpreted a concept from the transcript. I thus tried to make my exploratory notes more detailed and transparent in how I reached certain interpretations as I recognised my role in interpreting the participant's account.

Stage 3: Constructing Experiential Statements. This stage involved further analysing the exploratory notes with the aim of summarising the notes whilst retaining the complexity in them. Experiential statements were written in the left column of the 3-column table. In this process, I tried to retain the essence of participants' 'experience' by creating experiential statements that contained the words that participants had used. The creation of experiential statements also included my interpretation i.e., the use of psychological frameworks that combined the participants' experience and my understanding of their experiences. During this process, I felt some tension as I thought I was diverging from the participants' words. Research supervision and re-reading the analytic steps of IPA made me feel confident and reminded me of the importance of the 'I' (interpretation) in IPA. In other words, I recognised that although my interpretations were informed by my previous knowledge, these interpretations also stemmed from my understanding of the participants' understanding of their experience – and the analysis would thus be collaborative (Smith et al., 2022). An example of my exploratory notes and experiential comments is provided in Appendix H.

Stage 4: Searching for Connections Across Experiential Statements: This stage focused on my understanding of how experiential statements related to one another. I transferred all experiential statements to a separate Microsoft Word document and began colour-coding statements that I thought belonged together. As suggested by Smith et al. (2022), I kept my research question in mind during this process. Although clustering experiential statements is a creative process, I followed some guidelines such as abstraction (grouping ‘similar’ statements together), polarisation (recognising statements alluding to contrasting aspects of experience), subsumption (where one experiential statement can be a broader statement that encompasses other experiential statements), and function (similar statements where use of language indicates a specific sense-making strategy) (Smith et al., 2009, 2022). For example, statements relating to the meaning of being an adolescent were grouped together through abstraction, whereas the multiple (and often contrasting) meanings of a diagnosis or medical explanation of pain were placed together through polarisation.

Stage 5: Naming Personal Experiential Themes (PETs). This step involved provision of a name to each cluster of experiential statements, based on the core characteristics that tied these statements together. Above each cluster of the colour-coded experiential statements, a name or PET was written. In this process, I tried to name PETs based on the participant’s experience and my understanding of psychological concepts (e.g., sense of belongingness). However, I tried to remain grounded to the participant’s account by using the participant’s words to name PETs. Some PETs had two to three sub-themes to organise the PET, and these sub-themes were also given titles.

Stage 6: Continuing Individual Analysis of Other Cases. This step included selecting the next participant’s transcript for analysis, and Stages 1-5 were repeated. The same process was repeated for each subsequent transcript. In line with the idiographic focus of IPA, I aimed to be aware of the possible impact of the previously analysed transcript on my understanding of the newly selected transcript. For this purpose, I engaged in the timed-writing reflexive writing exercise to re-familiarise myself with the newly chosen transcript. I also made entries in my reflexive journal when I noticed myself being influenced by the analysis of a previous transcript. In such situations, I re-read the present transcript, recalled the specific interview, and read post-interview notes about the specific interview from my reflexive journal to ensure that my analysis was grounded in the present participant's account.

Stage 7: Developing Group Experiential Themes (GETs). The purpose of this step was to find patterns between PETs of each participant to create group experiential themes (GETs), to highlight similarities and uniqueness in experiences across participants. I started this process by looking at the PETs of each participant one after another. I created a separate Microsoft Word document, and colour-coded together similar PETs across participants. Some PETs (e.g., meaning of being an adolescent) were relatively straightforward to notice and cluster together as a GET. However, clustering other PETs together was challenging as some sub-themes within PETs of some participants 'stood out' within a potential GET (e.g., one participant's sub-theme of 'gaining new parts in identity' stood out in the potential GET regarding losing valued parts of identity). As described by Smith et al. (2022), I managed this by reviewing PETs and corresponding experiential statements to understand the essence of a participant's experience. Consequently, I recognised that particular sub-themes within a PET aligned more with another GET (e.g., the sub-theme 'gaining new parts in identity' aligned better with the potential GET of 'protecting identity from pain'). An example of initial process of creating some GETs is presented in Appendix I. Further discussion in research supervision helped me clarify the distinct features of each GET, following which I reorganised PETs into relevant GETs with corresponding sub-themes. Throughout this process, I continued to ask myself ‘what is the essence of this GET (and the PETs within it), and how is this different from another GET?’. This helped me choose appropriate names for each GET that highlighted the overarching experience across participants, whilst the sub-themes within each GET were named to illustrate unique experiences of participants. Finally, five GETs with corresponding sub-themes were created. A tabular representation of GETs and sub-themes recurring across participants’ accounts is presented in Appendix J.

Quality in Qualitative Research

A unique set of criteria can be utilised to enhance and evaluate the quality in qualitative research, as suggested by Yardley (2000). These criteria and my engagement with them are presented below.

Sensitivity to context involves the researcher’s awareness of participants’ experiences and context; the theoretical, social, cultural and linguistic context of the research; the relationship between the researcher and participants; the researcher’s previous knowledge; and how an interaction of the aforementioned elements may influence the participant’s account and the researcher’s interpretation of it. In my study, sensitivity to context has been demonstrated in my engagement with relevant theory and literature about identity and chronic pain, which contributed towards my understanding of the research gap in exploring adolescents’ perspectives about their identity in the context of chronic pain. Importantly, I demonstrated sensitivity to the perspectives of adolescents and issues of power by making my study accessible to participants at various stages, for instance, by using age-appropriate language in research material (e.g., information sheet, interview schedule) during recruitment and data collection. Lastly, sensitivity to the socio-cultural context of participants can be seen in my Analysis and Discussion chapters, where I considered the role of contexts (e.g., stigma of chronic pain, activities and relationships important for the adolescent age group) in relation to the identity of participants.

Commitment and rigour refer to continued engagement with the research topic and data, which can be facilitated by comprehensive data collection, developing skills in the research methods used, and conducting an in-depth analysis. In my study, commitment has been attended to by my prolonged engagement with the research topic not only as a researcher, but also through my personal experiences with chronic pain which contributed towards my interest in this topic. Commitment and rigour were also demonstrated by my efforts to support data collection and recruitment through varied sources such as pain-relevant charities and support groups. Further, through continued reading about IPA, I developed my skills in this analytic method, for instance, by closely following the analytic steps and analysing each transcript in-depth with complexity as demonstrated in the Analysis chapter.

Transparency focuses on the level of detail and transparency in presentation of the research process. I aimed to demonstrate transparency in all stages of my study i.e., by clearly stating my personal context in relation to the research topic, offering a detailed explanation of my ontological and epistemological position, and a clear rationale for choosing IPA whilst reflecting on alternative methodologies. My use of reflexivity in other methodological processes (e.g., ethical amendments and analytic steps) also enhanced the transparency of my study.

Chapter Summary

This chapter presented the philosophical underpinnings of my study. A rationale for choosing IPA as the analytic method for my study was offered, and details of the research procedure followed in my study were then provided. The importance of and use of reflexivity was embedded in various sub-sections of this chapter.

Analysis

Chapter Overview

This chapter offers a detailed and nuanced understanding of how participants with chronic pain made sense of their identity. The process of analysis yielded five overarching group experiential themes (GETs), with two to three sub-themes under each GET. Each GET represents the common aspect of participants' sense making process of their identity, and the individual meanings that participants had about their identity are presented under corresponding sub-themes. The order of organisation of GETs is based on my understanding of participants' identity (or parts of it) in a meaningful and coherent manner, and does not necessarily represent the exact order in which participants offered their account.

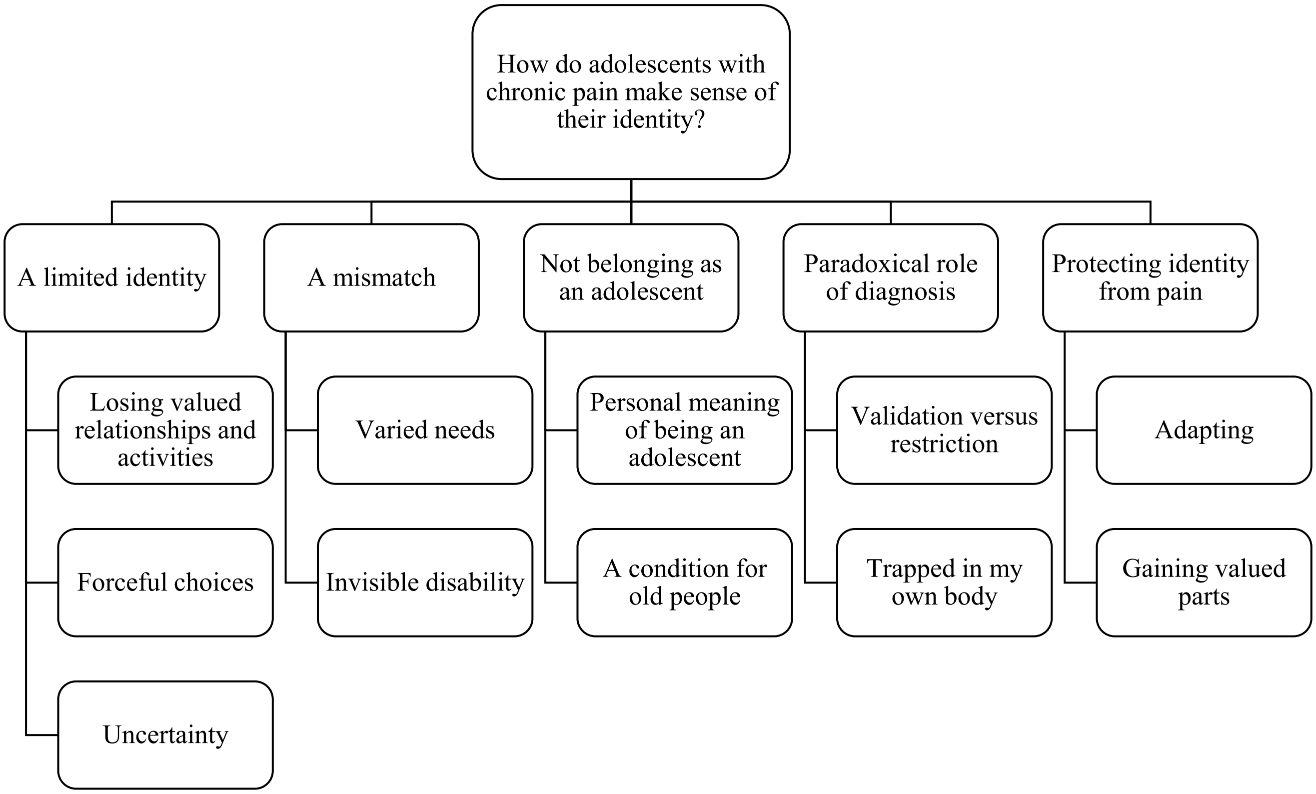
The hermeneutic underpinning of IPA suggests that interpretation involves the researcher making sense of the participant's sense making of their experience. As IPA aims to highlight the unique perspectives of participants as well as the researcher's subjective interpretation of these (Pietkiewicz & Smith, 2014), it should be acknowledged that participants' perspectives could have been interpreted differently by another researcher. Considering the subjectivity of interpretations, I follow Yardley's quality criteria of transparency by stating my interpretations clearly, which in turn can enhance the rigour of my study by demonstrating complexity of interpretations (Yardley, 2000).

A visual representation of GETs and corresponding sub-themes is presented in below (Figure 1). The first GET, 'a limited identity' illustrates the sense of limitation participants experienced in their identity in relation to chronic pain, and corresponding sub-themes highlight participants' understanding of the sources of the limitations to their identity. The second GET, 'a mismatch', with corresponding sub-themes, depicts the difference participants experienced between their own understanding of their identity versus how other people viewed them. The third GET 'not belonging as an adolescent' suggests participants' lack of belongingness from the collective identity of 'adolescent' as their personal and societal understanding of being an adolescent differed from how they actually perceived themselves. The fourth GET, 'paradoxical role of diagnosis' discusses the multiple meanings that a diagnosis or medical explanation of pain had for participants' identity. The final GET, 'protecting identity from pain' highlights participants' process of retaining valued parts of their identity and gaining important parts in their identity in this process.

A key for participants' extracts and transcription is provided in Appendix K. In this chapter, extracts from transcripts are presented below my commentary, with pseudonyms and corresponding line numbers from transcripts placed in brackets after the extract.

Figure 1

Visual Representation of GETs and Corresponding Sub-themes



GET One: A "Limited" Identity

This theme represents a common experience across participants about the limitations that they perceived chronic pain introduced to their identity. The word "limited" was used by Amy to describe how she viewed her current identity, and was chosen as the title of this theme as it highlighted participants' common experience of feeling restricted in engaging with valued parts of their identity such as being social or athletic. Participants seemed to experience this limitation in their identity uniquely based on what they considered as important for their identity, which in turn may be determined by their personal and social contexts. This uniqueness in participants' experiences is illustrated through three sub-themes, namely 'losing valued relationships and activities', 'forceful choices' and 'uncertainty'. Sub-themes were based on participants' experiences of losing valued parts of their identity, having to make choices between parts of their identity, and difficulty in engaging with valued parts of identity due to uncertainty of their pain – which jointly contributed towards limitations in their identity.

Sub-theme One: Losing Valued Relationships and Activities

This sub-theme focuses on the changes participants experienced in valued parts of their identity such as social roles, relationships, activities and hobbies. Due to their chronic pain, participants seemed to experience a reduction or complete lack of engagement with such parts of their identity, which I interpreted as a loss of these valued parts. For instance, Amy stated how her social life had been "cut down" when she was in pain:

> You know the mobility when the pain knocks you **((mhm))** decrease- because you experience decreased mobility, so you just have to relax. **((yeah))** You just don't have to move here, move there, no. So you have to be in one place so you don't go there, interact with people that- that means my social life has been somehow cut down. You don't have- you don't go to the malls, you don't go anywhere to interact with others, you just remain. (Amy, 151-161)

Amy's experience suggested the loss of an important part of herself i.e., her social life and interactions due to the limitations that chronic pain created in her mobility. Consequently, Amy's social interactions remained confined to her family members when she was in pain. This could also be understood in the context of her being an adolescent and being unable to engage in 'typical' social activities such as going to the mall to interact with friends, which seemed to limit her identity as a friend as well as an adolescent. The loss of or change to identity as an adolescent is discussed as a separate GET. Further, the words “when the pain knocks you” suggested the intensity of her pain, introducing a sense of possible defeat and powerlessness over the pain. This sense of powerlessness was further exemplified by Amy’s repeated use of “you have to”, as she seemed to have no choice but to witness the loss of the social part of her identity. I interpreted Amy’s interesting use of second person language to describe her experience as a way of creating distance from the lost parts of her identity, suggesting the profound sense of loss that she felt. A similar sense of loss in social relationships was expressed by Daisy:

> Oh, it's- it's tough because I've had fallouts with my friends sometimes because yeah, because maybe when they invite me to do something, maybe I'm in pain on that day, I won't go and some won’t understand. **((hmm))** So I've lost friendships but, I also have the other, they understand. (Daisy, 157-165)

Daisy’s account indicated the loss of friendships and the ‘friend’ part of her identity when she could not engage in shared activities due to chronic pain, leaving her seeing herself as “left out”. Additionally, the ‘friend’ part of her identity could only be maintained if her friends understood her chronic pain, which reiterated the power that pain seemed to hold in limiting her identity as a friend.

In addition to losing individual parts of identity, Beth talked about loss of her collective identity:

> I've really got to still limit myself, which brings me a lot of pain and um also bring I'd also say it also brings my family quite a lot of pain because we can't do the things we used to do. (Beth, 80-84)

Being unable to continue with athletics individually and collectively as a family may have contributed towards a loss in Beth's individual identity of an athlete or a sportsperson, as well as her collective identity of belonging to an athletic family. This seemed to induce feelings of guilt in Beth as limiting herself from being athletic also meant limiting her family from being athletic. Additionally, losing the identity of an athlete for Beth meant losing an essence of her identity, as athletics and sport were valued activities that made her 'her'. The deep sense of losing this part of her identity seemed to be reflected in the language of "which brings me a lot of pain".

Further, chronic pain not only created a sense of loss in important parts of participants' identity, but also seemed to introduce new unwanted parts into their identity as seen in Georgia's account:

> Because if you can't like, be around your friends as much as you'd like to, I think that takes a toll on you emotionally because you kind of see yourself as more quiet and withdrawn person because I am like, I'm quite talkative (Georgia, 552-558)

I understood Georgia's experience as how a loss of engagement with friends due to pain seemed to change her identity as her talkative part was lost, and new yet unwanted parts of being quiet and withdrawn were added to her identity. I interpreted these new parts (quiet and withdrawn) as unwanted as they were in contrast with her valued attribute of being talkative which was gradually lost. Georgia's experience also suggested a difference between her ideal pre-pain identity versus her actual identity that was moving closer to how she did not desire to be.

To summarise, this sub-theme highlighted how losing valued parts of identity was one source that participants perceived as limiting their identity.

Sub-theme Two: Forceful Choices

As another source of limitation to participants' identity, this sub-theme illustrates most participants' experiences of choosing between two parts of their identity that seemed to be equally important, to manage their chronic pain. Thus, chronic pain seemed to limit participants' identity as they could be only 'one' of the many parts of their identity. I interpreted this as participants having to make forceful choices between two or more important parts of their identity. This sub-theme was thus titled as 'forceful choices' to highlight the forceful nature of this choice, as participants appeared to have no choice but to 'have to' choose one part of their identity at the expense of another part. For instance, Frank discussed having to choose between being sporty or being healthy:

> So of course I feel bad but… considering my situation I have to like um… try to avoid those for the sake of my health. **((mhm))** I feel bad because its something that I used to do, um some sports. But now I can't because of that. (Frank, 81-87)

Frank's experience highlighted that he had to make a choice between two elements, both of which appeared to be important parts of his life and identity. The words used by Frank i.e., "I have to" depicted how he seemed to have little choice in terms of limiting or giving up the sport part of his identity. Further, Frank's use of language, specifically, "I used to do … but now I can't" seemed to suggest the permanence of the choice of giving up or limiting the sport part of his identity to manage his pain and continue being 'healthy'. Like Frank, Georgia had to choose between being social with her friends or being in pain:

> If they want to do something spontaneously, it's kind of in my head weighing up the do I want to be social and kind of have that experience? And- and like versus the pain sort of element that might come afterwards. So it's for me, that's the main difficulty that I've had with managing it like the spontaneity, because I used to be quite spontaneous person (Georgia, 501-510)

What seemed unique to Georgia’s experience was that in addition to making the choice between being social or being in pain, giving up being social to manage her pain also meant giving up on the spontaneous part of her identity that she valued. Georgia’s conscious process of “weighing up” if she wanted to be social or be in pain was thus understandable, as making the seemingly obvious choice of not being in pain would have the unwanted outcome of limiting her spontaneity.

Collectively, Georgia’s and Frank’s experiences was similar i.e., choosing to be ‘healthy’ or pain-free may initially appear as an obvious choice, however, on a deeper level, the implication of choosing to be healthy may mean having to limit other valued parts of identity. Further, making such choices seemed to create distance between the actual identity of participants versus their ideal pre-pain identity i.e., how they “used to be”. Similarly, Chloe discussed her difficult choice of being a friend, student, or healthy:

> I have to balance what I do throughout the week because if there's if I don't, if I don't balance, then I end up with more flare- like I tend to flare up more so normally I'm- I get quite paranoid over the weekends and like for example this weekend I- I've not felt the greatest so I'm- I'm too scared to like go out or to see friends cause I feel like I end up missing time out with uni (Chloe, 229-239)

Chloe's experience could be viewed as her feeling pressurised to choose between two equally important parts of her identity, as exemplified by her words of "I have to balance". This pressure could also be understood in the context of being an adolescent when friendships and academics can become important. The pressure for Chloe appeared to intensify as being outgoing was an important part of her identity. Her experience also highlighted the intense and intrusive nature of her chronic pain, as having her pain flare-up would mean limiting both i.e., the student and friend/outgoing parts of her identity. Consequently, it seemed more important for Chloe to give up on being outgoing rather than having a flare-up and missing out on academics as she feared that could potentially impact her future identity of having a job.

Jointly, I interpreted participants' experience of having to make a choice as suggestive of the intensity of their pain, making it important for them to continue choosing the healthy part of their identity at the expense of other valued parts. The process of making a choice itself appeared forceful as participants seemed to be 'forced' to choose, because if they did not choose, they would face the unpleasant experience of being in or aggravating their pain.

