Ji Yeon Park BSc, MSc

EXPERIENCES IN GROUP PAIN MANAGEMENT INTERVENTIONS

Section A: What Is the Experience of Participating in Group Pain Management Interventions for People living with Chronic Pain? A Literature Review

Word Count: 8,000 (300)

Section B: The Therapeutic Mechanisms That Are Unique in a Sickle Cell Pain Management Programme. A Grounded Theory.

Word Count: 8,000 (300)

Overall word count: 16,000 (plus 600 additional words)

A thesis submitted in partial fulfilment of the requirements of Canterbury Christ Church University for the degree of Doctor of Clinical Psychology

October 2020

SALOMONS INSTITUTE OF APPLIED PSYCHOLOGY

CANTERBURY CHRIST CHURCH UNIVERSITY

This Page Intentionally Left Blank

Acknowledgements

I would like to say thank you to all the participants who shared their time and experiences with me for this project. Thank you to Sue, for your guidance, encouragement and calmness throughout the project. Thank you also to Alexa for helping me with the recruitment when it seemed not possible. Lastly, I would like to say a massive thank you to Michael because without your support I could not have got to the end. Thank you.

Summary of the MRP

Section A: Presents a narrative literature review using a quality appraisal framework to evaluate the quality of studies exploring the experiences of people with chronic pain attending pain management programmes. Chronic pain and pain management programmes are discussed. The review presents three broad categories that summarise the qualitative findings: inter-relational group experience; introspective experience; and self-management skills. The clinical implications include encouraging discussions in the pain management programmes to foster these group processes. The research implications include exploring experiences of attending pain management programmes for specific disease conditions (e.g. sickle cell disease).

Section B: Presents a grounded theory study exploring the therapeutic mechanisms that are perceived in sickle cell pain management programmes. A model hypothesises that the processes of learning about pain, the sharing and relating within the group of participants may have contributed to the development of a more positive sickle cell identity through acceptance and making changes. Participants who attended non-specific pain management programmes highlighted the importance of the facilitators' knowledge in relation to sickle cell. The model contributes to understanding how people with sickle cell disease can be supported in managing their pain, and relevant clinical and research implications are considered.

Table of Contents

List of Figures

List of Tables

List of Appendices

Section A: Literature Review

What Is the Experience of Participating in Group Pain Management Programmes for People living with Chronic Pain? Literature Review

Word Count: 8,000 (300)

A thesis submitted in partial fulfilment of the requirements of Canterbury Christ Church University for the degree of Doctor of Clinical Psychology

October 2020

Abstract

Chronic pain is a condition that is closely linked to mental health difficulties and social issues that may lead to reduced quality of life. Pain management programmes have been developed, using the biopsychosocial approach, to support people with chronic pain to improve their functioning and manage their pain. The purpose of this review was to explore the experiences of people with chronic pain attending pain management programmes. Four major electronic databases were used to search for papers and the review included eight qualitative studies and a mixed method study with a distinguishable qualitative component.

The review found three broad categories that summarised the qualitative findings: inter-relational group experience; introspective experience; and self-management skills. Participants valued meeting other people and the therapeutic alliance with the group facilitators. The process of acceptance of pain seemed to facilitate changes in the mindset of the participants with chronic pain, increasing their sense of empowerment. Reported self-management skills learnt were new coping strategies, body-mind awareness and medication use change.

Key words: Chronic pain, pain management, group, qualitative, self-management, acceptance

Introduction

Chronic pain

Pain is defined as ‘an unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage’ (International Association for the Study of Pain [IASP], 2011). Chronic pain (CP), as opposed to short lived acute pain, is persistent for more than three months (Elliot et al., 1999). CP is closely linked to mental health difficulties (e.g. depressive symptoms) and social problems (e.g. increased likelihood of unemployment), and reduced quality of life (IASP, 2004; Linton & Bergbom, 2011). It is suggested that co-occurrence of physical, psychological and social difficulties can contribute to risk factors that lead to maintenance of CP (Dominick, Blyth & Nicholas, 2012). CP is cited as a global public health priority (Goldberg & McGee, 2011) and within the UK, 10-14% of adults describe living with CP that moderately to severely limits functioning (Fayaz, Croft, Langford, Donaldson, & Jones, 2016).

Treatment for CP broadly falls into categories of medical, psychological and/or physical rehabilitation depending on individual need. Partially due to concerns about overprescribing opioid and analgesics as a treatment for CP (Wilson, 2017), a multidisciplinary approach, safer prescribing and the offer of a range of support options have been highlighted as necessary and beneficial for supporting people with CP (British Medical Association, 2017; Royal College of Anaesthetists, 2015; Royal College of General Practitioners, 2014). There is, however, a lack of consensus regarding what the range of support options should be, based partly on how the pain experience is understood (Wilson, 2017).

Pain Management Programmes

Pain management programmes (PMPs) are offered in the UK as a multidisciplinary-led intervention for people with CP to improve functioning and promote self-management, which can improve the pain experience (Wilson, 2017, Devan, Hale, Hempel, Saipe, & Perry, 2018). Traditionally based on cognitive behavioural therapy (CBT), PMPs consist of a range of interventions such as exercise, activity pacing, relaxation, medication use and pain education based in neurophysiology (McCracken & Turk, 2003). However, despite national guidance (e.g. British Pain Society [BPS], 2013), in practice, there is not one single approach to PMPs, creating vast heterogeneity in delivery and content (Wilson, 2017).

Theories underpinning the treatment of CP

PMPs are typically based on a 'biopsychosocial' understanding of the pain experience in which biological, social and psychological factors are considered as important (Engel, 1977). The 'gate control theory' provides a further understanding of the pain mechanism, by linking physical and psychological factors (Melzack & Wall, 1965). Melzack and Wall (1965) describe the experience of pain as a series of events influenced by peripheral and cortical factors. Thus, as pain signals are sent to the brain from the body, the process becomes moderated by psychological, social and environmental factors that affect the subjective perception of pain.

Cognitive and behavioural theories, which are broadly consistent with the gate control theory, underpin the use of cognitive behavioural therapy (CBT) which has predominately informed the development of many PMPs. For example, the operant theory of pain behaviour explains that certain pain behaviours are likely to change as a result of the withdrawal of positive reinforcement and the avoidance of negative reinforcement (Fordyce, 1976). Further, the fear avoidance model (Vlaeyen and Linton, 2000) advances behavioural and cognitive components to understand pain experiences, by placing significance on the idiosyncratic interpretations of pain and subsequent behaviours depending on whether the pain is interpreted as either a temporary nuisance or a catastrophe to daily life. In practice, CBT-PMPs can address misinterpretation of CP and subsequent physical deconditioning (through reduced activity) through psychoeducation and taught self-management skills (Keefe, Dunsmore & Burnett, 1992), while self-monitoring can support individuals to recognise and modify maladaptive relationships between thoughts, emotions and behaviours (Keefe et al., 1992).

A further theory informing multidisciplinary PMPs (and social and health psychology more generally), is social cognitive theory (SCT; Bandura, 1986, Weinman & Petrie, 1997). SCT refers to ways that an individual's thoughts and behaviour can be influenced through observation and participation in social environments. SCT also relates to the concept of 'self-efficacy'- one's belief in one's ability to effectively manage or cope with specific situations (Bandura, 1997). In practice, PMPs use factors such as catastrophising, fear-avoidance and functional self-efficacy to understand the extent of disability due to CP (Sandborgh, Johansson, & Söderlund, 2016) while also enhancing pain-related self-efficacy (Strong et al., 2002).

Recent developments

PMPs have recently been influenced by acceptance and commitment therapy (ACT; Hayes et al., 2013, McCracken, 1998,) ACT-based PMP approaches focus on prioritising increasing psychological flexibility and physical functioning (Veehof, Oskam, Schreurs and Bohlmeijer, 2011). In the ACT approach, the situational context of a negative thought is central to understanding impact on functioning and behaviour, which represents the focus of intervention (Hayes, 2004). ACT contrasts to elements of CBT, that focus on identifying and challenging unhelpful thoughts related to pain (Hayes, Strosahal & Wilson, 1999). ACT approaches are supported by evidence that highlights the effectiveness of modifying behaviour in improving outcomes more than cognitive modification (Longmore & Worrell, 2007).

Pain is also a social experience. Pain responses, such as behaviours, beliefs and attitudes towards pain, are thought to be developed through social learning from childhood and interpersonal modelling (Goubert, Vlaeyen, Crombez & Craig, 2011). Individuals experiencing pain also cope within a wider social world through social support from their families or the community (Finlay & Elander, 2016). Therefore, professional bodies, such as the BPS, have argued for the provision of group-based over individual approaches to pain management (Egan, Lennon, Power & Fullen, 2017). They provide a clinical rationale that the normalisation of the pain experience is seen to be crucial for facilitating behavioural change and, practically, for maximising resources for treatment (Wilson, 2017). The importance of groups was further highlighted by Devan et al. (2018), who suggest that attending a group intervention alongside others in similar circumstances permits sharing and learning to occur within the group, which develops self-efficacy in self-management and problem-solving skills. Therapeutically, these processes can be explained by Yalom's therapeutic factors in group interventions, which are not restricted to PMPs (Yalom & Leszcz, 2005). For example, the therapeutic factor of universality, where group members learn that their suffering and difficulties are shared by others, can mirror the normalisation of the pain experience in PMPs.

Evidence base

The evidence base for PMPs has shown them to be a beneficial intervention for the management of CP, particularly in relation to physical and psychological functioning, with moderate improvements on measures of disability, mood and catastrophising pain (Fedoroff, Blackwell & Speed, 2014; Williams, Eccleston & Morley, 2012). However, the effectiveness of PMPs for specific pain conditions remains in some senses unclear, as reviews of PMPs typically considered mixed CP types, while reviews focussed on specific pain conditions are of limited quality (Wilson, 2017).

Previous research into PMPs is characterised by quantitative approaches, focused on treatment outcomes and the longevity of effectiveness. Indeed, a review of psychological therapies for relating to CP and PMPs called for different types of research to be undertaken in order to understand the key components and therapeutic mechanisms that are beneficial for certain patients with specific outcomes, with randomised controlled studies no longer needed (Williams et al., 2012).

The need to understand the experience of participating in PMPs

The underlying process for treatment effect and which treatment process is important in PMPs remains unclear (Keefe, Rumble, Scipio, Giordano & Perri, 2004; Wilson, Chaloner, Osborn & Gauntlett-Gilbert, 2017). Therefore, to understand important treatment processes inherent in PMPs, it may be necessary to explore the experience of participating in PMPs (Wilson et al., 2017). Furthermore, due to the subjectivity of the experience of pain, it has been argued that only individuals experiencing pain are able to capture changes in their experience of pain (Egan, Lennon, Power & Fullen, 2017). Qualitative research has been recognised as a valued way to explore the patient perspective in depth (Osborn & Rodham, 2010). Qualitative research in this domain has been previously used to augment quantitative data by capturing improvements in personal growth following a CP intervention (Wideman et al., 2016), and facilitators and barriers to the development and maintenance of self-management strategies within individuals following pain intervention groups (Devan et al., 2018).

Rationale for the current review

The current review aims to appraise the current qualitative literature concerning how people living with CP experience PMPs. Such a review may provide a way to explore the therapeutic processes that occur within group interventions that can enhance physical and psychological functioning. This differs from previous reviews that have looked at the changes in the individuals' perceptions of self-management after they completed the multidisciplinary pain management interventions (Devan et al., 2018), by keeping a broader focus on the experiences of attending the multidisciplinary group PMP. The current study may also complement the finding of Devan et al. (2018) by exploring how self-management strategies are accepted in PMPs.

Exploring the experience of attending PMPs may contribute to the design of future PMPs, by clarifying important therapeutic processes across a set of heterogenous interventions (Wilson, 2017).

Method

Review objective

The objective of this review is to explore the experience of people with CP participating in PMPs. It specifically asks: ‘what is the experience of participating in group PMPs for people living with CP?’

Inclusion and exclusion criteria

The inclusion and exclusion criteria are included in Table 1. No specific limit was set on physical health conditions that lead to CP. A quick search revealed that a number of group interventions for pain, that consist of similar content as PMPs, are not labelled as PMPs in the literature. For the feasibility of the review, the content description of the group intervention in the papers was examined to determine whether it could be considered as a type of PMP. Therefore, the current review focuses on papers that considered group provisions as their interventions for managing CP.

Table 1 *Inclusion and exclusion criteria for literature search*

Inclusion Criteria	Exclusion Criteria
Published in English	Research that looks at online intervention
Published in peer-reviewed journal	Research based on individual intervention for CP
Participants aged 18 and above and/or mean age above 18 and below 65	Quantitative design
Qualitative design or mixed design with clearly identifiable qualitative findings	Group interventions that did not clearly describe the group content in the method section.
Research based on group intervention based on a biopsychosocial approach towards CP	
Group intervention incorporating psychological approaches e.g. CBT, ACT.	
Group intervention using a multidisciplinary approach	
Interview questions included asking about the experience of the group intervention	

Literature search method

The systematic search was carried out in December 2019 on electronic databases, including PsycINFO, Medline, Web of Science and Applied Social Sciences Index and Abstracts. Boolean operators such as “AND”, “OR” and “NOT” were used with key terms and the search was limited to subject headings and abstracts to ensure that the relevant papers were included.

Following the initial search using the search terms (Table 2), titles and abstracts were screened for relevant papers. The references of the relevant papers and other review papers were then further reviewed for relevant papers. No time limit was applied in the search. Different stages of the systematic search are illustrated in Figure 1. The search terms used were in line with those used in a comparable review (Devan et al.,2018).

Table 2 *Search terms used in the systematic search*

Search Topic	Specific terms used
Exposure	“Pain management” intervention* AND
Outcome	Experience* OR perception*
	AND NOT
Population	Child*

Figure 1 *Flow of information through the different phases of the literature search*

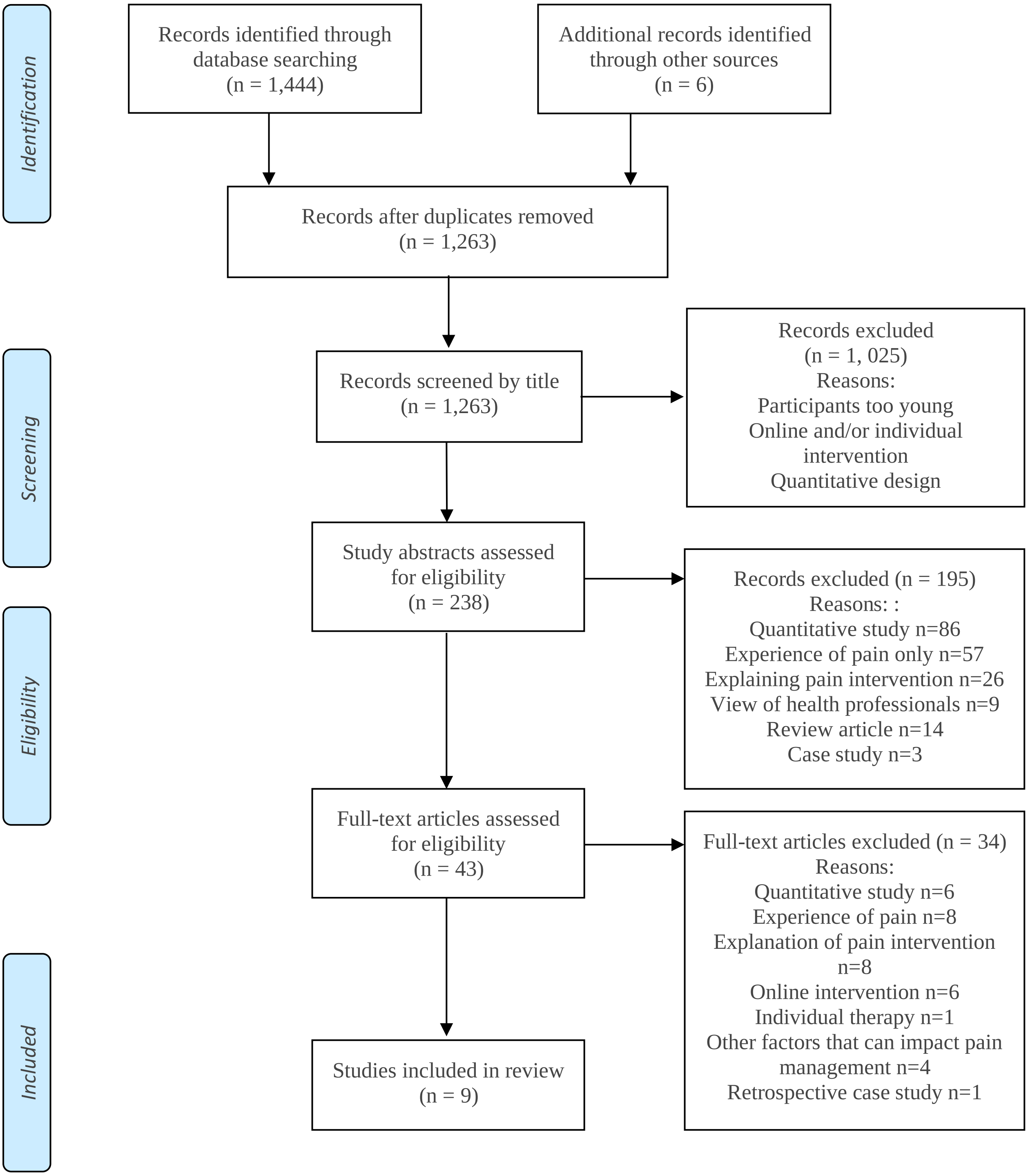


Table 3 *Papers' main data extraction*

Paper	Year	Country	Study Type	Methods	Participants (gender, age, sample size, duration of pain)	Pain related health condition	Pain Management Intervention	Purpose	Themes identified/Main findings
Casey, Smart, Hearty, Lowry, & Doody	2019	Dublin, Ireland	Qualitative; IPA	Focus groups	26 (57% female, 43% male, mean age 52.7 ±8 years) Pain duration 2–25 years (mean 8.8 years)	Mixed Pain Etiology. Chronic low back pain most common (n=9)	Acceptance-based PMP group	To explore individuals' perspectives related to 'acceptance', following participation in an eight-week multidisciplinary PMP based on the psychological approach ACT.	Three themes emerged: 'perception of acceptance as a step towards better living with chronic pain; contemplation of acceptance; non-acceptance'.
Dysvik, Kvaløy & Furnes	2014	Norway	Mixed methods; Phenomenological hermeneutic approach	Written reports	34 (mean age 49) Pain duration more than 6 years for n=21.	Mixed Pain Etiology.	CBT based PMP 8-week group	To explore and describe the suffering of patients that arises from chronic pain, and the alleviation of this suffering within a chronic pain management programme.	Qualitative findings describe the importance of group processes, enhanced self-understanding and there were other meaningful aspects to the participants'.
Egan, Lennon, Power & Fullen	2017	Dublin, Ireland	Qualitative; Content analysis	Four focus groups using semi-structured questions	16 (12 female, 4 men, mean age 54.3)	Mixed Pain Etiology. Chronic Pain	CBT-PMP	To determine patients' perceptions regarding cognitive behavioural PMP, and what, if any, strategies learned on the program patients continue to use long-term to manage their pain.	Six themes emerged: 'long-term positive feedback on the utility of the program; long-term changes facilitated in daily life; considering themselves as 'new me'; wanting more on new treatments/pain knowledge; learning that it is key to be open, to listen and accept to maximise gain; sharing pain management knowledge with others.

Paper	Year	Country	Study Type	Methods	Participants (gender, age, sample size, duration of pain)	Pain related health condition	Pain Management Intervention	Purpose	Themes identified/Main findings
Mathias, Parry-Jonesc & Huwse	2014	Wales, UK	Qualitative; IPA	Semi-structured interviews	6 (aged 46-64, white British females) Pain duration 1.5-10 years	Chronic non-malignant pain	Acceptance-based PMP group	To add to previous quantitative research by qualitatively exploring individual experiences of attending an acceptance based PMP and identifying the key constituents of the programme that participants felt facilitated change.	Five themes emerged: 'I'm not alone, others understand my pain, Freedom from pain taking over, A new self-one with pin, Parts of the programme participants facilitated change and Exercise is possible'.
Moore & Martin	2014	Australia	Qualitative; thematic analysis	Semi-structured interviews	17 (14 women, 3 men, mean age 54.6).	Chronic pain	MBCT programme	To understand the experiences of chronic pain patients in an MBCT group	Four themes were found: 'patients' belief in the programme, perception of control, struggles, acceptance of the presence of pain'.
Penney & Haro	2019	USA	Qualitative; thematic analysis	Semi-structured interviews; focus groups	Interview sample 41 (18 women, 23 men, mean age 53) Focus group sample 20 (13 women, 7 men, mean age 54)	Chronic Pain	Empower Veterans Program (EVP); a 10-week, 30+ hour whole health group training program	To describe Veterans' perceived impacts of participation in an interdisciplinary pain rehabilitation program	Eight themes were identified: 'new/adjusted daily practices; coping skills; accepting; adjusting and setting boundaries; feeling empowered; participating in life; adjusted medication use; stuck'.

Paper	Year	Country	Study Type	Methods	Participants (gender, age, sample size, duration of pain)	Pain related health condition	Pain Management Intervention	Purpose	Themes identified
Pietilä Holmner, Stålnacke, Enthoven & Stenberg.	2018	Sweden	Qualitative; Content analysis	Interviews	12 (7 women, 5 men, ages 29-63, mean age 47.8)	Chronic Pain	Multimodal rehabilitation (MMR) programme	To explore patient experiences of participating in primary care MMR.	Four categories were identified; 'from discredited towards obtaining redress; from uncertainty towards knowledge; from loneliness towards togetherness; acceptance of pain, an ongoing process'.
Toye & Barker	2012	Oxford, UK	Qualitative; GT	Semi-structured interviews	20 (13 women, 7 men, aged 33-67) Pain duration 3-23 years	Persistent non-specific low back pain (PLBP)	PMP group	To explore the differences in narrative between patients with PLBP who benefited from a PMP, and those who did not benefit.	Finding 'hope' was found to be importance to 'good outcome'. Hopes were restored by: 'deconstructing specific fears; constructing an acceptable explanatory model; reconstructing self-identity by making acceptable changes. Some had not restored hope.
Wilson, Chaloner, Osborn & Gauntlett-Gilbert	2017	UK	Qualitative; IPA	Semi-structured interviews	8 (6 women, 2 men, mean age 37) Pain duration mean 7.8 years	Mix of chronic, non-malignant pain diagnoses	Psychologically informed physiotherapy (PIP), 3 or 4-week group residential pain rehabilitation programme	To investigate patients' beliefs about, and experiences of, this type of treatment, and helpful and unhelpful experiences.	Four themes emerged: 'working with the whole of me, more than just a professional, awareness and working through challenges in the therapeutic relationship' as important to behavioural change alongside an increased sense of capability and physical capacity.

Review

The search found nine research papers that met the inclusion and exclusion criteria (Table 3). The details of each study are set out in Table 3. The Critical Appraisal Skills Programme Qualitative Research Checklist (CASP, 2018) was used as the quality appraisal framework to evaluate the quality of the qualitative design studies (Appendix 1). Appendix 2 provides information on how each study was assessed using the CASP criteria and a summary of the results are provided in Table 4. All nine papers were of sufficient quality to be included in the review.

Table 4 *CASP Summary, by criterion*

Criteria	Example	Met	Partially Met	Not Met
Aims	Explicitly stated aims/ objectives of research	9	-	-
Method	Appropriate use of qualitative methods	9	-	-
Research Design	Justification of the specific research design	8	1	-
Sampling	Appropriate sampling strategy, description of recruitment, discussion around recruitment	8	1	-
Data collection	Appropriate description of data collection methods	9	-	-
Reflexivity	Critical examination of researchers' own role and potential bias	4	-	5
Ethical Issues	Evidence of approval by an appropriate body	7	2	-
Data Analysis	Adequate and in-depth description of analysis process, sufficiently rigorous data analysis	8	1	-
Findings	Clear statement of the findings, discussion of evidence, credibility, integrity	9	-	-
Value of Research	Contribution to existing knowledge, transferability	6	2	1

Critique

Research question and design

All reviewed papers explicitly stated their main research questions and the aims were clearly outlined. Each aim was appropriate for studies adopting a qualitative research design. There were slight differences in the researchers' specific areas of research with regard to the participants' experience of attending pain intervention, which may add to the differences in their findings. For example, Egan et al. (2017) examined long-term follow-up of participants' perceptions of the PMP rather than immediately after the group completion, so their descriptive experience may qualitatively differ to those who completed recently. Some papers further examined the therapeutic mechanisms specific to the pain intervention. The process of acceptance was explored following the PMP based on ACT (Casey et al., 2019) and the experience of a mindfulness-based cognitive therapy (MBCT) group (Moore & Martin, 2015). In these papers, the participants were asked specific questions about acceptance or practising mindfulness, which may mean that the overall usefulness of the findings is therapy approach-specific rather than generalisable to other PMPs. Only two papers (Toye & Barker, 2012; Wilson et al., 2017) looked at the differences in the participants' experiences and these papers were useful as they add to the understanding of why some people benefit and some not from PMPs, which is reflective of the findings in quantitative effectiveness studies for PMPs.

The papers used different qualitative methods to address their aims. A qualitative approach was appropriate to the studies' aims in order to gain an in-depth understanding of the participants' experiences. One paper had a mixed method design and included both quantitative and qualitative data in the research (Dysvik et al., 2014). The core qualitative approach was complemented by supplementary quantitative findings, allowing Dysvik et al. (2014) to explore multiple aspects of the experience (Morse & Niehaus, 2009).

Most commonly, interpretative phenomenological analysis (IPA) was used in studies that explored individual perspectives, experiences and beliefs about the pain intervention (Casey et al., 2019; Mathias et al., 2014; Wilson et al., 2017). This was mainly because IPA allows the research to look for subjective meaning and how people make sense of their personal experiences (Smith, Flowers & Larkin, 2009). Other qualitative methods, such as thematic analysis and content analysis, were adopted by studies (Egan et al., 2017; Moore & Martin, 2015; Penney & Haro, 2019; Pietilä Holmner et al., 2018). Toye and Barker (2012) used grounded theory (GT) to explore different narratives of the participants. GT is suitable when there is limited existing theory about the process (Urquhart, 2013). Five papers justified their chosen qualitative method, such as IPA or thematic analysis (Casey et al., 2019; Dysvik et al., 2014; Mathias et al., 2014; Moore & Martin, 2015; Wilson et al., 2017), while the rest of the papers did not justify why their method of analysis was chosen over other methods (Egan et al., 2017; Penney & Haro, 2019; Pietilä Holmner et al., 2018; Toye & Barker, 2012).

Recruitment strategy

Each paper clearly provided details of the sampling strategies and ethical considerations. The sample sizes varied between the studies and were all appropriate for qualitative studies. Some studies that used IPA as their qualitative method had smaller sample sizes of six to eight participants (Mathias et al., 2014; Wilson et al., 2017). However, Smith, Flowers and Larkin (2009) suggest that a sample size of six for an IPA study is too small. Dysvik et al. (2014) had the largest sample size with 34 for their mixed method study, whilst Casey et al. (2019) had the largest sample of 26 for a qualitative-only design. The larger sample of the qualitative findings may increase breadth of the findings whereas the smaller sample numbers increase the depth of the individual experiences. The majority of the papers had a larger number of females than males in their sample and one paper included only female participants (Mathias et al., 2014). Although qualitative studies are not intended to be generalisable, having only female participants may limit the usefulness of the findings and male attendees' experiences are excluded. Penney and Haro (2019) was the only study to have overall similar number of males and females. Only one paper included ethnicity and race in the participant demographics (Penney & Haro, 2019). This missing information limits the application of the findings since there are cultural differences in the pain experience and management (Booker, 2016).

Most of the papers described using purposive sampling for their recruitment strategy, which suited the research aims. Penney and Haro (2019) used stratified purposeful sampling for recruiting interviewees and purposive random sampling for focus group members. In one paper, the sampling strategy was unclear, which meant it was impossible to determine their recruitment strategy (Dysvik et al., 2014). All the papers included their inclusion criteria except for Casey et al. (2019), which did not state any inclusion or exclusion criteria. Pietilä Holmner et al. (2018) was the only paper to explain why some participants declined to take part in the research. The remainder of the papers did not explain why some participants declined. Therefore, it is unknown whether there was a selection bias and whether the participants who declined to take part had a different experience from those who agreed to take part. It may be the case that participants in pain intervention who had a positive experience were more likely to agree to take part in research into their experience than those who had a negative experience. Three papers did not state the pain duration periods of the participants (Egan et al., 2017; Moore & Martin, 2015; Penney & Haro, 2019). The pain duration period could be important for considering possible differences in participants' experiences of the pain intervention. Those recently diagnosed with CP may experience the PMP differently from those who have had CP for long periods, which may further inform ideas about the timing of the intervention in relation to participant satisfaction.

Toye and Barker (2012) was the only study to offer a PMP to participants with CP due to their focus on a specific physical health condition: persistent non-specific low back pain, making their findings likely to be of more relevance for people experiencing low back pain. Only one study specified each participant's underlying CP diagnosis (Casey et al., 2019). Four studies did not specify the participants' physical ailment underlying the CP, or specific diagnosis (Dysvik et al., 2014; Moore & Martin, 2015; Penney & Haro, 2019; Pietilä Holmner et al., 2018). It was unclear whether this information was not mentioned or not thought of at the point of recruitment. This is important to consider since evidence suggests that people with different underlying causes experience PMPs differently. Without this information, the usefulness of the findings may be affected due to the vast heterogeneity of CP patients.

Ethical issues

All the papers discussed the ethical issues and highlighted that ethical approval was given by an ethics committee. The papers all explained how the researchers gained informed consent and considered issues of confidentiality. Only one paper outlined the support that was offered to the participants following their participation in the research (Mathias et al., 2014). The remainder of the papers omitted to provide any information about support or how the participants were signposted to other services. It was not stated whether this was due to the researchers not being concerned about the effects of the study because they thought that their aim did not expose the participants to any potential negative consequences. However, the effects of the study may have been more pertinent depending on their aims. Two papers aimed to explore the potential differences between participants who benefited and those who did not benefit from a PMP (Toye & Barker, 2012; Wilson et al., 2017). It may have been helpful for these researchers to check with the participants whether further support was needed when they were asked to speak about their negative experiences.

Data collection

The data collection method was explicitly reported in each paper and there were clear details on how data were collected. Some papers used semi-structured interviews (Pietilä Holmner et al., 2018; Moore & Martin, 2015; Wilson et al., 2017; Toye & Barker, 2012; Mathias et al., 2014). Focus groups were also used (Egan et al., 2017; Casey et al., 2019). Penney and Haro (2019) used both semi-structured interviews and focus groups, and the researchers justified the reasoning behind the use of different methods, which strengthened the findings compared to other papers that only included one method of data collection. Several papers included interview schedules, which would make replication of the research possible (Casey et al., 2019; Dysvik et al., 2014; Egan et al., 2017; Mathias et al., 2014; Penney & Haro, 2019; Toye & Barker, 2012; Wilson et al., 2017). The remainder of the papers did not include a comprehensive interview guide, which would make replication of the research more difficult.

