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Citation: Nizza, Isabella Elizabeth (2022) Unfolding portraits of pain: a longitudinal interpretative phenomenological analysis of chronic pain sufferers' self-management journeys as recounted through interviews and drawings of pain and self. [Thesis] (Unpublished)

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**Unfolding portraits of pain: a longitudinal interpretative
phenomenological analysis of chronic pain sufferers' self-
management journeys as recounted through interviews and
drawings of pain and Self**

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Declaration

I hereby guarantee that the work presented in this thesis is written by myself entirely except where other sources are clearly and identifiably cited.

Signed:

Isabella E Nizza

Abstract

Chronic pain is a common, profoundly disabling and complex condition whose effects on identity may hold a key to understanding the extreme distress experienced by sufferers. To help patients adapt to a life with pain, the English National Health Service has established chronic pain services which also offer multidisciplinary Pain Management Programmes (PMPs).

Despite its strong existential impact, chronic pain remains an elusive condition, difficult to describe and to understand. Drawings have successfully been used to complement Interpretative Phenomenological Analysis (IPA) interviews to investigate pain, eliciting vivid representations and rich descriptions.

This study explores how the relationship with pain and sense of self of sufferers evolves when they attend a community chronic pain service and participate in a PMP. Participants were eight unemployed English women, aged 40-60.

In a longitudinal design, data were gathered at three timepoints: before attending a PMP and one and six months later. To facilitate a deep description of the experience of pain and its effects, interviews were guided by participant-generated drawings of their pain and of themselves. In later interviews participants also reviewed their earlier drawings, leading to interesting reflections. Interviews and drawings were analysed longitudinally using IPA.

Different trajectories emerged from the drawings and narratives. Three participants had an upward and positive trajectory: over the course of the study, they were able to regain control over their lives. In contrast, two participants had a negative or unchanging trajectory, remaining locked in static identities with pain that seemed to worsen. Three participants had a positive but complicated trajectory, experiencing disruption but still integrating pain into their lives. Only participants who actively engaged with the chronic pain service experienced a positive change.

The results demonstrate the idiosyncratic nature of chronic pain and offer a nuanced account of its links to the lifeworld of sufferers. Results also highlight the value of using IPA in a longitudinal design to understand the temporal evolution of experience and of integrating interview data with drawings of pain and Self to obtain a deeper and richer account of participants' evolving experience.

Acknowledgements

This study would not exist without the unwavering support I have received from others, whom I would like to thank.

To all the wonderful participants in my study, who chose to share a portion of their chronic pain journey with me with their drawings and words, thank you for your warmth, openness, and generosity.

To Birkbeck University of London, particularly Professor Michael Thomas, thank you for believing in my potential and awarding me the Birkbeck Anniversary Studentship.

To the Kent Community Chronic Pain Service, particularly Dr Jamie Kirkham, thank you for your incredible logistical, moral, and emotional support.

To Professor Jonathan Smith, thank you for being such a great teacher, mentor and colleague and for always pushing me where I did not know I could go.

To my colleagues in the Birkbeck IPA research group, old and new, thank you for providing a community where we can share ideas, worries and chocolate.

Finally, to Maurizio and Valerie, thank you for believing in me more than I believe in myself and being there for me, always.

Parts of this thesis have been published in:

Nizza, I. E., Smith, J. A., & Kirkham, J. A. (2018). 'Put the illness in a box': a longitudinal interpretative phenomenological analysis of changes in a sufferer's pictorial representations of pain following participation in a pain management programme. *British Journal of Pain*, 12(3), 163-170.

Other publications drawing on parts of the thesis are:

Smith, J. A., & Nizza, I. E. (2022). *Essentials of Interpretative Phenomenological Analysis*. American Psychological Association.

Nizza, I. E., Farr, J., & Smith, J. A. (2021). Achieving excellence in interpretative phenomenological analysis (IPA): Four markers of high quality. *Qualitative Research in Psychology*, 1-18. <https://doi.org/10.1080/14780887.2020.1854404>

Farr, J., & Nizza, I. E. (2019). Longitudinal Interpretative Phenomenological Analysis (LIPA): A review of studies and methodological considerations. *Qualitative Research in Psychology*, 16(2), 199-217. <https://doi.org/10.1080/14780887.2018.1540677>

Contents

List of Figures	10
List of Tables	10
List of Boxes	11
List of acronyms and abbreviations	11
Chapter 1 - Introduction.....	12
The chapters	12
Chapter 2 - Literature review	15
Introduction.....	15
CP definition and epidemiology	15
The mechanisms underlying CP	16
Psychological models of pain	18
Behavioural model	18
Cognitive-Behavioural model	19
Psychological flexibility model and related constructs.....	20
Understanding CP experiences	21
Review of qualitative literature.....	21
Syntheses of qualitative studies and final considerations	40
Psychological approaches to treating CP	42
CBT.....	42
ACT.....	43
Pain self-management, pain education and peer support	44
Evidence of treatment efficacy	44
Visual research methods and drawings.....	46
Conclusions and research question	48
Chapter 3 - Context for my study.....	50
Pain management in England.....	50
Community Chronic Pain Service: organisation, services and patient pathway	51
Pain Education Session	52

PMP.....	52
Outcome assessment	53
Chapter 4 - Methodology	55
Which qualitative methodology?	55
Phenomenological approaches.....	56
Philosophical roots of phenomenological research.....	56
Phenomenological research.....	58
Interpretative phenomenological analysis.....	59
Why use IPA to explore the experience of CP?	61
Extensions to IPA: visual methods and longitudinal designs	63
Visual methods.....	63
Longitudinal IPA	67
Conclusions.....	70
Chapter 5 - Methods.....	71
Design decisions	71
Duration and timepoints.....	71
Size of sample	72
Eligibility criteria.....	73
Ethical considerations	74
Ethical approval	74
Ongoing consent	75
Anonymity	75
Artefact ownership.....	75
Recruitment and retention.....	76
Participants.....	77
Interview schedules.....	80
Interview location	87
Conducting the interview	88
Interview procedure	88

Participant experience	90
Researcher experience.....	92
Conclusions on data gathering	95
Data analysis	96
Data available.....	96
Analysing data from one interview.....	98
Analysing idiographic data longitudinally	106
Writing up Jane's pain as a case study.....	111
Cross-case analysis	111
Final writeup	116
Chapter 6: Introduction to results and first trajectory group.....	117
Introduction to all results	117
Upward and positive trajectory: Jane, Olga and Monica	120
Jane's journey: from dark oppression to serene normality	121
Olga's journey: from despondency to planning her future	127
Monica's journey: from resistance to self-compassion.....	133
Discussion of the upward and positive trajectory	140
Chapter 7 - Negative or unchanging trajectory: Helen and Alison	145
Helen's journey: increasingly isolated and unable to act.....	146
Alison's journey: an ongoing low mood and lack of engagement.....	154
Discussion of the negative or unchanging trajectory	161
Chapter 8 - Positive but complicated trajectory: Gillian, Kate and Lauren	166
Gillian's journey: from feeling alienated to being in control in a crisis	167
Kate's journey: a slow acceptance and integration of pain into life	173
Lauren's journey: from raging to being real	179
Discussion of the positive but complicated trajectory	188
Chapter 9 – Concluding discussion.....	193
Key findings from the study	193
Considering the three trajectory groups together	194

Considerations on the drawings and their metaphors	196
Considerations on the longitudinal design	199
Participants reflecting on the process.....	203
Study impact	205
Evaluation of the study	208
Limitations of the study	211
Future directions	211
Final words.....	212
References.....	214

Appendix

A fairly lengthy appendix is also being submitted which includes, amongst other things, a full-page reproduction of each drawing, in case the reader finds it helpful.

List of Figures

Figure 1. Timeline of study showing when the first, second and third interviews took place (M1 = month 1, M2=month 2, and so on).	72
Figure 2. Detail of Gillian's T1 pain drawing.....	90
Figure 3. Portion of Gillian's annotated transcript showing initial annotation and themes.....	100
Figure 4. Jane's drawings of her pain and Self – larger format drawings in Appendix D.1	121
Figure 5. Olga's drawings of her pain and Self – larger format drawings in Appendix D.2	127
Figure 6. Monica's drawings of her pain and Self – larger format drawings in Appendix D.3	133
Figure 7. Helen's drawings of her pain and Self - larger format drawings in Appendix D.4....	146
Figure 8. Alison's drawings of her pain and Self - larger format drawings in Appendix D.5..	154
Figure 9. Gillian's drawings of her pain and Self - larger format drawings in Appendix D.6..	167
Figure 10. Kate's drawings of her pain and Self - larger format drawings in Appendix D.7 ...	173
Figure 11. Lauren's drawings of her pain and Self- larger format drawings in Appendix D.8	179

List of Tables

Table 1. Number of participants who attended the first interview vs completed 3 interviews ...	73
Table 2. Details on study participants (order reflects how their results are presented)	79
Table 3. Complete dataset for Gillian: Pain and Self drawings and interview durations at T1, T2 and T3	97
Table 4. Gillian's themes from T1 after clustering	102
Table 5. Extract from Gillian's T1 table of themes, with themes related to pain	105
Table 6. Gillian's summary table of themes for Time 2	106
Table 7. First longitudinal cluster of Gillian's pain themes.....	108
Table 8. Gillian's table of trajectories.....	110
Table 9. Final draft of the table of longitudinal themes for the group – with details.....	115
Table 10. Three trajectory groups for the study and the individual trajectories within them ...	117

List of Boxes

Box 1. My recruitment speech at PES	76
Box 2. Extract from reflexive diary on recruitment.....	77
Box 3. Interview schedule for the first interview.....	82
Box 4. Interview schedule for the second interview	83
Box 5. Interview schedule for the third interview.....	86
Box 6. Extract from Gillian's first interview transcript, lines 151 to 194.....	89
Box 7. Extract from reflexive diary on the interview process	93
Box 8. Extract from reflexive diary about having a crisis	94
Box 9. Narrative description of Gillian's pain drawing at T1.....	99

List of acronyms and abbreviations

ACT	Acceptance and Commitment Therapy
CBT	Cognitive Behavioural Therapy
CCPS	Community Chronic Pain Service
CP	Chronic pain
EMA	Ecological Momentary Assessments
GCT	Gate Control Theory
GP	General practitioner
GT	Grounded theory
HCP	Healthcare professional
IPA	Interpretative phenomenological analysis
LBP	Lower-back pain
LIPA	Longitudinal interpretative phenomenological analysis
NICE	National Institute for Health and Care Excellence
PF	Psychological flexibility
PMP	Pain Management Programme
RCT	Randomised Control Trial
SCED	Single case experimental design
SEQ	Self experiences questionnaire
T1	Time 1 – First interview
T2	Time 2 – Second interview
T3	Time 3 – Third interview
TENS	Transcutaneous Electrical Nerve Stimulation

Chapter 1 - Introduction

Despite having always been driven in my professional life by a desire to learn and understand how people think, feel and behave, I started my university education only in my forties through a psychology degree at Birkbeck. I remember the excitement: religiously attending lectures, devouring textbooks, discovering the existence of journals and papers, feeling my mind expand. Nurtured by the new world of academia and an unexpected sense of achievement, I waited for inspiration to hit me. Eventually, two things struck me like lightening: Interpretative Phenomenological Analysis (IPA) and health psychology, because I knew humans to be complex beings that could only be fully understood when body and mind were considered as one, subjectively and in context. Determined to learn IPA from the source, I did everything in my power to have Professor Jonathan Smith as my undergraduate project supervisor. He suggested an organ donation project, where I could apply IPA to matters of life and death, body and soul: it was perfect. The project confirmed my love for IPA and its success gave me the confidence to go further with my academic career. I then spent a year at King's College learning about Health Psychology, where lightning struck again during a lecture on chronic pain by Professor Lance McCracken. I had read Professor Smith's early papers on pain and knew of the profound existential implications of the condition; although chronic pain interventions are predominantly psychological, outcome measures did not seem to take the broken sense of identity of sufferers into account. I could see this was an unanswered research question that IPA could help answer, so I took it to Professor Smith. Unbeknown to me, he and Jamie Kirkham had already been using visual methods in IPA to understand chronic pain. It felt natural to continue on that path and so this study was born: like much of my life, as a result of intuition and synchronicity.

The chapters

Following this introduction, **Chapter 2** provides a review of existing literature on chronic pain (CP). CP is a complex and extensively studied condition, so this chapter covers quite a lot of ground. It starts with a definition of CP and its potential mechanisms, followed by a brief review of the main psychological CP models (behavioural, cognitive-behavioural and psychological flexibility). Then the subjective experience of CP sufferers as reported in qualitative literature is discussed, through a review of individual studies and a mega-synthesis, to reach the conclusion that the existential impact of CP is a fundamental aspect of the intense suffering associated with CP. Following a brief review of quantitative evidence on the main psychological approaches for treating CP, I point out a gap between the existential impact of CP

emerging from qualitative literature and current quantitative outcome evidence, thus justifying this study which aims to investigate how learning about CP self-management affects the relationship with pain and the sense of identity of sufferers. Finally, I present a brief review of visual research methods, particularly drawings, to provide some context for my choice of using such methods with IPA.

Chapter 3 provides some further context for the study by presenting current English CP management policies, the community CP service from where participants were recruited, and the Pain Management Programme (PMP) where they were taught to self-manage their pain.

Chapter 4 explains the methodological choices for the study: the decision to use a phenomenological approach and why Interpretative Phenomenological Analysis (IPA) was the most obvious choice, given its particular suitability to understand the existential impact of CP. The value of combining IPA with visual methods, particularly drawings, and of employing a longitudinal design to understand in detail how experiences change over time is also discussed, concluding that a longitudinal IPA (LIPA) design where interviews are combined with drawings of pain and Self allows for a rich account of the evolution of participants' experiences.

Chapter 5 explains how the study was designed and organised in practice: which participants were recruited and how, which data were gathered and how this was done, with details on the interview procedures and schedules, and some reflections on the study experience for participants and for me as a researcher. The second half of the chapter is dedicated to the analysis of the data, which was a complex trial-and-error process. It starts with a description of how each interview was analysed on its own terms, by scrutinising each drawing on its own and alongside the transcript. Next is a description of how each participant's complete dataset, comprising three interviews and six drawings, was longitudinally analysed to identify the participant's personal trajectory in the study. Finally, in the cross-case analysis process, the personal longitudinal trajectories are considered together and compared, and, as a result, grouped into three trajectory types. These are the groupings used to present the study results in the chapters that follow.

Chapter 6 starts with a general introduction to the study results and then presents the results for the first group of three participants sharing an upward and positive trajectory. After a brief introduction to the group, each participant is presented as a separate case. Within each case, pain and Self drawings are discussed, integrated with meaningful verbatim quotes from the interview, one timepoint after the other, to chronologically follow that participant's journey in the study. Since later timepoint interviews include reflections by participants on earlier timepoints, based on memory or triggered by viewing their earlier drawings, as the case unfolds, there are opportunities for prospective and retrospective interpretative considerations that add

depth to the analysis. The chapter ends with a discussion, where similarities and differences between the cases of the group are highlighted and the overall findings for the trajectory group are considered in the context of current literature.

Chapter 7 presents the results for the second group of two participants who shared a negative or unchanging trajectory. With an equivalent structure to Chapter 6, each case is presented, and, in the discussion, comparisons are drawn between the cases, and also between this group and the previous group presented in Chapter 6. Again, aspects of the group's results are also discussed in relation to the wider literature. Similarly, **Chapter 8** presents the results from the third group of three participants who share a positive but complicated trajectory. Which are then discussed on their own, in relation to previous trajectory groups and in relation to literature.

Chapter 9 concludes the study by bringing together the findings from all three trajectory groups, reflecting on the study's use of drawings, on its longitudinal design and on the research process from the perspective of participants. Then the study's impacts are considered, mainly from a clinical perspective. Finally, the work is evaluated in relation to criteria proposed by Smith (2011) and Neale (2021), for IPA and longitudinal research respectively, and the study's limitations and potential future studies are discussed.

Chapter 2 - Literature review

Introduction

Chronic pain (CP) is one of the most difficult, elusive and extensively researched areas of health psychology. With this review, I aim to contextualise my study by briefly presenting CP as a health condition and discussing how thinking around its underlying mechanisms has evolved. After presenting the key models, I will discuss the aspects of the CP experience that qualitative research has shed light on. Quantitative and qualitative studies often influence each other, so I will highlight some recent trends in treatment and outcome measurement that, in my opinion, reflect a wide and overdue recognition of the contribution that qualitative research has made to our understanding of CP. I will then discuss the main types of interventions currently being offered to CP sufferers, concluding with the research question for my study.

CP definition and epidemiology

Pain is currently defined as “*an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage*” (IASP, 2014). This definition includes both acute and chronic pain and characterises pain as a subjective experience: what is described as pain should be recognised as pain, because no objective assessment is possible and there can be pain without tissue damage. Although conveying the complexity of pain, this definition does not acknowledge its cognitive and social components, and, by using the term “*unpleasant*,” does not recognise the sometimes dramatic impact that pain can have, particularly when it becomes chronic (Williams & Craig, 2016).

The International Association for the Study of Pain (IASP) is in the process of updating the definition. The current working version uses the term “*aversive*,” which only partly addresses the previous shortcomings: “*an aversive sensory and emotional experience typically caused by, or resembling that caused by, actual or potential tissue injury*” (Raja et al., 2020).

Pain is diagnosed as chronic when it persists for more than 3 months in the absence of progressive disease (such as cancer) or structural abnormalities (Turk & Swanson, 2012).

Unlike acute pain, CP serves no useful function. It can be spontaneous (i.e. experienced in the absence of a sensory input), an exaggerated response to a normal stimulus (hyperalgesia) or a response to touch (allodynia) (Torsney & Fleetwood-Walker, 2012). A variety of conditions fall under the CP umbrella: musculoskeletal disorders, including lower-back pain (LBP), neuropathic pain, visceral pain, post-surgical pain and headache.

Commonly preferred CP treatments are pharmacological (e.g. analgesics) and invasive (e.g. nerve blocks, implantable devices), despite the weak efficacy evidence and notable risks, such as the current opioid crisis (Edmond et al., 2019).

CP is a major health concern in most Western countries, although precise prevalence estimates have proven difficult to obtain. A meta-analysis estimated prevalence of CP in the UK to be between 38.4% and 48.6%, with severely disabling pain affecting between 10.4% and 14.3% of the adult population (Fayaz et al., 2016). A National Health Interview Survey in the US found the prevalence amongst adults of CP and high impact CP (which limits life and work activity) to be 20.4% and 8% respectively (Dahlhamer et al., 2018). In both studies, women were more affected than men and older adults were more affected than younger ones. CP also affects young people (Caes et al., 2016) and tends to affect more women than men (Greenspan et al., 2007), particularly fibromyalgia where the female-to-male ratio is 9:1 (Yunus, 2002).

The mechanisms underlying CP

The question of how CP develops and is maintained has challenged researchers for many decades. The ground-breaking Gate Control Theory (GCT), developed by Melzack and Wall (1967) and refined by Melzack (1999), offered a heuristic perspective on the wide range of phenomena associated with CP (Gatchel & Maddrey, 2004). Recent technological advances have allowed researchers to continue exploring potential mechanisms in areas such as neuroplasticity and genetics. A single all-encompassing explanation for how and why pain can become chronic has not yet emerged, many factors appear to concur, each suggesting new avenues for treatment.

GCT was developed in response to the ‘specificity’ theory of pain, which dominated medicine for centuries and assumed that, like other sensory modalities, pain would be driven by a specific central apparatus through a unidirectional process of transmission of stimuli from the body’s periphery to the brain. Any psychological impact of pain was addressed by treating its physical cause and pain with no obvious physical cause was considered psychogenic (Melzack, 1996). The growing evidence of a non-reproducible relationship between stimulus and response in pain and the need to explain how, through attention processes, previous experience and ascribed meaning, psychology could contribute to pain led to the formulation of GCT.

According to GCT, the spinal cord hosts a gating mechanism that facilitates or inhibits the transmission of impulses from the body to the brain. Information that arrives at the spinal cord is filtered and selected based on the total pattern of fibre activity and on information descending from the dynamic action of brain processes (Melzack, 1996).

GCT was well received and triggered the development of new therapeutic approaches to pain management, such as psychological therapies, Transcutaneous Electrical Nerve Stimulation (TENS) and acupuncture (Melzack, 1996). However, GCT failed to explain phantom limb pain, so it evolved into the ‘neuromatrix’ model.

The neuromatrix is a widespread network of convergent and divergent loops in the thalamus, cortex and limbic system areas of the brain. It aims to produce unified representations of the body and the Self (known as ‘neurosignatures’), each with its characteristic patterns of neural activity in response to interaction with the environment. Within this general-purpose system, pain constitutes a particular pattern of activity or neurosignature (Roy & Wager, 2017). A neurosignature’s brain processes, normally activated and modulated by sensory input from the body, can also occur without such input, as happens in phantom limb pain, because, although stimuli can trigger patterns of activation, they do not produce them (Melzack, 1996).

Despite empirical evidence for the role of the thalamus, anterior cingulate cortex, insula, primary & secondary somatosensory cortices and prefrontal cortices in the pain neurosignature, there is little or no evidence linking these regions specifically to pain. So current understandings assume large-scale neural networks spanning sensory, emotional and cognitive-evaluative brain regions (Roy & Wager, 2017).

Stress, meaning the disruption of the brain’s homeostatic regulation systems (Selye, 1956), produces a high release of cortisol which is functional to healing processes, but if prolonged, excessive or with abnormal patterning, can destroy tissues, producing the conditions of CP. So while genetic and sensory influences shape the neurosignature of pain experience, sensory inputs and cognitive events, such as psychological stress, modulate it (Turk & Monarch, 2002).

The evolution of GCT theory and cognitive sciences have followed similar trajectories: conceptualising pain as a set of distributed and parallel processes in which experience and memory play a sculpting role (Gatchel et al., 2007).

In the last two decades, scientific advances and the availability of neuroimaging technology have afforded further insight into the interaction between CP and the brain, particularly in terms of the dorsal horn’s role, the sensitisation resulting from neuroplasticity and the potential role of genetics and epigenetics (Morton et al., 2016).

As the understanding of pain mechanisms has evolved, there has also been a change of paradigm, from a purely biomedical perspective to a biopsychosocial view. The biomedical perspective’s assumption of a direct causal link between a disease and its psychological effects fails to explain the extreme variability in patient responses to CP. The biopsychosocial approach considers health to be the result of an interaction between physical, psychological and social aspects. In CP, biological changes, psychological status and socio-cultural context operate

together and determine each other in a dynamic equilibrium that shapes how sufferers perceive and respond to their pain. The same factors explain variability among patients and within the life course of a single individual. For instance, biological factors tend to play a more prominent role in acute illness phases, but as pain becomes chronic the balance often shifts (Turk & Monarch, 2002). The psychological condition of a patient, particularly negative affect, can influence their physiology through stress response mechanisms, as well as their appraisal and perception of symptoms. In turn, medical treatment may disrupt concentration and memory processes and a patient's social context may shape their behavioural responses. For example, to reduce their symptoms, some CP patients tend to avoid engaging in activities that in the long run would improve the same symptoms, but at the same time, engaging in physical activity can cause fatigue (Turk & Monarch, 2002). These examples suggest that the optimum management of each patient's condition requires all biopsychosocial factors to be considered, so that their personal combination and balance of factors can be addressed (Gatchel et al., 2007).

GCT and its successors have offered a strong rationale for otherwise unexplainable experiences of CP. The early assumption that pain is originated solely in the body no longer stands. Current evidence supports a view of CP as originating in the brain, and modulated, but not generated, by sensory inputs. Such a view can explain the absence of a direct proportional connection between the severity of pain and the level of distress and disability experienced by different patients (Turk & Monarch, 2002). The adoption of a biopsychosocial model for treatment has transformed the support offered to patients, with multidisciplinary pain clinics in which psychologists and psychological therapies play a growingly important role.

Psychological models of pain

Behavioural model

Early models of pain applied classical and operant conditioning principles to pain and well behaviours (Vlaeyen & Crombez, 2020). The assumption was that pain behaviours (e.g. complaining) are acquired through positive and negative reinforcement, while avoidance behaviours (e.g. inactivity), which are initially triggered by nociception, become associated with fear. Behavioural models focused particularly on pain behaviours because, although weakly related to subjective pain intensity, they are a risk factor for failing to return to work after an injury (Sanders, 1996). The meaning attributed to pain (appraisal) and the beliefs about pain acquired during a sufferer's life were found to strongly influence their behaviour, in terms of whether they would continue to work, move and socialise while in pain (Turk & Okifuji, 2002). These models have been criticised for focusing solely on motor pain behaviour, without considering underlying emotional and cognitive aspects (Turk & Monarch, 2002).

Cognitive-Behavioural model

The cognitive-behavioural (CB) model of CP stems from the recognition that cognitive factors can be pivotal to CP development and maintenance. An individual's interpretation, evaluation and beliefs about their pain symptoms, disability and coping abilities are thought to directly affect the level of emotional and physical disability they experience (Gatchel et al., 2007).

In the CB model, thoughts, mood and physiological processes are expected to reciprocally influence each other. Behaviour is triggered by thoughts and can influence thought processes, while being influenced by the individual and their environment. Maladaptive ways of thinking, feeling and behaving can be replaced with more adaptive ways, as long as the person is willing to collaborate in the process (Turk & Flor, 2013).

Applied to CP, the CB model posits pain behaviours as reactions to an idiosyncratic interpretation of reality, stemming from a framework of knowledge and beliefs shaped mostly by previous experience. This is exemplified by the **Fear-Avoidance model**, where, in a vicious circle, the fear of pain can cause CP sufferers to avoid movement and the lack of movement exacerbates both the pain and the fear (Lethem et al., 1983; Vlaeyen & Linton, 2000). From being an adaptive response to a real threat, fear becomes an anxiety for a presumed future threat. So, the fear of experiencing an increase in pain or of causing irreversible body damage triggers preventative behaviours such as avoidance and hypervigilance (Leeuw et al., 2007). These, in turn, generate disability, disuse and depression, and eventually affect future pain experiences by lowering the pain threshold of sufferers (Vlaeyen & Linton, 2000). In a comprehensive review of the fear-avoidance model, Leeuw et al. (2007) found strong evidence on single components: pain-related fear is significantly related to catastrophising about pain, hypervigilance, increased avoidance and escape behaviours, and disability; rather than causing a shift of attention, pain appears to create difficulties in disengaging attention from the pain stimuli, particularly for high catastrophisers. Structural equation modelling studies have found some evidence for mediation and moderation between some of the factors involved, but not sufficient to confirm causality (Leeuw et al., 2007).

Cognitive biases, an important component of the CB model, have also been explored for CP.

The initial hypotheses that sufferers might have an attentional bias towards pain which contributes to maintain it are not fully supported. For instance, LBP sufferers show an attentional bias towards sensory pain-related information, which does not however predict chronicity. Instead, chronicity is predicted by attentional avoidance (Sharpe et al., 2014). A meta-analysis on the effectiveness of commonly recommended coping strategies for CP found that neither distraction (directing attention away from pain), nor sensory monitoring (focusing on the objective sensory features of pain) were any different from control conditions in altering

the pain experience or reducing distress (Van Ryckeghem et al., 2017). The impression, reviewing this empirical evidence that underlies the CB model, is that the sheer complexity and idiosyncratic qualities of CP undermine any effort to pin down which factors determine how pain becomes chronic and remains so.

Psychological flexibility model and related constructs

Psychological flexibility (PF) is defined as “the capacity to persist or to change behaviour in a way that 1) includes conscious and open contact with thoughts and feelings, 2) appreciates what the situation affords, and 3) serves one’s goals and values” (McCracken & Morley, 2014, p. 225). The idea is that by changing one’s attitude to the pain, by being open, accepting, living in the present, trying to be aware of one’s thinking patterns, with no judgment and increased detachment, and by engaging with life by focusing on one’s values, one can develop the PF necessary to adapt to living with pain (Hayes et al., 2006; Hayes et al., 2011). The model is supported by empirical evidence, such as a correlational study investigating the relationship between self-discrepancy (a construct related to the impact of CP on the identity of sufferers – a topic I will return to later when discussing my study’s results), pain interference, distress and acceptance (Kwok et al., 2016). When measuring all constructs for CP sufferers using validated questionnaires, psychological inflexibility was significantly correlated with pain interference and emotional distress and negatively correlated with pain acceptance. It was also a significant mediator in the relationship between self-discrepancy and the three pain outcomes above. The findings suggest that having an inflexible attitude is associated with a more negative psychological experience of pain, a lack of acceptance and increased distress and that the level of flexibility may influence how these experiences are then connected to an increased sense of self-discrepancy.

PF as a construct introduces a paradigm shift: instead of focusing on negative factors maintaining pain, as the CB model does, there is a focus on the positive factors that counterbalance the effects of CP and promote adaptive responses. Resilience and self-compassion are two constructs closely related to PF. **Resilience** is defined as the “ability to restore and sustain a fulfilling life in the presence of pain” (Goubert & Trompetter, 2017, p. 1301). While validating the RS-18 questionnaire aimed at measuring resilience, Ruiz-Párraga et al. (2015) found that the ability to maintain relatively stable levels of psychological, emotional and social functioning were negatively related to functional impairment and positively related to daily functioning and acceptance, the latter with large effect sizes. Therefore, the ability to be resilient translates into better functioning and acceptance of CP.

Self-compassion is the ability to manage the challenging emotions elicited by pain-related difficulties through a comforting and soothing internal dialogue, free from social evaluations or

pressures to achieve. Moreover, self-compassion produces a release of oxytocin and opioids in the body (Purdie & Morley, 2016). In a cross-sectional multiple regression analysis involving 343 CP sufferers, self-compassion accounted for a significant amount of variance in all measures of functioning: higher self-compassion was associated with a lower fear of pain, depression and disability and with higher acceptance, success in valued activities and strategies for coping with pain (Edwards et al., 2019).

Although the evidence supporting them is recent and still limited, this new generation of positive constructs associated with PF seems promising and, as will become clear later in this review, has given a strong impulse to treatment strategies.

Understanding CP experiences

From what has been said so far, CP emerges as a complex phenomenon in which many factors are at play. Quantitative models juggle constantly between being too simplistic and over complicated, and even the most sophisticated models inevitably fall short of conveying the richness and multifaceted nature of the CP experience. Qualitative research approaches, being for the most part inductive, allow a wider and more in-depth exploration of what it means and feels like to suffer from CP.

The first qualitative study on CP dates back to the 1970s (Strauss et al., 1974); literature has since proliferated, with both original studies and qualitative literature syntheses. To consolidate the vast amount of literature available, Toye et al. (2017) published a ‘mega-synthesis’ collating findings from 11 meta-syntheses, which bring together the results from 187 qualitative studies. To get a sense of the breadth and depth of existing qualitative literature on CP, I decided to review a selection of original studies and inductively identify their themes, before comparing them to the Toye et al. (2017) mega-synthesis.

Review of qualitative literature

Qualitative literature encompasses a variety of approaches, adopting different epistemological stances, which allow them to answer different types of research questions. In broad terms, one could say that phenomenological research methods, which include phenomenology and IPA, are concerned with investigating lived experience, in the case of IPA from an interpretative and idiographic perspective, that grounded theory (GT) aims to build inductive theories through data analysis, that narrative analysis is concerned with the stories people tell about themselves and how these fit within their life stories and that discourse analysis is concerned with the role of language in the construction of social reality (Smith, 2007b). Based on this premise, to understand the experience of sufferers one might choose to focus only on phenomenological

studies, however, the experience of CP has been researched in different fields, including psychology, nursing, sociology and physiotherapy, and in each context certain methodologies seem to be preferred, independent of the research question being asked. To take advantage of this diversity and richness, I designed the review to include findings associated with the principal experiential qualitative approaches (phenomenology, IPA, narrative analysis, GT, and thematic analysis), excluding discourse analysis, because unsuitable to investigate experience subjectively.

In May 2015 I searched Google Scholar and Web of Science for articles in English published since 2000, using the keyword ‘chronic pain’ coupled with the ‘qualitative’, ‘grounded theory’, ‘thematic analysis’, ‘interpretative phenomenological analysis’, ‘phenomenology’ and ‘narrative analysis’ keywords. For each of the 5 qualitative methods considered, I selected the top 5 articles by number of citations (where an article appeared in both searches, Google Scholar citations were considered) focusing only on those reporting the first-hand experience of CP sufferers. To these I also added 10 purposively selected papers covering specific aspects (e.g., longitudinal, art, older and younger people). In total, I reviewed 35 articles in-depth (25 top-cited papers and 10 others). This approach was justified by a need to balance the size of the corpus, the time constraints, and an interest in reviewing in detail the most influential and relevant original research.

CP studies tend to focus on a specific type of pain or population: the majority of studies I reviewed concerned people with chronic musculoskeletal disorders (Dieppe, 2013), including conditions such as arthritis, LBP, and fibromyalgia. Populations were of varying ages and had suffered from CP for different lengths of time; some studies involved only women; others included participants from both sexes. Age and gender can be defining for certain aspects of the CP experience. Nearly all studies were conducted in the UK and Northern Ireland, Scandinavia or North America. Lastly, most studies recruited their participants in a healthcare setting (e.g. primary care, pain clinic or specialist outpatient clinic); sometimes participants had completed a treatment programme, and the research was evaluating its outcomes; few studies recruited from the general population, in one case via a General Health Survey. Due to this recruitment pattern, findings tend to reflect the experience of people who seek help for CP. Whether those who do not seek help are not affected enough by CP or do not know/believe that the healthcare system can provide support is a moot point.

I inductively reviewed the findings from the studies resulting from my search and clustered them into themes that describe the CP experience. In the next sections, the themes are presented as self-contained, however, there is a certain degree of overlap and interaction between them.

The first theme concerns the physical experience of living with a **body in pain**, which is tightly connected with the second major theme encapsulating perhaps the most important aspect of the psychological consequences of CP: its effects on **identity**, **role** and **self-esteem**, with role including aspects of age and gender as well. Another important theme is **time**, for how the physical reality of pain affects the sense of time and illness trajectory of sufferers. The fourth theme concerns the impact of pain on the **social life** of sufferers, both in the family and more widely. The fifth theme revolves around the issue of **legitimacy**, which is tightly connected with the sixth theme concerning the **relationship with healthcare professionals** of sufferers. The final theme, **coping**, explores how people deal with the consequences of pain, both physical and psychological and the strategies they adopt to improve their lives.

In the next paragraphs, each theme will be presented by describing the findings from different studies and using selected participant quotes to convey subjective experience. In the last paragraph, I will present the Toye et al. (2017) mega-ethnography and discuss it in relation to my findings.

The body in pain

I can feel my leg cramping, just like a steel rod was embedded, anchored in my toe and around up my leg, up to my groin, and somebody's drawing on the steel wire. (Thomas & Johnson, 2000, p. 691)

There's always crazy signals going through your body. Everything hurts, everything feels as if a truck ran over you. I feel like my body has been through a major physical exhaustion ... I feel like I've abused my body. I feel like I've been beaten, shook and twisted, everything hurts. (Sturge-Jacobs, 2002, p. 24)

The quotes above offer two different rich physical descriptions of being in constant pain: the first concerns a localised pain, the second refers to a more widespread pain, typical of fibromyalgia. Independent of the type of pain or diagnosis, the quotes provide a sense of what most CP sufferers describe as their daily experiences.

Pain is depicted as being constantly present in the awareness of sufferers, their most salient experience (Sturge-Jacobs, 2002; Thomas & Johnson, 2000). Most of us are not aware of having a body until our attention is drawn to it, we operate on a sort of 'automatic pilot' in which we take for granted that our body will respond to our will. CP sufferers describe a split between mind and body in that they have the intention and desire to act and find the body is unresponsive to the mind's will. This has been theorised as being part of the "*bodily constraint*" that characterises CP (Miles et al., 2005, p. 431) in which the body becomes slower, movements have to be deliberate and thought has to precede action instead of following it.

CP sufferers are constantly aware of their body, and they describe it as recalcitrant, unfamiliar, unreliable, unpredictable and baffling (Lempp et al., 2009; Thomas & Johnson, 2000): they are aware of something that is constantly with them yet feels completely alien.

Participants in a seminal IPA study by Osborn and Smith (2006) illustrate this sense of alienation when they describe their body as fractured, with an ‘old’ healthy part being taken for granted and a ‘new’ painful part being considered as outside the Self.

Oh yeah, it's in two parts, the old good bit and the pain bit, which has gone wrong [...] one bit works, the other doesn't, like a section has gone wrong, when it's bad and I can't move properly, it's like it's not part of me, it won't obey. (Osborn & Smith, 2006, p. 219)

In a two-year longitudinal study, Snelgrove et al. (2013) followed participants as they were treated with medication in a pain clinic. At the end of the study, those who had felt some respite from the pain, albeit temporarily, had been able to reconnect with their ‘real me’, moving beyond the fracture described by Osborn and Smith (2006). This partial pain reduction had also enabled them to experiment with alternative strategies to manage their pain. The participants who were not helped by the medication, a common experience in CP, at two years distance felt unchanged and were still enacting the same behavioural strategies, such as pain avoidance (Snelgrove et al., 2013). These findings on the experience of pain go beyond a mere physical description of the limitations it entails, they widen the perspective to include the existential implications of living with the condition, its impact on the sense of identity of sufferers, a key theme in its own right that will be expanded on further. From a methodological perspective, these findings illustrate how IPA, the method adopted by both Snelgrove et al. (2013) and Osborn and Smith (2006), enables researchers to move beyond a physical description of experience to a deeper level of analysis, providing a more complete insight into why CP is such a physically and psychologically debilitating condition.

An indirect confirmation of these findings comes from studies involving participants who have attended PMPs that contained elements of relaxation, mindfulness, and body awareness techniques. When sufferers understand the mechanisms of CP, they describe developing a more intentional and conscious awareness of their bodies, they stop attempting to ignore the body and learn to listen to it, integrating its signals and interpreting them as a guide to pace themselves, thus avoiding exacerbating the pain and regaining a sense of control (Gustafsson et al., 2004; Morone et al., 2008):

Upon first signs of pain, I stop and meditate, helpful at times (Morone et al., 2008, p. 844)

The new-found awareness affects their general level of pain but, more importantly, their sense of mastery over their bodies and, consequently, over their own lives.

In a phenomenological study of fibromyalgia, Raheim and Haland (2006, pp. 748-751) report their results by drawing the profile of three types of patients that they place on a continuum in terms of physical effects of the pain and ability to cope with it. The first patient type, which they

¹ Note: I use the ellipsis symbol [...] throughout the thesis when the participant data I report has been shortened to make it more relevant to the point I am wanting to convey.

define as ‘powerless’, has had old habits broken by the pain and feels abandoned in the hands of an overwhelmingly treacherous body in never-ending pain (“*I can’t do anything. This body is totally useless. Is this my body? You cannot imagine how useless I feel, how can it be? I’ve always been running around, doing everything. Now my body feels like my worst enemy.*”) The second type of patient is defined as ‘ambivalent’ because they are fighting their body for control but results are mixed: they carry out daily routines aimed at gaining control over the pain so that they can live their daily life but are still left exhausted at the end of the day (“*I’m used to enduring a lot of pain. Pain is not going to dominate my life. What kind of life is that? Coping with pain makes it possible to care for my body*”). The third type is the ‘coping’ patient, who has learned to listen to her body and developed a series of routines that allow her to function and live fully despite the pain, with moments in which the pain takes a backseat in terms of awareness and can almost be forgotten (“*I have to follow regular routines in the morning, everything is planned in advance. I have to set the table before sitting down for breakfast, see to it that nothing is missing. If I have to get up again it hurts. It’s so hard to concentrate, but I get things done, timing everything*”).

Some studies report sufferers losing their mental abilities alongside their physical ones. A common problem appears to be a lack of concentration that comes with CP (Walker et al., 2006) and cognitive problems are listed among the symptoms typical of fibromyalgia: sufferers describe what is commonly known as ‘fibro fog’, a sensation of having one’s mind wrapped in cotton wool that makes thinking difficult (Lempp et al., 2009; Sturge-Jacobs, 2002).

Identity

The experience of CP is challenging for the identity of sufferers at many levels: physical, psychological and social. For instance, people interviewed by Miles et al. (2005, pp. 435-436) felt their identity was being challenged by changes in body size following weight gain (“*I’ve put on two dress sizes... I feel suddenly self-conscious*”), by their inability to live up to their standards when carrying out daily activities (“*why aren’t I able to do that?*”) or by the actions and judgements of other people, whose offers for help emphasise an undesirable identity (“*it looks like you need help when you don’t want help*”).

Smith and Osborn (2007b) define pain as an ‘assault to the self’, suggesting that people suffering from CP can engage in a struggle for their identity that can cause them more distress than the pain itself. This particularly emotional quote from their study superbly encapsulates some of the key issues that arise in terms of competing selves:

It’s not who I am it’s just who I am if you know what I mean, it’s not really me, I get like that and I know like, you’re being mean now but I can’t help it. It’s the pain, it’s me, but it is me,

*me doing it but not me do you understand what I'm saying?
 If I was to describe myself like you said, I'm a nice person, but then I'm not, am I?
 And there's other stuff, stuff I haven't told you, if you knew you'd be disgusted I just get so
 hateful. [. . .] I know your gonna say it's all me, but I can't help it even though I don't like it.
 It's the mean me, my mean head all sour and horrible, I can't cope with that bit, I cope with
 the pain better. [. . .] [Tearful] Look do you mind if we stop now, I didn't think it would be
 like this, I don't want to talk any more. (Smith & Osborn, 2007b, p. 522)*

This woman describes a new “mean” self that is triggered by the pain and that she does not recognise as being her ‘true’ self because it is at odds with the “nice person” she knows she used to be. So for some people to live with pain means to be fighting a new undesirable identity and having to cope with the associated negative judgement. In the quote above, the participant judges herself harshly, expresses shame and, at the same time, appears concerned about how the interviewer may be judging her. The pain has given rise to a new identity that the participant is ashamed of and that she has difficulty in assimilating, causing her more suffering than the pain itself.

Other studies have found similar accounts of shame in the narratives of sufferers. Werner et al. (2004) interviewed women who had previously received treatment in a group context and found that during the interview participants went to great lengths to describe themselves in a positive light, emphasising their emotional strength and how they were not the “*whining and complaining*” type, but ‘good’ patients. Some of their narratives suggest they may be experiencing internalised stigma:

It was wonderful to meet other women who had the same symptoms, whether they accepted them or not. (y) Meeting other girls who were just as resourceful as I regard myself, who sat and felt the same; that they were not interested in whining and complaining, but in breaking out of an evil circle (y) (R: ‘After being in the group, did you regard them as resourceful?’) Yes, and I regarded them like this as we went along too, but when I started, I thought ‘these women lack resources’. (R: ‘The myth that...’) The myth that chronic muscular pain is only connected with whining and complaining, and people who can’t cope, and that it’s not a real disease, and - poor me in a way (Werner et al., 2004, p. 1040)

This person entered the programme fearing she would encounter in other participants her stereotypical image of a CP sufferer, which was different from the identity she was eager to present to the interviewer. This was a narrative study, with a declared feminist stance, which may have emphasised a gendered reading of results, however, it did include some rich data which, as in the quote above, offer insight into the complicated dynamics that surround identity when CP is involved. Perceived stigma in pain is tightly connected with legitimisation, another theme discussed later.

Lofgren et al. (2006), in their GT study of women with fibromyalgia, suggest a model that sets the ability of sufferers to undergo a grieving process, in which they work through the loss of their former self and body, as a prerequisite for developing positive coping strategies and the attitude required to enjoy life again despite CP. Although the Lofgren et al. (2006) study is not enriched by any participant quotes, which limits its transparency (Yardley, 2000), it presents a

convincing model of pain trajectory, particularly for its suggestion that pain rehabilitation programmes have the potential to facilitate the grieving process for the lost Self. Another GT study looking at the experience of people attending a rehabilitation programme (Gustafsson et al., 2004), found that participants followed a trajectory “*from shame to respect*” as they moved through the programme. Part of the trajectory entailed a transformation in the self-image of sufferers, who went from feeling a failure for being unable to manage their bodies and pain, to developing new and successful strategies that boosted their self-confidence. This new-found sense of Self also allowed them to renegotiate some of the identities that were important to them, such as, for example, their identity as housekeepers:

When there is a lot of ache and so on, then one wants to manage anyway, but now I don't care a bit about it. If I have decided to do the cleaning the next day, and then don't feel well, then I skip it. ... I think I demanded more of myself before. (Gustafsson et al., 2004, p. 100)

One interesting IPA study explored visual art-making as a resource for living positively with CP by interviewing older amateur or professional female artists (Reynolds et al., 2011). Findings from this study indicate that art-making can sustain and help develop a positive identity in CP sufferers in several ways. Art allows artists to experience a sense of continuity in their identity because they feel that the art keeps them in contact with who they have been since childhood; it is also a way for CP sufferers to confirm they have an able identity, where CP is no longer the only identity but becomes one aspect of a wider Self; art also allows ongoing self-development despite the illness, the ability to explore and refine new skills and express one's inner voice.

So I suppose I am actually expressing something more of myself although perhaps I don't actually realize it ... I'm expressing something that's coming from inside (Reynolds et al., 2011, p. 334)

Issues of identity emerge strongly also when the CP sufferer is a young person, because CP can be perceived as interrupting the natural flow of identity development, “stealing” the young person's budding identity as an adult person by replacing it with an identity as an ill-person, as described by 17-year-old Sophie below:

that's kind of how you're defined for a while by doctors and then your family and other people is like you will always be—you know—the person with this illness and it's hard to say when you're that person that you have interests in other things and your opinions about things because it's always kind of covered by what you haven't been doing what you have been doing what you've been able to be doing and I think it's difficult to establish an identity when you've already been given one you don't really want (Jordan et al., 2018, p. 4)

As with artists earlier, the pursuit of valued identity-defining activities such as hobbies can help adolescents navigate the difficulties of life with CP (Jordan et al., 2018).