Sub-theme Three: Uncertainty

The title of this sub-theme collates the experiences of most participants regarding the uncertain nature of their pain which seemed to contribute towards the limitations in identity, as participants could not fully engage with different parts of their current as well as future identity. Participants' experiences differed in the personal meanings that they had about the uncertainty of pain. For Amy, the uncertainty of her chronic pain limited the social part of her identity as she could not plan social activities and had to spend a considerable yet indefinite amount of time at home only interacting with family members when she was "knocked down" by her pain:

> It gets you while doing something you have to stop it. **((mhm))** It might stay a week, it might take a month, so it just- my- even I say my economic life, my social life, because [] the mobility is decreased, so I feel like… It has changed me. **((hmm))** I would wish to be somewhere out there interacting with people, but sometimes you feel bad (Amy, 120-128)

The uncertainty of chronic pain's impact on Amy's economic and social life seemed so intense that it changed Amy's identity, as interpreted by her saying that the arthritis 'has changed me'. This change in her identity seemed to create feelings of sadness or disappointment (as suggested by her language of feeling 'bad'), as her actual identity of being social differed from how she ideally wished to be.

Similarly, Beth's experience highlighted the powerful and uncertain nature of pain in completely changing and limiting who she was:

> I'd like to see umm I'd like to see that this pain has gone away, even though I- I still feel it, or it's some somewhat manageable [] I would have found a way to be able to run and be able to do the things I love without thinking about it constantly. [] just- just so I could kind of go back to the way I was (Beth, 428-437)

Here, Beth stated how she hoped to see herself in the future, which included returning to her ideal pre-pain identity. Being her ideal self in the future appeared possible only if her chronic pain became more certain or manageable, i.e., that she could run or be athletic without worrying 'if' she would be in pain the next day. Beth's experience suggested that the uncertainty of chronic pain not only limited her current identity, but also her future identity.

Uncertainty about one's future identity appeared to create anxiety, as elucidated by Ethan's account:

> Umm I'd like to be a children's nurse so and live in Wales in a house and have some pets. So that's that side, which should be really cool. **((mhm))** And then the other side would probably be still having to live with my parents and not being able to work. Umm, its really hard (Ethan, 208-215)

For Ethan, important parts of identity included his love for animals and being able to help other people. I interpreted Ethan's account in the context of his anxiety and fear of having his ideal future identity controlled by chronic pain, creating further uncertainty and powerlessness about who he can be. This fear about future identity can also be understood by the personal and societal norms for young adults to be independent and have a job, and how chronic pain may have the potential to take Ethan farther away from such norms. Thus, chronic pain and its uncertainty appeared to create some distance between Ethan's actual identity and how he ideally wished to be.

This sub-theme suggested how chronic pain's uncertainty seemed to change and limit the current identity and future identity of participants. Collectively, in this GET, participants alluded to varied sources behind the limitations that chronic pain added to their identity or valued parts of it.

GET Two: A Mismatch

This GET illustrates participants' shared experiences about the difference in how they perceived themselves and how others perceived them (or parts of their identity), which I interpreted as a mismatch between their internal and external identity. Considering that identity development can occur within one's social context, participants' external identity may play a role in how they perceive their overall identity. This gap between how participants saw themselves versus how they were viewed differently by others left participants feeling misunderstood, judged and upset. The idiosyncrasy in this shared experience is explained through two sub-themes of ‘varied needs’ and ‘invisible disability’.

Sub-theme One: Varied Needs

This sub-theme exemplifies the mismatch participants experienced as their experience of being in pain was misunderstood by others such as family, friends or peers. This sub-theme is titled ‘varied needs’ to highlight that when participants were in pain, their identity was seen inaccurately by others, but participants had varied needs behind why they wished for parts of their identity to be understood by others. For instance, Frank stated how he might be seen by others in two very different ways:

> Maybe people are sympathetic and they have you know, some empathy towards you. If you are like if you need to be excused of some activities but um unless um they categorise you as a sick person so they might try to um isolate you and um maybe request you or ask you not to do somethings and it makes people feel like they are so caring. (Frank, 300-309)

Frank spoke about helpful experiences with others where his pain was understood with sympathy, and the unhelpful experiences of being labelled as a “sick person” and being excluded from physical activities such as carrying objects. Importantly, there was a difference in the way Frank viewed himself as capable despite his pain versus how he was viewed externally as a sick or vulnerable person. This could be interpreted in a social/family context where being ‘caring’ might mean different things – to the ‘carer’, it may mean trying to be helpful by not asking Frank to perform an activity, however, for the person being cared for, this meant being labelled inaccurately.

Similarly, Georgia talked about how she was viewed by her friends and teachers when she was in pain:

> I think support wise it's also letting people know that like, oh I might have a day where I'm in pain, but please don't get concerned about it or feel like you need to offer support because I am used to it and I'm the sort of person I will push myself through that pain (Georgia, 1219-1226)

I interpreted Georgia's account as her external identity being viewed through a lens of concern, i.e., she was viewed as someone requiring support, as opposed to her internal view of herself as being capable to manage her pain. Common to Georgia and Frank's experience was the prominence that their external identity took over their internal identity, which seemed to create the motivation to prove their internal identity to others to bring consonance between their internal and external identity. This motivation may also be understandable as their external identity seemed to get closer to how they did not wish to be seen i.e., as someone who is "sick" or vulnerable.

In contrast, Ethan's extract suggested that he needed the internal experience of being in pain to be seen and understood more by others such as his family:

> Umm just like when I have umm been out with like family or whatever and they're just like I say, you know, I need a break or whatever and they're like, but, you know, I'm in pain and they're like, oh, but, you know, we're having a family day out and it's like, yeah, I know, but I'm in pain (Ethan, 291-298)

It appeared that Ethan's internal experience of being in pain was not fully understood by his family, which made him feel disconnected from his family as well as others who did not have chronic pain or chronic health conditions. I also interpreted this from the lens of a family context, where the collective identity of doing an activity as a family may take precedence over seeing Ethan's individual and internal experience of being in pain.

Collectively, this sub-theme suggested participants' struggle of experiencing the difference in their internal and external identities, thus prompting them to bring consonance between these differing parts.

Sub-theme Two: Invisible Disability

This sub-theme highlighted the invisibility of chronic pain, which seemed to create a mismatch between participants' internal and external identity. Beth used the words "invisible disability" to describe an experience with friends where she was unable to run spontaneously due her chronic pain, and how this was not fully understood by her friends as her pain was invisible. In other words, an "invisible disability" highlighted the physical intensity of chronic pain and its impact on participants' lives, and yet remained unseen and misunderstood by others due to its invisibility.

For example, Chloe stated how her chronic pain had been repeatedly dismissed and unseen by others, as it could not be seen externally. However, her experience suggested that even after receiving a diagnosis of fibromyalgia, her internal experience of being in pain remained unseen by others as although her pain had a name, it remained invisible:

> Yeah, yeah, I think that's what the thing is, even now it's still challenging, maybe not as bad as it was, but just because you can't see something, a lot of people still don't always understand that there- there's still things that can go on. (Chloe, 188-194)

Chloe expressed the challenge of explaining to others what fibromyalgia was, and still having her internal view of herself of being in pain misunderstood externally. I interpreted this mismatch through the lens of frustration that Chloe may have felt, as although ‘invisible’, fibromyalgia had been impacting her daily life for several years.

Similarly, Beth expressed how her internal view of herself of being in pain remained unseen by others:

> But I've the pain's always there currently, [] I think it's always going to be there, but people don't realise the impact it has and they're like, oh yeah, you're normal. You don't have, you're not- you haven't lost a leg, you you're not bleeding, so we can't see it, so you're fine. Obviously it's not the case. (Beth, 578-585)

Important to Beth’s experience was how her internal experience of being in pain was not only unseen, but also dismissed or invalidated by others as her pain could not be seen externally. Taken together, I interpreted Chloe and Beth’s experiences in the context of the societal understanding that a health condition that is invisible must not be serious compared to something that is visible such as bleeding.

This societal understanding of believing visibility over invisibility was also present in Georgia’s experience:

> But people will find reason to comment on like, oh, that doesn't look that nice or oh, what are you eating or why are you eating now? It's because of like, at certain times of the day because I know that if I don't eat then I'm going to be in pain later either from not eating or if I eat at a different time it is going to cause me pain. (Georgia, 475-484)

Georgia’s excerpt highlighted two things. First, her view of herself as having gastric pain remained unseen by her peers due to the invisibility of pain. Second, the more visible aspects of pain i.e., her pain management strategies of eating certain foods at certain times were ‘seen’ or ridiculed by her peers, leaving her feeling “awkward” to eat around others, as she possibly felt judged. This mismatch between the invisible experience of having pain being misunderstood externally may also suggest the repeated justification or explanation of identity that Georgia seemed to have to engage in, to make her invisible pain known to others.

To summarise, this sub-theme discussed the role of invisibility in contributing towards the mismatch of internal and external aspects of identity, creating possible feelings of frustration and being judged in participants.

GET Three: Not Belonging as an Adolescent

This theme encapsulates participants’ shared experience of lacking belongingness from the collective identity of being an ‘adolescent’. Participants’ identity did not match with their own as well as societal meanings of being an adolescent, leaving them feeling lonely and misunderstood. The meaning behind experiencing this lack of belongingness was unique to each participant, which is illustrated through two sub-themes: ‘personal meaning of being an adolescent’ and ‘a condition for old people’.

Sub-theme One: Personal Meaning of Being an Adolescent

This sub-theme captures participants’ personal understanding of what it meant to be an adolescent, and how chronic pain distanced them from the collective identity of an ‘adolescent’. In other words, chronic pain seemed to create a difference between participants’ actual identity versus their understanding of the ideal identity of an adolescent. For each participant, the meaning of being an adolescent was unique, based on their valued activities, social relationships and the attributes they associated with being an adolescent. This was exemplified by Daisy as she spoke about her difficulty in engaging with friends due to her back pain:

> It's really sad for me because **((mhm))** these are the some of the things that people do to connect with their friends. Now if my friends want to go, maybe do a sport or go bowling or something like that. See how that goes, sit back and watch there like I feel left out and it's- it's really sad for me. (Daisy, 136-144)

Daisy's experience highlighted her personal importance of developing and maintaining friendships during the period of adolescence, and how friendships can be maintained through shared activities. However, for Daisy, "sitting back" as her friends engaged in sport suggested isolation and loneliness, and seemed to distance her from the identity of an adolescent who can enjoy sporty activities with friends. Further, such experiences led Daisy to lose friendships which may have distanced her further from seeing herself as an adolescent, as friendships can be seen as important relationships during adolescence.

Similarly, Ethan expressed feeling isolated as he could not do the activities that he perceived were typical for adolescents:

> Yes, it's really hard to like go through it. [] you know everyone else in my age is just, you know, out having fun and doing stuff and I'm just constantly… really not up to much and it just feels quite isolating really. (Ethan, 48-53)

The intensity of Ethan's chronic pain made it difficult for him to engage in daily activities, such as going to school or going out with friends. Chronic pain seemed to reduce Ethan's sense of belongingness as an adolescent, as for him, being an adolescent simply meant doing the expected activities that he perceived an adolescent should be able to do. Ethan's experience also highlighted the role of social media in creating the societal and individual understanding of the 'typical identity' of adolescents. I interpreted this as an example of how separate Ethan may have felt as an 'adolescent' as he viewed the activities of his peers on social media, leaving him feeling lonely.

The reduced sense of belongingness as an 'adolescent' was intensified as chronic pain seemed to add unwanted parts to participants' identity, as reflected in Amy's account:

> I feel like I'm the odd one out and of course I'm the odd one out. **((hmm))** Because… you see how flexible they are, they move very fast, they move, everything is okay. The- their life is perfect. (Amy, 361-365)

For Amy, there was a lack of belongingness as an adolescent as well as an unwanted addition to her identity of being the "odd one out". This sense of being different seemed to stem from comparison with peers who did not have pain, which once again reduced her belongingness from the identity of an adolescent. Amy's experience also indicated the profound impact of her arthritis on her ability to move, and how movement difficulties may not be seen as 'common experience' for adolescents. This seemed to not only set her further apart from being an adolescent, but also made her see the lives of her peers as "perfect" as they could move flexibly without pain.

Similarly, Beth's experience with her peers seemed to not only set her apart as an adolescent, but also made her see herself as a "burden":

> I felt like almost I wasn't good enough to- to hang out with other people in a sort of sense 'cause I- I saw my obviously they didn't see me as a burden, but in their eyes I thought they'd see me as a burden because I couldn't do what they could do. (Beth, 192-197)

For Beth, being unable to engage in the valued activity of sport and athletics with peers due to chronic pain appeared to create a gap in her understanding of what an adolescent should be able to do versus what she was able to do. As Beth previously engaged in team sport, her sense of being a "burden" could be interpreted as seeing herself as separate from the team, lacking in her ability to participate, and seeing herself as "inferior" from others for needing extra support. Consequently, this seemed to take her further away from being an adolescent, as for her (based on her past experiences) being an adolescent meant being able to engage in sport with liberty.

This sub-theme depicted participants' unique meanings linked to being an adolescent, and how chronic pain seemed to reduce their sense of belongingness and add new, unwanted parts to their identity.

Sub-theme Two: A Condition for Old People

This sub-theme elucidates how participants' lack of belongingness from the collective identity of an 'adolescent' could also be understood in the context of how other people viewed chronic pain as a condition for older individuals. This theme is titled "a condition for old people" following Daisy's words regarding how her pain was viewed by others. This societal understanding of chronic pain seemed to have two implications. First, it appeared to shape participants' own understanding of what it meant to be 'young'. Second, it made participants feel invalidated or judged for having chronic pain, possibly increasing their lack of belongingness as an adolescent.

Daisy’s excerpt highlighted how her chronic pain was seen by others around her and in her culture:

> That's a condition for old people, they say. [] like my grandma, right, back home, they- they used to tell me like they used to carry water from the river with on their backs. That's why they started developing back pains. **((hmm))** But for me, I'm- I'm just 17! And now I'm going through the same thing my grandmother goes through. It’s like no, like, that's like something for old people. And some people might make fun of me. (Daisy, 408-420)

Daisy’s experience may emphasise the unfairness of having chronic pain as an adolescent, as in her culture, chronic pain was seen as something not only for old people, but also something that occurred after long periods of strenuous activity. However, for Daisy, having the same pain as her grandmother without having engaged in similar strenuous activity as well as being young, seemed to be unfair and made it difficult for her to view herself as an adolescent. Further, Daisy’s experience highlighted how having chronic pain as an adolescent may create stigma and make it difficult for others to accept her as an adolescent with an “old person condition” contributing towards possible feelings of isolation, sadness or even shame.

Similarly, Chloe’s experience suggested how it was difficult for others to see her as an adolescent with chronic pain:

> I just often get told that all you have, I'm too young to have all- all these problems and yeah (Chloe, 809-811)

> It kind of makes me feel quite guilty in a way like I kind of feel like I have no control of that. So it makes me feel like, **((mhm))** what can I do about that? (Chloe, 817-821)

Noteworthy of Chloe's account was the feeling of guilt and possible blame or personal responsibility for having chronic pain as an adolescent, which seemed to be linked to the societal understanding that chronic pain is not meant for adolescents. This societal understanding, in turn, may further contribute towards Chloe's lack of belongingness with being an adolescent i.e., by introducing a difference in how others perceived adolescents 'should' be, versus how Chloe actually perceived herself. Also important to Chloe's experience was the feeling of powerlessness over chronic pain, as she had no choice but to accept herself as an adolescent with an 'old person condition'.

It appeared that the lack of societal understanding about chronic pain in adolescents prompted some participants to keep justifying their chronic pain to others, as seen in Georgia's extract:

> But I have to eat really slowly 'cause, if I eat too quickly, like I'll get shooting pain and then- like it'll be aching for a while afterwards [] but then his gran goes oh, it's nice to not be the slowest eater at the table anymore and you sometimes, it really makes you fundamentally question people because you're like, well, why was that judgement necessary? (Georgia, 983-994)

> 'Cause I don't want to explain at the dinner table, but oh, by the way, I've got a medical condition (Georgia, 1001-1003)

Georgia's experience of having dinner with her friend's family for the first time highlighted how it may have been unusual for others to understand chronic pain in adolescents, which made Georgia feel misunderstood for having chronic pain. The ‘visible’ aspect of managing her pain (i.e., eating slowly) was picked up on by others as eating slowly did not seem to be linked with adolescents, which made Georgia feel judged. Georgia’s experience of feeling misunderstood and judged as an adolescent with chronic pain seemed to have two further implications. First, due to the lack of association between chronic pain and adolescents, she seemed to have to justify and explain her pain as a medical condition, possibly to feel understood and manage the possible difference between her actual versus ‘should be’ identity of an adolescent. Second, although explaining her medical condition made her feel understood, it appeared to be a vulnerable process to explain this to new people. Georgia’s experience thus highlighted the conflict of being an adolescent with chronic pain i.e., wanting to be understood by others but at the same time, having to be vulnerable to be understood.

However, for Amy, it was the disbelief from people and the recurrent questions about her arthritis that indicated to her that according to other people, chronic pain was not meant for adolescents:

> My society thinks, someone who is suffering from arthritis, they must be in their old age. They have that mentality. So they keep on asking you questions, how did it happen, or did you do, you see? So you you- you feel like, you feel sometimes you have to isolate yourself [] So the questions, the you know- the frequency of the questions **((yeah, yeah))** it irritates. (Amy, 388-399)

The disbelief from others suggested how even after being vulnerable and making it known to others that she had arthritis, Amy was still not fully understood as an adolescent with chronic pain. Conversely, it appeared that letting other people know about her arthritis made her feel even more isolated, judged and misunderstood.

Collectively, I interpreted the experiences of participants as a general lack of belongingness or being ‘stuck’ between being an adolescent and having an ‘old person condition’, which may have made it difficult for them to make sense of their identity.

GET Four: Paradoxical Role of Diagnosis

This theme places emphasis on the meaning that a diagnosis or a medical explanation of chronic pain had for the identity of participants. Amongst participants, or even for the same participant, receiving a diagnosis or some medical explanation of pain meant very different things for how they viewed themselves. For some participants, receiving a diagnosis involved a paradox of feeling validated for having an explanation of their pain, but also feeling restricted by this diagnosis. Additionally, for some participants, a diagnosis appeared to create a complicated relationship with their physical body. The uniqueness in participants’ understanding regarding the role of diagnosis on their identity is exemplified by two sub-themes i.e., ‘validation versus restriction’ and ‘trapped in my own body.’

Sub-theme One: Validation versus Restriction

A common experience amongst more than half of participants was experiencing a sense of responsibility for feeling or creating their chronic pain. This felt sense of responsibility seemed to stem from several unique sources for participants, such as the absence of a medical explanation or ‘name’ of participants’ chronic pain, the lack of societal association between chronic pain and adolescents, and the invisibility of pain. Thus, this sub-theme illustrates how a diagnosis or medical explanation of chronic pain helped participants feel validated, and reduced the sense of responsibility that their internal ‘self’ appeared to feel for creating the pain. However, this sub-theme also highlights how diagnosis appeared to create a sense of limitation and restriction in participants’ identity (or important parts of it), suggesting the paradoxical nature of receiving a diagnosis. This sub-theme is thus titled as ‘validation versus restriction’ to highlight the paradox of how sometimes the same participant had two seemingly contrasting meanings about a diagnosis in relation to identity. For instance, on one hand, having a medical explanation for gastric pain was a validating and relieving experience for Georgia:

> Umm it was quite relieving to finally know that like it wasn't in my head **((mhm))** 'cause I know that with like a lot of chronic pain when it's unexplained or like seemingly unexplained, it can go down as like stress or anxiety or like be psychosomatic and I didn't feel like that was the case? (Georgia, 343-351)

Georgia’s experience highlighted how chronic pain, its invisibility, and its lack of association with adolescents can be misunderstood or even overlooked by others, which left her feeling responsible for creating the pain ‘in her head’. Thus, receiving a medical explanation seemed to help Georgia to reduce the feeling of responsibility for causing her pain, which I interpreted considering how she had felt worried about causing or possibly imagining her pain when her blood tests had come back ‘normal’. In other words, a medical explanation may have helped in separating her ‘self’ from the chronic pain as her pain now had an organic cause. However, Georgia also highlighted the other side of having a diagnosis:

> You've got a label now and uh the label like having a label makes it difficult to kind of see yourself as like a health-like a healthy person, **((hmm))** so to speak, because you know that there's going to be certain restrictions on what you can do or what you should do (Georgia, 737-744)

In contrast to feeling relieved, a medical explanation seemed to take away the “healthy” part away from her identity. For Georgia, having the “healthy” part taken away involved a change in her identity as it added restrictions to her engagement with activities and made her question herself - “am I healthy enough to do this?” (Georgia, 568-569). I understood having a diagnosis/medical explanation of pain as making the pain ‘real’ and serious enough for Georgia to have restrictions placed on her activities to manage her pain. This seemed to change her identity as she saw her current identity as an “analytical critical person” in contrast with her pre-pain approach of being relatively carefree whilst engaging with activities.