Quality assurance in data collection was explored in relation to ensuring that the interviewers did not have any prior connection to the group interventions in all papers except for Egan et al. (2017). Therefore, the participants could openly discuss their experience of attending the group intervention and the interviewers would be less likely to unduly influence the direction of the interview, which would limit any potential bias in the findings. However, in Egan et al. (2017), one of the facilitators of the focus group had been previously involved in facilitating the PMPs where they recruited from. This may have had an effect on the findings as the participants may be less likely to discuss difficulties in their experience in front of the person associated with the PMPs.

Data analysis, quality assurance and findings

In order to ascertain the rigour of the data analysis, different aspects of the data reporting were examined. Wilson et al. (2017) offered only a limited description of how the IPA analysis process was used for their data analysis and it was unclear from the paper how the themes were derived. The other eight papers offered detailed descriptions of the chosen analysis method. These papers also clearly described how the main categories or themes were developed and quotes were adequately used to back up the reporting of the findings for each category or theme (Casey et al., 2019; Wilson et al., 2017; Mathias et al., 2014; Moore & Martin, 2015; Pietilä Holmner et al., 2018). In four papers, the researchers evidenced their critical thinking in relation to the possibility of their own bias in data analysis (Toye & Barker, 2012; Mathias et al., 2014; Dysvik et al., 2014; Casey et al., 2019). The reflexive positioning of the researchers was not clearly stated in the other papers and the absence of these statements may have weakened the quality assurance process of the papers. Corby, Taggart and Cousins (2015) spoke about the importance of multiple quality assurance methods being used as a way to lessen the potential impact of the researchers' preconceptions on how the data were interpreted. All the papers considered the credibility of their findings and their use of further quality assurance methods. Different methods, such as triangulation, were discussed in the papers (Egan et al., 2017; Pietilä Holmner et al., 2018). Several papers used more than one analyst (Penney & Haro, 2019; Moore & Martin, 2015; Mathias et al., 2014; Casey et al., 2019). There was explicit reporting of the findings in all papers and their findings were all linked to the paper's main aims.

Literature Summary

The literature summary is presented in a narrative format to reflect the relationships between the findings of the papers and the aims of the review. Theory is integrated into the discussion section. The thematic analysis followed the approach of Braun and Clarke (2006) and was informed by Thomas and Harden's (2008) synthesis methodology. The process involved three stages: line-by-line coding of the results of the papers; organisation of codes into descriptive themes; and interpretative theme clusters (Thomas & Harden, 2008). The line-by-line coding was conducted inductively by the researcher. The researcher then met with the lead supervisor to deductively develop the thematic categories (Appendix 23). Appendix 22 shows the process of theme development; the clusters of codes grouped into descriptive themes, and the development of the interpretive theme clusters into the final thematic categories.

The findings relating to experiences of attending group pain management interventions were grouped into three categories: inter-relational group experience; introspective experience; and self-management skills. Each category can be further divided into subcategories that capture the participants' overall experience. These categories should not be considered to be entirely independent of each other as some subcategories are interdependent, as discussed below.

Inter-relational group experience

Value of meeting other people

When invited to describe their experience of attending group pain management interventions through semi-structured interviews or focus groups, participants frequently spoke about the value of meeting other people in the same or a similar situation to themselves. Positive experiences of sharing with other people with CP were reported in five of the nine papers (Penney & Haro, 2019; Egan et al., 2017; Mathias et al., 2014; Pietilä Holmner et al., 2018; Toye & Barker, 2012). People described their pain experience being validated when they met other people with CP, which reduced feelings of isolation that had emerged as a result of the pain (Egan et al., 2017). This can be related to Yalom's therapeutic factor of universality as people learned that their suffering and difficulties were shared by others in the group (Yalom & Leszcz, 2005).

The need for validation was discussed in relation to previous experiences of not feeling understood after struggling to explain CP to others without CP. Mathias et al. (2014) reported that sharing experiences of pain gave participants a sense of support, normality and validation, which strengthened group cohesion and belonging. Egan et al. (2017) concluded that the group approach was valued due to interpersonal learning, in which group cohesion was thought to enhance individual engagement with the overall intervention. For example, as self-management strategies were practiced, participants were able to support each other (Toye & Barker, 2012). Pietilä Holmner et al. (2018) added that meeting others with more severe pain enabled people to compare experiences and re-evaluate their situation more optimistically.

Therapeutic alliance with group facilitators

In half of the papers, participants referred to the importance of a therapeutic alliance with the health professionals who facilitated the group (Dysvik et al., 2014; Mathias et al., 2014; Pietilä Holmner et al., 2018; Toye & Barker, 2012; Wilson et al., 2017). Participants described the value of "more, open human interaction" when the facilitators adopted the non-expert position, thereby reducing the "them and us" experience that can often be experienced within medical interactions (Wilson et al., 2017). Egan et al. (2017) reported that participants felt "believed" by the clinician, which is a key factor in group engagement. The participants highlighted the significance of therapeutic relationships with clinicians, which helped them to feel understood. As self-management strategies were practised, participants subsequently felt supported to overcome difficulties. Individualised and manageable self-management strategies were considered to be possible, as a result of both the therapeutic relationship and the clinician's ability to understand the participants holistically (Wilson et al., 2017). Participants spoke highly of group facilitators who were able to engage the participants and help them develop an understanding of the pain experience using psychoeducation (Dysvik et al., 2014; Mathias et al., 2014).

Sense of safety

When the participants experienced a sense of belonging, validation from other participants and therapeutic alliance with the facilitators, they felt that an environment of care and safety had been created (Wilson et al., 2017). This could be related to Yalom's therapeutic factor of group cohesiveness where group members develop feelings of security within themselves through a sense of belonging to the group, which can trigger a change (Yalom & Leszcz, 2005). Participants felt less hindered by perceived judgement from others, which encouraged them to move outside the comfort zone of the group. For example, the atmosphere was described as 'lighter' where the participants felt that their 'imperfect efforts at exercise were acceptable' during physiotherapy (Wilson et al., 2017).

Introspective experience

Acceptance of pain

Acceptance of CP was discussed in six papers (Penney & Haro, 2019; Egan et al., 2017; Mathias et al., 2014; Moore & Martin, 2015; Casey et al., 2019; Pietilä Holmner et al., 2018). Pietilä Holmner et al. (2018) found that acceptance of pain was a continuous process, where accepting pain enabled reconciliation; the pain no longer controlled their life and adjustment to pain was possible. Similarly, Penney and Haro (2019) described how participants accepted pain and learned skills that helped them to feel more in control as they were able to manage the pain based on their life demands.

The process of acceptance was also influenced by the therapeutic approach of the pain management group. Moore and Martin (2015) used the MBCT approach in the group and the participants described their acceptance process as accepting the presence of pain without resistance and instead coexisting with the pain. Notably, the process of accepting CP induced difficult emotions within the participants. The participants reported that their levels of distress reduced as they learned to accept CP and they cited anger as their predominant emotion prior to accepting CP (Moore & Martin, 2015). It was further noted that once they accepted the presence of pain, it helped them to move forward with their lives and promoted greater engagement with the group (Egan et al., 2017). The participants described accepting the presence of pain as necessary before they were able to progress towards managing their pain in the group intervention. It was noted that the process of acceptance was observed when the participants moved on from discussing the pain as an "invading sensation" to recognising the pain as being one with their body, moving towards a "new self" (Egan et al., 2017).

Mathias et al. (2014) described the participants accepting that they could continue to live their lives while experiencing pain and noted that this process was important for them in overcoming the "debilitating" influence of pain. It also emerged that the participants were able to move past their focus on finding a medical solution to the CP to achieve the elimination of pain, which was reflected in their previous experiences of trying various medical interventions. This pursuit had led to feelings of hopelessness about eliminating the pain, a lack of power and dissatisfaction with their experience with multiple health professionals who were unable to provide a solution to their CP. Mathias et al. (2014) referred to the process of acceptance as their ability to reconcile their experience of pain by living according to their values, and they highlighted that this process goes further than accepting and adapting to pain and instead moves towards forming new relationships with the pain and with themselves. These changes resulted in enhanced self-efficacy in relation to their pain, which instigated feelings of empowerment within the participants. Casey et al. (2019) concurred with the findings of Mathias et al. (2014) on the acceptance of pain. The participants described that in their pursuit of a medical cure, their hopes would be raised, before again experiencing dissatisfaction due to ineffective interventions. Casey et al. (2019) added that in order for the participants to move on from their search for a medical cure to eliminate their pain, the participants needed to acknowledge that there is no cure for CP.

For some participants, this idea can be a shock, but it can also create new hope for the future and they are thus able to find a balance between hope and reality. Casey et al. (2019) acknowledged that the acceptance of pain is a complex and personal journey for individuals. Pietilä Holmner et al. (2018) went further and described the acceptance of pain as an on-going process throughout the group intervention. They found that learning about CP and sharing the experience of CP with other people with CP facilitated the on-going process of acceptance. This could also be understood in terms of existential factors in group therapy, which suggest that through support from others, group members learn to live with the limitations and accept life as it is (Yalom & Leszcz, 2005)

Changes in mindset

The papers all suggested that the process of acceptance facilitates change in the mindset of people with CP. Casey et al. (2019) described that acceptance can include changes in self-identity and the process of acceptance can encourage personal growth. When self-identity is flexible, it can prompt individuals to change how they see themselves. This changed self-identity can be supported by increasing awareness of and living in line with the individual's personal values. Casey et al. (2019) reported that, in accordance with the ACT processes, the changed self-identity entails seeing "self as context"; this helps the participants to separate themselves from the "conceptualised-self" and these processes build a basis for learning self-management skills. The change in the way the participants perceived themselves was also noted by Mathias et al. (2014). They reported that participants changed their perception of themselves, and their pain experience was associated with recounting feeling more confident having improved self-esteem, and being motivated to live their lives in keeping with their values.

Sense of empowerment

Five papers described that the acceptance of pain and changes in mindset led to an increased sense of empowerment among the participants (Casey et al., 2019; Dysvik et al., 2014; Mathias et al., 2014; Moore & Martin, 2015; Penney & Haro, 2019). It was suggested that this sense of empowerment meant the participants were able to benefit from the intervention after it finished (Penney & Haro, 2019). The participants described this empowerment as having a sense of control and ability to manage their pain and their behaviours and feelings by practicing self-management skills (Moore & Martin, 2015). Other participants reported feeling empowered to lead a better life (Dysvik et al., 2014). Mathias et al. (2014) noted that by accepting the pain, the participants expressed a sense of freedom as they were able to take control of their lives and do things that they enjoy. Casey et al. (2019) stated that the participants expressed a sense of empowerment after they accepted the pain and acknowledged the lack of a cure for their pain. They reported increased self-efficacy in managing their pain and they were confident in their ability to manage their pain using self-management skills. This could extend to instillation of hope in group therapy, whereby group members develop a sense of optimism about their future (Yalom & Leszcz, 2005).

Frustration and non-acceptance

Whilst many participants experienced the group interventions for pain management in a positive light, feelings of frustration and being stuck were described in the papers (Casey et al., 2019; Penney & Haro, 2019; Pietilä Holmner et al., 2018; Toye & Barker, 2012; Wilson et al., 2017). It is important to recognise that the process of accepting their pain was difficult for some participants. Participants struggled to acknowledge the losses they had endured, and their distress often emerged from past life constraints (Wilson et al., 2017). Pietilä Holmner et al.

(2018) referred to the accepting or non-accepting of pain as an on-going process that is changeable and not a static process.

Some participants perceived there to be an overwhelming threat to their identity due to their pain, and self-management skills were seen as adding further limits to their lives (Toye & Barker, 2012). For example, they saw themselves as 'sacrificed for my back', and pacing strategry was seen as a further barrier to being active. The non-acceptance of pain was reported alongside a sense of perceived injustice and of feeling abandoned by the health services (Casey et al., 2019). The participants' previous experiences of treatments were found to be significant in their sense of frustration and hopelessness since they saw themselves as the 'problem' following multiple past experiences of feeling unsupported (Wilson et al., 2017).

Self-management skills

New coping strategies

In five papers, the authors discussed the practical strategies and tools that were introduced to promote self-management during and post group intervention (Dysvik et al., 2014; Egan et al., 2017; Mathias et al., 2014; Moore & Martin, 2015; Penney & Haro, 2019). In the groups that applied CBT principles, tools were the focus of the groups, such as relaxation, pacing and exercise, and learning these tools lowered the sense of powerlessness the participants experienced in relation to their pain (Egan et al., 2017). It was found that by using the new coping strategies, the participants were able to engage in more meaningful activities that helped them to shift from self-critical thoughts, and the participants felt able to re-connect with important people in their lives (Dysvik et al., 2014; Egan et al., 2017). Mathias et al. (2014) argued that the coping strategies helped the participants increase their sense of control over their pain.

Practising mindfulness through meditation or mindful movement was seen to support participants who felt stuck and who were focusing on the past or the future in a negative way

(Mathias et al., 2014). The strategies and tools that the participants learned in the groups became skills that were transferable to the real world. Wilson et al. (2017) added that the participants felt encouraged to experiment and take on challenges in their day-to-day lives and, for some, motivation was needed to continue their practice (Moore & Martin, 2015). Egan et al. (2017) found evidence that when CBT strategies were incorporated into their lifestyle, the process was sustained following the group intervention. This also meant that the participants were able to re-engage in activities such as exercise, whereas in the past they may have had a tendency to avoid activities that would provoke pain (Mathias et al., 2014). Therefore, the participants were able to minimise the loss they might have endured and lessen distress from possible life constraints, which could diminish the perceived impact on their self-identity (Toye & Barker, 2012).

Some participants experienced challenges to practising new strategies and skills due to conflicting demands in their daily lives (Moore & Martin, 2015). Certain demands came from other people in the participants' lives and practising setting limits with others was described (Pietilä Holmner et al., 2018).

Body mind awareness

One of the aims of a CBT-based pain management intervention is to support participants to become more aware of the connection between emotions, cognition and behaviours (Dysvik et al., 2014). This allows participants to become more aware of how their internal experiences influence their responses, which helps the participants to better understand their physical and psychosocial difficulties (Wilson et al., 2017). The aim of increasing awareness of these links is not limited to CBT-based interventions and it is widely applied in psychologically informed interventions since it has been found that awareness can support behaviour change (Wilson et al., 2017). Toye and Barker (2012) reported that participants who showed significant improvements acknowledged a connection between the mind and body, and some participants accepted that their problem was to do with their mind rather than their body.

Medication use change

As a result of the pain intervention, some papers highlighted the changes in their participants’ medication usage, even when that was not the aim of the intervention. Through practicing self-management skills, the participants were either able to change the patterns of use or reduce intake (Penney & Haro, 2019). This coincided with the participants’ new approaches to managing their pain, even for those who had a dependency on medication and relied on different medications to cope day-to-day (Egan et al., 2017). Discussions about the side-effects of pain relief medication and recognising the impact of long-term medication use allowed the participants to accept that other non-medical strategies are needed to cope with pain (Pietilä Holmner et al., 2018).

Discussion

What is the experience of participating in group PMPs for people living with CP?

The review specifically explored the experience of participating in group PMPs for people living with CP. This question can be answered in relation to the three broad categories that captured the people's experience of attending PMPs, drawn from the literature summary of the nine papers in this review. The three categories were: inter-relational group experience; introspective experience; and self-management skills. Inter-relational group experience highlights the role of other people in pain management programmes, whereby relationships with other people can bring about steps towards pain management. As discussed above, a number of Yalom's therapeutic factors in group therapy were relevant to inter-relational and introspective experiences. This could suggest that there is some overlap between the therapeutic experiences of people attending PMPs and generic therapeutic factors in group therapy. Inter-relational group experience highlights the role of other people in pain management programmes whereby the relationship with other people can bring about steps towards pain management.

A strong therapeutic alliance with the group facilitators is often cited as a helpful process in improving treatment outcomes and engagement in psychological therapies (Omylinska-Thurston & Cooper, 2014) and this was reflected in the findings.

The value of meeting other people is distinctive to group treatments and it may be overlooked by clinicians as this can be regarded as a less intensive approach than individual therapies (Bowden, 2002). The findings of this review support suggestions that group therapy offers different therapeutic factors compared to individual therapy (Shechtman & Kiezel, 2016). The therapeutic nature of social support has been noted as almost consistently positive in many areas of physical and mental health, such as lowering cardiovascular disease risk and improving psychological wellbeing (Gallagher, Luttik & Jaarsma, 2011; Taylor & Stanton, 2007). To understand these social processes, social comparison theory can be used (Festinger, 1954). Individuals are likely to self-evaluate through social comparison in their opinions and abilities when there is a lack of objective information and when they are felt to be under threat (Festinger, 1954). Without objective measures of pain levels and with CP posing a threat to self-identity, people with CP may be more likely to use social comparison as a coping strategy (Affleck & Tennen, 1997). In particular, downward comparison (against someone in a worse position) has been thought to provide a more positive view of self and emotional regulation (Affleck & Tennen, 1997). These processes, therefore, may have been present in the experience of meeting other people with CP through attending PMPs. For example, in Pietilä Holmner et al. (2018), the participants described meeting those with more pain as "that led to an awakening", which than changed their view of self as "fortunate" and "lucky".

SCT (Bandura, 1986) could add to how the experience of meeting other people with CP can influence one's own thoughts and behaviour, as discussed in the category of introspective experience. By observing and participating in PMPs, the participants were able to accept their pain and the process of acceptance seemed to facilitate changes in the mindset of people with CP. The participants' experience of increased sense of empowerment appeared to link with enhanced self-efficacy (Bandura, 1997) and their ability to manage their pain and behaviours. Therefore, the findings appear to support the assertion that PMPs can enhance pain-related self-efficacy (Strong et al., 2002). These findings also complement the findings of Devan et al. (2018), as they highlight the potential relationship between self-efficacy, distinguishing self from pain, and acceptance in self-management following the intervention. However, this finding was not universally present, since some participants described frustration and a sense of non-acceptance. Since only two papers (Toye & Barker, 2012; Wilson et al., 2017) have looked at the experience of people who did not find the PMPs beneficial or helpful, the current literature in this area may lack understanding of the reasons why some people find the PMPs helpful or unhelpful, which would be clinically relevant.

In the category of self-management skills, the participants discussed that learning practical strategies and tools enabled them to engage in more meaningful activities that helped them to shift from self-critical thoughts, and the participants then felt able to re-connect with important people in their lives (Dysvik et al., 2014; Egan et al., 2017). This was in contrast to their experience of deactivating to avoid pain prior to the group, which can be explained through the operant theory of pain behaviour (Fordyce, 1976). Pain behaviours such as reducing activity may become unhelpful in CP since they contribute to disability and result in withdrawal of positive reinforcement (e.g. disengaging from meaningful activities) (Jensen & Turk, 2014).

In the PMPs, however, the focus was on supporting the individuals to become more aware of how their internal experiences influence their responses (Wilson et al., 2017) and supporting the participants in self-monitoring of emotions, cognition and behaviours and how these interact (Dysvik et al., 2014). This is rooted in the fear avoidance model (Vlaeyen & Linton, 2000) and how pain is interpreted and the behaviour in response to the interpretation. These processes were found in the papers that looked at CBT-PMPs (Dysvik et al., 2014; Egan et al., 2017). The participants described an increasing sense of control over their pain and reduced self-critical thoughts as CBT addresses misinterpretation of CP and the subsequent consequences of unhelpful pain behaviours (Keefe et al., 1992). The findings in this review complement the findings from Devan et al. (2018) which highlighted the potential relationship between self-efficacy, distinguishing self from pain, and acceptance as important in self-management of CP following intervention.

The gate control theory (Melzack & Wall, 1965) further helps to explain the findings in this study, as the PMP studies looked at psychological, social and environmental factors moderating the perception of pain. It appears that the biopsychosocial approach in the PMPs brings together the physical and psychological factors, thereby enhancing self-management skills, encapsulating coping strategies, body-mind awareness and changes in medication use.

Some papers in the current review asked more questions about the specific therapeutic interventions (e.g. mindfulness, exercise), rather than the overall group processes. Whilst understanding interventions-specific therapeutic processes may be beneficial, the findings in these studies may be further limited in their applicability. The limited amount of qualitative research in this field also makes it difficult to unpick specific differences within the group processes (e.g. between CBT-PMPs and ACT-based PMPs). Moreover, the majority of the papers used an overarching diagnostic category of CP and did not specify the participants' physical ailment (where applicable) underlying the CP. Further, omission of participant details (e.g. ethnicity), assumes a level of homogeneity among CP patients when, in fact, they are a heterogeneous group since the pain experience is affected by gender (Samulowitz, Gremyr, Eriksson & Hensing, 2018), physical ailment or lack of identifiable medical cause (Wilson, 2017), and ethnicity (Booker, 2016).

Limitations of the review

One of the limitations of the current review was that due to the limited number of extant qualitative studies, studies that looked at different types of PMPs were combined. Although there are a number of overarching processes, therapeutic differences may have become apparent if the review had set out to identify group differences, e.g. between ACT-based PMPs and CBT-PMPs. Moreover, due to the small number of papers included in this review, the findings are not generalisable and caution should be taken in applying them. However, there might be some helpful considerations that clinicians could to take into account.

Implications for practice

When developing or facilitating PMPs for people with CP, clinicians may want to consider the three main components interpreted as important in the participants' experiences of attending PMPs. Since the participants valued the inter-relational experiences within the groups, facilitators could be mindful of allowing space for discussion where people can share their experiences.

This also means that PMPs may benefit from not being overly didactic or information-heavy, potentially suggesting the importance of the non-expert positioning of facilitators. Sharing between participants may allow the therapeutic group processes noted by Yalom and Leszcz (2005) to occur in the PMPs. It may be beneficial to not have overly large groups or for facilitators to encourage small group discussions among participants to enable people to feel accepted and not be seen as the 'problem'.

The review suggests that certain processes can facilitate the gradual acceptance of pain in participants' lives as a prerequisite for the participants' future adjustment and pain management. Some of this would be important for the group facilitators to keep in mind as they deliver PMPs. For example, the group attendees can be helped to recognise that they can continue with their lives while experiencing pain by focusing on what they are able to do rather than what they were able to do before CP. This might involve moving past the pursuit of a medical solution to eliminate pain. Such processes are consistent with the ACT model of therapy (Hayes, 2016).

Research recommendations

Future research into the experience of people with CP attending PMPs may want to sample participants who did not perceive the intervention to be beneficial or helpful. Qualitative studies of those who have not benefited may provide more information about why PMPs are helpful for some and not others. This may suggest differences in subgroups of participants that could be identified (Turk, 2004). This is important since it has been suggested that patients with CP can become discouraged from engaging in psychological interventions if they perceive previous interventions as not positive (Simons, Sieberg & Coakley, 2013).

Since there was a notable lack of male representation in the literature, future research may want to reduce the gender bias in their recruitment. Gendered norms have been shown to have negative consequences for men with CP in healthcare, so gender bias should be counteracted in the research in order to develop understanding that may translate into more equitable care (Samulowitz et al., 2018). Future research may also wish to be more transparent about the ethnicity of the participants, since pain experiences may vary across cultures. For example, a review found that African Americans perceived greater severity and intensity of pain for longer durations, which was also underassessed and undermanaged (Booker, 2016).

All studies except one, grouped CP together rather than grouping participants using diagnostic categories. This is a notable gap within the current literature because the outcomes of PMPs vary across different medical conditions that result in CP. Recent Cochrane reviews have shown that PMPs have a good effect on chronic low back pain (Kamper et al., 2015) but a weak effect on chronic neck pain (Monticone et al., 2015) whilst there is no robust evidence on chronic neuropathic pains, such as cancer pain or pain from traumatic injury (Eccleston, Hearn & Williams, 2015). Therefore, future research may wish to consider exploring PMP experiences for specific disease conditions, e.g. cancer pain or chronic pain in sickle cell disease. This may be important as it could highlight essential clinical adaptations that need to be made.

Conclusion

This review explored the current literature on the experiences of people with CP attending PMPs. The overall experience of the PMPs was reportedly positive. Three categories were identified: the inter-relational group experience; the introspective experience; and self-management skills. The papers described the value of meeting other people with CP and the therapeutic alliance with the group facilitators as supportive processes that occur between people. The group participants experienced a sense of acceptance of their pain that seemed to enhance feelings of empowerment, although some struggled with acceptance and expressed frustrations with their pain. A shift in how participants thought about themselves seemed to facilitate the development of self-management skills including learning new coping strategies, increasing body-mind awareness and changing their medication use. All papers, except for one, included participants with CP arising from different physical ailments. However, since there are differences in how effective PMPs are for different conditions, future research may wish to explore PMP experiences for people with different underlying health conditions that are contributing to the experience of CP.

References

Affleck, G., & Tennen, H. (1997). Social comparison as a coping process: A critical review and application to chronic pain disorders. In Buunk, B, P., Gibbons, F, X. (Eds), *Health, coping, and well-being: Perspectives from social comparison theory* (pp. 263-298). NJ: Lawrence Erlbaum.

Bandura, A. (1986). *Social foundations of thought and action: A Social Cognitive Theory.* Englewood Cliffs, NJ: Prentice Hall.

Bandura, A. (1997). *Self-Efficacy: The Exercise of Control.*, New York, USA: W. H. Freeman and Company

Booker, S. Q. (2016). African Americans' perceptions of pain and pain management: A systematic review. *Journal of transcultural nursing*, *27*(1), 73-80. https://doi.org/10.1177%2F1043659614526250

Bowden, M. (2002). Anti-group attitudes at assessment for psychotherapy. *Psychoanalytic Psychotherapy, 16*, 246-258. https://doi.org/10.1080/14749730210163453

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*, 77-101. https://doi.org/10.1191/1478088706qp063oa

British Pain Society. (2013). Guidelines for pain management programmes for adults. Retrieved from https://www.britishpainsociety.org/static/uploads/resources/files/pmp2013_main_FINAL_v6.pdf

British Medical Association. (2017). Chronic pain: supporting safer prescribing of analgesics. Retrieved from https://tinyurl.com/ydfzy7gn

Casey, M. B., Smart, K. M., Hearty, C., Lowry, D., & Doody, C. (2019). Acceptance of chronic pain. Perspectives of individuals following an Acceptance and Commitment Therapy pain management programme: An interpretative phenomenological analysis.

Physiotherapy Practice and Research, 40(1), 9-19. https://doi.org/10.3233/PPR-180120

Devan, H., Hale, L., Hempel, D., Saipe, B., & Perry, M. A. (2018). What works and does not work in a self-management intervention for people with chronic pain? Qualitative systematic review and meta-synthesis. *Physical therapy, 98*(5), 381-397. https://doi.org/10.1093/ptj/pzy029

Dominick, C. H., Blyth, F. M., & Nicholas, M. K. (2012). Unpacking the burden: understanding the relationships between chronic pain and comorbidity in the general population. *Pain, 153*(2), 293–304. https://doi.org/10.1016/j.pain.2011.09.018

Dysvik, E., Kvaløy, J. T., & Furnes, B. (2014). A mixed-method study exploring suffering and alleviation in participants attending a chronic pain management programme. *Journal of Clinical Nursing, 23*(5-6), 865-876. https://doi.org/10.1111/jocn.12270

Eccleston, C., Hearn, L., & de C Williams, A. C. (2015). Psychological therapies for the management of chronic neuropathic pain in adults. *Cochrane Database of Systematic Reviews, 10*, 1-30. https://doi.org/10.1002/14651858.CD011259.pub2

Egan, A., Lennon, O., Power, C. K., & Fullen, B. M. (2017). “I've actually changed how I live” Patients’ long-term perceptions of a cognitive behavioral pain management program. *Pain Medicine, 18*(2), 220-227. https://doi.org/10.1093/pm/pnw148

Elliot, A. M., Smith, B. H., Penny, K. I., Smith, C. W., & Chambers, A. W. (1999). The epidemiology of chronic pain. *The Lancet, 354*, 1248–1252. https://doi.org/10.1016/S0140-6736(99)03057-3

Engel, G. L. (1977). The need for a new medical model: A challenge for biomedicine. *Science*, *196*(4286), 129-136. https://doi.org/10.1126/science.847460

Fayaz, A., Croft, P., Langford, R. M., Donaldson, L. J., & Jones, G. T. (2016). Prevalence of chronic pain in the UK: A systematic review and meta-analysis of population studies. *BMJ open, 6*(6), 1-13. https://doi.org/10.1136/bmjopen-2015-010364

Fedoroff, I. C., Blackwell, E., & Speed, B. (2014). Evaluation of group and individual change in a multidisciplinary pain management program. *The Clinical Journal of Pain, 30*(5), 399-408. https://doi.org/101097/AJP.0b013e31829ea1f7

Festinger, L. (1954). A theory of social comparison processes. *Human Relations, 7*, 117–140. https://doi.org/10.1177/001872675400700202

Finlay, K. A., & Elander, J. (2016). Reflecting the transition from pain management services to chronic pain support group attendance: An interpretative phenomenological analysis. *British Journal of Health Psychology, 21*(3), 660–676. https://doi.org/10.1111/bjhp.12194

Fordyce, W. E. (1976). *Behavioral methods for chronic pain and illness*. Saint Louis, MO: Mosby.

Gallagher, R., Luttik, M. L., & Jaarsma, T. (2011). Social support and self-care in heart failure. Journal of Cardiovascular Nursing, 26(6), 439-445. https://doi.org/10.1097/JCN.0b013e31820984e1

Goldberg, D. S., & McGee, S. (2011). Pain as a global public health priority. *British Medical Council Public Health, 11*, 770–774. https://doi.org/10.1186/1471-2458-11-770

Goubert, L., Vlaeyen, J. W. S., Crombez, G., & Craig, K. D. (2011). Learning about pain from others: An observational learning account. *The Journal of Pain, 12*(2), 167–174. https://doi.org/10.1016/ j.jpain.2010.10.001

Hayes, S. C. (2016). Acceptance and commitment therapy, relational frame theory, and the third wave of behavioral and cognitive therapies. *Behavior therapy, 47*(6), 869-885. https://doi.org/10.1016/j.beth.2016.11.006

Hayes, S. C., Levin, M. E., Plumb-Vilardaga, J., Villatte, J. L., & Pistorello, J. (2013). Acceptance and commitment therapy and contextual behavioral science: Examining the progress of a distinctive model of behavioral and cognitive therapy. *Behavior Therapy, 44*(2), 180–198. https://doi.org/10.1016/ j.beth.2009.08.002

Hayes, S. C., Strosahl, K., & Wilson, K. G. (1999). *Acceptance and commitment therapy: Understanding and treating human suffering.* New York: Guilford.