Role

Tightly connected with identity is the question of the social role of sufferers, which can be lost or needs to be renegotiated as a result of CP. This includes one's role in society, but also within

the family. Like most chronic illnesses, CP is biographically disruptive, meaning that taken for granted behaviours and assumptions in how we relate to our bodies, to each other and our future are no longer functional and must be reviewed (Bury, 1982). According to Richardson et al. (2006), what is most disruptive for many adults with CP is not the onset of pain per se, but the fact that it often forces them to give up work, which plays an important part in maintaining a positive identity.

For example, all the women interviewed by Söderberg and Lundman (2001) described a transition in their working life as a result of developing fibromyalgia: they had either changed their function or had given up work completely. They had felt excluded and less valuable, with effects on their self-esteem, and had received a mixed level of understanding from their employers:

Then, when you get a disability benefit and you can't go back to work, I felt it was very difficult, it was like losing something of myself ... my identity... It was as if I'm nothing anymore in principle... Now I don't even have a job; so it was very difficult. (Söderberg & Lundman, 2001, p. 624)

In another study (Lofgren et al., 2006), most of the women suffering from fibromyalgia participating in a rehabilitation programme had not returned to work when interviewed 8 years later. The authors suggest that current work environments are not sufficiently flexible to accommodate the needs of people with CP wanting to return to work.

At the moment, like I say, I'm having every Wednesday off as annual leave until Christmas, but eventually, I've got no annual leave left, I've got to do full-time. You know, I can't have one day a week off. I've got to do full-time and I'm finding it very hard and I'm frightened that I'm going to do it because I have to, but then I end up getting worse and I just can't cope. What do I do?" (Corbett et al., 2007, p. 1590)

I've had a variety of jobs from security bus driver to making milk cartons, but it's always ended up where I've had to take a lot of time off of work because of the pain ... I've never told the employers I've had a back injury or I've had a back operation because you would never get a job (Walker et al., 2006, pp. 202-203)

The quotes above illustrate the difficulties sufferers experience in finding and keeping jobs, because the onus of living up to the requirements of employers and balancing these against the needs of their bodies in pain is entirely on them. They resort to juggling with their holidays, omitting truths and living in fear of becoming unemployed. Despite their efforts to resist, many people eventually do lose their jobs. The practical consequences, particularly when the person is the sole breadwinner, can be substantial, with effects extending to the family as a whole and, in extreme cases, causing the loss of personal relationships (Corbett et al., 2007; Walker et al., 2006).

There is so many ways life's changed. Well the obvious one, we used to have a three-storey town house, a nice pine kitchen, fitted carpets everywhere, now we're in a council place with unfitted carpets and not very nice furniture (Walker et al., 2006, p. 203)

The difficulties encountered by people who are in work when CP develops are substantial probably because the professional role of most people is central to their identity. Something similar happens to younger people who because of CP are unable to attend school (Forgeron et al., 2013). Older people appear to adapt better to CP, some consider it a fact of life and take the limitations it brings in their stride (Davis et al., 2002; Lansbury, 2000; Sofaer et al., 2005; Walker et al., 2006).

I am still the same person, as I used to be. [...] Before all this happened, I used to go out a lot, but I don't miss that now. [...] I think I am coming into that time of my life now where I like being at home. (Richardson et al., 2006, p. 1582)

Age-related expectations, especially professional, mean that the disruption of pain is better tolerated by older people, but it also means they often lack the motivation to engage with their pain or tend to adopt do-it-yourself strategies to manage it (Davis et al., 2002; Lansbury, 2000). Another common finding with older sufferers is they fear losing independence and control, which can affect how open they are about their pain with both their family and healthcare professionals (Lansbury, 2000; Sofaer et al., 2005).

I'm concerned of other's reactions. I don't like to tell others about my pain for fear of worrying them. I am concerned that they will try and take me over and I will lose control - My daughter - she is the last person I would tell! (Lansbury, 2000, p. 9)

So, while older people seem to adapt more easily to a life in pain, they can still experience and resist the change in role than it entails, particularly within their families.

It has been suggested that the extent to which CP is biographically disruptive should be interpreted in the context of a patient's life stage but also in the context of their perceived life expectancy (Richardson et al., 2006).

It's made me think about me more, and your age, and inevitably you're getting older and it's death as well in a way. [...] Well my parents died very young. I said to [husband], 'If you work it out on age like my mum I've got about 12 years left'. [...] I suppose deep inside at the back of my mind I'm thinking, 'Yeah, I'm only 44, but my mum was 57 and I've started up with this arthritis and different things'. (Richardson et al., 2006, p. 1582)

The woman in the quote above is only 44 years old and would be considered young by most standards, however, she feels old, not so much because of her pain, but because of her family history and, like older sufferers, she appears to associate her pain with a general ageing process. Incidentally, this extract comes from one of the few studies in which participants were recruited from a population survey, meaning they had not necessarily sought help from a pain clinic, possibly giving its findings a wider applicability.

Young people with CP also lament feeling older than their peers (Forgeron et al., 2013; Jordan et al., 2018):

If you really listen at school, you don't really hear anything of consequence – if you listen to the conversations that people are having, they're more concerned about their clothes, and

you know, what someone else said about them, and it just doesn't really seem that big of a thing (Forgeron et al., 2013, p. e118)

The 'trivial' concerns of adolescence pale in comparison to the experience of CP: young CP sufferers can feel obliged to mature ahead of their peers for their ability to handle complex emotions and life experiences. Some young people perceive this developmental superiority as an advantage over their peers (Jordan et al., 2018).

The fulfilment of family roles becomes an issue when CP enters the picture and this is an area in which findings are not linear. On one hand, some people strive to maintain their old family identities, adjusting them to their new limits and occasionally accepting to pay the relevant cost. For instance, people with CP describe how they have stopped feeling obliged to “*prepare for everything or everyone*” (Werner et al., 2003, p. 499), how they have restricted their hours of housework while still retaining responsibility for it (Gustafsson et al., 2004), how they are forced to ask for help because the invisibility of their pain makes it difficult for their family to understand their needs (Söderberg & Lundman, 2001) and the importance of “*keeping up a good front*” to maintain an illusion of normality and also to limit the consequences that the situation may have for loved ones (Sturge-Jacobs, 2002, p. 26), as this quote exemplifies:

I have two small children, and I don't want them to say when they're older, we couldn't do this or that because my mom was sick. They're entitled to better than that. As far as I can possibly do it, we live a normal life and do normal family things (Sturge-Jacobs, 2002, p. 27)

So there is an effort to mediate between the needs of the body, the needs of family and one's own needs to maintain a positive role within the family. However, not all narratives have a positive tone: some tell stories of a struggle with others and with one's own limits. Families often don't understand the new needs of sufferers and some sufferers in a caring role resent having to entirely retain their role and feel burdened by it, as illustrated in the quote below:

We shared the workload differently while I attended the treatment program, but now I feel it's all back where we started. I'm disappointed because the responsibility once again is left to me; I'm the one who plans who's going to take Beatrice to day care and pick her up afterwards. I'm the one who packs her rucksack, checks that she's got clean clothes, rubber-boots, and rainwear in her rucksack (Werner et al., 2003, p. 499)

CP sufferers also express feelings of anxiety and guilt for their inability to fulfil their family roles. They describe how their physical disability hinders them from being able to provide for the (perceived) needs of their children and/or their partners and they feel that they are letting them down (Smith & Osborn, 2007b; Snelgrove et al., 2013):

I know there's things my daughter would like for me to be there to see her and I cannot and I get frustrated with myself and feel I'm letting her down. My partner, he is more like a carer than a married partner. It is not fair but there's not a lot I can do (Snelgrove et al., 2013, p. 128).

I'm some waster, they should have someone who's impressive, to look up to but how can they look up to me with what I do all bad tempered and crippled, dossing about lying down every 10 minutes. All they see is a bit of a man [...] terrible. I try and keep out of their way or when

they're around I make sure I try to do lots so at least they have something to look up to, but I can't bear to have them see me like this, it's pitiful. (Smith & Osborn, 2007b, p. 525)

In the Snelgrove et al. (2013, p. 128) study a participant describes how family roles have been reversed (“*I have become the dependant instead of being the depended upon and this has affected me deeply*”), and this is an area in which gender may well have a part to play, as carer and housekeeping roles are traditionally played by women, and most of the studies cited so far involved female participants. In the only study which also involved men (Snelgrove et al., 2013), not being able to fulfil one’s role as the principal breadwinner is mentioned as an issue raised specifically by male participants. This suggests it could be interesting to explore gender differences in CP, particularly for social roles and expectations.

Self-esteem

As apparent when discussing identity and role, the physical, psychological and social transformations triggered by CP can negatively affect the self-esteem of sufferers. With CP, the range of activities people can engage in becomes very restricted (Miles et al., 2005) and it becomes important to do things that provide a sense of accomplishment, which can help preserve self-esteem (Söderberg & Lundman, 2001). As the participant in the quote below suggests, it is good to feel that you can do “*something*”, even though there are many things you can no longer do:

At the same time you will try to get something going still, because it's a lot to do with the feeling of self-esteem, that you sort of feel that you can manage something. (Söderberg & Lundman, 2001, p. 622)

CP sufferers find that they need to rely extensively on the help of others to accomplish things that they would have previously been self-sufficient with, but some feel that their inability to reciprocate the help they receive damages their self-worth (Walker et al., 2006).

An interesting occupational therapy study conducted by Borell et al. (2006, p. 80) provides a rich description of what ‘doing’ can mean for CP sufferers. Social activities included doing things ‘with’ people, which participants felt could be hindered by social perceptions of disability (e.g. “*one time I said to them that my illness isn't contagious*”), and doing things ‘for’ people, as a way of preserving self-esteem. Although at a cost in terms of self-sacrifice and pain, participants found ways of doing things for others that were compatible with CP and still self-satisfying, as illustrated in this quote:

They see me as their mom that can give good advice for example when they are worried and when they ask something: “Mom, shall I do it?” “What do you think Mom?” “Which insurance shall I get?” They ask me, so I feel that I am participating. (Borell et al., 2006, p. 81)

Helping others through charity work has been reported as a specific strategy to create well-being by older people (Sofaer et al., 2005) and artists (Reynolds et al., 2011):

Then I can do a proper exhibition, put an ad in the paper, get some publicity, and raise some money for Diabetes UK. I feel by doing things like that ... I can also do something useful, does that make sense? All of these things are self-imposed challenges which motivate me and give me deadlines that I have to meet otherwise I think I'd be simply lazy. Not dwelling on the pain, dwelling on [other] things, that helps. (Reynolds et al., 2011, p. 333)

By focussing on the needs of others and using deadlines to create pressure, the artist appears to have developed strategies that help keep her mind off the pain and make her feel useful, thus preserving her self-esteem.

Time

When in pain, people slow down because physical limitations mean that every task takes much longer and requires greater persistence than it normally would (Söderberg & Lundman, 2001). For example, for many sufferers, mornings are a critical moment because after having been in bed for the night they find that their body is stiffer and slower to respond.

I was so stiff and in a way my body didn't obey, I can make no movements automatically. I must consciously turn to the right position, I have to take control, try to tell myself to wake up properly so that I'm able to take control. I have to persuade the body to function: now, my friend, you have to get up. (Raheim & Haland, 2006, p. 751)

As emerged when discussing the body in pain earlier, a painful body is more difficult to coordinate, which makes adhering to old daily routines impossible, so people with CP find that they have to develop new rhythms (Raheim & Haland, 2006). The slower pace also fuels the sense of isolation and exclusion, because sufferers are unable to take part in the 'normal' life rhythm of those around them (Miles et al., 2005). In some (rare) cases, the change of rhythm can be welcomed and can acquire a positive connotation, in the sense-making process of sufferers:

Maybe there's a reason, maybe it's to slow me down [to] look around to see other people are in pain. I'm more and more interested and want to be involved with helping battered women. (Thomas & Johnson, 2000, p. 694)

A common finding across studies is that CP is associated with a radical change in the temporal dimension. According to Raheim and Haland (2006), CP reorganises the spatio-temporal field of sufferers so that their world shrinks to 'here and now'. The most consequential unit of time for CP sufferers becomes the moment, which, although theoretically small, they perceive as lengthy and heavy (Thomas & Johnson, 2000). People with CP feel they are forced to live day by day, in a sort of limbo in which time is suspended, the pain keeping them constantly in the present, with no ability to plan and facing a possibility of an eternity of suffering (Söderberg & Lundman, 2001; Thomas & Johnson, 2000).

"I just got this area fixed and now I've got another [painful] area. Is this what it's going to be like forever for me?" (Thomas & Johnson, 2000, p. 694)

In their LIPA study, Snelgrove et al. (2013) gathered data at three timepoints: at time zero, after one year and after two years. At the two-year follow-up, the participants who presented a sense

of continuity with the past appeared to be stuck in time and set apart from mainstream living. They talked a lot about ‘then and now’, referring to their previous life without pain, and expressed limited future orientation. In contrast, participants who appeared to have experienced a change between timepoints were able to express a perception of a meaningful future. The quote below is an extract from a participant’s second interview (at one year from the start):

On really bad days you think to yourself if this is what it is like now what am I going to be like in 10 years? (Snelgrove et al., 2013, p. 131)

One year later, at the end of year two, her perspective had substantially changed:

The medication I am on is helping. I am hoping that when I see the psychiatrist and go back to the Pain Clinic I can get further along with my life, try and get it back to what it was (Snelgrove et al., 2013, p. 131).

The relief resulting from the medication had opened up her future, given her the hope that she might regain the previous valued Self that she had lost.

The most marked focus on the philosophical issues of pain is offered by an anthropological study by Honkasalo (2000, p. 197), who aimed to understand “*how people give meaning to their pain and how pain, defined as mode of being-in-the-world bestows meaning on people’s life*”, in terms of intentional relations. The author claims that with pain the direction of intentionality is inverted: in a pain-free life, intentionality is directed towards the future, whereas when in pain there is a posture of passionate longing and yearning for the past. This interpretation seems at odds with a view of CP life as being constrained and turned inwards (Miles et al., 2005), but fits with the idea that, to integrate pain and move forward, sufferers need to complete a grieving process (Lofgren et al., 2006), other words, take leave from their past and turn their intentionality towards the future.

Social life

The physical and psychological limitations associated with CP often have a severe social impact for sufferers, who report changes in both their close relationships and their wider social lives.

To take part in social outings requires an expenditure of precious energy that is often lacking (Söderberg & Lundman, 2001) and, when they make an effort to participate, sufferers often find that their ability to enjoy themselves is limited (Lempp et al., 2009), resulting in an ‘enforced disengagement’ from others (Walker et al., 2006).

You lose your social contacts... You can’t be out and be with other people. Yes, at its worst it can be so that I’ve nothing in exchange for what would be nice because I’m so tired... You are so tired you don’t have the strength to take part in the conversation. (Söderberg & Lundman, 2001, p. 624)

For young people, CP can mean reduced school attendance, fewer shared experiences with peers and, more generally, fewer opportunities to build friendships which can cause a sense of social isolation (Jones et al., 2020; Jordan et al., 2018)

Some sufferers also describe gradually losing valued social activities such as sports, where they generally shift from being protagonists to being onlookers, to giving up altogether (Snelgrove et al., 2013). The most distressing aspect of how pain affects social life appears to be social isolation (Holloway et al., 2007): a feeling of being separated from the world (Lempp et al., 2009) and other people (Thomas & Johnson, 2000).

Fibromyalgia just feels sometimes engaging with life from behind it, a big screen of glass where you can see things going around you and you think: I want to be part of that, I am going to want to be part of that. And to do that, you have to kind of smash the glass through, but obviously you'll get hurt, there is going to be a bit of pain or consequences if you do sort of smash through. (Lempp et al., 2009, p. 5)

Participants in the Smith and Osborn (2007b) study described how the sense of threat to their Self caused by pain was exacerbated by social and relational contexts, to the point that some chose to retreat and avoid being with other people. Interaction with others was unbearable for the need to put up a 'front', to pretend to be something different from what they were:

When you go out you end up like you can't wait to get home. [...] People ask you or invite you and you think oh god do I have to and [...] you think, well I should make the effort. So you put a front on and you go out but all the time you're looking at your watch and thinking about when you can go home and go upstairs and lay on the bed and get some relief. (Smith & Osborn, 2007b, p. 524)

This finding echoes other CP studies in which participants have described feeling the need to conceal their true feelings to avoid damaging relationships (Holloway et al., 2007), concealing their condition altogether and making efforts to physically look normal for fear of being stigmatised (Sofaer et al., 2005; Thomas & Johnson, 2000). The incongruence between how one appears and how one subjectively feels inside is difficult to manage for some sufferers (Lempp et al., 2009), but can also have a positive effect, as suggested by a participant who felt stronger when others commented on how healthy she looked (Söderberg & Lundman, 2001). Similarly, some sufferers use downward social comparison as a motivator because it allows them to put their pain into perspective (Bair et al., 2009; Slade et al., 2009) or they simply compare themselves to others to establish a standard of normality and evaluate the impact of their pain (Miles et al., 2005).

Pain invisibility is a key aspect of CP that has a bearing on all social interactions and raises important issues of legitimacy, a topic discussed in the next paragraph. In social contexts, pain invisibility is considered a barrier because it hinders others from truly understanding what the CP sufferer is experiencing (Slade et al., 2009; Söderberg & Lundman, 2001):

"The thing is they can't see back pain. I don't have a cast on my arm, you know, if you cannot see the injury it's very difficult for people to understand". (Slade et al., 2009, p. 150)

Overall people with CP have negative opinions of how non-sufferers respond to a friend or acquaintance afflicted by CP. When pain is not visible, some expect scepticism and disinterest but, at the same time, when the pain can be seen, some resent being asked questions about it

(Thomas & Johnson, 2000). The perception that a stigma is attached to pain is a finding which emerges from many studies, particularly when social relations are being described (Lempp et al., 2009; Werner & Malterud, 2003). The assumption is that pain will be judged negatively and considered an excuse for poor performance (Slade et al., 2009).

Do you know where the stigma came from? They think people that have bad backs are either poor posture, lazy, they'll live with it because they're lazy, don't want to do anything about it. What they don't understand [is that] we want to do something about it (Slade et al., 2009, p. 149)

Participants in a study by Walker et al. (2006) agonised over what others thought of them, suggesting that stigma may also be internalised, as discussed earlier in relation to identity. Perceived stigma is the sort of problem that a PMP may help to address: participants in a study by Werner et al. (2003) described feeling less sensitive to the thoughts and reactions of others following programme participation. Another outcome from taking part in a programme, that can affect social interactions, is an improved ability to communicate the facts of pain to others and set limits to their demands (Gustafsson et al., 2004).

Before when people asked how I felt, how it was, then I said okay, but now I dare to say more, straight out. (Gustafsson et al., 2004, p. 100)

In the context of closer family, pain invisibility can make relationships change (Söderberg & Lundman, 2001) and can give rise to suspicions that the pain may not be real (Holloway et al., 2007). Intimate relationships seem to be the most vulnerable (Lempp et al., 2009; Söderberg & Lundman, 2001), while older sufferers report a welcomed increase in contact with family (Walker et al., 2006).

In their phenomenological study of the experience of people presenting different degrees of adaptation to living with pain, Raheim and Haland (2006) observed that with CP all existing family relationships are challenged, particularly intimate ones and that the key to successful coping lies in the ability to rekindle and transform relationships so that the sufferer can feel strong and not feel guilty for carrying out the behaviours required to manage their pain.

We have solved it by talking about it. That is easier for me, so he just had to listen. Long nights talking, because it was important that he should understand my situation, that he should know I loved him just as much, and that it was the pain. (Raheim & Haland, 2006, p. 752)

Unfortunately, many families fail to adapt, so sufferers may feel unsupported (Thomas & Johnson, 2000) or, even worse, that they are a burden (Smith & Osborn, 2007b). Some participants in the Smith and Osborn (2007b) study found that the negative side of their Self that they attributed to pain made them feel bitter, causing them to become hateful and direct their hatred at others, including family members:

This pain, it hurts but its evil gives me a nasty head and makes me hateful, irrational. I hate it when they all leave in the morning and I'm left on my own and I hate it when they all come back in the evening. [...] If something sad happens to someone, I'm not sad, sometimes I'm

pleased, [...] I'm just glad someone else is miserable and you have these stupid rows about nothing and you know they're stupid but you have them anyway because you get to spray a bit of hate about. (Smith & Osborn, 2007b, p. 525)

As with many other aspects of the lives of CP sufferers, social relations contract, partly for logistical reasons, but also because pain occupies a big part of sufferers' lives and social interactions are experienced as more difficult for a lack of understanding and perceived stigma. The most successful experiences occur when sufferers can communicate their pain with close ones and, as a result, relationships can be renegotiated.

Legitimacy

Pain invisibility, lack of understanding and perceived stigma all contribute to issues of legitimacy in CP. People with CP feel that their experience of pain is constantly being challenged by family and friends and by healthcare professionals (HCPs); sometimes they even challenge it themselves (Sturge-Jacobs, 2002). Part of the problem is that most CP is entirely subjective and cannot be substantiated objectively through any test or imaging study. This makes it difficult for doctors to formulate a diagnosis, which could confirm that the pain is real and not psychogenic (Holloway et al., 2007; Slade et al., 2009).

Obtaining a diagnosis is considered of paramount importance: it provides relief and legitimacy (Honkasalo, 2000; Huntington & Gilmour, 2005; Lillrank, 2003; Sturge-Jacobs, 2002) and failing to obtain a diagnosis is described as an invalidating experience (Holloway et al., 2007). Due to the mobile nature of pain in many CP conditions, it can be difficult for sufferers to locate the pain and provide unambiguous descriptions of it:

Well, there's two sorts of pain, and they always, really come... I'm alright in the day, it doesn't bother me in the day. It's after I've sat down at night, and then, when I go to bed, the pain... One of the pains is under the knee, under the knee-cap sort of that area and down, and it probably takes an hour or so for it to go off, you know. You can't sleep for an hour. But I have another sort of pain, where it is also down the side, below the knee again, but down the side of the legs as well, the outer side and that pain comes sometimes and that's uncomfortable. Yeah, so that's the two I get. (Ong et al., 2004, p. 540)

The patterns of pain of some people can be erratic, with pain coming and going, affecting different areas, at different times, in different ways. Sufferers need to understand the patterns of their pain before they can communicate them to HCPs, which further complicates obtaining a diagnosis and adds to the experiential unreality of CP, giving rise to issues of legitimacy (Ong et al., 2004).

In one interesting study, the first ten minutes of interviews were analysed and it was observed that participants made efforts to enhance their credibility by presenting themselves as people who fulfil their social and moral obligations (“*I'm not one for sitting still, so I carried on, even through work, because I keep two jobs*”) or to evoke legitimacy by presenting the clinical diagnosis they had received (Ong et al., 2004, p. 538). Similarly, Werner and Malterud (2003)

suggest that their participants were emphasising their ‘good’ behaviour as opposed to a genderised model of ‘whining’ patient. It’s interesting how even in an interview on CP, where the condition’s legitimacy is implicit, there is a need to affirm one’s credibility.

Once legitimacy is established, it can trigger an important change in the life of sufferers. Studies to evaluate the outcomes of group-based PMPs consistently report that being respected and appreciated in the group and feeling believed by the experts conducting the programme gives participants the strength and confidence they need to stop neglecting their own experience, express their limits and make others believe them (Gustafsson et al., 2004; Werner & Malterud, 2003).

Relationship with healthcare professionals

The elusive and untreatable nature of CP represents a challenge for HCPs and this could explain why CP sufferers often have problematic healthcare experiences. Some find it difficult to go beyond their GPs and access specialist care (Huntington & Gilmour, 2005; Lillrank, 2003). When they do access secondary or tertiary care, they describe going through a set of negative tests and, eventually, just being ‘passed on’ to registrars, as if they were being cast aside (Holloway et al., 2007).

CP sufferers express high levels of mistrust because HCPs have failed to find a cure (Holloway et al., 2007) or because they only prescribe pain killers (Davis et al., 2002; Liddle et al., 2007). Encounters with doctors tend to be described in negative terms: people lament consultations are rushed (Lansbury, 2000; Lempp et al., 2009), not receiving the sympathy they expected (Holloway et al., 2007; Slade et al., 2009), feeling disappointed and insulted (Lillrank, 2003) and feeling blamed or made to feel guilty (Slade et al., 2009), as exemplified by in the quotes below:

(I want) clinicians to be non-judgemental... I’ve been told ‘you’re an idiot for doing that’ and ‘how did you get to this situation?’ (Slade et al., 2009, p. 147)

And then he [the specialist] said to me that the pain does not exist if you do not think about it. But when you think of it you feel it. That sounded so simple. (Lillrank, 2003, p. 1050)

Even though they have accumulated several negative experiences, some sufferers are still searching and hoping they will come across a sympathetic doctor who will miraculously provide relief (Thomas & Johnson, 2000). A rich description of the ‘quest’ for a solution through the healthcare system comes from a study by Lillrank (2003) using the written narratives of 30 women suffering from back pain. With different patterns of pain onset, all participants had initially sought help from their GP, receiving normalising explanations which raised doubts about the reality of the pain and were followed by specialist consultations, also causing frustration and further uncertainty, until a legitimate diagnosis was obtained.

People with CP go to great lengths to ensure they are taken seriously within medical encounters and that their relationships with doctors remain good. Werner and Malterud (2003) ran a study specifically aimed at understanding the strategies employed by female CP sufferers to be taken seriously by doctors. Participants felt they had to be tenacious to convey information and request investigative tests, and did not express their dissatisfaction in unsatisfactory medical encounters for fear of alienating doctors. An interesting finding from this study concerns the efforts described by participants to have a physical appearance that would make them credible in the eyes of the doctor, i.e. looking ill enough to be believed, but not too much to be considered psychologically unstable:

Sometimes I feel that I should look groggy, my face should be grey, and I should wear no make-up; that I perhaps appear to be too strong (Werner & Malterud, 2003, p. 1414).

The authors define the importance of physical appearance in the medical encounter as a female issue. Whether it is a gendered phenomenon could be a matter of debate, as de-legitimisation is a cross-gender issue, however, the idea that sufferers are aware of the dynamics occurring within medical encounters and adopt strategies to ensure they reach their aims is echoed by others (Ong et al., 2004).

However unsatisfactory medical encounters are, HCPs are seen as having the authority to sanction the illness by issuing a legitimising diagnosis, so sufferers will make every effort to retain a good relationship and fight to obtain the attention they need.

Coping

Most pain sufferers face the prospect of living the rest of their lives in pain, so their ability to cope and adapt is important for their future quality of life. In the theory developed by Miles et al. (2005), living with CP is equated to managing bodily, identity and activity constraints. If the pain is assessed as having an impact on normal functioning, four possible coping patterns can ensue: sufferers can absorb the constraints, integrating the pain in their lives without allowing it to challenge their identity (assimilation); they can accept the constraints, changing their concept of what constitutes a 'normal' life and aiming to achieve as much activity as possible with the least possible pain (accommodation); they can refuse the constraints and search for a non-confrontational way of bypassing them (subversion); or they can resist the constraints and decide to live their life normally even though this will inevitably lead to increased pain (confrontation), as exemplified by this participant:

I'll do my normal chores I have to do, and I'll stick to that which I've been sticking to all my life, regardless of the pain like I'll do my prayers for about 20, 25 min which I must sit down and do it, to get up after I've sat down it's worse but I'll still do it, I'll still do it the same position as I used to do because changing the pattern is only giving in, to me it's giving in so I will not change. (Miles et al., 2005, p. 438)

This model is neat and well conceptualised, however, not all these coping strategies can be considered equally successful and will lead to a satisfactory quality of life. Another GT study investigating the successful strategies of women coping with fibromyalgia (Lofgren et al., 2006) concluded that prerequisites for successful coping include having undergone a grieving process for the life that is no more and being able to enjoy social support.

The availability of social support has also been suggested as a foundation for engaging in self-management by CP sufferers with co-morbid depression (Bair et al., 2009), as has the ability to listen to one's bodily reactions (Gustafsson et al., 2004) and to reconceptualise one's idea of pain (King et al., 2016). Overall, these studies indicate that a process of acceptance of the pain, which includes grieving and reconceptualization, and which may require a certain degree of change in activity and self-awareness, is the key to successful coping.

Coping strategies adopted by older people to deal with pain appear to differ slightly from those adopted by younger people in that they seem to express a higher degree of acceptance and, consequently, prefer do-it-yourself types of remedies, disliking medication and physical activity (Lansbury, 2000), but also strive to remain independent by relying on technical help for mobility (Sofaer et al., 2005). This raises the question of how much access older people have to specialist CP services and whether their choice of coping strategies might be connected to their age-related passive acceptance of pain.

Conclusion

The first aspect of the CP experience I described was the impact that pain has on the body of sufferers. Studies describe CP as a continuous intrusive presence that brings about a dramatic change in how people feel physically and psychologically. Sufferers talk about their 'new' body as feeling different from their 'old' body, some develop a sense of alienation because their body is no longer recognisable and does not respond to the will of the mind. When successful coping strategies are adopted, people stop attempting to ignore their body and learn to listen to it with a new awareness, using it as a guide for engaging in activity, allowing a sense of bodily mastery to be rekindled.

The impact of pain on the body also strongly affects the sense of Self of sufferers. Some describe discovering new unwelcome identities as a result of being in pain, others experience stigma, internalised and not, and a sense of shame. Accepting the physical and mental changes brought about by pain, including grieving for one's lost Self, appears to be a necessary step for coping. Whether people are actively working when they develop CP may have different repercussions: working sufferers often have to give up their job, with material consequences and deep effects on their sense of identity; younger people feel very different from their peers, while, for older people, who are retired when they develop CP, the change appears less

dramatic, and acceptance can be less difficult. Independent of age, all adult sufferers describe having to renegotiate their role within their families, an experience that may affect men and women differently, depending on whether a sufferer is a carer or the family's breadwinner. As a means of maintaining their self-esteem, people describe how, despite their pain, they make efforts to still accomplish things, particularly things for others.

The onset of CP is also associated with issues of temporality: people describe experiencing a change of rhythm in their lives, the unpredictability of pain forcing them to live in the here and now, day-by-day, projected towards the past rather than into the future.

CP sufferers feel that, since pain is invisible, others cannot truly understand it, and this, together with their reduced physical ability to participate in social life, can generate a sense of isolation. Invisibility also contributes to the feeling of illegitimacy described by sufferers who feel they are not believed by doctors and other people. A medical diagnosis is thought to confer legitimacy and sufferers often navigate the healthcare system for years before being able to obtain one. The relationship with HCPs is described as negative by many and requires balancing between the struggle to be considered credible by doctors, the need to preserve the relationship with them and the need to manage healthcare.

Thirteen of the 35 studies in my review had recruited only women and 4 of them claimed that some issues, such as negotiating one's carer role and needing to look credible in medical encounters, were genderised, affecting women differently from men. Whether such differences exist or whether they emerge because CP affects more women than men, would be worth investigating further. Differences between age groups appear more marked compared to gender. The claim by some authors that work status is the discriminant between different ways of coping with CP is plausible and, again, might afford more in-depth analysis.

Overall, the qualitative studies considered in this review, although limited in number and probably not exhaustive in scope, provide a rich picture of various aspects of the experience of living with CP. CP affects most areas of people's lives and the sense of identity of sufferers is the common thread that connects all themes: CP changes how sufferers feel about themselves, in relation to their bodies, in relation to others and in relation to who they used to be.

Syntheses of qualitative studies and final considerations

The increasing number of original qualitative studies investigating the experience of CP has been paralleled by an increase in metasyntheses collating their findings. Toye et al. (2017) summarised multiple syntheses into a mega-ethnography in which findings were conceptualised into categories and brought together into a theoretical model (Toye et al., 2017, pp. 3-4).

The mega-ethnography includes 7 themes: 1-*My life is impoverished and confined* (about how CP sufferers are forced to live in the moment); 2-*Struggling against my body to be me* (about the struggle of CP sufferers to maintain a sense of self when dealing with a body that feels alien); 3-*Quest for the diagnostic 'holy grail'* (about the need for a clear diagnosis that might lead to a cure); 4-*Lost personal credibility* (about how the invisibility of pain leads sufferers to not feel believed by others); 5-*Trying to keep up appearances* (about the need to hide one's pain not to burden others and make one's inner changes too obvious); 6-*Need to be treated with dignity* (about negative healthcare experiences and the feeling of being sent around in circles); and 7-*Deciding to end the quest for the grail is not easy* (about giving up searching for a diagnosis and learning to live with pain).

The line of argument offered by Toye et al. (2017) is that when pain takes over the life of sufferers, present and future, they respond by searching for a diagnostic 'holy grail'. They struggle with their bodies for a need to maintain a sense of Self and initiate a quest to find out what is wrong with their bodies. Since they can't find the answers they search, they feel robbed of their credibility and make efforts to keep up appearances to avoid being judged. Although HCPs can help preserve their dignity, ultimately sufferers need to learn to live with their pain.

For the most part the themes identified in my review overlap with the themes identified by Toye et al. (2017). For instance, *theme 1- My life is impoverished and confined* from the mega-ethnography, overlaps with my 'Time' and 'Body in pain' themes, *theme 2- Struggling against my body to be me* overlaps with my 'Identity, Role and Self-esteem' theme and so on.

In addition to a good overlap in findings, there are some differences between the Toye et al. (2017) review and mine that are worth commenting on and that justify my need to conduct my own literature search. By using 11 syntheses (covering 187 studies and involving 5000+ participants), one of which was a very comprehensive meta-ethnography (Toye et al., 2013a), the Toye et al. (2017) review covers most of the large corpus of qualitative literature available on CP, while my strategy was to work with a selected number of influential papers. My purpose was phenomenological: I wanted to get a sense of the experience of CP as reported by some sufferers, with a particular focus on those aspects having the strongest existential impact and most likely to be affected by participating in a PMP. Focusing on original studies also gave me the opportunity to report my synthesis using quotes from participants, which reinforced the phenomenological quality of my review. My ultimate purpose was to develop and make a case for the research question of my own study.

The purpose of the Toye et al. (2017) review was to produce new understandings by moving beyond a mere aggregation of findings, adding a conceptual level that would say more than the

sum of the existing syntheses. Their inputs were aggregated data that they analysed to create a model that could guide practitioners in addressing the issues encountered by CP sufferers.

Overall, the two reviews are complementary: where Toye et al. (2017) provide a high-level and integrated picture of the key aspects of the CP experience, my review zooms in on specific aspects and illustrates how they are manifest for particular individuals.

Psychological approaches to treating CP

The widespread acknowledgement that CP is a multifactorial condition that is best understood within a biopsychosocial framework has led to the development of various ways of supporting sufferers, beyond medical solutions. The main types of interventions that have been and are still being offered to sufferers are Cognitive Behavioural Therapy (CBT), Acceptance and Commitment Therapy (ACT) and Self-management and education interventions. I present them as discrete, because each has specific goals and theoretical underpinnings, however, everyday practice is less clear-cut so, for instance, in the real world, somebody may be attending a PMP aimed at self-management, with CBT components and elements of ACT. This lack of systematicity has partly affected the ability of researchers to measure outcomes and compare approaches, as I will discuss below.

CBT

Based on the CB model, CBT is designed to help sufferers live a more effective and satisfying life. CBT does not aim to eliminate pain as such, but to reduce its intensity and frequency, by increasing the activity level of sufferers, encouraging them to engage in feared activities, thus enabling a physical reconditioning. It also aims to equip CP sufferers with new cognitive and behavioural coping skills, to deal with residual pain and future relapses (Turk, 2002). Individual therapy in CBT focuses on the present, is time-limited and structured. It is viewed as a collaborative effort in which clients are expected to take an active role, work towards mutually agreed goals through a strong therapeutic alliance (Turk & Flor, 2013). When delivered to a group, it is presented as a toolkit of resources from which participants can choose according to their needs.

Evidence on the effectiveness of CBT programmes indicates that there is great heterogeneity in how treatments are being delivered (Morley et al., 2013). CBT is often combined with other physical therapies (e.g. physiotherapy and analgesia), as a component of wider multidisciplinary programmes (see PMPs later on). Treatment is delivered one-to-one, within a group setting or online, and durations vary. Also different are the skills provided to participants, so some programmes offer relaxation, others various types of physical therapy (Jensen, 2011).

A recent CBT development has been the introduction of mindfulness meditation, particularly useful for CP sufferers (Kabat-Zinn, 1982), and the accompanying concept of acceptance, which dramatically revises the pain management approach. The resulting ‘third wave’ of CBT, including approaches such as Mindfulness-based CBT, Contextual CBT and ACT (described below), has shifted the focus from the validity, frequency or form of psychological events to their context and function (Hayes et al., 2011).

ACT

Rather than aiming to improve the daily functioning of CP sufferers by reducing the thoughts and negative emotions associated with pain, ACT aims to improve functioning by increasing the psychological flexibility of sufferers so that they can develop more successful patterns of behaviour (McCracken & Morley, 2014). People who suffer with CP spend a lot of energy fighting their pain and this has wide effects on their thinking, emotions, memories and so on. For ACT, to be locked into this fighting situation means to be psychologically ‘inflexible.’ The goal of ACT is to help sufferers improve their responses to pain in a manner aligned with their personal values and goals, encouraging them to change their behaviour and be conscious and open about their discomfort. Pain acceptance is an important aspect of this approach, and so is the ability to not get stuck in the literal content of one’s thoughts, to establish a healthy distance from one’s thoughts and learn to live in the present moment (Feliu-Soler et al., 2018).

Although there do not appear to be prescriptive guidelines for what constitutes an ACT intervention, there are several recognised techniques, one of which is mindfulness (i.e. focusing awareness on the present moment, observing one’s thoughts, feelings and physical sensations). ACT interventions can vary in duration, target and setting. In one of the first ACT randomised control trials (RCTs), therapy was delivered to a group in-person over 4 sessions lasting 4 hours distributed over 2 weeks (McCracken et al., 2013). ACT has also been used successfully remotely: Veillette et al. (2019) delivered ACT as bibliotherapy, where participants received weekly emails with activities such as reading, written exercises and meditations, and a phone call mid-therapy for support and to encourage adherence. Herbert et al. (2017) compared in-person and telehealth ACT interventions and found them to be equivalent in terms of effectiveness, although the remote version did have significantly more withdrawals. ACT interventions are also used successfully with young people suffering CP and their carers (Kanstrup et al., 2019).

As I discuss later, the quantitative assessment of outcomes for both CBT and ACT is somewhat contentious. Results from an IPA study investigating participants’ experience of an 8-week ACT PMP suggest that ACT can be effective in those areas identified in qualitative studies as pivotal for CP sufferers, because many participants talked about accepting their ‘new self’ with

pain (Mathias et al., 2014). This is a notable finding, although the interviews occurred two weeks after the end of the PMP and were carried out by a student supervised by one of the PMP facilitators, raising questions of bias. Interestingly, a Self Experiences Questionnaire (SEQ) has been developed to measure treatment outcomes for ACT (Yu et al., 2016, p. 130). This is a 30-item questionnaire that includes, amongst others, 5 questions centred on identity, such as “*My life has changed and I no longer know who I am*”. Although it has not been formally acknowledged, I would consider the fact that ACT is addressing identity as evidence for the influence of qualitative literature on CP models, particularly the IPA studies that have explored these aspects in most depth.

Pain self-management, pain education and peer support

The term self-management refers to the need, true with most chronic illnesses, for sufferers to take an active role in managing their condition, to minimise its interference with their everyday life, mood and relationships (Nicholas & Blyth, 2016). Self-management strategies for CP include both passive strategies, such as resting or taking prescribed medication and, more importantly, active strategies, such as distraction, relaxation, seeking emotional support, and others (Blyth et al., 2005). Pain education and active self-management strategies are usually substantial components of PMPs, where participants are taught to exercise lightly, pace, solve problems, set goals, meditate and practice good sleep hygiene (Nicholas & Blyth, 2016). There is evidence that active strategies can significantly improve pain, disability and depressive symptoms: Nicholas et al. (2012) observed 791 participants daily as part of a 3-week long PMP and found that outcomes significantly improved post-treatment, both statistically and clinically. According to Devan et al. (2018) self-management interventions are most effective when participants feel empowered, develop self-awareness and are immersed in a supportive environment. There is however the question of what occurs longer-term when participants return to their daily lives. One way for people to continue to feel supported after a PMP is to join a CP peer-support group, where people come together regularly to engage in activities such as craftwork, in a fun and non-judgemental mutually supportive environment (Finlay et al., 2018).

Evidence of treatment efficacy

There is meta-analytic evidence on the efficacy of CBT (de C Williams et al., 2020), ACT (de C Williams et al., 2020; Hughes et al., 2017) and self-management (Du et al., 2017), which has underpinned a widespread adoption of psychological therapies to treat CP. For instance, in England, the National Institute for Health and Care Excellence (NICE; pathways.nice.org.uk) recommends offering, to people aged 16 or over with chronic primary pain, psychological

therapy based on CBT or ACT, alongside physical activity, acupuncture, pharmacological management and electrical physical modalities. Yet, effect sizes are small, so how effective the therapies are and how best to measure their effectiveness is far from established.

According to Eccleston and Crombez (2017), the paucity of meaningful results, despite the completion of 101 CP RCTs, is due to a lack of consistency in both intervention processes and outcome measurements. They suggest that researchers should be more rigorous in identifying which constructs to address, perhaps adjusting interventions to specific illnesses, as opposed to CP in general, and they encourage measuring idiographic outcomes. Part of the problem is that, methodologically, RCTs are designed to test medical treatments and their principles need to be adapted to measure psychological interventions, for example, by monitoring treatment provider performance and planning methods to increase participant adherence (Edmond et al., 2019).

New technologies are changing how outcome measures are captured: Salaffi et al. (2015) used a web interface to gather 'Ecological Momentary Assessments,' (EMAs) through online real-time symptom diaries. The finding that employment status, level of distress and acceptance were treatment outcome moderators in an ACT-based intervention reinforces the idea that different people may respond differently to the same intervention and that measuring idiographic outcomes could be more effective (Gilpin et al., 2019). Jones and Hurrell (2019) recently adopted a single case experimental design (SCED) to measure the outcomes of a one-to-one CBT CP intervention. They hypothesised that using outcome measures closer to the participant's experience would generate clinically more meaningful results, so they compared generic measures of anxiety and depression, with pain-specific and idiographic measures. The idiographic measures were created ad-hoc with the participant based on what was important to them including, in this case, questions such as: *'How much distress has my pain caused me today?'* *'How often have I thought I can't do anything?'* and so on (p. 8). For 51 days, from first assessment to end of therapy, they took daily idiographic measures, which they then compared to pre and post general and pain-specific measures, observing a substantial improvement in the idiographic measures compared to the others. They concluded that, since each person is different, what constitutes a significant change depends on that person and what is important to them.

Overall the role of psychology in the treatment of CP is well established and rooted in the biopsychosocial nature of the condition: psychology can contribute because CP has cognitive and affective consequences, but also because psychological aspects can influence the social and physical aspects of pain. Despite widespread interventions, the evidence base is weak and the quality of interventions is difficult to assess. A welcome change of paradigm appears to be underway, recognising how CP's idiosyncratic characteristics call for a more flexible and customised approach to treatment and outcome measurement.

Visual research methods and drawings

There has been an increasing interest in social sciences towards using visual methods with interviews to obtain a different kind of insight into experience (Reavey, 2020b). Such methods have often been employed to explore health experiences, especially living with serious health conditions, where alternative forms of expression can complement narratives in describing complex experiences and emotions (Fraser & al Sayah, 2011). Commonly utilised visual methods include photographs, collages and participant-generated drawings. Participant drawings, in particular, have been used to investigate the experiences of being HIV+ (Salmon, 1993), living with coronary heart disease (Guillemin, 2004a), lupus erythematosus (SLE) (Nowicka-Sauer, 2007), breast cancer (Ho et al., 2010), chronic vaginal thrush (Morgan et al., 2009), spinal cord injury (SCI) (Cross et al., 2006), Alzheimer's disease (Lev-Wiesel, 1998), post-natal depression (PND) (Guillemin & Westall, 2008), addiction (Shinebourne & Smith, 2011) and chronic pain (Henare et al., 2003; Kirkham et al., 2015).

Most of the studies listed above asked participants to create a drawing which was analysed alongside verbal data of some kind. The analysis was inductive and results were presented using a selection of drawings and participant quotes, to communicate the essence of the experience to the reader both verbally and visually (Guillemin, 2004b). A good example is the Nowicka-Sauer (2007) study reporting one key metaphor for SLE: an aggressive multifaceted hydra. The images are accompanied by relatively few participant quotes, so the task of communicating how patients experience the aggressiveness and the expansiveness of the disease is left to the hydra-like drawings, with surprisingly effective results.

In their systematic review of how drawings have been used in health literature, Broadbent et al. (2019) found that drawings were likely to relate to illness pathophysiology or symptoms and the emotions associated with illness. They also observed references to the social environment of participants, and to the activities inhibited by illness, and the use of metaphors to illustrate complex aspects of illness experience.

Drawings have been used several times to investigate CP, possibly for the elusive and difficult-to-communicate nature of the condition. Phillips et al. (2015) asked 54 people completing pain questionnaires at home to draw their pain on half an A4 page. Half of the resulting drawings concerned the nature of pain, with images of sensations (e.g. flames), at specific pain locations or on a time line (e.g. fluctuating pain). Pain was drawn as an external entity by 41% of participants, while 28% drew themselves in relation to pain. Almost a third of the drawings represented pain as an attacker, either by drawing a threatening object or a person under attack, and a smaller proportion represented beliefs about the impact of pain, with pain being drawn as a barrier, or as trapping the sufferer. Only 15% of the drawings in the Phillips et al. (2015) study

employed colour (mostly to indicate intensity and heat). In fact, drawings in this paper appear relatively simple, especially compared to the drawings from an IPA study by Kirkham et al. (2015), where pain was represented as a sinister violent object using more vivid imagery. This difference suggests that when drawing pain, context and methods are important: the communicative quality of pain drawings reflects the materials available and the drawer's engagement with the drawing process, which, in turn, might be influenced by the importance the drawing is assumed to have for those requesting it (i.e. being asked to draw at home while compiling a wider questionnaire might elicit less engagement than being given a range of drawing materials and time only to draw).