Chloe’s experience of being diagnosed with fibromyalgia involved a similar paradox i.e., the diagnosis seemed to have contrasting meanings for her identity. For instance:

> So to have a name put on it, definitely- I know people don't like labels and it for some people it impacts, you know, the stigma that comes with that. I think for me it's- it's helped me find awareness around it and just say, well, no, actually this is what it is. **((Yeah))** So then I am able to explain to people that it is a condition (Chloe, 175-183)

Like other participants, Chloe wondered if the pain was ‘in her head’, the sense of which was exacerbated by the invisibility of pain and being told by others to be more physically active. Taken together, these elements may have led Chloe to feel responsible for creating the pain. As suggested by the excerpt above, a diagnosis helped Chloe in two ways. First, it reduced the sense of responsibility that her internal self seemed to feel for creating the pain, as the diagnosis meant there was a medical cause for the pain and Chloe was not ‘creating’ the pain. Second, it seemed to help protect or separate her external identity from the pain by explaining to others that her difficulties were caused by fibromyalgia (the “condition”), and not by her actual self. However, Chloe also discussed the unhelpful meaning of having a diagnosis:

> Like when I was told it was long-term, that kind of. ((pause)) I don't even to this day like it- it still makes me feel like is it ever gonna get better if you know what I mean? Is there gonna be a day where suddenly I don't have these flare ups? (Chloe, 463-469)

What appeared crucial in Chloe's account was the layered meaning behind a diagnosis of chronic pain i.e., it is not only pain, but also chronic or "long-term". Chloe's pause during the interview suggested the profound meaning of being told that one has a long-term health condition i.e., the worry of having 'chronic' pain and the possibility of limiting the independent and outgoing parts of her identity for a long but indefinite period of time. I also interpreted Chloe's worry of having these parts of her identity limited in the context of her being an adolescent, and the importance of being independent, autonomous and social as an adolescent. Collectively, a diagnosis seemed to hold power to determine Chloe's identity in the present as well as the future, which made her feelings of worry, fear and difficulty in accepting this as long-term understandable.

Conversely, for Frank, being told that his head pain was chronic meant something very different: "But now I am confident that um like I have understood- understood my pain and um I need to now- I run my activities based on my understanding of that and my life is like normal." (Frank, 204-209). Frank discussed how knowing that his pain was chronic seemed to provide him with some sense of certainty or preparedness, which in turn may have helped with acceptance. A valued part of Frank's identity was being jovial and having a problem-solving viewpoint, which also seemed to help him continue with his routine activities albeit in a manner determined by his pain. In other words, Frank's knowledge about his pain being chronic as well as the optimistic part of his identity helped him accept himself with pain and retain parts of his pre-pain identity, as suggested by his language of seeing his life as "normal".

Overall, this sub-theme suggested how a diagnosis and the ‘long’ term nature of pain had multiple and often contrasting meanings for participants’ identity.

Sub-theme Two: Trapped in my Own Body

This sub-theme highlights yet another role of a chronic pain diagnosis in interacting with participants’ identity. Although a diagnosis helped in separating participants’ ‘self’ from the pain as suggested by the previous sub-theme, this sub-theme illustrates how participants then attributed the pain as created by their ‘body’, which they viewed as separate to their identity. Although the body was viewed as separate, there was still acknowledgement of the body being theirs, which seemed to contribute towards a feeling of being stuck or “trapped in my own body” as stated by Chloe, making these words apt as the title of this sub-theme. However, the meaning behind separation of their self from their body was unique for each participant i.e., for some, it created a dissonance between their actual versus ‘should be’ identity whereas for others, it created acceptance of their identity with chronic pain.

For Chloe, feeling trapped meant experiencing a dissonance between her young self and her older body:

> I don’t know if this is the right word to like- the way to describe it, but for me, I feel like I'm trapped in my own body… Like I feel like, I’m in like in an older body than which I should be (Chloe, 253-258)

Chloe’s account suggested how her ideal identity of wanting to be outgoing, social and attending university was restricted by her body (that created fibromyalgia) which felt older than her chronological age. I also interpreted Chloe’s separation from her body in the context of being an adolescent, when one’s body might be expected (by her as well as others around her) to be ‘fit’ or ‘healthy’, which may have contributed towards a divergence between Chloe’s current identity versus her ‘should be’ identity. Additionally, Chloe’s feeling of being “trapped” highlighted her fear of having her current as well as future identity (e.g., having a job) being held back by her “older body”. Specifically, Chloe discussed feeling worried about her daily choices to not cause any more health consequences to her body that she viewed as “worn out”, as experiencing more flare-ups could make it difficult for her to engage with her current identity of being a student (e.g., missing time at university) and her ideal future identity of having a job.

Similarly, Ethan stated how he felt angry with himself and his body for “not working very well”, as exemplified through the excerpt below:

> Umm, like whenever I try and go out and like do something or like go shopping and like sometimes I like have to sit down on the floor in the middle of the shops and it just feels like really like embarrassing. And everyone stares at you and you just feel like, oh, you know, kind of angry that you can't just walk around the shop, you know? (Ethan, 158-166)

Here, Ethan highlighted the intensity of his pain and the impact that it had on his engagement with routine activities. I interpreted this excerpt as Ethan’s understanding of the medical explanation behind his chronic pain and how that created anger towards his body for not supporting his ‘self’ in being able to do seemingly ‘taken for granted’ activities like being able to walk in a shop. In other words, a diagnosis or medical explanation seemed to separate Ethan’s identity from his body that was causing the pain, but the experience of still having to ‘be’ in that body may have induced anger, frustration, powerlessness as well as embarrassment for not being able to do activities which societally may be considered as ‘normal’.

For Daisy, her back pain suggested not only a separation from her body but also experiencing conflicting needs of her body:

> I see that I'm gaining weight and mostly it's because I have restricted movements, there are some things I can't do **((hmm))** and… it's really disturbing sometimes because I know what I'm supposed to do and I love food ((smiles)), I can't stop eating just because I want to lose weight. I want to exercise, but it's not everything I can do now it's tough. (Daisy, 245-255)

Daisy's experience could be viewed as a complex interaction between her 'self' that loved food and her body that restricted her movements and contributed towards weight gain. This seemed to be a disturbing conflict between two parts of Daisy's identity i.e., her love for food versus her restricting body. However, this conflict appeared to have an added layer of complexity as her body did not seem to support her regardless of the choice that she made – if she exercised, she risked being in pain and if she did not exercise, that may lead to weight gain.

Amy's experience of having the diagnosis of arthritis was similar yet different from other participants:

> Arthritis at my tender age. **((hmm))** You tend to- oh how did it happen to me, did I have- did I deserve this? Erm and sometimes you just have to accept you move on with the issue. So I guess, through the acceptance [] I've come to realise that everything is possible as long as you accept. (Amy, 31-37)

Receiving a diagnosis of arthritis was a shocking experience for Amy, specifically as an adolescent since arthritis was viewed as an 'old person' condition by herself as well as in her culture. With a diagnosis, Amy also became aware of the internal working of the body i.e., an autoimmune condition where her healthy joints were being affected as well as the chronicity of her pain, which led to feelings of shock, denial and frustration about her body experiencing this. However, for Amy, the feeling of being trapped in her body was managed through acceptance of her body which gave her hope. Interesting to Amy's experience was the lack of choice in accepting her body due to the diagnosis of arthritis being permanent. However, Amy appeared to give meaning to this forceful acceptance by viewing herself as "strong" as she was able to cope with her pain. As Amy considered it important to make the "best" out situations, this seemed to be her way of viewing herself in a helpful light.

To summarise, this sub-theme discussed the unique relationships that participants had with their bodies in the context of having chronic pain. Overall, this GET suggested that a diagnosis appeared to have a paradoxical role as it contributed towards validation or relief, and at the same time seemed to limit or trap participants' bodies and current and future identities.

GET Five: Protecting Identity from Pain

The final theme represents the shared experience across participants of protecting their identity or certain aspects of it from chronic pain. As illustrated in previous GETs, chronic pain limited participants' identity by taking over valued parts of it, creating a difference in their internal and external identities, and setting them apart from the collective identity of 'adolescents'. Consequently, the title of this theme as participants 'protecting' their identity was my interpretation of participants' effort of retaining helpful parts of their identity in a way that was important to them. Two sub-themes, namely, 'adapting' and 'gaining valued parts' illustrate the uniqueness of participants' experiences.

Sub-theme One: Adapting

This sub-theme refers to the process through which participants tried to retain important parts of their identity from being limited further by chronic pain. Common across most participants was the intentional and forceful nature of this adaptation process, perhaps because of the degree to which chronic pain had taken over valued parts of their identity. The intentionality and forcefulness of this process was evident in Amy's account:

> So I have to interact despite my situation despite having the issue. [] I have to tell myself no, maybe tomorrow you'll be okay, this will go for a week, then it takes months before it- yes. So I just motiv- motivate my own self. (Amy, 375-381)

Amy's experience depicted how she motivated herself to continue with social interactions despite being in pain, to retain the social part of her identity which she considered as important. Amy's language use suggested the intensity of her pain as she seemed to have to put considerable effort into retaining the social part of her identity as indicated by the words "I have to" and "despite my situation". Further, I interpreted the phrase "I motivate myself" as an internal dialogue between two parts of her identity i.e., the internal part of her identity that is in pain and the external part of her identity that continues to interact with other people to retain the social part of her identity from being taken by pain.

In contrast, Beth's way of trying to retain her valued athletic identity meant something quite different:

> It keeps me going thinking that one day I won't have to think about this if I just keep going the way I am. If I don't push myself to do too much. If I find a way to get rid of this, it will be better. Just- just makes me makes me give me hope, you know? (Beth, 445-450)

I interpreted Beth’s quote as suggestive of a paradox, as she had to limit her sport and athletic identity in the present by not engaging in sport much, being cautious and not straining herself to maintain the hope that she may be able to be athletic again in the future. In other words, Beth seemed to have to adapt and unfairly modify her current identity to protect the valued sport identity from being limited by pain in the future. This indicated the limiting nature of Beth’s pain, as it seemed more important for her to have a pain-free future identity even though it meant having to restrict the sport part of her identity in the present.

Yet another unique layer of protecting one’s identity from chronic pain through adapting was exemplified in Chloe’s account, as she tried to protect her external identity or the way that she was perceived by others:

> It’s quite confusing at times depending on who I talk to kind of thing and at times, especially when someone goes, what's that? I've never, never heard of that before, [] I don't wanna bore them or drain them so I'm like, I just get flare- I just get flare ups and aches and pains, so I just cut it short so. (Chloe, 776-785)

Chloe’s account suggested how fibromyalgia was not a well-known condition in her social circles. As a complex condition with several symptoms, Chloe found it difficult to explain fibromyalgia to some of her friends as it risked her external identity being seen as draining or boring. To reiterate, being outgoing was an important part of Chloe’s identity, which made her effort to protect her external identity understandable. However, this meant having to hide, modify or simplify her internal experience of being in pain to feel understood by her friends.

Taken together, the experiences of participants highlighted their motivation behind and attempts of protecting their identity from moving closer to the person that these participants were scared of becoming (e.g., losing social interactions for Amy, losing the sport part of her identity in the future for Beth, and being viewed as boring by friends for Chloe).

Sub-theme Two: Gaining Valued Parts

This sub-theme emphasises the common experience across most participants of gaining new parts to their identity in the process of protecting their identity from chronic pain. Importantly, participants grew to value these new parts and hoped to retain them within their identities. Participants differed in how they made sense of these new parts of their identity based on what they considered as similar to their pre-pain identity that they valued. For instance, Georgia talked about starting to be more appreciative and mindful:

> That's what I think I'm trying to do more is kind of appreciate the small moments, and take time to just think about and reflect on, that today was a good day [] and just kind of take it as it comes rather than look ahead sometimes because so much about me is like looking ahead that sometimes I don't appreciate present enough. (Georgia, 1086-1096)

Georgia's experience of being in recurrent and prolonged pain highlighted how important it had become for her to manage her pain daily and worry for the future. However, she had gradually realised that constant worries about the future kept her from noticing or appreciating the present. As Georgia became aware of this, she hoped to be more mindful and appreciative. Considering that a valued part of Georgia's identity included learning new skills, having new parts added to her identity of being appreciative and mindful of the present was something she wished to retain and looked forward to, as it seemed like learning a new skill for her.

Similarly, for Frank, being jovial and optimistic were important parts of his identity, which he hoped to retain:

> So I feel great about myself and I feel like everything is like possible **((mhm))** and um and you can still- still work with the pain and um also academics and family like relationships. Yeah. I feel great about myself. (Frank, 251-256)

What appeared important for Frank was that although managing his chronic head pain required him to make several adaptations (e.g., managing medication and not engaging in strenuous activities), this process had helped him become adept at planning activities and managing several elements of his life (e.g., relationships, academics). Being able to retain these new parts into his identity also seemed to help him enhance the pre-existing jovial and optimistic parts of his identity.

Similarly, Daisy discussed how she had learned a valuable skill of crocheting despite her back pain, “I have some things that I've learned to do just by sitting down… such as crocheting, it's something, I have learned yeah.” (Daisy, 440-443). Daisy’s experience highlighted how through the help of psychological therapy, she had been able to view herself as “enough” as she was able to see herself through an accepting lens and see the unique skills that she was able to engage with even whilst sitting. This seemed to be a helpful and prominent shift in Daisy’s identity from previously seeing herself as “left out” and “inadequate”. Further, being able to crochet seemed valuable to Daisy as it was something that her mother had taught her to do. Considering the importance of social and family relationships for Daisy, crocheting seemed to connect two valued parts of her identity together.

Finally, Beth’s unique experience suggested how she had learned a new way of engaging with her athletic identity:

> With my chronic pain I then started to coach people for athletics, for volunteer- I was volunteering as coaching so I could pass on the knowledge to them rather than me actually executing, so I thought yeah. (Beth, 280-284)

Beth’s account suggested her openness to the identity of coaching others for athletics, which helped her keep the valued part of her athletic identity intact, albeit from a different or vicarious perspective. Most importantly, this helped her redefine her identity as she was able to see athletics as a skill and as a valuable but one part of her identity rather than the only part of who she was. Moreover, the experience of coaching seemed to instill hope in Beth for new and alternative ways of being able to be her athletic self in the future as well.

To summarise, this sub-theme captured the unique ways in which participants had found a way of protecting their identity from chronic pain by recognising and engaging with new parts of their identity, despite these new parts coming into existence due to pain. I interpreted this as participants being able to view the chronicity of their pain from an alternative and more helpful viewpoint, which seemed to help bring coherence between their actual and ideal identity.

Discussion

Chapter Overview

This chapter offers an overview of the main findings of my study and discusses these in relation to extant literature and theory, and outlines the contributions of my study to the current literature. Clinical implications for the field of CoP and allied disciplines are then offered, followed by reflecting on the limitations of my study. Directions for future research are embedded throughout this chapter where relevant and are clearly stated. The chapter concludes with final conclusions regarding my study.

Summary of Analysis

Data analysis resulted in five GETs with corresponding sub-themes, suggesting how adolescents with chronic pain made sense of their identity. The first GET, ‘a limited identity’, focused on participants’ limited engagement with valued parts of their identity (e.g., being social or athletic) which they attributed to their chronic pain. Three corresponding sub-themes highlighted participants’ understanding of the sources that limited their identity i.e., a sense of loss in valued relationships and activities; choosing between valued parts of identity to manage chronic pain; and difficulty in engaging with valued parts of identity due to the uncertain nature of their pain. The second GET, ‘a mismatch’ depicted the difference between participants’ perception of their identity versus how they were perceived by others. Two corresponding sub-themes suggested how participants’ experience of being in pain was misunderstood by others (e.g., being seen as a ‘sick person’ by others), and how the invisibility of chronic pain contributed further towards this mismatch between participants’ internal and external representations of identity. The third GET, ‘not belonging as an adolescent’ and corresponding sub-themes underlined how participants' personal understanding as well as the societal understanding of being an 'adolescent' differed from how participants actually perceived themselves, which contributed towards a lack of association with the collective identity of being an adolescent. The fourth GET 'paradoxical role of diagnosis' highlighted the multiple roles that a chronic pain diagnosis or medical explanation of pain played in interacting with participants' identity. For instance, corresponding sub-themes stated how adolescents felt validated as well as restricted by a diagnosis, whereas some adolescents experienced a complicated relationship between their identity and physical body. The final GET, 'protecting identity from pain' and corresponding sub-themes highlighted participants' process of forcefully having to adapt to their chronic pain to retain helpful parts of their identity (e.g., being social), and how most participants gained valued parts to their identity in this process, such as being more mindful or learning new skills.

Discussion of Findings in Relation to Theory and Literature

This sub-section discusses the findings from my study in relation to theories of chronic illness and identity, and existing literature about chronic pain in adolescents. This discussion is divided into sub-sections based on the five GETs created in my study. For clarity, I refer to the present study as 'my study' to differentiate it from findings from the wider literature.

GET One: A "Limited" Identity

The first GET represented the experience across participants in my study about the sense of loss and limitation in valued parts of their individual identity (e.g., being a friend, being social) and collective identity (e.g., belonging to an athletic family). This sense of loss appeared to stem from three interrelated sources, as illustrated by corresponding sub-themes. The first sub-theme depicted participants' experiences of difficulty in engaging fully with valued relationships and activities due to their chronic pain, which left them feeling isolated and powerless over their pain. Considering the importance of social relationships (e.g., peer relationships) during adolescence (Carter et al., 2015), the sense of loss felt by some participants was profound. Similar findings about experience of change or loss in valued parts of identity due to difficulties with participating in activities have been alluded to in the adolescent chronic pain literature (e.g., Forgeron et al., 2013; Jordan et al., 2018; Meldrum et al., 2009; Sorensen & Christiansen, 2017).

Some quantitative studies have demonstrated that intensity of chronic pain can negatively impact adolescents' perception of their identity development compared to peers (Eccleston et al., 2008). My study adds to the literature by depicting the unique ways in which participants may have perceived their identity as 'negative' i.e., through losses in valued parts of identity, as well as through other sources. For instance, the second sub-theme 'forceful choices' in the first GET highlighted another source of loss or limitation in participants' identity: the process of participants trying to manage their pain, and forcefully having to choose being 'healthy' at the cost of other valued parts of their identity like being social or sporty/athletic. Some participants in my study discussed the permanence of the lost parts of their identity, whereas others discussed how making the choice of being 'healthy' came with the loss of being social, which in turn contributed towards the loss of a valued personal attribute of being spontaneous. Another important finding of my study was focusing on the context of being an adolescent whilst having to make the difficult and forceful choice between being healthy, being social or being a student, as participants perceived all of these as important parts of being an adolescent. The process of individuals with chronic illness losing valued parts of their identity is well-recognised in the literature as suggested by the theoretical framework of Loss of Self (Charmaz, 1983). Findings from my study align with this existing theoretical framework and also add to the current understanding of chronic pain and identity, as my findings highlight how adolescents with chronic pain experienced losses not only in individual parts of their identity, but also their collective identity of being a student or belonging to an athletic family. Such findings underline the profound impact that chronic pain can have on multiple layers of adolescents' identity.

Jointly, losses to one's identity in the context of chronic illness have been associated with depression in adults (Harris et al., 2003). However, such findings may apply differently to adolescents, as adolescence is a distinct developmental stage. It may be helpful for further research to explore the impact of losses in identity on adolescents, as evidence suggests that loss of engagement with important activities due to chronic pain in adolescents can contribute towards lower positive reinforcement and self-esteem, and difficulties with friendships, which in turn can contribute towards depression (Landry et al., 2015). In adolescents with chronic pain, depressive symptoms can contribute towards increased pain and disability (Zheng et al., 2020), which strengthens the need to conduct more research in this area.

The third sub-theme of 'uncertainty' in the first GET highlighted yet another source of potential limitation in identity i.e., the uncertainty of chronic pain that created difficulty for adolescents to engage with ideal parts of their identity in the present (e.g., interacting with people and being social) as well as who they wished to be in the future (e.g., having a job, living independently). These findings resemble extant literature where adolescents discussed the unpredictability of chronic pain as an obstacle to how they hoped to see themselves in the future (Meldrum et al., 2009; Szwimer et al., 2020). Findings from my study also suggested that such limitations seemed to contribute towards a discrepancy between participants' 'actual' and 'ideal' identities and created feelings of anxiety and sadness. Hence, findings from my study match with the Self-Discrepancy Theory (Higgins, 1987). My study thus enhances current literature by suggesting that adolescents with chronic pain may also experience self or identity discrepancies, as most evidence about self-discrepancies in chronic pain currently includes studies with adults (e.g., Waters et al., 2004). As discrepancies between one's actual and ideal identity can contribute towards feelings of sadness and decreased feelings of joviality, confidence and pride (Barnett et al., 2017), this may have an implication for future research to explore how identity discrepancies may impact adolescents with chronic pain. Corresponding clinical implications are discussed in the 'Implication' sub-section of this chapter.