International Association for the Study of Pain (2004). Unrelieved pain is a major global healthcare problem. Retrieved from https://tinyurl.com/y755r7cu

International Association for the Study of Pain (2011). IASP pain terminology. IASP Task Force on Terminology. Retrieved from https://www.iasp-pain.org/Education/Content.aspx?ItemNumber=1698

Jensen, M. P., & Turk, D. C. (2014). Contributions of psychology to the understanding and treatment of people with chronic pain: Why it matters to all psychologists. *American Psychologist, 69*(2), 105-118. https://doi.org/10.1037/a0035641

Kamper, S. J., Apeldoorn, A. T., Chiarotto, A., Smeets, R. J. E. M., Ostelo, R. W. J. G., Guzman, J., & Van Tulder, M. W. (2015). Multidisciplinary biopsychosocial rehabilitation for chronic low back pain: Cochrane systematic review and meta-analysis. *British Medical Journal, 350*, 1-11. https://doi.org/10.1136/bmj.h444

Keefe, F. J., Dunsmore, J., & Burnett, R. (1992). Behavioral and cognitive-behavioral approaches to chronic pain: Recent advances and future directions. *Journal of Consulting and Clinical Psychology, 60*(4), 528-536. https://doi.org/10.1037/0022-006X.60.4.528

Keefe, F. J., Rumble, M. E., Scipio, C. D., Giordano, L. A., & Perri, L. M. (2004). Psychological aspects of persistent pain: Current state of the science. *Journal of Pain, 5*(4), 195-211. https://doi.org/10.1016/j.jpain.2004.02.576

Linton, S. J., & Bergbom, S. (2011). Understanding the link between depression and pain. *Scandinavian Journal of Pain, 2*(2), 47–54. https://doi.org/10.1016/j.sjpain.2011.01.005

Mathias, B., Parry-Jones, B., & Huws, J. C. (2014). Individual experiences of an acceptance-based pain management programme: An interpretative phenomenological analysis. *Psychology & Health, 29*(3), 279-296. https://doi.org/10.1080/08870446.2013.845667

McCracken, L. (1998). Learning to live with pain: acceptance of pain predicts adjustment in persons with chronic pain. *Pain, 74*, 21–27. https://doi.org/10.1016/S0304-3959(97)00146-2

McCracken, L. M., & Turk, D. C. (2002). Behavioral and cognitive–behavioral treatment for chronic pain: Outcome, predictors of outcome, and treatment process. *Spine, 27*(22), 2564-2573. https://doi.org/10.1097/00007632-200211150-00033

Melzack, R., & Wall, P. D. (1965). Pain mechanisms: A new theory. *Science, 150*(3699), 971-979. https://doi.org/10.1126/science.150.3699.971

Monticone, M., Cedraschi, C., Ambrosini, E., Rocca, B., Fiorentini, R., Restelli, M., ... & Moja, L. (2015). Cognitive-behavioural treatment for subacute and chronic neck pain. *Cochrane Database of Systematic Reviews, 5,* 1-13. https://doi.org/10.1002/14651858.CD010664.pub2

Moore, K. M., & Martin, M. E. (2015). Using MBCT in a chronic pain setting: A qualitative analysis of participants' experiences. *Mindfulness, 6*(5), 1129-1136. https://doi.org/10.1007/s12671-014-0363-6

Morone, N. E., Greco, C. M., & Weiner, D. K. (2008). Mindfulness meditation for the treatment of chronic lower back pain in older adults: A randomized controlled pilot study. *Pain, 134*, 310–319. https://doi.org/10.1016/j.pain.2007.04.038

Morse, J. M., & Niehaus, L. (2009). *Mixed method design: Principles and procedures.* New York: Routledge.

Osborn, M., & Rodham, K. (2010). Insights into pain: A review of qualitative research. *Reviews in Pain, 4*(1), 2-7. https://doi.org/10.1177/204946371000400102

Omylinska-Thurston, J., & Cooper, M. (2014). Helpful processes in psychological therapy for patients with primary cancers: A qualitative interview study. *Counselling and Psychotherapy Research*, 14(2), 84-92. https://doi.org/10.1080/14733145.2013.813952

Penney, L. S., & Haro, E. (2019). Qualitative evaluation of an interdisciplinary chronic pain intervention: Outcomes and barriers and facilitators to ongoing pain management. *Journal of Pain Research, 12*, 865-878. https://doi.org/10.2147/JPR.S185652

Pietilä Holmner, E., Stålnacke, B. M., Enthoven, P., & Stenberg, G. (2018). "The acceptance" of living with chronic pain. An ongoing process: A qualitative study of patient experiences of multimodal rehabilitation in primary care. *Journal of rehabilitation medicine, 50*(1), 73-79. https://doi.org/10.2340/16501977-2286

Price C, Hoggart B, Olukoga O, Williams A and Bottle A (2013) Guidelines for pain management programmes for adults: An evidence-based review prepared on behalf of the British Pain Society, The British Pain Society: London. Retrieved from https://www.britishpainsociety.org/static/uploads/resources/files/pmp2013_main_FINAL_v6.pdf

Royal College of Anaesthetists. (2015). Core standards for pain management services in the UK. London: Royal College of Anaesthetists. Retrieved from https://fpm.ac.uk/standards-publications-workforce/core-standards

Royal College of General Practitioners. (2014). Pain management services: Planning for the future. London: Royal College of General Practitioners. Retrieved from https://www.rcgp.org.uk/-/media/Files/CIRC/Chronic-pain/RCGP-Commissioning-Pain-Management-Services-Jan-14.ashx?la=en

Samulowitz, A., Gremyr, I., Eriksson, E., & Hensing, G. (2018). “Brave men” and “emotional women”: A theory-guided literature review on gender bias in health care and gendered norms towards patients with chronic pain. *Pain Research and Management, 2018,* 1-14. https://doi.org/10.1155/2018/6358624

Sandborgh, M., Johansson, A. C., & Söderlund, A. (2016). The relation between the fear-avoidance model and constructs from the social cognitive theory in acute WAD. *Pain Research and Management, 2016*, 1-7 https://doi.org/10.1155/2016/8281926

Shechtman, Z., & Kiezel, A. (2016). Why do people prefer individual therapy over group therapy?. International Journal of Group Psychotherapy, 66, 571-591. https://doi.org/10.1080/00207284.2016.1180042

Simons, L. E., Sieberg, C. B., & Coakley, R. M. (2013). Patients with pain are not all the same: considering fear of pain and other individual factors in treatment. *Pain management, 3*(2), 87-89. https://doi.org/10.2217/pmt.12.85

Smarr, K. L., Parker, J. C., Wright, G. E., Stucky-Ropp, R. C., Buckelew, S. P., Hoffman, R. W., ... & Hewett, J. E. (1997). The importance of enhancing self-efficacy in rheumatoid arthritis. *Arthritis & Rheumatism: Official Journal of the American College of Rheumatology, 10*(1), 18-26. https://doi.org/10.1002/art.1790100104

Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretative phenomenological analysis: Theory, method and research.* Los Angeles: SAGE.

Strong, J., Westbury, K., Smith, G., McKenzie, I., & Ryan, W. (2002). Treatment outcome in individuals with chronic pain: is the Pain Stages of Change Questionnaire (PSOCQ) a useful tool? *Pain, 97*(1-2), 65-73. https://doi.org/10.1016/S0304-3959(01)00493-6

Taylor, S. E., & Stanton, A. L. (2007). Coping resources, coping processes, and mental health. *Annual review of clinical psychology*, 3, 377-401. https://doi.org/10.1146/annurev.clinpsy.3.022806.091520

Thomas, J., & Harden, A. (2008). Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC medical research methodology, 8*, 1-10. https://doi.org/10.1186/1471-2288-8-45

Toye, F., & Barker, K. (2012). 'I can't see any reason for stopping doing anything, but I might have to do it differently'–Restoring hope to patients with persistent non-specific low back pain–a qualitative study. *Disability and rehabilitation*, *34*(11), 894-903. https://doi.org/10.3109/09638288.2011.626483

Turk, D. C. (2005). The potential of treatment matching for subgroups of patients with chronic pain: Lumping versus splitting. *The Clinical Journal of Pain, 21*(1), 44-55. https://doi.org/10.1097/00002508-200501000-00006

Veehof, M. M., Oskam, M., Schreurs, K. M. G., & Bohlmeijer, E. T. (2011). Acceptance-based interventions for the treatment of chronic pain: A systematic review and meta-analysis. *Pain, 152*, 533–542. https://doi.org/10.1016/j.pain.2010.11.002

Vlaeyen, J. W., & Linton, S. J. (2000). Fear-avoidance and its consequences in chronic musculoskeletal pain: A state of the art. *Pain, 85*(3), 317-332. https://doi.org/10.1016/S0304-3959(99)00242-0

Weinman, J., & Petrie, K. J. (1997). Illness perceptions: A new paradigm for psychosomatics? *Journal of psychosomatic research, 42*(2), 113-116. https://doi.org/10.1016/s0022-3999(96)00294-2

Wideman, T. H., Boom, A., Dell'Elce, J., Bergeron, K., Fugère, J., Lu, X., Bostick, G. & Lambert, H. C. (2016). Change narratives that elude quantification: A mixed-methods analysis of how people with chronic pain perceive pain rehabilitation. *Pain Research and Management, 9570581*, 1-14. https://doi.org/10.1155/2016/9570581

Williams, A. C., Eccleston, C., & Morley, S. (2012). Psychological therapies for the management of chronic pain (excluding headache) in adults. *Cochrane Database of Systematic Reviews,* 2, 1-105. https://doi.org/10.1002/14651858.CD007407.pub3

Wilson, I. R. (2017). Management of chronic pain through pain management programmes. *British Medical Bulletin, 124*(1), 55–64. https://doi.org/10.1093/bmb/ldx032

Wilson, S., Chaloner, N., Osborn, M., & Gauntlett-Gilbert, J. (2017). Psychologically informed physiotherapy for chronic pain: Patient experiences of treatment and therapeutic process. *Physiotherapy, 103*(1), 98-105. https://doi.org/10.1016/j.physio.2015.11.005

Section B: Empirical Paper

The Therapeutic Mechanisms That Are Unique in a Sickle Cell Pain Management Programme. A Grounded Theory.

Word Count: 8,000 (300)

A thesis submitted in partial fulfilment of the requirements of Canterbury Christ Church University for the degree of Doctor of Clinical Psychology and prepared for submission to the British Journal of Health Psychology

October 2020

This Page Intentionally Left Blank

Abstract

Sickle cell disease is the most common genetic disorder in the UK that is life-limiting and lifelong for the individual. As pain is the main disease characteristic, Sickle cell pain management programmes (SCPMPs) have emerged as treatment options. This study aimed to explore the therapeutic mechanisms that are perceived to be present in SCPMPs.

Eight participants who attended SCPMPs, two from general pain management programmes and two group facilitators, were recruited from two haematology services. Semi-structured interviews with each participant were analysed using a grounded theory methodology. A model was derived that set out the perceived therapeutic process which included the key processes of learning about pain, sharing and relating within the group. All participants from the SCPMPs described a shift in their experiences of pain, which may have contributed to the development of a more positive sickle cell identity through acceptance and change. In contrast, non-specific ground attendees felt less understood in the group.

The model adds to the current literature on the unique medical experiences of SCD as an important variation in the SCPMP when compared to general PMPs. The therapeutic processes that can occur within a SCPMP provide tentative support for the acceptability of a SCPMP.

Keywords: Sickle Cell Disease, Pain management group, therapeutic process, group process

Introduction

Sickle cell disease

Sickle cell disease (SCD) is an inherited chronic blood disorder. It is the most common genetic disorder in the UK and most prevalent in the British Black African, Black Caribbean and Indian populations, affecting “1 in 4 West Africans and 1 in 10 Afro-Caribbeans” (Sickle Cell Society, 2008). There are different types of SCD, including HbSS, HbSC and beta-thalassemia, each varying in their severity.

SCD occurs due to haemoglobin being partly or entirely affected in red blood cells. The affected blood cells can distort into a sickle shape, which can lead to vaso-occlusion: circulation obstructed by sickle blood cells thus disrupting the oxygen supply to body tissues (Edwards et al., 2005). Resultantly, people living with SCD are at increased risk of developing serious physical health complications which can significantly impact the illness and death rate among people with SCD (National Institute for Health and Care Excellence; NICE, 2012). There are several notable psychosocial implications including experiencing discrimination and stigma associated with SCD and impacts on mental health and quality of life (Bergman & Diamond, 2013; Thomas & Taylor, 2002, Anie, 2005; Edwards et al., 2009).

Chronic pain and acute pain

The main characteristics of SCD are acute and chronic pain (SCP). Acute vaso-occlusive pain, known as a ‘crisis’, represents the most frequent cause of hospital attendance, often resulting in acute hospital admissions (Matthie et al., 2019). Chronic pain, defined as pain or discomfort that is persistent or sporadic, can last for more than three months (Elliot et al., 1999) and is persistent on most days for more than six months (Dampier et al., 2017). Unlike acute pain, clinical guidance for chronic pain is not as clear (NICE, 2012). For instance, opioids are commonly used despite insufficient evidence of effectiveness (Matthie et al., 2019). Some patients have even reported greater pain experience, worsened functioning and increased hospital usage on chronic opioid therapy (Carroll et al., 2016).

Pain management programmes

Pain management programmes (PMPs) are effective clinical interventions to help manage chronic pain, primarily aimed at improving coping with pain, rather than removing the experience of pain (Morley, Williams & Hussain, 2008; Williams, Eccleston & Morley, 2012). Current guidance on PMPs (British Pain Society, 2013) suggests that they include medication management, physiotherapy and psychological approaches. Programmes use a biopsychosocial model of chronic pain and cognitive-behavioural therapy principles (CBT; Adams, Poole & Richardson, 2005).

Recently, PMPs for adults with SCD (SCPMPs), based on principles of CBT, have been recommended by the Sickle Cell Society (2018), in tandem with core standards for highly specialised pain management services in the UK (Faculty of Pain Medicine, 2015). Despite examples of specialised PMPs for SCP emerging in some parts of the UK (e.g. St George's Hospital, 2020), there are no published guidelines describing best practices for SCPMPs. A gap in guidance on SCPMPs may mean that people with SCD are not offered the most appropriate chronic pain intervention (Matthie et al., 2019). The interaction between complex aspects of SCD (e.g. mental health and cultural awareness) and specialist PMPs are likely to present a number of unique differences and opportunities for clinicians (e.g. Thomas & Cohn, 2006) and warrants specific attention.

Mental health

There are many implications regarding the psychological well-being of people with SCD, which include impaired daily functioning that leads to reduced quality of life and unhelpful strategies to cope with pain, which compounds anxiety and depression and neuropsychological complications (Anie, 2005). Due to the lifelong nature of SCD, these complications begin in early life to adulthood. It is recommended that standards of clinical care should be flexible in order to accommodate the high levels of depression and anxiety that have been identified in people with SCD (Edwards et al., 2009).

A number of theories have been advanced that may account for the observed mental health difficulties that people with SCD can experience. Leventhal's common-sense model (CSM) considers the way people respond to illness, noting that coping strategies are influenced by the way personal experiences and information are interpreted by the individual managing a health condition (an 'illness perception'), which can impact outcomes (Huston & Houk, 2011). Additionally, the attributional model of depression explains that when difficulties are seen as uncontrollable, unchanging and pervasive, individuals are more vulnerable to developing depressive symptoms (Abramson, Seligman & Teasdale, 1978).

Psychological treatment-specific factors warrant consideration. Although CBT has been shown to be helpful for the affective component of pain severity in SCD, evidence is insufficient to demonstrate improved coping abilities (Anie & Green, 2015). Treatment outcomes from CBT for SCP are also not universally positive, with some recipients showing unexplained decreases in scores on pain coping and mental wellbeing (Thomas, Dixon and Milligan, 1999).

The medical experience of SCD

The unpredictable nature of SCD can mean that some struggle to manage symptoms (Anie, Steptoe & Bevan, 2002). Symptom management and treatment adherence do not directly address the difficulties with daily functioning and quality of life due to the complex nature of SCD (Masuda, Cohen, Wicksell, Kemani & Johnson, 2011). The experience of recurrent pain episodes across the lifespan, where opioids are used to manage crises, makes SCP unique among pain conditions (Taylor, Stotts, Humphreys, Treadwell & Miaskowski, 2010, Matthie et al., 2019). Given that the underlying mechanism of SCP is unclear, it has been suggested that SCP pathophysiology may be different from other chronic pain syndromes (Field, 2017). Consequently, there is limited information on chronic SCP, leading to undertreatment and challenging clinic management (Taylor et al., 2010; Matthie et al., 2019).

The experience of both acute and chronic pain among people with SCD suggests that PMPs for people with SCD need to be adapted for chronic pain to consider the nuances of the SCD pain experience. This may warrant special consideration by SCPMP facilitators as this is an aspect of the condition that general PMPs may overlook.

Stigma and culture

‘Stigma’ is a social phenomenon in which a label becomes attached to a person or group, leading to a negative effect on the individual (Link & Phelan, 2013). Illness stigma attached to SCD can be pervasive at multiple levels in the interaction between disease and treatment. People with SCD experience health-related stigma and discrimination in the healthcare system (Bergman & Diamond, 2013). The misconception that SCD only affects people of Afro-Caribbean descent also fuels racism and structural marginalisation, leading to inequalities within healthcare (Bulgin, Tanabe & Janerette, 2018). Fallacious beliefs about opioid use for pain management can perpetuate health-related stigma alongside the usual challenges of living with a chronic condition (Bergman & Diamond, 2013, Matthie et al., 2019).

People with SCD may also feel stigmatised within their own communities due to myths about SCD etiology and prognosis, meaning that SCD is often not discussed and the condition ‘hidden’ (Burnes, Antle, Williams & Cook, 2008). This can create burden on the individual which negatively impacts on health-seeking behaviour (Holloway, McGill & Bediako, 2017). Studies have described the effects of stigma on wellbeing, noting increased social isolation, anxiety and depression, and reduced treatment outcomes for people with SCD (Bediako et al., 2016; Bulgin et al., 2018). Such findings suggest the need to better understand how the issues relating to stigma in group SCPMPs are experienced and managed.

The intervention group experience

In the absence of SCPMPs, people with SCD may attend general, transdiagnostic PMPs which include attendees with a range of physical conditions (Brassington, 2016). In the case of SCD however, specific features (e.g. illness stigma) have been found to introduce unhelpful differences among group members, disrupting group processes (Brassington, 2016).

Given that individuals with SCD may feel misunderstood about their sickle cell pain by those who have not experienced it themselves (Coleman, Ellis-Caird, McGowan & Benjamin, 2016; Thomas & Taylor, 2002), it is possible that SCPMPs may reduce feelings of isolation as a result of being in a group with other people with SCD (Thomas & Taylor, 2002; Caird, Camic & Thomas, 2011). For example, people who attended general PMPs, described having their pain experience validated that reduced feelings of isolation that had emerged as a result of pain (Egan, Lennon, Power & Fullen, 2017). This is relevant, as interpersonal experiences are thought to be important in group therapy for facilitating beneficial and meaningful change through supportive and self-revelatory factors (Yalom & Leszcz, 2005). Accordingly, attending a SCD-specific group may further enhance the therapeutic processes. However, more research is needed to understand the role of similarity of interpersonal experiences within the SCPMP context.

Qualitative approaches

The value of qualitative research has been recognised for exploring the patient perspective in depth (Osborn & Rodham, 2010). While quantitative research can show effectiveness, it can also miss the nuanced and multi-layered experience of attending a therapy group, especially relevant when studying therapeutic group interventions (Wideman et al., 2016). In the case SCMPs, qualitative methods may also be useful for advancing understanding of the unique experiences specific to people with SCD, such as the impact of SCD on wellbeing, the experience of chronic and acute pain, stigma, and interpersonal group experiences.

More specifically, qualitative grounded theory designs can be useful in creating a conceptual understanding of the therapeutic mechanism and its components, which adds to the development of theory (Bulgin et al., 2018). Such exploratory approaches may help with understanding possible unique therapeutic mechanisms within SCPMP, and why these may be meaningful for SCD pain management and other aspects of life more broadly.

Aims

This study aimed to explore the therapeutic mechanisms that are perceived in a SCPMP. These findings may inform healthcare services and health professionals providing PMPs for people with SCD through helping to contribute to guidelines for clinical practice.

Methodology

Design

A qualitative research design was adopted in this study as it focuses on developing an understanding of a participant's experience of an event (Osborn & Rodham, 2010). Given the research aim, a grounded theory method was considered appropriate to understand the therapeutic mechanisms within SCPMPs. A scarcity of theoretical literature on the processes within the SCPMPs substantiated the appropriateness of the grounded theory design, which is useful when there is limited existing theory (Urquhart, 2012).

Epistemological stance

A critical realist epistemological position was adopted by the author (Bhaskar, 1978). This position in part aligns with a positivist principle whereby it is thought that a reality exists independent of a person's mind, and this reality consists of multiple layers of complex causal relationships (Oliver, 2011). Critical realism steers away from a purely positivist position by acknowledging that humans play a role in constructing what constitutes knowledge through science and the influence of language and social power (Gorski, 2013). The biological explanation of SCD is rooted in positivism, whereas the subjective and recounted experience of people living with SCD is grounded in a constructivist stance. Therefore, the assumptions and the epistemological position of the critical realist were deemed to be appropriate, in line with the grounded theory approach of Strauss and Corbin (1998).

Participants

In total, 12 participants volunteered to take part in the study. The recruitment of the participants entailed three stages. The first stage involved recruiting eight participants who attended a SCPMP in a metropolitan city in the UK, to which the author had no direct connections (Table 5). Nine participants were initially contacted but one participant was unable to take part due to related health reasons.

Table 5 *Stage 1 participant characteristics*

Pts	Age	Gender	Ethnic origin	Employment	Time since attended PMP	Current well-being	PMP helpfulness
P1	43	F	Black African	Student	> 1 year	4	5
P2	39	F	Black African/ British	Self-employed	> 1 year	4	5
P3	51	F	British African	Homemaker/carer	> 1 year	2	5
P4	57	F	British African	Homemaker/carer	> 1 year	4	4
P5	43	F	African	Self-employed	> 1 year	2	5
P6	46	F	Black African	Full time employment	> 1 year	4	4
P7	57	F	British African	Self-employed	> 1 year	3	5
P8	35	F	Black British	Part-time employed	> 1 year	3	5

Well-being: 1 = Very poor, 2 = Poor, 3 = Neither good nor poor, 4 = Good, 5 = Very good
Perceived helpfulness of PMP: 1 = Very unhelpful, 2 = Fairly unhelpful, 3 = Moderately helpful, 4 = Helpful, 5 = Very helpful

The second stage involved recruiting two facilitators of the same SCPMP (a specialist physiotherapist and clinical psychologist). The participant characteristics of the facilitators were omitted to protect their confidentiality. In the third stage, two participants were recruited who had each attended a general PMP which had taken place in a different hospital in second NHS trust (Table 6).

Table 6 *Stage 3 participant characteristics*

Pts	Age	Gender	Ethnic origin	Employment	Time since attended PMP	Current well-being	PMP helpfulness
P11	58	F	Black British	Retired	> 1 year	3	4
P12	48	F	Black British	Unemployed	> 1 year	3	4

Well-being: 1 = Very poor, 2 = Poor, 3 = Neither good nor poor, 4 = Good, 5 = Very good
Perceived helpfulness of PMP: 1 = Very unhelpful, 2 = Fairly unhelpful, 3 = Moderately helpful, 4 = Helpful, 5 = Very helpful

The inclusion and exclusion criteria were set out for the participants from stage 1 and 3 (Table 7). SCD was considered to include all types of SCD, as SCD is a frequently used medical classification that encapsulates occurrences when ‘the sickle gene is inherited from at least one parent’ (Ballas, 2018). These criteria also ensured that all patients who attended the SCPMP were eligible to volunteer. The exclusion criteria were specified to ensure that the potential participants had the capacity to consent to take part.

Table 7 *Inclusion and exclusion criteria of the participants from stages 1 and 3*

Inclusion Criteria	Exclusion Criteria
Adults with SCD 18 years old and above	Anyone in a physical health crisis.
Speaks fluent English.	Anyone who has experienced neurological episodes since taking part in PMP or has lost the capacity to consent.
Experiences SCP	

The three groupings of participants were employed to reflect the theoretical sampling used in grounded theory, whereby sampling develops as the theory builds from emerging concepts (Urquhart, 2012). The facilitators of the SCPMPs (stage 2) were included to check the emerging theory. The participants who did not attend the SCPMP (stage 3) were finally included to identify the unique process involved in the SCPMPs compared to the general PMPs for people with SCD.

Procedure

Recruitment

The recruitment procedure is detailed in Table 8. The relatively small number of people who attended the SCPMP meant that this limited the scope of the theoretical sampling. Interviews were arranged if participants agreed to participate. Following each interview, a brief demographic questionnaire was administered to identify heterogenicity (Appendix 7).

Table 8 *Recruitment strategy*

Stage	Procedures
Stage 1- SCPMP participants*	1. Potential participants from a SCPMP were initially identified by a clinical psychologist with whom they were familiar. 2. Verbal consent to be contacted by the author obtained. 3. Provided with a participant information sheet (Appendix 3) 4. Given the opportunity to ask any questions about the study by telephone. **
Stage 2 – SCPMP clinicians	5. Two facilitators of the SCPMP were approached by the author via written invitation, which included the clinician participant information sheet (Appendix 4). 6. Provided with the opportunity to ask any questions about the study. **
Stage 3 – General PMP participants*	7. Need for potential participants with SCD who attended a general PMP identified in line with the theoretical sampling procedure. 8. A clinical psychologist from a haematology service in second hospital identified eligible participants. 9. Potential participants sent an invite letter asking and followed up with a telephone call by a clinical psychologist who was unknown to them asking for consent to be contacted by researcher. 10. After verbal consent given, contacted by the author and provided with participant information sheet (Appendix 5) and given the opportunity to ask any questions about the study by telephone. **

*****Potential participants at these stages were informed that participation was voluntary and would not impact on the care that they received in the hospital regardless of their decision.

**Informed consent was gained at each stage (Appendix 6).

SCPMP

Stage 1 participants attended an eight-week SCPMP. This involved an average of six participants with SCD meeting weekly for eight sessions to learn to manage SCP and its impact on their lives. The SCPMP was led by a clinical psychologist and a specialist physiotherapist. Participants received psychoeducation about SCP, pain management strategies and physiotherapy. The SCPMP was informed by CBT (Wilson, 2017), acceptance and commitment principles (McCracken, 1998), mindfulness (Segal, Williams & Teasdale, 2002) and compassion-focused approaches (Gilbert, 2009). The SCPMP included a 'friends and family session' where participants' family members were invited to attend and ask questions about SCD and to hear about people's experience of living with SCD.

General PMP

Third stage participants came from a haematology service in a second hospital, attending a general chronic pain PMP at a well-established pain service. The PMP included transdiagnostic groups and was offered as a residential or outpatient format.

Data generation

The participants chose the location of the interview, where they could speak privately. The participants were given a choice of face-to-face or telephone interview. All except one participant chose a face-to-face interview.

A semi-structured interview was used, and questions were asked about their experience of attending the PMPs (Appendix 8 for stages 1 and 3. Appendix 9 for stage 2). The interview schedule was developed following discussions and feedback from the two research supervisors with relevant expertise. Questions were ensured to be open and non-leading to allow participants to respond freely and depth of data to be achieved. The interview schedule was adapted over time to fill in the perceived gaps in the data, as in grounded theory, the sampling of individuals contributes to building the open and axial coding of the theory (Strauss & Corbin, 1998). Interviews were audio-recorded and lasted between 60-70 minutes.

Data analysis

Each interview was transcribed and was open-coded line-by-line. This aided the process of constant comparison in which theoretical memos were written during the comparison of data. Subsequently, links were made between categories that drew on the similarities and differences in participant experiences.

In line with Strauss and Corbin (1998), a process of ‘axial coding’ was carried out, organising categories in keeping with their properties by making connections between and within the categories (shown in Appendix 10). The hypothesis that connects core category, categories and sub-categories facilitated development of a preliminary theory of the therapeutic mechanisms in the SCPMP. Diagramming was used to aid conceptual analysis and visually demonstrate analytic concepts and their relationships (e.g. Appendices 11, 12 & 13). Constant comparison was carried out to compare codes and to collapse them into categories across different stages. An ‘abbreviated version of grounded theory’ was employed, which is when the cyclical process involved in the data collection and analysis of grounded theory methodology is abbreviated to work with the original data only (Strauss & Corbin, 1998). Theoretical sufficiency was reached when the preliminary theory was seen as providing a good explanation (Dey, 1999).

Quality assurance

Quality was maintained through a number of approaches (Mays & Pope, 2000). A bracketing interview was carried out to ensure awareness of the author’s subjectivity (Tufford & Newman, 2012), which led to a reflexive positioning statement (Appendix 14). A reflective diary was used as a way to record the author’s thoughts and emotional responses in relation to the data and to consider whether they influenced the process of data analysis (Appendix 15).

Memos were written by the author to capture ideas and reflections during data analysis (Appendix 10). This included reflections on what was said, how the ideas may be connected and any further questions that arose to be explored. This increased transparency during decision-making in terms of what was important in the data and theoretical and conceptual ideas. A sample of coded transcripts was sent to a supervisor with expertise in grounded theory methodology to oversee the coding practices of the author (Appendix16).

Ethical considerations

A favourable opinion was received for this study from an NHS Research Ethics Committee and approval was granted from the two participating NHS trusts. Audio recordings were stored on a password-protected computer only accessible by the author. Transcriptions were anonymised to protect participant identity. Provisions were made for the possibility of a participant becoming distressed during or after the interview such as checking-in and signposting to appropriate services in line with ethical guidelines (British Psychological Society, 2010).

Results

Model overview

The model sets out the perceived therapeutic process in the SCPMP (Figure 2). The participants reportedly begin the SCPMP with the previous experience of not talking about pain or their pain experience in their lives. From participants' accounts, the therapeutic process appears to begin in the SCPMP with learning about pain, inclusion of friends and family and sharing within the group of participants. Based on the interview data, the model hypothesises how these experiences are processed by the participants in the SCPMP. Although the model begins in a linear form in the figure, it can become cyclical each time the experience is repeated, for example, each time a participant relates to another participant's description of pain. Over time, the participants described a shift in how they perceived their experiences and pain, and these processes can be further developed in a cyclical manner. The two boxes with thicker borders in Figure 2, indicate the greater reference to these categories in the overall participants' accounts about their experience. The facilitators 'experiences' contributed to the overall model and were included for triangulation. From the participants' accounts of those who did not attend a SCPMP, there were contrasting cases in their experience to the experience of the SCPMP and those cases were represented as underlined in Figure 2 and Table 9.