It must be noted that not all the studies that use drawings are aiming to investigate illness experience, some use drawings as a form of illness evaluation alongside or instead of verbal-based assessment methods in medical consultations. For instance, Broadbent et al. (2006) analysed size changes in the drawings of participants' hearts in the recovery period following a myocardial infarction to see whether the drawings could predict slow recovery and found that indeed they did. The authors concluded that the larger drawings could be markers of anxiety and intensified focus on the heart that might be unhelpful in promoting recovery.

Most studies using drawings have collected their data only once for each participant, looking at experience from a single perspective at a specific time point. A few studies have used drawings for longitudinal analysis, although research of this type is not common. Investigating PND, Guillemin and Westall (2008) asked women to draw their previous experience of the condition and how they were feeling at the time of the interview (when their PND had been cured), and then compared the two drawings. Whether this can be considered a true longitudinal design is questionable, since both drawings were made at one time, and the comparison was not between two evolving experiences or memories, but between a current experience and a memory.

In contrast, Shinebourne and Smith (2011) compared drawings of addiction created at different moments in time. This enabled them, during a later interview to elicit in their participant a reflection on her earlier drawings, offering thus an opportunity to look back onto the past represented in the drawings through an "objective" lens.

Similarly, Ho et al. (2010) used drawings to evaluate the effect of a psychosocial intervention. Participants were 67 breast cancer patients who were invited to create a drawing of their cancer before the start of the intervention and when attending the fifth and last weekly session of it. Both drawings were discussed within the programme in a group session. The analysis was based on a transcript of the group discussion, on the images, on the description of the drawings by participants and on the interpretation of the images by an art therapist. The thematic analysis showed that drawings changed from direct depictions of cancer to more symbolic

representations of hope, peace, and acceptance, suggesting that the application of visual methods to longitudinal research questions can yield very interesting and meaningful results.

In most studies participants have been asked to draw their illness, only in a few cases have participants been directly asked to draw themselves. In a study on dementia, Lev-Wiesel and Hirshenzon-Segev (2003), found that self-portraits revealed much about the relationship of participants with their social world. Similarly, in a study on acquired spinal-cord injury, Cross et al. (2006) observed that how participants represented themselves, in terms of body parts and assistive devices, spoke to their perceived identities. Although limited, these studies indicate that there is value in using drawings of Self to help participants discuss the sometimes abstruse concept of identity.

Conclusions and research question

Literature depicts CP as having a profound and far-reaching impact on the lives of those affected: people are dramatically and intimately changed by their illness and have great difficulties in coming to terms with their CP reality. There is widespread recognition, at least in England, of the need to support CP sufferers, and a range of models and approaches have been developed for this purpose. However, evidence on the efficacy of interventions is patchy, with a proliferation of study designs and outcome measures that make it difficult to draw firm conclusions. Also, the impact of CP on identity that emerges from qualitative literature is not reflected in how interventions are conceived, delivered and evaluated. Although there have been some isolated attempts at measuring identity-related outcomes for interventions, for instance through the SEQ questionnaire described by Yu et al. (2016) and the idiographic outcome measures described by Jones and Hurrell (2019), a systematic recognition of the role of identity when supporting CP sufferers still feels distant. If identity plays such a big part in the CP experience, what happens to people when they receive multidisciplinary treatment for their pain? This is the fundamental question of my study:

How does being referred to a multidisciplinary pain service and attending a PMP affect one's relationship with the pain and one's sense of identity?

CP is a special health condition because it is invisible, impossible to assess objectively and profoundly idiosyncratic in its effects. Even the medical definition of CP emphasises its subjectivity and emotional impact (Raja et al., 2020) and the efforts to provide quantitative models suitable for all sufferers have fallen short. McCracken (2020, p. 1002), an influential CP clinician and academic, recently stated that “*treatments for chronic pain need to address high complexity*” and that treatments must be “*delivered in a way that is sensitive to individual*

need.” In such a scenario, qualitative methodologies, particularly phenomenological and idiographic ones such as IPA, seem indispensable and uniquely positioned to explore the idiosyncratic aspects of the CP experience.

To my knowledge, only a few studies have already employed a prospective LIPA design to investigate changes following a CP intervention, two of which I mentioned in my literary review. Snelgrove et al. (2013) interviewed, three times over two years, ten participants referred to a pain clinic where they received pharmacological support. They reported cross-sectional results from the first interviews (Snelgrove & Lioffi, 2009), followed by longitudinal results from the second and third interviews (Snelgrove et al., 2013). In the latter paper there is a clear focus on change and continuity, with the majority of participants locked in an ongoing cycle of pain and social isolation and only a few experiencing change. Here participants received only pharmacological support, so this study’s results could provide a useful benchmark for my own results investigating change following a multidisciplinary intervention. Despite being supported by good and clearly labelled participant quotes, the Snelgrove et al. (2013) findings are weakened by a limited and unsystematic comparison between single participants’ quotes from different timepoints, which justifies my interest in obtaining visual data that will enable, amongst other things, a strong idiographic longitudinal comparison.

King et al. (2016) compared how participants spoke about their pain before and after a CP educational intervention and found that participants whose pain reconceptualization had changed substantially also received more clinical benefit from the intervention. This study is closer to mine for the nature of the intervention and confirms the value of investigating meaning-making around pain and it also provides a positive illustration of how a methodical comparison between pre and post quotes is fundamental to obtain plausible and resonant LIPA results.

Although these studies had different research questions to mine, together they suggest that a rigorous LIPA study, designed around participation in a PMP, can offer insight into changes in experience.

Also foundational for my work is the study by Kirkham et al. (2015), who used pain drawings with IPA to investigate the experience of pain. The vividness and depth of their results inspired me to use pain drawings and to extend the drawing task to include drawings of Self. In Chapter 4 I shall say more about this and other studies, and their influence on my methodological choices.

Chapter 3 - Context for my study

Pain management in England

Pain services have developed in the UK since the 1960s, in recognition that some people in pain would benefit from dedicated care. The most complete and up-to-date directory of pain management services in the UK and Ireland is the Public National Directory of PMPs (2020) compiled by the British Pain Society (<https://www.britishpainsociety.org/british-pain-society-publications/pain-management-programmes-directory/>), listing 55 national and regional service providers. Depending on the provider, PMPs involve different clinicians (e.g. physician, physiotherapist, psychologist, nurse, pharmacist and/or occupational therapist).

In April 2021 NICE (www.nice.org.uk) published a new set of guidelines for treating adults and young people with CP in England. The guidelines recommend clinical pathways for the management of generic primary CP (including fibromyalgia) or specific CP types (e.g. LBP, neuropathic pain, osteoarthritis and so on). Each pathway combines different components, including psychological and physical therapies. Previous NICE guidelines had recommended PMPs as the multidisciplinary format where different therapy types could be combined. However, due to the lack of consistent evidence on the effectiveness and ideal composition of PMPs, current guidelines only recommend specific components, such as ACT or supervised exercise (NICE, 2021). Other recommendations and standards for generic or specific CP conditions have been issued by other organisations such as the Royal College of Anaesthetists (RCoA), the International Association for the Study of Pain (IASP) and the British Pain Society (BPS).

The BPS's *Guidelines for Pain Management Programmes for adults* were designed to “provide guidance on what should constitute a PMP, its position within care pathways for people with chronic (non-cancer) pain and desirable content” and comprise a list of evidence-based recommendations on how to design and run a PMP (2013, p. 5), including treatment aims, methods, delivery and outcome measures. Since the ability to remain in work is key for the physical and mental wellbeing of CP sufferers, the guidelines also discuss how PMPs can assist retention and return to work.

In Kent, pain services consist of a primary care multidisciplinary service (Community Chronic Pain Service - CCPS) and a secondary care interventional service (East Kent Hospitals University NHS Foundation Trust). Through a multi-disciplinary team of expert clinicians operating across various locations in Kent, the CCPS aims to support sufferers manage and live well with CP, minimising its impact and overcoming its challenges. My study participants were

recruited from the Kent CCPS between 2015 and 2016 and, in the next sections, I will detail the support the CCPS was offering its clients while I gathered data for my project.

Community Chronic Pain Service: organisation, services and patient pathway

In 2015, the CCPS team included a GP specialising in CP, 3 nurses (consultants and clinical nurse specialists), 2 psychologists, 1 assistant psychologist, and 2 physiotherapists.

In Kent, GPs refer CP sufferers to a single point of access where, based on patient history, a ‘triager’ decides which service would be most suitable. Approximately 60% of referrals are directed to the hospital, while the rest are treated by the CCPS. Severe unstable psychiatric illness (i.e. certain personality disorders and untreated depression) and current substance abuse are exclusion criteria. Once a client is in the care of the CCPS, they attend an initial face-to-face assessment with a case nurse, who will remain their point of contact within the service.

During the assessment, nurse and client identify the specific CP issues, concerns, and problems of that person and how these impact on their life: clients are encouraged to identify what is important to them, what they need or would like to change and a plan for the future is agreed. The following could form part of the plan, which is the person’s individual pathway towards self-management:

- Medication review – performed with the nurse, aimed at achieving the most suitable mix of medicines considering the person’s wellbeing objectives (includes discussing opioid use).
- Alexander Technique (AT) – weekly individual lessons to teach participants how to sit, stand and move in daily life and to recognise when they are using too much tension; the number of lessons is agreed with the teacher.
- Tai-chi – 20 weekly group lessons over six months. This is a CP-specific adaptation of traditional Tai-chi, using gentle flow movements to help balance and strengthen the body.
- Acupuncture – 12 individual sessions (maximum) to reduce pain, unsuitable for fibromyalgia.
- Psychology – individual sessions with a psychologist to work through the emotional difficulties associated with CP, usually focussed on a specific problem. The number and timing of sessions is based on individual needs and progress.
- Physiotherapy – individual sessions to help understand and manage pain.
- Participation in a Pain Education Session (see below)
- Participation in a PMP (see below).

Pain Education Session

At the time I was recruiting almost all people referred to the CCPS were invited to participate in a Pain Education Session (PES), a one-off group session aimed at introducing CP management and the service. The session lasted 3 hours, comprised 5 presentations by a psychologist, a nurse and a physiotherapist, with coffee breaks during which participants could socialise. The topics included introducing CP self-management and the CCPS team, reviewing the difference between acute and chronic pain, ‘myths’ about CP and medication and an overview of the psychological aspects of living with CP.

Each PES was normally attended by 30 people, who could also bring a partner or carer. The tone of the session was friendly and informal: participants were encouraged to stand and move whenever they needed to, and, although interaction was welcome, people could also just sit and listen. A 15-page brochure summarising the key concepts of the session was available to take home.

At the end of the PES session, participants were asked to complete an evaluation form. Participation in the session appeared in clinical records. In later years, for logistical reasons these events have been replaced by smaller group sessions run in a surgery by a nurse.

PMP

If PES participation was a positive experience, meaning that the person felt comfortable in a group environment, was able to engage with the materials and expressed a desire to make changes, at their nurse’s discretion, they could be invited to a PMP.

At the time of my study, PMPs ran over 5 half-day sessions, with one session a week for a month and a follow-up session after 3 months, for a total of 19 hours. Each session lasted over 4 hours including breaks. The service ran more than 15 programmes a year across 5 locations. To avoid a clinical environment, meeting rooms were hired in local hotels or community centres and free refreshments were available. In recent years, the PMP structure has been reorganised and extended to last 6 sessions.

Approximately 15 participants take part in each PMP. Although late arrivals and early departures are tolerated, an effort is made to develop a sense of group belonging, so that participants feel both welcome and accountable. To this purpose, ground rules are shared, including the freedom to stand and move during sessions, the invitation to turn phones off, and the reminder that ‘what is said here stays here’. Once the programme has commenced, new participants cannot join a group, those unable to attend a session are expected to inform the service and participants who skip a week will not be able to catch up by joining another group.

The following topics are covered during sessions, with speakers alternating:

- Week 1: acute and chronic pain, the psychology of pain (living with pain and introduction to CBT and pain), anatomy and introduction to relaxation
- Week 2: pacing, CP & relationships, medication, relaxation
- Week 3: posture, acceptance, CP & stress, relaxation
- Week 4: goal setting, sleep, flare-ups, what next?
- Week 5: follow-up on action plan and key learning points from the PMP

Some of the topics discussed during the PES (e.g. acute and chronic pain, psychology) find more space here, to allow more in-depth and interactive discussions. In recent years, the longer PMP format has included new topics, such as nutrition and neuroplasticity.

Each session is supported by slides and a handbook summarising the key concepts. Each weekly session terminates with a relaxation exercise, using mindfulness body-scan and visualisations, so that these techniques can be added to the armamentarium. From Week 2, sessions start with a feedback moment to comment on the previous week and discuss changes in behaviour or perspective triggered by programme participation.

The CCPS PMP combines CBT and ACT components: early on, the CBT concept of a vicious circle connecting physical sensations, thoughts, behaviours and emotions is introduced, but there is limited guided practice, except for relaxation and mindfulness.

Participants in the PMP are encouraged to interact during breaks and in class, by asking questions and sharing their views and experiences. Often participants who feel less comfortable sharing their experience in public will use the breaks to communicate privately with staff. At the end of each session, the staff discuss each participant's progress and recommended actions, updating their clinical notes. For instance, if in class a participant has expressed psychological distress, a note is made for the case nurse to discuss the provision of individual psychology sessions.

The effects of pain on relationships are discussed during Week 2, and participants are encouraged to invite their partners or carers, so they can understand and discuss the impact that CP has on their relationship and, ultimately, their shared life. During the last session on Week 4, each participant is invited to give feedback on the programme and to set themselves a pain self-management goal, which will also be mentioned in the letter to participants and their GPs summarising programme attendance. Only people who have participated in at least 75% of the programme (3/4 weeks) are invited to the Week 5 follow-up session.

Outcome assessment

When people are first referred to the CCPS, they complete a Pain Self Efficacy Questionnaire (PSEQ) to assess their level of confidence in carrying out basic activities despite their pain. The

same questionnaire is completed at each follow-up appointment and scores form part of the clinical notes.

At the start of the PMP a set of questionnaires is completed, including the PSEQ, the Patient Health Questionnaire (PHQ-9) for depression and the Generalised Anxiety Questionnaire (GAD-7). The same set is completed at the end of Week 4 and at follow-up.

A report by the service on PMPs run between May 2015 and March 2016 (2016), included the following statistics derived from the questionnaires (note that average scores are reported with no indication of standard deviations or statistical significance).

Sixteen PMPs were run in the May 2015-March 2016 period, attended by 213 of the 361 booked participants (59%). Of these, 97% completed the first four weeks of the programme, while only 59% attended the Week 5 follow-up session. Among participants, 68% were female, the average aged was 51 years, 97% were of White British ethnicity and 66% were unemployed.

The average anxiety levels of participants measured using GAD-7 decreased from a high moderate score (13.85) to a low moderate score (11.48) between pre-PMP and Week 4, which was maintained (11.87) at Week 5. The average depression levels of participants measured using PHQ-9 decreased from 11.37 (moderate) to 9.92 (mild) between pre-PMP and Week 4, and then further decreased slightly to 9.7 at Week 5, remaining within the mild range. The level of self-efficacy, as measured using the PSEQ, increased from 19.69 pre-PMP to 21.88 at Week 4 and 27.49 at Week 5, showing a continuing improvement in patients' confidence in dealing with their condition after attending the PMP.

In terms of satisfaction with the programme, over the first 4 weeks, 94% of participants found the whole programme helpful or very helpful, with 86% planning to make changes as a result of it. The programme topics that participants most appreciated were pacing (27%), sleep (18%), medication (14%) and acceptance (13%). The aspect of the programme considered most helpful was sharing with others (43%). At the follow-up session in Week 5, 50% of participants intended to make further changes to their lives.

According to CCPS staff, people who do well on the programme are those who have attended a PES, can commit to all weeks, commit to work with/towards change, are open-minded, are prepared to give things a go, have expectations of what a PMP is and what they could gain from it and are at the right stage of readiness.

Chapter 4 - Methodology

In this chapter I will present the rationale for my methodological choices, by discussing why IPA, among phenomenological experiential qualitative approaches, is the most suited to meet the aims of my study. I will also review how IPA can be used in a longitudinal design and how visual methods have, in recent years, helped IPA researchers access increasingly deep and resonant descriptions of experience.

Which qualitative methodology?

Qualitative research in psychology can be traced back to the late Nineteenth Century, with Fechner's (1801-1887) studies on sensation, Wilhelm Wundt's (1832-1920) self-observation and William James' (1842-1910) stream of consciousness writing. Subsequently, while in the US the behaviourist and cognitivist movements were intent on denying the value of experience and introspection to investigate the human mind, in Europe, Husserl (1859-1938) was founding phenomenology, a philosophical movement specifically interested in human experience, that has strongly influenced the development of qualitative research (Ashworth, 2015).

Today there are many qualitative methodologies, methods and variations of both for researchers to choose from, where a methodology is defined as being more directly informed by the researcher's epistemological positioning compared to a method (Willig, 2013). A useful classification is to differentiate between **experiential and discursive methodologies** (Reicher, 2000). The focus of experiential methodologies is subjective experience, normally accessed through the narratives of those who have had the experience. Research questions tend to concern what has happened and the associated thoughts and feelings. Depending on which epistemological position they take, experiential researchers will assign different value to participants' narratives (e.g. a realist researcher might assume what participants describe to be a true reflection of reality, while a phenomenological researcher will acknowledge that any experience is a reflection of the participant's subjectivity and lifeworld). Discursive methodologies, on the other hand, assume a strongly social constructionist view, seeing reality and our understanding of it as resulting from social processes and reflected in our use of language (Burr, 2006). Instead of focusing on what participants describe as experiential researchers would, discursive researchers look at how language is used for those descriptions, as means of revealing our common understandings of reality. A discursive researcher might gather data from individual participants (or use other sources such as the media) to extrapolate what the discourses that they, as humans, perform can tell us about our collective beliefs.

For my literature review, I purposively focused only on studies that had explored the experience of CP sufferers. Accordingly, my search terms included experiential approaches such as ‘grounded theory,’ ‘interpretative phenomenological analysis’ and so on. I excluded **discursive** studies because I wanted a subjective perspective on the experience of CP. Had I considered discursive methodologies, I would have come across studies illustrating the types of discourses CP sufferers rely on when they talk about their experience. An example would be the study by Robinson et al. (2013, p. 95) who identified a moral discourse in how participants described themselves “*as moral beings who are conducting themselves in a correct manner.*” The data for this study was similar to that of an experiential study, but the use researchers made of it, the aim of their analysis was not to understand what having CP is like, but rather how it affects how people talk about themselves, what discourses they rely on and what this tells us about society. These are interesting findings, no doubt, but too far removed from the thick description of the existential impact of CP on personal identity that I aim to achieve with my study.

With my research question I aim to explore in-depth the lived experience of CP, and particularly how, over time, the relationship of sufferers with their pain evolves and how it affects their sense of identity. Different authors use different terms to classify possible researcher epistemological positions, meaning their assumptions about what can be known through research (Crotty, 1998; Lincoln et al., 2018; Willig, 2019). Using the classification proposed by Willig (2019, p. 798), I would define myself as phenomenological, in that I believe I can and should access the “*experiential world of individuals rather than a shared, external ‘real’ world*”, which points to a phenomenological qualitative methodology as the most suitable to answer my question.

Phenomenological approaches

Phenomenology is an area of philosophical enquiry aiming to understand human experience from a subjective standpoint. Its focus are our motivations and actions, particularly regarding the relationships and events that are important to us. A phenomenological tenet is that experience should be investigated free from predetermined theories, on its own terms (Ashworth, 2015).

Philosophical roots of phenomenological research

Husserl (1859-1938) is the philosopher considered the founder of phenomenology. He offered a new conceptualization of experience through ‘intentionality’, the principle that our consciousness (or awareness) cannot be separated from the world around us and that when we are conscious, we are always conscious of something, be this something outside ourselves, our

own body or an idea (Langdrige, 2007). He suggested that we can understand experience by moving out of our 'natural attitude', where we act with no awareness, into a 'phenomenological attitude', in which our gaze turns inwards from the objects of the world to our conscious and reflexive experience of them. Husserl tried to systematically explore his own experiences in this manner, aiming to identify and describe the essential features of specific phenomena, which he called 'essences', that are independent of circumstances and can thus be considered common to humans. Husserl was critical of the positivistic turn in psychological research, believing that a scientific account of the world should start from our everyday experience of it. He suggested that researchers, when investigating a phenomenon, should attempt to "bracket" their prior understandings of it, as a way of increasing their access to essences; however, contemporary phenomenological researchers question whether this is possible. Although Husserl's ultimate aim was to study consciousness as a phenomenon unto itself, it is his earlier work on being conscious and reflexive about lived experience that has most influenced phenomenological researchers (Smith et al., 2009).

Heidegger (1889-1976), who studied with Husserl, developed phenomenology further by shifting the focus to the more existential aspects of experience. He introduced the concept of '*dasein*' (literally there-being), suggesting that we are unable to separate the world from our experience of it, because we are inevitably inter-related to all things worldly. Additionally, knowing that we are finite and that death is a boundary beyond which we can only imagine, adds a temporal dimension to all our experiences of the world (Moran, 2002). Heidegger also questioned the possibility of capturing the 'things themselves' as Husserl aimed to do, suggesting that phenomena are not necessarily immediately visible, some 'things' may be latent and require to be brought to the surface. To grasp the complete meaning of a phenomenon, a researcher must take an active role, move beyond perceptual descriptions and bring the phenomenon to light through reasoning. Heidegger thus brings hermeneutics to phenomenology: to be phenomenological means to be interpretative, both of one's own experience and of the experience of others. However, interpretation is subjective, influenced by existing understandings and beliefs. Husserl's idea of bracketing preconceptions does not consider how beliefs and assumptions can be integral to thinking and hidden from consciousness. Heidegger recognises that the analytical process is influenced by preconceptions about an experience, but it can also reveal them, which is why researchers should accept their interpretative role, while also striving to be aware and reflexive about it (Smith et al., 2009).

Gadamer (1900-2002) added to hermeneutic phenomenology the view of language as central to the interpretative process. He suggested that not only can preconceptions influence the analytical process and be revealed by it, they can be influenced by the process, so that as new understandings emerge from the analysis, they contribute to shape the interpretation. The

analytical process is thus a dynamic interplay between preconceptions, interpretations and new understandings, that happens through language (Moran, 2002).

Ricoeur (1913-2005) added another tile to the phenomenological puzzle by suggesting two alternative approaches to interpreting a text: empathy and suspicion (also known as demythologizing and demystifying). An empathic interpretation implies a fusion of horizons between participant and researcher, with the researcher taking the participant's words at face value and aiming for the type of dynamic interplay described by Gadamer. In contrast, a suspicious approach seeks to go beyond the surface, taking a critical stance in the interpretation, questioning the participant's motives and hidden understandings of which even the participant may be unaware (Langdridge, 2007).

Finally, **Merleau-Ponty (1908-1961)**, another influential phenomenologist, emphasised the embodied nature of our relationship with the world. Our body, which can never be considered separate from our Self, is the means through which we communicate with the world. We live our experiences through our body, yet we are never fully able to access the embodied experience of another, a limitation that researchers should take into account (Moran, 2002).

Thus phenomenological philosophers inspire researchers to think in terms of humans being immersed in a world of objects, relationships and language in which experience is temporal, relational, embodied and perspectival (Smith et al., 2009). As there are different voices within phenomenological philosophy, so different approaches to phenomenological research have developed, each with its own take on how best to investigate the phenomenology of human experience. In the next sections, I discuss some of the approaches I encountered in my literary review, before discussing IPA and why I consider it the most suitable choice for my study.

Phenomenological research

The first phenomenological research methodology to be formalized was **descriptive phenomenology** proposed by Giorgi (2012) in the Seventies. This is the most Husserlian approach, because it aims for a close description of phenomena 'as they appear,' in contrast with the interpretative approaches that developed later. Although the methods of descriptive phenomenology are non-prescriptive, there are some defining features: studies rely on first person accounts of a specific experience, analyses aim to identify the structures common to each experience and results are presented in terms of universal essences of the experiences, alongside the idiosyncratic meanings associated with them. Also, sampling aims for maximum variation (so that essential structures can emerge); data is gathered via written concrete descriptions, talking aloud or semi-structured and unstructured interviews; and researchers are expected to bracket their preconceptions about the research topic during the analysis (Langdridge, 2007).

A variation on this method has been proposed by Ashworth (2016), who, acknowledging Heidegger's suggestion that experience necessarily occurs in relation to the world, opts for a less inductive analysis revolving around specific aspects of the **lifeworld** of participants (i.e. self-hood, sociality, embodiment, temporality, spatiality, project, discourse and mood).

Heidegger's thinking influenced **hermeneutic phenomenology**, with authors such as Van Manen (1997), Todres (2007) and Smith (2004) moving beyond a strictly descriptive approach. Hermeneutic phenomenological approaches share an explicit use of interpretation to access the deepest and most hidden meanings of experience. There is an acknowledgement of the context within which participant and researcher engage with phenomena, and a recognition of the researcher's need to be reflexive about their interpretations, and of how their predilections and prejudices may impact on the research processes and outcomes. In hermeneutic phenomenology there is also a commitment to humanities, with an opening towards alternative methods through which experience can manifest itself, with the use of art, poetry and metaphors to convey it (Finlay, 2011). Despite these communalities, there are also notable differences between the various hermeneutic approaches, in terms of how widely they have been adopted, how structured the approaches are, and, more importantly, which other influences they incorporate. A case in point is IPA, in which, as the name suggests, the analytical approach is profoundly interpretative, but also idiographical, a characteristic that sets it apart from other phenomenological methodologies.

Interpretative phenomenological analysis

IPA was first described by Smith (1996) as a way of investigating experience from an insider's perspective, in which participants' subjective accounts are interpreted through the researcher's cognitive framework. Three features characterize IPA: it is a phenomenological methodology, inspired by hermeneutics and committed to an idiographical approach, considering each individual account as a case unto itself before comparing it to others.

IPA is phenomenological in the husserlian sense, because IPA researchers are primarily concerned with the examination of specific lived and embodied experiences, through the first-person subjective accounts of people who have had those experiences. IPA studies often investigate experiences that have been or are still important to participants, such as key life events or illness. Data is gathered primarily through semi-structured interviews. To obtain close, deep and insightful descriptions, rather than abstract conceptualizations, questions tend to focus on specific experiential instances and the physical and emotional responses they elicited. In IPA, participants are seen as embodied sense-making beings, who live in dynamic and

interactive worlds, which are both personal and complex, as suggested by Heidegger's phenomenology (Smith et al., 2009).

Hermeneutics are fundamental to IPA in different ways. Firstly, the analysis in IPA is purposefully detailed and in-depth, with the particular informing the general and, at the same time, being illuminated by it, in an iterative hermeneutic cycle. Also linked to hermeneutics is IPA's focus on sense making. IPA researchers aim to help participants describe their experience as deeply as possible and to understand how they make sense of their world. Participants are considered, in the Heideggerian sense, 'persons-in-context,' and the IPA research process aims to understand the experience of each particular person in their particular context (Larkin et al., 2006). This aim also affects sampling decisions: IPA studies usually involve small homogenous groups of participants, because rather than capturing the generalisable essence of an experience, the aim is to understand how a given experience manifests for a certain group of people in a specific context (Smith et al., 2009). Finally, IPA is hermeneutic because it is interpretative. Given that the experience of another is not directly accessible, the researcher will enter the participant's world and engage in a 'double hermeneutic circle,' making sense of the participant's sense making (Smith & Osborn, 2007a, p. 51). This interpretative process is one of active engagement: as researchers approach and make sense of the world of participants, they reflexively acknowledge their own viewpoints, question their responses, strive to be open in discovering the other's lifeworld, recognising that the encounter may also tell them something about themselves and may change their understandings (Shaw, 2010). Reflexivity is critical at all stages of the research process, particularly when gathering data and during the analysis, therefore researchers are constantly questioning their interpretations and making efforts to ground them in the data (Finlay, 2011). The analytical process in IPA is not linear: it is an iterative endeavour through which the analysis progresses to increasingly deeper levels of understanding of the text and, ultimately, of the phenomenon being investigated (Smith et al., 2009).

Idiography is a focus on the particular, in contrast to the general laws that a positivistic empiricism would aim to establish. The value of an idiographic approach to psychology is the possibility it affords of understanding how meaning making occurs (Smith et al., 1995). The analysis of a single case can reveal aspects that would not emerge in a group study and the comparison of multiple single cases can highlight similarities and differences within a group (Platt, 1992). In IPA, each individual's experience is analysed inductively and within the context of that individual's narrative, before being compared to the experience of others or being considered in relation to theoretical models. Even when general statements are made about the data, there is an attention to always link them to specific instances, by grounding them in the idiographic data (Smith et al., 2009).

Why use IPA to explore the experience of CP?

Various characteristics of IPA, attributable to its phenomenological, hermeneutic and idiographic philosophical underpinnings, make it particularly suitable to explore the psychology of health (Brocki & Wearden, 2006; Smith, 1996) and especially to investigate CP (Smith & Osborn, 2015).

Firstly, IPA is particularly suited to study experiences that are of profound importance to the people who are having them (Smith et al., 2009). As evident from my literature review, the impacts of CP on the life of most sufferers are profound and far-reaching, often overwhelming. From a phenomenological standpoint, the depth afforded by IPA allows subjective experience to be explored in its embodied, cognitive, emotional, and social dimensions, which is in perfect alignment with the biopsychosocial model of illness recognised as applicable to CP. Through IPA these dimensions are considered in relation to and integrated with all other aspects of the participant's lifeworld, resulting in a holistic and in-depth account of subjective experience, which with CP can mean going above and beyond a biopsychosocial model, for instance, to consider issues of temporality and identity.

The interpretative nature of enquiry with IPA encourages researchers to look below the surface and explore the deepest aspects and meanings of their participants' experiences (Smith, 2019). With CP this means understanding not only what having CP is like physically or emotionally but also understanding its existential implications. IPA's hermeneutic stance also directs researchers towards understanding how participants make sense of their experience and its underlying processes. Most sufferers with complex health conditions are constantly engaged in a sense-making effort (Radley, 1994). This is particularly true of CP, on account of its invisible and highly subjective nature, where symptoms are unexplainable, unpredictable, ever changing and puzzling, where comorbidity is frequent and emotional responses are paramount. IPA's in-depth approach to enquiry allows such sense making efforts to be elicited and explored, sometimes even in the form of hot cognition (Eatough & Smith, 2017). During the inductive and iterative analysis phase, the researcher engages in a double hermeneutic cycle where they make sense of the participant's sensemaking, revealing ambiguities, tensions, and bringing new interpretative layers to the surface. Such an in-depth analytical process is necessary for the complex psychological mechanisms underlying CP to be revealed and fully understood.

The idiosyncratic nature of CP means that, to be fully assessed, its impacts must be considered in the context of each individual sufferer's lifeworld and their unique response to their condition. In the close case-by-case analysis advocated by IPA's idiographic approach, the individual CP experience is contextualised and understood in-depth, on its own terms, before any comparisons are drawn across cases to identify patterns of similarity and difference.

A good example of what IPA can achieve is offered by the first ever IPA CP study published by Osborn and Smith (1998), which, along with the other studies by this research team, inspired my own research question. The study captured most of the themes that define the CP experience: the bewilderment at having an unexplainable condition, the distress caused by social comparison, the mourning of the life that once was and the fear for the future, the stigma associated with CP and the social withdrawal that occurs when sufferers do not want to elicit pity and are physically unable to participate socially. As seen in Chapter 2, these are common themes in qualitative research on CP, however, compared to other methodologies, the Osborn and Smith (1998) study achieved a different level of depth, by shifting the focus from a descriptive report of what the CP experience is, to an interpretative report of what the experience means to the person having it. The focus on meaning making in IPA can be both at experiential and at existential level (Smith, 2019). For instance, in the Osborn and Smith (1998) study, Linda described the impact of pain on her life in these terms:

I'm only 50 and I should be doing this that and the other cos they say life begins at 40 but I can't and I s'pose it does bother me, it's frustrating that people of my own age are you can see them flying their kite and you feel as if you can't. (Osborn & Smith, 1998, p. 70)

At a descriptive level, Linda was frustrated with the pain stopping her from doing what she would have liked to do. At a deeper level, her frustration can be interpreted as deriving from comparing herself to the people around her and to a normative idea of what she should be doing (her 'ought self'). Her frustration, however, was more profound: it had an existential impact, it affected her view of her life as no longer expanding ("*flying their kite*") as she assumed other people's life was. This layering of interpretations, looking for the meaning of experience at a deeper, experiential and existential level, is the hallmark of good IPA, allowing IPA studies to reach a depth of understanding of phenomena which is rarely found with other methodologies (Smith, 2019). The Osborn and Smith (1998) study also points towards self-identity as being central to the CP experience, an aspect that the authors' subsequent studies further explored, first by considering the impacts of the sense of alienation from their body of sufferers (Osborn & Smith, 2006) and then by revealing how the identity of sufferers is transformed by CP (Smith & Osborn, 2007b).

What is the connection between the fractured body in pain, perceived as being "me but not me", the identity of pain and of the person in pain? Reading the studies by Osborn and Smith, I found myself asking this and other questions: what happens to the pain, to the person in pain and to their sense of who they are when they learn to self-manage their CP? Do they become whole again? Do they go back to being who they were? Do they become somebody else? How does how they feel about their pain and about themselves evolve? I am hoping that my study will help answer some of these questions and believe that IPA, with its depth of analysis and idiographic approach, is the method that will enable me to do so. As I shall describe in the next

sections, I plan to use IPA in a longitudinal design and integrate interviews with visual methods to enhance my ability with IPA to reveal how the idiosyncratic aspects of each sufferer's experience of themselves and their CP relate to each other and evolve over time.

Extensions to IPA: visual methods and longitudinal designs

Visual methods and longitudinal designs are areas of growing interest among IPA researchers: visual methods as the means of accessing a wider range of aspects of a phenomenon, including pre-reflexive, embodied, atmospheric and affective aspects (Boden et al., 2018), and longitudinal designs because they allow temporal aspects of phenomena to be explored (Farr & Nizza, 2019). By using both in my study, I aim for an in-depth exploration of how the relationship with CP and the sense of Self of participants developed over time.

Visual methods

Experiential qualitative methods have traditionally privileged narrative accounts, however our experience of the world is not predominantly narrative, it is multisensorial. The value of using a multi-modal approach to research, particularly to investigate the affectual and embodied aspects of experience, is being increasingly recognised (Reavey, 2020a). The use of visual methods in research originates in sociology and cultural studies, where visual objects were initially explored in terms of cultural significance, power relations and sociocultural practices (Guillemin, 2004b). Initially, it was popular in studies involving children and other participants with a limited capacity for verbal communication (Guillemin, 2004b; Mitchell et al., 2011). Today the use of visual methods has extended to other disciplines including psychology and health research, involving adult participants and employing a broader range of analytical methods, beyond the initial relativistic and discursive approaches, to include phenomenological approaches.

The visual media currently used in research can be grouped into two classes: static media, such as photography, drawings and artwork in general, and dynamic media, such as videos and online social media (Fraser & al Sayah, 2011). Visual materials can be used in three (combinable) ways: as stimuli to facilitate data gathering (e.g. by using existing materials or materials created by or with participants to navigate discussions during interviews); as data to be analysed by the researcher; and to disseminate research findings (Silver, 2013).

Compared to narratives on their own, visual materials allow for more complex and layered accounts: an old photograph can elicit a past emotion or an embodied state and generate a different account compared to a purely narrative memory. The emotional resonance of images can unlock ambiguous, contradictory or difficult feelings. The complexity and multiplicity of

emotions associated to an image can be explored in an interview and incorporate more aspects of the experience than a simple narrative might do (Boden et al., 2018; Reavey, 2020a). For example, Hughes et al. (2019) used participant-generated photographs with IPA to investigate the quality of life of people with paraplegia and CP. The photographs stimulated reflections on how different perceptions of Self as symbolised in the images increased or reduced the quality of life of participants. In another IPA study by Bartoli (2019), participants were invited to bring an image or object representing their professional transition within social work. The objects triggered reflections, allowing the expression of elusive and difficult feelings. The act of choosing how to visually represent their experience can also be empowering for participants and redress some of the power imbalance inherent in research (Reavey, 2020a). A recent particularly innovative application of IPA to the visual is the interviewing images process proposed by Andrews (2020) for research in the field of art and design.

My orientation towards visual methods stems both from the nature of my research question and from the type of experiential accounts that visual methods can enable: CP is a complex, invisible and profoundly embodied experience, very difficult to describe. Its psychological impacts are equally complex and profound, affecting all spheres of sufferers' life, including their sense of identity. Visual methods have the potential to help participants express the CP experience and its impact on identity in a more nuanced manner, revealing more of its underlying issues and contradictions than an interview alone might do.

Of all visual methods, I chose participant drawings because the act of drawing enables participants to reflect on and articulate their experience, and then the drawing itself remains as product to elicit additional meaning making during the interview, for the researcher during the analysis and subsequently in the viewer as part of the research output. Drawings offer a different way of exploring experience compared to written or spoken words, they elicit a different kind of response (Gauntlett & Holzwarth, 2006) and may produce different and independent meanings (Boden & Eatough, 2013). They appear to create a unique and direct path to reveal the feelings and emotions of the drawers (Kearney & Hyle, 2004). In health studies, drawing makes participants think about their disease in a different way (Nowicka-Sauer, 2007). For instance, researching post-natal depression, Guillemin and Westall (2008) observed that while during interviews participants discussed their condition in biomedical terms, their drawings contained no biomedical imagery, suggesting that in drawings experiential knowledge is expressed through emotions rather than cognitions.

Drawing can allow pre-reflexive insights, as illustrated by this quote: "*I just went for it and it was only afterwards when I analysed it...*" (Shinebourne & Smith, 2011, p. 316). Especially when participants are unacquainted with drawing as a form of expression, aspects of themselves and their experience of which they were previously unaware can be revealed (Salmon, 1993).

This is one of the principles of art therapy: the belief that drawings allow unconscious feelings to emerge (Angheluta & Lee, 2011; Lev-Wiesel, 1998). Drawing also engages the drawer in a reflexive process: with enough time participants are able to think before they draw and, while drawing, reflect back and change their drawing engaging in deep thought on the matter being investigated (Gauntlett & Holzwarth, 2006).

Finally, drawings allow participants to express feelings and fears that cannot be expressed in words and, like metaphors, they can act as a 'safe bridge' towards the expression of painful feelings (Angheluta & Lee, 2011; Shinebourne & Smith, 2010), which is particularly useful in health research, where experiences can be difficult to describe in words (Fraser & al Sayah, 2011).

I chose to use drawings rather than another visual method hoping that the act of drawing would stimulate both pre-reflexive and reflexive insight. The drawings of pain were aimed at allowing participants to give a form to the invisible aspects of their pain, helping them to understand and explain the unexplainable, shedding light onto their physical and psychological suffering. The drawings of Self had the aim of eliciting the expression of alternative narratives about themselves, their identity and their personal worlds. That the drawings of pain could complement and increase the insight from the interviews was justified by the rich existing literature with CP drawings (Kirkham et al., 2015; Phillips et al., 2015). Evidence on the value of using drawings of Self when investigating health issues was more limited (Cross et al., 2006; Lev-Wiesel, 1998), but still strong enough to suggest that asking participants to draw themselves would help understand how they felt in relation to their pain and their life more widely, and would allow me to explore the impacts of pain on identity that lay at the heart of my research question. A subsequent paper by Boden et al. (2018) confirmed the power that drawings of Self can have in exploring the lifeworld of participants.

The availability of multiple drawings to guide the interview, meaning drawings of pain and Self and, during later interviews, drawings from earlier interviews, was an innovative aspect unique to my study, as no previous study that I was aware of had ever considered it. My thinking here was that as the pain drawings would shed light on participants' relationship with their pain and the Self drawings would shed light on their wider lifeworld, the two drawings combined could help illustrate the interaction between these aspects and help understand the impacts of pain on identity and its links to the lifeworld of participants. As I describe in the next chapter, my participants were invited to create their drawings just before the interview and the interview guide revolved around the drawings, which acted as a map for our conversations. The drawings as objects often enabled my participants to distance themselves from their pain and during the interview reflect deeply on its effects on their lives.

The study by Kirkham et al. (2015) that I mentioned earlier is the most impactful IPA study of CP using drawings combined with interview data. Here participants recruited from a CP service drew their pain and the drawings were used to guide an in-depth IPA interview. Although the vivid abstract pain representations were communicative in themselves, when analysed with the interview, they brought the distressing pain experience to life. Involving metaphors related to tools of torture, the pain was described as an external malevolent object attacking the body. Drawings in visual IPA studies are mostly metaphorical and, as such, offer an opportunity to express the inexpressible, communicate difficult emotions and stimulate deeper understandings (Shinebourne & Smith, 2010). In the Kirkham et al. (2015) study, drawing unleashed participants' creativity and once the pain was on paper, participants were able to give words to the unexplainable.

One participant in the Kirkham et al. (2015) study was interviewed shortly after attending a PMP and created a 'before and after' image, with her pain after the PMP being "*a softer, gentler pain, something that I can manage*" (Kirkham et al., 2015, p. 403). The authors suggest that the change in representation may have been aspirational and influenced by learnings from the PMP. This reinforced my belief that asking participants to create and discuss their pain and Self drawings, comparing current drawings with earlier ones and analysing all drawings longitudinally, would offer insight into the evolution of their relationship with pain and sense of Self.

To what extent a researcher's impressions of a participant's drawing should influence the analysis warrants a reflection. There is consensus in literature that allowing participants to interpret their own drawings is important (Cross et al., 2006; Kearney & Hyle, 2004; Mitchell et al., 2011), to avoid misinterpretations (Ho et al., 2010), to take the drawer's context into account (Mitchell et al., 2011) and to move away from a positivistic 'truth seeking' approach (Cross et al., 2006). Prioritizing participants' interpretations, as opposed to imposing pre-existing meanings on the images, is a choice shared by the IPA studies using drawings (Boden et al., 2018). In the Kirkham et al. (2015) study the analysis was grounded in participants' accounts of their drawings and the authors suggested that in IPA drawings create a "triple hermeneutic," in which the researcher is making sense of the participant, who is making sense of their drawing. I would add that researchers cannot but develop their own impressions of the art, thus creating multiple parallel hermeneutic circles (Nizza et al., 2018), in which the researcher's analysis of the participant's impression of their own drawing is inevitably influenced by the researcher's experience of the drawing itself. An analysis that accounts for the viewer's perception, if well-grounded in the art and conducted sensitively, can add to the understanding of the phenomenon being investigated. Andrews (2019) suggests that when it comes to interpreting images, objects or artifacts, the hermeneutic circle can have a 'decolonising' effect on our pre-understandings.

The analyst/viewer encounters the material and by interrogating it with an open phenomenological attitude, the artifact can speak to them visually and through their body revealing new meanings which can also make evident the viewer's pre-assumptions about what is being represented.

The corpus of IPA studies that have used visual methods, particularly drawings, to complement interviews is small but promising and some clear methodological guidelines emerge from it: drawings can afford additional depth to IPA interviews, open up new avenues for the description, understanding and interpretation of difficult experiential phenomena, such as CP, with the drawings speaking directly to the reader, which increases the resonance of research outputs.

Longitudinal IPA

Qualitative longitudinal designs add a temporal dimension to standard designs by gathering data at multiple timepoints. While multiple interviews with a participant are used in IPA to explore a phenomenon in depth (Flowers, 2008), in longitudinal IPA, or LIPA, gathering data at different timepoints is specifically aimed at capturing participants' subjective experience as it evolves over time (Farr & Nizza, 2019).

Through qualitative longitudinal studies, researchers can gain insight into segments of life journeys, revealing how they are experienced, the factors that shape them, including the role of personal agency and context. Through a specific focus on cases, inherent in IPA, complex mechanisms of causality can be explored and the fluidity of time can be conveyed as participants and researchers 'travel' through past, present and future (Neale, 2021).

IPA's phenomenological and hermeneutic stances and its idiographic commitment make it particularly suitable for longitudinal designs. Temporality is recognised in phenomenology as a key aspect of participants' experience and lifeworld (Ashworth, 2016) and LIPA designs allow the flow of temporal experiences to be captured and analysed as it occurs, revealing the dynamic nature of subjective experience. IPA's hermeneutic approach affords insight into participants' evolving prospective and retrospective sense making (Farr & Nizza, 2019).

The first LIPA study ever published was an exploration of the transition to motherhood by Smith (1991, 1994), who interviewed 4 first-time mothers at 3 timepoints during pregnancy and after their child's birth. The study illustrates the findings that a LIPA design can yield, such as differing and contrasting emphases depending on what is personally relevant at a given time and the reconstructive nature of memory. The impact of time on narratives of Self in this study was particularly resonant for me, reinforcing my conviction that investigating the evolution of the sense of identity of CP sufferers could provide rich insight.

The analysis and interpretation in LIPA designs is both complex and rich, because researchers are working with different layers of meaning that need to be negotiated: participants' meaning making in multiple presents, their various projections into the future and reflections about their past (McCoy, 2017). Thus the double hermeneutic characteristic of IPA, in which the researcher is making sense of the participant's sensemaking (Smith et al., 2009), has the potential to become very complex, especially if data is analysed while the interviews are still ongoing. As I will discuss in Chapter 5, I chose to analyse my data when all interviews were complete, to increase my naïveté and reduce the complexity of the analysis.

During a LIPA analytic process, the concept of part and whole interplay derived from hermeneutics is extended and amplified (Smith, 2007a): while considered as a whole, each timepoint interview is also a part of the participant's corpus of interviews, so it contributes to understanding the corpus and is, at the same time, illuminated by it. The use of drawings in a LIPA design further adds to this dynamic interplay, with each element of a drawing being a part of the whole drawing, each drawing being part of the participant's set of drawings, and drawings and interviews illuminating each other too. This proliferation of hermeneutic circles can make the analysis complex and deep.