To summarise, findings of my study included participants' subjective understanding behind the sources of loss and limitations in multiple layers their identity. Thus, my study provides the unique contribution of adolescents' perspectives on existing literature and theories on chronic illness and identity.

GET Two: A Mismatch

The second GET in my study suggested that participants experienced a difference in their own perception of their identity (internal identity) with how they thought others perceived them (external identity). Specifically, participants' experience of 'being' in pain was seen inaccurately by others such as friends, peers, family and teachers, which made participants feel misunderstood, judged and upset. As suggested by the first sub-theme, 'varied needs', participants had unique needs for how they wished to be perceived when they were in pain. For some participants, their experience of being in pain was viewed by others by labelling them as 'sick' or seeing them as needing extra support, which was not in consonance with participants' own view of their identity as being capable. In other words, participants' external identity seemed to be defined by their pain condition. Chronic pain defining adolescents' external identity has been noted in the findings of a small number of studies (Jordan et al., 2018). Nevertheless, other studies have found that adolescents with chronic pain desire to be seen as “normal” by others (Ghio et al., 2021; Meldrum et al., 2009; Sorensen & Christiansen, 2017; Wakefield et al., 2021), which may suggest an underlying difference in the way adolescents wished to be seen versus how they were seen by others. These findings alongside findings from my study are in contrast with those of Kashikar-Zuck et al. (2007), where adolescents as well as their peers and teachers viewed them similarly i.e., as isolated and sensitive. However, the same authors suggested that adolescents in their study had JPFS which has been linked to a higher likelihood of psychiatric difficulties, which may account for the social difficulties experienced by this population. Thus, an area for further research may involve exploring internal and external identity differences in adolescents with specific chronic pain conditions to understand if certain types of pain conditions have a different interaction with identity.

The first sub-theme of this GET also alluded to an important finding i.e., a sense of difference in perception of provision of ‘care’ between participants and others (e.g., family), which was perceived by participants as being labelled inaccurately as ‘sick’. This difference in perception of ‘care’ has been identified by Forgeron et al. (2013) in the context of friendships, where adolescents with and without chronic pain expressed difference in their views of care, which made adolescents with chronic pain feel stigmatised by friends. Such findings in conjunction with findings from my study may suggest a difficulty that adolescents may have around communicating about chronic pain and their needs to others, which may lead to misunderstanding in social relationships. Clinical implications regarding this are presented in the ‘Implications’ sub-section of this chapter.

The first sub-theme also discussed how participants tried to bring consonance between the internal and external understandings of their identity, by continuing with activities and proving their capable identity to others. Similar findings have been observed in other studies where adolescents tried to preserve their “normal” identity despite being in considerable pain (Sorensen & Christiansen, 2017; Wakefield et al., 2021). This motivation to bring consonance in parts of identity may be explained by the Self-Discrepancy Theory, specifically through the concept of the ‘feared self’ (the person one worries about becoming), which can drive one’s motivation to avoid becoming the feared self (Carver et al., 1999). Studies with adults have demonstrated that being closer to one’s feared identity can predict anxiety and depression (Kindermans et al., 2011). This may suggest that adolescents with chronic pain may require additional support or psychological intervention to bring greater coherence within their identity.

Another unique finding from the first sub-theme highlighted the need for some participants to be seen differently when they were in pain i.e., to be seen as someone who may require a break during family activities. Accordingly, the absence of this understanding from others seemed to make adolescents feel lonely and misunderstood, creating a possible tension between the collective family identity and adolescents’ experience of pain. Similar results have been seen in some studies which highlight parents’ perception of the difficulties on a family level to undertake shared activities (Jordan et al., 2017). Such findings strengthen the need for clinical practice to focus on improving social relationships in adolescents with chronic pain.

The second sub-theme ‘invisible disability’ discussed how participants’ experience of being in pain was misunderstood and dismissed by others due to the invisibility of pain. This highlighted the paradox where something having a profound impact on participants’ life remained unseen by others, making participants feel judged and possibly frustrated. Findings from my study echoed the well-recognised element of invisibility of pain, which left adolescents feeling alone and misunderstood as their chronic pain was not believed or understood by others (Forgeron et al., 2013; Meldrum et al., 2009; Wakefield et al., 2021). Not being believed about one's pain can contribute towards stigma (Jakson, 2005), shame, and humiliation which in turn can affect the individual's identity negatively (Newton et al., 2013). In the chronic pain population, experiencing stigma has been associated with higher disability, depressive symptoms, withdrawing from activities and lower self-esteem (Bean et al., 2022). Considering the limited knowledge available on adolescents' experiences of stigma in the context of chronic pain (Wakefield et al., 2018; Wakefield et al., 2023), my study adds to the literature by identifying the specific role of invisibility in contributing towards stigma in adolescents with chronic pain. However, as stigma was not the primary aim of my study, future research can continue exploring in depth the role of invisibility of pain and stigma on adolescents' identity, wellbeing and mental health.

Overall, interesting findings from the second GET include differences in adolescents' internal and external identities, with their external identity being defined by pain, and adolescents' efforts to bring consonance in this difference. Further, differences in perception of care were observed, along with the role of invisibility of pain in contributing towards dissonance in internal and external representations of adolescents' identity.

GET Three: Not Belonging as an Adolescent

The third GET of my study highlighted participants' felt sense of lack of belongingness from the collective identity of being an 'adolescent', as their actual identity was different from their own as well as societal understanding of how a typical adolescent 'should be'.

The first sub-theme suggested that participants differed in their personal understanding of how an adolescent 'should' be i.e., for some being a friend was important whereas for others routine activities like attending school and 'going out to have fun' were important. Nevertheless, participants experienced a difficulty in engaging with such 'typical adolescent' social roles or activities which created feelings of sadness and isolation. These findings match with existing literature that suggests adolescents with chronic pain experienced a sense of difference or altered sense of being "normal" compared to their peers (Corser et al., 2023; Ghio et al., 2021; Meldrum et al., 2009; Wakefield et al., 2021) and questioned themselves as a 'student' (Forgeron et al., 2013). Consequently, adolescents with chronic pain may continue engaging in developmentally "normal" behaviours despite being in pain to maintain a sense of belongingness (McDonagh et al., 2016). Isolation and a sense of difference between adolescents with chronic pain and their peers may contribute towards reduced availability of peer support (Jordan et al., 2017), which is important to consider as strong peer relationships can help in adapting to chronic pain (Ross et al., 2018) and with better emotional adjustment in adolescents with chronic pain (Eccleston et al., 2008).

A unique finding in the first sub-theme included participants' perception of having new yet unhelpful parts being added to their identity as they experienced a distance from the collective identity of being an adolescent. For instance, some participants in my study viewed themselves as a "burden" or as the "odd one out" due to being unable to engage in activities they viewed typical for adolescents such as being sporty or moving freely. These findings add complexity to the limited knowledge about identity development in adolescents with chronic pain – such adolescents may experience unique changes to their identity which can include addition of unhelpful parts to their identity. Future research should explore how these unhelpful parts of identity may have an impact on adolescents' mental health and social relationships. Specifically, as some evidence suggests that adolescents may conceal their pain to avoid feeling like a "burden" on others, however, concealment can lead to further social isolation as well as cognitive burden for such adolescents (Wakefield et al., 2021).

In the second sub-theme, participants discussed how chronic pain was viewed as a 'condition for old people' in their social and cultural contexts, which set participants further apart from the collective identity of being an adolescent. Participants discussed experiencing guilt, disbelief, repeated questions, judgment and being made 'fun of' from others in the context of being 'too young' for this 'old person condition'. Such experiences could be understood through the concept of 'felt stigma' (perception of not being believed regarding pain symptoms or being judged negatively) (Major et al., 2018). Another element within felt stigma can be 'ageism', or being told that one is too young for experiencing a particular health condition, as described by Wakefield et al. (2023). The same authors highlighted a gap in research regarding the felt stigma experiences of ageism in adolescents with chronic pain, thus, my study contributes to the limited literature on adolescents' experiences of stigma.

In my study, participants' experience of seeing themselves as different from their own as well as others' perception of what an adolescent 'should be' can also be explained in the context of the Self-Discrepancy Theory (Higgins, 1987). Evidence suggests that self-discrepancies may have some association with anxiety, depression and eating disorders, and emotions of anger, guilt and shame (Mason et al., 2019).

Overall, this GET highlighted how participants' perceived distance from the collective identity of 'adolescent', based on their own and societal understanding of how adolescents 'should' be. This distance from a collective identity warrants attention as losing group or collective identity can be associated with lower self-esteem (Slotter et al., 2015). Similarly, group or collective membership has been associated with reduced symptoms of depression as well as protection against future depression (Cruwys et al., 2013). Clinical implications regarding issues of stigma, social belongingness, and self-discrepancies are discussed in the subsequent ‘Implications’ section.

GET Four: Paradoxical Role of Diagnosis

The fourth GET depicted the multiple and often paradoxical roles that a diagnosis or medical explanation of pain had in shaping adolescents’ understanding of their identity. The first sub-theme, ‘validation versus restriction’ suggested how a diagnosis contributed towards feelings of validation as well as a sense of restriction for the identity of adolescents. For instance, for some adolescents, having a diagnosis created feelings of relief as their experience of pain was validated by others and by themselves. This finding matches partially with the wider adolescent chronic pain literature which suggests that adolescents (and parents) perceived a diagnosis as the solution for alleviating chronic pain (Meldrum et al., 2009; Szwimer, 2020), which may be suggestive of feelings of relief.

Moreover, a unique finding in the first sub-theme suggested that a diagnosis served a potentially protective function as it created distance between participants’ ‘self’ and the pain, as some adolescents described feeling blame or responsibility for ‘creating’ the pain ‘in their heads’ prior to receiving a diagnosis. As stated previously in this chapter, participants experienced stigma and disbelief from others due to the invisibility of their pain and for being ‘too young’ to have chronic pain. Thus, this sense of blame for ‘creating’ pain may be understood in this context as evidence has demonstrated that adolescents experiencing stigma from others may consequently have internalised stigma (e.g., blaming oneself) (Wakefield et al., 2022).

The potentially protective function of a diagnosis observed in my study has interestingly been seen in individuals with mental health conditions (which can also be ‘invisible’) where a diagnosis may provide relief by separating one’s ‘true’ self from an external disorder, thus reducing the blame one may experience for their symptoms (O’Connor et al., 2018). Future research can explore this further, specifically to see if a diagnosis can play a protective role in the identity of adolescents with chronic pain.

However, the first sub-theme also highlighted some unhelpful meanings that a diagnosis had for participants’ identity. Interestingly, sometimes the same participants had contrasting meanings behind a diagnosis. Although it provided relief, it also appeared to diminish and restrict the ‘healthy’ part of their identity. On a slightly similar note, Jordan and colleagues (2018) alluded to the unhelpful impact of a diagnosis on “stealing” the identity of some adolescents for themselves and in the eyes of others. Another study identified diagnosis as a “life changing event”, prompting adolescents to try to retain their pre-diagnosis identity (McDonagh et al., 2016). As a unique finding, one participant in my study also alluded to the ‘chronic’ part of her diagnosis, and the meaning of chronicity in indefinitely limiting valued parts of identity like being outgoing. In contrast, another adolescent stated how knowing about the chronicity helped with acceptance of pain and modifications to activities to help him retain parts of his pre-pain identity. Similar findings have been seen in some studies about acceptance about the long-term nature of pain that can help in improving quality of life in adolescents (Szwimer et al., 2020). Collectively, these findings demonstrate that a diagnosis and its ‘chronicity’ can have multiple and often paradoxical meanings for adolescents. This may have a clinical implication for providing adolescents with more support to make sense of a diagnosis and its potentially ‘long-term’ nature, as chronic pain in adolescence may persist in adulthood (Walker et al., 2010).

Adding to the complexity of a diagnosis, the second sub-theme, ‘trapped in my own body’ suggested participants’ sense of separation between their identity and physical body. In essence, a diagnosis or medical explanation of pain separated participants’ ‘self’ from creating the pain, but the pain was then seen as created by their ‘body’ which was viewed as a separate entity. However, this process seemed to exist alongside the recognition of still having to live in the body that was restricting and creating pain. This appeared to create a dissonance between adolescents’ actual bodies versus the ideal ‘fit’ and ‘healthy’ bodies of young people, which led to feelings of anger and embarrassment. These findings are partially consistent with the wider adolescent chronic pain literature, where adolescents discussed a sense of separation between their ‘selves’ and their body (or ‘physical limitations’) (Corser et al., 2023; Szwimer et al., 2020), however, these studies do not allude to the role of a diagnosis in contributing towards this separation. Hence, my study adds to the literature as it introduces a potential dimension of diagnosis that may be linked to a sense of separation of adolescents’ self and body. As my findings provide preliminary results about self and body separation in adolescents with chronic pain, future research can explore this further as one’s body can be an important part of identity as suggested by Erikson’s theory (1968) and contemporary research (Kling et al., 2018). Findings from adults with chronic pain suggest that separation or rejection from the body can contribute towards lower self-esteem (Bode et al., 2010) and can impede acceptance of pain which can be important for pain management (Osborn & Smith, 2006), which strengthens the need to conduct further research in this area.

In summary, this GET highlighted that a diagnosis had multiple and paradoxical meanings for participants’ identity, such as feelings of relief on one hand, and restriction of the ‘healthy’ part of identity on the other hand.

GET Five: Protecting Identity from Pain

The final GET represented participants' efforts to protect their identity from chronic pain. The first sub-theme, 'adapting' demonstrated participants' effortful and forceful process of adaptation, to retain helpful parts of identity (e.g., being social, being sporty) and protect their identity from experiencing further limitations, losses or discrepancies due to chronic pain. Participants had unique ways of adapting, such as continuing to engage in social interactions despite pain, limiting engagement with sport (to manage pain) with the hope of being sporty in the future, or by concealing pain from friends to protect themselves from being seen as boring or draining. Continuing to engage with activities which are important to one's identity despite pain has been recognised in the adolescent chronic pain literature (Jordan et al., 2018; McDonagh et al., 2016; Sorensen & Christiansen, 2017), which could be understood as an attempt to preserve the 'normalcy' of belonging as an adolescent (Sorensen & Christiansen, 2017). Further, the use of concealing pain symptoms to preserve normalcy and avoid stigmatisation has been recognised in the adolescent chronic pain literature (Forgeron et al., 2013; Ghio et al., 2021; Meldrum et al., 2009; Wakefield et al., 2021). However, to reiterate, continued use of concealment in adolescents with chronic pain can have unhelpful outcomes like experiencing cognitive burden (Wakefield et al., 2021). These findings highlight the importance of adaptation for adolescents, however, the strategies used by adolescents such as concealment may not be helpful. Thus, psychological interventions can focus on helping adolescents adopt more helpful strategies of adapting with chronic pain.

The second sub-theme 'gaining valued parts' indicated that in the process of protecting their identity from chronic pain, participants also gained valuable parts to their identity that they wished to retain. These new valued parts were viewed by participants as similar to some elements of their pre-pain identity. For instance, some participants noticed themselves being more mindful, appreciative and optimistic whereas others had found new avenues for engaging with valued parts of their identity (such as engaging in sport vicariously through coaching others). Similar findings have been observed in the adolescent chronic pain literature, as adolescents discussed increased emotional maturity (Forgeron et al., 2013; Jordan et al., 2018) and better problem-solving capacity compared to peers (Eccleston et al., 2008), and new ways of engaging with valued activities (Meldrum et al., 2009). Such findings in addition to findings from my study may allude to the concept of flourishing (positive changes such as benefit finding, resilience, and optimism despite experiencing chronic pain) as suggested in a recent scoping review (Parsons et al., 2022). The same review also indicated a paucity of research in flourishing in adolescents with chronic pain, and a lack of cultural diversity in participants of the research studies that provide current knowledge about this topic. Although flourishing was not the primary focus of my study, findings from my study provide preliminary knowledge about this under-researched area, specifically as participants in my study belonged to varied cultural backgrounds. This suggests that flourishing can be a common experience across cultures in adolescents with chronic pain, however, this finding may require additional support which can be facilitated by future research with adolescents from varied cultural backgrounds. My study also highlights the unique meaning that participants had behind flourishing i.e., hoping to retain newly gained parts of identity that matched their ideal pre-pain identity.

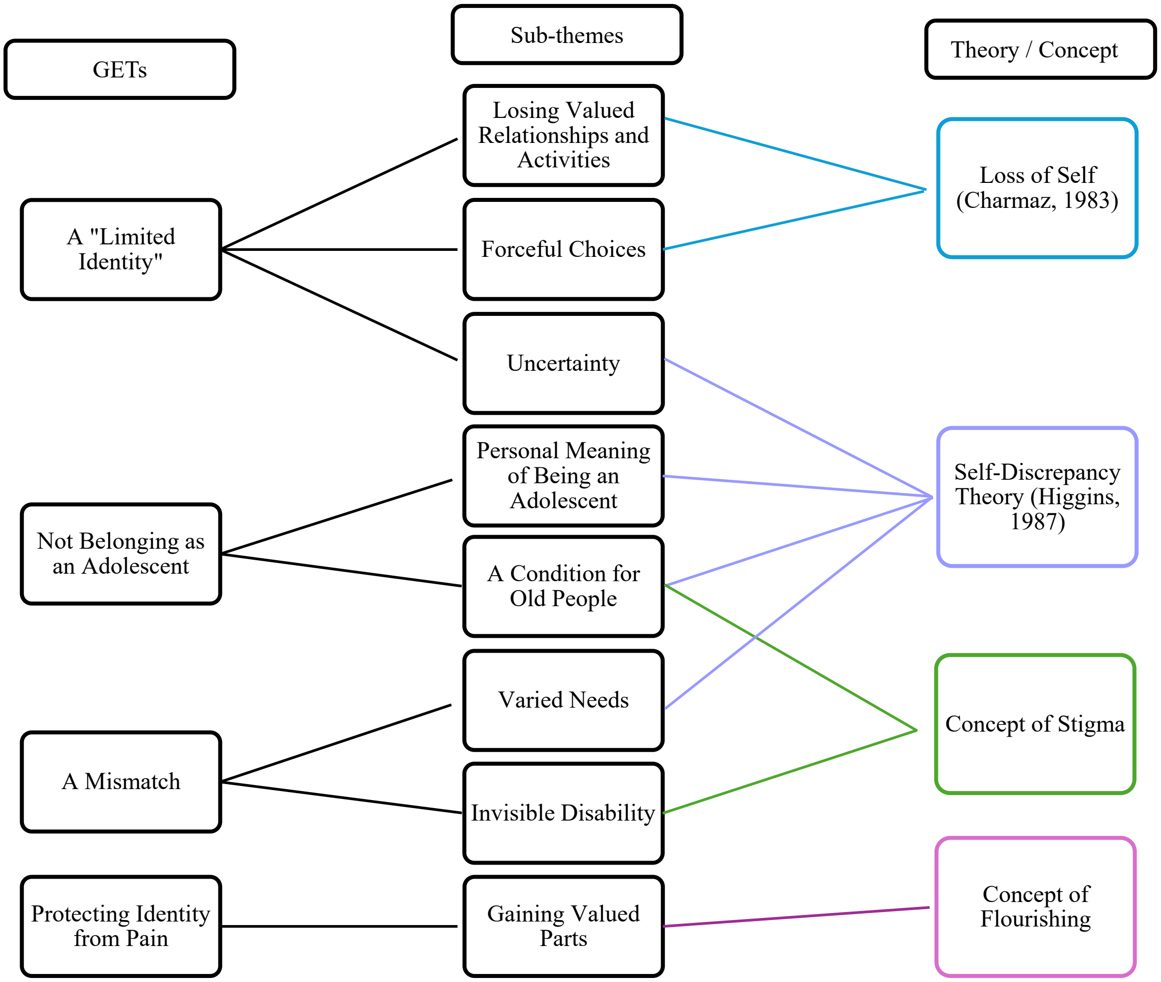
In summary, this GET illustrated participants' unique processes of retaining valued parts of their identity as well as gaining new parts to identity. Implications regarding resilience and flourishing in relation to identity are presented in the 'Implications' section.

Summary of Findings and Relationship with Theory and Concepts

This sub-section summarises the overarching and unique findings of my study, and their relationship with extant theory and concepts. The diagram presented below includes the GETs and sub-themes of my study that can be directly linked a theory or concept, and thus not all GETs and sub-themes are reflected in this diagram.