Figure 2 *Attending a group to accept pain and make changes, develops one's positive sickle cell identity* - *a model of the perceived experience of the participants in the SCPMP.*

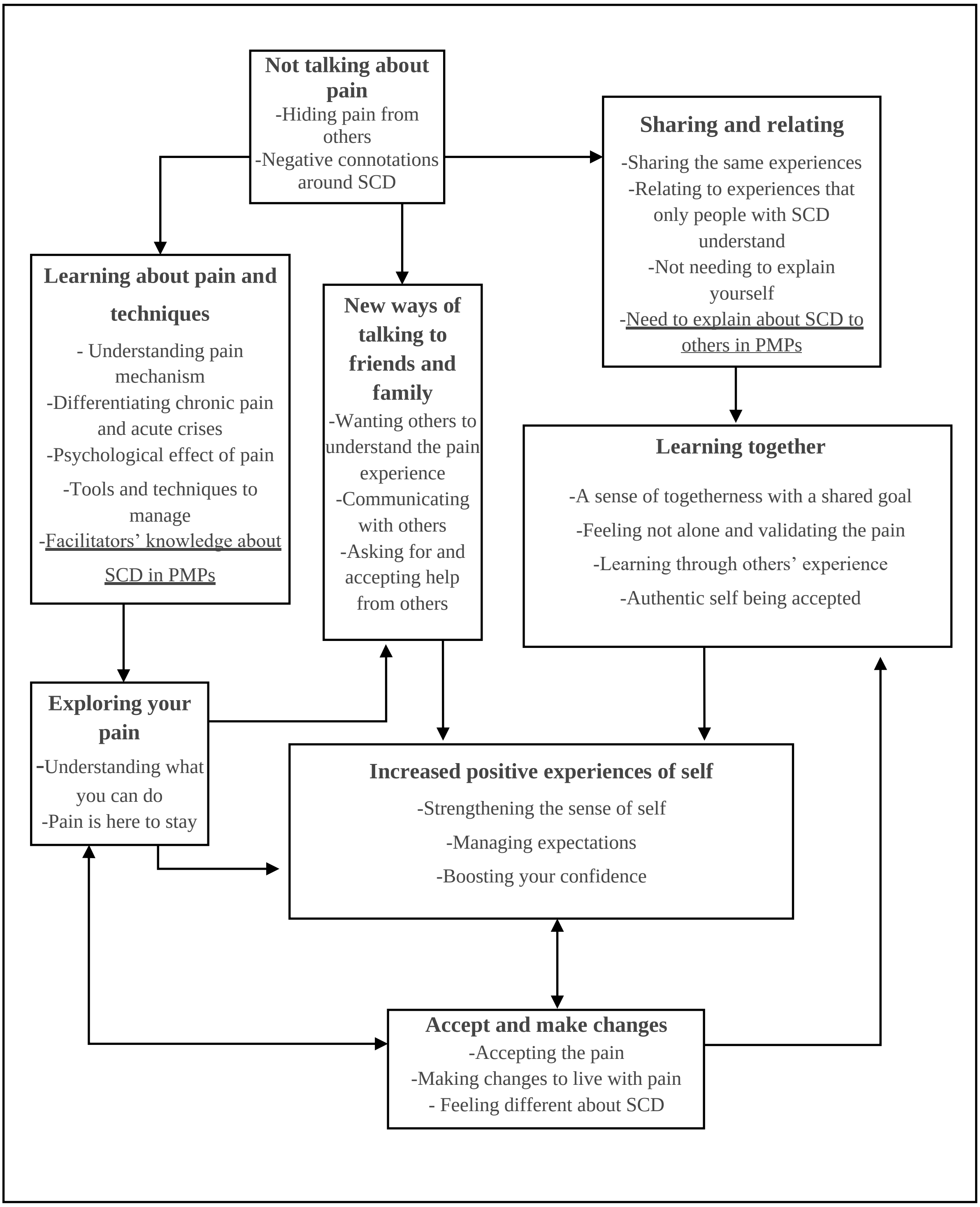


Table 9 *Categories and sub-categories of a model on the experience of the SCPMP*

Categories	Sub-categories
1. Not talking about pain	a. Hiding pain from others b. Negative connotations around SCD
2. Learning about pain and techniques	c. Understanding pain mechanism d. Differentiating chronic pain and acute crises e. Psychological effect of pain f. Tools and techniques to manage g. Facilitators' knowledge about SCD in PMPs
3. New ways of talking to friends and family	h. Wanting others to understand the pain experience i. Communicating with others j. Asking for and accepting help from others
4. Sharing and relating	k. Sharing same experiences l. Relating to experiences that only people with SCD can understand m. Not needed to explain yourself n. Need to explain about SCD to others in PMPs
5. Learning together	o. A sense of togetherness with a shared goal p. Feeling not alone and validating the pain q. Learning through others' experience r. Authentic self being accepted
6. Exploring your pain	s. Understanding what you can do t. Pain is here to stay
7. Increased positive experiences of self	u. Strengthening the sense of self v. Managing expectations w. Boosting your confidence
8. Accept and make changes	x. Accepting the pain y. Making changes to live with pain z. Feeling different about SCD

Core category

Derived from the data was the core category of 'attending a group to accept pain and make changes, develops one's positive sickle cell identity'. This category explains how experiences in the SCPMP provide therapeutic processes that may allow for the development of one's identity. The processes, such as sharing and relating, exploring your pain and increasing more positive experiences of self, facilitates the participants to think about themselves in a more positive way. These processes suggest the development of a sickle cell identity that supports the participants to put new ways of managing pain into practice in their day-to-day lives.

Category 1: Not talking about pain

The participants discussed not talking about pain outside the SCPMP. This absence of the experience of sharing and relating meant that the SCPMP experience was particularly supportive and therapeutic for the participants. The participants shared **hiding pain from others**: "*if you are sickle cell, you are so used to do that hiding all the time*" (P5). Some felt that it came from their culture: "*the culture is, people don't really talk about sickle cell*" (P8). Some described not talking about their pain so that they would not be judged negatively: "*just to avoid being looked at like, oh, you're always whingeing or you're moaning or, you know*?" (P1). When the participants reported talking to friends and family about pain, it was described as being a practical approach, such as about taking medication or going to hospital. For others, SCD or pain was not discussed due to the **negative connotations**: "*it's still very well stigmatised... people have this conception that you have sickle cell, you always die, you die before you're 21*" (P3).

Category 2: Learning about pain and techniques

The participants described **understanding the pain mechanism** as a new experience: *"before this therapy started, I didn't know how pain works... It was really mind-opening to see that, yes, I do feel pain, but until then I didn't know really the concept of pain"* (P5). A sense of importance was given to understanding how pain works as a way to understand experience. This category was particularly salient as it was adapted for people with SCD and the facilitator described that *"we talk about sickle cell disease, and the mechanisms of sickle cell, and then we talk about kind of pain layered on that*" (P9). When they discussed **differentiating chronic pain and acute crises,** this was highly relevant to their experience of SCP. This appeared to be new learning for the participants: "*I didn't know that I have, I'm struggling with two kind[s] of pain. They made me understand what is chronic pain. And what is acute pain, and like the difference between both*" (P6).

For participants who did not attend a SCPMP, experiences of learning about pain differed in whether their pain was explained in relation to SCD and **the facilitators' knowledge about SCD in PMPs**. One participant felt that her pain was clearly explained as SCP and thought that the facilitator had a good understanding of SCD pain. "*[facilitator] took everybody's ailment. And talked about it, and you know, expanded on it*." (P11). Conversely, another participant thought that their facilitators had a limited understanding of SCD because the pain discussions were also redirected to discussions of chronic pain only: "*any time you know you did try to explain certain things living with sickle cell, it kept being sort of brought back to, 'no, bring it back to the chronic pain'*" (P12). Therefore, the role of the facilitator appeared to be significant in their experiences and there is a potential reinforcement of not talking about pain if the SCD is not included in the group discussions. "*I mean I did mention myself a few times when I would like to talk about certain aspects of sickle cell we're always shut down [by the facilitator], and that was quite, that was upsetting*." (P12).

Another important process in this category was recognising the **psychological effect of pain** and learning that their reaction to pain can shape their overall experience: "*I know that if I'm feeling a bit low, my pain is more intense. It probably isn't, but I feel as though it is. It did help me to understand more about my emotional wellbeing*" (P7). The participants found the process of learning about their pain experience was therapeutic as it helped them to think about aspects of their pain that they can change: "*if you know what is happening, you are able to relax and have a mindset that it will go and, and, and it has a positive effect that way too. Whereas at first, I didn't know any of this*" (P4). The participants also valued learning about **tools and techniques to self-manage** their pain experience: "*the practical things like the* *exercises, like mindfulness, the mindfulness thing was really cool. I liked that*" (P2). The techniques were thought to be relevant and feasible in their situation: "*what the group taught me was very important to me. Like, you know, doing those stretches when I'm in hospital and I'm confined to a room*" (P3).

Category 3: New ways of talking to friends and family

The inclusion of the participants' friends and family was frequently reported as impactful based on the experience of the SCPMP. This was facilitated through a friends and family session. The participants described **wanting others to understand the pain experience** and being concerned about not being believed: "*it was good for them to hear from other people that we're not making this up, this is really important, and it really does cause us a lot of grief.*" (P7). Hearing from the participants' friends and family about their experience of being close to someone experiencing SCP also helped the participants to consider **communicating with others** about their pain experience. One participant noted, "*they're like, 'you don't ask for help, you don't let us help you', and it's the same thing that was going on with me*" (P2). Improving communication with friends and family, meant that the participants could **ask for and accept help from others**: "*if you communicate that, it's already good that they can help you as best as they can*" (P6).

Category 4: Sharing and relating

This category relates to the experience of being in a group with other people with SCD and how the participants experienced being given the space to have discussions about their experiences that were unique compared to the interactions in other groups. The participants reported learning that they **shared the same experiences** of pain and SCD. Prior to the group, the participants had not considered that other people may have similar experiences: "*you think that, 'is other sickle cell patient really experience what I'm experiencing, or is it just me?'*"

(P6). There was a sense of revelation that other people had the same experience: "*you listen to someone else telling you your own struggle through the mouth of [an]other person, like, yeah, wow, she's telling this like she's telling you my life*!" (P5). For some, they noted that: "*we all kind of were on the same page… the different experiences had the same theme*" (P2).

The sharing of experiences was followed by **relating to experiences that only people with SCD can understand**: "*we related very well on those terms. Definitely because we've all gone through that*" (P7). These comments contrasted with feeling that others do not understand their experiences because they do not have SCD: "*you might want to talk to your family, but they won't really understand what you're feeling or what you're going through*" (P1). The experience of being able to relate to each other's experiences meant that the participants felt understood and thus, **not needing to explain oneself**: "*if I said, 'ouch, I'm in pain', I would know that they would understand what is that. If they saw me limping they would understand what is that*" (P5). This was highlighted as contrasting with the difficulties of being understood by people without SCD: "*it's difficult to do that because you feel like you're justifying, you're explaining yourself over and over again. So it can be challenging*." (P8). The participants frequently cited that people do not know about SCD compared to other physical health conditions, e.g. diabetes, which exacerbated the sense that they needed to explain themselves. "*Sickle cell, is not well, the information about sickle cell is not that out there in the public. So a lot of people don't really know what sickle cell is all about*." (P1).

As a contrast, the participants, who attended the general PMPs, described their experiences of being in PMPs for chronic pain with people with different health conditions. They outlined contrasting processes that differed from the SCPMP. The **need to explain yourself** was prominent in PMPs and to explain about SCD for others in the group to understand their pain. The lack of awareness about SCD by other attendees was also noted: "*they had no understanding of it [SCD]*" (P11). A participant explained she felt she felt understood when the group facilitators who knew about SCD. “*I didn’t feel that I lost anything by not having anybody else [with SCD] there with me because everybody that stood in front of us as a professional knew what I was going through.*” (P11). However, another participant thought: “*people couldn’t relate*” (P12).

Category 5: Learning together

Following the repeated experience of sharing and relating, a group relationship appeared to emerge in how they used the group to manage pain, which goes further than the initial experience of sharing and relating. The participants reported developing a perception of others and themselves with **a sense of togetherness with a shared goal**: “*we’re a group of individuals who have an understanding. We’ve shared something. So… it’s kind of like a family type scenario*” (P2). This sense of unitedness enhanced the feeling of being understood and supportive of each other: “*encouraging each other even from the small thing like, it’s not small! That was a big thing!*” (P6). The participants felt connected in their aims: “*People with one mind, one set, one goal. Coming there to strengthen ourselves and to face the world*.” (P4).

Despite their experiences of not talking about pain and being concerned about others judging them, within the group, the participants described **feeling not alone and validating the pain** experience. “*I thought, ‘oh great, so I’m not the only one then, who felt this way*’” (P7) “*You always go through life thinking that like, you are the unique one and your problems can never be solved because you are the unique individual.*” (P2). The therapeutic process in the group facilitated feelings that their experiences were valid and individuals expressed a sense of relief that their experiences were not unusual. “*I heard somebody say she, they see stars (when they are in pain). And was so happy to hear that! Because I know I’m not seeing things. So I went to tell my doctor ‘I see stars, is it something you’ve ever heard?’, and the doctor said he[‘d] never heard that! But I’m confident that yes, somebody, people see stars! I’m not the only person that ever see[s] stars*” (P6).

When people shared different experiences in the group, the participants spoke about **learning through others' experiences**: "*taking bits and pieces from other people's experiences and trying to, you know, apply it to your own situation as well*" (P8). The differences within the group appeared to facilitate a process of reflection on their own situation. "*Other people, other people were coping better and as to whether it was their mindset… So it helped me to really look at how I look at my ailment again*." (P4). These experiences in the group translated into how they perceived themselves within the group. The participants described hiding their pain experience outside the group, whereas within the group, they experienced their **authentic self being accepted**. "*Being with sickle cell patients, I think I could just be myself without having to use masks*" (P5). "*You talk about things without having to be cagey, nobody's going to judge you…*" (P1). They expressed that they did not feel the need to hide because of the uniqueness of being with other people with SCD: "*When you're sitting in a group of eight other people and they go through the same thing, you're able to let your guard down*." (P8). The SCPMP facilitator agreed that the participants can worry about impact of what they say on others e.g. family: "*space where actually I can talk about stuff without having to censor, without having to worry about the impact of what I'm saying*." (P10).

Category 6: Exploring your pain

Following learning about pain, the participants described being able to better understand their body and mind when they experienced pain. This process of application of knowledge to their own experience appeared to be important in enabling change in their lives. The participants described **understanding what you can do**: "*So I've started to like make changes, try to keep myself as healthy as possible*." (P1). Since people with SCD can experience chronic pain and acute crises, where the latter can lead to hospitalisation, there is a significant importance placed on their ability to disentangle and distinguish their pain experience. "*I try to think about things… And take them off, that it might not be it, it might not* *be that… Before the group it was like, I'm sick, ambulance, hospital, where is medication. But at home, since the group, I unpick the problems*." (P4). This also meant that some participants learned to use their medication differently: "*I don't have to take morphine for the chronic pain like I have to take morphine for the acute pain. That's why I said it [the PMP) was beneficial. Because it stops you using medication all the time*." (P6).

With the increased understanding of their ability to manage the pain, the participants spoke about recognising that their **pain is here to stay**. "*This is a pain that you're going to have for the rest of your life. It's an illness that you have for the rest of your life*" (P3). For some, this was different from their view of the pain prior to the group: "*I was in pain so all I wanted to do was just, you know, take some painkillers. I just wanted to go to hospital and I wanted the pain to go right away*." (P8). This also changed their expectations about the pain and how it should be managed: "what *I learnt is that we cannot kill the pain, hundred percent. You are, we are always with pain. But it's just the degree of the pain. So we're trying to get it down to a level where you can function*." (P7). The recognition that pain was here to stay reinforced the need to ask for and accept help from their friends and family.

Category 7: Increased positive experience of self

The categories of learning together and exploring pain within the SCPMP contributed to shifting how they viewed their own experiences and themselves. The participants reported **strengthening the sense of self**: "*It's like the sickle cell was drowning me, because of the pain and things like that. The pain is there, but it's not drowning me now. I've resurfaced. I've almost like, I'm facing it squarely*." (P4). For some, the group provided a space to develop themselves: "*I feel like you can only learn and grow from experiences and workshops like this*." (P8). This meant that people learned to respond differently to their difficulties: "*I'm a bit more… I don't know the word, sturdier myself? I don't let things faze me as much as they used to. I mean they still do, but my reaction to it is different.*" (P2). Their increased sense of self influenced by meant that they felt better able to **manage expectations** of other people and themselves. Their experiences of managing expectations included learning to put themselves first: "*I'm taking hold of my own identity, I'm taking hold of my own humanness by saying that I too matter*." (P4). This was in contrast to how they struggled prior to the group: "*I wanted to be this superwoman who was doing everything, you know, I didn't want to ask for help*." (P7) and the new ways of talking to friends and family also contributed to a change in asking for help. However, this remained difficult in certain families due to cultural expectations: "*culturally, where we come from, even with all the education, even with all the ways that women have grown in their work lives, everything, we are still the main caregivers of the children*." (P7).

The participants described that the experience of attending the SCPMP helped them to **boost their confidence** in their perceived ability to cope with the pain: "*it just gives you the courage to go through every day. That's why I say I have a good group.*" (P6). This was a marked difference from how disempowered they may have felt in the past: "*because it's quite easy, you know, being a sickler, to give off, I say, you know life has dealt me these lemons so I might as well just suffer it*" (P1). Participants described a sense of empowerment in relation to SCD: "*it [the SCPMP) helped me to see, to be in charge of sickle cell. And not allow sickle cell to be in charge of me.*" (P5).

Category 8: Accept and make changes

Following on from augmenting experiences and strengthening the self, the participants described feeling able to **accept the pain**. The recognition that the pain will not go away helped the to accept it: "*that's why I say accept. Because, it's there. It's going to be there. It's not going away, that pain, it's just there. Because they give you tips, technique[s] how to live with it.*" (P6). For some, this meant accepting the pain experience: "*but also accept that it's okay to, you know, be in pain*" (P8). For others, it meant accepting the impact of pain: "*acceptance, almost, you know? It's okay. It's just, I'm having a bad day, a very bad day, that's it.*" (P5).

The changed relationship with the pain facilitated the process of **making changes to live with pain**: "*I'm trying to incorporate on my, on my day-to-day, really. I'm able to take time for myself more frequent, and yes, listening to my body when I'm tired. Reduce activities that I know that they will exhaust me.*" (P5). The participants described incorporating what they had learned they can do into their lives: "*I'm constantly applying all these bits and pieces. Mindfulness, I'm also applying it almost daily*." (P4). The practical techniques further provided the participants to **feel different about SCD** and, for several participants, the experience of the SCPMP helped them to accept the SCD: "*To accept that I, I do have sickle cell, I'm going to have this for the rest of my life. But also what I need to accept is that there's also tools in place to help me change the way I think about sickle cell, it's not always negative.*" (P8). They also acknowledged struggles with SCD: "*being kinder to myself. Accepting and acknowledging that I do have a disorder. My life is not ruined by it, it's augmented by it, but it's not ruined* " (P2).

For some, this was about accepting SCD as part of themselves: "*I would deny it [SCD], oh God. Like, I wasn't mentally ready to accept it*" (P1); "*I've really accepted it like, yes, this is me. Sickle cell is who I am, it's part of me. It's never going to change, it's never going to go away*." (P1).

Discussion

Summary of the findings

This study highlights the unique therapeutic processes can occur within a SCPMP, and provides a model representing these processes. The key themes to emerge from the model were the benefits of learning about sickle cell pain, the opportunity to share and explore the experience of pain with others, the positive effects on sense of self and identity, the impact on participants' ability to make changes in their lives and feeling an increased sense of agency and ownership. Some of these processes, however, closely relate to the findings emerging from prior research into PMPs for chronic pain, such as the positive effects of validating pain (Mathias, Parry-Jones & Huws, 2014) and the impact of accepting pain (Penney & Haro, 2019). This therefore suggests that some of these processes are trans-diagnostic in nature. Some of these processes also converge with generic group therapeutic factors that have been outlined, such as universality and group cohesiveness (Yalom & Leszcz, 2005).

The unique medical experiences of SCD were an important variation in the SCPMP compared to general PMPs and generic group therapeutic factors. Learning about pain and the pain mechanism was done with consideration of the specific features of SCD, such as the acute crises and SCP. General PMP participants supported the importance of understanding their pain in relation to their specific physical health condition (SCD), as when these discussions were discouraged, feelings of not being understood increased. Additionally, the SCPMP provided a the powerful sense of solidarity and support that appeared to be achieved by members by being part of a group that was united in a common experience of living with SCD. Participants described the SCPMP experience as reducing isolation, which, in turn, seemed to increase positive experiences of the self. Participants subsequently appeared able to accept and make changes in their lives in order to manage SCP. In contrast, those who attended non-specific PMPs felt that they had to explain to others about SCD. Although this study did not examine the effectiveness of PMPs for SCP, this research provides tentative support for the acceptability of a SCPMP for people with SCP.

Limitations

It is important to consider that due to the unique nature of the clinical intervention, the majority of participants in this study were recruited from one hospital (though separate SCPMPs), which may have introduced an element of bias into the data.

In terms of methodology, grounded theory recommends that the emerging categories be triangulated within a heterogeneous sample. Although the findings from the SCPMP were compared with findings from two participants who attended a general PMP, the overall heterogeneity within the sample demographics was limited by gender and a preferential attitude towards the PMP they attended. Furthermore, due to the remits of the current study, theoretical sufficiency was met instead of theoretical saturation i.e. when it was thought that a good explanation was achieved. This ‘abbreviated version’ of grounded theory ay have resulted in potential new codes being overlooked.

Although the author tried to ensure that biases were brought into self-awareness to minimise influence on the data (in line with critical realist epistemology), it is plausible that another researcher from a different professional background could have derived different findings.

Theoretical considerations

The CSM for chronic health conditions may explain health outcomes for people with SCD, since people with SCD have been found to have more negative illness perceptions compared to other chronic illnesses (Ramondt, Tiemensma, Cameron, Broadbent & Kaptein, 2016). Illness perception theory derived from CSM suggests that individuals develop belief patterns about their illness which then affects their behaviour in managing the illness (Weinman

& Petrie, 1997). The current findings suggest processes consistent with this theory. For example, the categories of *exploring your pain* and *accept and make changes* specifically challenge their illness perception that the pain experience is uncontrollable. If people with SCD believe that they can make meaningful changes in their lives to manage pain, they are more likely to practice techniques to manage their pain. Similarly, for the attributional model of depression (Abramson et al., 1978), people with SCD may become less vulnerable to developing depressive symptoms. This is important, as people with SCD are often overburdened with psychosocial challenges that negatively impact their quality of life (Thomas & Taylor, 2002).

Stigma is theorised in Goffman's (1986) theory of social stigma as an attribute assigned to an individual that socially discredits them. Studies have found that the most significant level of stigma for people with SCD is related to anticipated stigma (expectation of being stereotyped negatively in future encounters), compared to other domains of stigma, such as actual experience (Bediako et al., 2016; Jenerette, Brewer, Crandell & Ataga, 2012). The findings of the present study suggest that anticipated stigma (concerns about being negatively judged) influenced how participants could manage pain in the category of 'not talking about pain', which could be seen as hiding pain to avoid negative judgements. The therapeutic process of the authentic self being accepted in the 'learning together' category also seems to have been experienced as particularly beneficial for participants due to its contrast with the anticipated stigma and expectation that their authentic self would not be accepted.

The therapeutic processes in the SCPMP overlap with a number of Yalom’s therapeutic factors in group therapy (Yalom & Leszcz, 2005). For example, *not feeling alone and validating the pain* reflect the therapeutic factor of universality where group members learn that their suffering and difficulties are shared by others. *A sense of togetherness with a shared goal* illustrates a level of group cohesiveness similar to that which Yalom and Leszcz (2005) described as creating a sense of acceptance and belonging among the group members, which is empowering. *Boosted confidence* may exemplify aspects of instillation of hope in the group process, which can promote optimism about the future and perceived ability to manage. The importance of meeting others with similar experiences have also been explored in PMPs for CP (Dysvik, Kvaløy & Furnes, 2014).

Clinical Implications

The findings highlight the need for PMPs for SCP to recognise the pervasive (e.g. life limiting) and unchanging (e.g. lifelong) aspect of SCD that may be unique compared to other conditions underlying CP. Therefore, in transdiagnostic PMPs, features specific to SCD should be included in explanations of pain, in order to help support acceptance and enable change. Consideration of the medical experiences of SCD in the context of chronic pain would require the facilitators to gain specific knowledge about SCD. The findings from this model highlight important medical considerations for pain from SCD compared to other conditions, such as chronic back pain. Therefore, there is a need to develop clinical guidance for chronic pain in SCD to guide health services in service provision.

Despite pain being a main characteristic of SCD, many participants in this study highlighted that they had never received information about pain, (e.g. differences between acute crises and chronic pain), during their hospital appointments with haematology doctors or nurses. Therefore, it may be useful for haematology services to consider other ways of making such information accessible to patients and families.

People with SCD can experience the cumulative effects of health-related and racial stigma when they access services and they may adapt their behaviour in anticipation of such stigma (Bulgin et al., 2018), which can serve to further powerfully reinforce existing health inequalities present in the UK (Smith et al., 2000). When individuals with SCD experience health complications, they may delay help-seeking or access to services may be hindered due to perceived stigma (Bulgin et al., 2018). The current model provides an understanding of such behaviour in relation to perceived stigma. This raises profound implications for clinicians working with sickle cell patients, highlighting the need to develop compassionate understanding for those accessing services, to resist the label of the ‘difficult patient’ (Bergman & Diamond, 2013) and for the development of anti-discriminatory health services (Archibong, 2001).

The current findings suggest ways to best support people with SCD experiencing chronic pain. However, specialised SCPMPs are not widely available across the UK. Given participants’ accounts of therapeutic processes within the SCPMP, and the tentative evidence from participants who attended a non-SCD-specific PMP, it would seem important to increase equity of service for SCP in order to support people and living fulfilling lives.

Research recommendations

The current findings suggest that participants experienced SCPMPs as positive and therapeutic processes that may impact low mood. Therefore, future research may similarly wish to explore how a group treatment for depression for people with SCD may be experienced qualitatively, since a Cochrane review has only found quantitative studies in this area (Anie, 2015).

There may be differences and similarities with the model in this study and other therapeutic mechanisms. Some categories, such as *relating to experiences that only people with SCD understand*, *authentic self being accepted* and *increased positive experience of self*, may show as a commonality in other treatment groups for people with SCD. Given that the role of the PMP facilitator was highlighted as important in bringing about a positive experience for the group attendees, it would be useful to gain an in-depth understanding of the health clinicians’ experience of supporting sickle cell patients with chronic pain. This could indicate the clinicians' perceived difficulties and the ways they would like to be supported, which may include, but not be exclusive to, further training.

The current findings show that there is interaction between stigma and pain management. The issues of stigma and identity could therefore be studied in relation to the treatment for people with SCD. Stigma against people with SCD in health services has mostly been studied in America, where there is an additional layer of stigmatisation against people using opioids (Bergman & Diamond, 2013). A research indicates lower levels of opioid misuse in the UK than in America (Weisberg, Becker, Fiellin, & Stannard, 2014). Further consideration of stigma in UK healthcare systems for people with SCD is needed to understand the extent of the problem. Moreover, since SCD predominately affects people of Afro-Caribbean descent, the interaction of racial stigma and illness stigma may be both present (Wailoo, 2006). Future research could look at how anticipated stigma can be reduced in this population.

To ensure that people are able to access specialised services and they are not discriminated against, future research could look to study the feasibility of developing an online SCPMP, as it has been trialled for low mood and SCD (Jonassaint et al., 2020). Since people with SCD often do not feel understood by those without SCD (Coleman et al., 2016), when considering future research, people with SCD should be included as co-researchers in order to meaningfully incorporate their expertise and valuable insight into the research. This would work towards both reducing the assumptions about "recipients and providers" of services, and tackling the imbalance of power (Filipe, Renedo & Marston, 2017).

Conclusion

This is the first study to explore the experience of therapeutic processes in a PMP for people with SCD. It appeared to develop the participants' positive (as opposed to negative) sickle cell identity and enhance their perceived ability to accept the pain and make changes. The current model describes a linear process where the participants begin from a position of not talking about pain and move to experiencing the SCPMP, where discussions about pain are shared and related to each other. This seems to shift the participants into a position where they are able to learn from each other, as well as learning about pain, and communication with the inclusion of friends and family. It then identifies a cyclical process where participants are able to explore their pain, build on their positive experiences of self and accept and make changes. This final process suggests the development of a sickle cell identity that supports the participants to put new ways of managing pain into practice in their day-to-day lives. In contrast, those who attended non-specific PMPs, felt that they had to explain to other about SCD, which may have limited their experience of relating to each other about SCD. This model adds to the current literature about how people with SCD can be supported in managing SCP.

References

Abramson, L. Y., Seligman, M. E., & Teasdale, J. D. (1978). Learned helplessness in humans: Critique and reformulation. *Journal of Abnormal Psychology, 87*(1), 49-74. http://dx.doi.org/10.1037/0021-843X.87.1.49

Adams, N., Poole, H., & Richardson, C. (2006). Psychological approaches to chronic pain management: Part 1. *Journal of clinical nursing, 15*(3), 290-300. https://doi.org/10.1111/j.1365-2702.2006.01304.x

Anie, K. A. (2005). Psychological complications in sickle cell disease. *British journal of haematology, 129*(6), 723-729. https://doi.org/10.1111/j.1365-2141.2005.05500.x

Anie, K. A., & Green, J. (2015). Psychological therapies for sickle cell disease and pain. *The Cochrane Library, 5. CD001916.* https://doi.org/10.1002/14651858.CD001916.pub3

Anie, K. A., Steptoe, A., & Bevan, D. H. (2002). Sickle cell disease: Pain, coping and quality of life in a study of adults in the UK. *British journal of health psychology, 7*(3), 331-344. https://doi.org/10.1348/135910702760213715

Archibong, U. (2001). Frameworks for anti-discriminatory strategies in the health service. In D. Tomlinson & W. Trew (Ed.), *Equalising opportunities, minimising oppression: A critical review of anti-discriminatory policies in health and social welfare* (pp. 98-116). Oxon: Routledge.

Ballas, S. K. (2011). Update on pain management in sickle cell disease. *Hemoglobin, 35,* 520-529. https://doi.org/10.3109/ 03630269.2011.610478, 2011.

Ballas, S. K. (2018). Sickle cell disease: Classification of clinical complications and approaches to preventive and therapeutic management. *Clinical hemorheology and microcirculation*, *68*(2-3), 105-128. https://doi.org/10.3233/CH-189002

Bhaskar, R. (1978). On the possibility of social scientific knowledge and the limits of naturalism. *Journal for the Theory of Social Behaviour*. https://doi.org/10.1111/j.1468-5914.1978.tb00389.x

Bediako, S. M., Lanzkron, S., Diener-West, M., Onojobi, G., Beach, M. C., & Haywood Jr, C. (2016). The measure of sickle cell stigma: Initial findings from the improving patient outcomes through respect and trust study. *Journal of health psychology, 21*(5), 808-820.

Bergman, E. J., & Diamond, N. J. (2013). Sickle cell disease and the "difficult patient" conundrum. *The American Journal of Bioethics, 13*(4), 3-10.