Due to IPA's idiographic commitment, a complete data set from one participant will usually be analysed as a case before being compared to others, so that each person's trajectory can be inductively analysed within its own context. Trajectories encompass narrative changes, reinterpretations of previous narratives or lack of change (Lewis, 2007). Thus the search for convergence and divergence, another hallmark of IPA research, initially occurs within the trajectory of a single participant, before being extended across cases.

A good example of the interplay between idiographic detail and cross-case analysis comes from the LIPA study on receiving a kidney from a living donor by Spiers et al. (2015). Here, the changing recipients' perception of their relationship with their donor throughout the transplant process is illustrated by comparing the trajectories of four cases differing for whether and how they negotiated ambiguity in their bond with their donor. One participant felt immediately comfortable with their donor, while another gradually renegotiated an emotional connection. Idiographic details provide context to each trajectory so that it can be understood on its own terms, while comparisons between cases speak to the wider issues raised by living donations.

During my PhD, I realised the great variability in how existing LIPA studies had been conducted and the lack of methodological guidelines, so I published a review of 66 LIPA studies with a colleague (Farr & Nizza, 2019). The full article is in Appendix C.2 and, as I describe in detail in Chapter 5, some of its findings informed my methodological choices.

As mentioned earlier, I have come across few LIPA studies of CP, including one by Snelgrove et al. (2013), who gathered data from CP sufferers at three timepoints over 2 years, while they were receiving pharmacological treatment from a pain service. The paper presents 4 themes spanning time: three related to continuity (*The essential nature of pain*, *Loss of social roles and valued self* and *Managing the pain*), and one related to change (*Pain relief: a window of opportunity*). The grouping of themes as representing continuity and change worked well in this study, but there was a notable lack of idiographic focus. I believe that the potential richness of a LIPA study lies in the individual trajectories resulting from an inductive and idiographic analysis and that the challenge is to find a way of comparing participant trajectories without losing idiographic detail. A way of achieving this when there are more than a few participants is to group different types of trajectory, such as positive and negative ones, or changing and unchanging ones (Farr & Nizza, 2019), which is the approach I eventually settled on for my study (see Chapter 5).

As other longitudinal approaches, LIPA projects call for heightened reflexivity in the researcher because, through repeated encounters, researcher and participant can develop a strong empathetic bond. Although such bonds can increase the depth of interviews, an advantage in IPA, boundaries need to be sensitively managed, for the wellbeing of both participant and researcher. Remaining inductive and not theorising or drawing conclusions before data gathering is complete is also a challenge (Snelgrove, 2014).

To my knowledge, no IPA study so far has combined interviews and drawings longitudinally, so mine will be the first. In the first study combining art with IPA to investigate recovery from addiction (Shinebourne & Smith, 2011), participants brought to the interview artwork they had created during their recovery programme and drew how they saw their recovery at that moment in time during the interview. Although technically the study was not longitudinal, because each participant was interviewed only once, the drawings from different timepoints illustrated recovery trajectories. The 2011 paper presents one case with 6 drawings and three themes: one about the representation of recovery in the present, one related to the participant's retrospective analysis of her earlier drawings and one comparing old and new drawings to understand the process of changing Self in recovery. This study demonstrates how IPA's approach to interviewing using drawings from different timepoints can enhance retrospective reflection, uncovering new and deeper levels of meaning. For instance, one drawing was originally conceived as a flower and later interpreted as a screaming figure. The interpretation changed as the recovery evolved and the participant was able to face the darkness of her past. In a LIPA design, subsequent drawings, like diaries, allow you to look back into the past. The Shinebourne and Smith (2011) analysis is deep and insightful because, through the drawings, the participant embarked on a deep analysis of the process of transformation she had undergone. The

availability of the previous drawings during follow-up interviews provides participants with a trace of their previous experience which, unlike memories, is stable.

In this study, at each interview a drawing of pain and a drawing of Self will be created and then reviewed, giving participants an opportunity to reflect on their experience, adding depth to the discussion. As I describe in greater detail in the Methods section, in the second half of the second and third interviews, drawings from earlier interviews will also be presented. The aim is to stimulate in participants a reflection on the past, on their change or lack thereof, which may or may not be in contrast with their own memories of what has happened. The sets of drawings will constitute a trace of their journey over the duration of the study, acting as a map of what has been and what is, that, in my intention, will provide participants with an additional stimulus to reflect on their experience. So how the drawings of pain change, how the drawings of Self change and the interaction between the two sets of images will hopefully open up reflections on more profound and possibly unexpected facets of the temporal experience of participants. This aspect is possibly the most novel of the study and in keeping with the quest for depth and self-reflection that characterises IPA studies.

Conclusions

In literature, CP emerges as a complex condition, often with profound existential consequences. Multidisciplinary pain services and PMPs teach people about CP and how to self-manage it, but do not directly address identity issues, nor do their current outcome measures provide detailed insight on how experiences might change (de C Williams et al., 2020). There is value in exploring how sufferers' complex relationship with pain and their identity evolve when they are referred to a pain service and attend a PMP. LIPA, with its idiographic, existential and sense-making focus, is particularly apt to obtain an in-depth account of the temporal evolution of the experience of people with CP (King et al., 2016; Snelgrove et al., 2013). The addition of drawings, particularly of pain, to IPA interviews has enabled rich descriptions of the elusive CP experience (Kirkham et al., 2015). To develop this further, I shall interview PMP participants three times, incorporating their drawings of pain and of Self, to obtain an in-depth account of how their pain and their lives unfold over time.

Chapter 5 - Methods

The study aimed to explore how the experience of pain and the sense of self are depicted by CP sufferers and evolve over time when they attend a multidisciplinary pain service and participate in a PMP.

This chapter describes how the study was designed, and how data was collected and subsequently analysed. The first section is dedicated to the decisions that shaped data collection, including the study design and sampling approach, and the second section discusses ethical considerations. Next, I describe how data was gathered for the study, who the participants were, how interview schedules were designed and how the actual interviews developed, including considerations on participant and researcher wellbeing. Finally, I describe in detail how the data was analysed. The combination of visual and verbal data in a LIPA design was a particularly innovative aspect of the study, so the analysis process was long and proceeded through trial-and-error. I will present the final approach to the analysis that generated the results as they appear in subsequent chapters, while also describing the iterative journey through which the final procedure was refined.

Each stage of the project presented its challenges, partly due to my inexperience and partly due to the complexity and innovativeness of the project itself. I have interspersed the narrative with reflexive considerations that I hope will help illustrate the genesis of some key decisions and my personal learning along the way.

Design decisions

Design decisions for the study, such as when to gather data and which participants to include, were driven by both pragmatic and theoretical considerations.

Duration and timepoints

A longitudinal qualitative design allows for change to be captured, but the duration of a study and the number of timepoints at which data is gathered determine how effective a study can be in realising its potential (Farr & Nizza, 2019).

The assumption for this study was that participation in the PMP would be an important milestone in the journey of participants within the CCPS, so the first two interviews were arranged to occur before and after that event. Figure 1 shows indicatively when interviews took place. All participants were recruited during a PES, which everybody attends shortly after being referred to the service (discussed in Chapter 3). The biggest unknown was whether and how

long after the PES participants would be attending the PMP, since PMP referral is the result of a clinical assessment of a person's readiness for its contents. At the time, the average time for PMP referral within the service was a few months and, on average, the time between the first and second interview of my study participants was 4 months.

The PMP itself developed over 4 consecutive weeks, with a follow-up 3 months later. The second interview was arranged one month after the first 4 weeks of the PMP to allow for the enthusiasm I expected the weekly sessions would raise in participants to die down. The third timepoint was positioned 5 months after the second interview, assuming that by then participants would have settled into a 'new normal' and, in some cases, have been discharged from the service. The average overall time in the study of participants was 9 months.

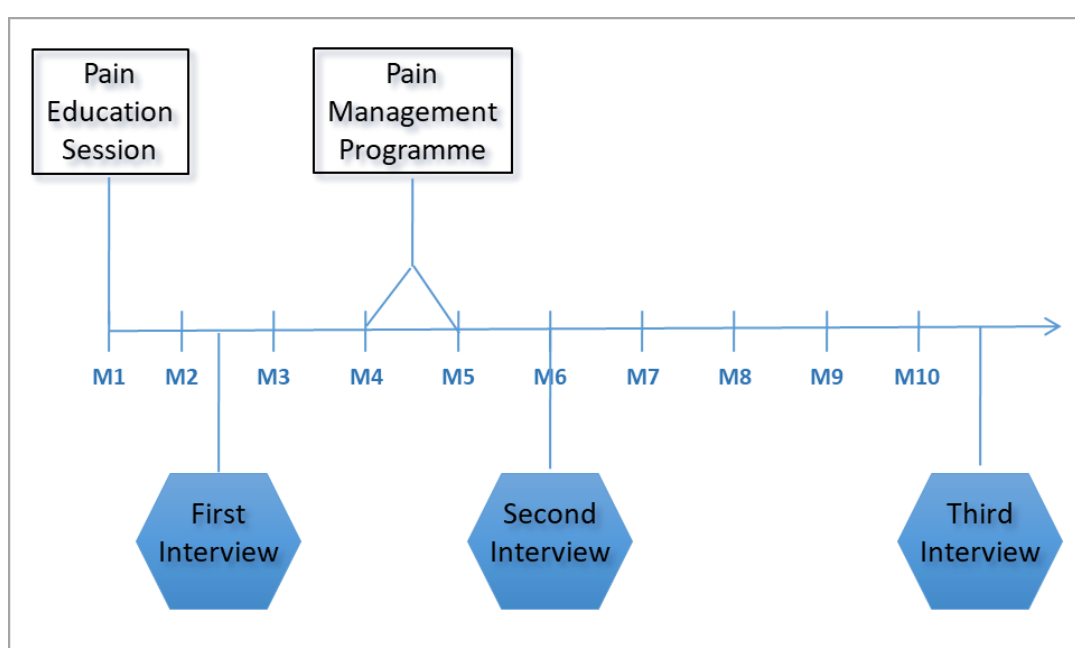


Figure 1. Timeline of study showing when the first, second and third interviews took place (M1 = month 1, M2=month 2, and so on).

Note: from this point onwards, I shall be referring to the three interviews and any data gathered at that point using the terms Time 1 (T1), Time 2 (T2) and Time 3 (T3).

Size of sample

The depth of analysis that can be achieved with IPA makes it best suited for a relatively small and homogenous group of participants (Smith et al., 2009). Due to the study's longitudinal and multimodal design, I knew each participant's complete dataset would include three interviews and six drawings, so the size of the sample needed to be limited. This consideration, however, was weighed against the expectation that study retention would be a problem (Hermanowicz, 2013).

Initially I aimed to include both men and women in the study and assumed a 50% attrition rate.

Table 1 shows how many people were interviewed originally and how many stayed in the study and completed three interviews. As you can see from the table, the retention rate was slightly higher than envisaged. Recruiting men proved to be far more difficult than recruiting women, mostly because they are underrepresented in the CP population (Fayaz et al., 2016).

	Women	Men
Attended first interview	13	9
Completed three interviews	8	5
Retention rate	62%	56%

Table 1. Number of participants who attended the first interview vs completed 3 interviews

Most participants left the study between T1 and T2, either because they had not been referred to the PMP or because they had not completed it. Only two women and one man who had attended the second interview did not attend the third and they were not asked for a reason.

By the end of the data gathering phase, the transcripts of 39 interviews (corresponding to 50 hours of recordings) and 78 drawings were available for analysis. I agreed with my supervisor that to analyse such a volume of data at an appropriate level of depth would not be feasible within the PhD's timeframe, so for the next stages my focus would be only on the female participants. I hope that analysing the male participants and comparing them to the women will be my first post-PhD personal project!

Eligibility criteria

For **inclusion** in the study, participants had to be:

- Aged 40-60 years
- Of White British ethnicity
- Currently unemployed (by choice or necessity)
- Referred to the PMP by their case nurse
- Able to read and speak English fluently

Just for the fact of having been referred to the service, I could assume that participants had been experiencing CP for at least two years and had no severe or enduring mental health problems, so these were implicit inclusion criteria.

Participants were **excluded** from the study if, despite meeting the inclusion criteria, they meet the following conditions:

- Professional or amateur artist
- Currently receiving medical interventions for CP (i.e. operations, injections)

- Migraine as the only presenting problem
- Had attended a PMP in the past
- Had already received psychological support for their pain

Inclusion criteria were established based on what was known of the average person referred to the PMP, in terms of age and ethnicity. The choice of recruiting only White-British participants was justified by the respect that IPA has for cultural differences and the recognition that they may be an important factor that can affect homogeneity. Most people referred to the service were not in active work and literature suggested that work status can affect how CP is experienced (Giladi et al., 2015). Similarly, people who were receiving medical interventions were excluded because it was assumed this might affect the perceived chronicity of their condition.

With the aim of ensuring that drawings would be the most spontaneous possible, people suffering only from migraine were excluded (for the characteristic visual disturbances associated with migraine), as were people who might have expertise in the production of visual artefacts (professional or amateur artists).

To ensure that all participants had a comparable exposure to the psychological aspects of dealing with CP, people who had attended this or other PMPs in the past and people who had previously received psychological support for their CP were excluded.

Only participants who had attended 3 out of 4 PMP sessions were contacted for the first follow-up interview at T2, as this is the criteria that the CCPS uses to establish whether a patient has completed the programme.

Ethical considerations

Ethical approval

The study was approved by the Birkbeck Ethical Approval Board and by the London Stanmore Research Ethics Committee of the NHS Health Research Authority REC (15/LO/1872). The REC application was submitted for Proportionate Review, taking advantage of the fact that a study using drawings to investigate pain had just been run in the same trust (Kirkham et al., 2015). To obtain permission for conducting the research, the Kent Community Health NHS Foundation Trust, from where participants were recruited, requested that I obtain Health and DBS clearance and attend a Good Clinical Practice course.

Ongoing consent

Ongoing consent is considered an important aspect in longitudinal studies, particularly in healthcare research (Murray et al., 2009). Although my study was longitudinal, formal consent was obtained only once through the Participant Consent Form (Appendix A.2), which explicitly referred to all three interviews. This choice was motivated by the desire to emphasise with participants how important it was for me to have complete datasets, while still asserting their right to withdraw from the study at any moment without having to motivate their decision. When calling participants for the second and third interviews, I always explicitly verbally checked whether they were happy to be interviewed again.

Despite what was specified in the consent form, I never contacted the participants who did not complete the study to ask whether I could use their interviews and their drawings because, having obtained enough complete datasets, I decided I would not need to use their data.

Anonymity

All participants were assigned a pseudonym and all references within their transcripts to specific people, locations, employers or other information that could affect anonymity were either omitted or modified. Since participants were not professional or amateur artists, I considered the risk of their drawing style being recognisable to be negligible. However, a few participants did include in their drawings some characterising elements, such as names, so I edited the drawings electronically to either remove or change any details.

Artefact ownership

The Participant Consent Form included a specific clause authorising me to copy and publish the drawings (Appendix A.2, item 6). During participant debriefing at the end of each interview, I explained that I would keep the drawings until the end of the data gathering phase of the study and that participants would be able to ask for the originals to be returned to them in due course. After the third interview, I explicitly asked each participant (on tape) whether they wanted me to return their drawings or dispose of them safely. Nobody asked that I return the drawings, but a few did ask to be able to take a picture of one or more drawings, which of course I allowed them to do. The original drawings are still in my possession and will be destroyed once they have been professionally photographed for my records.

Recruitment and retention

At the time of the research, the CP service was organising a few PES sessions each month, in different geographical locations. To facilitate interviewing, I chose to recruit people from a limited area in the most South-Eastern part of the county (Ashford, Canterbury, Thanet and Dover). People attend a PES shortly after they are referred to the service and approximately 30 people attend each session. I recruited the bulk of my participants by attending 7 PES sessions between December 2015 and April 2016. I personally recruited all the women, while two of the men were recruited on my behalf by the service staff during the Summer months.

PES sessions include various brief presentations about different aspects of the service. After the first presentation, I was given a few minutes to address the audience and introduce my research, saying something along the lines of:

Hello everybody, my name is Isabella, I am a PhD student based at Birkbeck College in London. I am conducting a research on the experience of chronic pain and how this changes over time and I would like to invite you to be a part of my research.

What does participation involve? Essentially this is an interview-based study but using quite a new method that includes drawing, no need to be an artist! – on the contrary, it's important that you are not professional or amateur artists.

The interviews will be one-to-one, with me, in a place that we'll agree together and could also be your own homes.

Because the study looks at change, everyone will be interviewed three times in the course of one year, more or less.

To participate, you need to have the following characteristics: [read from information sheet]

If this sounds interesting or if you would like to understand better what this is about, I have prepared some information sheets that you can take home. I will be here all morning with you, so just come up and talk to me in a break, so that I can answer any questions and you can register your interest.

Thank you.

Box 1. My recruitment speech at PES

At most sessions I was approached by a few people and most of them registered their interest immediately, asking almost no questions. I handed them a Participant Information Sheet (Appendix A.1), checked that they actually did match the inclusion/exclusion criteria and made a note of their details (name, phone number and email) with the agreement that I would get in touch by phone a few days later, allowing them time to think over their decision.

When I then called, I made sure not to assume that participation would be a given and to ask them whether they were happy to go ahead. Then we agreed where and when to meet for our first interview. Only few people who had registered their interest at the PES changed their minds later.

A few times I attended a PES session and received no interest at all, which was hard. Occasionally I was tempted to approach participants that looked eligible (for their age or gender) but learnt quite early on that the participants most likely to stay in the study were those who had volunteered spontaneously (see Box 2).

At the Canterbury PES there were two people who came in late and therefore did not hear my presentation of the research. I decided to approach them separately to explain the study and ask them if they wanted to take part. Both agreed readily, I was over the moon. During the following weeks one did not return my calls and the second cancelled at the last minute. My reflection is that people find it very hard to say no to your face, they prefer to say yes and then back out because in fact they don't feel like it. (03/03/2016)

Box 2. Extract from reflexive diary on recruitment

As mentioned earlier, retention rates were slightly higher than expected. At the end of each interview, as part of the debriefing, I made sure to remind participants that they needed to attend all three interviews for their data to be usable in the study and gave them an idea of the approximate time when I would get back in touch. When I called for subsequent interviews, I always checked whether they were happy to meet again before arranging for a new interview.

Between interviews I did not keep in touch directly with participants. Instead, I monitored participants' PMP attendance with the service, so I knew when to call them again for their second interview. Before calling for a last interview, since some months had passed and to avoid embarrassments, I asked the service to check the participants' notes for any major events. With hindsight, my retention strategies were effective and most participants remained in the study, allowing me to have a good number of complete datasets to work with. However, when I completed my first round of interviews, retention was a large concern of mine and a source of anxiety: the first round of interviews had taken a heavy toll on me, I was physically and emotionally tired (more on this further on) and retention felt like a reasonable thing to worry about. Upon reflection, I realised that I needed to trust the relationship I had built with participants and their inherent interest in taking part in the study.

Participants

Table 2 below provides a list of the female participants in the study.

The average age of participants was 49 years. Half of them had been suffering with CP for 3-4 years, while the other half had suffered for over 15 years. Most had been diagnosed with fibromyalgia, with or without other comorbidities, while two had developed chronic back pain following minor work accidents.

All participants were taking some form of medication for their pain and some were also self-medicating with vitamin supplements. One of the responsibilities of the CCPS clinical nurse

specialist is to review the medication regime of people because, when they are first referred to the service, they are often taking high doses of pain killers (including opioids). Consequently, the medication treatment of many participants changed over the course of the study; those using opioids were encouraged to try and discontinue them, but only Olga was successful.

The other non-medical treatments, including tai-chi, physio and hydrotherapy, a TENS machine and psychology sessions, were offered to participants on an as-needed basis and at the discretion of the clinical team.

Name	Diagnosis	Age	Years with pain	Medication ²	Non-medical treatments received from service ³	Months between interviews 1 and 2	Months between interviews 1 and 3
Jane	Fibromyalgia, degenerated disks, depression	47	3	Opioid painkiller, anticonvulsant, antidepressant, paracetamol and supplements		4	8
Olga	Fibromyalgia and seronegative rheumatoid arthritis (RA)	55	20	RA medication	tai-chi	6	11
Monica	Fibromyalgia	40	30+	Opioid painkiller, antidepressant, paracetamol and treatment for hiatus hernia	psychology	3	8
Helen	Fibromyalgia	60	25+	Opioid painkiller, anticonvulsant, antidepressant, paracetamol and sleeping pills	psychology	4	9
Alison	Low back pain, ME	51	5	Other painkillers and two antidepressants later replaced by other antidepressant recommended for nerve pain	TENS machine	5	10
Gillian	Fibromyalgia	46	4	Anticonvulsant	tai-chi, psychology, hydrotherapy	3	8
Kate	Fibromyalgia, Holmes-Adie Syndrome	45	3	Anticonvulsant and paracetamol, heat pads and supplements	tai-chi, TENS machine (CBT and nutritional courses through other channels)	2	7
Lauren	Osteoarthritis & lumbosacral radiculopathy	51	17	Opioid painkiller	tai-chi, physiotherapy	3	8

Table 2. Details on study participants (order reflects how their results are presented)

² The contents of the Medication column are for the most part derived from the participants' clinical records at the end of the study.

³ All participants also had regular personal appointments with a clinical nurse specialist and participated in the PMP

Interview schedules

When designing the schedules for my interviews, I had two starting points: (a) wanting the drawings to be an integral part of my dataset; (b) having a temporal focus, so that change and continuity could emerge from the data as clearly as possible.

In LIPA studies, there are different approaches to designing the schedule for prospective studies (i.e. in which data is gathered before and after an event): asking the same questions at different timepoints allows what is important to a participant at that moment to emerge, potentially postponing the identification of change to the analysis phase. In contrast, adapting the interview schedule to each timepoint, by explicitly asking about change, can stimulate a reflection on the change process (Farr & Nizza, 2019). I decided to combine these approaches, but also to leverage the drawings as additional means for reflection.

The schedule for the first interview was designed to focus on the present. As you can see in the interview schedule shown in Box 3 below, the interview opened with an explanation of the interview process. Then participants were asked to create two drawings: one of their pain and one of themselves (I discuss the drawing process decisions in detail later when describing the interview procedure). Only once the drawings had been created, did the interview (and recording) start.

During the interview, as the interviewer, I controlled which of the newly-created drawings would be on the table, visible to both of us, at any moment. This enabled me to focus the attention of participants first on their pain drawing, then on their Self drawing, and then on both.

I started by presenting the pain drawing they had just created and asking participants to describe it, why they drew it as they did and what meaning they ascribed to it (Box 3, Q1 – prompts are in brackets). Q2 offered participants an opportunity to use words or other metaphors to describe their pain, beyond what they had been able to express in their drawing. Then I put the pain drawing away and brought out the Self drawing, asking them to describe it, using similar probing questions (Q3). Then I brought out the pain drawing again and, looking at both pain and Self drawings together I created a link between them with Q4 in which I asked participants how the pain made them feel about themselves. Then, with question Q5, I broadened the horizon to consider their closer and wider social circles and, with Q6 and Q7, invited them to look ahead at their future. Finally, to understand how the act of drawing had affected participants, I used Q8 to ask about how drawing and the interview had made them feel.

I am now going to ask you to create two drawings using the materials provided. I would like to emphasize that the point of this exercise is to give you a chance to express your experience pictorially. I am not going to evaluate your artistic abilities and I am not trying to see whether you can make an impressive artistic image.

Once you have finished drawing, in about half an hour, we'll discuss your experience with chronic pain and look at your drawings together to see what they can add to our understanding.

Please draw an image of what YOUR PAIN feels like to you. (15")

Please draw an image of YOURSELF as you are now in your life. (15")

1. Can you describe your drawing of your pain to me?
(How did you choose to draw what you drew? Can you explain your choice of colours? Can you explain your choice of shapes? How did you decide where to position the image on the sheet of paper? How did you decide what materials to use? What is your reaction to looking at it?)
2. How might you use words to describe your pain?
(What does it feel like? What words come to mind? Are there additional images that come to mind?)
3. Can you describe your drawing of yourself to me?
(How did you choose to draw yourself as you did? Can you explain your choice of colours? Can you explain your choice of shapes? How did you decide where to position the image on the sheet of paper? How did you decide what materials to use? What is your reaction to looking at it?)
4. Is there anything more you would like to add to explain how your pain makes you feel about yourself?
5. Thinking about your pain, how do you think others see you?
(People close to you like family? Close friends? Acquaintances? Do you think they are aware of how you feel? How do you think they feel about you and your pain?)
6. How would you like to feel about your pain?
(What would you consider an improvement?)
7. How would you like to feel about yourself?

(What would you consider an improvement?)

8. How has this experience of drawing and this interview in general made you feel?

Thank you, debrief and questions.

Box 3. Interview schedule for the first interview

The second and third interview schedules had a similar structure for the first part, but changed substantially for the second part of the interview, where participants were also presented with their earlier drawings to comment on similarities and/or differences. The drawings were intended to act as memories and stimulate a discussion on any change that may have occurred since the previous interview(s).

Please draw an image of what YOUR PAIN feels like to you. (15’)

Please draw an image of YOURSELF as you are now in your life. (15’)

1. Can you describe your drawing of your pain to me?

(How did you choose to draw what you drew? Can you explain your choice of colours?

Can you explain your choice of shapes? How did you decide where to position the image on the sheet of paper? How did you decide what materials to use? What is your reaction to looking at it?)

2. Can you describe your drawing of yourself to me?

(How did you choose to draw yourself as you did? Can you explain your choice of colours? Can you explain your choice of shapes? How did you decide where to position the image on the sheet of paper? How did you decide what materials to use? What is your reaction to looking at it?)

3. Is there anything more you would like to add to explain how your pain makes you feel about yourself now?

4. Thinking about your pain, how do you think others see you now?

(People close to you like family? Close friends? Acquaintances? Do you think they are aware of how you feel? How do you think they feel about you and your pain?)

5. How would you like to feel about your pain? (What would you consider an improvement?)

6. How would you like to feel about yourself? (What would you consider an improvement?)
7. [Bringing out the previous drawing of pain that they have not had the opportunity to look at again since]: Let's compare this with what you drew last time. What do you notice? (change in representations, colour choice, size, shape, etc.) I notice that... (point out any change that captures my attention and they have not referred to)
8. What do you think about these differences?
(What do they say about your pain? How aware were you of this change/lack of?)
9. Is there any other change you have perceived since last time that you don't feel appears in this drawing?
10. [Bringing out the previous drawing of Self that they have not had the opportunity to look at again since]: Let's compare this with what you drew last time. What do you notice? (change in representations, colour choice, size, shape, etc.) I notice that... (point out any change that captures my attention and they have not referred to)
11. What do you think about these differences?
(What do they say about how you see yourself? How aware were you of this change/lack of?)
12. Is there any other change you have perceived since last time that you don't feel appears in this drawing?
13. What part did the PMP programme play in the change you describe? Does it appear in the picture?
14. Thinking back to the time since our last meeting, have you had any thoughts about doing the drawings?
15. I just wondered whether you discussed participation in this study with the other people who attended the PMP with you at all? If so, can you tell me something about what you discussed?

Thank you, debrief and questions

Box 4. Interview schedule for the second interview

As you can see in Box 4 above, questions Q1 to Q6 are almost identical to the equivalent questions in Box 3, except that they refer to the new pain and Self drawings created at T2 and include the word “now” to acknowledge that the same question had already been asked at T1.

Once the discussion of the newly created drawings was complete, leaving only the new pain drawing on the table (pain at T2), I brought out the previous pain drawing (pain at T1) to enable a comparison. Through Q7 participants were asked what differences they noticed and through Q8 they were invited to comment on such differences or lack thereof. Then, Q9 explicitly invited a reflection on what may have changed pain-wise since the previous interview. At this point, the pain drawings were put aside and the T1 and T2 Self drawings were placed on the table so that through Q10, Q11 and Q12 a similar comparison between Self drawings and reflection were encouraged.

Although many had possibly already mentioned the PMP which they attended between T1 and T2, only at this point were participants explicitly asked about their attendance and the extent to which they believed it may have affected their situation at T2 (Q13). Finally, with Q14 participants were invited to provide more input on the drawing experience. Given that in some cases more than one participant in the study attended the same PMP session, the last question (Q15) was aimed at establishing whether they had identified and communicated with each other and what influence this may have had on the study (note that only two participants became friends during the PMP, but both said they had not discussed the study).

The schedule for the third interview is shown in Box 5 below.

Please draw an image of what YOUR PAIN feels like to you. (15’)

Please draw an image of YOURSELF as you are now in your life. (15’)

1. Can you describe your drawing of your pain to me?
(How did you choose to draw what you drew? Can you explain your choice of colours?
Can you explain your choice of shapes? How did you decide where to position the image on the sheet of paper? How did you decide what materials to use? What is your reaction to looking at it?)
2. Can you describe your drawing of yourself to me?
(How did you choose to draw yourself as you did? Can you explain your choice of colours? Can you explain your choice of shapes? How did you decide where to position the image on the sheet of paper? How did you decide what materials to use? What is your reaction to looking at it?)

3. Is there anything more you would like to add to explain how your pain makes you feel about yourself now?
4. Thinking about your pain, how do you think others see you now?
(People close to you like family? Close friends? Acquaintances? Do you think they are aware of how you feel? How do you think they feel about you and your pain?)
5. It's been X months since I last saw you, then you had just completed your PMP, what has life been like for you since? (Have you had any ongoing help from the pain service? Can you describe what has it been like?)
6. Generally, how does how you feel now compare to how you have felt in the past (when we first met over X months ago? better/worse?)
7. What role do you think the PMP and the pain service may have played in making you feel this way?
8. [Bringing out the two previous drawings of pain]: Let's compare this with what you drew during the last two times. What do you notice? (changes in representations, colour choice, size, shape, etc.) I notice that... (point out any change that captures my attention and they have not referred to)
9. What do you think about these differences?
(What do they say about your pain? How aware were you of this change/lack of?)
10. [Bringing out the two previous drawings of Self]: Let's compare this with what you drew the last two times. What do you notice? (changes in representations, colour choice, size, shape, etc.) I notice that... (point out any change that captures my attention and they have not referred to)
11. What do you think about these differences?
(What do they say about how you see yourself? How aware were you of this change/lack of?)
12. [Presenting the whole sequence of pain and Self drawings] What do you think these drawings say about what has happened to you since we first met? How does it feel like to

look at them together like this?

13. Thinking back to the time since our last meeting, have you had any other thoughts about doing the drawings?

14. What are your expectations for the future?

Thank you, debrief, farewell and discussion about the possibility of sending the drawings back in due course, if desired. I hand them the card and small gift at the very end with my last thank you.

Box 5. Interview schedule for the third interview

As you can see in Box 5, the schedule for the third interview was very similar to the schedule for the previous interviews in that the first portion (Q1-Q4) concerned the discussion of participants' new pain and Self drawings. In the second part of the third interview schedule however, a slightly different strategy was used compared to the second schedule (Box 4), because, before presenting previous drawings for comparison, participants were asked to reflect back on the time since the previous interview: in Q5 they were asked about what had happened to them in the previous six months, in Q6 they were invited to compare how their feelings had changed and in Q7 they were encouraged to think back at the role the PMP may have had in any change. Then, the comparison between current drawings and previous ones was made, comparing pain drawings (Q8 and Q9) and Self drawings (Q10 and Q11) from all three timepoints. Finally, with Q12, participants were able to review the 6 drawings that made up their complete set in one sweep and comment on the thoughts and feelings they elicited. Then, as previously, impressions on the drawing process were gathered (Q13) and, to close, participants were asked about their expectations for the future (Q14).

The rationale for designing the second and third interview schedules as they were was rooted in theoretical assumptions related to longitudinal designs and visual methods:

- I gathered input on the present before discussing the past, both in the second and third interviews, to obtain a snapshot of the present the least influenced as possible by participants' reflections on their past, so that, during the analysis, I could inductively compare multiple presents.
- In the third interview, unlike the second, after discussing the present, I asked questions about the intervening time because: (a) I assumed that sufficient time had passed for something meaningful to have happened in participants' lives that I may have needed to know about to contextualise subsequent timepoint comparisons; (b) I wanted to be able to compare their subjective view of what had happened over the course of the study based on

memory, with the hot cognition on their change that reviewing their previous drawings might elicit.

The schedules as presented in Box 3, Box 4 and Box 5 above are the final versions after drafts were piloted with Alison. After piloting the second interview schedule, I decided to include the option for me to comment on some things I noticed in the drawings (Box 4, Q7 & Q10) and to explicitly ask what part the PMP had played in the changes described and whether this appeared in the picture (Box 4, Q13). After piloting the third interview schedule, I decided to add the questions on intervening events (Box 5, Q5-Q7).

Interview location

At the start of the study I gave participants the option to be interviewed in their own home, or at a surgery or local community centre. As the study progressed, the interview location turned out to be more than just a logistical decision.

When planning home-interviewing I had considered my own safety and added some procedures to that effect to my study protocol. What I had not considered and turned out to be an issue was the fact that my interview procedure included a phase in which participants needed to draw some pictures, selecting colours from a variety of mediums that I spread out on a table, and be alone in the room while drawing. Controlling the environment and moving around freely in the home of somebody you have never met before can be difficult, particularly for a less experienced researcher.

For instance, Alison chose to be interviewed at home and welcomed me into her living room, where she had a table with chairs and some large armchairs. At the first interview she immediately sat on one of the armchairs claiming that she was having a bad day and that was the only place where she felt comfortable, so I did not feel free to ask her to move elsewhere. In subsequent interviews I asked her to stay at the table, at least while she was drawing. Due to the layout of her apartment and the fact that we did not know each other well, I did not feel I could leave the room while she was drawing. Her drawings turned out to be the least engaged and I suspect her seating position and my presence may have contributed to their basic quality. After my experience with her, I arranged home interviews only when there was no feasible alternative.

The logistical support of the CCPS was invaluable because they allowed me to use their rooms in various health centres free of charge. For participants in areas in which an NHS room was not available, I sourced rooms from local community centres. In all cases, participants were able to draw sitting at a table and I was able to leave them alone in the room while they were drawing.

I offered to pay for transport costs for participants, but only one person actually asked for a contribution (Kate) and only for her first interview.

Conducting the interview

I have already provided some information on the interview process in the sections above, specifically about how the interview schedule was designed so that drawings would be central to the interview process. Here I will provide some additional details on the process and on some aspects of the interview experience, from my own and participants' point of view.

Interview procedure

The very first interview started with a brief description of what was to follow and signing of the Participant Consent Form (Appendix A.2), a copy of which I left to participants.

There are different views among IPA researchers using visual methods on how data should be gathered: Boden and Eatough (2013) chose to observe while participants were drawing and took notes that became part of the dataset; Kirkham et al. (2015) left their participants alone to draw, which was also my approach. My argument was that if the aim was to create an opportunity for participants to 'discover' a new aspect of their experience through drawing, a situation in which they could focus on the task without feeling self-conscious seemed more suitable and less open to respondent bias.

Participants were asked to draw two pictures, one of their pain and one of themselves, on two A4 blank sheets of heavy paper using any of the available materials: coloured pencils, crayons and felt-tips. They were left alone in the room and allowed 15 minutes to complete the drawing of their pain (*"Draw a picture of what your pain feels like to you"*). I then returned to the room briefly, put their first picture aside, gave instructions for them to draw themselves (*"Draw a picture of yourself as you are now in your life"*) and left again for 15 minutes. This allowed for a short break between the two drawings to limit priming effects.

Once the drawings were complete, the audio-recorded interview started. The interview was semi-structured and, as described earlier, revolved around the newly created drawings, while leaving the space required to follow-up any unexpected relevant topic raised by participants.

Box 6 below shows an extract from the transcript of Gillian's first interview where we were discussing her first pain drawing (Appendix D.6.1). Specifically, in this portion she is describing two components of her wider drawing that I have extracted and labelled in Figure 2 below.

This (1) is basically, I've got quite a pain right deep in my ear and that again is today and I mean that's not there all the time but it is actually there today and it's, it's a really weird feeling, sometimes it comes with a completely like stiff neck, and things like that, and other times it's just there and it can be a throbbing, it can be, that's meant to be a drum, so like a, like a drum, you know, like a drum sort of thing, it can sort of come and go, and come and go and come and go. Having said that, the going it's still there a little bit, if you see what I mean, it just throbs every now and then, ahm, I know, actually, from, ahm, I go to an acupuncturist and I know that that is actually related to some of the nerves and muscles that are down here.

I: On your shoulders?

G: Yeah, yeah and on, here

I: On top of the arm?

G: And along the back, yeah, yeah, and sometimes down to the shoulder blade as well, they can shoot the pain up to the back of the... yeah, so that's just down the neck, that's just here, that's just down there (2), so that's obviously connected to this (1).

I: It's only on one side?

G: Yeah, yeah, I mean for me, for some reason, my right side of my head is much more prone, sometimes I get it on the left, but mainly on the right.

I: Although this is on the left side

G: [big laughter] Yeah, it's on the wrong side, yeah, yeah. So for some reason I don't know why, in my head, I get it on the right side a lot, I also get what feels like a, I should have drawn that as well, a lot of, ahm, it feels like sinus pressure, from childhood, again they thought I had a lot of sinus infections, ahm, and I think that is due to, because again that is due to this all tensing up here and it actually connects somehow, I don't know how, via the neck and the ear and to here, and I get a lot of those, still. That's directly, definitively directly related to stress.

I: Okay

G: Directly, I know that, if I've been stressed, if I've been worried, I know that I get that, so, ahm, so that...

I: While you're worried?

G: Not necessarily, no, not exactly at that point, I mean I could be worried maybe for a day or two and then it would come on, so that's a, I think it's a follow-on from, I must tense these (muscles at back of head) while I am worried and that must be like a follow-on, I think from that point.

Box 6. Extract from Gillian's first interview transcript, lines 151 to 194.

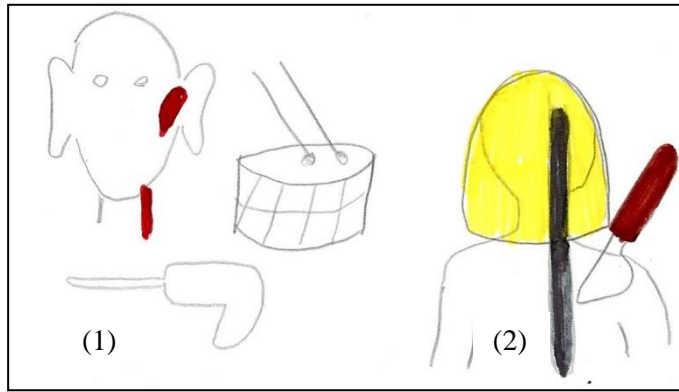


Figure 2. Detail of Gillian's T1 pain drawing

As you can see from the transcript and figure, in her first interview, Gillian went to great lengths to describe both visually and verbally in detail the physical symptoms that she was having. Accordingly, our interaction during the interview was very geared towards me making sure

that I understood and clarified exactly which parts of the drawing she was referring to. For instance, at the end of the first paragraph, when talking about element (1) in Figure 2, she said, “*muscles that are down here*” pointing to the shoulders, which are actually in element (2), and I interjected to clarify what she was talking about. Since interviews were only audio recorded, I often clarified out loud when participants were pointing to something, to ensure that all the necessary information would be available for future analysis. The second half of the transcript in Box 6 also shows how describing her physical symptoms became for Gillian an opportunity to reflect on the meanings she ascribed to her pain, in relation to her childhood and stress levels, an aspect that I was particularly interested in understanding fully.

The structure of all interviews closely followed the alternation between drawings, so that the pain drawing was discussed before the Self one and separately, before looking at them together and, in later interviews, retrospectively. However, if other topics potentially relevant emerged (for instance, some participants discussed the impact of family issues or the benefit system), these avenues were always followed up with additional questions.

Interview durations were quite varied between participants and timepoints, with an average duration of 78 minutes, and a minimum and maximum duration of 42 and 132 minutes respectively.

Participant experience

Various authors have commented on the anxiety raised in participants by drawing as a data gathering method (Guillemin, 2004b; Morgan et al., 2009), others have observed that drawing allows participants more access to emotions compared to a standard interview (Kearney & Hyle, 2004), and participants in some studies even claim that the experience of drawing has had therapeutic effects on them (Rollins, 2005).

Drawing did not appear to create anxiety for my participants, although some were apologetic for their lack of artistic abilities (e.g. Olga who always drew stick figures). It could be that those who felt intimidated by the idea of drawing simply did not volunteer for my research.

The interview experience was an emotional one for many participants, particularly the women and especially during their first interviews. For many participants this was the first time they were telling their story to somebody and the drawings undoubtedly contributed to raising the emotional impact of the interviews. Whenever a participant became teary, I would make sure tissues were available and patiently waited for them to recover. I always asked whether they were okay to continue with the interview, but nobody ever asked me to stop.

Some participants described having had suicidal thoughts in the past, but were quick to reassure me that they had not been followed by active suicidal ideations. One male participant (who then left the study because he was considered unsuitable for the PMP), in the course of a difficult interview in which he did not engage with the method and had an apathetic attitude, talked about having suicidal thoughts on the days immediately preceding the interview. This was one of my first interviews and, although I had planned for such instances in my ethics application, I felt disconcerted. His words were alarming, especially in the context of the unemotional tone of our conversation, so I explained to him that I would have to break my confidentiality clause and discuss what he had told me with the service's senior counsellor, which he gladly accepted. We ended the interview shortly after and, before leaving him, I explicitly asked him whether he was feeling okay and, seeing his mother waiting for him outside the interview room, understood he would not be alone. I then called the CCPS senior counsellor who rang the participant to further assess his psychological wellbeing and the associated risks.

Luckily this was an isolated episode. In all cases, according to the standard ethical practice in psychological research, each interview ended with a debriefing moment during which participants were encouraged to ask questions about the study and I was able to assess whether taking part in the research had caused them a level of discomfort that needed to be followed up.

At the start of some interviews, the mood of participants appeared depressive (i.e. low tone of voice, negative outlook) and I was struck by how this could change as the interview progressed. For instance, Alison's tone was always low at the start of her interviews and by the end she would be buoyant, visibly sorry that I needed to leave. During her third interview, she explained how talking to me had affected her:

I do feel you're the only one out of everybody that's listened. [...] when I have said things to you and you've gone, I've thought about it and I've tried to change my mood, or I've tried to do things a little bit different [Alison, Time 3]

For others the drawings also seemed to have an important impact in terms of mood. For example, at the start of her third interview, Lauren had been low, because she was facing some

new health issues. As the interview progressed, she became increasingly upbeat, a change of mood which culminated when she reviewed her complete set of drawings:

If I hadn't looked at them together and just looking at this one [Pain, T3], I would have thought, "oh my God, you've gone so far back" and that's exactly how I felt when I walked in this morning [...] actually, I haven't, I don't feel that I have, pain-wise I don't feel that I've gone backwards, I feel a lot clearer [Lauren, Time 3]

Among other effects, the possibility of reviewing one's current drawings in the context of their longitudinal trajectory seemed to have a normalising effect on the low mood of some participants.

Researcher experience

Researcher reflexivity, meaning the awareness of one's responses to the research topic and process, is considered a cornerstone of good qualitative research (Finlay, 2017). I believe myself to be naturally reflexive, because I assign great importance to my feelings and am watchful of their embodied manifestation. Keeping a reflexive diary during the project was not only a question of good practice for me, it was a need, especially while I was conducting interviews. The possibility of reviewing my own experiences, thoughts and impressions as recorded in the diary had a great impact on many aspects of the research, from my interviewing style, to my analytical choices.

My initial interviewing experiences were difficult, partly because I felt unsure of myself, partly because some of the people I interviewed initially were, with hindsight, my most challenging participants. As I grew in confidence, I started to really enjoy the interview process. Box 7 below contains an extract from my reflexive diary two months into the interviewing phase.

Before I started I was very concerned about learning the schedule and being able to control what was happening. The initial parts of the interviews are still difficult now because I never know how engaged with drawing my participants are going to be and I always fear that when I come back into the room they will have drawn a simple stick man. When, after the first drawing, I see that they are engaging, I start to get a high. During the next 15 minutes I can't wait to get back into the room and start talking. Once I am back into the room again the most wonderful part starts: looking back at some of my interviews it's as if in that moment when I say, "Well, describe what you've drawn" I were diving into a fresh pool on a hot day, I am ready to close my eyes and let myself be carried by the participant's words into their world. It is a beautiful feeling, a feeling of getting lost into another world that you can explore in wonder. I have never personally been scuba-diving, but I would make a parallel between being in an interview and exploring the underwater world. Even when the other world is painful and sad and horrifying as it sometimes can be, I just get lost in it, I gasp and laugh and allow myself to respond emotionally. For an hour or so I belong to another world and my own life is never really present. I don't think of myself or my study or my personal life outside that room. I think I am in a fully receptive mode and my participants, particularly the women, respond to this by slowly opening up more and more, giving ever more of themselves to me. I know, in that moment, that I am lucky, and I feel immense gratitude towards them. Sometimes I lose my critical sense in that I am totally on their side, I believe everything they tell me and I agree to everything they say. If they feel the world has wronged them, I feel for them and I also feel that they have been wronged. I know this is necessary for them to trust me. Many of my participants are people I would not normally be meeting in my life or who would not normally become my friends. Yet I feel an enormous emotional connection with them, while we're there and afterwards. I can feel their trust in me, and I am amazed that, although they don't necessarily know about the scientific method, they are all very clear about the fact that I am not their psychotherapist, so they don't want answers from me, but at the same time they know that they can and should open up as much as possible with me. I have had amazing feedback in this sense. Although the emotional link is strong during and after the interview, when participants have cried in the interview (which has happened at least three times now – but always in a gentle manner), I did not feel like crying at all, there or later. When participants did start to cry, I supported them with Kleenex, sometimes making a small delicate joke about the Kleenex just to normalise the situation a little and then let them decide how to take it further. Often the tears would continue to emerge intermittently for the rest of the interview and, in this case, I just ignored it. So for the duration of the interview I am in another dimension. I forget about my life and myself, I am only there for them, to understand their story and to protect their body, so I am very vigilant on heat, light, comfort, water etc. I feel I am there for them and them only. It's a strange feeling. A few times it has become too much. Once or twice I have felt dizzy during an interview (and dizziness is not a problem I normally have). I have taken that physical feeling as a sign that I was getting a bit too involved, a bit too high, a bit too outside of myself. In these cases, I just made an effort during the interview to 'switch myself off' for a few seconds, by closing my eyes and mentally leaving the room in order to get back to myself. I found that sufficient to find my ground again and I don't think participants were even aware of me doing it. (26/02/2016)

Box 7. Extract from reflexive diary on the interview process

As the extract in Box 7 shows, the interview experience was an intense one for me. My main priority was to make participants feel comfortable physically and psychologically, so that a high level of disclosure could be achieved and a bond strong enough to keep participants in the study would develop. The tone in the extract is also rather buoyant, probably excessive, revealing a level of emotional involvement that proved not to be sustainable in the long run. Two months later, the sad stories I was hearing and some external personal circumstances had begun to take a toll (Box 8).