Figure 2

Visual Representation of Overarching Findings and their Relationship with Theory and Concepts



Findings from the first GET, specifically the sub-themes of ‘losing valued relationships and activities’ and ‘forceful choices’ add to the theoretical framework of Loss of Self (Charmaz, 1983). Such findings suggest that adolescents with chronic pain can also experience losses in valued parts of their individual identity (e.g., being social) as well as collective identity (e.g., belonging to an athletic family). Findings from my study also align with the Self-Discrepancy Theory (Higgins, 1987), highlighting the unique ways in which adolescents with chronic pain may experience self-discrepancies. For instance, findings from the sub-theme of ‘uncertainty’ from the first GET illustrated how participants experienced discrepancies in their actual and ideal identities due to the uncertainty of chronic pain. Further, the sub-theme of ‘varied needs’ in the second GET demonstrated participants’ efforts to bring consonance between their internal and external identities, thus linking with the concept of the ‘feared self’ of the Self-Discrepancy Theory. The third GET ‘not belonging as an adolescent’ suggested that participants also experienced discrepancies in their actual and ‘should’ be identity as chronic pain appeared to set participants apart from their own as well as others’ understanding of how a ‘typical’ adolescent ‘should’ be.

Additionally, findings from my study contribute towards the understanding of concepts such as stigma and flourishing. In terms of stigma, the sub-theme of ‘invisible disability’ in the second GET highlighted how invisibility of pain was linked with participants experiencing stigma in the form of misunderstanding and disbelief from others. The sub-theme of ‘a condition for old people’ in the third GET also added to the concept of felt stigma by recognising participants’ experiences of age-related stigma i.e., being told that by others that one is too young for having a particular health condition (Wakefield et al., 2023). Finally, my study also provides an insight into the concept of flourishing (experiencing positive changes whilst living with chronic pain) (Parsons et al., 2022). Specifically, the sub-theme of ‘gaining valued parts’ in the fifth GET suggests how participants perceived that they had gained new and valuable parts to their identity (e.g., being more mindful or appreciative, and finding new ways to connect with sport) whilst living with chronic pain, and how they wished to retain these new parts in their identity.

Implications for Clinical Practice

Prior to discussing implications for clinical practice, it is important to consider that IPA’s commitment to idiography may not facilitate generalisable results but can enhance the understanding regarding a phenomenon (Cassidy et al., 2011). As the Literature Review chapter of my study suggested, identity development in adolescents with chronic pain is an under-researched area. Thus, my study makes a timely contribution to the literature and clinical practice in CoP and allied disciplines, as findings from my study can enhance clinicians’ understanding of identity difficulties that adolescents with chronic pain may experience. As the multimodal training of CoPs can help them work in physical health settings (Davies, 2016), it can be helpful for CoPs to explore such identity difficulties with adolescents with chronic pain.

Findings from my study highlighted how adolescents with chronic pain experienced limitations and losses in valuable parts of their identity, which introduced feelings of sadness, fear, and powerlessness. In adults with chronic pain, evidence suggests that group based Cognitive Behavioural Therapy (CBT) interventions can help individuals identify and process losses and grief associated with chronic pain in a supportive environment, which in turn can help with accepting pain and improvement in living with pain (Haraldseid et al., 2014). However, as this evidence stems from adults, additional research should examine the efficacy of these interventions for adolescents. Nevertheless, adolescents with chronic pain can also experience losses to their identity as suggested by my study and other studies across adolescent chronic pain literature. For CoPs working with adolescents with chronic pain, it may thus be helpful to identify and process losses to their identity and associated emotions in a manner consistent with the developmental stage of adolescents, considering that therapeutic processes can vary across different developmental stages (Sugarman, 2004). Further, adolescents in my study and in the wider literature attributed identity losses to a reduction in engagement with activities. A randomised controlled trial with adolescents and their families completing an internet-based CBT intervention (e.g., recognising stress and negative emotions, staying active, relaxation techniques) suggested an improvement in adolescents' activity limitations and pain intensity (Palermo et al., 2009). Thus, it may be helpful for CoPs working with adolescents with chronic pain to use or adapt such interventions to improve adolescents' activity engagement, considering the unhelpful impact of reduction in activities for adolescents (Landry et al., 2015).

Adolescents in my study also experienced a dissonance or discrepancy in parts of their identity (e.g., actual versus ideal or 'should be' identity, or being closer to their 'feared' identity), and self-discrepancies may be associated with negative outcomes such as anxiety and depression (Mason et al., 2019). Psychological interventions with adolescents can thus focus on identifying and understanding the way adolescents perceive themselves, and work on helping adolescents adapt the goals that they have for themselves based on their understanding of their 'ideal' or 'should be' identity. This may be helpful as flexibility with one's goals can help in managing the negative emotions that may arise due to self-discrepancies (Goossens et al., 2010).

An important finding of my study highlighted adolescents' experience of stigma from others regarding the invisibility of their pain, or for experiencing a condition perceived for 'older' individuals. Considering the harmful outcomes of being stigmatised on individuals with chronic pain (Bean et al., 2022), several clinical and societal interventions can be considered. First, on a societal level, it can be helpful to increase knowledge and improve communication about chronic pain in adolescent-specific contexts such as in schools, for instance, through mass media platforms. For adolescents experiencing stigma, it can be helpful for healthcare professionals to introduce education about chronic pain (e.g., social, environmental and emotional elements impacting pain intensity), which can be reassuring and validating for individuals and can reduce internalised stigma and feelings of shame or fear (Ashton-James, 2024). Research also suggests that individuals at a younger developmental age might be more vulnerable to stigma as they might be less likely to manage such situations with resilience strategies compared to adults (Earnshaw et al., 2022). Thus, mental health professionals can support adolescents with managing stigma-associated distress by introducing helpful coping strategies such as emotional regulation and enhancing resilience (De Ruddere & Craig, 2016). However, this also implies that clinicians and mental health professionals may have to continue increasing their understanding about working with chronic pain.

Another crucial finding of my study was about the role of diagnosis in shaping adolescents' understanding about their identity and their bodies. Considering the multiple meanings that a diagnosis (and its chronicity) can have for adolescents as demonstrated in my study, it may be helpful for adolescents to receive more psychological support to understand the personal meanings that a diagnosis can hold for them. Helping adolescents understand personal meanings behind a diagnosis aligns particularly well with the humanistic values of CoP focusing on individuality and meaning making (Donati, 2016). Further, the separation of self and body as experienced by adolescents in my study as well as in other studies can have an implication for trying to help adolescents build a positive personal identity that involves understanding, acceptance and appreciation of one's whole self (Gill, 1997). Thus, psychological interventions can include increasing acceptance and helping adolescents make sense of their bodies, as separation from one's body can be associated with lower self-esteem (Bode et al., 2010).

Findings from my study and wider adolescent chronic pain literature highlight the multiple social difficulties that such adolescents experience. Considering the importance of social support and peer relationships for adolescents with chronic pain, several clinical implications can be considered. First, CoPs can help adolescents develop helpful communication strategies for discussing their needs for care and support with others, which may reduce the confusion or misunderstanding in social relationships about how adolescents view themselves versus how they are viewed by others. Second, interventions focusing on adapting and maintaining interpersonal relationships alongside living with chronic pain can be helpful as adolescents can experience losses or changes in their engagement with social relationships. For such purposes, therapeutic approaches focusing on social skill development can be used with adolescents over multiple sessions as suggested by Forgeron et al. (2018).

Finally, considering the potential helpful role of resilience and flourishing in protecting the identity of adolescents as discussed in my findings, psychological interventions can focus on enhancing resilience in adolescents with chronic pain. For instance, interventions such as positive activity interventions, which aim to enhance resilience by increasing positive affect and reducing negative emotions (Hassett & Finan, 2016).

Limitations

This study adopted a cross-sectional approach for understanding identity development in adolescents with chronic pain. Considering that identity can change over time or in response to important life events (Schwartz et al., 2011), the cross-sectional approach of my study can be viewed as a limitation as it provided insight into adolescents' identity from a single time point. To address this, the interview schedule used in my study included questions about adolescents' perceptions of their identity before and after the onset of chronic pain to understand the 'process' of identity development from multiple time points. However, memories about past identity can be constructed based on an individual's 'current' characteristics, goals or beliefs (Wilson & Ross, 2003) and thus participants' account of their identity before the onset of pain may have been influenced by their current experience of pain, especially as some participants had experienced pain for several years. This may not necessarily be a limitation of my study, as the study's aim was to understand subjective experience and not the accuracy of memory or recall. However, it may be helpful for future research to understand identity development in adolescents with chronic pain using a longitudinal approach, to explore changes in adolescents' identity across time and understand its impact on their lives.

Following IPA's recommendation to have a homogenous sample, the participants in my study were aged between 16 and 18 years and had experienced chronic pain for more than three months. However, participants differed in the type of chronic pain they had and the ages at which their pain started. Some evidence suggests that identity development can differ based on when an individual is diagnosed with chronic pain (specifically juvenile idiopathic arthritis) i.e., during childhood or adolescence (McDonagh et al., 2016). Having participants in my study with varied overall durations of chronic pain may have added some heterogeneity to the sample. However, findings from studies including adolescents with varied chronic pain conditions and durations (e.g., Forgeron et al., 2013; Jordan et al., 2018) have suggested the presence of shared experiences regarding identity, as indicated in the Literature Review chapter. Further, according to my knowledge, there is limited evidence to suggest that specific chronic pain conditions can have a specific interaction with adolescents' identity. Thus, varied chronic pain conditions were decided to be included in my study. Moreover, participants in my study seemed to have shared experiences and perceptions about their identity as suggested by the GETs in my analysis. This suggests that chronic pain can have a shared or similar interaction with adolescents' identity, regardless of the pain duration or specific chronic pain diagnosis (or lack of it). Nevertheless, future research can examine this in greater detail, specifically to understand what kind of interactions varied chronic pain conditions and durations can have with the identity of adolescents.

As my study included adolescents with varied chronic pain conditions, findings should thus be interpreted and transferred with caution to other chronic pain conditions that were not included in my study, such as complex regional pain syndrome. Further, experiences of stigma can vary based on the type of chronic pain i.e., unexplained pain (e.g., primary chronic pain conditions) compared to clearly diagnosed conditions (e.g., juvenile idiopathic arthritis) (Wakefield et al., 2023). Thus, further research can explore if specific chronic pain diagnoses (or lack of one) contribute towards varied levels of stigma, and how stigma in turn can interact with adolescents' identity.

The sample of my study included only 2 male participants. This could reflect the general finding in adolescent chronic pain literature about higher prevalence of chronic pain in girls compared to boys (Gobina et al., 2019). Nevertheless, having 2 male participants in my study can be seen as a limitation as although lesser in prevalence compared to females, males also experience chronic pain. Hence, findings of this study should be interpreted considering this limitation. Further, in my study, interviews with male participants were shorter in duration compared to interviews with female participants. This may be a potential limitation; however, the length of interviews may not necessarily be related to gender as only two male participants were present in my study. However, this potential limitation may be understood in relation to gender related stigma. Specifically, current evidence suggests varied experiences of gender related stigma in expressing chronic pain i.e., men may be expected to 'tolerate' pain whereas women can be perceived as 'hysterical' or 'emotional' (Perugino et al., 2022). As both gender and stigma can play a role in forming one's identity, it may be helpful for future research to explore identity in adolescents with chronic pain with a particular focus on gender, which can help in tailoring specific support for adolescents based on gender-related stigma.

A common limitation of IPA is its view of language as a medium for understanding a participant's experience, however, it is argued that language may not provide direct access to a participant's experience but only to the way a participant 'talks' about the experience (Willig, 2013). To address this limitation to a certain extent, an attempt was made to understand the role of language by interpreting specific phrases, words and non-verbal communication (tone of voice, pauses) and by considering the adolescent's social context during analysis. However, the concept of identity itself has been argued as discursively constructed, as the use of language can facilitate individuals to express their identities in varied ways (Schwartz et al., 2011). As the primary aim of my study was to understand the sense making behind identity development, and not on how adolescents 'talked' about their identity, IPA appeared to be a helpful analytic method for understanding adolescents' sense making process. However, I acknowledge alternative possibilities of looking at identity as discursively constructed, and using different methodologies may yield different findings. Future research, specifically using discursive or narrative methods can be a helpful way for studying how language may shape identity development in adolescents with chronic pain.

Conclusion

My study explored how adolescents with chronic pain made sense of their identity, by using semi-structured interviews with a sample of seven adolescents with chronic pain. My study used IPA as it facilitated a focus on embodied and individual experiences, and the sense making process behind identity development.

My study contributes towards the literature on identity development in adolescents with chronic pain and provides novel findings in relation to this under-researched topic. Overall, findings from my study highlighted the unique changes and difficulties that chronic pain seemed to introduce in adolescents' identity, which are summarised as follows. Participants felt a sense of limitation and loss in valued parts of their identity (e.g., being social, having a job in the future). Participants also experienced differences in their internal and external representations of identity, and had very a unique understanding of how they wished to be seen by others when they were in pain (e.g., wanting to be seen as capable, or as someone who may need a break from activities). Further, participants' lack of belongingness from the collective identity of being an 'adolescent' appeared to introduce new and unwelcome parts into their identity such as being the "odd one out". Additionally, my study illustrated the multiple and paradoxical meanings associated with a diagnosis or medical explanation of chronic pain (as well its 'chronicity) i.e., providing a sense of validation and relief, but also restricting other parts of identity (e.g., being healthy). Yet another important finding from my study depicted the role of a diagnosis in contributing towards a sense of separation between adolescents' sense of selves and their bodies, and participants' experiences represented a struggle of still having to live in a body creating pain.

Nevertheless, my study also illustrated participants' motivation to protect their identity by adapting and trying to retain important parts of their identity despite their chronic pain, and even gaining new parts in their identity in this process. Finally, findings of my study were discussed in relation to existing theories such as the Self-Discrepancy Theory (Higgins, 1987) and psychological concepts such as stigma.

Jointly, the findings of my study are relevant to CoP as they offer subjective and developmentally appropriate knowledge about potential identity difficulties in adolescents with chronic pain. The clinical implications offered are also relevant as the multimodal training of CoPs enables them to work in settings with adolescents who have chronic pain.

Based on the findings offered by my study, some of the important recommendations for future research with adolescents with chronic pain included exploring identity discrepancies, the role of new and unwelcome parts, and experiences of self and body separation. Limitations of my study were discussed, which included some additional directions for future research.

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Appendices

Appendix A – Ethical Approval

University of
East London

School of Psychology Ethics Committee

NOTICE OF ETHICS REVIEW DECISION LETTER

For research involving human participants

BSc/MSc/MA/Professional Doctorates in Clinical, Counselling and Educational Psychology

Reviewer: Please complete sections in **blue** | **Student:** Please complete/read sections in orange

Details	
Reviewer:	**James Walsh**
Supervisor:	**Sharon Cahill**
Student:	**Gauri Rajiv Joshi**
Course:	**Professional Doctorate in Counselling Psychology**
Title of proposed study:	**A Phenomenological Exploration of Identity Development in Adolescents with Chronic Pain**

Checklist
(Optional)

	YES	NO	N/A
Concerns regarding study aims (e.g., ethically/morally questionable, unsuitable topic area for level of study, etc.)	☐	☐	☐
Detailed account of participants, including inclusion and exclusion criteria	☐	☐	☐
Concerns regarding participants/target sample	☐	☐	☐

Detailed account of recruitment strategy	☐	☐	☐
Concerns regarding recruitment strategy	☐	☐	☐
All relevant study materials attached (e.g., freely available questionnaires, interview schedules, tests, etc.)	☐	☐	☐
Study materials (e.g., questionnaires, tests, etc.) are appropriate for target sample	☐	☐	☐
Clear and detailed outline of data collection	☐	☐	☐
Data collection appropriate for target sample	☐	☐	☐
If deception being used, rationale provided, and appropriate steps followed to communicate study aims at a later point	☐	☐	☐
If data collection is not anonymous, appropriate steps taken at later stages to ensure participant anonymity (e.g., data analysis, dissemination, etc.) – anonymisation, pseudonymisation	☐	☐	☐
Concerns regarding data storage (e.g., location, type of data, etc.)	☐	☐	☐
Concerns regarding data sharing (e.g., who will have access and how)	☐	☐	☐
Concerns regarding data retention (e.g., unspecified length of time, unclear why data will be retained/who will have access/where stored)	☐	☐	☐
If required, General Risk Assessment form attached	☐	☐	☐
Any physical/psychological risks/burdens to participants have been sufficiently considered and appropriate attempts will be made to minimise	☐	☐	☐
Any physical/psychological risks to the researcher have been sufficiently considered and appropriate attempts will be made to minimise	☐	☐	☐
If required, Country-Specific Risk Assessment form attached	☐	☐	☐
If required, a DBS or equivalent certificate number/information provided	☐	☐	☐
If required, permissions from recruiting organisations attached (e.g., school, charity organisation, etc.)	☐	☐	☐
All relevant information included in the participant information sheet (PIS)	☐	☐	☐
Information in the PIS is study specific	☐	☐	☐
Language used in the PIS is appropriate for the target audience	☐	☐	☐
All issues specific to the study are covered in the consent form	☐	☐	☐
Language used in the consent form is appropriate for the target audience	☐	☐	☐
All necessary information included in the participant debrief sheet	☐	☐	☐
Language used in the debrief sheet is appropriate for the target audience	☐	☐	☐
Study advertisement included	☐	☐	☐
Content of study advertisement is appropriate (e.g., researcher's personal contact details are not shared, appropriate language/visual material used, etc.)	☐	☐	☐

Decision options

APPROVED	Ethics approval for the above-named research study has been granted from the date of approval (see end of this notice), to the date it is submitted for assessment.
APPROVED - BUT MINOR AMENDMENTS ARE REQUIRED BEFORE THE RESEARCH COMMENCES	In this circumstance, the student must confirm with their supervisor that all minor amendments have been made **before** the research commences. Students are to do this by filling in the confirmation box at the end of this form once all amendments have been attended to and emailing a copy of this decision notice to the supervisor. The supervisor will then forward the student's confirmation to the School for its records. **Minor amendments guidance:** typically involve clarifying/amending information presented to participants (e.g., in the PIS, instructions), further detailing of how data will be securely handled/stored, and/or ensuring consistency in information presented across materials.
NOT APPROVED - MAJOR AMENDMENTS AND RE-SUBMISSION REQUIRED	In this circumstance, a revised ethics application **must** be submitted and approved **before** any research takes place. The revised application will be reviewed by the same reviewer. If in doubt, students should ask their supervisor for support in revising their ethics application. **Major amendments guidance:** typically insufficient information has been provided, insufficient consideration given to several key aspects, there are serious concerns regarding any aspect of the project, and/or serious concerns in the candidate's ability to ethically, safely and sensitively execute the study.

Decision on the above-named proposed research study

Please indicate the decision:	APPROVED

Minor amendments

Please clearly detail the amendments the student is required to make

Major amendments

Please clearly detail the amendments the student is required to make

Assessment of risk to researcher

Has an adequate risk assessment been offered in the application form?	**YES** ☒	**NO** ☐
	If no, please request resubmission with an **adequate risk assessment.**	
If the proposed research could expose the researcher to any kind of emotional, physical or health and safety hazard, please rate the degree of risk:		
HIGH	Please **do not approve a high-risk** application. Travel to countries/provinces/areas deemed to be high risk should not be permitted and an application not be approved on this basis. If unsure, please refer to the Chair of Ethics.	☐
MEDIUM	Approve but include appropriate recommendations in the below box.	☐

LOW	Approve and if necessary, include any recommendations in the below box.	☒
Reviewer recommendations in relation to risk (if any):	Please insert any recommendations	

Reviewer's signature

Reviewer: (Typed name to act as signature)	**James Walsh - Note: Application received by me today; may have been held up elsewhere.**
Date:	**02/10/2023**

This reviewer has assessed the ethics application for the named research study on behalf of the School of Psychology Ethics Committee

RESEARCHER PLEASE NOTE

For the researcher and participants involved in the above-named study to be covered by UEL's Insurance, prior ethics approval from the School of Psychology (acting on behalf of the UEL Ethics Committee), and confirmation from students where minor amendments were required, must be obtained before any research takes place.

For a copy of UEL's Personal Accident & Travel Insurance Policy, please see the Ethics Folder in the Psychology Noticeboard.