Brassington, L., Ferreira, N. B., Yates, S., Fearn, J., Lanza, P., Kemp, K., & Gillanders, D. (2016). Better living with illness: A transdiagnostic acceptance and commitment therapy group intervention for chronic physical illness. *Journal of Contextual Behavioral Science, 5*(4), 208-214 https://doi.org/10.1016/j.jcbs.2016.09.001

British Pain Society. (2013). Guidelines for pain management programmes for adults. An evidence-based review prepared on behalf of the British Pain Society. Retrieved from https://www.britishpainsociety.org/static/uploads/resources/files/pmp2013_main_FINAL_v6.pdf

British Psychological Society. (2010). Code of human research ethics. Leicester: British Psychological Society. Retrieved from http://www.bps.org.uk/sites/default/files/documents/code_of_human_research_ethics.pdf

Brown, S. E., Weisberg, D. F., Balf-Soran, G., & Sledge, W. H. (2015). Sickle cell disease patients with and without extremely high hospital use: Pain, opioids, and coping. *Journal of pain and symptom management, 49*(3), 539-547. https://doi.org/10.1016/j.jpainsymman.2014.06.007

Bulgin, D., Tanabe, P., & Jenerette, C. (2018). Stigma of sickle cell disease: A systematic review. *Issues in mental health nursing, 39*(8), 675-686. https://doi.org/10.1080/01612840.2018.1443530

Burnes, D. P., Antle, B. J., Williams, C. C., & Cook, L. (2008). Mothers raising children with sickle cell disease at the intersection of race, gender, and illness stigma. *Health & Social Work, 33*(3), 211-220. https://doi.org/10.1093/hsw/33.3.211

Caird, H., Camic, P. M., & Thomas, V. (2011). The lives of adults over 30 living with sickle cell disorder. *British journal of health psychology, 16*(3), 542-558. https://doi.org/10.1348/135910710X529278

Carroll, C. P., Lanzkron, S., Haywood Jr, C., Kiley, K., Pejsa, M., Moscou-Jackson, G., Haythornthwaite, J. A., & Campbell, C. M. (2016). Chronic opioid therapy and central sensitization in sickle cell disease. *American journal of preventive medicine, 51*(1), S69-S77. https://doi.org/10.1016/j.amepre.2016.02.012

Coleman, B., Ellis-Caird, H., McGowan, J., & Benjamin, M. J. (2016). How sickle cell disease patients experience, understand and explain their pain: An Interpretative Phenomenological Analysis study. *British journal of health psychology, 21*(1), 190-203. https://doi.org/10.1111/bjhp.12157

Dampier, C., Palermo, T. M., Darbari, D. S., Hassell, K., Smith, W., & Zempsky, W. (2017). AAPT diagnostic criteria for chronic sickle cell disease pain. *Journal of Pain, 18,* 490-498. https://doi.org/10.1016/j. jpain.2016.12.016.

Dey, I. (1999) *Grounding Grounded Theory*. Academic Press, San Diego, CA.

Dysvik, E., Kvaløy, J. T., & Furnes, B. (2014). A mixed-method study exploring suffering and alleviation in participants attending a chronic pain management programme. *Journal of Clinical Nursing, 23*(5-6), 865-876. https://doi.org/10.1111/jocn.12270

Edwards, C. L., Scales, M. T., Loughlin, C., Bennett, G. G., Harris-Peterson, S., De Castro, L. M., ... & Wood, M. (2005). A brief review of the pathophysiology, associated pain, and psychosocial issues in sickle cell disease. *International Journal of Behavioral Medicine, 12*(3), 171-179. https://doi.org/10.1207/s15327558ijbm1203_6

Edwards, C., Green, M., Wellington, C., Muhammad, M., Wood, M., Feliu, M., . . . McNeil, J. (2009). Depression, suicidal ideation, and attempts in Black patients with sickle cell disease. *Journal of the National Medical Association, 101,* 1090–1095. https://doi.org/10.1016/S0027-9684(15)31103-2

Egan, A., Lennon, O., Power, C. K., & Fullen, B. M. (2017). “I've actually changed how I live” Patients’ long-term perceptions of a cognitive behavioral pain management program. *Pain Medicine, 18*(2), 220-227. https://doi.org/10.1093/pm/pnw148

Faculty of Pain Medicine. (2015). Core standards for pain management services in the UK. Retrieved from https://fpm.ac.uk/sites/fpm/files/documents/2019-07/Core%20Standards%20for%20Pain%20Management%20Services.pdf

Field, J. J. (2017). Five lessons learned about long-term pain management in adults with sickle cell disease. *Hematology 2014, the American Society of Hematology Education Program Book, 2017(1),* 406-411. https://doi.org/10.1182/asheducation-2017.1.406

Gilbert, P. (2009). Introducing compassion-focused therapy. *Advances in psychiatric treatment*, 15(3), 199-208. https://doi.org/10.1192/apt.bp.107.005264

Gorski, P. S. (2013). What is critical realism? And why should you care? *Contemporary Sociology: A Journal of Reviews*, 42, 658-670. https://doi.org/10.1177/0094306113499533

Holloway, B. M., McGill, L. S., & Bediako, S. M. (2017). Depressive symptoms and sickle cell pain: The moderating role of internalized stigma. *Stigma and health, 2*(4), 271-280. https://doi.org/10.1037/sah0000060

Huston, S. A., & Houk, C. P. (2011). Common sense model of illness in youth with type 1 diabetes or sickle cell disease. *The Journal of Pediatric Pharmacology and Therapeutics, 16*(4), 270-280. https://doi.org/10.5863/1551-6776-16.4.270

Jenerette, C., Brewer, C. A., Crandell, J., & Ataga, K. I. (2012). Preliminary validity and reliability of the sickle cell disease health-related stigma scale. *Issues in mental health nursing*, 33(6), 363-369. https://doi.org/10.3109/01612840.2012.656823

Jonassaint, C. R., Kang, C., Prussien, K. V., Yarboi, J., Sanger, M. S., Wilson, J. D., ... & Sarkar, U. (2020). Feasibility of implementing mobile technology-delivered mental health treatment in routine adult sickle cell disease care. *Translational behavioural medicine*, 10(1), 58-67. https://doi.org/10.1093/tbm/iby107

McCracken, L. (1998). Learning to live with pain: Acceptance of pain predicts adjustment in persons with chronic pain. *Pain, 74,* 21–27. https://doi.org/10.1016/S0304-3959(97)00146-2

Masuda, A., Cohen, L. L., Wicksell, R. K., Kemani, M. K., & Johnson, A. (2011). A case study: Acceptance and commitment therapy for pediatric sickle cell disease. *Journal of pediatric psychology, 36*(4), 398-408. https://doi.org/10.1093/jpepsy/jsq118

Mathias, B., Parry-Jones, B., & Huws, J. C. (2014). Individual experiences of an acceptance-based pain management programme: An interpretative phenomenological analysis. *Psychology & Health, 29*(3), 279-296. https://doi.org/10.1080/08870446.2013.845667

Matthie, N., Ross, D., Sinha, C., Khemani, K., Bakshi, N., & Krishnamurti, L. (2019). A qualitative study of chronic pain and self-management in adults with sickle cell disease. *Journal of the National Medical Association, 111*(2), 158-168. https://doi.org/10.1016/j.jnma.2018.08.001

Maxwell, K., Streetly, A., & Bevan, D. (1999). Experiences of hospital care and treatment-seeking behavior for pain from sickle cell disease: Qualitative study. *Western Journal of Medicine, 171*(5-6), 306. PMCID: PMC1308742

Mays, N., & Pope, C. (2000). Qualitative research in health care: Assessing quality in qualitative research. *British Medical Journal*, 320, 50-52. Retrieved from http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1117321/

Morley, S., Williams, A. & Hussain, S. (2008) Estimating the clinical effectiveness of cognitive behavioural therapy in the clinic: Evaluation of a CBT informed pain management programme, *Pain, 137* (3), 670 - 680. https://doi.org/10.1016/j.pain.2008.02.025

National Institute for Health and Care Excellence (NICE). (2012). Sickle Cell acute painful episode: Management of an acute painful sickle cell episode in hospital. Retrieved from http://www.nice.org.uk/nicemedia/live/13772/59765/59765.pdf

National Institute for Health and Care Excellence. (2017). Medicines optimisation in chronic pain. Key therapeutic topic. Retrieved from www.nice.org.uk/guidance/ktt21

Oliver, C. (2011). Critical realist grounded theory: A new approach for social work research. *British Journal of Social Work*, 42, 371-387. https://doi.org/10.1093/bjsw/bcr064

Osborn, M., & Rodham, K. (2010). Insights into pain: a review of qualitative research. *Reviews in Pain*, *4*(1), 2-7. https://doi.org/10.1177/204946371000400102

Penney, L. S., & Haro, E. (2019). Qualitative evaluation of an interdisciplinary chronic pain intervention: Outcomes and barriers and facilitators to ongoing pain management. *Journal of Pain Research, 12*, 865-878. https://doi.org/10.2147/JPR.S185652

Ramondt, S., Tiemensma, J., Cameron, L. D., Broadbent, E., & Kaptein, A. A. (2016). Drawings of blood cells reveal people's perception of their blood disorder: A pilot study. *PloS One*, 11(4). https://doi.org/10.1371/journal.pone.0154348

Segal, Z. V., Williams, J. M. G., & Teasdale, J. D. (2002). *Mindfulness-based cognitive therapy for depression: A new approach to preventing relapse*. New York: Gilford Press.

Sickle Cell Society (2008). Standards for the clinical care of adults with sickle cell disease in the UK. London: Sickle Cell Society. Retrieved from http://www.sicklecellsociety.org/resource/standards-clinical-care-adults-sickle-cell-disease-uk/

Sickle Cell Society (2018). Standards for the clinical care of adults with sickle cell disease in the UK. London: Sickle Cell Society. Retrieved from http://www.sicklecellsociety.org/resource/standards-clinical-care-adults-sickle-cell-disease-uk/

Smith, G. D., Chaturvedi, N., Harding, S., Nazroo, J., & Williams, R. (2000). Ethnic inequalities in health: A review of UK epidemiological evidence. *Critical public health*, *10*(4), 375-408. https://doi.org/10.1080/09581590010005331

St George's Hospital (2020). Red Cell Pain Management Service at St George's Hospital. Retrieved from https://www.stgeorges.nhs.uk/service/diagnostic-services/haematology/sickle-cell-disease-pain-management-programme/

Strauss, A., & Corbin, J. (1998). *Basics of qualitative research techniques*. CA: Sage publications.

Taylor, L. E. V., Stotts, N. A., Humphreys, J., Treadwell, M. J., & Miaskowski, C. (2010). A review of the literature on the multiple dimensions of chronic pain in adults with sickle cell disease. *Journal of pain and symptom management, 40*(3), 416-435. https://doi.org/10.1016/j.jpainsymman.2009.12.027

Thomas, V. J., & Cohn, T. (2006). Communication skills and cultural awareness courses for healthcare professionals who care for patients with sickle cell disease. *Journal of advanced nursing, 53*(4), 480-488. https://doi.org/10.1111/j.1365-2648.2006.03741.x

Thomas, V. J., & Taylor, L. M. (2002). The psychosocial experience of people with sickle cell disease and its impact on quality of life: Qualitative findings from focus groups. *British journal of health psychology, 7*(3), 345-363. https://doi.org/10.1348/135910702760213724

Thomas, V. J., Dixon, A. L., Milligan, P., & Thomas, N. (1999). Cognitive ‐ behaviour therapy for the management of sickle cell disease pain: An evaluation of a community ‐ based intervention. *British Journal of Health Psychology, 4*(3), 209-229. https://doi.org/10.1348/135910799168588

Thomas, V. N., Wilson ‐ Barnett, J., & Goodhart, F. (1998). The role of cognitive-behavioural therapy in the management of pain in patients with sickle cell disease. *Journal of advanced nursing, 27*(5), 1002-1009. https://doi.org/10.1046/j.1365-2648.1998.00584.x

Tufford, L., & Newman, P. (2012). Bracketing in qualitative research. *Qualitative social work*, *11*(1), 80-96. https://doi.org/10.1177/1473325010368316

Urquhart, C. (2012). *Grounded theory for qualitative research: A practical guide*. London: Sage.

Wailoo, K. (2006). Stigma, race, and disease in 20th century America. The Lancet, 367(9509), 531-533. https://doi.org/10.1016/S0140-6736(06)68186-5

Weinman, J., & Petrie, K. J. (1997). Illness perceptions: a new paradigm for psychosomatics? *Journal of psychosomatic research, 42*(2), 113-116. https://doi.org/10.1016/s0022-3999(96)00294-2

Weisberg, D. F., Becker, W. C., Fiellin, D. A., & Stannard, C. (2014). Prescription opioid misuse in the United States and the United Kingdom: Cautionary lessons. *International Journal of Drug Policy*, 25(6), 1124-1130. https://doi.org/10.1016/j.drugpo.2014.07.009

Williams, A. C., Eccleston, C., & Morley, S. (2012). Psychological therapies for the management of chronic pain (excluding headache) in adults. *Cochrane Database of Systematic Reviews, 2012(11)*, Article No. CD007407. https://doi.org/10.1002/14651858.CD007407.pub3

Wilson, I. R. (2017). *Management of chronic pain through pain management programmes. British Medical Bulletin, 124*(1), 55–64. https://doi.org/10.1093/bmb/ldx032

Yalom, I., & Leszcz, M. (2005). The theory and practice of group psychotherapy (5th ed.). New York, NY: Basic.

This Page Intentionally Left Blank

Section C: Appendices

A thesis submitted in partial fulfilment of the requirements of Canterbury Christ Church University for the degree of Doctor of Clinical Psychology

May 2020

This Page Intentionally Left Blank

Appendix 1 *Section A CASP qualitative study appraisal tool*

This has been removed from the electronic copy

Appendix 2 *Section A CASP reviewing table*

Paper	Aims	Method	Research Design	Sampling	Data collection	Reflexivity	Ethical Issues	Data Analysis	Findings	Value of Research
Egan, Lennon, Power, & Fullen (2017)	yes	yes	partial - not clear why content analysis was used over another method.	yes, purposive sampling. Clear inclusion criteria but not mentioned exclusion criteria. not clear they chose 20 participants as their sample size, not explained how many declined to take part.	yes, focus groups were used. Clear focus group protocol. Yes form of data is clear. Saturation of data discussed in the analysis.	No, they did not set out a reflexive statement about their research so they could have biased their results	informed consent (YES) or confidentiality (YES) the effects of the study during (N) and after the study (NO) ethical approval (YES)	In-depth description of the analysis process? (YES); clear how categories/themes were derived? (YES) explained how data analysed from original data (**Yes**); enough data to support the findings? (YES); researchers' own bias during analysis (No)	findings are explicit (YES) adequate discussion of the evidence both for and against the researcher's arguments (NOT AGAINST) •researcher has discussed the credibility of findings (YES) findings discussed to the original research question (YES)	discussed the contribution the study makes to existing knowledge (relevant research- based literature) (YES) identify new areas where research is necessary (No) discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used (Partial)
Dysvik, Kvaløy & Furnes (2014)	yes	yes	yes - justified why they used structural analysis.	Partial, not clear which sampling strategy. Clear inclusion criteria but not mentioned exclusion criteria. Not explained why some dropped out or did not complete the PMP.	yes, written reports were used. Yes, clear how data were collected. Yes form of data is clear. Saturation of data NOT discussed.	yes, they did set out a reflexive statement about their roles which could have biased their analysis.	informed consent (YES) or confidentiality (YES) the effects of the study during (N) and after the study (NO) ethical approval (YES)	In-depth description of the analysis process? (YES); clear how categories/themes were derived? (YES) explained how data analysed from original data (**Yes**); enough data to support the findings? (YES); researchers' own bias during analysis (Yes)	findings are explicit (YES) adequate discussion of the evidence both for and against the researcher's arguments (NOT AGAINST) •researcher has discussed the credibility of findings (YES) findings discussed to the original research question (YES)	discussed the contribution the study makes to existing knowledge (relevant research- based literature) (YES) identify new areas where research is necessary (Y) discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used (Y)

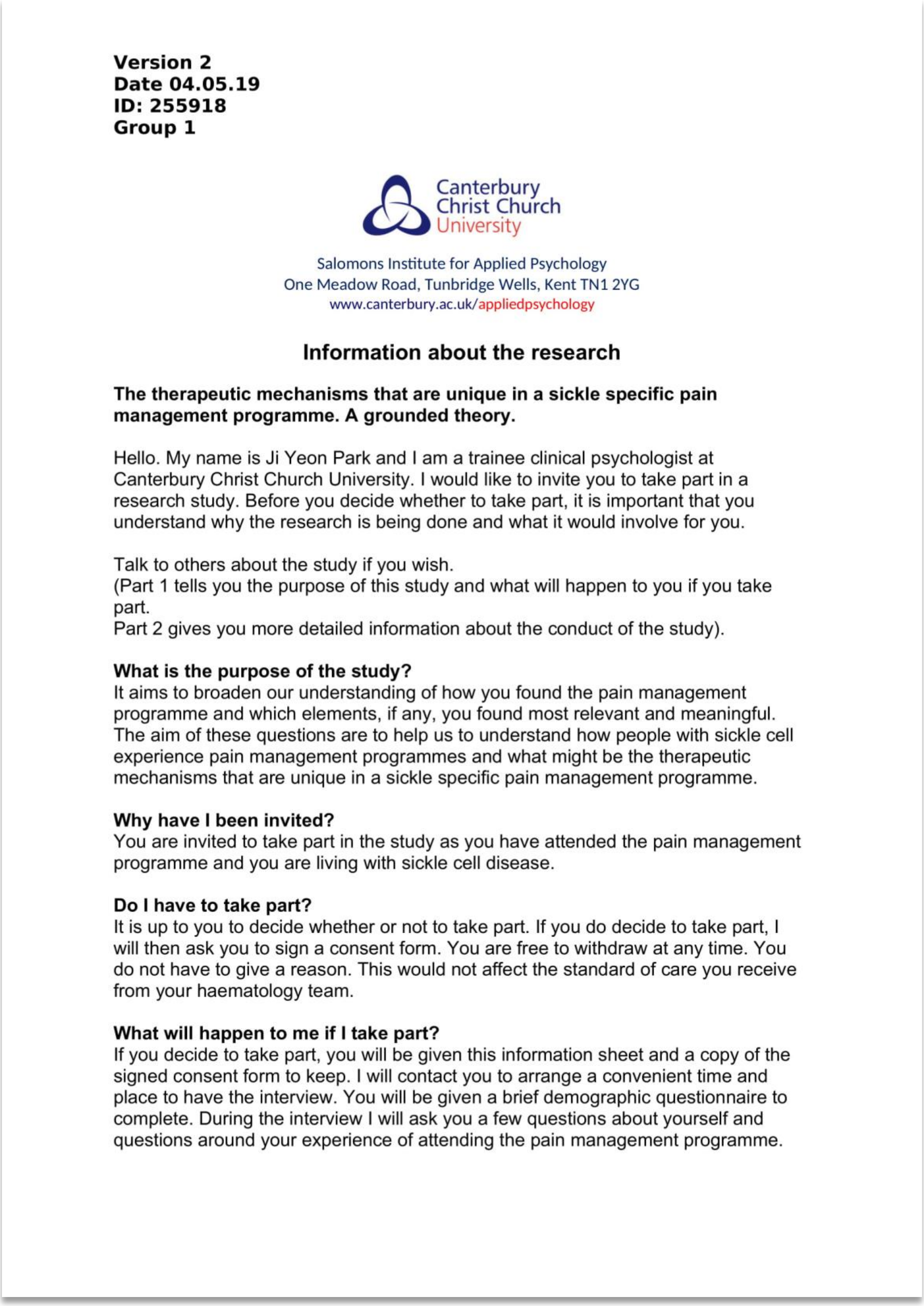
Paper	Aims	Method	Research Design	Sampling	Data collection	Reflexivity	Ethical Issues	Data Analysis	Findings	Value of Research
Mathias, Parry-Jonesc, & Huwse (2014)	yes	yes	yes - justified why they used IPA	yes, purposive sampling. Clear inclusion criteria and exclusion criteria. Not explained why 2 men declined to take part.	yes, semi-structured interviews were used. Yes, clear how data were collected. Yes form of data is clear. Saturation of data NOT discussed.	yes, they did set out a reflexive statement about their roles which could have biased their analysis.	informed consent (YES) or confidentiality (YES) the effects of the study during (N) and after the study (Y) ethical approval (YES)	In-depth description of the analysis process? (YES); clear how categories/themes were derived? (YES) explained how data analysed from original data (**Yes**); enough data to support the findings? (YES); researchers' own bias during analysis (yes)	findings are explicit (YES) adequate discussion of the evidence both for and against the researcher’s arguments (NOT AGAINST) •researcher has discussed the credibility of findings (YES) findings discussed to the original research question (YES)	discussed the contribution the study makes to existing knowledge (relevant research- based literature) (YES) identify new areas where research is necessary (Y) discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used (Y)
Casey, Smart, Hearty, Lowry & Doody (2019)	yes	yes	yes - justified why they used qualitative	yes, purposive sampling. Did not mention inclusion criteria and exclusion criteria. Not explained why some participants declined or failed to take part.	yes, focus groups were used with semi-structured questions. Yes, clear how data were collected. Yes form of data is clear. Saturation of data NOT discussed.	No, they did not set out a reflexive statement about their roles which could have biased their analysis.	informed consent (YES) or confidentiality (No) the effects of the study during (N) and after the study (N) ethical approval (YES)	In-depth description of the analysis process? (YES); clear how categories/themes were derived? (YES) explained how data analysed from original data (**Yes**); enough data to support the findings? (YES); researchers' own bias during analysis (yes)	findings are explicit (YES) adequate discussion of the evidence both for and against the researcher’s arguments (NOT AGAINST) •researcher has discussed the credibility of findings (YES) findings discussed to the original research question (YES)	discussed the contribution the study makes to existing knowledge (relevant research- based literature) (YES) identify new areas where research is necessary (Y) discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used (N)

Paper	Aims	Method	Research Design	Sampling	Data collection	Reflexivity	Ethical Issues	Data Analysis	Findings	Value of Research
Toye & Barker (2012)	yes	yes	yes appropriate, not justified why they used GT	yes, purposive sampling. Yes, mentioned inclusion criteria, not exclusion criteria. Yes, explained why some participants declined or failed to take part.	yes, semi structured interviews were used. Yes, clear how data were collected. Yes form of data is clear. Saturation of data was discussed.	Yes, they did set out a reflexive statement about their roles which could have biased their analysis.	informed consent (YES) or confidentiality (No) the effects of the study during (N) and after the study (N) ethical approval (YES)	In-depth description of the analysis process? (YES); clear how categories/themes were derived? (YES) explained how data analysed from original data (**Yes**); enough data to support the findings? (YES); researchers' own bias during analysis (yes)	findings are explicit (YES) adequate discussion of the evidence both for and against the researcher’s arguments (Yes) •researcher has discussed the credibility of findings (YES) findings discussed to the original research question (YES)	discussed the contribution the study makes to existing knowledge (relevant research- based literature) (YES) identify new areas where research is necessary (Y) discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used (Yes)
Penney & Haro (2019)	yes	yes	yes appropriate, not justified why they used deductive and inductive approaches.	yes, stratified sampling (interviewees) and purposive sampling (focus group members). Yes, mentioned inclusion criteria, yes exclusion criteria. Not explained why some participants declined or failed to take part.	yes, semi structured interviews and focus groups were used. Yes, clear how data were collected. Yes form of data is clear. Saturation of data was discussed.	No, they did not set out a reflexive statement about their roles which could have biased their analysis.	informed consent (YES) or confidentiality (Yes) the effects of the study during (N) and after the study (N) ethical approval (YES)	In-depth description of the analysis process? (YES); clear how categories/themes were derived? (YES) explained how data analysed from original data (**Yes**); enough data to support the findings? (YES); researchers' own bias during analysis (No)	findings are explicit (YES) adequate discussion of the evidence both for and against the researcher’s arguments (not for against) •researcher has discussed the credibility of findings (Yes) findings discussed to the original research question (YES)	discussed the contribution the study makes to existing knowledge (relevant research- based literature) (YES) identify new areas where research is necessary (Yes) discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used (Yes)

Paper	Aims	Method	Research Design	Sampling	Data collection	Reflexivity	Ethical Issues	Data Analysis	Findings	Value of Research
Wilson, Chaloner, Osborn & Gauntlett-Gilbert (2017)	yes	yes	yes appropriate, justified why they used IPA	yes, purposive sampling. Yes, mentioned inclusion criteria, yes exclusion criteria. Not explained why some participants declined or failed to take part.	yes, semi structured interviews were used. Yes, clear how data were collected. Yes form of data is clear. Saturation of data was NOT discussed.	No, they did not set out a reflexive statement about their roles which could have biased their analysis.	informed consent (YES) or confidentiality (Yes) the effects of the study during (N) and after the study (N) ethical approval (YES)	In-depth description of the analysis process? (Partial); clear how categories/themes were derived? (No) explained how data analysed from original data (**Yes**); enough data to support the findings? (YES); researchers' own bias during analysis (No)	findings are explicit (YES) adequate discussion of the evidence both for and against the researcher’s arguments (not for against) •researcher has discussed the credibility of findings (Yes) findings discussed to the original research question (YES)	discussed the contribution the study makes to existing knowledge (relevant research- based literature) (YES) identify new areas where research is necessary (Yes) discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used (Yes)
Moore & Martin (2014)	yes	yes	yes appropriate, justified why they used thematic analysis	yes, purposive sampling. Yes, mentioned having no inclusion criteria and no exclusion criteria. Not explained why some participants declined to take part.	yes, semi structured interviews were used. Yes, clear how data were collected. Yes form of data is clear. Saturation of data was NOT discussed.	No, they did not set out a reflexive statement about their roles which could have biased their analysis.	informed consent (YES) or confidentiality (Yes) the effects of the study during (N) and after the study (N) ethical approval (YES)	In-depth description of the analysis process? (Yes); clear how categories/themes were derived? (yes) explained how data analysed from original data (**Yes**); enough data to support the findings? (YES); researchers' own bias during analysis (No)	findings are explicit (YES) adequate discussion of the evidence both for and against the researcher’s arguments (not for against) •researcher has discussed the credibility of findings (Yes) findings discussed to the original research question (YES)	discussed the contribution the study makes to existing knowledge (relevant research- based literature) (YES) identify new areas where research is necessary (Yes) discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used (Yes)

Paper	Aims	Method	Research Design	Sampling	Data collection	Reflexivity	Ethical Issues	Data Analysis	Findings	Value of Research
Pietila Holmner, Stalnacke, Enthoven & Stenberg (2018)	yes	yes	yes appropriate, did not justify why they used content analysis	yes, purposive sampling. Yes, clear inclusion criteria and not exclusion criteria. Yes, explained why some participants declined to take part.	yes, semi structured interviews were used. Yes, clear how data were collected. Yes form of data is clear. Saturation of data was NOT discussed.	Yes, they did set out a reflexive statement about their roles which could have biased their analysis.	informed consent (YES) or confidentiality (Yes) the effects of the study during (N) and after the study (N) ethical approval (YES)	In-depth description of the analysis process? (Yes); clear how categories/themes were derived? (yes) explained how data analysed from original data (**Yes**); enough data to support the findings? (YES); researchers' own bias during analysis (No)	findings are explicit (YES) adequate discussion of the evidence both for and against the researcher’s arguments (Yes) •researcher has discussed the credibility of findings (Yes) findings discussed to the original research question (YES)	discussed the contribution the study makes to existing knowledge (relevant research- based literature) (YES) identify new areas where research is necessary (No) discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used (No)

Appendix 3 *Section B SCPMP patient participant information sheet*



Version 2
Date 04.05.19
ID: 255918
Group 1

Canterbury
Christ Church
University

Salomons Institute for Applied Psychology
One Meadow Road, Tunbridge Wells, Kent TN1 2YG
www.canterbury.ac.uk/appliedpsychology

Information about the research

The therapeutic mechanisms that are unique in a sickle specific pain management programme. A grounded theory.

Hello. My name is Ji Yeon Park and I am a trainee clinical psychologist at Canterbury Christ Church University. I would like to invite you to take part in a research study. Before you decide whether to take part, it is important that you understand why the research is being done and what it would involve for you.

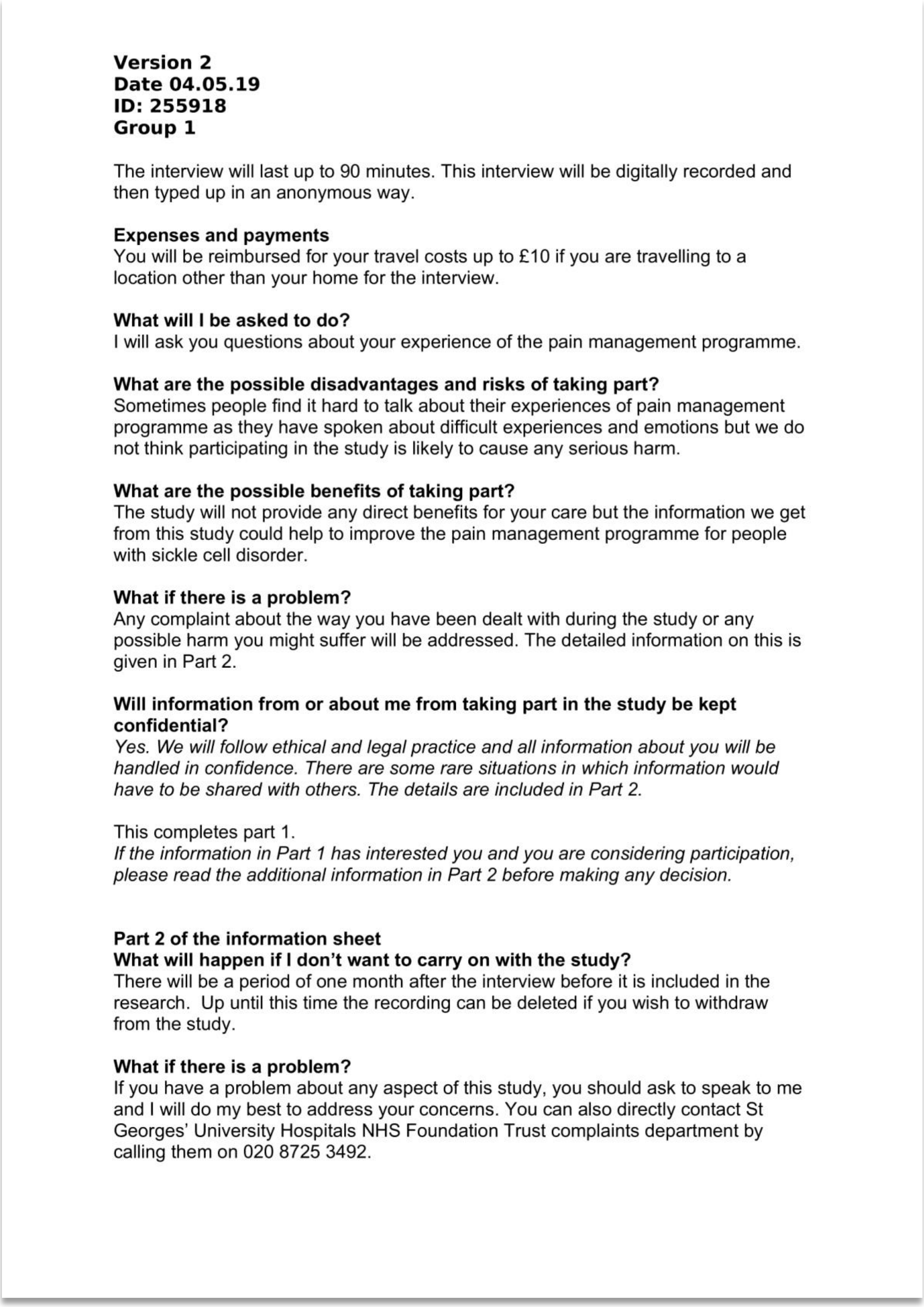
Talk to others about the study if you wish.
(Part 1 tells you the purpose of this study and what will happen to you if you take part.
Part 2 gives you more detailed information about the conduct of the study).