I have been having a real crisis in the last few weeks. The two interviews on Friday were very heavy for me. Paula's story particularly rough and Richard's particularly depressed. I found myself not looking forward to doing more or transcribing, feeling extremely tired physically and mentally and almost wanting to run away from all this pain and suffering. Also, to be fair, there have been other stories of death and illness around me in this period, which have certainly made things worse.
(4/4/2016)

Box 8. Extract from reflexive diary about having a crisis

I think these extracts well-illustrate the trajectory of my first encounter with CP: I obviously threw myself heart-first into the mix and then was forced by my own physical and psychological response to find a more balanced approach. My lack of direct or indirect experience with CP and a clinical population probably made the learning curve steeper.

In relation to my interviewing experience and these extracts, there are three aspects that are worth commenting on, related to my wellbeing as a researcher, to pushing boundaries within interviews and to the value of feelings in the research process.

Although, in the ethics process, I had considered practical issues related to my wellbeing, such as lone working protocols, I had underestimated the potential impact of the research on my psychological wellbeing. By the time of the extract in Box 8, I had conducted 16 first interviews. Participants were all new to CP management, so their levels of distress were high. I was finding it increasingly difficult to recover after each interview, with participants' words running in my mind for days, sometimes weeks. After discussing my feelings with my supervisor, we agreed that I should seek support, which came in the form of regular clinical supervision meetings with the service's senior counsellor. His experience with CP sufferers was useful to help me put some of the stories into perspective and find a better way of dealing with them. For example, in one conversation, he drew on psychoanalytical models of countertransference to suggest there might be a parallel between the sense of entrapment that I felt during some of the interviews (the desire to run away mentioned in Box 8) and the sense of entrapment that most sufferers experience with CP. I found his insight helped to normalize my feelings. I don't think my interviewing style changed as a result, creating an empathic bond continued to be my priority, but I was able to enjoy the interview process again. The second and third rounds of interviews were in fact much easier, partly for my increased experience and balance, but also, I think, because many participants had committed to a pain self-management journey that reduced their levels of despair.

As I mentioned in Box 7, most participants were open with me and the resulting interview data were generally rich. There were moments when, faced with the possibility of pushing boundaries further with interviewees by probing for more depth, I experienced a surge of fear that stopped me from asking an extra question. Brinkman and Kvale (2015) talk about interviews becoming 'quasi-therapeutic relationships' in which researchers are called to decide how far to take their enquiry. The decision is an ethical one: could disclosure have an effect on

the participant's wellbeing that the researcher, not being a therapist, cannot provide support for? I believe my decisions were based on such considerations, however, at times I did wonder whether my reluctance was motivated by a need to protect myself from a level of intensity that was becoming unbearable.

My feelings during the interviews, often rekindled during the analysis and that I made note of in my diary, were a resource to give my work depth, but also a potential source of bias that I had to monitor closely. During later interviews, as I grew to know participants, I became more emotionally involved in their outcomes, rooting for them and rejoicing in their successes. My response to them reinforced our empathetic bond, generating more disclosure from them and a deeper understanding for me of their experience. However, when participants elicited difficult emotions in me, I needed to be extra careful because there could be impacts on the project.

It is worth pointing out that although initially I had planned to start analysing the first and second interviews before conducting the third ones, as time progressed, it became apparent that there wouldn't be much time to do so because transcribing (which I did mostly myself) was proving quite onerous. I considered this a positive development because it allowed me, during the third interviews, to remain relatively naïve and avoid the risk of coming to the third encounter too overloaded with expectations (and interpretations). I did, however, prepare for the third interviews by briefly rereading the earlier ones, to make sure I remembered the people and the key facts they had already told me about themselves.

Conclusions on data gathering

Data collection lasted almost a year, during which my time was spent recruiting, interviewing, transcribing and reviewing transcripts. I conducted a total of 52 interviews, most of which I also transcribed, for the impossibility of knowing beforehand which participants would be lost to follow-up. The transcripts of participants who did not attend all three interviews remain in my files and sadly will probably never be used, because such is the nature of longitudinal designs.

At the end of the interviewing phase, when my supervisor and I took stock of how many complete datasets were available for the analysis, we agreed that for the purpose of my thesis I should focus only on the women.

Data analysis

The analysis phase was complex, for the sheer amount of data to be analysed and for the iterative and trial-and-error nature of the process. The analysis needed to combine multiple drawings with interview data from 8 participants longitudinally over three timepoints. The optimal format for the output of the analysis could not be defined upfront, nor could the process that would lead to it. Although iteration is a hallmark of all IPA projects, this study was more experimental than usual and there were no examples to draw from because such a design had never been attempted before. The only option was to proceed step-by-step, trying to understand what worked and what did not. The iteration concerned multiple aspects of the analysis and of the writeup, with the following key issues needing to be addressed:

- How to handle the large volume of data of different kinds (24 pain drawings, 24 Self drawings, 24 interview transcripts)?
- How to compare, longitudinally and cross-case, text and drawings?
- How to mediate between the inductive approach traditional to IPA and the desire to make the drawings central to the analytical process?

In the next sections I shall guide the reader through the steps of the analysis process. To explain this rather complex process, I shall use examples and highlight the rationale for the decisions taken at each stage.

Data available

As mentioned earlier, each participant dataset included:

3 drawings of pain (Pain T1, Pain T2 and Pain T3)

3 drawings of Self (Self T1, Self T2 and Self T3)

3 transcripts (first interview – T1, second interview – T2, third interview – T3)

For example, Gillian's data set included the drawings and interviews shown in Table 3 below.

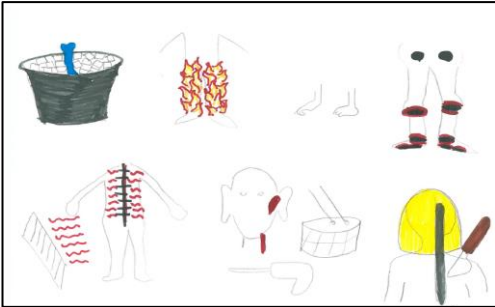





	Time 1	Time 2	Time 3
Pain drawings			
Self drawings			
Transcript of interview lasting	1 hour and 35 minutes	1 hour and 14 minutes	2 hours and 6 minutes

Table 3. Complete dataset for Gillian: Pain and Self drawings and interview durations at T1, T2 and T3

Analysing data from one interview

In line with IPA's idiographic approach, I analysed data from each interview on its own, loosely adopting the analysis process in Smith et al. (2009).

Step 1: Analyse the pain and Self drawings using Visual Analysis

Framework

Before analysing each interview, I always completed an in-depth analysis of its pain and Self drawings. For each drawing in turn, with the original A4 sheet in front of me, I spent time looking at it as a gestalt and in detail, reflecting on my first impressions, considering the mediums used, the artistic choices and the meaning of the various elements. I then proceed to analyse the drawing more systematically by using the Visual Analysis Framework proposed by Boden and Eatough (2013) and Rose (2011). The framework is a guide to fully understand an image by working through a series of questions related to the image's composition, balance, geometry, materials, texture, colour, depth/perspective, temporality/dynamism, focus, expressive content, symbolism, style, text and noise. Appendix B.1 contains the example of a completed Visual Analysis Framework for Gillian's Pain at T1 (Table 3, top left corner). Through a series of questions, this approach is aimed at widening the viewer's perspective. In a manner not dissimilar to that described by Andrews (2020), the images are 'interviewed' phenomenologically: they are encouraged to speak to the viewer, who tries to be explicit about what the image communicates to them, by listing what comes to their attention, moving beyond their own perceptual habits as they work through the questions in the framework. With the completed framework as a basis, I proceeded to summarise the image narratively, producing an output like Box 9 below (which also refers to Gillian's first pain drawing in Table 3).

This drawing of pain is composed by seven different elements each describing a physical symptom associated with fibromyalgia. The first element is a blue bone immersed in a black bucket of ice. The second element are human legs covered in flames, from the ankles to the hips. The third element contains two contracted feet, like the claws of a bird. The fourth element are lower limbs, with a black mark on both hips, black and red marks on the knees, the ankles and the feet. The fifth element is a human figure with no head, with its spine and vertebrae marked in black and with red waves extending towards the sides. Next to it on the left is a diagonal ladder-like shape from which red waves also depart towards the body. The sixth element is the shape of a face with no mouth or hair. There are two red marks: one next to the left ear and one along the left side of the neck. Next to it there is a drum with two sticks and below it another shape which is difficult to discern, perhaps a saw? The last element is the top back of a figure with blonde long hair. There is a black long vertical rod drawn against it and, to the side, there is a knife positioned diagonally as if striking the right shoulder.

The elements have a homogenous look and feel about them: the outlines are all in pencil and only some sections of some elements have been filled-in using a felt-tip, mostly with strong colours: the black bucket, the blue bone, the red and yellow flames, the red and black painful points and the yellow hair. The colours also draw the viewer's attention so that the viewer's eyes will alternate between the reds and the blacks.

All elements are basic and independent snapshots focusing on the physical sensation they are intended to describe. They are distributed over two rows, with four on top and three below, filling the landscape page entirely. Although each element is proportionate, they seem to be drawn to different scales, so that the bucket is as tall as the legs of the figure next to it. The equilibrium with which the elements are distributed on the page reminds me of an illustration in an encyclopaedia.

Many of the elements are metaphors: the bucket of ice with a blue bone stick symbolises the feeling of having cold bones typical of fibromyalgia; similarly, the reds, be these flames, emanating radiations or black and red points, represent other specific kinds of pain in other areas of the body. Finally, the drums and various tools are an attempt to describe the feelings generated by pain: a rhythmic pulsating head pain, a contraction in the back and a cutting pain in the shoulder.

Overall, this is a very physical image, almost scientific, and the sheer number of representations for pain and the copious use of red and black succeed in conveying the variety and unpleasantness of the physical sensations experienced by the drawer.

Box 9. Narrative description of Gillian's pain drawing at T1

Creating a narrative description of each drawing served various purposes: it ensured I was systematic in reviewing each drawing in depth, understanding it on its own grounds before approaching the transcript in which it was being discussed; it also served as useful summary for when I came to analyse the drawings longitudinally; finally, I could draw on the narrative when writing up the results later in the process.

Step 2: Re-listen to the interview recording

Normally, the first step in an IPA analysis is to relisten to the interview recording while looking at the transcript (Smith et al., 2009). While listening, I also looked at the drawings and, on the transcript, I highlighted the areas in which the participant was talking specifically about their pain (blue) or Self (pink) drawing.

Step 3: Note taking and initial theme development

I underlined key passages or words in the transcript and added handwritten notes to the right-hand margin of the transcript page, with observations, questions, comments, ideas on what was occurring in the corresponding transcript portion. When relevant, the notes indicated which elements of the drawing corresponded to what was being expressed and anything specific happening in the drawing. I then reviewed the notes and used them to generate themes that could capture the crux of the experience discussed in that portion of transcript and/or drawing. These went in the left margin. See Figure 3 for an example from Gillian's annotated first interview transcript.

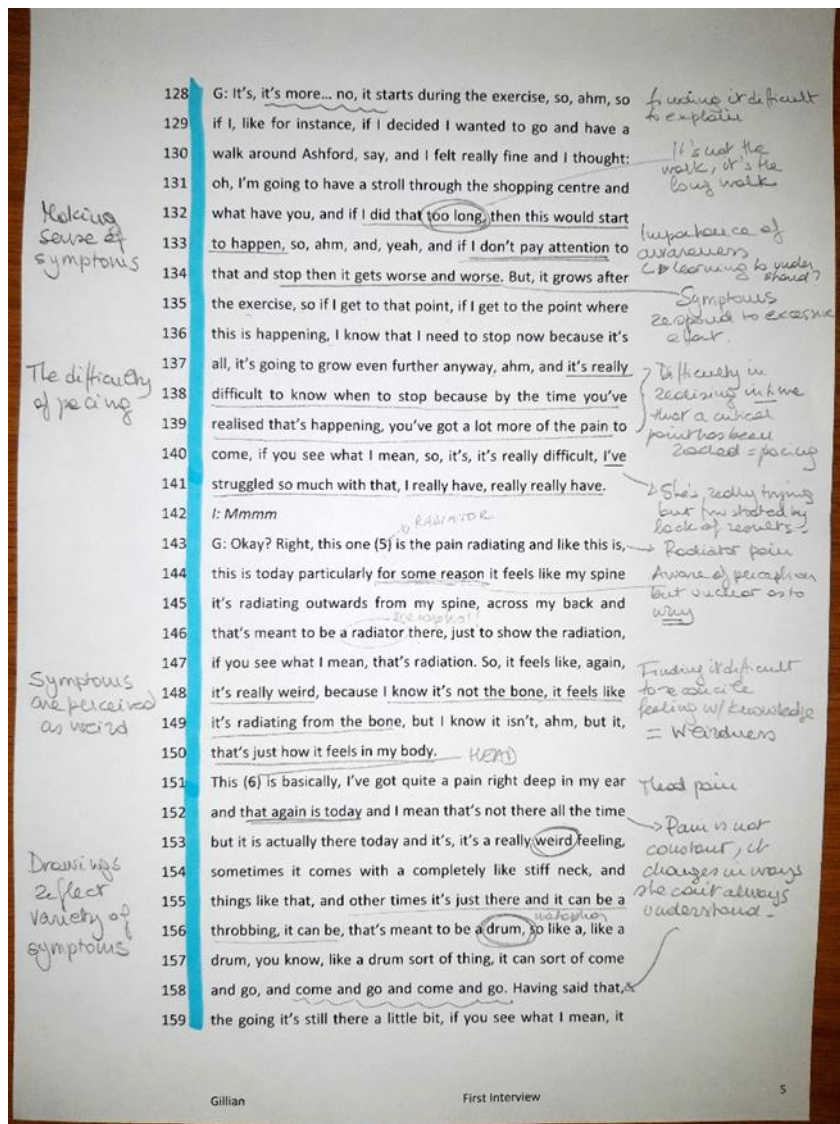


Figure 3. Portion of Gillian’s annotated transcript showing initial annotation and themes

In this portion of transcript, Gillian was describing the fourth element in the top row of her first pain drawing (Table 3, top right), where we see her hips and legs with black and red marks (lines 128-141), and then the elements on the row below. In the first paragraph she gave an example to explain how the sensation was exacerbated by effortful activity in a way that she found difficult to control. My comments in the right-hand column focused on her sense making around her symptoms (i.e. the observation that long walks could be a trigger, the need to “pay attention” to her body to discern early signs of pain flaring up, and so on). I underlined sentences such as “if I don’t pay attention” and key words such as “too long” that pointed to how Gillian was learning about how her body responded to exertion.

Then, when reviewing the notes to define themes, I aimed to capture at a higher level the psychological experiences occurring for Gillian in this portion of text. I identified two themes, reflecting two different aspects of what was happening here: the “*Making sense of symptoms*” theme captured Gillian’s efforts to understand and communicate to me her symptoms, which were apparent both in the interview transcript and in the pain drawing; the second theme, “*The*

difficulty of pacing,” encapsulates her difficulties in enacting suitable behaviours to control her symptoms. I tried to word themes in a succinct but explanatory manner, to facilitate their use in subsequent stages of the analysis.

Step 4: Clustering and draft table of themes

I then typed up the list of hand-written themes from the transcript’s left-hand column adding a ‘P:’ for ‘pain’ or an ‘S:’ for ‘self’ to specify which drawing each theme was linked to, or, when a theme could not be linked to a specific image, adding an ‘O:’ for ‘others’.

I then printed out the list of themes and cut up the paper so that each theme was on a separate strip, and I could position all strips on a table and shuffle them around randomly. Then I started to cluster the themes bringing the strips together into groups.

The most basic form of clustering was by drawing. Within each drawing’s themes, I looked for similarities, differences, and connections, to obtain a logical representation of the aspects of the participant’s experience that the drawing illustrated. Thus the analysis was deductive by drawing, but also inductive within each drawing, and the eventual table of themes reflected this structure.

Why start with a deductive focus when one of the founding principles in IPA is that the analysis should be inductive? The main reasons were the presence of the drawings, that had the ability to convey a holistic sense of each participant’s feelings in relation to their pain and to their sense of Self, and the fact that these two aspects were central to my research question. The drawings acted as strong magnets in the clustering process and I felt that, although there were some aspects of the experience of participants that cut across images, if I moved my focus away from the drawings I was at risk of losing an important thread that would serve me both in communicating my results and in analysing them longitudinally.

The need to decide whether to remain focussed on the drawings or to take a more inductive approach came up again when I analysed the idiographic data longitudinally and then cross-case. Every time that I was tempted to break away from the drawings in my thematic structures, I found that their power was bringing me back to them as the only possible common thread for the analysis.

Cluster 1	P: Symptoms can be traced far back into her past
	P: Symptoms are challenging
	P: Making sense of symptoms and pain
	P: Symptoms are perceived as weird
	P: Drawings reflect variety of symptoms
	P: Real but not real
	P: Diagnosis was a relief
Cluster 2	P: Aware of being non accepting
	P: Fantasizing about switching pain off
	P: Focusing on keeping pain even

	P: The difficulty of pacing
Cluster 3	S: Reading as a coping behaviour
	S: Candy floss brain
	S: Sleep necessary but symbol of an undesirable identity
	S: Green with envy
	S: Red in anger
	S: Moving but not doing
Cluster 4	S: Being a different person
	S: Old self was a super woman
	S: No longer being in control
	S: Old perfectionism is no longer viable
	S: Wondering whether previous identity caused illness
Cluster 5	O: Mixed feelings about husband
	O: Supportive family
	O: Talking was cathartic

Table 4. Gillian's themes from T1 after clustering

Table 4 shows the clustering for Gillian's themes at T1. There were 5 large clusters: two related to how she understood and managed her pain, two related to Self, in terms of the psychological effects of pain and how she was mourning her old Self, and one with the 'other' themes. In bold I have indicated the four themes from the transcript in Figure 3. The five clusters were then used to define Gillian's detailed table of themes for T1. In the detailed table of themes, for each theme, I also included some portions of transcript and indicated the relevant line numbers from the transcript. Table 5 below contains a subset of Gillian's final table of themes, including only the themes related to her Pain drawing. The table is structured on three levels: there is a higher level "T1 – IMAGE OF PAIN" theme, broken down into two lower level themes ("*Pain as a baffling illness*" and "*Managing pain*"), which are then broken down into detailed subthemes (e.g. "*Drawings reflect variety of symptoms*", "*Symptoms are perceived as weird*", etc.) each of which is illustrated by multiple rather long quotes and their relevant line numbers from the transcript (the quotes in bold correspond to the portion of transcript in Figure 3).

There are two anomalies here in relation to how IPA is usually done: there are three levels in the table (Pain/Self, lower level themes and detailed subthemes) and the table is very detailed, perhaps too much, and certainly not optimised (why all those quotes, one is surely enough?). Since I did not know yet how the longitudinal analysis would develop and what information would be relevant from a longitudinal perspective, I chose to postpone most analytical decisions allowing my single timepoint tables to be complex and lengthy.

The themes corresponding to portions of transcript not specifically related to a drawing were grouped in a generic "OTHER THEMES" category.

T1 - IMAGE OF PAIN	Line nos	Keywords
Pain as a baffling illness		
Drawings reflect variety of symptoms	9-13	it just felt like my whole skeleton, right the way throughout my body, was frozen and [...] I could feel the cold radiating outwards [bucket]
	66-69	my feet feel like they're scrunched that way [...] whereas my hands feel like they're scrunched that way
	92-94	It feels like the bone is hitting something other than the bone [...] and it's creating huge pain all around that area
	114-125	It's as if the bone is jolted into the receptacle [...] it's like a shock wave rips through that part of the area [lower back]
	154-158	sometimes it comes with a completely stiff neck and things like that, and other times it's just there and it can be a throbbing [...] like a drum sort of thing, it can sort of come and go, and come and go and come and go.
Symptoms are perceived as weird <i>[note: weird used 20 times in the interview]</i>	38-39	It's just weird [...] it seems to come from the bone outwards which I know is not right, but that's how it feels
	96-98	...while you're doing the exercise but afterwards it seems to grow and grow and grow, so [...] it expands itself [...] that's quite weird
	148-150	it's really weird, because I know it's not the bone, it feels like it's radiating from the bone, but I know it isn't, but that's just how it feels in my body.
Symptoms are challenging	76-77	going to the toilet in the middle of the night is a minefield [laughs] because I'm sort of quite wobbly
	302-303	it's constant, it's wearing, it's depressing [laughs], it's [pause] it's just frustrating
Making sense of symptoms and pain	131-135	I'm going to have a stroll [...] and if I did that too long, then this would start to happen, and if I don't pay attention to that and stop, then it gets worse and worse
	177-185	for some reason I don't know why, in my head I get it on the right side a lot [...] because again that is due to this all tensing up here and it actually connects somehow, I don't know how, via the neck and the ear and to here [...] that's definitively directly related to stress.
	522-525	the pain makes your brain exhausted, it's the only way I can explain it, because I don't have to sleep if I'm not in that much pain, so it is the pain that drains the energy and it also, I think it drains brain power
	542-545	[poor memory] the body, because it's trying to deal with the pain, takes the reserves from areas where it doesn't think it's needed and tries to use them for other things, so I think that's why
Symptoms can be traced far back into her past	42-43	I used to get this as a child, where it felt that my legs were on fire [...] we always thought I was maybe allergic
	872-879	I used to have what we thought was a hormone imbalance [...] and we actually now think that that was probably fibromyalgia
	1219-1220	They say also it's related to trauma as a child and I do have that as well

Real but not real	325-328	if I could switch off those sensors it wouldn't matter, because it's not real, it is real, but it's not real [...] it's my body telling me that it's there, but for a normal person it is not there
Diagnosis was a relief	575-585	I saw a specialist and he gave me a leaflet and to see everything listed there was just such a relief, because I did think I was nuts, I really didn't know what was happening to me then [...] to actually go through this list and think, "Oh, my God, it all makes sense," it was just huge, huge, <u>huge</u> relief.
Managing pain		
The difficulty of pacing	137-141	it's really difficult to know when to stop because by the time you've realised that's happening, you've got a lot more of the pain to come [...] it's really difficult, I've struggled so much with that, I really have
	322-324	I have been trying to push through it and trying to do as much as I can and it doesn't work, it really doesn't work
	385-388	for the last three years, since I've been diagnosed, it's been a whole round of that, I've sort of tried to push on and push on and my body collapses and then I'm taking weeks, months sometimes to recover
	1126-1135	it's almost like false hope, you get to a stage where you think you've got it, you think you know how to cope and you think I'm doing really well [...] so you're managing to a degree and then suddenly, bam, it seems to go up a level, because I've pushed it too far without realising
Aware of being non accepting	322	I just don't accept it
	355-358	if they can do it and they're sixty, seventy, why can't I do it? You know, I am forty something, it's just ridiculous [...] I've been fighting for a long long time
	397-402	part of me has always been so determined that this is not happening, I will get through this, I will get over this and I will push through it, but it doesn't work, that doesn't work for what I've got
	410-415	it's like two voices in my head, one wants to still push through it and the other is saying, "No, remember, you can't do this", but what is also difficult is drawing the line, because I don't want to become, where's the other thing? [self drawing] this person who is just sat there
	1192-1195	[upcoming PMP] it should get me to that point, which I am desperately needing, where I am comfy with being me, because I am clearly not at the moment, I am still clearly wishing that I was the previous me
Fantasizing about switching pain off	304-306	what I would love is to get rid of feeling [...] I would switch off my receptors completely if I could
	358-361	I know that the way fibromyalgia works it is your brain is just mixed up with the signal processing, so if we could just switch the receiving or the sending off...
	1139-1151	if I could wave a magic wand, I would just turn it off completely, I would turn off the pain receptors and I would go carefully if I'm boiling water and things like that, you know? I would watch where I'm walking and I would take particular care if I'm lighting a match or something [...] it just feels like it's just my body's overreaction to a normal

		everyday task, so if I could turn that off, I could do that again and I could go back to having a life
Focusing on keeping pain even <i>Note: uses we to refer to her and husband only when discussing pain management</i>	1042-1045	trying to keep me on an even pain level because I've not got to the point where the pain goes, but if I can keep it at a point where it's bearable, then our days are better
	1051-1055	I've got this scale from one to ten of the pain level, and if we can keep the pain level at about four, then I can do a few bits, not every day, things like that don't happen every day, but [...] it's really nice to actually be able to do that
	1120-1126	I would like to be able to properly retain it at that level where, if it's just a niggle in the background, then that's fine, I can cope with a niggle, I've never been the wossie type, I can cope with a niggle [...] if it could be kept even and bearable, I could cope with that

Table 5. Extract from Gillian's T1 table of themes, with themes related to pain

Step 5: Analysing data from subsequent timepoints

Once I had fully analysed a participant's T1 data, I proceeded to analyse their T2 and T3 data, following the same steps used for T1. However, since during the T2 and T3 interviews participants had also reviewed their previous drawing(s), in Step 2, while relistening to the recordings, I highlighted the transcript areas related to reviewing and comparing previous pain drawings and previous Self drawings. Analogously, for clustering in Step 4, the names of themes emerging from portions of transcript where previous drawings had been reviewed, were preceded by 'RP:' (for 'retrospective pain') and 'RS:' (for 'retrospective self'). I felt it was important, from an analytical perspective, to keep track of whether reflections on change or continuity with the past had been made with or without having seen the previous drawings. My assumption was that any differences would enrich my longitudinal analysis by making explicit participants' reflections on and revisitations of their own change processes (Neale, 2021). So, for instance, in Table 6 containing Gillian's summary table of themes for T2, there is a "*Feeling better on all fronts*" pain theme capturing how her T2 pain drawing (Table 3, middle column first line) only had localised red marks because her pain was now 'liveable' and also a "*Feeling that pain is hugely improved*" retrospective theme in which Gillian was comparing her current 'liveable' pain with her previous pain.

This specific perspective/retrospective distinction in the data was reflected in the way I organised the tables of themes for T2 and T3 where, at the highest level, alongside the basic PAIN, SELF and OTHER themes described in Step 4 above, there was also a "LOOKING BACK" theme (see Table 6).

T2 – IMAGE OF PAIN**Feeling better on all fronts**

Red markings are liveable pain
 Sky as a symbol of feeling calmer
 Recovering memory and brain ability as a result of reduced pain
 More aware of own body through meditation
 New tablets make a difference – or not?
 Having a bit of a life

Making it happen

Rigorously following advice as a way to improve
 Pacing has paid off
 Feeling cautiously hopeful

T2 – IMAGE OF SELF**Aspiring to a normal life****T2-T1 - LOOKING BACK****Looking back on pain**

Feeling that pain is hugely improved
 Images reflect a calmer, happier, more positive self
 Not trusting new tablets completely
 Focussing on building up strength to prevent flare-ups

Looking back on self

Different person, different life
 Wanting to work
 Hopeful but not completely trusting self and pain

T2 – OTHER THEMES**PMP Experience****Experience with the method**

Table 6. Gillian's summary table of themes for Time 2

Analysing idiographic data longitudinally

Once I had analysed all three interviews of one participant, I was ready to look across timepoints to what had changed (or not) over time. It took some time to work out how best to do this, with a certain number of iterations necessary, and, as with individual interviews, before working with the verbal data I considered the drawings.

Step 6: Longitudinally analyse the pain and Self drawings using Visual Analysis Framework

In a manner akin to what I had done for single pain and Self drawings, my first step in the longitudinal analysis was to look across the 2 sets of pain and Self drawings to see whether an evolution was apparent. Again, I spread the drawings before me to gain a first impression and a sense of gestalt of how different (or similar) they were from each other. Then, using the same framework (Boden & Eatough, 2013; Rose, 2011), I systematically searched for similarities and differences between the drawings within each set. In Appendix B.2 is a completed framework comparing Gillian's pain drawings from the three timepoints.

This initial comparison was aimed at fleshing out how the drawings had evolved between timepoints, both as a whole and in detail. For instance, looking at Gillian's three pain drawings (Table 3, top line), I noticed that at T3 her pain was visibly worse than at T2, yet her representation of her as a person in the drawings was less fragmented than at T1, nor limited to a portion of the page as it was at T2.

The completed framework then led to the final output which was, again, a narrative describing how the images compared to each other (Appendix B.3 contains an example related to Gillian's Self drawings). The act of comparing the drawings and writing the narrative helped me formulate an initial impression of how the person and their relationship with their pain and their sense of Self had evolved over the course of the study in preparation for the next step.

Step 7: Reviewing timepoint tables for longitudinal analysis

Here I revisited the three tables of themes from T1, T2 and T3. The comprehensiveness of the tables was an advantage, but also a challenge. On one hand, the richness and depth of the data had been retained, on the other hand the sheer amount of data made it difficult to gain a high-level view of the three tables together. As I looked through them repeatedly, I started to develop an understanding of the dataset as a whole, which gave me the confidence to prioritize. Through multiple recursions (Neale, 2021), or hermeneutic cycles shifting between the part-single table and the whole-complete dataset (Smith et al., 2009), I started to reduce the data's complexity by trimming and optimising the quotes and themes, aiming to retain only what was relevant in the context of the participant's longitudinal journey within the study.

Step 8: Longitudinal clustering of themes

From the trimmed tables, I extracted a summary list of all the timepoint themes. I prefixed theme names with P1, P2, P3 and R2, R3 to clarify what timepoint each originated from and whether it was retrospective or not. I also linked them to the visual elements in the drawings. I printed the list, cut it up and positioned all the themes on a flat surface for clustering. I needed to identify what Neale (2021) describes as the narrative linking events and interactions through time to develop a processual understanding of the data. I therefore grouped the themes into trajectory-like clusters answering the question: 'what are the main aspects of this person's experience which are present across the study?' Table 7 below shows one of these groupings for Gillian, where you can recognise themes from Table 5 earlier.

Themes	Visual cue
P1: Making sense of symptoms and pain	<i>Various symptoms in pain picture</i>
P1: Symptoms are perceived as weird	<i>Bucket & joints</i>
P1: Real but not real	<i>All body</i>
P1: Symptoms can be traced far back into her past	<i>Legs on fire</i>
P1: Diagnosis was a relief	<i>All symptoms</i>
P2: Red markings are liveable pain	<i>Red marks</i>
P2: Recovering memory and brain ability as a result of reduced pain	<i>Brain and sky</i>
R2: Feeling that pain is hugely improved	<i>Less red in drawing of pain</i>
R2: Hopeful but not completely trusting <i>[extensive use of touch wood]</i>	<i>Smiling</i>
P3: Pain as different physical symptoms	<i>Image of pain</i>
P3: Throbbing pain is stress overload	<i>Radiowaves</i>
R3: Small improvements but looking bad	<i>Three pain pictures together</i>
R3: Experiencing a flare-up	<i>Comparative amount of red in pain T3</i>
R3: Pulsating brain as a symbol of stress	<i>Radio waves in pain picture</i>
R3: Understanding the link between pain and stress	<i>Pain and Self pictures at T3 together</i>

Table 7. First longitudinal cluster of Gillian's pain themes

As you can see there is still a good level of detail being retained here and one might question why I did not work with the high-level themes from the timepoint tables. In other words: why did I not cluster using the higher level “*Pain as a baffling illness*” theme from T1 rather than the P1: subthemes above? The details felt necessary because they described what was happening for Gillian at each timepoint, providing a clear idiographic trace. At this stage my focus was on understanding what specific elements were changing or remaining the same, so that in the next step I could decide how best to describe that change.

The integration between drawings and narratives was particularly important in establishing what had changed or not, so my thinking during the clustering process was always shifting between what participants had drawn and what they were saying. For instance, whenever some substantial change was notable in the narrative, I would check how it could be detected in the drawings and vice versa.

Step 9: Creating a personal table of trajectories

Through the longitudinal clustering I identified several trajectories for each person. Each cluster translated roughly into a trajectory and the timepoint themes within it were grouped together and named to capture the essence of what was going on at that timepoint within that trajectory.

The high level of detail retained up to that point enabled me now to take decisions on what should be highlighted at each timepoint and choose a single illustrative quote.

The trajectories were organised into a hierarchy. Table 8 shows Gillian's table of trajectories: timepoints are presented horizontally, using colour coding. The advantage of this layout was that it provided a summary of how the key aspects of each participant's experience evolved over time which was also sufficiently concise to allow a cross-case analysis. For example, the higher-level trajectory named "*Increasing understanding of pain and confidence in dealing with it*" is broken down into four sub-trajectories: "*Developing a connection with her body and learning to recognise her limits*," "*Changing understanding of brain fog*," "*Growing confidence in the effects of medication*" and "*Subsiding pain reveals problems, triggering a flareup*." These trajectories capture how Gillian's growing understanding of her pain concerned her physical symptoms, her cognitive ones, her changing perception of the impact of medication and the effects of pain on other areas of her life.

Most sub-themes in the high-level "*Increasing understanding of pain and confidence in dealing with it*" trajectory are pain-related and can be traced to aspects and changes in the pain drawings. For instance, in the first sub-trajectory ("*Developing a connection with her own body*"), the T1 theme "*Body and pain feel unreal*" can be traced back to the "*Symptoms are perceived as weird*" theme first appearing in the page of transcript in Figure 3 (and in Table 5 and Table 7), while the T2 theme, "*Aware of the body's signs*" is the evolution of the "*More aware of own body through meditation*" theme from Table 6.

Not all trajectories were directly linked to a set of drawings, be it pain or Self. For example, brain fog was represented in Gillian's first Self drawing (Table 3, first column, second row) and in her second pain drawing (Table 3, second column, first row) and was only discussed at T3. So the "*Changing understanding of brain fog*" sub-trajectory is under a generic pain trajectory, despite relying on a details from a Self drawing. Considering what was happening to Gillian at T1, this makes perfect sense, because her pain symptoms were so overwhelming that they were affecting all areas of her life. Although the drawings remained the main drive for my longitudinal analysis, I also looked across drawing sets to consider the person as a whole. This 'conflict' between being inductive (working with what is there) and deductive (being driven by the drawings) remained throughout my analysis. Theoretically, this conflict resonates with what Neale (2021) describes as the need in a longitudinal study to balance between cases, processes and themes. Although at this stage I was still working on individual cases, I was already balancing the pain and Self themes against the processes developing for each case over time.

Main trajectory	Sub-trajectories	Time 1	Time 2	Time 3
Increasing understanding of pain and confidence in dealing with it	Developing a connection with her body and learning to recognise her limits	Body and pain feel unreal <i>it's really weird</i>	Aware of the body's signs <i>that's the precursor to the pain growing</i>	Knowing the signs and what to expect from body during a flare-up <i>I know now the signs and I can tell what's going to happen</i>
		Not realising when she should stop <i>I've pushed it too far without realising</i>	Unsure whether reading signs is enough <i>I am sure it's going to knock me sideways every now and then</i>	
	Changing understanding of brain fog	Candyfloss brain tentatively explained as pain draining energy <i>I think it drains brain power</i>	Improved brain fog assumed to be the result of less pain <i>my brain is more equipped now that it's not dealing with all of the pain</i>	Candyfloss is brain-fog and explained by illness <i>I know that it's part of fibromyalgia</i>
	Growing confidence in the effects of medication	n/a	Feeling unsure in attributing improvement to new tablet <i>this new tablet I am hoping will continue, touch wood, to make me feel better</i>	Ascribes change in intensity of flare-ups to medication <i>it doesn't happen as quickly as it used to</i>
	Subsiding pain reveals problems, triggering a flareup	No longer able to control family life due to brain fog <i>I'd always been in control [...] I'd always been in control</i>	Reduced pain creates mental space to deal with other things <i>able to deal with other stuff</i>	Believes personal problems triggered flare-up <i>while I was letting that go, I was doing really really well</i>
From a negative emotional state, to feeling optimistic, to losing her balance but expressing agency	Changing life and mood: from despondence and resistance, through optimism, to acceptance and coping with a crisis	Negative emotions for losing old self <i>anger and frustration</i>	Being more calm and accepting <i>I am less fraught, less worried</i>	Responding to new upset with self compassion and agency <i>need to do whatever I can to help myself</i>
		Resenting life having completely changed <i>I am just a completely different person and I want to go back</i>	Feeling able to recover some of her life <i>I'm doing things and I'm hoping to be able to do more in the future.</i>	
	Pacing as a symbol of struggling with a new identity	Pacing represents an unwanted identity <i>if I'm pacing myself, I'm less that person, but also slightly more that person</i>	Rigorous pacing as an identity-affirming action <i>I have done it definitely to the letter</i>	Interpreting pacing difficulties as a sign of lack of acceptance <i>I just seem to push myself back, so I think I need to content myself with doing what I'm doing</i>
	Gaining control and dealing with a new uncontrollable situation with increased agency	No longer being in control was a shock <i>just not be in control any more was a real shock [...] I thought I was turning into a zombie</i>	Feeling calmer and more in control <i>the world is not ending and my life is not ending</i>	Dealing with a challenge with agency <i>I just need to do something to get me back to there [t2] really</i>

Table 8. Gillian's table of trajectories

Writing up Jane's pain as a case study

While I was conducting the idiographic analyses, my supervisor and I decided it would be a good idea to select a subset of the available data to publish as a preliminary output from my work. We decided Jane's pain drawings would be the most suitable, partly for the intrinsic qualities of her drawings, which were evocative and attractive, partly because her story was sufficiently simple and impactful to make a good case study. The result is the Nizza et al. (2018) paper included in Appendix C.1.

Cross-case analysis

The starting point for the cross-case analysis were the 8 individual tables of trajectories, formatted like Gillian's in Table 8, and each participant's set of 6 drawings. To start, I spent a certain amount of time just looking over the tables and drawings, comparing, thinking in terms of how similar and different they were. To facilitate this comparison, I condensed each participant's pain and Self trajectory into a "From... To..." naming format, that would help me clarify whether there had been any change in that area and in what terms. So, for instance, Gillian's "*Developing a connection with her own body and learning to recognise her own limits*" sub-trajectory from Table 8 was renamed as a "*From baffling to manageable*" pain theme.

Looking across all tables I could see three types of pain trajectory: a positive one where the relationship with pain had consistently improved from one timepoint to the next; a negative one where pain seemed to have worsened in some way; and a disrupted one where, despite an overall improvement, there had been some difficulties. Within each trajectory type, I could clearly identify and describe an individual path for each participant, so that despite the common type of trajectory, how it developed was profoundly idiosyncratic.

I then did the same with the Self trajectories, and found that the same groupings could be applied, with the pain groupings influencing how the Self ones were seen. The three types of Self trajectories reflected how participants had been able to overhaul their lives following the PMP: a radical change trajectory, a no change/worsening trajectory and a difficult adjustment one. Again, although different aspects of each participant's life were involved in their change, there was communality within the trajectory types in terms of how the change (or lack thereof) had unfolded.

Table 9 below is the resulting table of longitudinal themes for the group which I used to prepare the first draft of my thesis.

Theme	Tr aj.	Particip ant	Trajectory description	Time 1	Time 2	Time 3
1. Changing relationsh ip with pain	Positive	Jane	From overwhelming to concealed	Pain as an overwhelming weight affecting normality <i>confining, crushing heavy</i>	Pain is perceived as localised <i>I can pinpoint these targets</i>	Pain is in the background but still present <i>it's there and it is sharp</i>
		Monica	From aggressive to controllable	Pain as an aggressor with many weapons <i>some of it can feel aggressive</i> Pain as an angry controlling agent <i>something that sits in my brain and decides</i>	Pain as an obstacle course <i>something happens and there's a spanner thrown in the works</i> Increasing acceptance reflected in management goal <i>eventually we'll get down to here; not much more accepting</i>	Pain as a balancing act for every spanner it throws in the works, I can now, mostly... Accepting pain as part of life <i>just the way my life is; something to be dealt with, rather than something to fight against</i>
		Olga	From depersonalisin g to liveable	Using metaphors and colours to explain symptoms <i>I call it toothache; I wanted it to be red, because it's angry</i> Cloud and sadness symbol of uncharacteristic low mood <i>it weighs on you and it does get you down</i>	Diminished pain reflected in fewer symbols <i>I lost an awful lot of the pain</i> Reducing medication affects brain and mood <i>not having your brain quite so foggy; despite the pain I can still feel like, yes</i>	Greatly reduced pain, fewer symbols and lighter colours <i>it's nothing like it used to be; I wanted it to be a lighter colour</i> Mood is greatly improved <i>it used to be really, really bad all the time; I just feel so much brighter</i>
	Negative	Alison	From avoidance to more pain	Pain flare-up equated to an ongoing electric shock <i>hurts for a split second [...] over hours.</i> Dissociation from body in pain <i>the more you think about it, the worse it gets in your head</i> Accepting own limitations <i>because I know my limitations, I can manage the pain</i>	There is more to it than just pain <i>it's not just the pain, it's everything else that comes with it.</i> Co-morbid ME makes mood predominant over pain <i>my mood's overtaking the pain this time that [PT2] is worse than that [PT1]</i> Still doing more than is good for her <i>it's just your bodily instinct</i>	Using a pain scale <i>I'm sort of just past the middle</i> New medication upsets both physical and psychological balance <i>when you're feeling bad about yourself, the pain seems 20 times worse</i> Shattered illusions <i>when it doesn't work, it's like you're at the bottom again</i>
		Helen	From aggressive and distressing to relentless and confusing	Pain as an overshadowing aggressive demon <i>it's faceless and relentless</i> Feeling cut off and low <i>Wherever you move, the brick wall just comes up.</i> <i>If I start crying I'm never going to stop</i>	Feeling under attack and confused <i>it's like someone is just constantly firing pain at you</i> Isolated and a bit crazy <i>I spend a lot of my life listening to what everyone else is doing</i>	Pain as relentless and confusing <i>it never really stops</i> <i>it looks really confused</i> Out of control and worried <i>this is madder</i>

	Disrupted	Gillian	From baffling to manageable	Body feels unreal <i>it's really weird</i> Not realising when she should stop <i>I've pushed it too far without realising</i>	Aware of the body's signs <i>that's the precursor to the pain growing</i> Unsure whether reading signs is enough <i>I am sure it's going to knock me sideways every now and then</i>	Knowing the signs and what to expect from body during a flare-up <i>I know now the signs and I can tell what's going to happen</i>
		Kate	From unreal to acceptable	Questioning the reality of illness <i>"it must be in my head, I must be imagining it"</i> Feeling that to accept means giving up on quality of life <i>I don't want to give up, I still want a quality of life</i>	Illness perceived as cruel for raising hopes <i>it gives me that little bit of hope</i> Feeling that to accept doesn't mean you're giving in <i>acceptance isn't giving in</i>	Still not totally believing she's ill <i>I suddenly think, "Oh actually, are you really ill?"</i> Acceptance linked to quality of life <i>I have got to do these little, little steps to have that quality of life</i>
		Lauren	From alienation to realness	Pain constant and aggressive <i>I feel like I am being strangled at times</i> Cloud as low mood and poor thinking <i>I just cannot think straight</i> Pain has crushed her expectations <i>I'm not how I envisaged myself to be.</i>	Worse symptoms but more acceptance <i>I've started to accept it</i> Admitting to the level of pain would have increased the sense of failure <i>I am not a failure</i>	Same pain, better coping <i>a more positive person in my mind as to where I'm going with the pain</i> Feeling clearer <i>I think because I feel clearer in my mind</i> Taking control from pain <i>I am living with my pain, I am not being judged by it</i>
	Radical change	Jane	From questioning her future to living a natural life	Tired with an uncertain life <i>you haven't got the energy; you get tired of struggling, quite honestly</i> Feeling unsupported and obliged to function <i>I could stay in bed for weeks, but I don't</i>	Reaching the end of the rainbow <i>the end of my rainbow.</i> Learning that duty is a choice <i>I am allowed.</i>	Settling into a naturally uncertain existence <i>that's natural</i> Feeling she still has to help others <i>I can't, you know, not</i>
		Olga	From despondence to feeling in control of her life	Disappointed by a contracting life <i>my world's getting quite small; I don't want it to continue</i> Sense of isolation is very upsetting <i>I feel very distanced from them</i>	Having normal life concerns and thinking ahead into a rosy future <i>then my daughter is in there as well; it's a little bit more rosy</i> No longer feeling distant from family <i>I definitely don't feel distant from the family</i>	In control of her life and having a plan <i>I can control me, myself and my destiny; I am trying to focus on different things</i> No longer feeling a burden <i>I just felt like I was being a burden</i>
		Monica	From resistance to active self-care	Compartmentalisation as a strategy to survive psychologically <i>trying to keep control of it all</i> Burdened by duty and responsibility for others <i>they're all my responsibility because they're hopeless</i>	Experiencing a moment of disruption and confusion <i>it's like a hornet's nest</i> Aware of having previously ignored her own needs <i>It's listening to me and how I am actually feeling</i>	Having two selves as a form of protection <i>this bit is what carries my Little Me</i> Realising that duty and responsibility are a choice <i>I have a choice in this</i> Still working on saying no to mother <i>the first time I said no, I felt horrendously</i>

**2. Relations
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Self (+
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and life)**

				Being at the centre of everything <i>I don't have time for me!</i> Resisting by having a positive mental attitude <i>if I give in to it, I've lost myself</i>	Learning to say no to mother <i>that's given the sting but also the sweetener</i> Admitting she wants to flee <i>Trying to get away from it all!</i>	<i>guilty</i> Coping better by being more self forgiving <i>I've stopped being so hard on myself</i>
	No change/worsening	Alison	From negative emotions to more negative emotions	A range of emotions yearning for a life that is no more <i>just like a vicious circle, you just go round and round and round</i> Feeling unsupported by HCP <i>couldn't get hold of them</i>	Drawing does not reflect negative emotions which are there <i>I'm actually living that this week, I wasn't living it last time.</i> Most HCP continue to be unsatisfactory <i>I know I'm overweight, because of the medication you keep giving me</i>	Negative emotions are displayed again <i>it's like numb</i> <i>I just want my life back</i> HCP don't understand what it's like for patients <i>I don't need somebody telling me to do it!</i>
		Helen	From worrying isolation to feeling unable to help herself	A worrying life with no prospects <i>that's how I feel about my future</i> Feeling unsupported in dealing with drugs & symptoms <i>they say they're going to give you all this support, they haven't got time</i> Family don't understand <i>They definitely don't get it, no, but does anyone ever really get it?</i>	Deeply sad and anxious <i>this desert island, this is where I am</i> <i>I'm just a bit scared</i> Unable to help herself <i>We are our own worst enemies</i> Family still distant <i>it makes me feel that I am a nuisance to need it</i>	Isolated & broken <i>broken, in pieces, not good</i> Still feeling unsupported <i>there is no one to talk to</i> Bleak outlook <i>this pain is always going to be there, it's part of me, it's really what I do with this bit [SelfT3] that really matters, and I am not good at asking for help</i>
	Difficult adjustment	Gillian	From emptiness to balance and control	No longer being in control was a shock <i>I thought I was turning into a zombie</i> Negative emotions for losing old self <i>anger and frustration</i> Resenting life having completely changed <i>I am just a completely different person and I want to go back</i>	Feeling calmer and more in control <i>the world is not ending and my life is not ending</i> Being more calm and accepting <i>I am less fraught, less worried</i> Feeling able to recover some of her life <i>I'm doing things and I'm hoping to be able to do more in the future.</i>	Dealing with a challenge with agency <i>I just need to do something to get me back to there [t2] really</i> Responding to new upset with self-compassion and agency <i>need to do whatever I can to help myself</i>
		Kate	From muddled resentment to peaceful adaptation	Hanging on to her personality as last bastion in fighting pain <i>the middle represents my personality</i> Finding silver linings <i>it made me stop and smell the roses</i> Wanting to project a positive image despite having negative feelings <i>I have to hold on to that glass half full.</i> Having a caring, responsible and nurturing personality <i>that sense of responsibility and that</i>	Proud to have hung on to herself <i>I feel proud in the fact that I am still holding on to me</i> Stop and smell the roses <i>I've actually stopped and looked at the world around me</i> Emphasising her positive side while admitting negative emotions <i>that's how I like to see myself, I'm a happy person</i> Being given permission to say no and	Feeling at peace, yet the same person <i>I like me being me, for the first time ever I can say that</i> Feeling forced to live in the moment and doing her best to adapt <i>I try and look in on the bright side, but it's [illness] definitely made me stop</i> Making a conscious choice to look ahead and be positive <i>I could [...] make everybody living with me's life a misery, couldn't I? But I don't</i>

				<i>nurturing and that mothering thing</i> Feeling socially isolated <i>you can't keep up with everybody else</i>	look after herself <i>[the course] was a validation of all the things I was already thinking</i> Focusing on the world around <i>you can't say no to everything</i>	Having a duty only to herself <i>I've got to look after me, because [...] it's no good not to</i> Wanting to make memories <i>I'm going to go and make some memories</i>
		Lauren	From fighting herself to being real	Willing herself to think positively <i>turn that frown upside down, start smiling.</i> Pain and self are separate <i>it's not me, but I know it's me</i> Family provides identity, motivation and wellbeing <i>they keep me going</i> Shielding family from pain <i>it's not fair to them, it's not their problem</i>	Accepting what comes <i>This is me throwing the doors open to all possibilities</i> Focusing on self while still engaging with family <i>it's now about what I can do for me</i> Asking for help is interpreted positively <i>it's not wrong to ask for help</i>	Claiming the right to be herself <i>I'm not going to apologise for being the way I am</i> Pain and self are one <i>that jolly Lauren that I always am and always was</i> No longer taking on other people's problems <i>all I'm doing is taking their stress on</i> Being open with family about pain <i>I didn't tell anybody how I felt</i>

Table 9. Final draft of the table of longitudinal themes for the group – with details

Although I have described the process culminating in Table 9 in a linear form, starting from the initial analysis of each person's timepoint drawings/interview to the idiographic longitudinal analysis of each participant's data, to the cross-case analysis looking for similarities and differences between participants, the journey was far more iterative than my description suggests. Often tables were drafted multiple times, themes were revisited, renamed, joined or let go. Similarly, the approach I took to writing up the first draft of my thesis reflected the structure of Table 9, with one chapter related to Pain and one related to Self, but this decision eventually had to be revisited.