Confirmation of minor amendments

(Student to complete)

I have noted and made all the required minor amendments, as stated above, before starting my research and collecting data

Student name: (Typed name to act as signature)	Please type your full name
Student number:	Please type your student number
Date:	Click or tap to enter a date

Please submit a copy of this decision letter to your supervisor with this box completed if minor amendments to your ethics application are required

Appendix B – Information Sheets (Adolescents and Parent/Guardian)

University of
East London

PARTICIPANT INFORMATION SHEET - Adolescents

Exploring Identity Development in Adolescents with Chronic Pain

Contact person: Gauri Joshi
Email: u2042426@uel.ac.uk

You are being invited to participate in a research study. Before you decide whether to take part or not, please carefully read through the following information sheet which states what participation would involve. Feel free to talk with others about the study (e.g., friends, family, etc.) before making your decision. If anything is unclear or you have any questions, please contact me on the above email.

Who am I?

Hello! My name is Gauri Joshi. I am a student in the School of Psychology at the University of East London (UEL) and am studying a Professional Doctorate course in Counselling Psychology. As part of my course, I am conducting a research study that you are being invited to participate in.

What is a research study?

A research study helps us understand new things about a particular topic. This can be done through many ways, such as interviews or surveys. Information from such interviews or surveys is then analysed by the researcher, and the results are written up. Results from research may be helpful for others (e.g., academicians, clinicians, policy makers and general public). For example, clinicians can use research results to improve how they deliver care to people.

What research am I doing, and what is the purpose of it?

My research study focuses on identity development in adolescents who have chronic pain. In other words, I am interested in understanding how you make sense of your identity. Your identity can include the thoughts and feelings you have about yourself, the groups you belong to, and your role in different relationships (e.g., friendship). I want to do this research study *with* you, and I would like to understand your unique experiences, views and feelings related to your identity.

I am doing this research because identity development can be important for our overall wellbeing. Our identity usually starts developing during the period of adolescence (the ages between 10 to 24 years). The development of our identity can be influenced by many things, including long-term health conditions such as chronic pain. However, we currently do not know much about how identity develops in adolescents who have chronic pain. Doing research about this topic can be helpful because psychological therapy for long-term health conditions usually involves making sense of your own identity. As a result, this research can help in creating age-appropriate psychological therapy/support for adolescents who experience chronic pain.

Why have I been invited to take part?

To address the goals of my research study, I am inviting adolescents who have chronic pain to participate. If you are between the ages of 14 to 18 years and have been diagnosed with chronic pain, you are eligible to participate in this research study. Remember, it is entirely up to you whether you take part or not, and it is okay to say 'No'.

If you are aged 16 and above, you can provide your consent to participate in the study independently. However, you are still encouraged to let your parent/guardian know that you are participating in this research study. If you are below the age of 16 years, then I will need your approval as well as your parent/guardian's consent for you to participate in this research study.

What will I be asked to do if I choose to take part?

If you agree to take part, you will be asked to participate in an online interview with me. This interview will be like an informal chat, and I will be asking you some questions about your experiences of living with chronic pain, and the thoughts/feelings about yourself in light of your chronic pain condition. Please remember that there are no right or wrong answers to these questions, and I am interested to know your unique experiences, feelings and views. It is also okay for you to say 'No' for answering a particular question. We will be having this interview on Microsoft Teams (videocall), and the interview will be audio recorded. It can take around 60 minutes to complete the interview. If you feel a little tired, we can also take short breaks between the interview according to your preference.

I understand that your parent/guardian may want to be present when we have the interview, or you may want your parent/guardian to be there during the interview. In this case, I will agree with your views and wishes regarding your parent/guardian's presence for the interview. Once we complete the interview, I would like to offer you a £10 Amazon voucher to thank you for your time for participating in this research. This voucher will be sent to you via the email that you/your parent/guardian used to contact me. You can also participate in the research study without opting to receive the voucher.

Can I change my mind?

Yes, you can change your mind later and withdraw from the research study without explanation, disadvantage or consequence. If you would like to withdraw before we have had the interview, you or your parent/guardian can contact me on the email provided at the top of this information sheet. You can also choose to withdraw during the interview. To do this, you can let me know at any time that you want to stop the interview. We will then stop the interview, and you do not need to provide me with a reason for withdrawing. If you withdraw, your audio interview recording and data will not be used as part of the research.

Separately, you can also request to withdraw your data from being used even after we have had the interview. If you would like to do this, you or your parent/guardian can email me within 3 weeks after we have had the interview (after which point the data analysis will begin, and withdrawal will not be possible). Please remember that it is okay to withdraw, and this will have no impact on the care you might be receiving from the charity. No one will be upset if you choose to withdraw.

Are there any disadvantages to taking part?

- Because this research study focuses on your identity and experiences of living with chronic pain, you may feel slightly upset whilst talking about your experiences during or after the interview. If you do feel upset during the interview, you can say 'No' for answering a particular question or let me know that you would like to stop the interview at any point. After the interview, I will provide you with an information sheet which will have contact details for support organisations if you need to get in touch with them.

- If your parent/guardian is present during the interview, they may feel slightly upset as they listen to your experiences. In this case, I will be providing a separate information sheet to your parent/guardian after the interview, which will contain contact details of support organisations.

How will my information be kept secure and confidential?

The research study data includes your personal information (name, age etc.), your consent form, the interview audio recording, and interview transcripts (the word-to-word write-up of what we spoke about in the interview). I will be taking the following steps to ensure that all data is kept secure:

- You will not be identified through the data collected, through any material created through the data, or when I write up this research study. In other words, this means that no one will be able to identify 'you' through any material that is produced in this research study.
- When I write a transcript of our interview, identifying information (e.g., your name, names of locations and names of other people) will be changed, so that your identity remains protected. This is called **anonymisation**.
- Consent forms will be stored securely in separate password protected files on my UEL OneDrive, for a three-week period. Only I will have access to this data. After the three-week period, consent forms will be deleted unless we have previously agreed that you would like to receive an update from me about the results of this research study.
- Audio recording of our interview will be transferred and stored on UEL's password protected OneDrive, and only I will have access to these. These recordings will be deleted after I complete transcribing the interview.
- When I transcribe the audio recording, your name, names of locations and names of other people will be changed. This will ensure that your identity remains protected. These transcripts will be stored in UEL's password-protected OneDrive, and only I will have access to these. These transcripts will be backed up on my supervisor's (Dr. Hannah Sela) UEL password protected OneDrive.
- When I write up my thesis, these anonymised transcripts will be included in the thesis (as it is a requirement of my course) so my examiners will have access to them. I may also use short quotes or sentences from our interview when I write the findings of the research study in my thesis. These quotes or sentences will be anonymised, which means that it will not be possible for anyone to identify you personally.
- Anonymised transcripts will be stored on my supervisors' password-protected OneDrive for three years, after which this data will be destroyed or deleted.

For the purposes of data protection, the University of East London is the Data Controller for the personal information processed as part of this research project. The University processes this information under the ‘public task’ condition contained in the General Data Protection Regulation (GDPR). Where the University processes particularly sensitive data (known as ‘special category data’ in the GDPR), it does so because the processing is necessary for archiving purposes in the public interest, or scientific and historical research purposes or statistical purposes. The University will ensure that the personal data it processes is held securely and processed in accordance with the GDPR and the Data Protection Act 2018. For more information about how the University processes personal data please see www.uel.ac.uk/about/about-uel/governance/information-assurance/data-protection

What will happen to the results of the research?

The research study will be written up as a thesis and submitted for assessment. The thesis will be publicly available on UEL’s online Repository (https://repository.uel.ac.uk/). Findings of this research (which may include short, **anonymised** quotes/sentences from the interview) may also be shared with academics, clinicians, chronic pain charities, or other adolescents who have chronic pain. These findings will be shared through journal articles, blogs or conference presentations. When these findings are shared, your identity will remain anonymous, which means that it will not be possible to identify you personally. Personal information such as names, locations and names of other people will be removed or changed.

You will be given the option to receive a summary of the research findings once the study has been completed, for which relevant contact details will need to be provided.

Who has approved the research?

My research has been approved by the School of Psychology Ethics Committee. This means that the Committee’s evaluation of this ethics application has been guided by the standards of research ethics set by the British Psychological Society.

Who can I contact if I have any questions/concerns?

If you would like further information about my research or have any questions or concerns, please do not hesitate to contact me.

Gauri Joshi
u2042426@uel.ac.uk

If you have any questions or concerns about how the research has been conducted, please contact my research supervisors Dr. Hannah Sela and Professor Rachel Tribe. School of Psychology, University of East London, Water Lane, London E15 4LZ,
Email: Dr. Hannah Sela h.sela@uel.ac.uk
Professor Rachel Tribe: r.tribe@uel.ac.uk

or

Chair of School Ethics Committee: Dr Trishna Patel, School of Psychology, University of East London, Water Lane, London E15 4LZ.
(Email: t.patel@uel.ac.uk)

Important things to keep in mind:

- It is your decision to take part or not.
- You can say ‘No’ or you can say ‘Yes’.
- No one will be upset if you say ‘No’.
- If you say ‘Yes’, you can always say ‘No’ later. For example, if you have decided to take part, you can still say ‘No’ during the interview.

If you think you require additional support, below is a list of resources you might find helpful:

Mental health support (organisations which provide confidential support for any kind of issue you might be going through):

- **Childline** (open 24 hours, every day)
  Telephone: 0800 1111
  Website: https://www.childline.org.uk/get-support/contacting-childline/
- **The Mix**
  Telephone: 0808 808 4994 (open from 4 pm to 11 pm, Monday to Friday)
  Email form: https://www.themix.org.uk/get-support/speak-to-our-team/email-us
- **Shout** (open 24 hours, 7 days a week)
  Send a text saying ‘SHOUT’ on: 85258
- **CALM**
  Telephone: 0800 585858 (open 5 pm to 12 am, every day)
  Webchat: https://www.thecalmzone.net/get-support (open 5 pm to 12 am, every day)
- **Samaritans**
  Telephone: 116 123 (open 24 hours, every day)
  Email: jo@samaritans.org

Support for talking about chronic pain in a safe space:

- **Pain concern**
  Telephone: 0300 123 0789 (call at any time and leave a message with your phone number/email, and someone from the team will contact you in the next working day)
  Email: help@painconcern.org.uk
- **Shout** (open 24 hours, 7 days a week)
  Send a text saying 'SHOUT' on: 85258
- **Action on Pain**
  Telephone: 03456031593 (open between 10 am to 4 pm, Monday to Friday)
  Email: aopisat@btinternet.com
- **Fibromyalgia Action UK**
  Telephone: 0300 999 3333 (open between 10 am to 4 pm, Monday to Friday)

In an emergency, please call 999.

Thank you for taking the time to read this information sheet.

☺

PARENT/GUARDIAN INFORMATION SHEET

Exploring Identity Development in Adolescents with Chronic Pain

Contact person: Gauri Joshi
Email: u2042426@uel.ac.uk

Your child is being invited to participate in a research study. Before deciding with your child if he/she/they would like to take part or not, please carefully read through the following information which outlines what your participation would involve. Feel free to talk with others about the study (e.g., friends, family, etc.) before making your decision. If anything is unclear or you have any questions, please do not hesitate to contact me on the above email.

Who am I?

My name is Gauri Joshi. I am a Doctorate student in the School of Psychology at the University of East London (UEL) and am undertaking a Professional Doctorate course in Counselling Psychology. As part of my course, I am conducting a research study that your child is being invited to participate in.

What is the purpose of the research?

My research aims to understand how adolescents with chronic pain make sense of their identity (e.g., thoughts and/or feelings about themselves, the groups they belong to, and their role in different relationships such as friendships). Identity development usually begins during adolescence and is considered important for one's overall wellbeing. Several factors may influence one's identity, such as gender, culture, and long-term health conditions like chronic pain. However, we currently know little about how identity develops in adolescents who have chronic pain. Research into this area can be helpful to tailor age-appropriate psychological interventions or support for adolescents who have chronic pain, as psychological therapy for long-term health conditions generally involves making sense of one's identity.

Why has your child been invited to take part?

To address the aims of my research, I am inviting adolescents with chronic pain to take part in my research. If your child is between the ages of 14 to 18 years and has been diagnosed with chronic pain, he/she/they are eligible to take part in the research. If your child is below the age of 16 years, your consent as well as your child's assent to participate in the study will be required.

What will my child be asked to do if I provide consent for him/her/them to participate?

If you are happy for your child to take part in the research, he/she/they will be invited to participate in an online interview with me. The interview will be like an informal chat, and your child will be asked questions regarding their experience of living with chronic pain, and the thoughts/feelings they have about themselves in light of their chronic pain condition. There is no right or wrong answer to these questions, and the unique viewpoint of your child is valued and encouraged. Your child can also say 'no' for answering a particular question. This interview will be conducted on Microsoft Teams and will be audio-recorded. It will take approximately 60 minutes to complete the interview. Keeping your child's chronic pain in mind, we can take short breaks between the interview if your child requires them. I understand that you may want to be present during the interview, or your child may wish for you to be present. In this case, I will respect and agree the wishes of your child and the interview will be set up accordingly. After the completion of the interview, your child will be offered a £10 Amazon voucher to thank him/her/them for taking part in the research. The voucher will be sent on the email address that was used to contact me.

Can my child change his/her/their mind?

Yes, your child can change your mind later and withdraw from the research study without explanation, disadvantage or consequence. If you or your child would like to withdraw before we have had the interview, you or your child can contact me on the email provided at the top of this information sheet. Your child can also withdraw during the interview. If your child wishes to withdraw during the interview, he/she/they can do so by letting me know that they want to stop the interview. This will have no impact on the care and support offered by the charity. If your child chooses to withdraw, their data will not be used as part of the research.

Separately, you or your child can also request to withdraw his/her/their data after the completion of the interview. However, this request will need to be made within 3 weeks after we have completed the interview (after which point the data analysis will begin, and withdrawal will not be possible).

Are there any disadvantages to taking part?

  - This research and the interview focus on identity and the experience of living with chronic pain. As we will be talking about such experiences in the interview, your child may experience some emotional/psychological distress during or after the interview. To manage this, your child will be reminded before the interview that he/she/they can say ‘no’ for answering particular questions, or stop the interview at any time point. After the interview, your child will also be provided with a debrief sheet which contains contact information of support agencies.
  - If your child wishes for you to be present during the interview, you may experience some emotional/psychological distress whilst listening to your child’s experiences. To manage this, you will be provided with a separate debrief sheet with contact information of support agencies.

How will the information my child and I provide be kept secure and confidential?

- Your child will not be identified by the data collected, or through any material created through the data collected, or through the write-up of this research. Personal details such as names, locations, and names of others will be pseudonymised or changed. Personal details will be stored on UEL’s password protected OneDrive, and will be destroyed after 3 weeks of data collection/completion of interviews.
- Consent forms will be stored securely in separate password protected files on my UEL OneDrive, for a three-week period. Only I will have access to this data. After the 3 week period, consent forms will be deleted unless there is a prior agreement made with you to receive an update from me on the outcomes of the research.
- Audio recordings of the interview will be transferred from an external audio recording device to UEL’s password protected OneDrive and will be stored there. Only I will have access to these recordings. These recordings will be deleted after the interviews have been transcribed.
- All audio recordings will be transcribed, and your child’s name, names of locations and names of other people will be pseudonymised or changed during this process. These transcripts will be stored in my UEL’s password-protected OneDrive, and only I will have access to these. This data will be backed up on my supervisor’s (Dr. Hannah Sela) UEL password protected OneDrive.
- When I write up my thesis and submit it for assessment, my examiners will have access to the anonymised transcripts (as including anonymised transcripts in the thesis is a requirement of my course). In the write up of my thesis, I may include short, anonymised quotes from the interview. These quotes will be anonymised and it will not be possible to identify your child personally.
- Anonymised transcripts will be stored on my supervisor, Dr. Hannah Sela’s password-protected OneDrive for three years, after which this data will be destroyed or deleted.

For the purposes of data protection, the University of East London is the Data Controller for the personal information processed as part of this research project. The University processes this information under the ‘public task’ condition contained in the General Data Protection Regulation (GDPR). Where the University processes particularly sensitive data (known as ‘special category data’ in the GDPR), it does so because the processing is necessary for archiving purposes in the public interest, or scientific and historical research purposes or statistical purposes. The University will ensure that the personal data it processes is held securely and processed in accordance with the GDPR and the Data Protection Act 2018. For more information about how the University processes personal data please see www.uel.ac.uk/about/about-uel/governance/information-assurance/data-protection.

What will happen to the results of the research?
The research will be written up as a thesis and submitted for assessment. The thesis will be publicly available on UEL’s online Repository (https://repository.uel.ac.uk/). Findings of this research (which may include short, **anonymised** quotes from the interview) may also be shared to academics, clinicians, chronic pain charities, or other adolescents with chronic pain through journal articles, blogs or conference presentations. When these findings are shared, your child’s identity will remain **anonymous,** which means that it will not be possible to identify your child personally. Personal information such as names, locations and names of other people will be removed or changed.

You will be given the option to receive a summary of the research findings once the study has been completed, for which relevant contact details will need to be provided.

Who has reviewed the research?
My research has been approved by the School of Psychology Ethics Committee. This means that the Committee’s evaluation of this ethics application has been guided by the standards of research ethics set by the British Psychological Society.

Who can I contact if I have any questions/concerns?
If you would like further information about my research or have any questions or concerns, please do not hesitate to contact me.

Gauri Joshi
u2042426@uel.ac.uk

If you have any questions or concerns about how the research has been conducted, please contact my research supervisors Dr. Hannah Sela and Professor Rachel Tribe. School of Psychology, University of East London, Water Lane, London E15 4LZ,
Email: Dr. Hannah Sela h.sela@uel.ac.uk
Professor Rachel Tribe: r.tribe@uel.ac.uk

or

Chair of School Ethics Committee: Dr Trishna Patel, School of Psychology, University of East London, Water Lane, London E15 4LZ.
(Email: t.patel@uel.ac.uk)

If you require any additional support, below is a list of resources you might find helpful:

Mental health support (organisations which provide confidential support for any kind of issue you might be going through):

- **The Mix**
  Telephone: 0808 808 4994 (open from 4 pm to 11 pm, Monday to Friday)
  Email form: https://www.themix.org.uk/get-support/speak-to-our-team/email-us
- **Shout** (open 24 hours, 7 days a week)
  Send a text saying 'SHOUT' on: 85258
- **CALM**
  Telephone: 0800 585858 (open 5 pm to 12 am, every day)
  Webchat: https://www.thecalmzone.net/get-support (open 5 pm to 12 am, every day)
- **Samaritans**
  Telephone: 116 123 (open 24 hours, every day)
  Email: jo@samaritans.org

Chronic pain related support (as a parent/guardian of an adolescent who has chronic pain)

- **Pain concern**
  Telephone: 0300 123 0789 (call at any time and leave a message with your phone number/email, and someone from the team will contact you in the next working day)
  Email: help@painconcern.org.uk

Thank you for taking the time to read this information sheet.

Appendix C – Research Advertisement (Adolescents and Parent/Guardian)

University of East London

Invitation to Participate in a Research Study

Hello! My name is Gauri Joshi, and I am undertaking a professional doctorate course in counselling psychology at the University of East London.

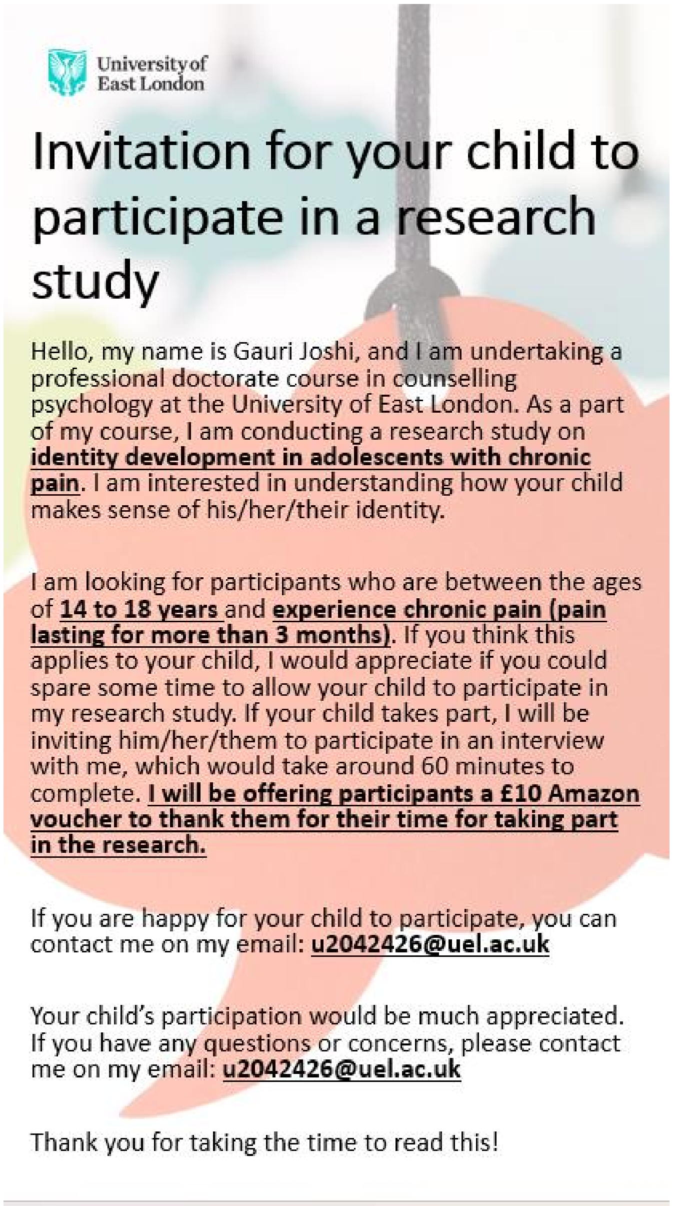
As a part of my course, I am conducting a research study on **identity development in adolescents with chronic pain**. I am interested in understanding how you make sense of your identity. Your identity can include the thoughts and feelings you have about yourself, the groups you belong to, and your role in different relationships (e.g., friendship).