What is the purpose of the study?
It aims to broaden our understanding of how you found the pain management programme and which elements, if any, you found most relevant and meaningful. The aim of these questions are to help us to understand how people with sickle cell experience pain management programmes and what might be the therapeutic mechanisms that are unique in a sickle specific pain management programme.

Why have I been invited?
You are invited to take part in the study as you have attended the pain management programme and you are living with sickle cell disease.

Do I have to take part?
It is up to you to decide whether or not to take part. If you do decide to take part, I will then ask you to sign a consent form. You are free to withdraw at any time. You do not have to give a reason. This would not affect the standard of care you receive from your haematology team.

What will happen to me if I take part?
If you decide to take part, you will be given this information sheet and a copy of the signed consent form to keep. I will contact you to arrange a convenient time and place to have the interview. You will be given a brief demographic questionnaire to complete. During the interview I will ask you a few questions about yourself and questions around your experience of attending the pain management programme.



Version 2
Date 04.05.19
ID: 255918
Group 1

The interview will last up to 90 minutes. This interview will be digitally recorded and then typed up in an anonymous way.

Expenses and payments
You will be reimbursed for your travel costs up to £10 if you are travelling to a location other than your home for the interview.

What will I be asked to do?
I will ask you questions about your experience of the pain management programme.

What are the possible disadvantages and risks of taking part?
Sometimes people find it hard to talk about their experiences of pain management programme as they have spoken about difficult experiences and emotions but we do not think participating in the study is likely to cause any serious harm.

What are the possible benefits of taking part?
The study will not provide any direct benefits for your care but the information we get from this study could help to improve the pain management programme for people with sickle cell disorder.

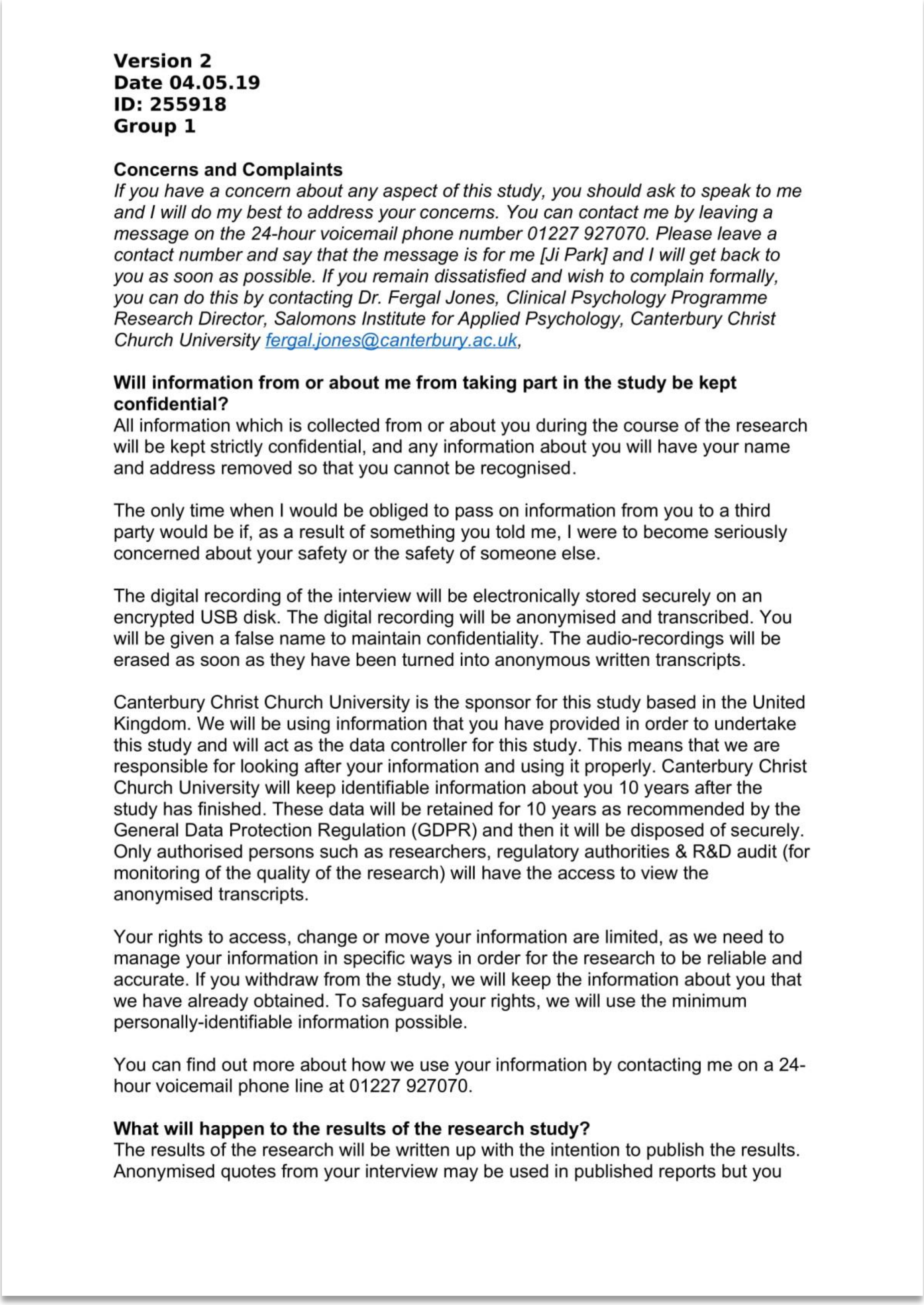
What if there is a problem?
Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. The detailed information on this is given in Part 2.

Will information from or about me from taking part in the study be kept confidential?
Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. There are some rare situations in which information would have to be shared with others. The details are included in Part 2.

This completes part 1.
If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.

Part 2 of the information sheet
What will happen if I don't want to carry on with the study?
There will be a period of one month after the interview before it is included in the research. Up until this time the recording can be deleted if you wish to withdraw from the study.

What if there is a problem?
If you have a problem about any aspect of this study, you should ask to speak to me and I will do my best to address your concerns. You can also directly contact St Georges' University Hospitals NHS Foundation Trust complaints department by calling them on 020 8725 3492.



Version 2
Date 04.05.19
ID: 255918
Group 1

Concerns and Complaints

If you have a concern about any aspect of this study, you should ask to speak to me and I will do my best to address your concerns. You can contact me by leaving a message on the 24-hour voicemail phone number 01227 927070. Please leave a contact number and say that the message is for me [Ji Park] and I will get back to you as soon as possible. If you remain dissatisfied and wish to complain formally, you can do this by contacting Dr. Fergal Jones, Clinical Psychology Programme Research Director, Salomons Institute for Applied Psychology, Canterbury Christ Church University fergal.jones@canterbury.ac.uk,

Will information from or about me from taking part in the study be kept confidential?

All information which is collected from or about you during the course of the research will be kept strictly confidential, and any information about you will have your name and address removed so that you cannot be recognised.

The only time when I would be obliged to pass on information from you to a third party would be if, as a result of something you told me, I were to become seriously concerned about your safety or the safety of someone else.

The digital recording of the interview will be electronically stored securely on an encrypted USB disk. The digital recording will be anonymised and transcribed. You will be given a false name to maintain confidentiality. The audio-recordings will be erased as soon as they have been turned into anonymous written transcripts.

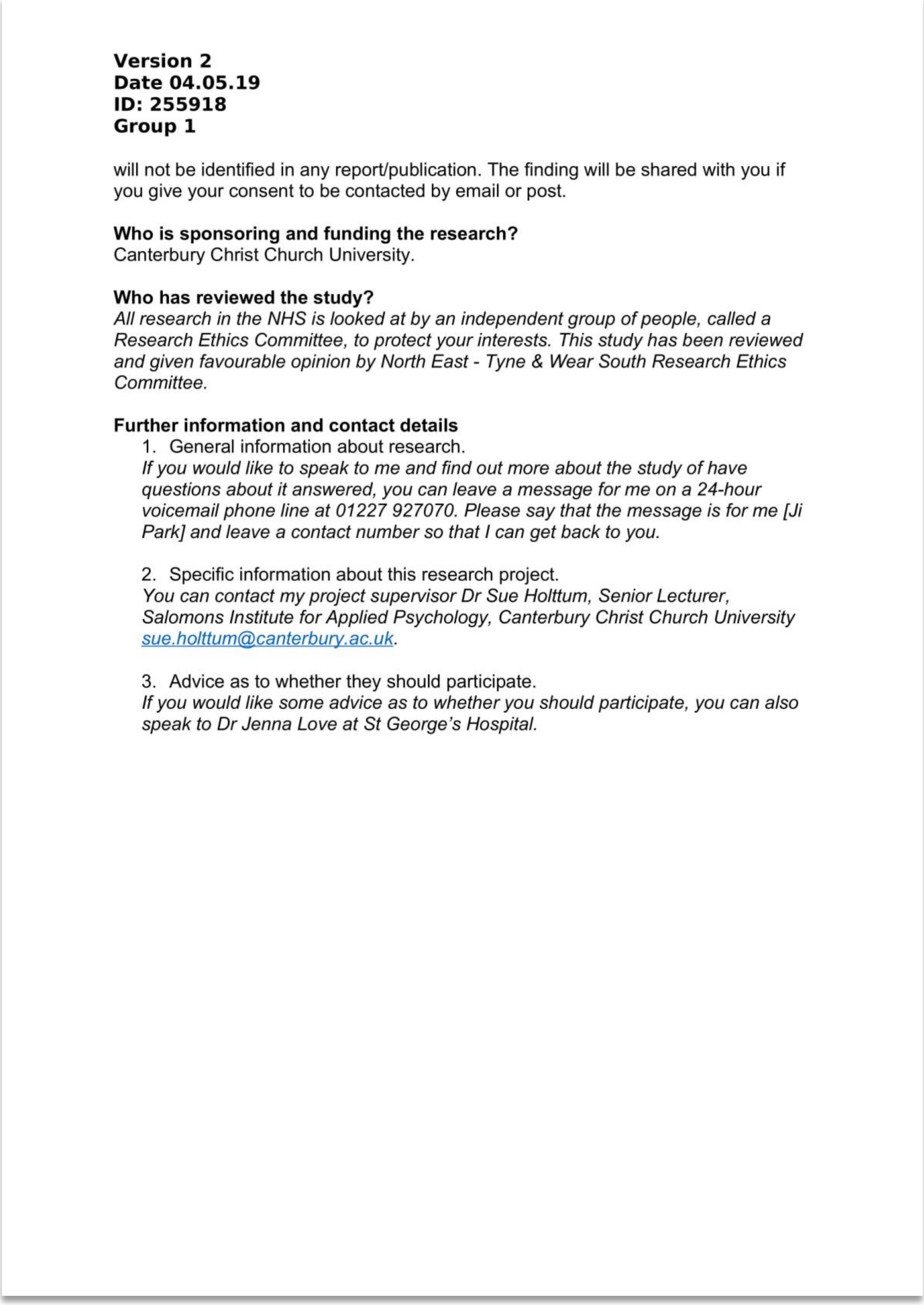
Canterbury Christ Church University is the sponsor for this study based in the United Kingdom. We will be using information that you have provided in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. Canterbury Christ Church University will keep identifiable information about you 10 years after the study has finished. These data will be retained for 10 years as recommended by the General Data Protection Regulation (GDPR) and then it will be disposed of securely. Only authorised persons such as researchers, regulatory authorities & R&D audit (for monitoring of the quality of the research) will have the access to view the anonymised transcripts.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

You can find out more about how we use your information by contacting me on a 24-hour voicemail phone line at 01227 927070.

What will happen to the results of the research study?

The results of the research will be written up with the intention to publish the results. Anonymised quotes from your interview may be used in published reports but you



Version 2
Date 04.05.19
ID: 255918
Group 1

will not be identified in any report/publication. The finding will be shared with you if you give your consent to be contacted by email or post.

Who is sponsoring and funding the research?

Canterbury Christ Church University.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by North East - Tyne & Wear South Research Ethics Committee.

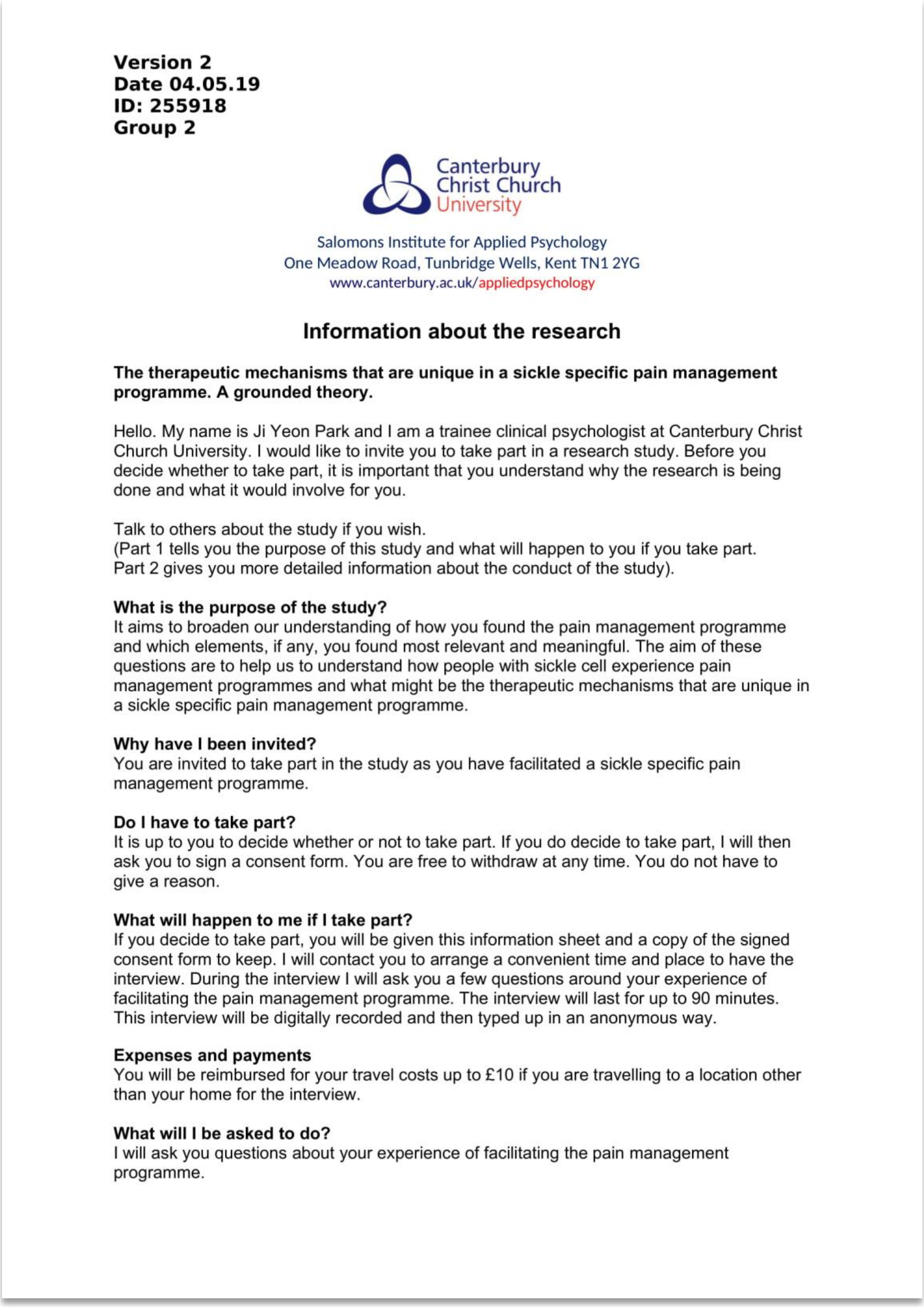
Further information and contact details

1. General information about research.
   If you would like to speak to me and find out more about the study of have questions about it answered, you can leave a message for me on a 24-hour voicemail phone line at 01227 927070. Please say that the message is for me [Ji Park] and leave a contact number so that I can get back to you.

2. Specific information about this research project.
   You can contact my project supervisor Dr Sue Holttum, Senior Lecturer, Salomons Institute for Applied Psychology, Canterbury Christ Church University sue.holttum@canterbury.ac.uk.

3. Advice as to whether they should participate.
   If you would like some advice as to whether you should participate, you can also speak to Dr Jenna Love at St George's Hospital.

Appendix 4 *Section B clinician participant information sheet*



Version 2
Date 04.05.19
ID: 255918
Group 2

Canterbury Christ Church University

Salomons Institute for Applied Psychology
One Meadow Road, Tunbridge Wells, Kent TN1 2YG
www.canterbury.ac.uk/appliedpsychology

Information about the research

The therapeutic mechanisms that are unique in a sickle specific pain management programme. A grounded theory.

Hello. My name is Ji Yeon Park and I am a trainee clinical psychologist at Canterbury Christ Church University. I would like to invite you to take part in a research study. Before you decide whether to take part, it is important that you understand why the research is being done and what it would involve for you.

Talk to others about the study if you wish.
(Part 1 tells you the purpose of this study and what will happen to you if you take part.
Part 2 gives you more detailed information about the conduct of the study).

What is the purpose of the study?

It aims to broaden our understanding of how you found the pain management programme and which elements, if any, you found most relevant and meaningful. The aim of these questions are to help us to understand how people with sickle cell experience pain management programmes and what might be the therapeutic mechanisms that are unique in a sickle specific pain management programme.

Why have I been invited?

You are invited to take part in the study as you have facilitated a sickle specific pain management programme.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part, I will then ask you to sign a consent form. You are free to withdraw at any time. You do not have to give a reason.

What will happen to me if I take part?

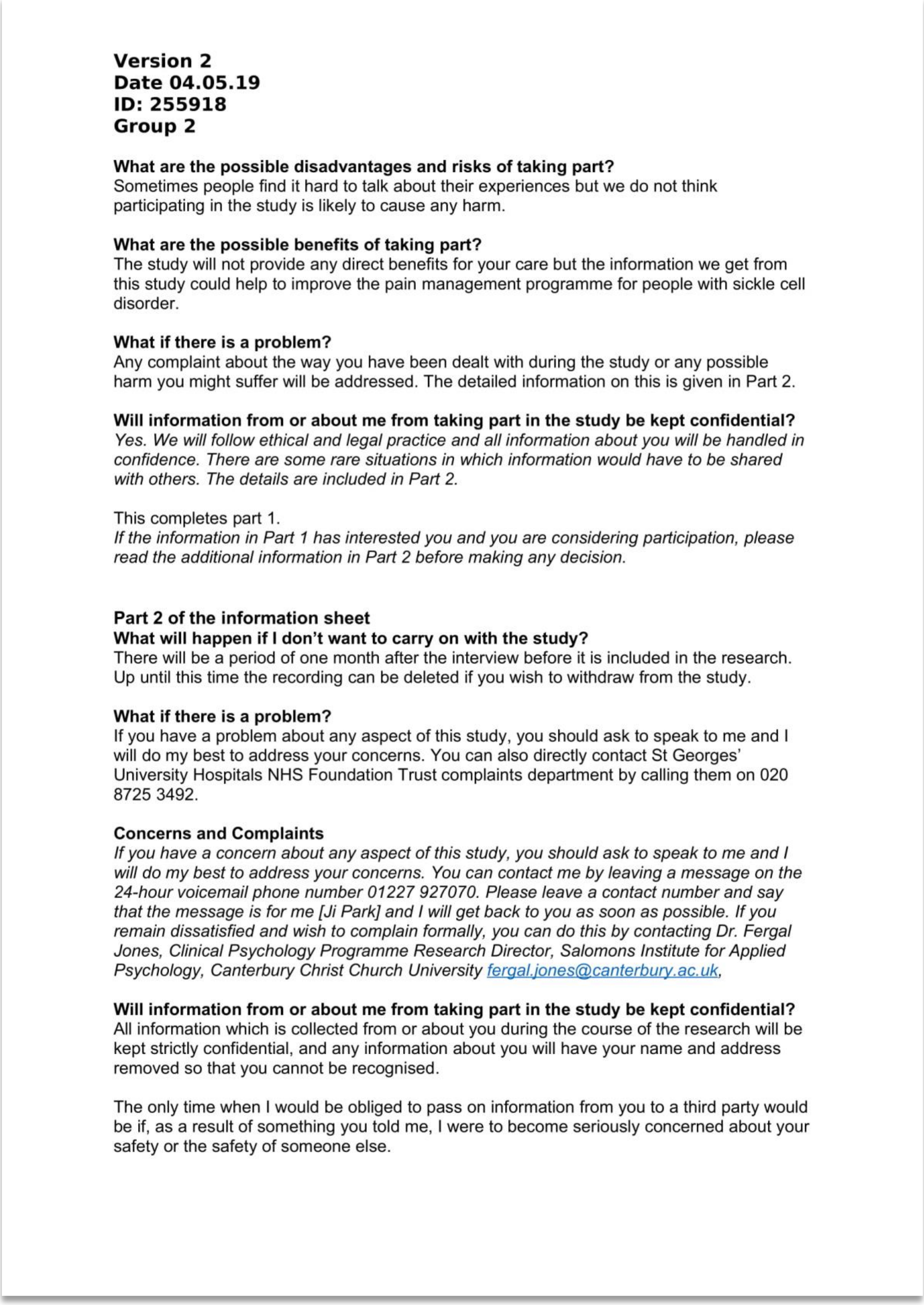
If you decide to take part, you will be given this information sheet and a copy of the signed consent form to keep. I will contact you to arrange a convenient time and place to have the interview. During the interview I will ask you a few questions around your experience of facilitating the pain management programme. The interview will last for up to 90 minutes. This interview will be digitally recorded and then typed up in an anonymous way.

Expenses and payments

You will be reimbursed for your travel costs up to £10 if you are travelling to a location other than your home for the interview.

What will I be asked to do?

I will ask you questions about your experience of facilitating the pain management programme.



Version 2
Date 04.05.19
ID: 255918
Group 2

What are the possible disadvantages and risks of taking part?
Sometimes people find it hard to talk about their experiences but we do not think participating in the study is likely to cause any harm.

What are the possible benefits of taking part?
The study will not provide any direct benefits for your care but the information we get from this study could help to improve the pain management programme for people with sickle cell disorder.

What if there is a problem?
Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. The detailed information on this is given in Part 2.

Will information from or about me from taking part in the study be kept confidential?
Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. There are some rare situations in which information would have to be shared with others. The details are included in Part 2.

This completes part 1.
If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.

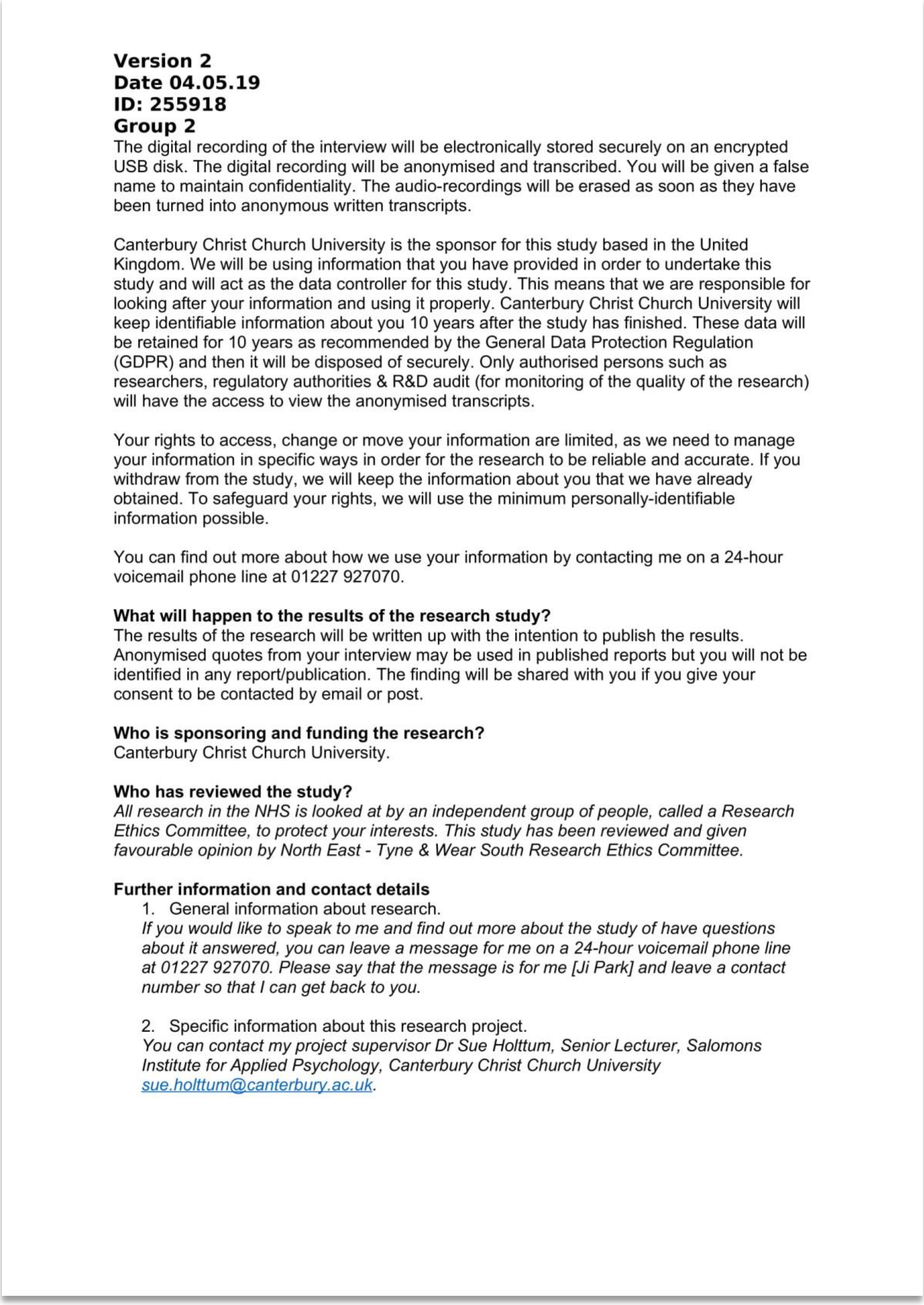
Part 2 of the information sheet
What will happen if I don't want to carry on with the study?
There will be a period of one month after the interview before it is included in the research. Up until this time the recording can be deleted if you wish to withdraw from the study.

What if there is a problem?
If you have a problem about any aspect of this study, you should ask to speak to me and I will do my best to address your concerns. You can also directly contact St Georges' University Hospitals NHS Foundation Trust complaints department by calling them on 020 8725 3492.

Concerns and Complaints
If you have a concern about any aspect of this study, you should ask to speak to me and I will do my best to address your concerns. You can contact me by leaving a message on the 24-hour voicemail phone number 01227 927070. Please leave a contact number and say that the message is for me [Ji Park] and I will get back to you as soon as possible. If you remain dissatisfied and wish to complain formally, you can do this by contacting Dr. Fergal Jones, Clinical Psychology Programme Research Director, Salomons Institute for Applied Psychology, Canterbury Christ Church University fergal.jones@canterbury.ac.uk,

Will information from or about me from taking part in the study be kept confidential?
All information which is collected from or about you during the course of the research will be kept strictly confidential, and any information about you will have your name and address removed so that you cannot be recognised.

The only time when I would be obliged to pass on information from you to a third party would be if, as a result of something you told me, I were to become seriously concerned about your safety or the safety of someone else.



Version 2
Date 04.05.19
ID: 255918
Group 2

The digital recording of the interview will be electronically stored securely on an encrypted USB disk. The digital recording will be anonymised and transcribed. You will be given a false name to maintain confidentiality. The audio-recordings will be erased as soon as they have been turned into anonymous written transcripts.

Canterbury Christ Church University is the sponsor for this study based in the United Kingdom. We will be using information that you have provided in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. Canterbury Christ Church University will keep identifiable information about you 10 years after the study has finished. These data will be retained for 10 years as recommended by the General Data Protection Regulation (GDPR) and then it will be disposed of securely. Only authorised persons such as researchers, regulatory authorities & R&D audit (for monitoring of the quality of the research) will have the access to view the anonymised transcripts.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

You can find out more about how we use your information by contacting me on a 24-hour voicemail phone line at 01227 927070.

What will happen to the results of the research study?
The results of the research will be written up with the intention to publish the results. Anonymised quotes from your interview may be used in published reports but you will not be identified in any report/publication. The finding will be shared with you if you give your consent to be contacted by email or post.

Who is sponsoring and funding the research?
Canterbury Christ Church University.

Who has reviewed the study?
All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by North East - Tyne & Wear South Research Ethics Committee.

Further information and contact details

1. General information about research.
   If you would like to speak to me and find out more about the study of have questions about it answered, you can leave a message for me on a 24-hour voicemail phone line at 01227 927070. Please say that the message is for me [Ji Park] and leave a contact number so that I can get back to you.

2. Specific information about this research project.
   You can contact my project supervisor Dr Sue Holttum, Senior Lecturer, Salomons Institute for Applied Psychology, Canterbury Christ Church University sue.holttum@canterbury.ac.uk.

Appendix 5 *Section B general PMP patient participant information sheet*

Version 2
Date 04.05.19
ID: 255918
Group 3

Canterbury
Christ Church
University

Salomons Institute for Applied Psychology
One Meadow Road, Tunbridge Wells, Kent TN1 2YG
www.canterbury.ac.uk/appliedpsychology

Information about the research

The therapeutic mechanisms that are unique in a sickle specific pain management programme. A grounded theory.

Hello. My name is Ji Yeon Park and I am a trainee clinical psychologist at Canterbury Christ Church University. I would like to invite you to take part in a research study. Before you decide whether to take part, it is important that you understand why the research is being done and what it would involve for you.

Talk to others about the study if you wish.
(Part 1 tells you the purpose of this study and what will happen to you if you take part.
Part 2 gives you more detailed information about the conduct of the study).

What is the purpose of the study?
It aims to broaden our understanding of how you found the pain management programme and which elements, if any, you found most relevant and meaningful. The aim of these questions are to help us to understand how people with sickle cell experience pain management programmes and what might be the therapeutic mechanisms that are unique in a sickle specific pain management programme.

Why have I been invited?
You are invited to take part in the study as you have attended the pain management programme and you are living with sickle cell disease.

Do I have to take part?
It is up to you to decide whether or not to take part. If you do decide to take part, I will then ask you to sign a consent form. You are free to withdraw at any time. You do not have to give a reason.

What will happen to me if I take part?
If you decide to take part, you will be given this information sheet and a copy of the signed consent form to keep. I will contact you to arrange a convenient time and place to have the interview. You will be given a brief demographic questionnaire to complete. During the interview I will ask you a few questions about yourself and questions around your experience of attending the pain management programme. The interview will last for up to 90 minutes. This interview will be digitally recorded and then typed up in an anonymous way.