Final writeup

I realise now how my iterative analytical process was not only due to the fact that I was covering new ground methodologically, it was the manifestation of recognised tensions when conducting longitudinal research. Neale (2021) describes the development of a case history as “a balancing act between condensing data and reframing the richness and particularities of a case narrative” (p. 287) which explains my reluctance to condense too early the individual tables of themes (Table 5) and the individual tables of trajectories (Table 8). She also usefully points out that longitudinal research implies an interaction between three competing but complementary analytical strategies: cases, processes and themes. I can see how in my cross-case analysis iterations, themes (most notably pain and Self) were in conflict with a more processual aspect, in which issues of temporality, or perhaps even cause and effect, needed to be addressed for each person as a whole. When I first drafted my results for inclusion in this thesis, I had two chapters, one for pain and one for Self, reflecting the contents of Table 9. But the “story” did not work: the separation between the drawings felt artificial because although the drawings were separate artifacts and my original research question considered the two concepts of pain and Self as separate, the journey of each participant within the study had been a cohesive process where pain and Self had been inexorably entwined.

So, through yet another iteration, my table of themes was simplified and structured around three general trajectory types that could encompass the pain and Self trajectories, as you can see in Table 10 in Chapter 6.

Chapter 6: Introduction to results and first trajectory group

Introduction to all results

The results from my analysis of visual and verbal data from the 8 female participants in my study are summarised in Table 10 below.

Type of trajectory	Name	Individual trajectory
Upward and positive	Jane	From dark oppression to serene normality
	Olga	From despondency to planning her future
	Monica	From resistance to self-compassion
Negative or unchanging	Helen	Increasingly isolated and unable to act
	Alison	An ongoing low mood and lack of engagement
Positive but complicated	Gillian	From feeling alienated to being in control in a crisis
	Kate	A slow acceptance and integration of pain into life
	Lauren	From raging to being real

Table 10. Three trajectory groups for the study and the individual trajectories within them

As you can see in Table 10, the journey of participants in the study is defined as a trajectory and I identified three types of trajectories: an upward and positive one, a negative or unchanging one and a positive but complicated one.

I chose to use trajectories to summarise results at the highest level because I wanted to bring focus to the process of change, emphasising its presence (or lack thereof) and its quality. Within each trajectory type, I then prioritised cases over time and theme. Alternative approaches would have been to prioritise themes (notably pain and Self, as in Table 9) or time (by discussing results of all trajectory participants together, timepoint by timepoint). My decision was driven by the fact that drawings could only be considered as a whole and could not be collapsed or summarised in any way and by my determination to adhere to and capitalise on IPA's idiographic stance: as you will see, the case-by-case approach allows each participant's drawings to be considered together and in the context of that participant's narrative, bringing the idiosyncratic nature of CP to the fore.

All participants, with no exception, entered the study at a very low point in their life: pain was dominant and they felt dejected. Everyone attended the PMP between their first and second interview and the trajectories reflect the different ways in which their lives developed thereafter. The **upward and positive trajectory** includes three participants who wholeheartedly embraced the change encouraged by the PMP and whose lives, in the following months, were transformed and normalised. In contrast, the two participants in the **negative or unchanging trajectory** found it difficult to engage with the CCPS and their relationship with their pain and life in

general appeared ‘stuck’, in some ways deteriorating. If we consider the above trajectories as the two ends of a spectrum, the three participants in the **positive but complicated** trajectory would be somewhere in the middle. While still progressing, they had a more difficult time because they had to deal with disrupting events and their progress was less linear and/or slower.

I have named the individual trajectory of each participant, with its idiosyncratic features. For instance, Jane’s upward and positive trajectory is described as a journey “*From dark oppression to serene normality,*” while in Helen’s negative or unchanging trajectory she was “*Increasingly isolated and unable to act.*” The individual trajectories cover all drawings from each participant, addressing therefore the evolution of both their pain and their Self drawings and the accompanying narratives.

This and the next two chapters are dedicated to the three trajectory types, one per type, in the order in which they appear in Table 10 above. Within each chapter, once the trajectory group has been introduced, the individual trajectories of participants are presented as single cases. Each case develops chronologically so that I discuss what happened to a participant at T1 before discussing T2 and T3 and, within each timepoint, I focus on pain drawings first and Self drawings later. The actual drawings from each participant are all included in a single table, with one row per timepoint, and a pain and Self column, to enable a horizontal comparison between the pain and Self drawings from a given timepoint and a vertical comparison between the pain or Self drawings from different timepoints. Larger versions of the same drawings are provided in Appendix D. The narrative includes comparisons between the drawings of each participant in terms of similarities and differences. Comparisons between participants are briefly presented in the introduction to each chapter, and then developed more fully in the discussion section of the chapter. Here I consider similarities and differences between the individual trajectories within the group, make comparisons with previously discussed trajectory groups and consider key aspects of each trajectory group in relation to literature.

While reading through the cases and the trajectories, keep in mind that the first interviews (T1) occurred a few weeks after participants had attended the PES, a three-hour presentation of CP management principles and of the CCPS (see Chapter 3 for more details); the second interviews (T2) occurred one month after participants had attended a PMP and been introduced to various self-management techniques, with some attending the PMP sooner than others (for specific times see Table 2); the final interviews (T3) were six months after the PMP. Also, consider that, although the data were gathered at equivalent timepoints, each participant arrived at the service with a long personal history of CP and the support they received was tailored to their needs. Although a few participants did experience a reduction in pain levels during the study, my focus was on how their relationship with the pain had changed, if at all, and how this was reflected in the drawings. In the Self drawings, each participant represented different aspects of their lifeworld and identity, so the topics they discussed were quite varied (e.g. in some

narratives family is more central than others). I tried to remain focused on the impact that CP was having on their sense of who they were and on their psychological wellbeing in relation to their pain and to what was important to them in their life.

Upward and positive trajectory: Jane, Olga and Monica

Jane, Olga and Monica's stories and drawings share a consistent progress over time, although what constituted progress was different for each of them. As will become apparent reviewing their individual trajectories, they all started from a position in which the pain was represented as an aggressive and oppressive presence in their lives and they appeared under great psychological stress in their initial Self drawings. Step-by-step, through attending the PMP, but not only, their drawings, their narratives and indeed their lives, changed for the best. Pain stopped being the main feature of their lives, they were able to integrate it and find a new balance and sense of control. Stimulated by the CCPS, all three women took important life-changing decisions.

Jane's transformation was the fastest and most outstanding: she broke up from her partner and started to focus on her own needs. The change was the key for a new life of wellbeing and independence that led her, eventually, to start working and return to a quasi-normal life.

Olga's decision to come off opioids transformed her pain levels and, most importantly, her outlook, so she soon progressed to a future-oriented mood, in which she felt happy, optimistic and determined to address her long-standing obesity.

Monica's was a profound psychological transformation: through individual counselling she embarked on a journey of self-discovery at the end of which she understood herself better and felt able to take control of her life.

All women in this trajectory group embraced their time in the CCPS and their PMP attendance as a unique opportunity to work on themselves and their situation and regain control over their own lives.

Jane's journey: from dark oppression to serene normality

Jane's journey over the course of the study was one of the most successful: from a very low and lonely place, in which pain was an oppressing presence, she was able to regain an overall sense of control and naturalness. Her pain drawings evolved to reflect the increasingly less important presence of pain in her life while, in parallel, how she depicted her life in her Self drawings changed from a dark arduous path to a lighter more natural one.


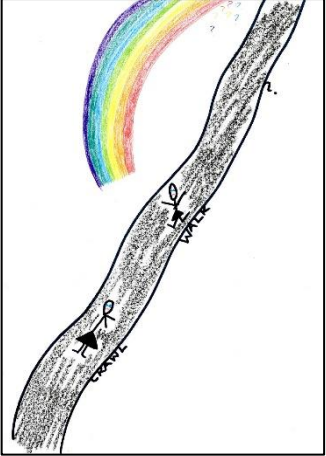
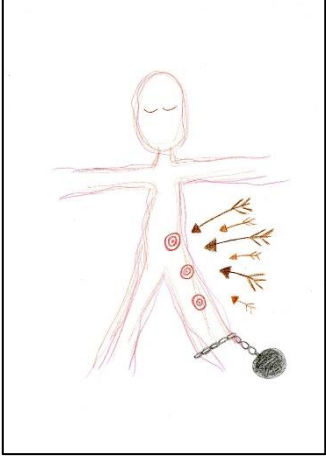
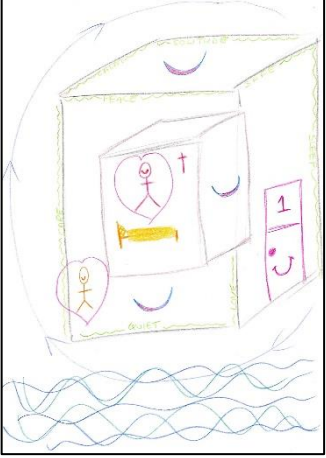
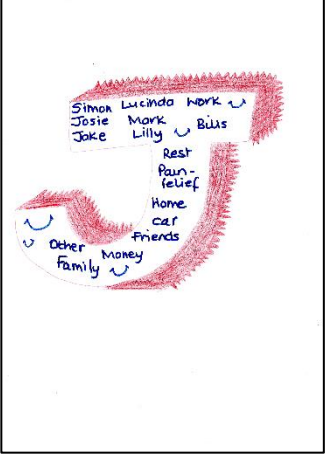

	PAIN	SELF
TIME 1	 A drawing of a person in a blue dress being crushed by a large, dark, triangular weight labeled '1 TONNE'. Arrows point down from the weight onto the person.	 A drawing of a person walking a dark, winding path towards a bright rainbow at the top.
TIME 2	 A drawing of a person with arrows pointing to their chest and a ball of pain at the bottom.	 A drawing of a person inside a box with a heart and a door. The box is labeled '1' and 'GUILT'.
TIME 3	 A drawing of a person surrounded by names: Simon, Lucinda, Mark, Josie, Mark, Lilly, Jake, Billy, Rest, Pain, Relief, Home, car, Friends, Other, Money, Family.	 A drawing of a person walking a path through a forest with trees and a path leading to a house.

Figure 4. Jane's drawings of her pain and Self – larger format drawings in Appendix D.1

Time 1. All of Jane's drawings were powerfully symbolical and included a representation of her, either in relation to her pain or in relation to her life at that time. At the first timepoint, Jane drew her pain as a heavy one-tonne weight hanging above the head of a small stick figure (Figure 4, Pain T1). The weight was out of proportion compared to the figure and the arrows beneath it suggest it was moving downwards and would possibly crush her, while the figure's little muscles were flexed in an effort to resist. Jane described her pain as "confining" and "crushing heavy." She equated the arrows projecting from the weight towards and around the stick figure's body to a cloak:

Then when you're kind of cloaked in this sort of pain, you haven't got the energy [...] you're so focussed on this [weight] [...] you're trapped in this sort of bubble of what you want to do, what you can do and what you actually feel like doing [Jane, T1]

By enveloping her and keeping her trapped in that position, the pain was attracting all Jane's focus, forcing her look inwards, limiting the energy she would have needed to act normally. She perceived a conflict between what she wanted to do and what she could do, and between what she could do and what she actually felt like doing, suggesting that the pain was having a strong effect on her mood as well.

Her first pain drawing also contains a line below the stick figure, which Jane explained using a metaphor a counsellor had used with her many years earlier:

"you've got all these people that you're supporting on your raft," she said, "but who's supporting you?" [Jane, T1]

The line/raft represented Jane's tendency to assume a supportive role with the people she loved and at present she was not feeling supported in return, in fact she observed how lonely the figure in the picture looked: "what there should be is other people stood next to me and there isn't." Although there were people in Jane's life, she felt alone in dealing with her pain.

The sense of feeling overwhelmed and lonely is echoed in Jane's first Self drawing (Figure 4, Self T1). It includes two stick-figure versions of her positioned on a long dark path that develops uphill across the page: the first figure is crawling, the second is walking, and further along the path there is an interrogation mark, questioning what lies ahead. A half rainbow hanging over the path ends somewhere beyond the page, as if hope had been interrupted:

when you've got this pain all the time [pause] it's hard to be sort of optimistic [...] there are times when quite honestly I don't even want to know what is at the end of there [path], I'm not, I said to my GP actually, I want to see my son grow up, I want see him get married, have a career, I want to see him do all these things, but quite honestly, if I could fast forward through it all to the end, I would [...] just get to the end and just let me have a rest, just stop, enough [Jane, T1]

Jane's life with pain felt like a dark and difficult path, where she was finding it hard to look ahead and be hopeful. She had lost her desire to savour even her young son's major milestones, so she was prepared to zoom through them to reach "the end" and finally have some respite. Although she clarified that she was not suicidal, Jane felt the need to "rest" because living was a struggle for her.

As with her pain picture, Jane commented on the loneliness of her Self picture: *“there’s no background to it, there is no [pause] no trees, no pictures of anybody else, just me, pain and an uncertain future.”* Her sense of isolation was exacerbated by living with a partner who did not *“really understand”* her plight and feeling unable to effectively assert her own needs with him.

At the start of the study Jane was crushed, overwhelmed and isolated by a pain that was preventing any form of ‘normal’ life. She felt trapped in a dead-end situation: with a crippling tiredness, an unsatisfactory relationship and an uncertain sense of her future.

Time 2. At the second timepoint, Jane drew her pain as an ethereal Christ-like figure with a ball and chain tied to its left ankle and some targets down its left leg (Figure 4, Pain T2). The impact of the pain appeared more limited compared to earlier: she said that the pain was *“direct in certain places”* and from there *“blurring everything else,”* suggesting that, although still present, the pain was now localised and less overwhelming (e.g. no longer *“crushing,”* but *“blurring”*). It was as if the weight from her first pain drawing (Figure 4, Pain T1) had lifted from her head and was now simply tying her down.

She also described the body of the figure in her second pain drawing as being *“bisected”*: one half was associated with her heavy painful past (the one with the pain marks and ball and chain) while the other free half she described as her more positive *“going forward side”*:

*I’ve only done that on one side because of how my life is changed over the past few weeks
[...] this half of my body is more positive [...] and that’s the sort of going forward side [Jane,
T2]*

By her second interview, Jane’s life had changed radically. During the PMP she had bonded with other CP sufferers and this had given her the strength to leave her partner and move out of his home. She had also been offered a part-time job by a relative, which had the effect of *“reinforcing the positive side”* by making her feel supported by others.

When comparing her first and second pain drawings (Figure 4, Pain T1 & T2), Jane said, *“I’ve isolated the pain,”* and suggested that before she had *“allowed the pain to take over.”* In these expressions there is a marked shift in agency from the pain to Jane: where previously the control had been with the enveloping cloak of pain, now that the pain was more localised, the space it occupied seemed to have been reduced, allowing Jane to express agency and reclaim some control over her life. Jane ascribed this shift to the PMP having provided her with tools through which she had been able to *“take ownership”* of the pain and *“put it in its place”*. The result was a more balanced view of herself, reflected in the symmetrical posture of the figure in her second pain drawing. Although pain was present and half of her still felt heavy from the ball and chain, this was counter-balanced by new psychological resources, which had enabled Jane to take responsibility for self-managing her pain and made her feel more empowered.

Breaking up from her partner had been a release for Jane. Her second drawing of her Self (Figure 4, Self T2) illustrates her new living situation: by the sea, in her own flat (outer cube), with her beloved son and in her own bedroom (inner cube):

I just shut that door, that's my room, that's my space. [...] I am quite happy in my single bed and it's really lovely in there [...] I've got solitude, safe, sleep, love, quiet and care and calm, because they're the things that I want in life, they're the things that [...] I haven't had for quite a long time [...] I've kind of got to the end of my rainbow [Jane, T2]

The words listed by Jane in the quote appear along the perimeter of the external cube. Her home and bedroom were places where she could experience a tranquillity and a security that had not been possible while she was living with her partner. By deciding to break up and live on her own, Jane had finally affirmed her own needs over the needs of others. This impetus had extended to her relationship with her son, who appeared in her Self drawing in a heart but outside the inner cube, because new understandings acquired during the PMP had redefined how she conceived her role as a mother:

...it's okay to have, say, a bad day, it's okay to say I am going to bed, you know, tea is not happening tonight [...] I don't have to worry about, you know, well I am the mum here, I should be doing x, y, z. It's okay for me to be at this point in my life being who I am and doing what I want to do [Jane, T2]

It was as if at the PMP Jane had been given permission to behave and think of herself differently. Her previous beliefs about what her mother/partner role entailed had led Jane to engage in behaviours that were damaging her physically, for instance by forcing her, when having a “*bad day*”, to stay up rather than go to bed. She took responsibility for her previous behaviours (“*I was making life harder for myself*”) and was now recognising her own physical needs and acting accordingly.

The Self in Jane’s second picture was a new version of her: free from her previous role constrictions, focussed on her own needs and happy to the point of ecstasy. She described her new home as “*her sanctuary*” and dotted it with smiles and hearts. As Jane pointed out, the drawing contained the colours of the rainbow of which she had previously questioned the existence. The end of the rainbow had been reached. As the arrows around the cube in her second Self drawing showed, she had come “*full circle*,” finally coming home, both physically and metaphorically.

Jane’s drawings of pain and Self at the second timepoint convey a new serenity and sense of control over her life. The role of pain was more contained than previously, and her Self drawing pointed to a newfound calmness and self-focus. The PMP had stimulated her to make substantial changes and, more importantly, to achieve a new positive outlook.

Time 3. Five months later, at the third timepoint, Jane’s life appeared to have stabilised. She drew her pain as a three-dimensional letter J, her initial, with its depth coloured in red and spiky teeth in the background (Figure 4, Pain T3). By representing herself (the letter J) as a working

front, with all the key words of a ‘quasi-normal’ life, Jane had been able to relegate the pain to the background:

People can't see it, which is why I've done it behind me, it's there and it's sharp, and it is all over, but people, they don't see it, because I don't whinge and I don't moan about it [Jane, T3]

Jane felt able to live her life without making others aware of her pain, which she considered an achievement. The words she added to the front of the letter J provide insight into what was important to her at the time: there were names of family members, because the improvement of her pain and general wellbeing had been accompanied by a re-kindling of her family ties; there were words such as “money”, “car”, “work” and “bills” to emphasise a return to normality; but there were also “rest” and “pain relief” to indicate that, although not visible to others, pain was still an ongoing concern of hers.

Over the course of the study, Jane’s pain had not ceased, but had been transformed from being an overwhelming presence, to being a part of her life that she felt control over and could conceal from others, within a routine of quasi-normality.

This new sense of normality also emerges from Jane’s third Self drawing, which is a soft-coloured representation of her “*path through life*” (Figure 4, Self T3). The drawing depicts a slightly uphill white path, with colourful obstacles, skirted on the left by a wood and on the right by the sea. A pink stick figure representing Jane stands at one end of the path, next to a clock. A dotted line weaves its way from her, through the obstacles, to another clock at the end of the path and back.

I put the trees and the sea because they're ongoing, they never change and they keep going and going, so this is like the path through life and the two clocks are the beginning of the day and the end of the day, and these are hurdles, because whichever way I turn, every day, it's just hurdles, they're not insurmountable hurdles, they're hurdles nonetheless [Jane, T3]

Jane was describing her daily routine, weaving her way over hurdles, in an unchanging pleasant environment. Although this description may seem low-key, particularly compared to her blissfulness at T2, a regular alternation of small and large obstacles, within pleasant surroundings well-exemplifies the serenity that often underlies “normality”. The obstacles Jane was facing were the ones she had listed in her third pain drawing (Figure 4, Pain T3): having to work, pay bills, manage a home, money, and so on. Considering that Jane had started her journey in the study on a dark path, to find her just six months later in control of her pain and working again almost full-time was astounding.

From being unemployed and financially dependent, Jane had become employed and running her own home. In her time off, she was also providing care for her sister’s toddler:

I can't say no, because there's nobody else she can ask [...] that was originally my day to just stop and do nothing [Jane, T3]

Was Jane’s sense of sisterly obligation pushing her back into old behaviour patterns, after having realised the importance of prioritizing her own needs at T2? Relationships of mutual

support are fundamental building blocks of a 'normal' life, so Jane's choice of helping her sister, despite adding to her hurdles, was another sign of regained naturalness and normality. What had changed was how Jane felt in control of her duties. When reviewing her third Self drawing alongside her previous ones (Figure 4, Self), she observed:

there's no black on this picture at all, my road isn't black, they're all natural colours, that's life, isn't it? Green and blue. So that's, that's the way of life, that's natural, I know what I'm doing, I'm just stepping over my hurdles, not crawling on a black road anymore [Jane, T3]

The black path leading off the page to emptiness from T1 had been replaced at T3 by a "natural" white path. Her mood and outlook at T3 were normalised, and, more importantly, she was expressing a sense of control over her life ("I know what I am doing"): she was "just" stepping over her hurdles and owning her normality. The inner renegotiation of her roles, that had led to changes at T2, had been metabolised and she felt once again able to take care of others without damaging herself. It felt as if her previous caring Self was cautiously starting to emerge again.

Summary. Jane's pain and Self drawings show a very positive trajectory. At the start of the study her pain had been overwhelming and she had felt dispirited, with no sense of future. The PMP stimulated her to make important changes to her life as a result of which at T2 her pain appeared more contained and she had acquired a home of her own and a new outlook that made her feel elated. By her third interview, she had settled down, was able to handle her pain in the background and was in control of her life again, facing the obstacles of "normality". There had been a substantial shift in power during the study: where previously the pain had controlled Jane's being, by the end she was able to assert herself over the pain and feel in control of herself and her life.⁴

⁴ For a more extensive review of Jane's pain trajectory, see Nizza, I. E., Smith, J. A., & Kirkham, J. A. (2018). 'Put the illness in a box': A longitudinal interpretative phenomenological analysis of changes in a sufferer's pictorial representations of pain following participation in a pain management programme. *British Journal of Pain*, 12(3), 163-170. This is a case study entirely dedicated to Jane's pain drawings in Appendix C.1.

Olga's journey: from despondency to planning her future

Olga stayed the longest time within the study and was the only participant to successfully wean herself off opioids after having taken them for over 5 years. She illustrated her journey with two sets of surprisingly simple stick figures that evolved from her having overwhelming pain and extremely low mood, to having less pain and a strong sense of purpose in her life.

	PAIN	SELF
TIME 1		
TIME 2		
TIME 3		

Figure 5. Olga's drawings of her pain and Self – larger format drawings in Appendix D.2

Time 1. Olga's first pain drawing (Figure 5, Pain T1) is a faceless stick figure on which the pain she was experiencing is described via metaphors: pokers in her joints, hammers on her knees, flames on her neck, toothache at the base of her spine, buckets of fizzy water at her feet. The variety of symptoms and the violence of some of the metaphors (e.g. flames and pokers) suggest a very aggressive pain. Olga had chosen what to draw very carefully:

I had to draw my hands because my hands are a part of me that's really affected, this [top] part of my hands, so it's, it's the red... I wanted it to be red, because it's angry and it hurts, and it's like somebody was pushing a hot poker or hot needles into my joints [Olga, T1]

Olga defined her painful hands as being “a part of me,” she ascribed agency to the pain (“it’s angry and it hurts”) and imagined “somebody” pushing hot pokers into her joints. Her pain was not only strong, it was separate from her and attacking parts of her. In fact, Olga as a living person does not appear at all in this drawing, because the figure has no face and no identifying features. The drawing is literally just about the pain. I have the impression that pain had taken over Olga’s body completely, turning it into a passive puppet to which things were being done by an external force.

Olga had been tearful during her first interview and profoundly upset by the effects that pain was having on her life. She described the cloud above the stick figure’s head as a constant overhanging “heaviness” and expressed frustration with the pain, because it isolated her from other people. It was clear that her physical pain was compounded by a low mood, possibly a form of depression, a diagnosis that would fit well with the sense of emptiness expressed by the figure’s blank face.

Olga’s first Self drawing (Figure 5, Self T1), with its large head and small stick figure body, is clearly her and illustrates in more detail the impact of pain on her mood. The face has a forlorn expression, with a downturned mouth and Olga’s green sad eyes. As in the first pain drawing, a large grey cloud hovers above the head. This is how Olga described her feelings:

[tearful] I feel a bit angry [...] because I think why have I got all of these problems, you know? I'd like it to improve, I would really like to think I could improve on it, I don't want this, sometimes it kind of makes you feel, if this is it, if this is the best you're gonna feel, I don't want it to continue [...] I don't ever feel suicidal or like I'm going to kill myself, but you just kind of think, right, if this is it for the next twenty years, do you really want the next twenty years? [Olga, T1]

This quote is rich and captures the depth of Olga’s despair and the sense of hopelessness that her “problems” were evoking. The problems themselves are listed as labels on the drawing: “inactive”, “bad posture”, “distant from family”, “frustrated” and “pain”. They include the pain, but not only. Olga was physically “inactive,” for her pain and also because she was overweight. She disliked her body (“I’m big, so I try not to think about it”), which is why it is out of proportion compared to the head and almost invisible, apart from having a “stoop” (the slight bend in the stick figure). Olga felt very self-conscious because her stoop caused a “bad posture” (although, interestingly, I never noticed her stoop, nor her posture). Her physical limitations

affected her ability to engage with her loved ones, making her feel isolated and “*distant from family*,” and her overall situation made her “*frustrated*”.

Going back to the quote, Olga felt that her current situation made for a life that was not worth living (“*if this is the best you’re gonna feel, I don’t want it to continue*”). However, her desire for something better (“*I would really like to think I could improve it*”) felt tentative, she wanted to change, or rather, she wanted to “*think*” that she could change, but did not entirely believe that this was possible. Her impulse for change was weak. She referred to her situation using pronouns such as “*this*” and “*it*”, almost distancing herself from it, conveying a sense of impotence, as if her life were beyond her control and she were a victim of something that had been imposed on her.

At her first interview, Olga was suffering greatly both physically and psychologically: she was sad, in a body that she disliked, feeling victimised by her pain and passively unable to react.

Time 2. By her second interview, which in her case occurred six months after the first, Olga was feeling much better. She had been referred to the PMP later than most and in the meantime her medication regime had been revised. Her second pain drawing (Figure 5, Pain T2) is, again, a stick figure with pain marks and, although it shares many similarities with her first one (Figure 5, T1), there are also some important differences. Many of the metaphors are retained (notably, pokers and hammers), but some are omitted (e.g. no tooth and no flames), suggesting that the level of physical pain had diminished. Olga confirmed that she was feeling better:

I think my pain has definitely improved to what it was when I was here last time, which again, that straight away increases the quality of your life, doesn’t it? [Olga, T2]

Olga saw a link between her pain levels and her mood. Her pain drawing reflected her improved mood, particularly in comparison to her previous drawing. For starters, the stick figure in her second pain drawing had blonde hair (like Olga), a smiling face and no cloud above its head. The absence of a cloud was also indicative of increased mental clarity from taking less morphine. The inclusion of a recognisable smiling face, where previously there had only been emptiness, suggests that in the relationship between Olga and her pain the balance had changed: while previously pain had been the protagonist of the drawing, her second pain drawing was a picture of her with pain. It was as if she had reconquered some of the space previously occupied by the pain and was affirming herself in relation to it.

When asked how she explained the change in her pain, Olga said:

maybe coming off some of the pain killers, although you expect them to deal with all the pain but actually they don’t always, do they? [...] now I understand that they can cause as much pain as they relieve and, yes, and just maybe not having my brain quite so foggy with the drugs and stuff, [...] makes you feel a bit better. Certainly having, understanding what tools are available to you and using some of those tools as well, [...] when I did the PMP, it laid some of the fears for the future, so, ahm, I didn’t realise how many different aids there were

to help you with different things, so, ahm, yes, all of that, it's all just sort of takes worry away from you, doesn't it? [Olga, T2]

Olga had experienced on her own skin the detrimental effects of opioids, in terms both of mental fog and actual pain, a counter-intuitive effect of this type of medication difficult to believe for many pain sufferers. Participating in the PMP had also played a part, and, interestingly, the most important aspect for Olga had been learning about disability aids, such as kettle tippers. This detail speaks to the idiosyncratic nature of CP, whereby each sufferer is burdened by their own particular fears and concerns, but also illustrates how PMP participation can change participants' perspective about their future, as we shall see when discussing Olga's second Self drawing below.

Olga's second Self drawing (Figure 5, Self T2) is, again, a stick figure, but this time fairly proportionate and with hands and feet. The figure's round face has Olga's blonde hair, green eyes and a happy smile. Above the head there is no dark cloud, but three thought bubbles which, from left to right, contain a shining sun with flowers and red crosses, a house with the text "house move?" and three other stick figures identified as members of Olga's family.

Although simple, Olga's drawings were always well thought-out. As previously, her Self drawing gives us insight into what was on her mind. Of the first bubble she said:

this is my future, I feel like it's a little bit more rosy, I know that there's a little bit of help out there should I need it, and obviously the sun is shining [Olga, T2]

The bubble included roses because her future looked rosier to her; the red crosses (meaning first aid), were the "little bit of help out there" from the CCPS and the disability aids mentioned earlier; and the sun was shining because she felt optimistic and hopeful about the future.

The second and third bubbles illustrate issues unrelated to her health that Olga discussed at length during her interview: whether she and her husband should be relocating and various family events. What was notable about these bubbles was Olga's focus beyond the boundaries of her own bodily reality, her new-found sense of closeness with family and her projection into the future.

The body of the stick figure in Olga's second Self drawing (Figure 5, Self T2) has its hallmark stoop and is also scattered with pain marks. Olga said that the pain marks were there to show how well she was feeling, despite the pain. She did not discuss the stoop but, for the first time, she talked about the possibility of losing weight:

I've got the motivation, because I know the quality of my life will improve, but I just can't, or I haven't at the moment clicked it the right place here [head] [Olga, T2]

Olga, who would be classed as obese, knew that her weight had an impact on the pain and on her overall quality of life, yet she had only touched on the topic during her first interview. This time she discussed the need for a more structured approach to dieting, but, despite feeling motivated, she was not psychologically ready yet to address the problem. There was a sense of

purpose and self-awareness in Olga's words that seemed promising and boded well for the months to come.

Overall, at her second interview, Olga was feeling visibly better in herself. Her pain had reduced and her mood had improved, she was smiling in both drawings, enjoying life and starting to look ahead.

Time 3. At the third interview five months later, Olga's situation was even better. Her third pain drawing (Figure 5, Pain T3) is quite similar to her previous one, but lighter, on account of being drawn in pencil rather than a felt-tip. The general lightness of the drawing, particularly the pain marks, was a deliberate choice to show how much the pain had changed:

I definitely wanted that in pink, because I wanted it to be a lighter colour than it was, not in red, because the red I feel is the real angry colour [Olga, T3]

Since Olga's pain had changed in intensity, it required the use of milder colours; it had also changed in aggressiveness, so that the red was no longer of the "angry" type but a milder pink. The figure itself, clearly identifiable as Olga, appeared increased in size, with a larger smile and much lighter compared to the previous ones, because instead of a black felt tip, she had used a softer skin-coloured pencil mark to draw the outline, giving the figure a more 'natural' look. This normalisation reflected a change in Olga's overall narrative: her focus was no longer the pain but the weight-loss plans that she had finally been able to put in place.

Looking across Olga's three pain drawings (Figure 5, Pain) it is interesting how they all present the same subject, and the subtle changes in tone and detail define a positive trajectory, over which the pain, from being a strong, depressing and depersonalising presence, had reduced, allowing Olga to gently re-emerge and take centre stage with a large smile on her lips, ready to live the rest of her life.

Olga's final Self drawing (Figure 5, Self T3) provides more detail on the new Olga and her plans for the future. As always, it is a stick figure, this time drawn in brown and with a large red smile. Compared to the previous Self drawings (Figure 5, Self T1 & T2), the figure is more complete because it has full hands and feet, the characteristic stoop is less accentuated, and it has no pain marks. To the left of the figure's foot there is a clumsy representation of a wall, with some bricks lying around. Above the head there is a halo of words. The words in red are negative things ("bad day", "size", "weight!!!", "health" and "self-conscious"), while the green words are positive things ("better (for health)", "I know to ask for help", "relationships", "planning", "exercising", "less pain", "hopeful", "more control of life", "positivity", "evaluation", "I can do it! (mostly)" and "3-year plan").

At her third interview, Olga was smiling like the figure in the drawing, feeling more in control of her life and hopeful about the future. She had successfully completely weaned herself off

opioids and, with her husband, had devised a “3-year plan” to improve their wellbeing, which included losing weight. Olga was cautiously optimistic about succeeding in her intent, so she added “(mostly)” to the “I can do it!” statement in the drawing. Previously her motivation to lose weight had been lagging because she had not “clicked in the right place,” now she felt ready to tackle her weight loss project:

I know I've gone on about my weight every time I've seen you but I really feel like I've got my head around it now, yes, I'm going to be able to make a difference to myself [Olga, T3]

Weight loss had hardly been prevalent in Olga’s previous interviews, but in the last months it had probably been central to her thoughts and now it was her main focus. In her drawing, three of the five red negative words in the figure’s halo are weight-related (“size”, “weight” and “self-conscious”).

A notable (and new) aspect of her third Self drawing was the contrast between positive and negative elements. It was as if Olga had engaged in a battle with herself and was counting her soldiers: the red words in her drawing were her opponents and those in green were her allies. Since there were more of the latter, she was optimistic about being successful.

The meaning of the crumbling wall in Olga’s final Self drawing was more ambiguous. Initially she described it as “the thing that stops me from doing things, the negativity in my life”. When comparing her new Self drawing to her previous ones, she gave a different reading:

The pain is probably part of the wall, I would think, the fact that I feel a lot less pain now [...] it's still there, but I'm not focusing on it as much, I suppose, I am focusing on other things as well, maybe that's why the wall has come there, because I know that my focus has shifted, whereas I was probably completely enclosed before [Olga, T3]

The wall/negativity in Olga’s drawing seemed to represent both her pain and her emotional response to it. Olga had previously been “completely enclosed” by her pain. Now that she was no longer taking morphine and was in less pain, the wall had crumbled, she was able to focus away from her pain, to “hop over” the wall and get on with her life. This was a pivotal moment:

I am much better than I was, I feel better in myself, my pain has improved, I feel like my life is sort of at a bit of a turning point really, I'm in control of what I do and what's happening to me, I can make it change [Olga, T3]

Summary. Olga’s closing tone in this last quote feels miles away from the despair and impotency of her first interview. She was not only better, she felt in control and empowered to bring about the changes she needed in her life. Her overall trajectory, so powerfully illustrated in her simple pain and Self drawings, had been extremely positive. The pain that initially was controlling her life was dramatically reduced, her mood lifted and gradually she was able to re-engage with her life and embark on making important changes that would further improve her quality of life.

Monica's journey: from resistance to self-compassion

Monica's time in the study was a transformative journey of self-discovery. Her pain drawings evolved from pain being an aggressor to be resisted, to pain being a manageable challenge. In parallel, her Self drawings evolved from a precarious balance to a symbolic revelation of Monica's true identity.

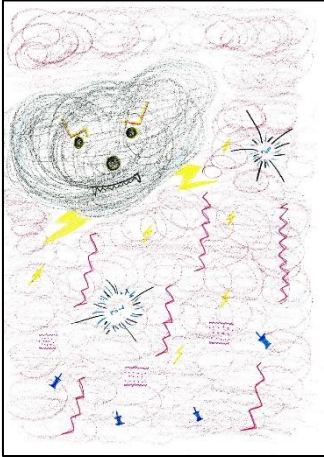
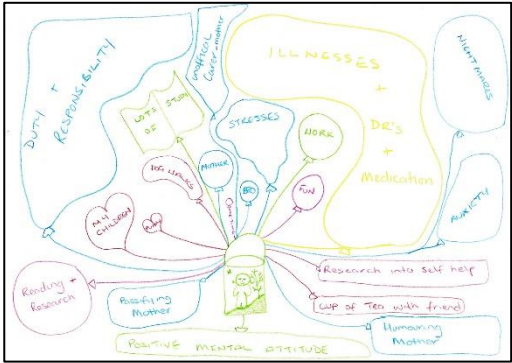
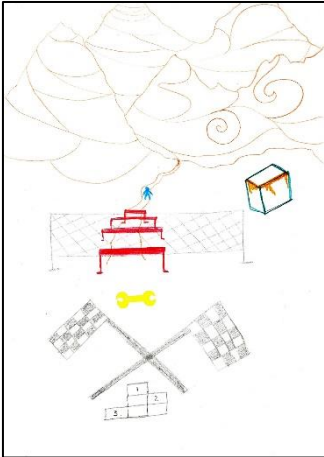
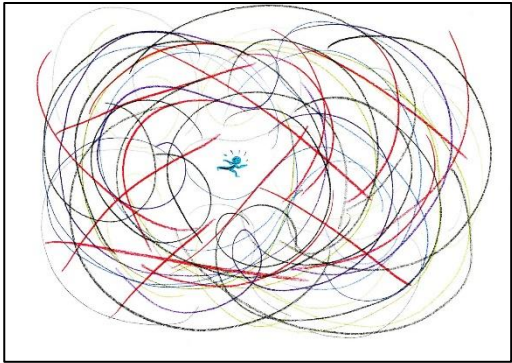
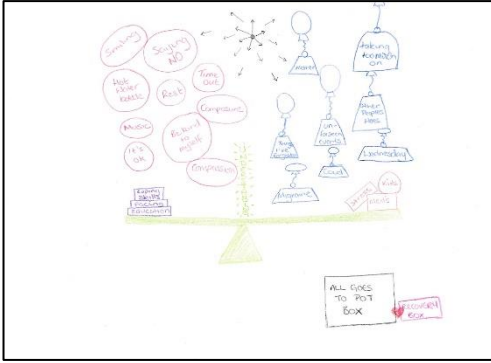

	PAIN	SELF
TIME 1		
TIME 2		
TIME 3		

Figure 6. Monica's drawings of her pain and Self – larger format drawings in Appendix D.3

Time 1. Monica's first pain drawing is dense and slightly eerie (Figure 6, Pain T1). On the left it contains a grey cloud with a teddy bear-like face, and prominent vampire teeth; the rest of the page is occupied by a dense pink fog interspersed with shapes: blue pins, yellow lightning, pink zigzag lines, small "pop" and "pow" explosions. There is a chilling contrast between the comic-book tone of the drawing and Monica's description of it:

it's got different stabbing bits of different degrees, it will rumble around my head [...] some of the pain can feel cold and some of it can feel aggressive [...] it's like an aggressive being just sitting there waiting to... "What shall I do with you today?" [Monica, T1]

Along with the physical aspects of her pain (e.g. "stabbing" and "cold"), Monica described the 'teddy bear' as aggressive, spiteful and agentic, intent on spoiling her life daily. Although the drawing contains some elements that could be interpreted as playful, it conveys the sense of a pain which is widespread, complex and aggressive.

During her first interview, it became apparent that Monica was not coping well. She was a single mother of two young children, caring for her mother, with an unwell sibling, studying to become a counsellor and working as a volunteer in a care home. With so many things going on, she was finding it difficult to focus on herself and her pain. Her first Self drawing (Figure 6, Self T1) is a dense and elaborate diagram of all the things she was juggling. Monica represented herself as a minute figure in a green basket attached to many balloons occupying the whole page above and beside her. The balloons are colour-coded, with negative ones in blue (i.e. "duty and responsibility", "stresses", "mother", "brother", etc.) and positive ones in red (i.e. "reading and research", "children", "puppy," etc.). Other important elements such as "study" and "work" are in green, while the largest balloon ("illnesses + dr's + medication") is yellow. The balloons appear constrained, oppressive for how they fill the space around the small figure and give the image a claustrophobic quality. Also, the blue and yellow balloons occupy in proportion considerably more space than the others, particularly the red ones which represent love and self-care.

The "duty and responsibility" balloon on the left is large because Monica spent most of her time taking care of her family who were unable to look after themselves ("they're all my responsibility because they're hopeless"). Four of the negative balloons concern her mother ("mother," "unofficial carer-mother," "pacifying mother" and "humouring mother"), with whom Monica had a strained relationship because her mother expected Monica to be at her "beck and call." Monica spent little time looking after herself: in the drawing, her red "me time" balloon is so small that the label is written on the string. Having given herself entirely to others, Monica felt that there was none of her available to look after herself: "I kind of need me more than anybody else does and I don't have time for me!"

Could a simple lack of time explain why Monica wasn't taking care of herself? This quote offers insight on what was occurring at a deeper level:

I should be allowed to go and be sick and get over it [laughs] in an ideal world. But I don't want to be like other people, I don't want to give in to it, because if I give in to it, I've lost my self, because if I do that, there won't be me, there will just be the illnesses and the pain and the yuck and there can't be that, because there would be no point, there has to be everything else. That balances out quite nicely, without me even realising it [Monica, T1]

This dense quote captures the existential battle that Monica was fighting against her illness. She perceived her illness and her Self as two separate mutually exclusive entities. She knew that she should look after herself, yet she felt unable to do so because she was afraid that the illness would take over her life and that she as a person would cease to exist (“*if I give in to it, I've lost my self*”). Despite her “*ideal world*” claims, to stop her illness from winning the battle, Monica was not allowing herself to invest time and energy into caring for herself. Hers was an act of resistance.