I am looking for **participants** who are between the **ages of 14 to 18 years** and **experience chronic pain (pain lasting for more than 3 months)**. If you think this applies to you, I would appreciate if you could spare some time to participate in my research study. If you take part, I will be inviting you to participate in an interview with me, which would take around 60 minutes to complete. **To thank you for your time, I will be offering a £10 Amazon voucher.**

If you wish to participate, you or your parent/guardian can contact me on my email: **u2042426@uel.ac.uk**

Your participation would be much appreciated. If you or your parent/guardian have any questions or concerns, please contact me on my email: **u2042426@uel.ac.uk**

Thank you for taking the time to read this!



University of East London

Invitation for your child to participate in a research study

Hello, my name is Gauri Joshi, and I am undertaking a professional doctorate course in counselling psychology at the University of East London. As a part of my course, I am conducting a research study on **identity development in adolescents with chronic pain**. I am interested in understanding how your child makes sense of his/her/their identity.

I am looking for participants who are between the ages of **14 to 18 years** and **experience chronic pain (pain lasting for more than 3 months)**. If you think this applies to your child, I would appreciate if you could spare some time to allow your child to participate in my research study. If your child takes part, I will be inviting him/her/them to participate in an interview with me, which would take around 60 minutes to complete. **I will be offering participants a £10 Amazon voucher to thank them for their time for taking part in the research.**

If you are happy for your child to participate, you can contact me on my email: **u2042426@uel.ac.uk**

Your child's participation would be much appreciated. If you have any questions or concerns, please contact me on my email: **u2042426@uel.ac.uk**

Thank you for taking the time to read this!

Appendix D – Consent Form Templates (Adolescent Above 16 years Consent Form, Parent/Guardian Consent Form, Adolescent Below 16 years Assent Form)

CONSENT TO PARTICIPATE IN A RESEARCH STUDY – Adolescent (16 years and above)

Exploring Identity Development in Adolescents with Chronic Pain
Contact person: Gauri Joshi
Email: u2042426@uel.ac.uk

	Please initial
I confirm that I have read the participant information sheet dated 05/12/2023 (version 4) for the above study and that I have been given a copy to keep.	
I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
I understand that my participation in the study is voluntary and that I may withdraw at any time, without explanation or disadvantage.	
I understand that if I withdraw during the study, my data will not be used.	
I understand that I have 3 weeks from the date of the interview to withdraw my data from the study.	
I understand that the interview will be audio recorded on Microsoft Teams.	
I understand that my personal information and data, including audio recordings from the research will be securely stored and remain confidential. Only the research team will have access to this information, to which I give my permission.	
It has been explained to me what will happen to the data once the research has been completed.	
I understand that short, anonymised quotes from my interview data may be used in material such as conference presentations, reports, articles in academic journals resulting from the study and that these will not personally identify me.	
I would like to receive a summary of the research findings once the study has been completed and am willing to provide contact details for this to be sent to.	

I would like to receive a £10 Amazon voucher after completion of the interview, and I agree to receive this via email.	
I agree to take part in the above study.	

Participant’s Name (BLOCK CAPITALS)

………

Participant’s Signature

………

Researcher’s Name (BLOCK CAPITALS)

………

Researcher’s Signature

………

Date

………

CONSENT FOR ADOLESCENT TO PARTICIPATE IN A RESEARCH STUDY – Parent/Guardian

Exploring Identity Development in Adolescents with Chronic Pain
Contact person: Gauri Joshi
Email: u2042426@uel.ac.uk

	Please initial
I confirm that I have read the participant information sheet dated 05/12/2023 (version 4) for the above study and that I have been given a copy to keep.	
I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
I understand that my child's participation in the study is voluntary and that my child may withdraw at any time, without explanation or disadvantage.	
I understand that if my child withdraws during the study, his/her/their data will not be used.	
I understand that my child has 3 weeks from the date of the interview to withdraw his/her/their data from the study.	
I understand that the interview will be audio recorded using Microsoft Teams.	
I understand that my child's personal information and data, including audio recordings from the research will be securely stored and remain confidential. Only the research team will have access to this information, to which I give my permission.	
It has been explained to me what will happen to the data once the research has been completed.	
I understand that short, anonymised quotes from my child's interview data may be used in material such as conference presentations, reports, articles in academic journals resulting from the study and that these will not personally identify my child.	

I would like to receive a summary of the research findings once the study has been completed and am willing to provide contact details for this to be sent to.	
I would like my child to receive a £10 Amazon voucher after completion of the interview, and I agree to receive this via email.	
I agree to let my child take part in the above study.	

Adolescent’s Name (BLOCK CAPITALS)

………

Parent/Guardian’s Name (BLOCK CAPITALS)

………

Parent/Guardian’s Signature

………

Researcher’s Name (BLOCK CAPITALS)

………

Researcher’s Signature

………

Date

………

ASSENT FORM FOR ADOLESCENT TO PARTICIPATE IN A RESEARCH STUDY – Adolescent (Between the ages 14-16 years)

Exploring Identity Development in Adolescents with Chronic Pain
Contact person: Gauri Joshi
Email: u2042426@uel.ac.uk

	Please type 'Yes' or 'No'
I have read the participant information sheet for this study, and I have been given a copy to keep.	
I have asked any questions that I might have, and my questions have been answered in a way that I can understand.	
I understand that it is up to me if I want to participate in this study and I can withdraw or say 'No' at any time, without explanation or disadvantage.	
I understand that if I withdraw during the study, my data will not be used.	
I understand that I have 3 weeks from the date of the interview to withdraw my data from the study.	
I understand that my interview will be audio recorded using Microsoft Teams.	
I understand that my personal information and data, including audio recordings from the research will be securely stored and remain confidential. Only the research team will have access to this information, to which I give my permission.	
It has been explained to me what will happen to the data once the research has been completed.	
I understand that that short, anonymised quotes from my interview may be used in material like conference presentations, reports and articles in	

academic journals. I understand that these quotes will be anonymised, which means that my personal identity will be protected.	
I would like to receive a summary of the research findings once the study has been completed and am willing to provide contact details for this to be sent to.	
I would like to receive a £10 Amazon voucher after completion of the interview, and I agree to receive this via email.	
I am happy to take part in the above study.	
I would like my parent/guardian to be present during the interview.	

<u>Please don't sign your name if you don't want to take part or if you answered 'NO' to any one question!</u>

Please type your name and today's date if you want to take part.

Your name:	
Today's date:	

Your parent / legal guardian must also sign this form:

Parent / guardian full name:	
Parent / guardian signature:	
Today's date:	

The researcher who explained the study to you must also sign this form:

Researcher's Name:	
Researcher's signature:	

Today’s date:	

Appendix E – Ethics Amendments (All Versions)

School of Psychology Ethics Committee

REQUEST FOR AMENDMENT TO AN ETHICS APPLICATION

For BSc, MSc/MA and taught Professional Doctorate students

Please complete this form if you are requesting approval for proposed amendment(s) to an ethics application that has been approved by the School of Psychology

Note that approval must be given for significant change to research procedure that impact on ethical protocol. If you are not sure as to whether your proposed amendment warrants approval, consult your supervisor or contact Dr Trishna Patel (Chair of the School Research Ethics Committee).

How to complete and submit the request

1	Complete the request form electronically.
2	Type your name in the 'student's signature' section (page 2).
3	When submitting this request form, ensure that all necessary documents are attached (see below).
4	Using your UEL email address, email the completed request form along with associated documents to Dr Trishna Patel: t.patel@uel.ac.uk
5	Your request form will be returned to you via your UEL email address with the reviewer's decision box completed. Keep a copy of the approval to submit with your dissertation.
6	Recruitment and data collection are **not** to commence until your proposed amendment has been approved.

Required documents

A copy of your previously approved ethics application with proposed amendment(s) added with track changes.	**YES** Note: Sections where changes are made have been highlighted in blue.

	☒
Copies of updated documents that may relate to your proposed amendment(s). For example, an updated recruitment notice, updated participant information sheet, updated consent form, etc.	**YES** ☒
A copy of the approval of your initial ethics application.	**YES** ☒

Details

Name of applicant:	**Gauri Rajiv Joshi**
Programme of study:	**Professional doctorate in Counselling psychology**
Title of research:	**A Phenomenological Exploration of Identity Development in Adolescents with Chronic Pain**
Name of supervisor:	**Dr. Sharon Cahill**

Proposed amendment(s)

Briefly outline the nature of your proposed amendment(s) and associated rationale(s) in the boxes below

Proposed amendment	**Rationale**
Section 2.3: Changed to 'to be confirmed'.	Additional supervisor Dr. Vanessa Contreras-Negretti has left UEL. The Director of Research has mentioned that I will be notified once a new DoS has been allocated.
Section 4.2: Changed 'video' recording to 'audio' recording.	Change suggested by supervisor, in order to protect the identity of vulnerable participants and reduce the size of the recording file.
Section 4.5: Changed that interviews will be audio recorded, and transferred to UEL's password protected One Drive.	Change suggested by supervisor, in order to protect the identity of vulnerable participants and reduce the size of the recording file.
Parent and adolescent information sheets: Changed video recording to audio recording in the parts that are highlighted in blue.	Change suggested by supervisor, in order to protect the identity of vulnerable participants and reduce the size of the recording file.
Parent and adolescent consent forms: Changed video recording to audio recording in the parts that are highlighted in blue.	Change suggested by supervisor, in order to protect the identity of vulnerable participants and reduce the size of the recording file.

Risk assessment form (section about activity description): changed video recording to audio recording in the part that is highlighted in blue.	Change suggested by supervisor, in order to protect the identity of vulnerable participants and reduce the size of the recording file.
Parent and adolescent participant information sheet: Removed Dr. Vanessa Contreras-Negretti's name and contact details as my supervisor. Changed parts are highlighted in blue.	Change made as supervisor is no longer working at UEL.
Parent and adolescent debrief sheet: Removed Dr. Vanessa Contreras-Negretti's name and contact details as my supervisor. Changed parts are highlighted in blue.	Change made as supervisor is no longer working at UEL.
Appendix E: Research Advert. UEL's logo/symbol has been added to the advertisement.	UEL's logo had not been added to the advertisement previously. Having a logo increases the credibility of the advertisement.

Confirmation

Is your supervisor aware of your proposed amendment(s) and have they agreed to these changes?	**YES** ☒	**NO** ☐

Student's signature

Student: (Typed name to act as signature)	**Gauri Rajiv Joshi**
Date:	**12/10/2023**

Reviewer's decision

Amendment(s) approved:	**YES** ☒	**NO** ☐
Comments:	**Please ensure an updated DMP is submitted for review to include audio recordings via an external device before transfer to your UEL OneDrive.**	
Reviewer: (Typed name to act as signature)	**Trishna Patel**	

Date:	**17/10/2023**

University of East London

School of Psychology Ethics Committee

REQUEST FOR AMENDMENT TO AN ETHICS APPLICATION

For BSc, MSc/MA and taught Professional Doctorate students

Please complete this form if you are requesting approval for proposed amendment(s) to an ethics application that has been approved by the School of Psychology

Note that approval must be given for significant change to research procedure that impact on ethical protocol. If you are not sure as to whether your proposed amendment warrants approval, consult your supervisor or contact Dr Trishna Patel (Chair of the School Research Ethics Committee).

How to complete and submit the request

1	Complete the request form electronically.
2	Type your name in the 'student's signature' section (page 2).
3	When submitting this request form, ensure that all necessary documents are attached (see below).
4	Using your UEL email address, email the completed request form along with associated documents to Dr Trishna Patel: t.patel@uel.ac.uk
5	Your request form will be returned to you via your UEL email address with the reviewer's decision box completed. Keep a copy of the approval to submit with your dissertation.
6	Recruitment and data collection are **not** to commence until your proposed amendment has been approved.

Required documents

A copy of your previously approved ethics application with proposed amendment(s) added with track changes.	**YES** Note: Sections where changes are made have been highlighted in blue. ☒
Copies of updated documents that may relate to your proposed amendment(s). For example, an updated recruitment notice, updated participant information sheet, updated consent form, etc.	**YES** ☒

A copy of the approval of your initial ethics application.	**YES** ☒

Details	
Name of applicant:	**Gauri Rajiv Joshi**
Programme of study:	**Professional doctorate in Counselling psychology**
Title of research:	**A Phenomenological Exploration of Identity Development in Adolescents with Chronic Pain**
Name of supervisor:	**Dr. Hannah Sela and Professor Rachel Tribe**

Proposed amendment(s)

Briefly outline the nature of your proposed amendment(s) and associated rationale(s) in the boxes below

Proposed amendment	Rationale
Section 2.2: Supervisor's name changed to Dr. Hannah Sela.	Dr. Hannah Sela has been allocated as my new supervisor after Dr. Vanessa Contreras-Negretti has left UEL.
Section 2.3: Additional supervisor's name changed to Professor Rachel Tribe.	Professor Rachel Tribe has been allocated as my new secondary supervisor.
Section 3.6: Recruitment Strategy. The following has been added: Participants will be recruited from chronic pain charities such as Pain Concern, Fibromyalgia Action UK, Burning Nights CRPS, Pain UK, The Brain Charity and FlippinPain. Participants will also be recruited from online chronic pain forums/support groups such as Reddit and Scope. The research advertisement (Appendix E) may be posted on these forums' social media such as Twitter, Facebook, Instagram and possibly on their website. A message or an email will be sent to these forums to ask if they could advertise the study.	This change has been to aid participant recruitment, so that the research advertisement can reach a wider group of adolescents with chronic pain and/or their parents. In addition to charities for chronic pain, adolescents may also seek support or talk about their chronic pain through online forums.
Section 4.4: Data storage and Backup	This change will further protect the security of data.

Instead of backing up anonymised data in an external hard-drive, data will now be backed up on my supervisor's UEL OneDrive account.	
Section 4.6 and 4.7: Long term retention of data. Changed supervisor's name to Dr. Hannah Sela.	Dr. Hannah Sela will be storing data of long-term value in her password protected UEL OneDrive account, as she is my new supervisor.
Parent and adolescent information sheets and debrief sheets: Changed the contact details of my supervisors to Dr. Hannah Sela and Professor Rachel Tribe.	Change made as previous supervisors, Dr. Vanessa Contreras-Negretti and Dr. Sharon Cahill no longer work at UEL.
Appendix E: Research advert (adolescents and parents) Changed the sentence "diagnosed with chronic pain" to "experience chronic pain (pain lasting for more than 3 months)".	This change has been made for the following reasons: 1. The word 'experience' may be more appropriate as pain can be a subjective experience i.e., pain is felt inside one's body and may not be visible externally (Ojala et al., 2015). 2. Research suggests the presence of diagnostic uncertainty in the area of adolescent chronic pain (Neville et al., 2019). Further, receiving a chronic pain diagnosis can take time (Eccleston & Malleson, 2003 & Palermo et al., 2019). Hence, using the words 'experience chronic pain' may help in reaching a wider group of adolescents with chronic pain.
Appendix A (proof of permission from charities/organisations for recruitment): Two new charities/organisations added (The Brain Charity and FlippinPain).	This change has been made to help with participant recruitment and reach a wider group of adolescents who have chronic pain.
Parent and adolescent information sheets: Information about data backup has been changed to reflect the changes made in section 4.4 of the Ethics Application Form. Anonymised data will be backed up on supervisor's UEL OneDrive.	Change made to reflect how data will be stored and backed up. This change will protect the security of data.

Consent form: Changed the version and date of participant information sheet.	Change made to reflect the updated date and version of participant information sheet.

References

Eccleston, C., & Malleson, P. (2003). Managing chronic pain in children and adolescents. *BMJ*, *326*(7404), 1408-1409.

Neville, A., Jordan, A., Beveridge, J. K., Pincus, T., & Noel, M. (2019). Diagnostic uncertainty in youth with chronic pain and their parents. *The Journal of Pain*, *20*(9), 1080-1090.

Ojala, T., Häkkinen, A., Karppinen, J., Sipilä, K., Suutama, T., & Piirainen, A. (2015). Chronic pain affects the whole person–a phenomenological study. *Disability and Rehabilitation*, *37*(4), 363-371.

Palermo, T. M., Slack, M., Zhou, C., Aaron, R., Fisher, E., & Rodriguez, S. (2019). Waiting for a pediatric chronic pain clinic evaluation: a prospective study characterizing waiting times and symptom trajectories. *The Journal of Pain*, *20*(3), 339-347.

Confirmation

Is your supervisor aware of your proposed amendment(s) and have they agreed to these changes?	**YES** ☒	**NO** ☐

Student's signature

Student: (Typed name to act as signature)	**Gauri Rajiv Joshi**
Date:	**20/11/2023**

Reviewer's decision

Amendment(s) approved:	**YES** ☒	**NO** ☐
Comments:	**4.4. data storage and backup: what is the location of the locked filing cabinet that anonymised transcripts will be stored in? Please ensure they are stored at UEL. 4.7 long term retention of data: still names Sharon Cahill, please replace with new supervisor.**	

Reviewer: (Typed name to act as signature)	**Trishna Patel**
Date:	**21/11/2023**

School of Psychology Ethics Committee

REQUEST FOR AMENDMENT TO AN ETHICS APPLICATION

For BSc, MSc/MA and taught Professional Doctorate students

Please complete this form if you are requesting approval for proposed amendment(s) to an ethics application that has been approved by the School of Psychology

Note that approval must be given for significant change to research procedure that impact on ethical protocol. If you are not sure as to whether your proposed amendment warrants approval, consult your supervisor or contact Dr Trishna Patel (Chair of the School Research Ethics Committee).

How to complete and submit the request

1	Complete the request form electronically.
2	Type your name in the 'student's signature' section (page 2).
3	When submitting this request form, ensure that all necessary documents are attached (see below).
4	Using your UEL email address, email the completed request form along with associated documents to Dr Trishna Patel: t.patel@uel.ac.uk
5	Your request form will be returned to you via your UEL email address with the reviewer's decision box completed. Keep a copy of the approval to submit with your dissertation.
6	Recruitment and data collection are **not** to commence until your proposed amendment has been approved.

Required documents

A copy of your previously approved ethics application with proposed amendment(s) added with track changes.	**YES** Note: Sections where changes are made have been highlighted in blue. ☒

Copies of updated documents that may relate to your proposed amendment(s). For example, an updated recruitment notice, updated participant information sheet, updated consent form, etc.	**YES** ☒
A copy of the approval of your initial ethics application.	**YES** ☒

Details

Name of applicant:	**Gauri Rajiv Joshi**
Programme of study:	**Professional doctorate in Counselling psychology**
Title of research:	**A Phenomenological Exploration of Identity Development in Adolescents with Chronic Pain**
Name of supervisor:	**Dr. Hannah Sela and Professor Rachel Tribe**

Proposed amendment(s)

Briefly outline the nature of your proposed amendment(s) and associated rationale(s) in the boxes below

Proposed amendment	**Rationale**
Section 3.5 (Participants) Changed inclusion criteria wording from ‘diagnosed with chronic pain’ to ‘experience chronic pain’.	The proposed change had been made for the research advertisement in Version 2 of Ethics Amendment Form (and was approved). However, this had not been corrected/changed in Section 3.5 of the Ethics Form. Rationale for changing the word ‘diagnosed’ to ‘experience’ chronic pain: 1. The word ‘experience’ may be more appropriate as pain can be a subjective experience i.e., pain is felt inside one’s body and may not be visible externally (Ojala et al., 2015). 2. Research suggests the presence of diagnostic uncertainty in the area of adolescent chronic pain (Neville et al., 2019). Further, receiving a chronic pain diagnosis can take time (Eccleston & Malleson, 2003 & Palermo et al., 2019).