Expenses and payments
You will be reimbursed for your travel costs up to £10 if you are travelling to a location other than your home for the interview.

What will I be asked to do?

Version 2
Date 04.05.19
ID: 255918
Group 3

I will ask you questions about your experience of the pain management programme.

What are the possible disadvantages and risks of taking part?

Sometimes people find it hard to talk about their experiences of pain management programme as they have spoken about difficult experiences and emotions but we do not think participating in the study is likely to cause any serious harm.

What are the possible benefits of taking part?

The study will not provide any direct benefits for your care but the information we get from this study could help to improve the pain management programme for people with sickle cell disorder.

What if there is a problem?

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. The detailed information on this is given in Part 2.

Will information from or about me from taking part in the study be kept confidential?

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. There are some rare situations in which information would have to be shared with others. The details are included in Part 2.

This completes part 1.
If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.

Part 2 of the information sheet

What will happen if I don't want to carry on with the study?

There will be a period of one month after the interview before it is included in the research. Up until this time the recording can be deleted if you wish to withdraw from the study.

What if there is a problem?

If you have a problem about any aspect of this study, you should ask to speak to me and I will do my best to address your concerns.

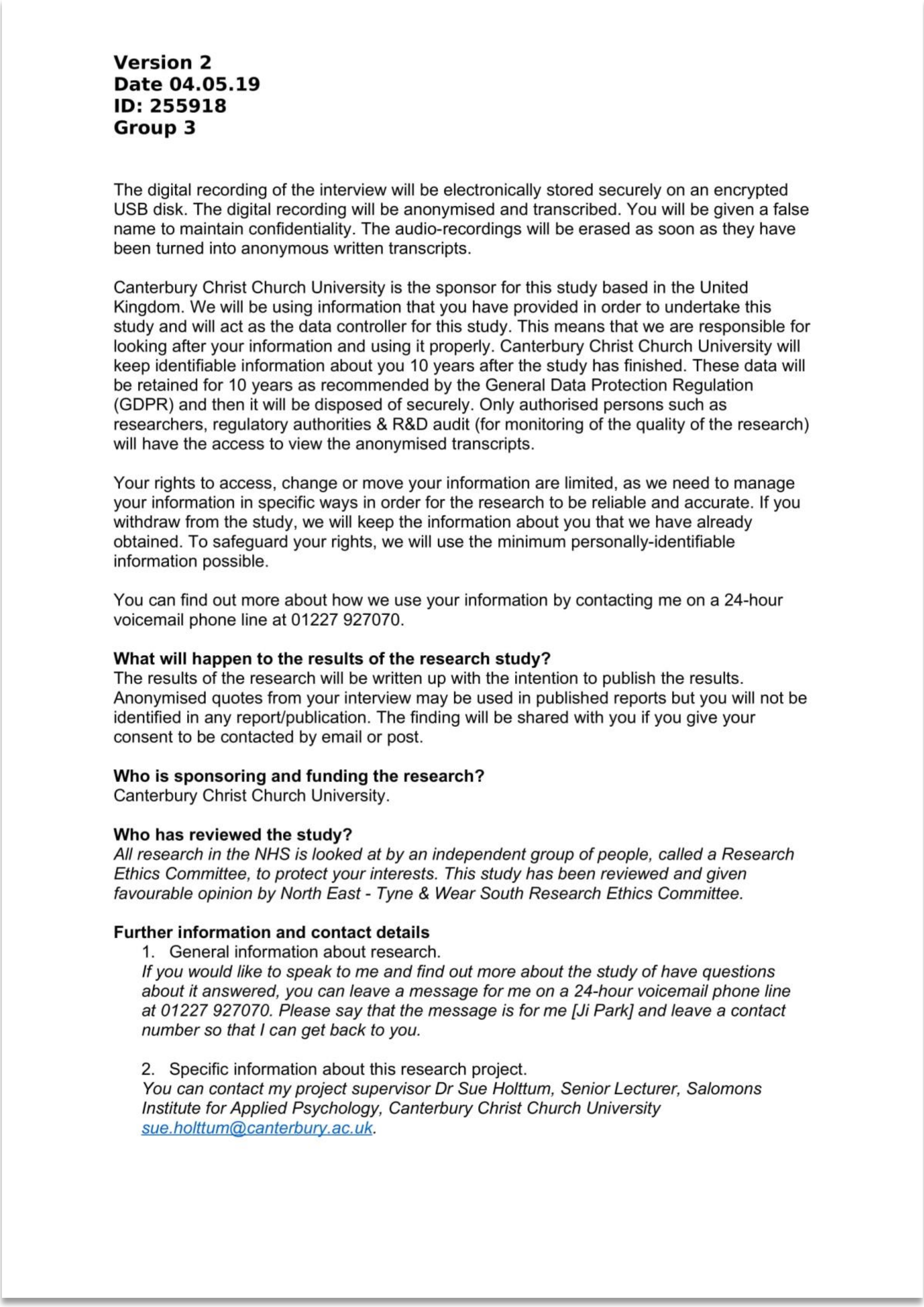
Concerns and Complaints

If you have a concern about any aspect of this study, you should ask to speak to me and I will do my best to address your concerns. You can contact me by leaving a message on the 24-hour voicemail phone number 01227 927070. Please leave a contact number and say that the message is for me [Ji Park] and I will get back to you as soon as possible. If you remain dissatisfied and wish to complain formally, you can do this by contacting Dr. Fergal Jones, Clinical Psychology Programme Research Director, Salomons Institute for Applied Psychology, Canterbury Christ Church University fergal.jones@canterbury.ac.uk,

Will information from or about me from taking part in the study be kept confidential?

All information which is collected from or about you during the course of the research will be kept strictly confidential, and any information about you will have your name and address removed so that you cannot be recognised.

The only time when I would be obliged to pass on information from you to a third party would be if, as a result of something you told me, I were to become seriously concerned about your safety or the safety of someone else.



Version 2
Date 04.05.19
ID: 255918
Group 3

The digital recording of the interview will be electronically stored securely on an encrypted USB disk. The digital recording will be anonymised and transcribed. You will be given a false name to maintain confidentiality. The audio-recordings will be erased as soon as they have been turned into anonymous written transcripts.

Canterbury Christ Church University is the sponsor for this study based in the United Kingdom. We will be using information that you have provided in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. Canterbury Christ Church University will keep identifiable information about you 10 years after the study has finished. These data will be retained for 10 years as recommended by the General Data Protection Regulation (GDPR) and then it will be disposed of securely. Only authorised persons such as researchers, regulatory authorities & R&D audit (for monitoring of the quality of the research) will have the access to view the anonymised transcripts.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

You can find out more about how we use your information by contacting me on a 24-hour voicemail phone line at 01227 927070.

What will happen to the results of the research study?
The results of the research will be written up with the intention to publish the results. Anonymised quotes from your interview may be used in published reports but you will not be identified in any report/publication. The finding will be shared with you if you give your consent to be contacted by email or post.

Who is sponsoring and funding the research?
Canterbury Christ Church University.

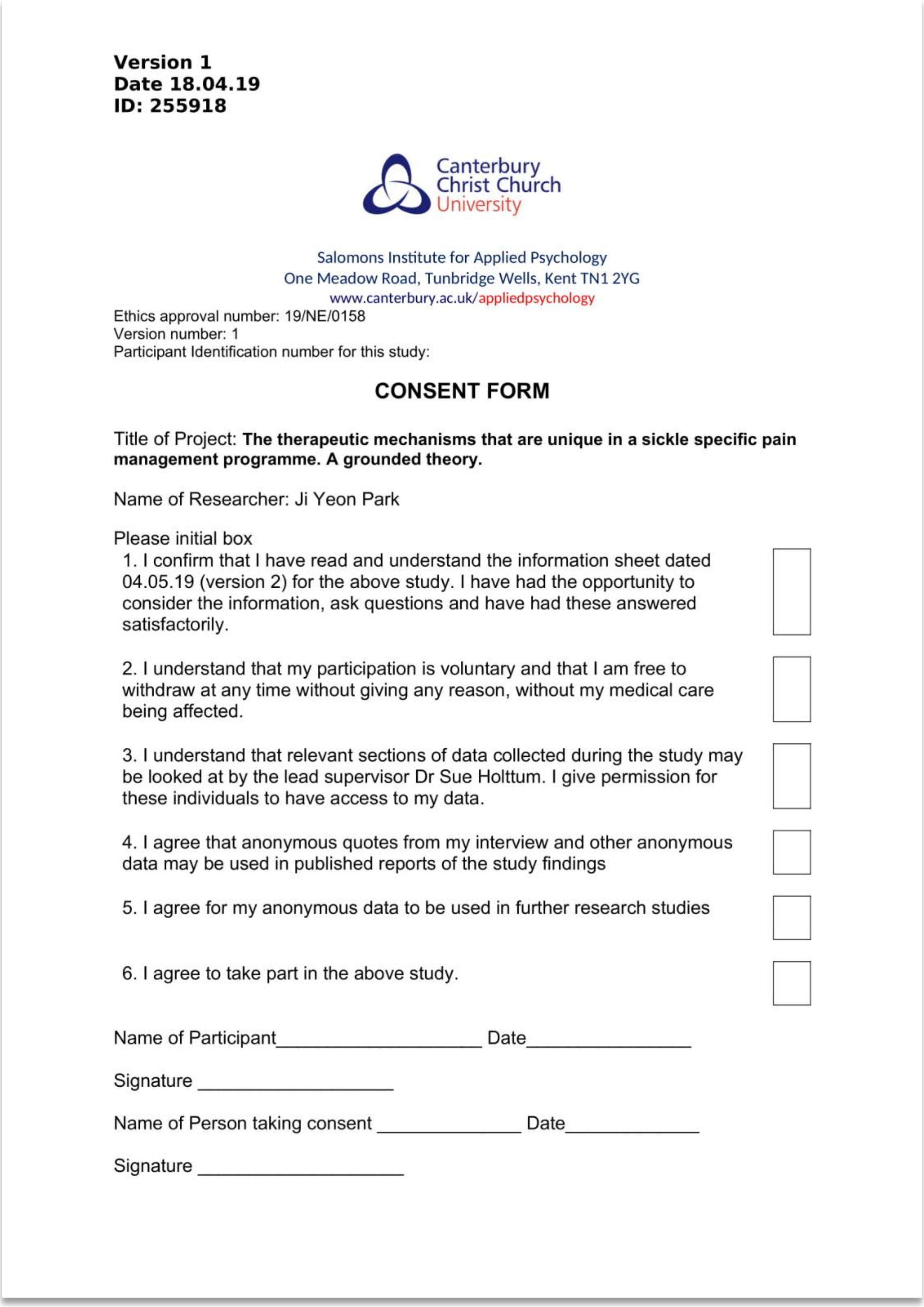
Who has reviewed the study?
All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by North East - Tyne & Wear South Research Ethics Committee.

Further information and contact details

1. General information about research.
   If you would like to speak to me and find out more about the study of have questions about it answered, you can leave a message for me on a 24-hour voicemail phone line at 01227 927070. Please say that the message is for me [Ji Park] and leave a contact number so that I can get back to you.

2. Specific information about this research project.
   You can contact my project supervisor Dr Sue Holttum, Senior Lecturer, Salomons Institute for Applied Psychology, Canterbury Christ Church University sue.holttum@canterbury.ac.uk.

Appendix 6 *Informed consent form*



Version 1
Date 18.04.19
ID: 255918

Canterbury
Christ Church
University

Salomons Institute for Applied Psychology
One Meadow Road, Tunbridge Wells, Kent TN1 2YG
www.canterbury.ac.uk/appliedpsychology

Ethics approval number: 19/NE/0158
Version number: 1
Participant Identification number for this study:

CONSENT FORM

Title of Project: **The therapeutic mechanisms that are unique in a sickle specific pain management programme. A grounded theory.**

Name of Researcher: Ji Yeon Park

Please initial box

1. I confirm that I have read and understand the information sheet dated 04.05.19 (version 2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care being affected. ☐

3. I understand that relevant sections of data collected during the study may be looked at by the lead supervisor Dr Sue Holttum. I give permission for these individuals to have access to my data. ☐

4. I agree that anonymous quotes from my interview and other anonymous data may be used in published reports of the study findings ☐

5. I agree for my anonymous data to be used in further research studies ☐

6. I agree to take part in the above study. ☐

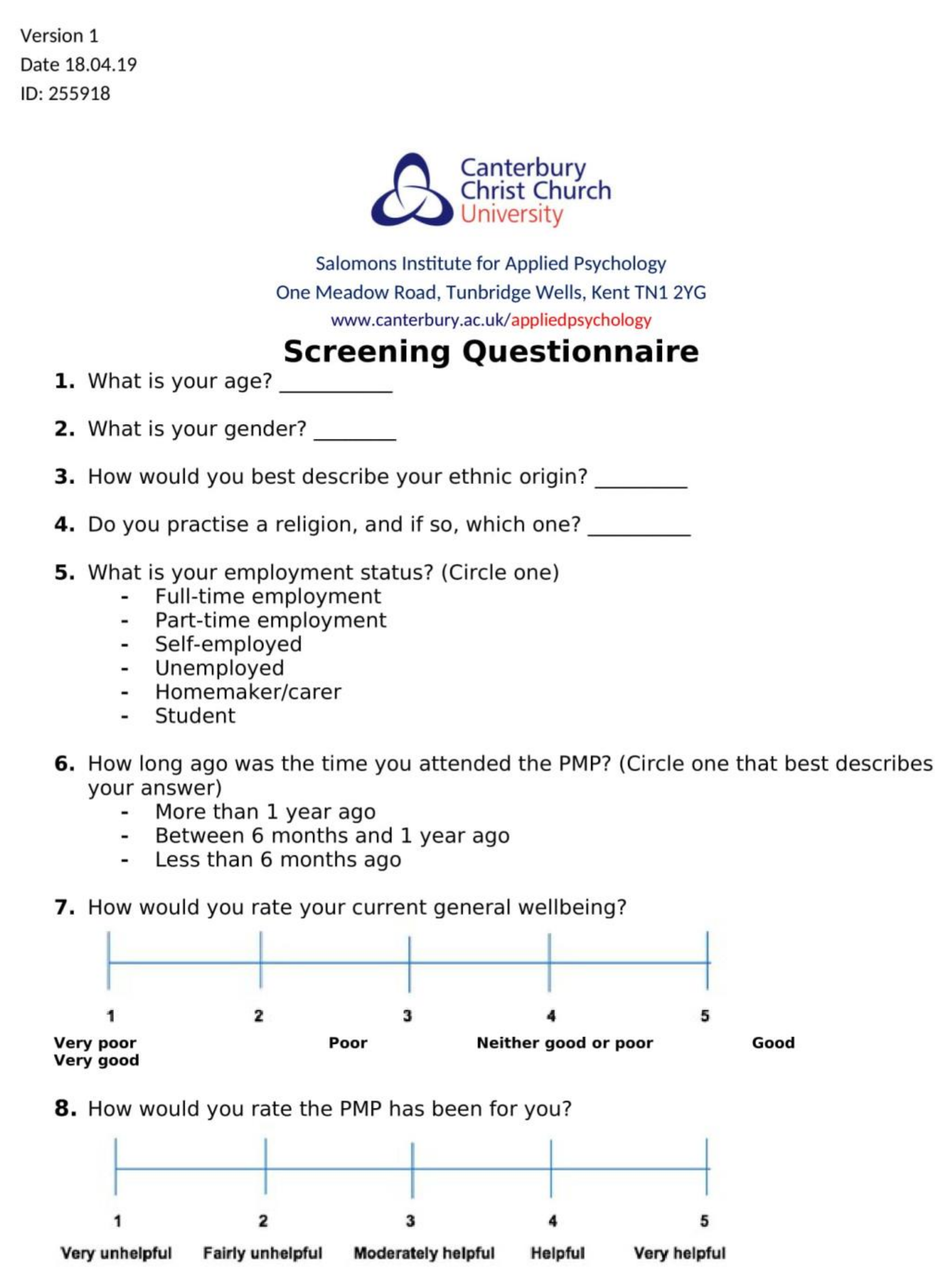
Name of Participant____________________ Date________________

Signature ___________________

Name of Person taking consent ______________ Date_____________

Signature ____________________

Appendix 7 *Demographic questionnaire*



Version 1
Date 18.04.19
ID: 255918

Canterbury
Christ Church
University

Salomons Institute for Applied Psychology
One Meadow Road, Tunbridge Wells, Kent TN1 2YG
www.canterbury.ac.uk/appliedpsychology

Screening Questionnaire

1. What is your age? __________

2. What is your gender? _______

3. How would you best describe your ethnic origin? ________

4. Do you practise a religion, and if so, which one? _________

5. What is your employment status? (Circle one)
- Full-time employment
- Part-time employment
- Self-employed
- Unemployed
- Homemaker/carer
- Student

6. How long ago was the time you attended the PMP? (Circle one that best describes your answer)
- More than 1 year ago
- Between 6 months and 1 year ago
- Less than 6 months ago

7. How would you rate your current general wellbeing?

1 **2** **3** **4** **5**

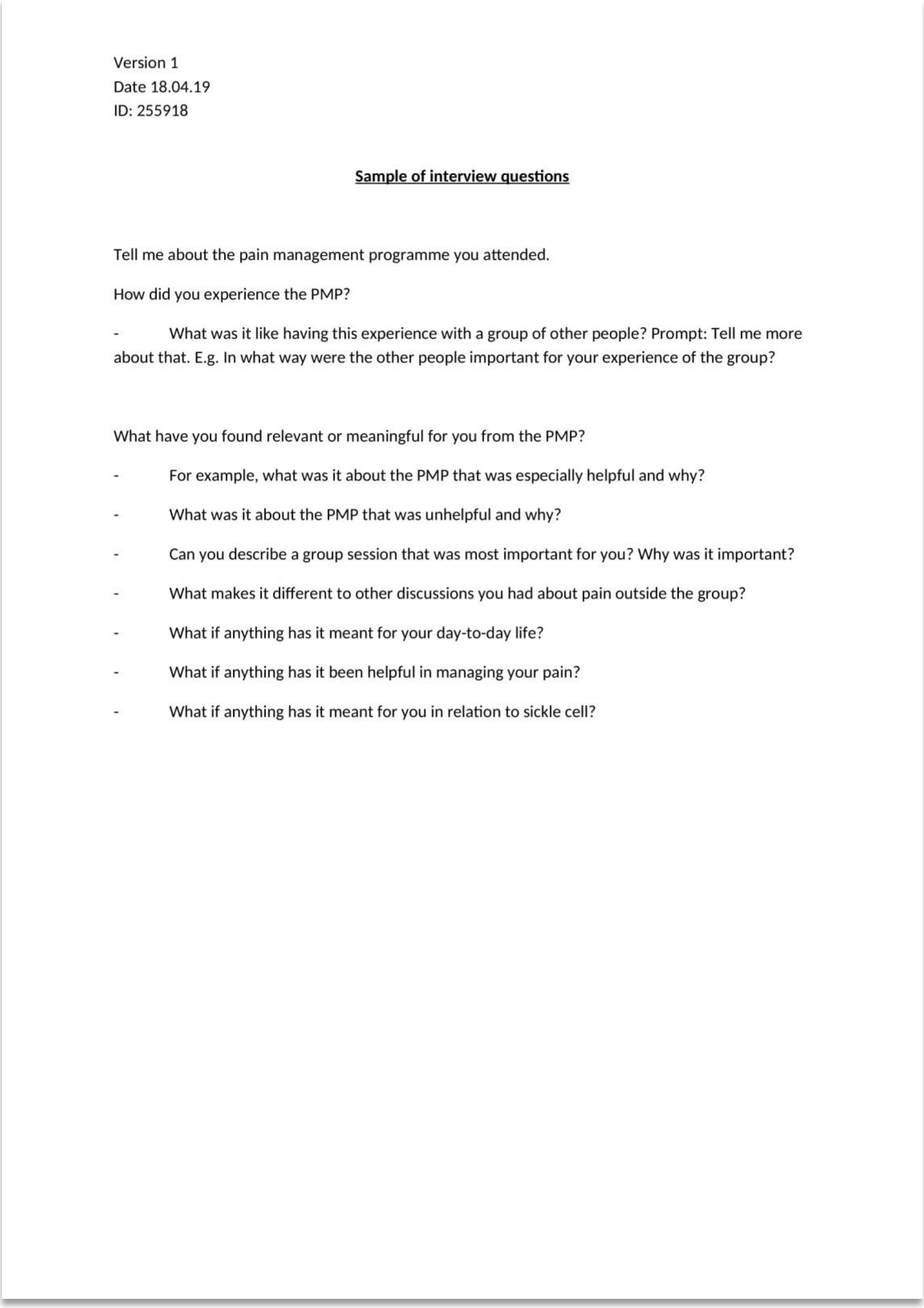
Very poor **Poor** **Neither good or poor** **Good**
Very good

8. How would you rate the PMP has been for you?

1 **2** **3** **4** **5**

Very unhelpful **Fairly unhelpful** **Moderately helpful** **Helpful** **Very helpful**

Appendix 8 *Interview schedule*



Version 1
Date 18.04.19
ID: 255918

Sample of interview questions

Tell me about the pain management programme you attended.

How did you experience the PMP?

- What was it like having this experience with a group of other people? Prompt: Tell me more about that. E.g. In what way were the other people important for your experience of the group?

What have you found relevant or meaningful for you from the PMP?

- For example, what was it about the PMP that was especially helpful and why?
- What was it about the PMP that was unhelpful and why?
- Can you describe a group session that was most important for you? Why was it important?
- What makes it different to other discussions you had about pain outside the group?
- What if anything has it meant for your day-to-day life?
- What if anything has it been helpful in managing your pain?
- What if anything has it meant for you in relation to sickle cell?

Appendix 9 *Interview schedule stage 2*

Version 1
Date 18.04.19
ID: 255918

<u>Sample of interview questions for the facilitators</u>

Tell me about the pain management programme you have facilitated.

How did you experience facilitating the PMP?

- What was it like facilitating a group of people who are living with sickle cell disease? Prompt: Tell me more about that.

- What do you think the group participants' experiences might be attending the sickle specific PMP?

-What do you think the group participants might get out from this?

-Which aspects of the group sessions do people appreciate and why do you think that is?

-What do you think people have found relevant or meaningful from the PMP?

- For example, what was it about the PMP the group participants said was especially helpful and why?

- What was it about the PMP the group participants found difficult or challenging and why?

-Can you tell me about a group session that you felt that participants valued even if it did not go according to the session plan? E.g. you can have a good plan for a session but does not happen according to the plan.

-Do they vary their practice?

-Do they find themselves having to change their practice to accommodate people?

-Can you describe a group session that was most important for you? Why was it important?

Appendix 10 *Tables of coding examples*

Core category: Attending a group to accept pain and make change, develops one's positive sickle cell identity.		
Example quotes	Links to other categories	Theoretical memos
"Now I'm taking, I'm taking, I'm taking hold of my own identity, I'm taking hold of my own humanness by saying that I too matter"	Manage expectations	Taking hold of own identity is directly referenced. The SCPMP seemed to have facilitated this shift in how they think about their needs and firming up their identity.
"I think the group's just, it helped me to see, to be in charge of sickle cell. And not allow sickle cell to be in charge of me."	Boosting confidence	Previously SC being in charge reflects a sense of powerlessness that people can experience in relation to SCD and the SCPMP appears to have helped them to feel more in control of their chronic illness.
"It's like the sickle cell was drowning me, because of the pain and things like that. The pain is there, but it's not drowning me now. I've resurfaced. I've almost like, I'm facing it squarely."	Pain is here to stay	Describing self as "I've resurfaced" appeared to be related to how they see themselves and towards developing an identity facing the pain "squarely". What helped them to do that?
"Because that's the other thing, because we all have our success stories and we're all doing our different things, and we're all kind of surviving this thing called sickle."	Relating to experiences that only people with SCD can understand	The focus on the success stories and externalising the SCD as something to survive may be a part of developing one's sickle cell identify from being able to relate to each other in the SCPMP.
"I know how to identify certain pains, but it shouldn't define me, at all, you know? So it's accepting that there are other things you can do, while you're in pain with sickle cell."	Strengthening the sense of self	Not allowing pain to define self and acceptance feels like describing a therapeutic change where one is developing an identity that is not engulfed by SCD.
"I'm not going to go back to trying to force myself and giving myself kind of like a task on something I can't control. I've accepted the fact that there's certain aspects of this disease I can control, but when I'm in a crisis, I can't control it. "	Feeling different about SCD	So the SCPMP has helped to accept the parts of SCD that are controllable and uncontrollable, which seems to have shifted from trying to force self to be control all aspects and developing acceptable identity.
"It's helped me to understand my sickle cell, it's helped me to be comfortable in, you know, speaking about the pros and the cons and negatives and the positives about sickle cell also as well."	Feeling different about SCD	Feeling more comfortable talking about SCD feels significant. The sharing and relating in the SCPMP appeared to have helped one to develop a sense of self that is more comfortable and authentic.

Category 1: Not talking about pain

Description: Participants explained that people usually do not talk about pain and SCD and some noted that this is a norm in their culture. Others described hiding pain from others to avoid negative judgement. Concerns about negative connotations around SCD were mentioned as a further reason for not feeling able to be open about their pain and SCD.

Sub-categories	Example open codes	Example participant quotes	Theoretical memos
a. Hiding pain from others	Might not talk to be judged	“I might not talk because I don’t want to give the wrong impression that people might say that, okay, being judged” (P5)	It feels like people are concerned about how other people may view them because of worrying about being judged. I wonder if they are suggesting that they had been judged previously? This experience of hiding pain may have contributed to their overall experience why they valued sharing and relating the experiences that only people with SCD can understand.
	Pretending to be fine	“I wouldn’t talk to them one-on-one. Like if I was having a crisis, there and then, in the old days what I would do was I would pretend that everything’s fine, and then I would just disappear.” (P2) “I’m not going to say nothing. I’m just going to keep that from you and keep that with me. ” (P5)	
	Suppressing your feelings	“You subsidised your whole feeling, suppressed your whole feelings, just to appear to be okay” (P8)	
	Not talking about pain	“personally, my normal day-to-day, I don’t talk about pain. That was the place only where I could go and talk about the pain.” (P6)	
	Not having the opportunity to be open	“I’m not sure how often people get the opportunity to have these actually very emotive, very brave, very open conversations” (P10)	
b. Negative connotations around SCD	Feeling SCD might be used against	“I never mentioned having sickle cell. I never disclosed my health issues because I just always feel that it would be used against me.” (P3)	It sounds like the participants are explaining their perceived experience of stigma due to SCD. The reference to death and examples of what other people may say may be a way to empathise their point from feeling not understood by the interviewer.
	SCD like a taboo back home	“Because well, back home, for example, it is like a sickle cell almost like a taboo” (P4)	
	Connotations with death	“oh my goodness, this poor girl has sickle cell, the possibility of her dying is about when she’s about twenty-five, if she’s still twenty-five and she hasn’t died, then maybe, you know, maybe thirty-five.” (P4)	
	Still being stigmatised	“obviously it’s still very well stigmatised, especially in Africa, where people have very primitive ideas.” (P3)	

Category 2: Learning about pain and techniques

Description: Participants described learning about pain and techniques in the SCPMP and they were mostly unfamiliar with this. The participants also described learning beyond the medical treatments about the negative impact of stress and anxiety on their pain. Learning about techniques, such as mindfulness, pacing and exercise, was considered useful.

Sub-categories	Example open codes	Example participant quotes	Theoretical memos
c. Understanding pain mechanism	Learning about pain theory	“I’m thinking, ‘breaking the cycle? Well there must be something that I’m not doing right here’” (P4)	How does the process of gaining knowledge add to therapeutic processes in the SCPMP? It sounds like people are trying to say learning about pain is really important because it is not something they discussed before or previously thought about.
	Realising not all pain is bad	“Understanding that pain is also, not just a bad thing, it’s probably a good thing in a sense where you can recognise what pain, you know, you’re feeling at a time, and trying to identify what you’re going through also as well.” (P8)	
	Understanding pain doesn’t mean danger	“It doesn’t necessarily mean that, yes, there is danger. There is imminent danger” (P5)	
	How pain works	“I know that I will have this influx of pain that will build up. It will build up, I know that, knowing really how pain works in me, or what pain is.” (P5)	
	Pain in relation to the nervous system	“where we’re thinking more about the nervous system and how we make sense of, of pain. You know, it might come up in that kind of discussion” (P9)	
d. Differentiating chronic pain and acute crises	Pain because of SCD	“apart from the acute pain that I’m having, so this pain is not sickle cell pain, but it’s a pain maybe because of sickle cell.” (P6)	This feels very much sickle specific. It sounds like people are trying to make sense of their pain experiences in a way they haven’t before, trying to unpick whether their pain is chronic or acute pain. If people are in an environment where their pain is not discussed than it is understandable that people may not be used to thinking about their pain in this way.
	Two concepts of pain	“I was able to see the two concept of the pain mechanism, of the acute and the persistent. Whereas I didn’t know.” (P4)	
	Mistaking what is acute and chronic pain	“we started off with [doctor] telling us whether we understood what chronic pain and acute pain was, I got that wrong, I thought that acute pain was the pain I was undergoing and that chronic pain was something else” (P7)	
	Insight to know the difference	“I think for me it was just understanding acute and chronic pain within the pain management programme. That’s what I found insightful.” (P8)	
	Emotional effect of pain	“I would get emotionally affected by the pain. So it’s not just the physical, it’s my emotional as well, being affected.” (P5)	

e. Psychological effect of pain	When feeling content, your pain is not so painful	“I can do for me that would make me feel better. Because when, one of these through lines was when you feel better when, when you feel content, even if the pain is high, it doesn’t feel quite so painful.” (P7)	This feels like introspection of their emotional experience of pain. People are able to recognise that pain is not just physical but also psychological experience.
	Low mood can make your mood worse	“If you’re like, in a bad mood, or you’re not happy, and you have pain, you sometimes feel the pain is actually worse than what it actually is.” (P2)	
f. Tools and techniques to manage	Exercises particularly helpful	“The exercise helped me to know that by strengthening my muscles and things, it wouldn’t be too stiff and therefore, you know, it would help me in the long run” (P4) “[PMP] was good at giving us some exercise through, I don’t know if it’s through make your joint more stronger.” (P6)	Tools and techniques appears to have been valued by the participants here. I wonder why some tools were more helpful for some than others… It sounds like the techniques were helpful after learning about pain and the psychological effect of pain.
	Soothing practices can be anything	“soothing practices can be anything, can be just putting some practical action, listen to music, distracting the mind, calling a friend, watching television, lie down and relax” (P5)	
	Breathing exercises most helpful	“it was the techniques, the breathing exercises that we did. They were, they have, they were most important” (P1)	
g. Facilitators’ knowledge about SCD in PMPs	Extra dimension in SCPMP about pain described by the SCPMP facilitators	“we’ve got this extra dimension that we don’t really have in other pain, in some other pain management groups.” (P10) “in a general programme crisis wouldn’t need to be in there, but we’re holding both much more. So that’s section’s a bit different as well.” (P9)	It sounds like those who did not attend the SCPMP placed a significance on the role of the facilitators. I wonder what was the social process that is happening? The explicit description of wanting the PMP facilitators to know about SCD is important.
	Facilitators could guide me	“What I was going through was relatable to what their knowledge was and they could guide me still.” (P11)	
	Facilitators did not know SCD very well	“I don’t feel that they [facilitators] had a brilliant understanding of sickle cell.” (P12)	
	Could feel left out if facilitators did not know about SCD	“if it was somebody that was just dealing with that and wasn’t too sure about the sickle then I would feel a bit left out.” (P11)	

Category 3: New ways of talking to friends and family

Description: The participants frequently cited the positive impact of including their friends and family in one of the sessions. They noted that this session gave them the space to find new ways of talking to friends and family about their pain and SCD. It changed how they communicated and received support from the people close to them.