Monica’s drawing of her Self made perfect sense in these terms. Pain (yellow balloon), occupied a large amount of space in the picture, but it was almost invisible. When I asked about it, she said:

the illness and the meds [are] always, always there, constantly throughout the day [...] it's in a colour I really really detest, and if I look like that [sideways] I can't actually see the yellow, so that could be a nice big empty space, so if it's an empty space I can fill it with something, but you can't, because it is there [Monica, T1]

She rejected her illness, so she drew it using a colour she detested; the same colour allowed her to pretend it did not exist. Yet she knew that the apparent empty space of the yellow balloon was just an illusion and that it could not really be filled by anything else. What she could do was fill the rest of the space with other things, so that the yellow balloon, however big, could not expand and occupy more space than it already did. Filling her day to the brim was Monica’s way of keeping her illness at bay and resisting it.

It felt as if Monica were under constant threat of being annihilated by her illness. From the outside, her life appeared too full, but from Monica’s perspective, all the elements were well balanced (“*that balances out quite nicely*”). Monica described her system of balloons as “*compartmentalisation*” which she considered a successful strategy to keep a good psychological balance. The miniature idyllic environment surrounding the green figure at the bottom of the drawing was a symbol of her “*positive mental attitude*,” also part of her psychological survival toolkit.

At the start of the study, Monica was desperately resisting the attacks of pain towards her body and her very being. She was defending herself by filling her life so compactly that a psychological balance of sorts was achieved, although seen from the outside it appeared precarious and unsustainable.

Time 2. After attending the PMP, Monica was referred for individual psychological support within the service, where she had the opportunity to explore what was happening to her. Her

second pain drawing (Figure 6, Pain T2) shows the results of her efforts to manage her pain. Pain is presented as an obstacle course, where every day is a race towards the finishing line:

you seem to be going around in circles, covering the same ground [...] then you make a bit of headway and then you get down to here [...] and then you get all these hurdles put in front of you and so, "okay, right, okay, we'll get over some of these hurdles," [...] and then something happens and there's a spanner thrown in the works [Monica, T2]

The second-person voice in this quote suggests detachment and the expression "you get all these hurdles put in front of you" is passive, implying that Monica was still seeing the pain as an external entity exercising control over her. Indeed, her description of pain was still confrontational:

It's a constant battle, it holds me back, it stops me from doing what I'd like to be able to do and it does get me down, it really does. But it's [...] a case of staying focussed and trying not to think about how much I'd like to be doing and knowing that eventually I might be able to, but not dwelling on that, and taking the days as they come [Monica, T2]

Monica was still learning. Although her situation was far from ideal, she was dealing with the pain by staying focussed on the present, confident that eventually she would be able to get down from the mountain and finally have a 'good day,' reaching the podium in her pain drawing.

Monica's second drawing of Self (Figure 6, Self T2) is the epitome of disruption, especially compared to her pain drawing (Figure 6, Pain T2) and her previous Self drawing (Figure 6, Self T1). It is a bundle of lines surrounding a tiny green figure on the run. The image is strong, colourful and scary, but also playful in how the figure resembles Keith Haring's dynamic figurines. The day of her second interview, Monica was in the middle of a crisis because she was organising her mother's imminent relocation. She described the bundle as a "hornet's nest" and "being in the middle of a tornado," and the figure at the centre of the bundle she described as:

Trying to get away from it all! It will be fine once it's done, it's just everything at once and it's all beyond my grasp, I will pull it all together, it will be fine, it's just right here, right now it's just "Ahrgh!" [Monica, T2]

As with the image, there is an element of playfulness in this quote: everything around Monica was out of control and overwhelming, but she was surviving to tell the story! Despite the catastrophic metaphors, Monica was confident that the situation was temporary and would soon be resolved.

The PMP and counselling had improved Monica's ability to cope. Looking at her second Self drawing (Figure 6, Self T2), she said:

I would have panicked about something like this before and I wouldn't have drawn it, because it shows that "Oh my God, you're insane!" No, I am not, what is going on here is that there is so much going on that this is the only way I can express it to you, but actually I am all right, I am not upset about it, I am not climbing the walls, this is just how it is [...] it [PMP] has given me an allowance to accept that that's okay [Monica, T2]

Monica had gained the understanding that not having everything under control could be normal and acceptable. She was not necessarily coping better with the chaos, she was interpreting her

anxious response to chaos as within the range of ‘normality’ and not as a sign of deteriorating mental health. By saying that previously she would not have allowed herself to create such a drawing, Monica was also shedding new light on her previous representation of her Self (Figure 6, Self T1). This second Self drawing (Figure 6, Self T2) felt much less constrained and disturbing than the first, the irony and freedom of the wild lines to me felt energetic, healthy and refreshing in comparison to the oppressive concentration of the balloons. Monica confirmed that despite being under pressure, she felt relaxed and accepting of her feelings. Listening to herself had been one of her main learning points from the PMP:

It's listening to me and how I am actually feeling and not ignoring it, whereas before I have always ignored it and just carried on, but I am learning to listen [Monica, T2]

Previously too busy looking after others and resisting the pain, Monica was starting to “listen” to her needs and, occasionally, when her body would tell her to, she would stop. She had also started to change how she interacted with her mother, by saying no to some of her requests.

Although the pain still had a strong and limiting presence in Monica’s life, her pain drawing reflected how she was learning to live with it. Her Self drawing showed the confusion of a challenging moment, but also her new-found ability to cope with chaos.

Time 3. Monica’s third pain drawing (Figure 6, Pain T3) represents her new pain management equilibrium. It includes a large scale, with various elements balanced on either side: “stress”, “meds” and “kids” on the right, the three constants in her life, kept into balance by “coping skills”, “pacing” and “education”, the new skills acquired at the PMP. Hovering above on the right there are ‘negative’ blue weights hanging from balloons (e.g. her mother), to be balanced, on the left, with ‘positive’ pink bubbles of behaviours and attitudes, such as “composure” and “compassion”. It is interesting to note how the negative weights on the right are all external forces over which Monica had no control, while the positive bubbles on the left are resources through which Monica could exercise agency. From a superficial viewpoint this drawing resembles Monica’s first Self drawing (Figure 6, Self T1), with its numerous balloons. Yet here the components are tidier and less oppressive; there is plenty of white ‘breathing’ space around the scale and the sensation one gets looking at it is indeed of balance.

Here is a practical example of how the balance was working for Monica:

I did not sleep at all last night, I couldn't get comfortable, my brain wouldn't switch off, I wanted to take my legs off, so rather than doing what I'd normally do and get screwed up about it, I was listening to my relaxation music. It didn't work, I didn't sleep, but it did work because I wasn't stressed out, I was nice and relaxed. [...] Normally I'd have woken up in a foul mood, because I would have been wound up because I didn't sleep, and I would have been irritated, and strung out, and really tired, and really grotty and... and I'm not, and I've got a really busy day at work today, but I'm quite happy, it's Friday, the sun is shining, it's going to be chaos when I get back to work, but it'll be alright. [...] Normally, it would have thrown the whole day out, and everything would have been wrong even if it was right, it would have been wrong. So just a little bit of learning, a little bit of understanding and being

nice to myself [laughs] has made it something to be dealt with, rather than something to fight against [Monica, T3]

This quote really brings the concept of self-management to life: faced with a difficult night of pain and restlessness, Monica turned to her tools (“*my relaxation music*”); although the tools did not eliminate her symptoms (“*it didn’t work, I didn’t sleep*”), her emotional response to the symptoms was different (“*but it did work because I wasn’t stressed out*”); as a consequence, the downward spiral of increasing distress that a bad night could have triggered (“*I would have been irritated, and strung out...*”) was not initiated, and in the morning Monica felt able to face her day with optimism (“*I am quite happy*”). With the tools and the “*understanding*” acquired through the CCPS and PMP, Monica had found a new way of living with her pain and complex life that felt balanced. Monica’s relationship with her pain had changed substantially: pain had become “*something to be dealt with, rather than something to fight against.*”

Self-compassion (“*being nice to myself*”) was a key component of Monica’s ability to deal with the uncertainty of CP. The “*all goes to pot box*” on the bottom right of her third pain drawing (Figure 6, Pain T3) symbolises Monica’s awareness that, however well-balanced her new situation, there was always the risk of something disruptive occurring. For such cases, she had her pink “*recovery box*,” the ability to accept that not everything can always go to plan. When something went wrong in her day, Monica had a new strategy:

No, it's ok, it's fine, it's just all gone to pieces, so, let's start again, let's not try and carry on with it all going to pieces, so let's just put a line under it and calm down, and be very nice to myself [Monica, T3]

Monica’s self-talk, a frequent feature in her interviews, conveys her conscious effort to maintain a balance and accept imperfection, learn to stop and, most importantly, be “*nice*” to herself.

Self-compassion was a new skill for Monica and her third drawing of Self (Figure 6, Self T3) sheds light on the underlying psychological transformation it entailed. At the centre there are two figures, one inside the other like a Russian doll, standing next to a red suitcase. On the left there is a blue sea with small black boats, labelled “*past*” and on the right there is a path winding through pale green land. Monica explained that the two figures represented her: the outer figure was the person she presented to the world, while the inner figure was her “*Little Me*”, her true Self:

this is what carries me, really, I seem to exist inside me, I always have done, what's more important is how I feel inside as opposed to the person I wear [...] my Little Me gets hurt a lot, a lot of my life I disassociate how I feel from who I am, I have done it for a very, very long time. I've had a horrible little life. So I'm in there and this bit is what carries my Little Me, because the outside bit gets battered and bruised and abused and that's the bit that hurts [...] the little bit, it's the bit that gets protected inside and the little bit is happy at the moment [Monica, T3]

This is a complex quote, reflecting the understanding that Monica was developing during therapy. Her traumatic past, the extent of which had not been apparent up to that moment, became central to her representation and discussion of Self. The abusive relationships that she

had experienced had caused her to protect her most vulnerable Self from the world by enclosing it in a carapace-like external Self visible to others. Most of the time she had been playing a role for others, trying to live up to their standards and pushing herself beyond her own limits. Being “nice” to herself was part of the process of embracing her “*Little Me*” and giving it the love and care that it had never received before.

As part of her inner journey, Monica had reassessed the people in her life and cut many old toxic relationships (“*because of how they were, who they were, and how they made me feel*”), symbolised by the little black boats departing by sea in her Self drawing (Figure 6, Self T3). The red suitcase contained what was worth keeping:

what I've learnt, what I've been through, if I hadn't been through everything I've been through, I wouldn't be who I am now [Monica, T3]

As part of her self-analysis, Monica had accepted that even negative experiences had taught her something and added to who she was today.

Monica's third interview felt like a breakthrough: she was making peace with a difficult past, that she had briefly mentioned but never represented in her Self images. Her early Self drawings had reflected her efforts to keep her complex emotional world in balance (Figure 6, Self T1) and, later, the acceptance that control was not always possible (Figure 6, Self T2). Her third drawing was, literally, a drawing of her Self (Figure 6, T3): with her fragilities, her difficult past, but also with a clear path into the future. It was a serene and spacious drawing that bode well for the times to come. When reviewing the three drawings together, talking about the “*duty and responsibility*” balloon from her first Self drawing (Figure 6, Self T1), Monica said:

duty and responsibility: no, it's actually my choice [...] big progress, nobody's holding a gun to my head and making me do it, I have a choice in this [Monica, T3]

This view of responsibility as a choice was in sharp contrast with how Monica had described the support she gave her family, particularly her mother, during her first interview (“*they're all my responsibility because they're hopeless*”). In her second interview, she had described learning to say 'no' to her mother, now she felt empowered and recognised her agency in shaping her own life, including her family relationships.

Summary. Over the course of the study, from an external aggressive being, pain had been transformed into an integrated and manageable part of Monica's life. In parallel, Monica had embarked on a journey of self-discovery which brought her face to face with her own fragilities and from which she was emerging as an assertive woman determined to take care of herself.

Discussion of the upward and positive trajectory

There are many parallels between the journeys of Jane, Olga and Monica through the study: their trajectories all included a successful transition from being oppressed by pain and depressive symptoms towards reclaiming agency from the pain and regaining some normalcy and control over their life. The trajectories are also consistently positive, so that there are visible improvements when comparing their drawings from T1 to T2 and from T2 to T3. The narratives reflect these improvements, also illuminating the idiosyncratic events that characterised the change within each of their lives.

At T1 all women in this trajectory group represented their pain as an oppressor having an overwhelming presence in their drawing: Jane was a small figure crushed by a one-tonne weight; Monica was exposed to the whims of an evil being engulfed in a fog of pain; and Olga was so oppressed that she was faceless, with only pain on her body and a heavy cloud over her mind. Each of these drawings combines different pain metaphors of the types reported in literature. Jane's resisting figure with its overhanging one-tonne weight represents pain as an external, threatening, trapping and crushing entity, while Monica's aggressive monster in a dense scattering of pain symbols includes metaphors of pain as an embodied attacker and as having physical properties (Bullo & Hearn, 2021; Kirkham et al., 2015; Munday et al., 2020; Phillips et al., 2015). By representing pain as an aggressive external agentic being, these drawings convey the disempowering psychological distress caused by pain and the sense of helplessness that Jane and Monica were experiencing at the time.

Olga's stick figure drawing, although apparently simpler and more literal in its description of pain symptoms, is more graphic than the others. It associates each type of pain to a specific implement attacking the body (pins and hammers) and illustrates LBP through the common experience of toothache (Munday et al., 2020), eliciting an almost physical recoiling response in a careful viewer. Olga's stick figure also has a blank face overhung by a dense cloud, suggesting a depersonalising pain accompanied by depressive symptoms. Quantitative evidence has linked the use of particular pain metaphors to different types of distress, with pressure and weight pain metaphors associated to higher levels of depression and stress, and metaphors of physical damage caused by sharp objects linked to higher pain interference (Munday et al., 2021).

Each in its own way, the first pain drawings of women in this trajectory communicate a sense of being overwhelmed by an unbearable physical and psychological pain. This impact is complemented and further explained by the initial Self drawings, where Jane drew herself as crawling on a steep dark path, Monica appeared suffocated by illness, duties and responsibilities and unable to care for herself, and Olga had a desolate face and felt distant from family. The accompanying narratives spoke of depression, social isolation and hopelessness. Both Jane and Monica had a history of depression, while Olga was displaying depressive symptoms at the

interview. During their first interview, both Olga and Jane questioned whether their current life was worth living. Instead, Monica was desperately resisting her pain in an attempt to save her Self from it. The Self drawings thus illustrate the known correlations between CP and depression (Linton & Bergbom, 2011) and psychological distress more widely (Toye et al., 2013b), which underly many CP treatment models (de C Williams et al., 2020). These Self drawings are also unique in that, to my knowledge, no other CP study has invited its participants to draw themselves to probe the existential impacts of having CP (I will return to this topic when I discuss the value of drawing as a methodology further on). Together, the T1 pain and Self drawings illustrate how, at the start of the study, participants in this trajectory group were profoundly oppressed by their pain and afflicted by extremely low mood.

The PMP was a breakthrough moment for all participants in this trajectory group and by T2 each of them had embarked on a new life course: Jane had left an oppressive relationship, started to work again and moved into a new home; Monica had started therapy to tackle her history of trauma and mental health difficulties; Olga was successfully weaning herself off opioids. Accordingly, Jane and Monica's Self drawings at Time 2 were very different from their earlier ones, with Jane's dream-like house and Monica's hornet's nest respectively representing a new ecstatic happiness and a new acceptance that life could be chaotic without this being a sign of deteriorating mental health. In contrast, Olga's second Self drawing was more subdued, but also relaxed for its concern with everyday family life.

At the same time, in the pain drawings, the pain became less prominent: it was relegated to one leg for Jane, to fewer body parts for Olga, and, in Monica's representation, the external agentic pain was replaced by pain management strategies. A visible change had occurred for all three women and their second interviews shared a sense of relief from having broken free from previous constraints (i.e. Jane's toxic relationship, Monica's fear of losing herself and Olga's obnubilation by morphine). Each woman was expressing a new understanding of herself and her condition, starting to feel like herself again and daring to hope for the future.

From a longitudinal perspective, the change that occurred for these participants within the relatively short period between T1 and T2 can be defined as a turning point, with the PMP acting as a trigger leading to "changing perceptions, identities and understandings, and opening up the possibility of an alternative pathway for the future" (Neale, 2021, p. 75). Indeed, the PMP and CCPS had stimulated all three women to reconsider their life, break old patterns of behaviour and challenge their own status quo. The cathartic quality of Jane and Monica's Self drawings, particularly in comparison to their earlier drawings, conveys this sense of radical transformation. Olga's Self drawing, although less dramatic in tone, is more proportionate and serene compared to her previous one, and illustrates her engagement with normal life.

Six months later, at T3, the progression towards normality appeared steady for all women. Pain drawings changed to give the pain even less space: Jane relegated hers to the background,

representing daily chores on the front of the J which represented her; Monica's pain was a careful balance of self-management strategies counterweighing life stressors; Olga's was a larger version of her smiling, with limited soft pink pain, in contrast to her previous bright red pain. The pain had not disappeared, but it was now manageable, and the drawings showed how: Monica's carefully balanced scale, Olga's light colours and smile and Jane's background pain with a front including "*pain relief*" and "*rest*". The accompanying Self drawings were images of serene normal lives, with a predominance of green, which appeared in Jane's path, Olga's words and Monica's plain. The form that normality took for each of them was different: for Jane it was a life scattered with surmountable obstacles, for Olga it was making plans to tackle her ongoing obesity and for Monica it was clearing up her life and taking care of her "*Little Me*."

In response to their changing pain drawings, all three women talked of having taken back control from their pain, expressing a sense of agency which had previously not been present in their narratives. They talked of finally feeling in control of their lives and able to take decisions as they had previously felt unable to do. As a construct, agency (Hitlin & Elder Jr, 2006) is rarely discussed in relation to pain; when loss of agency in CP is described, it is in terms of autonomy and independence from other people (Karos et al., 2018). What the experience of these women and their drawings suggest is that agency is lost and, in this case, found, also in relation to the pain itself and that the process of regaining agency from pain has wide-ranging impacts on the life of sufferers. A useful construct to describe this process could be self-efficacy, which has been described in the context of pelvic pain as including a sense of responsibility towards oneself and feeling an impulse to action towards fulfilling one's personal needs (Albert, 1999). Yet, in a systematic review of the outcomes reported for multidisciplinary chronic pain therapy programmes, Deckert et al. (2016) found that only 9 out of 70 studies included a self-efficacy measurement, using mainly the Pain Self-efficacy Questionnaire that measures the ability to live a normal lifestyle despite the pain (Nicholas, 2007). The sense of control and agency experienced by participants in this trajectory group appears to be a psychologically more sophisticated concept, that goes beyond the ability to engage in daily tasks, possibly more akin to a change in locus of control in relation to illness and life in general, a dimension that existing outcome measurements do not seem to capture.

Another aspect that emerged for all women was the ability to focus on their own needs. It can be detected in Olga's "*I know to ask for help*" statement in her Self drawing and in her decision to finally lose weight, in Jane's inclusion of "*Rest*" and "*Pain relief*" in her pain drawing and in Monica's listing "*Rest*," "*Compassion*," and "*Be kind to myself*" among her self-management strategies in her pain drawing. All women had transitioned to a new normality, in which they were prioritising their own wellbeing in a way that they had not done before. A useful construct to understand this change is self-compassion, which is receiving growing attention in CP, and includes being understanding towards oneself rather than self-critical (Neff, 2003). It is considered an adaptive process that can help reduce the impact of CP on the life of sufferers.

Higher self-compassion is associated with lower depression, disability and pain-related fear, and greater pain acceptance, successful engagement in valued activities and use of pain coping strategies (Edwards et al., 2019). Higher self-compassion has also been found to predict lower depressive symptoms at 6 and 12 months (Carvalho et al., 2020).

If we review Monica's trajectory through a self-compassion lens, we see how at T1 she had been entirely focussed on looking after others and finding it difficult to look after herself. In her first Self drawing she appeared in a small green basket overwhelmed by balloons representing her burdens (her duties, her family, her illness). At T3, she drew herself as two Russian-doll figures on a serene green path, with the inner doll representing her "*Little Me*" whose happiness the outer one was protecting. Her focus had changed substantially: being nice to herself had become a priority and she was aware that it was up to her to prioritise her needs over the needs of others. Jane's decision to leave her partner was also dictated by a recognition that her own needs should take priority, as Olga's desire to lose weight stemmed from her wanting to finally take care of her body. We see here how self-compassion and regaining control are interlinked: being in control enables self-compassionate behaviours and the sense of self-compassion is empowering.

The PMP seemed to have been an empowering experience for these women: it stimulated in them a desire to take responsibility for their own wellbeing and gave them the tools to rethink their life with pain and take action towards managing it, each in her own way. The ACT psychological flexibility model (Hayes et al., 2006) offers a useful framework to understand what may have happened. The model advocates for a shift from experiential avoidance to experiential acceptance, which, for CP, means acceptance of the physical and psychological experiences of pain. The reduced space occupied by the pain in their drawings over time and these participants' return to some 'normality' is a testament to their ability to accept and incorporate pain and its consequences into their lives. Becoming psychologically flexible also entails a shift from being attached to one's concept of oneself and unable to act, to a more flexible view of oneself where, driven by actions in tune with one's personal values, a more vital life can be lived. The ability of participants in this group to challenge their view of themselves, reassess their lives and engage with what was important to them by taking concrete actions suggests a good degree of psychological flexibility. In a recent IPA study investigating perspectives on acceptance following an ACT-based PMP, participants spoke of acceptance as a journey encompassing enhanced self-efficacy, altered and flexible self-identity and openness to change (Casey et al., 2019), three experiences that resonate with what happened to participants in this trajectory group. Biguet et al. (2016) talk of "acceptance as personal empowerment" (p. 1261), which they identify as the best possible outcome for CP sufferers, while Toye et al. (2021) see empowerment as a necessary step in the CP sufferer's journey towards healing. The sense of control over their pain developed by Jane, Olga and Monica over time, their growing

sense of empowerment and the practical and psychological changes they underwent during the study suggest they were on a steady march on their path to healing.

The three women in this trajectory group started from a very low point and by the end were feeling much better in themselves and had made important changes to their lives. Statistics from the CCPS for the period in which my participants attended their PMP (2015-2016) show measurements of pain self-efficacy (PSEQ), anxiety (GAD-7) and depression (PHQ-9) improving after PMP participation. Similarly, recent meta-analytic evidence on PMP efficacy (Romm et al., 2021) points to group-based PMPs having significant effects on disability/function, pain intensity, psychological health, general health and quality of life, mainly with medium effect sizes.

The women themselves attributed a role to the CCPS and PMP in their change processes. For Jane, understanding the multidimensionality of pain had been key:

you're not faced with this big thing of pain, wall of pain, but it's kind of like made into individual bricks and it's easier to break the wall down if you do it brick by brick, than it is to try and knock the whole thing down in one go [...] you can't do it all in one go, but if you can make a change here or a change there, you can make the wall not so tough and that's what the program did [Jane, T3]

The CCPS helped Jane reconceptualise CP (the wall) into its different constituent components (the bricks), which made changing the aspects of her life that needed to change more feasible. For Olga the CCPS helping her to come off morphine was a “*pivotal point*” and the PMP had shown her that she was “*not alone in this sort of spiral of painkillers and pain and feeling miserable and isolated,*” stimulating reflections on her future. For Monica, the PMP and the CCPS counselling had “*set the ball rolling*” in terms of her understanding of herself and her condition. Understanding the biopsychosocial nature of pain, being with similar others, and understanding oneself better are outcomes from PMP programmes considered self-management enablers (Devan et al., 2018).

Causal conclusions are always problematic in research, particularly when phenomena occur in a complex environment, where multiple events, motives and meanings interact, yet a careful longitudinal analysis can reveal interesting details of how processes unfold (Neale, 2021). At least partly in response to the stimuli they received from the CCPS and the PMP, the women in this trajectory group had taken life-changing decisions which had made them feel better, reclaimed agency from their pain, expressed new feelings of self-compassion, gained a sense of control over their lives, and were able, by the end of the study, to live an almost ‘normal’ and serene life that would have been unthinkable at the start of the study.

Chapter 7 - Negative or unchanging trajectory: Helen and Alison

Helen's and Alison's trajectories are at the opposite end of the spectrum compared to the upward and positive trajectories of the first group. They are also profoundly different from any of the other trajectories because there were no positive developments in the pain and Self representations, nor in the narratives. The trajectory of participants in this group included a mixture of negative and unchanging aspects. Alison hardly engaged with the drawing process, unlike Helen, whose drawings were complex and vivid. Whereas Helen's pain drawings became increasingly unwieldy and intense, in her narrative her actual pain levels did not seem to change; Alison's drawings became simpler and less connected to the physical aspects of pain, and she talked about the pain becoming worse. Their Self drawings and emotional response to their condition had a similar conflicting evolution. Helen's drawings became more dramatic as she realised her inability to change her situation, while Alison's Self drawings were almost unchanged and she persisted in defending her situation. Helen had a complicated history of health and family issues that explained her inability to disentangle herself, while Alison, who also had ME, seemed more unwilling than unable to address her issues. The CCPS and the PMP seemed not to have had much effect, because neither of the participants in this group embraced any self-management principles or techniques.

Helen's journey: increasingly isolated and unable to act

Helen's drawings were rich, colourful and increasingly terrifying. Pain was one of many issues she was facing and, despite enjoying the PMP and receiving individual counselling, her pain and Self drawings changed for the worse, as she became increasingly isolated from others, confused by her pain and unable to free herself from a pattern of inertia.

	PAIN	SELF
TIME 1		
TIME 2		
TIME 3		

Figure 7. Helen's drawings of her pain and Self - larger format drawings in Appendix D.4

Time 1. Helen's first drawing of her pain is elaborate and full of meaningful details (Figure 7, Pain T1). She appears trapped inside a balloon in front of a blue brick wall. Below her on the left there is a skull-like face, with rugged red/grey hair, empty large eyes and a chilling grin. On the other side there are some happy figures singing in the sun. In the top-right corner, there is a

female figure with zeds coming out of her mouth. Helen explained that pain isolated her from other people:

it does isolate you [...] it's like you're behind a brick wall and wherever you move, the brick wall just comes up [...] it's like being trapped really in a world, a different world to this one [bottom-right] [Helen, T1]

Helen felt separated from others by the brick wall, enclosed in the bubble with her pain, in a “different world” to that inhabited by ‘other’ people who were enjoying the sun. She had red stars on her body, corresponding to fibromyalgia trigger points, and red, yellow and black marks all around her, inside and outside the bubble, indicating the relentlessness of the pain. Pain also appeared in the drawing as an anthropomorphic entity, the sinister squared skull-face in the bottom left corner of the page:

It's faceless and relentless [laughs], it looks a bit scary, donnit? But then the whole... it is scary, this is anger, it makes me angry sometimes, because it never lets up, so it's got to be something on the dark side, if you know what I mean, in my head, which I think... so that's basically what that was. And, that there's no, the reason I did the arrows is 'cause it's a continuous, there's no doors [Helen, T1]

This quote is difficult because the narrative is not linear, but it illustrates Helen's sense-making and her developing interpretation of the face. Initially she associated it with pain, describing it as being “faceless and relentless,” then it became “anger”, Helen's anger towards the pain that “never lets up.” Then she suggested that it must be “something on the dark side” and “in my head,” before finally changing the subject. This latter interpretation is rooted in Helen's spiritual worldview, in which positive and negative energies collide. As “something on the dark side”, the pain was being interpreted as a negative force which was pervading her (“in my head”), almost as if she were being possessed, an upsetting idea that could explain her immediate change of subject. A less esoteric and more rational interpretation could be that Helen was fighting off depression, that she had suffered from in the past and was probably still experiencing, judging by the cloud above the bubble and the black cap over her head. She explained how she tried not to dwell on the sadness of her situation for fear that her mental health might deteriorate:

if I start crying I'm never going to stop, about everything, not just the pain and I think I don't really want to do that, I'll end up in a nut ward! [Helen, T1]

The tears of the figure inside the bubble are very small in comparison to the large tears outside the bubble. The reference to crying “about everything” points to other distressing aspects of Helen's life, that will be discussed later. She was fighting both her pain and her dark thoughts, however the bubble that was isolating Helen from others might also have been symbolically preserving her mental health, because it was protecting her from the rain above and the monster below.

Helen's first drawing of Self is also dense and busy, and occupies only half of the page (Figure 7, Self T1). It includes her as a full figure, with characteristic hair and lipstick and, again, pain marks on the fibromyalgia trigger points. Like in her pain drawing, she is surrounded by

lightning marks. There are also question marks, words and symbols of her current life: a walking stick, a toilet into which a ring is falling, two chairs and a scooter. The fullness and position of the drawing are intentional:

I think the reason I've shoved all this here is that's how I feel about my future, that I haven't really got one [...] because this is my life, isn't it? This is where I am at [...] I can't think of tomorrow, I can only do one day, because this is enough to cope with [Helen, T1]

One half page was the present, filled with the things that Helen was having to “cope” with, while the other half was empty because she was unable to see a future for herself.

As suggested by the words in her drawing (“drugs”, “clinics”, “assessments”, “Dr’s”), Helen’s concerns at the time were mostly health-related. Years before the fibromyalgia diagnosis and CCPS referral, she had been wrongly diagnosed with ankylosing spondylitis and had spent many years expecting to become severely disabled. Poor health had been a feature of her life: she had experienced a mild stroke at 23, a pregnancy after being sterilised, a difficult hysterectomy, a gallbladder operation, breast cancer, nephritis, knee replacements, salmonella and two serious car accidents. When we met, she was bouncing between doctors trying to obtain a diagnosis for a new problem in her genital area. As Helen pithily put it: “I’m just one of them people.”

Helen’s interactions with HCPs had been mostly unsatisfactory. She felt that she needed more help than she was receiving, both in general and specifically from the CCPS (“they say they’re going to give you all this support, they haven’t got time, have they?”). She ascribed her current low mood to a recent change in medication but did not want to ‘bother’ doctors to discuss the problem.

Some objects in her Self drawing described her family relationships: the falling ring symbolised the decline of her marriage since her husband was struggling to recover from severe illness; the scooter symbolised her adult children, born from a previous marriage, who did not understand her plight with pain. She had bought a mobility scooter to have more freedom but her sons questioned its utility:

“Oh, do you want to use your scooter?” I wanna go, well sometimes I do though, “Yeah, it’s a fashion accessory, you know!” [Helen, T1]

Her family was oblivious to Helen’s suffering and needs. She found their question about the scooter irritating because it demonstrated their lack of understanding that a scooter was not a choice, but a necessity, and she felt they were questioning the reality of her pain.

As her first interview was ending, Helen revealed having recently discovered that, as a boy, her youngest son had been systematically abused by a trusted family friend:

If you face your pain, there’s other stuff in there that’s caused your pain that you don’t know what to do with [Helen, T1]

Although Helen had been suffering from pain for many years prior to becoming aware of her son's abuse, she was drawing a causal link between them. She had asked the CCPS for psychological support in dealing with the issue and was on a waiting list.

Helen's had been a tragic life of ill-health and traumatic experiences, in which the fibromyalgia diagnosis had come relatively late. Her first pain and Self drawings showed how she was low, isolated and dissatisfied with all the people around her, while carrying a heavy burden from the past.

Time 2. Helen's second pain drawing (Figure 7, Pain T2) has many stylistic points in common with the first, but seems more chaotic. Again, it revolves around a central figure representing Helen, with characteristic pain marks on her joints and a dark cloud over her head. The figure is attacked by arrows coming from a colourful ball above and from a bundle of colour below her. As previously, her expression is sad, while next to her a sun is shining over a crossed-out tree, as if it were being denied. Helen described the drawing as feeling constantly under attack:

it's like someone is just constantly firing pain at you, isn't it? Arrows. Have this one today, that one [...] it moves around your body [...] there is always some degree of it [Helen, T2]

The pain continued to be constant and widespread, but Helen seemed more exposed and vulnerable to it than previously. By equating it to "someone" taking the form of a hot-coloured ball above her and bundle below her, she ascribed agency to the pain. In contrast, her own lack of agency was emphasised when she described the need for pain acceptance:

at the end of the day, this sort of pain that lives with you all the time in your house, in your life, in your bed, you just have to accept it, you can't, it's no point, because it wears you out more than what you're already worn out, but it is confusing, that's why my pain looks like that, because it is confusing [Helen, T2]

This description of the pain as living "in your house, in your life, in your bed" conveys a sense of invasion, where all private spaces have been taken over. Pain was attacking Helen from all directions and, while in her previous drawing she had appeared somewhat shielded, the pain was now touching her directly, it was penetrating all her personal spaces, making her feel confused. At the same time, she was talking about acceptance, giving the impression that the PMP lesson was being remembered and repeated without having actually been metabolised, which could explain the greater confusion in the drawing.

Helen still felt isolated and described how she was no longer receiving social invitations, spending most of her time "listening to what everyone else is doing." She was feeding her imagination on the stories from other people's lives, which felt like a denial of life, well-represented by the red cross over the tree in her drawing.

The worsening of Helen's situation and increased sense of isolation is vividly depicted in her second Self drawing (Figure 7, Self T2), where her face appears behind bars, again surrounded by zig-zag signs and question marks. Her expression is scared and unhappy, with tears rolling

from her large sad eyes, looking straight at the viewer, with, outside the cage, a single-tree island. Helen said:

there are days where I just want to cry, it's like this, this desert island, this is where I live [...] and these are bars, it's really about the isolation, [...] being trapped, [...] it is how I feel lots of days, but I never, rarely or never really show that to the world [...] I just think it's pointless, because I don't really think the world wants to know, do you? [...] so I smile, so I don't ever do that frown thing and I can't remember the last time I cried, it's just pointless
[Helen, T2]

Helen continued to feel isolated, particularly from her family (“the world”). She was also overwhelmed by sad emotions, expressed in her drawing, but not in ‘real life’. At T1, Helen had said that she could not cry for fear of never stopping again. Now she was saying that she wanted to cry but it would be “pointless” because others did not “want to know”. Crying appeared to have a communicative function for Helen, but she did not normally do it because others were not receptive. Was drawing allowing her to express her tears? Or was it because I was listening? In fact, unlike most other participants, Helen never cried during her interviews, but she did unload her burden verbally because her interviews were long and rambling. Her reluctance to make her feelings public could also have been due to internalised stigma about her pain. I say this because she defined her pain as meaningless compared to the terminal illness of a young friend (“I think of her and I think of how much worse off she is”).

The ongoing lack of family support certainly contributed to Helen chastising her emotions. She again discussed her children’s reactions to her mobility scooter, explaining that their attitude made her feel bad about herself (“it makes me feel that I am a nuisance to need it”). Although her family triggered resentment for their lack of understanding, they also triggered a sense of guilt:

I was brought up to have a massive guilt complex, which I am better than I was, but it's still there [...] I don't think my boys can really accept anything wrong with me, they can't [...] mums are meant to be strong aren't they? When I had this tumour, they went to pieces
[Helen, T2]

Helen was embroiled in an ambiguous relationship with her children: she felt guilty but also blamed them for not responding to her fragilities. When saying “mums are meant to be strong, aren't they?” it was unclear whether she felt she should be strong, or whether she was lamenting her children’s immaturity expecting her to always be strong. Her unresolved sense of guilt for her son’s abuse was probably hindering her from resolving these conflicts.

As the study progressed, it became obvious that for Helen change was difficult. Before her second interview she had attended the PMP and had enjoyed it, particularly hearing other people’s stories. Despite her low mood, Helen understood from the PMP that she needed to help herself. Talking about the bars in front of her face in the drawing, she said:

If I can just get out of here [cage], but that's down to me really, that's what the swimming I could be doing and the fibromyalgia [support group] and then tai-chi. So that's three things that I could be doing, that could help me. We are our own worst enemies, aren't we? [Helen, T2]

Helen had been offered abundant support from the service but had not engaged with any of it. “Swimming”, “fibromyalgia support group” and “tai-chi” were possible activities to self-manage her pain, but she had not started any of them. The cage in her drawing was self-made, it represented Helen’s self-sabotaging attitude, stopping her from helping herself: she was her “own worst enemy”.

Despite having enjoyed the PMP, Helen’s drawings of pain and Self had worsened: the pain was evermore confusing and isolating, while she remained sad and unable to help herself to move on.

Time 3. Helen’s third pain drawing is abstract with an eye at the centre (Figure 7, Pain T3). Long dotted arrows come in and out and colourful lines and marks converge towards the focal point in the image. The colour scheme is similar to Helen’s previous pain drawings, using red, yellow and black, and her description is also similar:

It comes in, it goes out, it comes in, it goes out, it never really stops [...] it looks really confused, I think that’s what’s inside my head [Helen, T3]

The pain continued to be relentless, confusing and aggressive. The main difference was that this time Helen chose an abstract representation, so the arrows were not directed towards a human figure but a symbolic core. Looking at the image, particularly in the context of her earlier drawings (Figure 7, Pain), the pain seemed to have overcome all barriers and to have finally reached the centre of Helen’s being, inside her “head”. While the narrative was relatively unchanged, the images seemed to have deteriorated, as if Helen’s situation had become increasingly out of control. Helen herself, when looking at the pain drawings retrospectively, was alarmed by what she saw:

this is madder [T3], [...] this [T1] I was thinking, this is the pain, it’s a monster the pain, but this is what I want to be [...] but it’s kind of controlled, do you know what I mean? Whereas we’ve fallen apart a bit here [T2] but [...] there is still space, there is still not... this [T3] has gone [tut] [laughs] dear old lord [tut], yeah, I think maybe I need to sort myself out, it is hard though, it is hard [taps nail on table while reflecting] you just want it to go away, don’t you? [Helen, T3]

The quote above is heart-breaking because it illustrates Helen’s sad realisation that she had made no progress, that her desire for the pain to “go away” was not sufficient and that a more active effort was needed on her part to improve an otherwise deteriorating situation. Helen found it “hard” to act because her pain was one of a number of inter-connected issues that together she found overwhelming and left her stuck in a rut of inertia. Her Self drawings provide additional insight into such issues and the cycle of unrealised intentions that Helen was locked in.

In her third Self drawing, Helen is again behind bars, but with a full figure (Figure 7, Self T3). Her body is mutilated, cracked in various points and surrounded by a red and yellow aura. As before, the sense of confinement and isolation is central:

I knew that I had to draw myself in a cage or in a prison, if you like, because that's how I feel at the moment, that's how pain makes you feel [Helen. T3]

Helen felt enclosed, unable to move away, partly because of the bars and partly because she appeared to have no hands nor feet (“*I’ve lost my feet and my hands*”) and a body “*broken*” by pain. The feeling of isolation described months before was persisting. Her face in her third and second Self drawings was strikingly similar (Figure 7, T2 & T3): with wide teary eyes, blonde hair over her cheeks and frowning mouth with lipstick. While in the second drawing the bars had been almost invisible, this cage was well-defined, relatively small and trapping her like an animal. Her head and body were surrounded by a yellow and red aura, which according to the principles of reiki that Helen practiced, made her aura “*too slow*” and “*not drawing the energy in*” as it should on a healthy person.

Helen’s relationship with HCPs continued to be frustrating. She had arbitrarily reduced her medication dosage because side effects had become unbearable and nobody had any time for her (“*there is no one to talk to, there is no one*”). Psychologically, Helen’s guilty feelings persisted, especially towards her son:

I was meant to protect him and I didn’t, so I’ve got to learn to live with that and learn to either forgive myself or whatever and I know that, so for the future I would like to get rid of that because it sits here and it will sit there on my neck until every time I look at him [Helen, T3]

Helen spent a large portion of her third interview discussing her son’s abuse, which she had finally felt able to talk about with him as well. He was receiving psychotherapy and was moving on. Despite receiving psychological support herself, Helen felt stuck and acknowledged that this was something she needed to work on. Yet her tone and choice of words (“*forgive myself or whatever*” and “*to get rid of that*”) are dismissive, suggesting distrust in her ability to overcome this trauma.

All Helen’s Self drawings are sad (Figure 7). At T1 she appears overwhelmed by worries, but her eyes are closed so, despite the surrounding chaos, there is a sense of peace that the T2 and T3 drawings do not have because her eyes were wide open and crying and she is isolated behind bars. When reviewing the drawings together, Helen realised the full extent of her unhappiness:

this pain is always going to be there, it’s part of me, it’s really what I do with this bit [Self T3] that really matters, and I am not good at asking for help, so I need to go and find it, because otherwise I am going to be here for ever [Helen, T3]

She recognised that while it would be unrealistic to expect her pain to change, she could change how she felt within herself and needed to seek help to do so. Although these assertions were a step forward and an important declaration of intents, given Helen’s history of inertia, they were no guarantee that something would actually happen. Despite knowing that she needed to change, Helen felt an inhibiting force deep within her:

I need to change me, this is silly [touching her three Self drawings] and it is a waste of time. Two weeks ago that lady said to me, “Why don’t you make an appointment to see Audrey?” “Yeah, I’ll think about it.” Then another two weeks. I could have done it, though, couldn’t I?

[...] [husband] always says, if I am in a shop and I see something [...] if it was for [...] anyone else, I would just buy it, if it's for me, I am going to have a big conversation with myself and I think that is what it boils down to, I think a lot of mums are like that [...] it all boils down to our self-worth, doesn't it? [Helen, T3]

She recognised a pattern of procrastination when it came to doing things for herself and she ascribed it to her motherly instinct and to her lack of self-esteem. These were deeply rooted causes for inaction and a lot of motivation would be needed for Helen to break free. Her relationship patterns with her children, in particular, seemed deeply engrained and not conducive to change. She was ridden with guilt towards them all, but especially her son who had been a victim of abuse. Family dynamics made looking after herself a low priority for Helen.

Summary. The trajectory of Helen's drawings seemed like a negative one: her pain representations had become increasingly wild and her Self ones increasingly sad and isolated. Her narrative had changed less, except for a growing awareness of her impossibility, despite the support available, to act and help herself. The discrepancy between drawings and narrative may be explained by the growing intimacy between us, which may have encouraged introspection and disclosure.

Alison's journey: an ongoing low mood and lack of engagement

Alison was the only participant I interviewed in her own home and, for logistical reasons, the only one who drew while I was in the room, although seated as far away as possible. Her pain and Self drawings were basic and not particularly expressive, accompanied by a narrative of pain and resentment. She did not engage with the CPPS and maintained a relatively unchanged low mood.

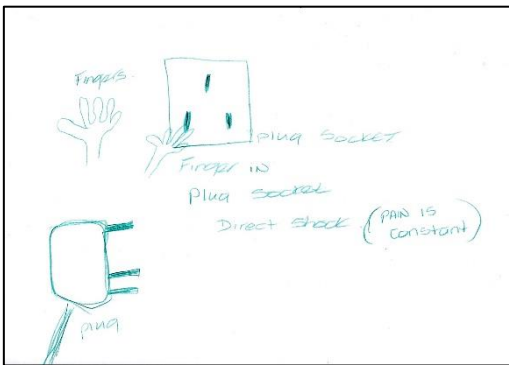

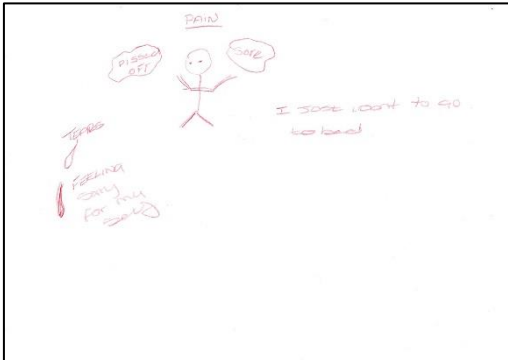

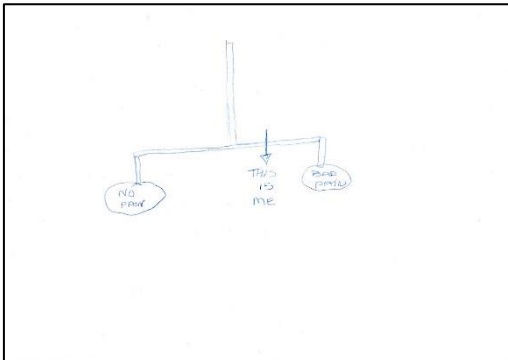
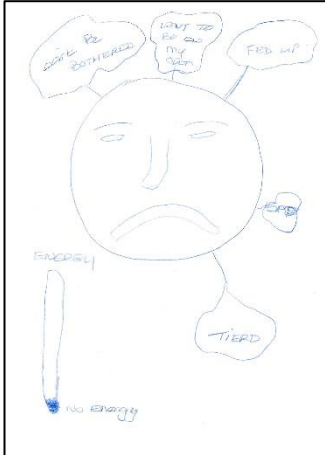
	PAIN	SELF
TIME 1		
TIME 2		
TIME 3		

Figure 8. Alison's drawings of her pain and Self - larger format drawings in Appendix D.5

Time 1. Alison's first pain drawing contains a plug, a socket and two hands, with text to specify that the pain felt like a constant electric shock (Figure 8, Pain T1). The image was meant to represent her worse pain, when she was having a flare up. She had chosen this metaphor assuming that most people would have experienced an electric shock at some point of their life and would be able to understand her pain by imagining the split second of an electric shock "over hours". Alison was resistant to talk about her pain because she felt it would make it worse:

when you have got real physical pain, the more you think about it, the worse it gets in your head, it's weird [...] the more you tell yourself it's really hurting, it's really hurting, you feel as though it's getting worse and worse and worse and worse and worse, but you need to take [pause] your brain off that thought [Alison, T1]

Years earlier, a counsellor she had been referred to for her co-morbid Myalgic Encephalomyelitis (ME) had introduced Alison to distraction as a pain management technique. She described at length how, when the pain was unbearable, she pinched her finger to take her mind off it. It was as if Alison were constantly dissociating herself from her pain: her drawing of it contained no mention of her actual body nor of the fact that she was suffering specifically with low back pain. She did not want to talk about it and all her efforts were directed towards mentally disconnecting from it. This distance was confirmed when Alison described casually talking about CP with another sufferer she had just met:

you don't talk about it as though it's you that you're talking about, it's like you've been aware of it, but it could be from somebody else [Alison, T1]

With this casual acquaintance she had only talked about pain in general, as something that she had knowledge of and could provide advice on. When I explicitly asked, she admitted not telling the person that she also suffered from CP ("I don't tell them it's me that's going through that pain, no"), which struck me as another sign of her attempt to distance herself from pain.