	Hence, using the words ‘experience chronic pain’ may help in reaching a wider group of adolescents with chronic pain.
Section 3.6 (Recruitment Strategy) The following source of recruitment has been added: “Participants can also be recruited through Instagram based chronic pain influencers. A separate research-based Instagram account will be made for this. Such influencers will be contacted to post the research advert on their page.”	This change has been made to reach the target population, as recruitment with adolescents has been challenging. Recent evidence suggests that adolescents prefer being recruited through social media platforms, specifically Instagram (Jong et al., 2023).
Section 3.10 (Will participants be reimbursed?) Changed from ‘No’ to ‘Yes’. Provided rationale. 10 pounds Amazon voucher.	As participants will be spending approximately an hour for the interview, I will be offering a 10 pounds Amazon voucher to thank them for their time. This decision has been made after careful consideration, and keeping in mind The British Psychological Society’s code of ethics (2021). For instance, the reimbursement is offered in the form of a voucher and not cash. The amount of the voucher is not that high that it undermines potential participants’ free decision to take part in the research. The amount was decided following BPS (2021) guidelines of keeping the National Minimum Wage as a baseline. In my case, participants are aged between 14 – 18 years. Minimum wage for apprentices and 16-17 years old individuals is 5.28 pounds, and 7.49 pounds for 18-20 years old individuals (U.K. Government, 2023). As the minimum wage rate is varied for my target population, the reimbursement amount has been rounded off to 10 pounds. Further, the ‘time’ taken for participants to engage in my research is not limited to interviews only, as participants also spend some time reading information sheets. Hence, 10 pounds may be appropriate for reimbursement. All participants will be offered the same amount of reimbursement.

Section 7.1 (Details of other organisations) Added the names of The Brain Charity and Flippin Pain.	The proposed change was made for recruitment strategy in Ethics Amendment Form version 2 (and was approved). However, this change/correction had not been made in Section 7.1.
Parent and adolescent information sheets: Added a sentence to state that the participant will be offered an Amazon voucher worth £10 after the completion of the interview, to thank them for their time. This voucher will be sent via the email that they used for contacting me.	This amendment has been made to reflect the changes in Section 3.10 regarding reimbursement.
Adolescent and parent consent forms Changed the date of the information sheet version to reflect the latest version.	This amendment has been made to reflect the changes in Section 3.10 regarding reimbursement.
Adolescent and parent advertisement Added a sentence to state that I will be offering a £10 Amazon voucher to thank participants for their time.	This amendment has been made to reflect the changes in Section 3.10 regarding reimbursement.

References

British Psychological Society. (2021). *BPS Code of Human Research Ethics. The British Psychological Society.* https://cms.bps.org.uk/sites/default/files/2022-06/BPS%20Code%20of%20Human%20Research%20Ethics%20%281%29.pdf

Eccleston, C., & Malleson, P. (2003). Managing chronic pain in children and adolescents. *BMJ*, *326*(7404), 1408-1409.

Jong, S. T., Stevenson, R., Winpenny, E. M., Corder, K., & van Sluijs, E. M. (2023). Recruitment and retention into longitudinal health research from an adolescent perspective: a qualitative study. *BMC Medical Research Methodology*, *23*(1), 1-13.

Neville, A., Jordan, A., Beveridge, J. K., Pincus, T., & Noel, M. (2019). Diagnostic uncertainty in youth with chronic pain and their parents. *The Journal of Pain*, *20*(9), 1080-1090.

Ojala, T., Häkkinen, A., Karppinen, J., Sipilä, K., Suutama, T., & Piirainen, A. (2015). Chronic pain affects the whole person–a phenomenological study. *Disability and Rehabilitation*, *37*(4), 363-371.

Palermo, T. M., Slack, M., Zhou, C., Aaron, R., Fisher, E., & Rodriguez, S. (2019). Waiting for a pediatric chronic pain clinic evaluation: a prospective study characterizing waiting times and symptom trajectories. *The Journal of Pain*, *20*(3), 339-347.

U.K. Government. (2023). *The National Minimum Wage in 2023.* https://www.gov.uk/government/publications/the-national-minimum-wage-in-2023/the-national-minimum-wage-in-2023

Confirmation

Is your supervisor aware of your proposed amendment(s) and have they agreed to these changes?	**YES** ☒	**NO** ☐

Student's signature

Student: (Typed name to act as signature)	**Gauri Rajiv Joshi**
Date:	**05/12/2023**

Reviewer's decision

Amendment(s) approved:	**YES** ☒	**NO** ☐
Comments:	The offer of a £10 Amazon voucher is only approved if no participants have been recruited yet – it is unethical to reimburse some participants and not others for taking part in the same study. If a voucher is offered, in the PIS, please include the level of information required to receive a voucher (e.g., name, DoS, address and NI number), make it clear that they can take part without opting to receive the voucher and include a statement in the consent form that they understand what information will be required to receive the voucher.	
Reviewer: (Typed name to act as signature)	**Trishna Patel**	
Date:	**08/12/2023**	

Appendix F – Interview Schedule

1. Warm up question: Can you tell me about the things that make you, ‘you’?
   Prompt: If you had to use a few words to describe yourself?
   Prompt: What do these [words/things] mean to you?
2. Can you tell me about your chronic pain / [or name of pain condition, if known]?
   Prompt: How did it start and progress?
3. Can you tell me what each day is like for you (in light of your pain)?
   Prompt: What sort of activities do you typically do every day (in light of your pain)?
   Prompt: What does it mean for you? [if they have found it difficult to engage in certain activities due to pain].
4. How did you think or feel about yourself when you first started experiencing pain / or when you were diagnosed with chronic pain?
   Prompt: How did you think/feel about yourself before you started experiencing pain?
   Prompt: How do you see yourself or think/feel about yourself now?
5. What might this [possible change in identity] mean for you or your life?
   Prompt: What areas of your life or identity do you think have changed?
   Prompt: How do you feel about that?
6. How do you see yourself in the future?
   Prompt: How do you feel about that?
7. How do you feel around others [friends/peers/family]?
   Prompt: What do you make of that?
   Prompt: According to you, how is your pain seen in your culture/by others around you?
8. What kind of support do you think might be helpful for you?
9. Is there anything else you would like to add that we have not covered?
10. Do you have any questions for me?

Appendix G – Debrief Sheets (Adolescents and Parent/Guardian)

PARTICIPANT DEBRIEF SHEET - Adolescents

Exploring Identity Development in Adolescents with Chronic Pain

Thank you for participating in my research study on identity development in adolescents who have chronic pain. This document offers information that may be relevant in light of you having now taken part.

How will my data be managed?

The University of East London is the Data Controller for the personal information processed as part of this research project. The University will ensure that the personal data it processes is held securely and processed in accordance with the GDPR and the Data Protection Act 2018. More detailed information is available in the Participant Information Sheet, which you received when you agreed to take part in the research.

What will happen to the results of the research?

The research will be written up as a thesis and submitted for assessment. The thesis will be publicly available on UEL's online Repository (https://repository.uel.ac.uk/). Findings of this research may also be shared with academics, clinicians, chronic pain charities, or other adolescents who have chronic pain. These findings may be shared through journal articles, blogs or conference presentations. When these findings are shared, your identity will remain anonymous, which means that it will not be possible to identify you personally. Personal information such as names, locations and names of other people will be removed or changed.

You will be given the option to receive a summary of the research findings once the study has been completed for which relevant contact details will need to be provided.

Anonymised research data will be securely stored by my supervisor (Dr. Hannah Sela) for a maximum of 3 years, following which all data will be deleted.

What if I been adversely affected by taking part?

Generally, participation in the interview will not have had a negative impact on you. I have taken several steps to ensure that there is a low chance of you feeling upset due to the interview. However, I understand that it may have been upsetting, challenging or uncomfortable for you **during** or **after** the interview in some way. If you think that you have been affected in any of these ways, the following resources can offer information, help and support:

Mental health support (organisations which provide confidential support for any kind of issue you might be going through):

- **Childline** (open 24 hours, every day)
  Telephone: 0800 1111
  Website: https://www.childline.org.uk/get-support/contacting-childline/
- **The Mix**
  Telephone: 0808 808 4994 (open from 4 pm to 11 pm, Monday to Friday)
  Email form: https://www.themix.org.uk/get-support/speak-to-our-team/email-us
- **Shout** (open 24 hours, 7 days a week)
  Send a text saying 'SHOUT' on: 85258
- **CALM**
  Telephone: 0800 585858 (open 5 pm to 12 am, every day)
  Webchat: https://www.thecalmzone.net/get-support (open 5 pm to 12 am, every day)
- **Samaritans**
  Telephone: 116 123 (open 24 hours, every day)
  Email: jo@samaritans.org

Support for talking about chronic pain in a safe space:

- **Pain concern**
  Telephone: 0300 123 0789 (call at any time and leave a message with your phone number/email, and someone from the team will contact you in the next working day)
  Email: help@painconcern.org.uk
- **Shout** (open 24 hours, 7 days a week)
  Send a text saying 'SHOUT' on: 85258
- **Action on Pain**
  Telephone: 03456031593 (open between 10 am to 4 pm, Monday to Friday)
  Email: aopisat@btinternet.com

- **Fibromyalgia Action UK**
  Telephone: 0300 999 3333 (open between 10 am to 4 pm, Monday to Friday)

In an emergency, please call 999.

Who can I contact if I have any questions/concerns about the research?
If you would like further information about my research or have any questions or concerns, please do not hesitate to contact me.

Gauri Joshi
Email: u2042426@uel.ac.uk

If you have any questions or concerns about how the research has been conducted, please contact my research supervisors Dr. Hannah Sela and Professor Rachel Tribe. School of Psychology, University of East London, Water Lane, London E15 4LZ,
Email: Dr. Hannah Sela h.sela@uel.ac.uk
Professor Rachel Tribe: r.tribe@uel.ac.uk

or

Chair of School Ethics Committee: Dr Trishna Patel, School of Psychology, University of East London, Water Lane, London E15 4LZ.
(Email: t.patel@uel.ac.uk)

Thank you for taking part in my study.

PARENT/GUARDIAN DEBRIEF SHEET

Exploring Identity Development in Adolescents with Chronic Pain

Thank you for agreeing to let your child participate in my research study on identity development in adolescents who have chronic pain. This document offers information that may be relevant in light of you being present during the interview.

How will my child's research data be managed?

The University of East London is the Data Controller for the personal information processed as part of this research project. The University will ensure that the personal data it processes is held securely and processed in accordance with the GDPR and the Data Protection Act 2018. More detailed information is available in the Participant Information Sheet, which you received when you agreed to take part in the research.

What will happen to the results of the research?

The research will be written up as a thesis and submitted for assessment. The thesis will be publicly available on UEL's online Repository (https://repository.uel.ac.uk/). Findings of this research may also be shared with academics, clinicians, chronic pain charities, or other adolescents who have chronic pain. These findings will be shared through journal articles, blogs or conference presentations. When these findings are shared, your child's identity will remain anonymous, which means that it will not be possible to identify your child personally. Personal information such as names, locations and names of other people will be removed or changed.

You will be given the option to receive a summary of the research findings once the study has been completed for which relevant contact details will need to be provided.

Anonymised research data will be securely stored by my supervisor (Dr. Hannah Sela) for a maximum of 3 years, following which all data will be deleted.

What if I been adversely affected by taking part?

It is not anticipated that you will have been adversely affected by taking part in the research, and all reasonable steps have been taken to minimise distress or harm of any kind. Nevertheless, it is possible that being present during the interview – or its after-effects – may have been challenging, distressing or uncomfortable in some way. If you have been affected in any of those ways, you may find the following resources/services helpful in relation to obtaining information and support:

Mental health support (organisations which provide confidential support for any kind of issue you might be going through):

- **The Mix**
  Telephone: 0808 808 4994 (open from 4 pm to 11 pm, Monday to Friday)
  Email form: https://www.themix.org.uk/get-support/speak-to-our-team/email-us
- **Shout** (open 24 hours, 7 days a week)
  Send a text saying 'SHOUT' on: 85258
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  Telephone: 0800 585858 (open 5 pm to 12 am, every day)
  Webchat: https://www.thecalmzone.net/get-support (open 5 pm to 12 am, every day)
- **Samaritans**
  Telephone: 116 123 (open 24 hours, every day)
  Email: jo@samaritans.org

Chronic pain related support (as a parent/guardian of an adolescent who has chronic pain)

- Pain concern
  Telephone: 0300 123 0789 (call at any time and leave a message with your phone number/email, and someone from the team will contact you in the next working day)
  Email: help@painconcern.org.uk

Who can I contact if I have any questions/concerns about the research?

If you would like further information about my research or have any questions or concerns, please do not hesitate to contact me.

Gauri Joshi
Email: u2042426@uel.ac.uk

If you have any questions or concerns about how the research has been conducted, please contact my research supervisors Dr. Hannah Sela and Professor Rachel Tribe. School of Psychology, University of East London, Water Lane, London E15 4LZ,
Email: Dr. Hannah Sela h.sela@uel.ac.uk
Professor Rachel Tribe: r.tribe@uel.ac.uk

or

Chair of School Ethics Committee: Dr Trishna Patel, School of Psychology, University of East London, Water Lane, London E15 4LZ.
(Email: t.patel@uel.ac.uk)

I would like to thank you and your child for taking part in the study.

Appendix H – Example of Analysis Process

Experiential statements	Transcript	Exploratory notes
	112. Interviewer: Okay, yeah, so around a year ago.	
	113. And now can you tell me what each day is like	
	114. for you in light of the arthritis and the pain	
	115. that you feel?	
Feeling of loss linked with not being able to engage in activities due to pain.	116. Participant: Uhh… yes, if I backdate- if I get to-	
	117. you see flashback in my days. Before realising	Feeling of loss - arthritis has made her lose things
	118. this, I feel like I've lost much **((mhm))** because	
Uncertainty about duration of pain.	119. most of the things you don't have to do things,	How intense the pain is - she has to stop what it is doing and the nature of pain is 'instant' or sudden - so perhaps some uncertainty?
	120. the thing is it's instant, it gets you while doing	
	121. something you have to stop it. **((mhm))** It	
	122. might stay a week, it might take a month, so it	
Identity has changed as pain interferes with several areas of life and mobility.	123. just- my- even I say my economic life, my social	
	124. life, because when you see the mobility	
	125. **((yeah))** the mobility is decreased, so I feel	The time that pain lasts for is uncertain
Change in actual sense of self versus wished/desired for sense of self.	126. like… It has changed me. **((hmm))** I would wish	
	127. to be somewhere out there interacting with	Several areas of life and possibly self have been impacted by pain
	128. people, but sometimes you feel bad… **((yeah,**	
	129. **hmm))** It's bad, especially at this tender age.	
	130. You feel bad because sometimes you think	The pain and consequent mobility issues are so intense that her sense of self has changed
	131. such things umm such illness, they should	
	132. happen to those people at their old age. Sorry	
	133. to say so but yes,	
Feelings of frustration or unfairness about having	134. that's according to me how I feel I think that I	Things that she cannot or is not able to do because of pain
	135. have to get this bad. It can knock in any time	

arthritis at a tender age, as arthritis is seen as an old person condition. Timing of pain is uncertain, but pain is seen as an external agent that can knock one down and create uncertainty.	and for anyone so, maybe among the that percent of people suffering from arthritis **((mhm))** it's not that- in that group of these percent suffering from arthritis **((yeah))** It doesn't feel okay. Like me saying it's okay, I'm okay. Because you don't know when to the- the pain will knock you down. Don't know when- when, so you can't plan your things well because there is that barrier.	Sadness, possible frustration about having arthritis or pain at a young age, how this condition is typically seen in much older people, some sense of unfairness that she has experienced this at a young age Inability to plan things due to the uncertain nature of pain
	Interviewer: Mhm, yeah. And I hear you, it sounds really difficult. And you said it's difficult to plan things or it has an impact on your social life or economic life. Can you just tell me a bit more about that please?	
Pain creates a lack of choice in 'how' she can engage in activities, if at all. Social life, social self and social relationships have been cut down because of pain.	Participant: Okay, let's say maybe you have some events you are to attend. You know the mobility when the pain knocks you **((mhm))** decrease- because you experience decreased mobility, so you just have to relax. **((yeah))** You just don't have to move here, move there, no. So you have to be in one place so you don't go there, interact with people that- that means my social life has been somehow cut down. You don't have- you don't go to the malls, you don't go anywhere to interact with others, you just remain. You reduce mobility **((hmm))** umm yes, that's all about my social life.	Language - intensity of pain, defeated – knocks you 'Having' to do things differently, or not doing them at all because of pain Negative impact on social life as she has reduced mobility so cannot go out to the malls (probably like other young people) and interact with others. Social life 'has been' cut down - again, not by her choice.

Appendix I – Example of Clustering PETs to form GETs

Final GET Title: Not Belonging as an Adolescent

Initial ideas for title of GET based on essence of PETs and experiential statements: Isolation and loneliness, an adolescent with an old person condition, unfairness, reduced belongingness

PETs:

- Beth: The isolation of being a young person with chronic pain (Sub-themes: societal view of adolescents, comparison with peers, personal view of qualities of adolescents)
- Amy: Unfairness and isolation of being an adolescent with chronic pain
- Georgia: Being an adolescent with chronic pain is misunderstood (Sub-themes: societal view of chronic pain and young people)
- Chloe: Being an adolescent with an old person condition (Sub-themes: differences in actual and should be identity of young people, lack of belongingness)
- Daisy: The meaning of being an adolescent with an old person condition
- Ethan: Isolation of being a young person with chronic pain (Sub-themes: lack of belongingness, reduced engagement with young person activities and roles)

Final GET Title: A Limited Identity

Initial title ideas: a lost identity, loss of valued parts

PETs:

- Amy: A world full of limitations (Sub-themes: acceptance of pain into identity, changes in valued parts of identity, uncertainty of pain)
- Beth: Pain dismantles identity (Sub-themes: loss of valued activities and social roles, pain is external to self but powerful)
- Georgia: Identity defined by pain (Sub-themes: internal and external identity defined by pain, loss of valued parts of self, introduction of new parts to identity, lack of choice in accepting pain into identity)

- Chloe: Gains and losses in identity (Sub-themes: losing parts of self to pain, gaining new parts in identity because of pain, accepting pain into identity, uncertainty and lack of stability in identity)
- Daisy: Losing valued parts of identity (Sub-themes: loss of valued activities, changes in valued relationships, lack of choice in making sense of identity, unwanted parts introduced into identity by pain)

Final GET Title: Protecting Identity from Pain

Initial ideas for title of GET: Forceful adaptation, holding on to positives

PETs:

- Amy: Preserving or protecting identity from chronic pain (Sub-themes: holding on to positive parts of identity)
- Beth: Defending identity from intrusions of pain (Sub-themes: Embracing positive parts of identity)
- Frank: Efforts to retain identity from pain (Sub-themes: holding on to the positive side of self)
- Chloe: Protecting internal and external identity (Sub-themes: protecting internal and external identity, considerable effort to retain positive parts of identity)
- Georgia: Negotiating with pain (Sub-themes: effort to protect external identity from pain)

Appendix J - Theme Recurrence Table

		Amy	Beth	Chloe	Daisy	Ethan	Frank	Georgia
GETs	Sub-themes							
A limited identity	Losing valued relationships and activities	✓	✓	✓	✓		✓	✓
	Unfair choices	✓	✓	✓		✓	✓	✓
	Uncertainty	✓	✓	✓	✓	✓		✓
A mismatch	Varied needs		✓		✓	✓	✓	✓
	Invisible disability	✓	✓	✓	✓			✓
Not belonging as an adolescent	Personal meaning of being an adolescent	✓	✓	✓	✓	✓	✓	✓
	A condition for 'old people'	✓		✓	✓			✓
Paradoxical role of diagnosis	Validation		✓	✓		✓	✓	✓
	Trapped in my own body	✓		✓	✓	✓		✓
Protecting identity from pain	Adapting	✓	✓	✓	✓		✓	✓
	Gaining valued parts	✓	✓	✓	✓		✓	✓

Appendix K - Key to Transcription and Quote Presentation

In-text Example	**Description**
Text	Sentences spoken by participant
Text	Sentences/words spoken by researcher/interviewer
((text))	Researcher’s speech/words during interview, overlapping with participant’s speech
…	Short pause
((pause))	Long pause
[]	Omitted text
((text))	Nonverbal communication or audible aspects of speech such as laughter
((inaudible))	Participant’s words or phrases which were inaudible or unclear in the interview recording
Text-	En dash after text denotes unfinished or cut-off words or phrases
[*text*]	Additional comments from the researcher, to provide additional context or clarity