Sub-categories	Example open codes	Example participant quotes	Theoretical memos
h. Wanting others to understand the pain experience	Put yourself in others' shoes	"I mean the family day, that was memorable for me. Because you know, you put yourself in a situation, you put yourself in other people's shoes and you've got everyone, you know, sitting around you also" (P8)	I feel like this is connected to the previous codes about not talking about or hiding pain to others. I think they are saying that they want to be understood by their friends and family. The discussions with friends and family appears to have allowed an understanding to develop in relation to their pain experience.
	Other families did not understand the difficulties	"they were shocked to see that there was so much tension in other families who didn't seem to understand how difficult the disease was" (P7)	
	Helping families to understand	"with that sit-in session that we had, with the families and loved ones, it became obvious to them that, it's not because we intentionally want to shut them out" (P1)	
	Family only seeing the outside	"I don't even feel good. Like, I look crap, I feel crap, my body's… do you understand what I'm saying? But on the outside, but to other people, friends and family, this is the norm." (P8)	
i. Communicating with others	How to communicate to others	"the pain management made me to communicate with people around me. Which helped them, because it's frustrating for them to knowing I'm, you know, I'm in pain and there's nothing they can do." (P6)	Having friends and family attend the SCPMP seems to have improved communication between them. I wonder what specific processes that has helped them to change in their communication and at what speed? Did the change happen gradually or straight after? How about with friends and family who did not attend the friends and family session?
	Using creative ways to communicate	"they're flashcards basically to create for friends and family when you don't really want to speak, and it's just got a little message saying that I'm feeling tired today" (P8)	
	Feeling able to talk to others	"your story is not unique. So you can talk to people about it." (P2)	
	Learning that it is good to share	"I may change the way I'm doing thing. Instead of withdrawing myself and not talking, maybe would be good to share and to talk a little bit more, so the communication part was really good."	

j. Asking for and accepting help from others	People can help you with pain	"to bear in mind that there's people around you that can help as much as they can" (P6)	This may be one of the example of how the communication with friends and family shifted following the SCPMP. Being able to ask for and accept help feels like an important change in how they communicate.
	How to ask for support	"it just made me think, "okay, how am I able to communicate and, you know, get my family to be of support like this towards me?", also as well I found it inspiring" (P8)	
	Realising I don't ask for help	"I said, the family day was a big thing and the fact that, yeah, but you don't ask for help… it was just like, yeah, having that realisation. Yeah. So I think it did help" (P2)	
	Learning to ask for help	"Which means that if I need help, I need to be able to ask for help… And you just have to adjust and you have to ask for help." (P2)	

Category 4: Sharing and relating

Description: Being in a group with other people with SCD was a new experience for most of the participants. They noted that even when they know other people with SCD, they rarely discuss the pain experiences in the way they did in the SCPMP. Sharing allowed the same or different experiences with same themes to be heard and the relating of experiences that only those with SCD can understand. Some mentioned that they do not feel understood in their SCD, even by the health professionals. Feeling understood by each other in the group appeared to be of importance and unlike other experiences of being in a group.

Sub-categories	Example open codes	Example participant quotes	Theoretical memos
k. Sharing same experiences	Hearing somebody's life is like mine	"it's like an open window, I'm seeing somebody's life that is like mine." (P5)	The expression "like an open window, I'm seeing", it captures so clearly what their experience had been like to hear somebody describe their life, which feels similar to own. This feels like a unique process.
	Different people going through the same theme	"it was different people, different demographics, different experiences, but we all had the same theme, which was dealing with pain." (P2)	
	Feeling comfortable with sharing	"I just felt our experiences were, when I say the same, it's, you feel comfortable speaking about your experiences because someone else also understands what you're going through" (P8)	
l. Relating to experiences that only people with SCD can understand	Could relate to everything	"you could relate to everything they had to say about their experience, you know, because you go through the same thing." (P7)	I think this is connected to sharing. 'We get each other' seems to describe the process well. It feels quite powerful to experience where people "totally get it". I wonder how this translate to their overall impression about their group.
	What he says, that's what I do	"I do understand what he was saying, and then you say, wow that's, that's what I do." (P5)	
	We get each other	"There's some things that individuals would say, and then we'd look at each other and we would totally get it." (P3)	

	People talk and you know what that is	"people know what I'm going through. People know. That's why it's good to, because when they talk, you know what they talking about." (P6)	
m. Not needed to explain yourself	They can know your pain from your position	"Even in a position that you sit, they could tell, okay, that position means you are in pain" (P5)	Similarly connected to "we get each other". Not needing to explain yourself feels like in an addition to relating each other. I wonder possible implicit reference that their perception that there is a need to explain yourself to people without SCD?
	Not needing to explain yourself to group members	"you don't need to say much for them to know where you're coming from because they, they would have been in that issue one time, or they know exactly what you're feeling" (P1)	
	Don't need to explain yourself	"So you didn't have to explain yourself, they knew exactly what the pain is." (P7) "unless you've experienced the pain that a sickle cell patient has experienced, they can't just talk about it. You don't know how it feels." (P3) "I actually understand how they feel, because I, I've experienced that pain" (P3)	
	Can spot the signs just physically	"Some of us may have not been feeling well that day but we could spot the signs just physically." (P8)	
n. Need to explain about SCD to others in PMPs	People wanted to know about SCD in PMPs	"to speak about my experience of sickle, people were really keen to ask more questions about it because they didn't understand it, 'it's a blood disorder, it does this, it does that', and what have you, but here I am." (P11)	This contrasts with 'not needing to explain yourself to group members' in the SCPMP. A need to explain to others about SCD is linked to other people not understanding it or knowing about it. This sense of being judged by others in the group, I wonder the consequence of that was they "held back" contributing to the group.
	Feeling judged in non-specific group	"there was a bit of judgement around it, about pain, the tablets or medication that we were on. Because they're very very major, you know, medications. And quite, a few people were sort of, gasp, stunned, and 'how come you're…'. People made comments and things. They were negative comments" (P12)	
	Could not be open about SCD	"we weren't able to be as open as you would like to be regarding your illness" (P12)	
	Being held back to talk about SCD	"I just stopped talking about it… So it was like, any time you thought 'oh, I need to mention this about sickle', it was, you had to hold, well, I held back. I didn't sort of talk about it too much afterwards." (P12)	

Category 5: Learning together

Description: This category explores the process within the sharing and relating category. Participants reported learning together, with this sense of togetherness referred to by some as a "family" with a shared goal. After hearing about others' struggles, participants spoke about learning about themselves by being able to compare/contrast and reflect on others' experiences. Not feeling like the only one was described and they noted feeling that the pain experiences had been validated. Participants explained that they did not need to worry about being judged or disbelieved in the group, so they could be open and authentic and feel accepted by other group members.

Sub-categories	Example open codes	Example participant quotes	Theoretical memos
o. A sense of togetherness with a shared goal	Having a common goal	"we were, because we have this common, would I say goal" (P1) "So it's nice having that there, that camaraderie, it's like, 'yes, we're doing this!'" (P2)	A strong group identity appears to be indicated here. Describing a sense of unity and support, as people referred the SCPMP as like a "family".
	Feeling like a community	"they were also a community there. There was a community, a common reason why we are there, to, to reduce, to help reduce the impact of our pain" (P4)	
	Feeling like a family	"you know, just is like, we're like a family. Even though we're all individual, we came there, we met there" (P3) "It felt like a family because, you know, their experiences, it's almost similar." (P4)	
p. Feeling not alone and validating the pain	Not the only one going through this pain	"you're not the only one going through this horrible pains, and the fact that you, you hear other people share their experience." (P6) "who thinks that, you know, you're the only person going through this situation, but no, you're not" (P8)	Feeling like not the only one describes a therapeutic process that is happening in the group. I wonder if their experience feels more acceptable? Feeling like you are not the only one appears to affect how you view yourself and the expectations you may have about yourself.
	I'm not the only one	"And it was nice to know that, even though I'm not the only one, I'm not the only one who's being too hard on myself either." (P2)	
	Feeling validated	"To validate, to go to the doctor and say, 'I'm feeling this', and you know it's not strange. You're not being funny, you've heard somebody and you're confident like, 'yes I'm not the only one, it's not happening just to me, only to me, it happens to people.'" (P6)	
q. Learning through others' experience	Learning that others cope differently	"I have this problem, this person has the same problem but in a different way, and they've been able to come out through the other side" (P2)	Subsequent to hearing that people share the same problems, then it sounds

	Learning how others treat SCD	“it kind of became an interest then, that you know, everybody’s sickle cell was so unique and, and, and how they’re treating it.” (P4)	like they are able to learn from each other? Could social comparison be happening here? But it is not specifically about other people doing better or worse than you.
	Learnt through others	“Because I learnt through them things that I experience myself but I didn’t know what it was.” (P6)	
	Comparing their experiences of pain	“you share, you compare notes and learn things from them that you didn’t even know.” (P1)	
r. Authentic self being accepted	I can talk about what I’m feelings	“having everybody sharing their own experience is the place you feel that, yes, that’s the place I can talk about what I’m feeling and people know what I’m talking about” (P6)	“Mask is able to come off “ again, really well captures the participants’ experience of being their authentic self. A consequence of hiding pain, putting the “mask” on.
	Mask is able to come off	“you’re able to let your guard down. Do you know, the mask is able to come off, you’re allowed to take your jacket off, you’re allowed to loosen up” (P5)	
	Comfortable with being myself	“I feel comfortable because I’m able to be myself” (P8)	

Category 6: Exploring your pain

Description: Having an understanding of their pain experience and exploring what they can do appeared to be important within the learning about pain category. Participants described feeling more confident about exploring their pain experience and recognising that the pain is for life. Whilst they cannot get rid of the pain, they described feeling able to manage the degree of pain.

Sub-categories	Example open codes	Example participant quotes	Theoretical memos
s. Understanding what you can do	Feeling equipped with practical aspects	“it did equip me with knowledge. Practical, very practical aspects of this group” (P5)	This follows on from learning about tools and techniques because there is something about applying what they learned to their day-to-day lives.
	Find ways to cope in our own lives	“find ways to cope with our pain in our own family situations” (P7)	
	What I can do in pain	“But the pain management clinic told me that I can pace my movement or what I’m doing, but I have to keep on moving. Not stay, not stop moving.” (P6)	
t. Pain is here to stay	Pain is still here	“It’s not going to go away. The pain is still there.” (P5)	Maybe here, what is significant is that the participants are explicating stating that their pain is not going away.
	Pain is not going away	“It’s going to be there. It’s not going away, that pain, it’s just there.” (P6) “The crisis, you feel better about the acute pain, but the chronic pain is still there. And you still have to live with that.” (P6)	

	SCD for rest of my life	“I do have sickle cell, I’m going to have this for the rest of my life” (P8)	

<table>
<tr><td colspan="4">Category 7: Increased positive experiences of self
Description: Participants described being able to have increased positive experiences of self. Managing expectations about themselves facilitated the process of strengthening the sense of self and boosting confidence in their achievements and abilities.</td></tr>
<tr><td>Sub-categories</td><td>Example open codes</td><td>Example participant quotes</td><td>Theoretical memos</td></tr>
<tr><td rowspan="4">u. Strengthening the sense of self</td><td>Feeling stronger</td><td>“It makes you, it’s just like, making you feel stronger.” (P6)</td><td rowspan="4">There is a sense seeing oneself more positively. Wanting to rise above SCD and pain and feeling more able to do that.</td></tr>
<tr><td>Strengthening ourselves</td><td>“Coming here [SCPMP] to strengthen ourselves and to face the world.” (P4)</td></tr>
<tr><td>Empowerment moment for me</td><td>“I’ve really felt it was an empowerment moment for me.” (P8)</td></tr>
<tr><td>Not wanting SCD to define me</td><td>“I don’t want this thing [SCD] to define me” (P2)</td></tr>
<tr><td rowspan="4">v. Managing expectations</td><td>Knowing my limits</td><td>“Strategies would be then, be modest. In the sense of, I have to tell to myself, I can’t do this. I reach my limit.” (P5)</td><td rowspan="4">I think this is closely related to seeing oneself more positively. By managing their expectation about themselves, they are able to develop more positive views of themselves. I think it reveals how they may have struggled with managing unrealistic expectations about themselves.</td></tr>
<tr><td>Not need to do everything</td><td>“But I would say for me, that made me think, okay, right, yes, it is true I don’t have to do everything that is expected of me” (P7)</td></tr>
<tr><td>I don’t beat up on myself</td><td>“I’m just a bit more relaxed. If I don’t finish a task, I don’t beat up on myself because I’ve not finished the task” (P2)</td></tr>
<tr><td>Not pushing yourself too much</td><td>“not pushing yourself too much. Do what you can when you can. Giving a break to yourself to do better maybe tomorrow.” (P6)</td></tr>
<tr><td rowspan="3">w. Boosting your confidence</td><td>Be confident to face the world</td><td>“So I’m applying that to be confident in myself, to be independent in myself, and then maybe hopefully that way I’ll be able to face the world better.” (P4)</td><td rowspan="3">What are people trying to say here? Is it that the challenge to live with SCD is continuing so they need the courage and confidence to face the world?</td></tr>
<tr><td>Gave you the courage</td><td>“Seeing all the people going through it just gave you the courage to go through.” (P6)</td></tr>
<tr><td>Feeling confident to talk about SCD</td><td>“it’s made me a lot more confident in, when speaking about my sickle cell experiences.” (P8)</td></tr>
</table>

Category 8: Accept and make changes

Description: Being able to accept the pain and pain experience was a significant outcome following the SCPMP and this shift in their positioning seemed to facilitated the participants to make changes in their lives. For some, it further shifted how they thought about SCD.

Sub-categories	Example open codes	Example participant quotes	Theoretical memos
x. Accepting the pain	Accept the pain	“To best, to best accept, it’s a, when I say accept, best, try to live with that pain. Yeah.” (P6)	I wonder what they may have meant through using the word, acceptance. Acceptance is a process on a continuum rather than dichotomous. Though I think the important take is that in their interpretation, they were able to accept the pain.
	Accepting and being patient	“So accepting and being, being patient and trying to put things in place, doing the right things, will make the pain subside a bit.” (P4)	
	Accept and identify what you go through	“Accept and to identify what pain you’re going through” (P8)	
y. Making changes to live with pain	Applying bits and pieces	“I’m constantly applying all these bits and pieces. Mindfulness, I’m also applying it almost daily.” (P4)	I think these are referring to the changes they have been able to put into practice and are able to do now since the SCPMP.
	Exercises I can still doing	“So it’s that exercise that I’m still doing today.” (P6)	
	Transferring skills	“You want to just go that extra mile, above and beyond, just so that you’re able to transfer those skills also.” (P8)	
	Changing how I use medication	“That’s why I said it was beneficial. Because it stops you using medication all the time. You say that, this is, okay it’s my knees? It made the way you take my medication different.” (P6)	
z. Feeling different about SCD	Important on how I look at sickle cell everyday	“I think there should be more groups like this because it’s important, it’s important for, not only for my wellbeing but for my mental wellbeing and for, you know, just how I look on sickle cell every day” (P8)	Feeling different about SCD was mentioned by the majority of the participants who attended the SCPMP but not all. I wonder why there were differences… Possibly to do with the difference in how they thought about SCD at the start of the group. Important to remember that people with SCD will have different relationships with SCD.
	Best way of living and accepting SCD	“The best way of living with sickle cell. And the pain management directs us in, in, into that way. Best way of living and accepting it.” (P4)	
	Made peace with sickle cell	“I think I would say I’m more grounded, yeah. I have finally made peace with who I am, what I am, what I have.” (P1)	
	Accepting sickle cell	“accepting it. Because I didn’t accept it for, I didn’t want to talk about sickle cell” (P4)	

Appendix 11 *Diagram of participant 2 codes*

This has been removed from the electronic copy

Appendix 12 *Diagram of participant 6 codes*

This has been removed from the electronic copy

Appendix 13 *Diagram of participant 12 code*

This has been removed from the electronic copy

Appendix 14 *Reflexive positioning statement*

This has been removed from the electronic copy

Appendix 15 *Abridged reflective research diary*

This has been removed from the electronic copy

Appendix 16 *Coded transcript example*

This has been removed from the electronic copy

Appendix 17 *Ethics approval letter*

This has been removed from the electronic copy

Appendix 18 *Ethics further approval*

This has been removed from the electronic copy

Appendix 19 *End of study summary for participants*

Dear Participant,

I am writing to you because you took part in a research study on the experience of attending pain management programmes for people with sickle cell condition. Firstly, I would like to thank you again for taking the time to be interviewed for this study. I am hoping to publish the results in an academic journal to increase health care professionals and providers' awareness of the therapeutic processes that occur in pain management programmes specifically designed for people with sickle cell condition.

The study

I interviewed 12 participants, of whom two attended a non-specific pain management programme for chronic pain and two were facilitators of a sickle cell pain group. I then used a grounded theory methodology to analyse the interview transcripts. This methodology was used to build a theory from the data. I hoped that the theory would provide more information as to how the sickle cell pain group facilitates experiences that are therapeutic for those who attend.

The results

The results are my subjective interpretation of what people said during the interviews. Therefore, not everything in the theory will be applicable to everyone; nonetheless the theory tries to capture the overall experience of attending the sickle cell pain group. The results are shown in the diagram below, alongside the description. I have also included a number of quotes.

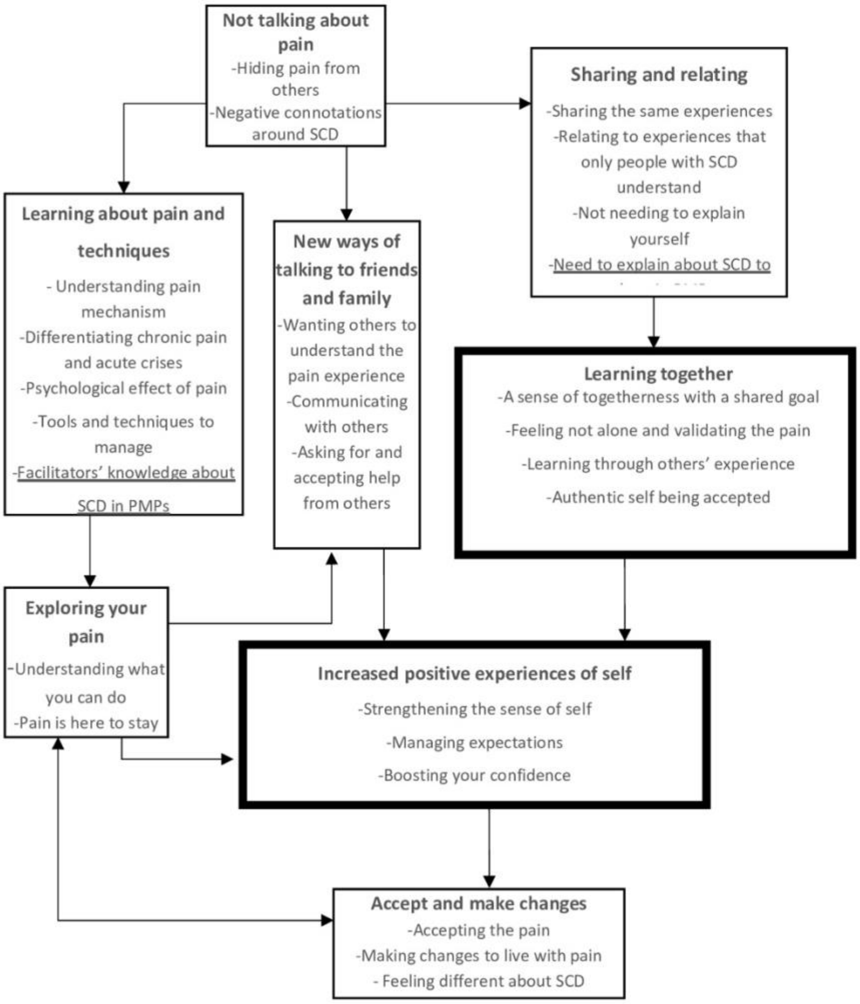
Description

This study contributes to the current knowledge base as it suggests that unique therapeutic processes can occur within a sickle cell pain group, providing a model that represents these processes. This study provides tentative support for how a sickle cell pain group is accepted by people with sickle cell condition. Participants described the experience of the sickle cell pain group as reducing feelings of isolation, which in turn seemed to increase positive experiences of the self, and they seemed better able to accept and make changes in their lives in order to manage the sickle cell pain. In contrast, those who attended non-specific pain management programmes felt that they had to explain sickle cell to the other people. The unique medical experiences of sickle cell was an important variation in the sickle cell pain group compared to general pain management programmes. Learning about pain and the pain mechanism was done in consideration of the specific features of sickle cell, such as the acute crises and chronic pain experienced. The participants who attended the general pain management programmes further supported the importance of understanding their pain in relation to their specific physical health condition.

I hope that some of these results fit with your own experiences of attending the sickle cell pain group. Thank you again for taking part in this study.

Yours sincerely,
Ji Yeon Park

Developing a sickle cell identity that enhances perceived ability to accept the sickle cell pain.



Appendix 20 *End of study summary for ethics panel*

Dear Chair of Research Ethics Committee,

Study title: The Therapeutic Mechanisms that are Unique in a Sickle Cell Pain Management Programme. A Grounded Theory Study.

I am writing to inform you that the above research project has been completed and a thesis has been submitted in partial fulfilment of the degree of Doctor of Clinical Psychology at Canterbury Christ Church University. The following states a brief summary of the study.

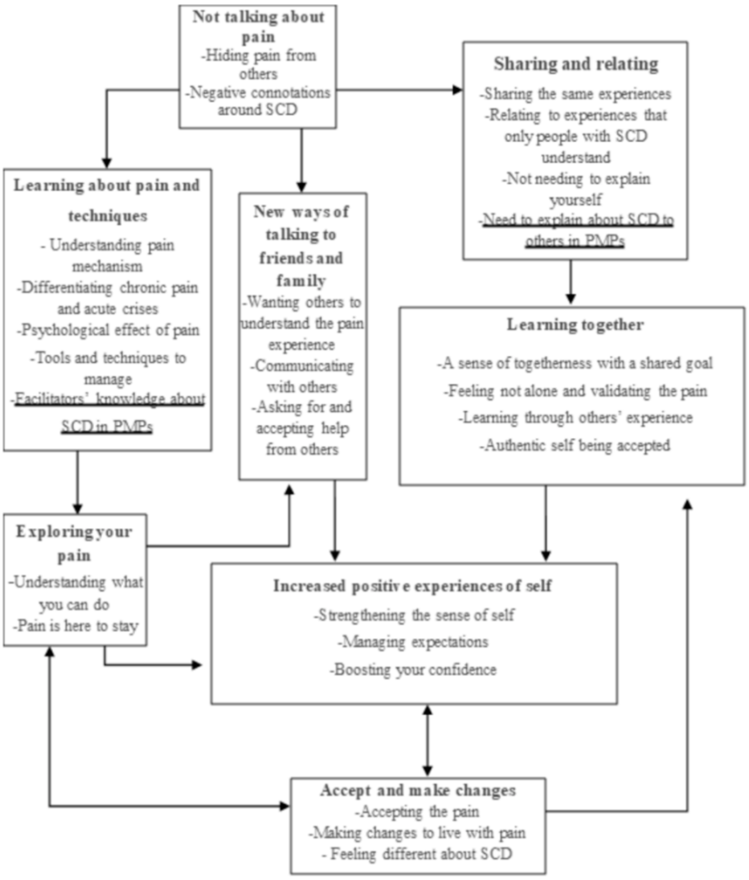
Summary

Sickle cell disease is the most common genetic disorder in the UK that is life limiting and lifelong for the individual. Pain is the main characteristic of sickle cell disease, with chronic pain alongside acute crises. Sickle cell pain management programmes have begun to be offered to people with sickle cell disease. This study, therefore, aimed to explore the therapeutic mechanisms that are perceived in sickle cell pain management programmes. Although this study did not examine the effectiveness of sickle cell pain management programmes, this research provides tentative support for the acceptability of a pain group for people with sickle cell pain.

A total of 12 participants volunteered to take part in the study from two different hospitals. Semi-structured interviews were analysed using a grounded theory methodology. A model was derived from the interview data to set out the perceived therapeutic process.

The current model describes a linear process where the participants begin from a position of not talking about pain and move to experiencing a sickle cell pain group, where discussions about pain are shared and related to each other. This seems to shift the participants into a position where they are able to learn from each other, as well as learning about pain and communication with the inclusion of friends and family. It then identifies a cyclical process where participants are able to explore their pain, build on their positive experiences of self and accept and make changes. This final process suggests the development of a sickle cell identity that supports the clients to put new ways of managing pain into practice in their day-to-day lives. In contrast, participants who attended non-specific pain management programmes felt a need to explain sickle cell disease to others.

This model adds to the current literature on how people with sickle cell disease can be supported in managing their pain. The unique medical experience of sickle cell disease was an important variation in the sickle cell pain group as compared to general pain management programmes. Learning about pain and the pain mechanism was done in consideration of the specific features of sickle cell disease, such as the acute crises, sickle cell pain and chronic pain. Those who attended non-specific pain management programmes supported the importance of understanding their pain in relation to their specific physical health condition (sickle cell disease), as when these discussions were discouraged, feelings of not being understood increased. This is the first study to highlight the unique therapeutic processes that can occur within a sickle cell pain group, and it provides a model representing these processes. The model contributes to how people with sickle cell disease could be supported in managing their pain and there were relevant clinical and research implications considered.



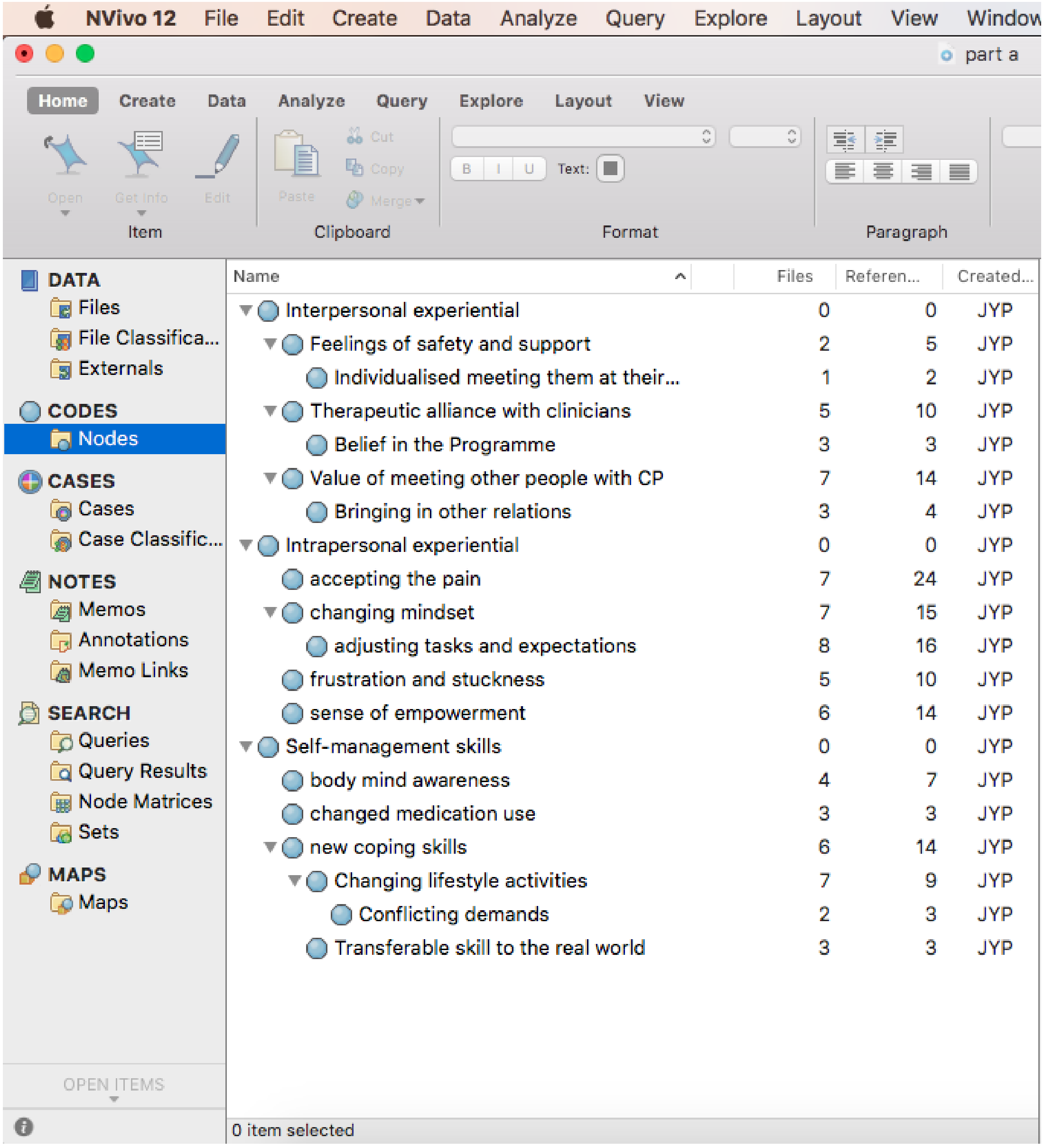
I intend to prepare the findings for submission for publication in the British Journal of Health Psychology for dissemination. An additional summary report has also been prepared to send to the research participants.

Yours sincerely,
Ji Yeon Park

Appendix 21 *British Journal of Health Psychology author guidelines*

This has been removed from the electronic copy

Appendix 22 *Section A: Inductive coding process*



Name	Files	Referen...	Created...
Interpersonal experiential	0	0	JYP
Feelings of safety and support	2	5	JYP
Individualised meeting them at their...	1	2	JYP
Therapeutic alliance with clinicians	5	10	JYP
Belief in the Programme	3	3	JYP
Value of meeting other people with CP	7	14	JYP
Bringing in other relations	3	4	JYP
Intrapersonal experiential	0	0	JYP
accepting the pain	7	24	JYP
changing mindset	7	15	JYP
adjusting tasks and expectations	8	16	JYP
frustration and stuckness	5	10	JYP
sense of empowerment	6	14	JYP
Self-management skills	0	0	JYP
body mind awareness	4	7	JYP
changed medication use	3	3	JYP
new coping skills	6	14	JYP
Changing lifestyle activities	7	9	JYP
Conflicting demands	2	3	JYP
Transferable skill to the real world	3	3	JYP

0 item selected

Appendix 23 *Section A thematic map*