Alison's first Self drawing (Figure 8, Self T1) is also simple and entirely monochromatic, but more personal. It is a stylised frowning face surrounded by speech bubbles with negative emotions ("depressed", "angry", "sad", "useless" and "lonely"). She described them as forming a vicious circle:

this is the circle and you have to break it, but how do you break it? Because you can try and break it, you can take antidepressants which help you come out of depression, but, you always feel lonely and this, you always feel useless, because there is always something that you used to be able to do that you can't do, and it's just like another thing off the tick-list, "Oh, there's another thing I can't do," instead of concentrating on the things that you can't do, like they say, concentrate on the positives, what you can do, but when you're having them 'can dos' chipped away to 'you cannot do' it's hard [Alison, T1]

Alison felt that her negative emotions were connected because they could trigger each other and whenever she was able to control one, another would crop up. At the root of many of these emotions were the things she was no longer able to do because of pain. She appeared to be keeping a mental "tick-list" of activities she wanted to carry out ("can dos") and every time she discovered something new that she could no longer do, the activity would come off the list,

reactivating the cycle of negative emotions. No longer engaging with her preferred activities, be these professional or social, made her feel “*useless*” and “*lonely*”. Anti-depressants were only a partial solution, because they could lift her mood, but they could not stop her being upset about her former life being “*chipped away*,” one activity at a time.

Alison had lived with depression for a long time. She had received counselling and tried various forms of therapy prior to her CCPS referral. She had been on antidepressants for years and said that she had already tried most of the techniques and types of support that the CCPS could offer (e.g. tai-chi, mindfulness, counselling). From the start, she displayed a pre-emptive attitude, evident in the quote above when she rebuts the common advice to “*concentrate on the positives*”. Although she claimed to “*be willing to try anything*”, she discarded most of what was suggested to improve her condition and her feelings towards the service appeared hostile:

I went to the pain clinic, she gave me a TENS machine, asked me a load of questions, gave me a TENS machine, and I've not seen her since. Put me, changed, doubled my medication, put me on morphine, couldn't take it, I had a really bad reaction to it, couldn't get hold of them [Alison, T1]

The tone in this quote was resentful: even the prescription of a TENS machine, which had actually helped relieve her pain, was described in aggressive terms (“*I've not seen her since*”). Alison had also disliked the initial PES, for the irritating attitude of a nurse (“*did not make me feel comfortable at all, I thought [person] was taking the mickey out of me*”) and because none of its contents were new to her.

Whereas Alison’s first pain drawing was cool and detached, her first Self drawing well-illustrated her low mood and the frustration she felt for what was happening to her. Her anger extended to the CCPS, yet she was determined to attend the PMP in the hope of learning something new.

Time 2. Alison’s second pain drawing (Figure 8, Pain T2) makes no reference to the physical experience of pain, focusing instead on her mood by including a small stick figure surrounded by text (“*pissed off*”, “*sore*”, “*tears*”, “*feeling sorry for myself*” and “*I just want to go to bed*”). At the start of her second interview, Alison’s mood was very low indeed: her answers were short and her tone of voice often inaudible; as the interview progressed, her mood gradually lifted. She said that describing her pain was difficult for her:

I don't think you can describe pain, it's just there, you can't, there's no word for it, it's just some days it's worse than others, today it's not good, but it's not just the pain, it's everything else that comes with it [Alison, T2]

Alison was having a “*not good*” day, both in terms of pain and, more importantly, emotionally. The “*everything else that comes with it*” in the quote includes ME, that she had been diagnosed with long before developing low back pain. ME and CP have many symptoms in common: ME

causes pain and both ME and CP are associated with low mood. Alison found it difficult to distinguish between CP and ME symptoms:

I think my mood's overtaking the pain this time [pause] and this is where I get confused, because I don't know whether it's the vicious circle from the pain or the vicious circle from my ME, because both symptoms are very similar, I don't know which one it is [Alison, T2]

ME and CP are both cyclical (“vicious circle”) and symptoms can be exacerbated by overexertion. Alison’s aim to ascribe her symptoms to one specific illness and the confusion derived from being unable to do so warrant a reflection, because they highlight her attitude towards CP and partly explain why, despite having attended the PMP, she was making no attempt to self-manage. Alison had not enjoyed the PMP. In response to the emphasis on activity pacing, she defended her tendency to “do a bit more” as a “bodily instinct”:

you know what you can do and what you can't do, and you always do a bit more because you have a good day, it don't matter how many times people say to you don't, you do, it's just your bodily instinct [Alison, T2]

By dismissing overexertion as a natural and therefore unavoidable behaviour and focusing her attention on the confusion caused by co-morbidity, Alison seemed to be covering up the fact that, whatever the cause of her symptoms, she was making no attempt to manage them. Alison’s dissociation from her pain shown at T1, was reiterated and reinforced at T2 by bringing ME into the equation and by defending her behavioural patterns as natural. In a sense, Alison was continuing to distance herself from her pain, taking no responsibility for managing it, using co-morbidity and instinct as justifications.

Having already described her mood in her pain drawing, Alison’s second Self drawing was a fairly neutral standing stick figure holding a walking stick, with Alison’s short hair, straight mouth and blue eyes (Figure 8, Self T2). She said little about the figure itself, except that the stick was an important part of her life:

it's my saviour at the moment [...] I feel more secure when I've got it, it's like a comfort blanket [Alison, T2]

Alison’s stick made her feel safe. She now appreciated the value of aids (“aids are a good thing and I'll embrace them now, I don't want to, but I'll have to”), since they had been discussed at the PMP (“now”), but she did not acknowledge any source for her change in attitude. PMP participation had not been enjoyable for Alison. She had “hated every single minute of it,” it had not taught her anything that she did not already know and she had felt awkward during the “meditating malarkey” at the end of each session. She appreciated only the session on spine anatomy, where she had been able to “actually see what was wrong” with her.

As previously, Alison’s general tone was of complaint and resentment towards the CCPS and HCPs in general. When given the opportunity to compare her previous and current Self drawings (Figure 8, Self T1 & T2) she found them incongruent:

I am that [T1] this week, I am it, but yet I haven't written it and I don't know why [pause] I don't know why, because I actually put all them on my arm today and that [T1] is how I

really feel, or should I say: I'm actually living that this week, I wasn't living it last time
[Alison, T2]

Alison felt that the Self she had just drawn did not really reflect her emotions, which instead were well illustrated by her Self drawing at T1. In truth, she has listed similar emotions in her second pain drawing (Figure 8, Pain T2), which was not on the table at this stage of the interview. Indeed, during her second interview she was visibly low, upset and irritated, particularly when discussing the PMP. However, what is most puzzling in this quote is her retrospective assertion about her first interview. She said that today she was “*actually putting all them [emotions] on my arm*” as opposed to last time when she had not been “*living it*”. The actual data from her first interview suggests otherwise, yet, Alison was adamant that she was now feeling the negative emotions that she had listed in her first drawing more strongly than she had felt them when the drawing had been first created. Alison’s distorted memory could be the effect of a ‘rosy retrospection’ bias, by which the past is recollected in more positive terms than it was originally experienced. Such a distortion could have served the purpose of aggrandising the negativity of her current situation, since Alison appeared eager to convey an adverse narrative, which her current Self drawing was dampening.

Overall, at her second interview Alison continued to feel low and angry about her pain and her life. PMP participation had, if anything, exacerbated her resentment towards the CCPS and her conviction that there were no pain management strategies that could improve her wellbeing.

Time 3. Alison’s third pain drawing is a basic representation of a scale, ranging between “*no pain*” and “*bad pain*” with an arrow in the “*bad pain*” half of the scale to indicate “*this is me*” (Figure 8, Pain T3). Alison was still in a lot of pain, particularly at night:

A: I'm not in no pain. The worst pain now seems to happen more at night and I'm sort of just past the middle. So I'm always in pain, but night-time is worse.

I: So this scale, so you're able to establish what the middle would be?

A: Yes.

I: On this scale, okay, and this is you at night?

A: No this was me right this minute.

I: This minute, okay. And at night what happens?

A: It would be here [indicating the far-right end of the scale].

I: Okay, on the bad pain. And how does it make you feel at the moment?

A: I'm exhausted because I can't sleep, because they took me off my amitriptyline, they took me off my naproxen, they took me off my fluoxetine, they took me off my tramadol, they've given me one tablet.

Alison had been very demotivated at the start of her third interview: in this quote her answers are short and require much prompting. Similarly, her drawing is very simple and, to a certain extent, impersonal. Whereas Alison’s first pain drawing had depicted a physical sensation and

the second had illustrated her emotions accompanying pain, this third drawing was the measurement of her pain levels using a quasi-clinical scale. The images had become increasingly empty as time progressed, as if the amount of effort invested in conceiving them had decreased. From this simple drawing, and the few words with which Alison described it, her pain appeared to be worsening and her willingness to engage with drawing was decreasing, in a manner that reminded me of her reluctance to engage with the CCPS. Having said this, to be fair, I was in the room while she was drawing, which may have reduced her ability to immerse herself in the drawing task.

As Alison mentioned in the quote above, a few weeks before the third interview, the CP service had reviewed her drug regime: instead of taking multiple pills for different problems, she had been prescribed a single pill for everything. The transition had not been smooth, and Alison was upset because she felt that her night pain levels had increased and her mood had deteriorated. Reviewing her pain drawings together, she said:

I think the middle one [T2], even though I was teary and feeling sorry for myself, I think I had come to terms with me, and then when they change your medication [...] it builds your hopes up again thinking that you might just get better and [...] when it doesn't work, it's like you're at the bottom again [Alison, T3]

This quote is interesting because it provides a reading of the past which is different from the actual data from the past. The idea that at T2 she had “*come to terms*” with herself was new and found no confirmation in her previous interview. Also new was the admission about her ongoing hope for a solution to her pain and the description of her life as a constant alternation of hope and disillusionment. Never in previous interviews had a sense of acceptance emerged, nor had a sense of hope. Previously Alison had made efforts not to discuss her pain, almost denying it at T1 and shifting the focus to her low mood and ME at T2. It felt as if, in her interviews, Alison were constantly moving the cards as a defensive strategy to avoid digging deeper into her feelings.

It is difficult to identify a trajectory for Alison’s pain because she did not invest much energy into representing it, nor talk about it during her interviews. From her few words, her physical pain seemed to have worsened, while her drawings became increasingly basic.

Alison’s third Self drawing (Figure 8, Self T3) is strikingly similar in subject and layout to her first one: a monochromatic round face, surrounded by bubbles with descriptors of her low mood: “*can’t be bothered*”, “*want to be on my own*”, “*fed up*”, “*sad*” and “*tired*”. At the side, there is also a thermometer to indicate that she had “*no energy*”.

In the past, Alison had described some of the emotions she listed (“*sad*”, “*fed-up*”, etc.), but she was expressing “*can’t be bothered*” for the first time:

I am tired and I'm fed up, but it's like I've got no feeling, I don't know if I am explaining it right, it's like numb, and I don't like feeling like this, because it feels like it drags me down and it makes me worse [Alison, T3]

Alison was feeling “*numb*,” and at the start of her third interview her tone of voice was low and her answers comparatively restrained, suggesting a worsening of her depressive symptoms.

The tone of the interview changed after Alison was able to review her Self drawings all together, which allowed her to temporarily see herself from outside:

even if I didn't know who I was and I looked at these, I would be quite worried [...] because it looks like a very sad depressed person, who's got a lot of issues [Alison, T3]

This realisation had a lifting effect on Alison’s mood: she became more talkative and also started to express more anger, particularly towards HCPs. She complained about the lack of support with her new medication that made her feel numb and, again, was negative about the PMP and the staff:

It's not just about chronic pain, it's all the other things that go with it. You know, and it's no good medical staff standing up there telling you to do this, do that, do this, do that when they've never been through it, because it's all right saying, yes, you can do it, you can do it, if I could do it, I would bloody do it [angry tone], I don't need somebody telling me to do it! [Alison, T3]

On account of not having ever experienced CP, HCPs had no authority to tell people what they should do. Alison was using this rationale to dismiss the contents of the PMP. At a deeper level, Alison seemed to be building up an elaborate defence to justify her lack of change over the course of the study. In the quote above she said that she wasn’t doing what had been suggested because she was unable to; elsewhere she explained that having suffered with CP for nearly 6 years, she had already done everything that could be done (“*I think I have changed everything I can change, I can’t change any more.*”). She had consistently refused to engage with any of the proposed self-management activities, including pacing, a cornerstone of pain self-management and, incidentally, also pivotal in the treatment of ME. In this last interview, Alison appeared more defensive than she had ever been. Her Self drawings showed no change and she was justifying her refusal to engage, lest she should be blamed for her lack of improvement and for still being unwell. The CCPS had “*not changed any part*” of her life “*whatsoever*”: a failing on the part of the service, not the consequence of her refusal to follow advice.

Summary. Interviewing Alison was difficult: she was quite eager to talk but determined to do so on her own terms. Her narrative throughout the study was focused on her low mood and was predominantly negative, with complaints about the CCPS and PMP. She was not interested in drawing, and her pain and Self drawings were mostly interchangeable and unchanged. The main feature from her time in the study was her detachment from her pain and ongoing depressive mood. She had refused to engage in self-management and was persistent in defending her own approach to handling her illnesses.

Discussion of the negative or unchanging trajectory

The drawing styles in this trajectory group were diametrically different from each other, with Helen's drawings consistently expressive and Alison's very basic, but there are many similarities in how both women were unable to use their CCPS referral and PMP attendance as an opportunity to embark on a process of change. This is especially true in comparison to the previous trajectory where, in an equivalent period and each in their own way, participants had been able to turn their lives around.

Like all other participants, when Helen and Alison joined the study they were in a dark place. Helen's first pain drawing shows her trapped in a bubble of pain, feeling isolated from others, surrounded by lightning bolts and threatened by a pain monster. Alison's first pain drawing is a monochromatic plug and socket. Although the drawings share a reference to the relatable experience of an electric shock (Munday et al., 2020), they reflect very different attitudes to pain. As seen in the drawings from the first trajectory group, Helen's pain is rich in detail, using many metaphors, including an external agentic being (Phillips et al., 2015) to illustrate how overwhelmed she felt at the time. In contrast, Alison's basic and descriptive drawing and the accompanying distancing narrative suggest that she was attempting to dissociate from her pain.

The behaviours Alison reported in relation to her pain at T1 included: distraction as a pain management technique (Goubert et al., 2004); pain avoidance (Vlaeyen & Linton, 2000), which she also enacted by refusing to sit on a chair for her first interview and by focusing on pain-relief medication; and experiential avoidance, which is the avoidance of unwanted emotions and thoughts associated with pain and one of the key indicators of psychological inflexibility (Hayes et al., 2006; McCracken & Zhao-O'Brien, 2010). The concurrent presence of these behaviours points to Alison having a particularly maladaptive attitude to her pain (Peres & Lucchetti, 2010).

A notable aspect of Helen's initial pain drawing and narrative was her sense of feeling isolated from others, who she depicted as singing in the sun in a corner of her drawing. Feelings of social isolation are common in CP sufferers and have been found to longitudinally predict higher levels of pain-related interference, but not physical function (Karayannis et al., 2019). In other words, the social context can affect the coping ability of sufferers by making them feel hindered by pain possibly more than they actually are. Helen felt profoundly misunderstood and unsupported by her family; she drew herself as cut off from them by a wall and enclosed in a bubble of pain, evoking metaphorical representations of pain as a barrier (Phillips et al., 2015).

The Self drawings of both women complemented their pain drawings. Alison's first Self drawing was more expressive than her pain one: it showed her locked in a vicious circle of negative emotions. In comparison, Helen's drawing was more descriptive, presenting her with pain, tired and confused in a jumble of medical and family references. Like participants in the

previous trajectory, both Helen and Alison had a history of depression, a common co-morbidity in CP sufferers (Bair et al., 2003). Helen appeared to be resisting a recrudescence of her depressive symptoms, while Alison's Self drawing, and her general demeanour, suggest that she was still deeply immersed in them.

An aspect common to their narrative, and that had not featured in the upward and positive trajectory group, was a dissatisfaction with HCPs. The need to negotiate the healthcare system is a common CP experience, with sufferers feeling ambivalent about engaging with a system that does not meet their needs while continuing to seek a possible cure from HCPs (Toye et al., 2017). In her Self drawing, Helen was surrounded by health-related words and described a life of ongoing health issues, but she claimed that HCPs had no time for her. Alison also talked a lot about HCPs and always in confrontational terms. Neither of them saw in HCPs a source of support, but both relied on them for care.

Following PMP participation, Alison's pain drawing and all of Helen's drawings looked markedly worse. Helen's pain drawing had stronger colours, and in it she appeared increasingly exposed to pain and even more cut off from the social life she craved. To emphasise how lonely and isolated she continued to feel, in her Self drawing she appeared behind bars next to a deserted island. Alison's second pain drawing was a collation of pink words of irritation and low mood, while in her Self drawing she appeared as a fairly normal stick figure. When reviewing her Self drawing, Alison disavowed it, stating that her true feelings were much worse than they appeared in the drawing. Their second drawings overall suggest the situation had deteriorated.

The PMP had not been a successful experience for either of them: Helen had just been a passive observer, while Alison had "*hated every single minute of it.*" Alison was very dismissive of pain management strategies and ascribed her ongoing difficulties to the confusion caused by co-morbid ME. Helen continued to feel cut off from the world and, although she recognised that the bars on the cage of her Self drawing were self-made, she was struggling to come to terms with deep family trauma. In comparison to participants in the previous upward and positive trajectory, the CCPS and PMP had not stimulated any major change for Alison and Helen, who seemed locked in a state of rage and despair.

RCT evidence on the efficacy of PMPs has been consistently weak (de C Williams et al., 2020) partly because different people respond to different aspects of interventions, with some people not responding at all. In order to offer interventions only to those likely to respond, researchers have tried to identify outcome predictors. In a review of BT and CBT CP interventions, McCracken and Turk (2002) found that better outcomes were experienced by patients with strong beliefs of control over pain, who engaged in less catastrophising and other forms of negative thinking in response to pain, and who had lower levels of depression and anxiety. They also found that psychological distress could interfere with treatment by decreasing participation

and that those with less supportive families had fewer benefits from treatment. Helen and Alison certainly displayed signs of psychological distress before the PMP: Alison had drawn herself surrounded by negative emotions, while Helen was cut off from a family that she perceived as unsupportive. However, the same could be said of participants in the upward and positive trajectory, who had depressive symptoms and also felt isolated and not understood by loved ones. In fact, Jane and Olga from the first trajectory group, felt so low at T1 that they could not see a future for themselves, which could be a sign of catastrophising, yet their outcome was very positive, which is in conflict with the McCracken and Turk (2002) findings.

An alternative explanation for what made Helen and Alison different from the other women in my study comes from a qualitative review of pain self-management intervention outcomes (Devan et al., 2018). Some PMP participants struggle to engage because they are fixed on a biomedical explanation for CP, which prevents acceptance and undermines the motivation required to practice self-management. Ongoing psychological distress also negatively influences the ability to self-manage, because fear/avoidance mechanisms lead sufferers to dismiss strategies such as pacing, and depressive symptoms affect problem solving abilities and lead to self-blame (Devan et al., 2018). Both Alison's and Helen's responses to the PMP fit well with these patterns, but in different ways. Alison avoided thinking and talking of pain and refused to practice pacing, she conceptualised her pain in biological terms (e.g. the only thing she enjoyed was learning about her spine), was avoiding her pain and was visibly caught in a spiral of low mood, as testified by her second pain drawing, which instead of being a drawing of pain was a drawing of low mood. Helen, on the other hand, was locked in a state of distress (which she literally represented as being behind bars in her Self drawing), unable to take action and blaming herself, not so much for the pain, as for her son's trauma. Devan et al. (2018) also identify an 'unsupportive ambience' as a barrier to self-management, referring to conflict with clinicians and lack of acknowledgement of the struggle of CP by significant others. Both these aspects resonate strongly with Helen's experience and, while Alison did not talk much about her family, she talked profusely of how she disliked HCPs.

A final explanation for Helen's and Alison's failure to engage could be that they were not "ready" for the PMP. Nielson et al. (2008) devised a questionnaire to assess the readiness for change of potential PMP participants by asking them about their engagement or willingness to engage in certain pain management behaviours (e.g. distraction, relaxation, pacing etc.). Although reliable and valid, the tool has not been picked up by many studies in literature, so its predictive power is difficult to assess. However, the idea of self-management as being a challenge that not all CP sufferers are equally 'ready' to face at a given time is an interesting one, but also a controversial one for its potential to exclude already disadvantaged participants (NICE, 2021).

Six months after the PMP, the situation with Alison and Helen was no different, if anything, it was worse. Alison's pain had deteriorated, and her mood was lower than ever. Helen's pain was relentless and appeared out of control in her third pain drawing, while, in her Self drawing, she presented herself caged like an animal, feeling increasingly isolated from others. Neither of them had adopted any pain self-management strategies, Alison by choice and Helen for inertia, and both continued to find their experience with HCPs frustrating. The third interview was difficult for both participants. When reviewing their drawings retrospectively, neither could ignore the visible deterioration. However, the realisation that nothing had changed and was possibly worsening triggered different responses: Alison expressed anger towards HCPs and seemed to be almost blaming them for her lack of change; Helen, on the other hand, thought that her low self-esteem was the reason why she had not done anything to help herself.

Alison's arc in the course of the study resonates with the assimilative coping strategy described by Van Damme et al. (2008): in an effort to pursue valued activities and goals, sufferers ignore pain, persist in their tasks and/or search for a biomedical solution. As their efforts repeatedly fail, they are overcome with despair and depression. Such a coping strategy can become entrenched and difficult to replace with a more adaptive one. From the very start of the study, Alison described the growing number of things that she could no longer do, yet she dismissed any of the self-management strategies proposed and remained focussed on a biomedical explanation, persistent in her hope that medication could free her from pain. Her drawings reflect this arc: from her first descriptive representation of pain as a plug and socket, to her final pain scale, she consistently kept a distance from her pain, while in her Self drawings her mood deteriorated.

Helen's coping strategy seemed to be an even more passive one: she was hoping that the problem would be miraculously solved just by the passing of time (Peres & Lucchetti, 2010). In her pain drawings she appeared increasingly exposed to the violence of her pain and, in her Self drawings, she was increasingly unhappy and isolated. Looking at her drawings at T3, she realised that it was her responsibility to help herself out of her cage, but her sense of guilt towards her son and her low self-esteem were obstacles she was unable to overcome.

Compared to Jane, Monica and Olga from the upward positive trajectory group, Alison and Helen are on the opposite end of the spectrum. Whereas Jane, Monica and Olga had actively engaged with the service and the PMP, used their referral as an opportunity to review their life and made profound changes, for Alison and Helen referral was not an opportunity for change, they did not engage with HCPs, followed none of the advice given and remained victims of their pain and deteriorating mood. Unlike their peers, Alison and Helen were unable or unwilling to take responsibility and act to improve their own lives.

Thanks to the longitudinal design we can witness how Alison's and Helen's inability to change persisted and became more entrenched, timepoint after timepoint, in the context of the internal

and external idiosyncratic aspects of their lives. We see their sense making evolve, as at each timepoint they bring new elements into their narrative, new information about themselves, thus deepening our understanding of their difficulty and their inability to disentangle themselves from their suffering. Alison's efforts to portray her present as more negative than her past and Helen's recursive process of revealing deeper and more distressing details of her sad life uncover "how the narrative of a life – the life as told, interpreted and understood – is continually re-adjusted to the life as lived and experienced" (Neale, 2021, p. 178). The moment in the final interviews, where all the drawings were reviewed together, had a tragic quality, it felt like a moment of reckoning for both women, like a last call for action:

I think maybe I need to sort myself out, it is hard though, it is hard [Helen, T3]

It looks like a very sad depressed person, who's got a lot of issues [Alison, T3]

Although we have no way of knowing what happened next, it is important for the story of those who for whatever reason are unable to change their path with pain to be told and for their voice to be heard. It reveals how profoundly transformational, idiosyncratic and perhaps irreversible the effects of CP can be and why efforts to find new ways to improve the quality of life of sufferers must continue.

Chapter 8 - Positive but complicated trajectory: Gillian, Kate and Lauren

The trajectory of participants in this third group could be positioned somewhere in between the previous two trajectories. Like the first group, during the study they progressed, but their progress was disrupted. Unlike the negative or unchanging trajectory group, they definitely engaged with the service and the PMP, but, due to their individual circumstances, participants in this positive but complicated trajectory group encountered more obstacles and their positive outcome was more complicated than the first group.

At the start, Gillian, Kate and Lauren all perceived their pain as having an alien quality: they either could not understand it or distanced themselves from their body in pain. As the study progressed, there were improvements, so that by the end they all grew closer to their body, learnt to understand it and to live with their pain. Their mood, outlook and sense of control also improved, but with a trajectory that was neither linear, nor particularly smooth or fast. Their paths were disrupted and complicated by various events: Gillian had to contend with a family crisis, Kate struggled to renounce her professional identity and Lauren had to face new health challenges. As a result, compared to the upward and positive trajectory group, the trajectory of participants in this group felt incomplete, as if a good portion of the path towards a full adjustment to CP might still be ahead of them.

Gillian's journey: from feeling alienated to being in control in a crisis

During the study, Gillian worked hard to regain control over her body and her life and to a certain extent she succeeded. At the start she had been distressed for feeling alienated from her body and having lost her previous identity. Through self-management she was able to understand her body more and re-engage with daily life. A crisis then challenged her balance and became the opportunity for Gillian to express an agency and a control that felt new. Her pain and Self drawings reflect this troubled trajectory.

	PAIN	SELF
TIME 1		
TIME 2		
TIME 3		

Figure 9. Gillian's drawings of her pain and Self - larger format drawings in Appendix D.6

Time 1. Gillian's first pain drawing (Figure 9, Pain T1) contains seven different elements, each illustrating an aspect of her experience: cold bones, burning legs, contracted feet, painful joints,

pain radiating from her spine, pulsating and painful jaw and metal rod in her back. The drawing is detailed, but also impersonal for how it resembles an inventory of symptoms. The wide range of pain manifestations was rather baffling for Gillian and her visual description of them was detailed, possibly because she was still trying to make sense of them. For instance, about the pain radiating from her spine she said:

it's really weird, because I know it's not the bone, it feels like it's radiating from the bone, but I know it isn't, but that's just how it feels in my body [Gillian, T1]

Gillian defined most of her symptoms as “weird,” using the term 20 times in her first interview. The discrepancy she described between her subjective perception of the pain in her bones and her understanding of fibromyalgia as not being located in her bones is illustrative of a general sense of alienation from the pain, and, ultimately, her body which Gillian was experiencing.

Gillian’s first Self drawing (Figure 9, Self T1) has a similar inventory-like quality and illustrates how the sense of alienation extended to her life and her identity. It contains multiple versions of her: reading on a couch, with a “candyfloss brain”, crying and sleeping. There are also two ugly masks: a red one representing rage and a green one representing envy, negative emotions that Gillian was experiencing at the time.

Gillian had previously had an active lifestyle and now her life was limited to the few activities depicted in her drawing: resting and reading. The effects of this change were profoundly distressing and affecting her sense of who she was:

I've always been an active outdoors person and my life has changed completely, I am not me anymore, I am just a completely different person and I want to go back [...] [I] just want to... [pauses] be me again and not this shell of what I am, or what I used to be [Gillian, T1]

Gillian had always thought of herself as an active person. The lack of activity forced upon her by the pain had transformed her life and, by extension, her sense of identity. The blankness and desolation in the sad and absent expressions of the top three figures in her first Self drawing illustrate Gillian’s sense of being “a shell” of what she used to be, as if her core identity had been lost to the pain. Gillian wanted to “go back,” because she felt no acceptance of her new life, or indeed any identification with the new person she had become. As far as she was concerned, the person she currently was was not her, it was just a “shell” of her and of who she had once been.

Gillian’s sense of alienation from herself was accompanied by negative emotions, symbolised by the red (anger) and green (envy) masks in her drawing:

Jealousy of how I used to be, people who are my age and older who are fine and, you know, and why isn't it me? Why can't I be fine? Anger as well, it's anger and frustration, I don't know at who, it's just, again, why me? [Gillian, T1]

She was comparing her current Self to her old Self and to other people older than her and feeling envious for a life that she no longer had and the victim of a new life that she thought she

had done nothing to deserve. She was in the grip of an anger that she could not even direct at somebody, leaving her stranded in her confusion.

The “*candyfloss brain*” in the Self drawing illustrates fibro fog, a typical fibromyalgia symptom. Perfectionism had been a defining trait for Gillian and since developing the illness, partly due to fibro fog and partly because of reduced stamina, she had experienced a loss of control over her life that had caused her much fear. Talking about the past, she said:

I was active, I did everything [...] I ran the show and [...] to suddenly [deep sigh] just not be in control any more was a real shock [...] I really didn't know what was going on, I thought I was turning into a zombie really [Gillian, T1]

The fibro fog had affected Gillian's ability to think, resulting in her no longer being able to organise her home and manage her family life. When combined with her other symptoms, it meant that she could no longer “*run the show*,” i.e. control most aspects of her own and her husband's life. In the quote, she equated this lack of control to being a “*zombie*”, a walking dead, which is a strong metaphor that captures her fear of no longer being herself and unable to operate in the real world.

At her first interview, Gillian had felt alienated from a body whose symptoms she couldn't understand, that did not allow for the lifestyle she yearned. She no longer recognised herself and felt that she had lost control of her life.

Time 2. Gillian's second drawing of her pain (Figure 9, Pain T2) is a full-body representation of a smiling figure, clearly identifiable as her from the hair. The figure is only partly covered by red pain marks and vibration symbols. The pain seems to affect fewer areas of the body compared to her previous pain drawing (Figure 9, Pain T1), because, for instance, it does not affect hips and legs. Gillian explained how the reduced pain was connected to a change in behaviour:

Because of what I have done, those past months that I have been taking it very easy and the aspiring to do one thing per day, they've obviously paid off because I feel the best I have for years now. So, I'm doing well and I am hoping now, I am just hoping that I can start to build on that, very slowly obviously [Gillian, T2]

Gillian had embraced the teachings from the CCPS and had been pacing herself in the last few months. She felt that her efforts had paid off because she was feeling much better. Her quote above is positive, but also tentative for how she was “*hoping*” to further improve, but “*very slowly, obviously*.” Despite her hesitancy, Gillian seemed much better, and not only because of the smile on the figure's face and the sun in the sky. In her second pain drawing (Figure 9, Pain T2) she drew a whole human figure, very different from the fragmented and faceless elements of her first pain drawing (Figure 9, Pain T1). The new drawing conveys a sense of wholeness, as if by feeling better in her body, Gillian had overcome her previous sense of alienation from it.

The sense of positivity permeates Gillian's colourful and lively second Self drawing as well (Figure 9, Self T2). It shows a smiling figure standing under a blue sky with the sun shining bright. Around the figure there are positive scenes enclosed in thought bubbles: tea with friends, walking dogs in a field, picking flowers and working at a computer. Some of these scenes were already a reality for Gillian, others were more of an aspiration, but her general tone was of hope for the future:

I am starting to have a bit of a life, which is nice [...] I didn't see an end to it really and now I am starting to see a light at the end of the tunnel! [Gillian, T2]

These optimistic words and the sunny drawing were in stark contrast with the bleak picture of multiple unhappy selves that Gillian had drawn only a few months earlier (Figure 9, Self T1). Thanks to the improved symptoms apparent in her pain drawing (Figure 9, Pain T2), Gillian had resumed a social life, symbolised by the bubble of her having tea with a friend. This made her hopeful about potentially returning to other activities, such as work, also appearing in one of the bubbles. Alongside feeling hopeful, Gillian was also realistic, for instance, about the impossibility of practicing sport again:

I don't think I'll ever be able to do that [sport] and that's fine. I've sort of, that was the past me, which before [...] I would have been desperately upset about and wanting to get back to [...] now I know I am never going to be able to do that again [Gillian, T2]

There is a sense of clear acceptance in this extract ("now I know I am never going to...") in stark contrast with Gillian's previous refusal to accept what was occurring in her life. Here she talked of a "past me," who would have wanted to "get back to" her old life, almost quoting the words from her first interview ("I want to go back" and "I want to be me again"). Things had changed: Gillian knew that she would no longer be able to be her old Self, instead, she was expressing a new calm and realistic Self:

I just know that I feel more in control and more, more calm, just calmer, just like the world is not ending and my life is not ending and I am not going to be an invalid for ever [...] it's more positive and more chilled really. The sun is out there in the distance! [Gillian, T2]

Gillian felt calm and in control, unlike her first interview where she had felt like a "zombie". Interestingly, in the quote above, referring to the past she used another death metaphor ("my life is not ending") to convey her previous fear of being forever disabled by her illness. Death is the ultimate form of lack of control and Gillian's use of these metaphors highlights just how utterly lost and devastated she had previously felt. Her current improvement had increased her sense of control and allowed her to think again in terms of having a future. She symbolised her renewed hope by including a shining sun in her second Self image, while the blue clouds accompanying the sun were a symbol of the calmness she was now feeling.

At her second interview Gillian appeared in less pain, serene and hopeful; she had regained a sense of calm and control, was engaging with life again and could see a future ahead of her. With hindsight, this was to be the calm before the storm.

Time 3. At her third interview, Gillian was experiencing a flare-up triggered by a major family problem and her third pain drawing is a powerful illustration of what a flare-up can feel like (Figure 9, Pain T3). It presents her from different points of view and the combination of black rigid lines, overpowering red on most of her body and pulsating signs, particularly around the head, conveys how bad Gillian must have been feeling while drawing. She thought that the flare-up had not reached its full potential yet:

it's not got the worse that it's going to get, either, I can feel it building [...] it's going to get a lot worse [...] I know now the signs and I can tell what's going to happen and I'm feeling really quite exhausted and throbbing today, tomorrow's going to be worse, the next day is going to be worse, and as the week goes on, I'm just going to get worse and worse for a few days and then I'll slowly start to improve [Gillian, T3]

Although the flare-up was making Gillian very unwell, in the quote above she appears confident in her understanding of what to expect (“*it's going to get a lot worse*”). Learning to pace had been of paramount importance to Gillian and part of the process had been an increased understanding of her body’s signs (“*I know now the signs*”). While a superficial review of her three pain drawings together might suggest a worsening of symptoms (Figure 9), the knowledge that the third drawing was created during a bad flare-up and her description of it suggest a positive trajectory of increased understanding. From being baffled by her symptoms at T1, Gillian now understood that a major stressor could trigger a flare-up, how the flare-up would develop over time and felt confident in handling it. There is an authority in Gillian’s words and a sense of being in control despite the severe symptoms that are very different from the puzzlement and sense of alienation that she had expressed at T1 (“*weird*”) or even the tentative optimism she expressed at T2 (“*I am hoping...*”).

Her reaction to the problem that had triggered Gillian’s flare-up is represented in her third Self drawing (Figure 9, Self T3). As previous Self drawings, the image contains different versions of her doing different things: crying, lying in bed with worrying thoughts and having tea with a friend. Her description of it was distraught:

I don't know how to deal with it, I don't know how to fix this situation [...] I've tried absolutely everything and nothing I do works [Gillian, T3]

Although the situation was serious and Gillian was upset about it, reading between the lines of her quote above, a sense of agency transpires. For instance, when saying “*I don't know how to fix this situation*” and “*nothing I do works,*” she was looking for actions that she could undertake to improve the situation. Later in the interview, her sense of agency became even more explicit:

you can't be stress-free completely, but you can do things to help yourself as much as possible and I just need to do whatever I can, I think, to help myself [Gillian, T3]

Despite feeling at a loss on how to resolve the problem, Gillian was taking responsibility for her own wellbeing. The inclusion of tea with friends among the scenes of her third Self drawing (Figure 9, Self T3), illustrates this coping mechanism of hers and, not by chance, it is the only

part of the image in which she appears smiling. At the time of the interview the problem was far from resolved and she was still lying awake at night trying to find a solution, however, as with her pain, she was expressing agency and actively coping.

Gillian expands on the expression of her negative feelings at the time:

I have wanted to stand in a field and just scream and scream and scream and scream, and, yes, I have actually done that at home [...] it's just such a bizarre experience because you don't even realise you're doing it, you just suddenly hear this noise and realize it's you
[Gillian, T3]

Although Gillian's description of hearing her own screaming voice has a disembodied quality which sounds scary, her lucidity in portraying her reaction was a testimony to her balance within herself. Even while narrating highly distressing events, she sounded more aware and in control of what was happening within her than she had ever seemed before.

Summary. Despite the difficult circumstances, Gillian's trajectory overall had been a positive one. From a state of passive emptiness and rage in the face of a baffling illness that was depriving her of her identity, she had achieved a sense of calm and control that sustained her and continued to develop through a major crisis. Gillian could lose control temporarily without fear of losing herself, a sign of strong inner balance, that, hopefully, enabled her, over time, to recover well from the crisis and restore her positive trajectory.

Kate's journey: a slow acceptance and integration of pain into life

Despite its progress, Kate's path through the study seemed the slowest, maybe because she was in the study for the shortest time (see Table 2). At the start she was still questioning the reality of her pain and grieving its impact on her professional identity; over time, reality started to sink in, and Kate became more accepting of her limitations. She always had a determination to think positive which transpired from the soft colours of all her drawings, but, as the study progressed, her pain drawings became increasingly real, while her Self drawings appeared increasingly serene.







	PAIN	SELF
TIME 1		
TIME 2		
TIME 3		

Figure 10. Kate's drawings of her pain and Self - larger format drawings in Appendix D.7

Time 1. Kate's first pain drawing is a strange butterfly, with a colourful and pretty body, full of hearts and flowers, but wings that are dark and not as extended as they would need to be for the butterfly to fly (Figure 10, Pain T1). Kate described her drawing in these terms:

It's a butterfly with tiny wings and the middle is my happy, flowery, colourful, sunny disposition, and the wings, the two smaller wings are black because that's my pain and tiredness that's stopping me from flying and being the person that I used to be [...] I still am that person, but I feel I'm like stunted growth [Kate, T1]

The incongruity of Kate's drawing reflected the contrast between her natural "sunny disposition" on the inside and, on the outside, the constraining effect that pain was having on her ability to express that disposition. She was "like stunted growth," because pain was blocking her development, stopping her from doing what she wanted to do and being who she wanted to be. Kate felt that there was a person that she "used to be" that her pain was no longer allowing; at the same time, she felt that she was still that person ("I still am that person"). This conflict suggests a problematic identity transition from being without pain to being with pain. Kate was attached to her old identity and reluctant to let it go, while at the same time admitting that the expansion that had characterised her old identity was no longer possible. As we shall see later when discussing her Self drawing, the crux of the matter for Kate was having to retire from work. Also affecting her ability to let go was that she could not wholly believe that her illness was real and not imagined:

I can wake up and think, "Oh, I feel quite well today", and then an hour later, bam, it's like, and you're forever thinking you've dreamt, because of that, you think, "it must be in my head, I must be imagining it." [Kate, T1]

I can see a parallel between how Kate's illness felt unreal to her, how she represented it using an image which was almost a fantasy, and how she was struggling to accept its consequences. It felt as if she were projecting an image of serenity to avoid facing reality. Kate's first pain drawing reflected a journey with CP that was still in its early days: although obviously suffering pain, she was questioning its reality and struggling to come to terms with its chronicity and consequences.

In Kate's first Self drawing (Figure 10, Self T1) there is also an inside/outside dichotomy, but here the contrast is between her true feelings and what she is showing to the world. Outside, she represented herself dressed in colourful clothes, with a speech bubble saying "I'm fine!" while the words on her body illustrate what was actually going on inside her:

I look like a clown because I like colour, it cheers me up, but inside, this is sort of a muddle of me, this is what I feel inside: fatigue, pain, brain fog, confused, happy, joyful also, because I naturally am, with a chronic cough, frustration and sadness, sad for I am still grieving the life I had, not as bad as I was, I think I am another step along the way, I think the pain management course will help me a lot in coming to terms with it and realising I am still a person, I still have value in this world even though I can't do what I did and I'm thankful that I haven't got an illness that's actually going to kill me right now, so I have to hold on to that glass half full [Kate, T1]

Although smiling and "fine" on the surface, internally Kate was struggling with a range of emotions and symptoms ("a muddle of me"). The presence of positive emotions reflected Kate's

natural sunny disposition (“*naturally joyful*”), while the negative ones showed how she was “*still grieving*” and struggling to come to terms with what was happening in her life.

As mentioned earlier, Kate was in the process of retiring from work for ill health and, with her job, she was losing her professional identity, a fundamental part of who she was. She questioned whether she was “*still a person*” having any “*value in this world*” because she found it difficult to imagine a life in which she was no longer productive. Despite trying her best to present a positive outlook, her use of the verb “*have*” in “*I have to hold on to that glass half full*” and her example of silver lining (“*I haven’t got an illness that’s actually going to kill me*”) have a desperate wilful quality, suggesting that her ability to remain positive was being challenged.

Kate’s first pain and Self drawings are closely entwined: in her pain drawing we see a positive innermost nature constrained on the outside by pain, while in her Self drawing the outside is a positive façade covering up her inner turmoil. Together, they show the struggle between Kate’s perception of herself as naturally positive (the inside of the pain butterfly and the smiling Self figure) and the impact of CP as an evolving negative predicament stopping her from working and doing the things she needed to do in order to feel that she was still her positive Self.

Time 2. Kate’s second interview occurred during a flare-up. She drew her pain as a train about to run her over (Figure 10, Pain T2), which she described as “*being hit by a steam train.*” Flare-ups were still frequent with her:

you think “oh, I don’t think I feel bad,” you know? And then, “oh, I can think of getting my life back on track to how it was,” and then, bam! You’re floored, you’re in bed, you can hardly move, you just feel terrible [Kate T2]

Kate was still questioning the reality of her illness: her belief that each sign of improvement could be a sign of recovery explains her inability to pace herself and reduce the occurrence of flare ups. Flare-ups felt unpredictable and arbitrary to her, hitting her suddenly, unexpectedly and with devastating consequences (“*bam! You’re floored*”).

Like the first, Kate’s second pain drawing was focussed more on the emotional effects of pain than on the pain itself. However, compared to the pretty butterfly of her first pain drawing (Figure 10, Pain T1), the train in her second pain drawing (Figure 10, Pain T2) feels more real, because it conveys the horror and surprise of dealing with a sudden and uncontrollable surge in pain. Something was beginning to change in Kate’s relationship with her pain, the realness of her train drawing suggests that she was starting to come to terms with it:

learning that acceptance isn’t giving in, because that’s what it feels like [...] if I accept this, that’s it, but it isn’t, it’s accepting it and working out what you can and can’t do [Kate, T2]

The PMP had taught Kate the value of acceptance as a steppingstone towards integrating the pain into her life and moving on. She had heard the lesson and was repeating it to me, however, her didactic tone in the quote suggests that this new understanding was still being assimilated.

Kate's second drawing of Self (Figure 10, Self T2) is a pretty girl standing below a blue sunny sky, among colourful flowers, holding a bunch of flowers to her nose and "*smelling the roses*". It is an idyllic picture, soft and colourful, apparently serene, however, the dialogue we had when I asked her to describe it points to a more nuanced reading:

K: That's me, that's me stopping and smelling the roses. I feel that, on a... to try and look at this as a positive thing is, it's made me stop and smell the roses; I have always been the sort of person that my mind has always been, "Oh I want to do the next thing, and the next thing, and the next thing..." whereas I've actually stopped and looked at the world around me and seen joy in simple things that I probably didn't have time to notice before, you know, I've learnt new hobbies and, ahm, yes. That's how I look on it because I think, yes, I could say it's ruined my life and, you know, I can't work and I can't... but I like to think that way. Is that the right answer for that?

I: There is no right answer, whatever is the right answer for you, so this is how you see yourself?

K: Well, it's how I like to... [pauses] yes, that's how I like to see myself, I'm a happy person, I think everyone that knows me thinks I'm a happy person [Kate, T2]

This exchange suggests that Kate's idyllic Self image was an aspiration and that her actual feelings were more complex. When working, Kate had been a high achiever constantly projected into the future. The pain had forced her to stop. She said that she was learning to live in the moment, so in the drawing she emphasised her fundamentally positive disposition. However, her narrative was hesitant and effortful ("*I try to look at this as a positive thing*") and culminates with a disconcerting question ("*Is that the right answer for that?*"), as if she were putting on a show and asking me to confirm its plausibility. Kate was drawing her most positive Self to contrast an illness that she felt had ruined her life, she was offering evidence to convince me (and probably herself) that she was indeed a happy person ("*everyone that knows me...*"). Although this drawing might look like a step forward from her previous Self drawing, where she had been contending with confusing emotions (Figure 10, Self T1), Kate was still having many negative thoughts and her projected positivity was a wellbeing strategy more than an established state of mind:

If you're feeling sorry for yourself, everything feels ten times worse [...] I think it's the frame of mind and it's good to try and be positive [...] it's not always easy, I'd be lying if I didn't say it got me down sometimes [Kate, T2]

Kate's overly positive drawing of Self was part of her strategy to cope with the negative emotions that continued to be a part of her.

Kate's flare-up at T2 was a sign of how her wider situation was still a work in progress. She was learning to accept her pain and its impact on her life, and she was projecting and practicing a positive identity as a way of coping with her difficulties adapting to pain.

Time 3. In her third pain drawing Kate drew an inventory of her symptoms (Figure 10, Pain T3) using various metaphors:

This is like lightning bolts, because you get like, it feels like an electric shock running through your body at random times, ahm, I also get waves of pain, it radiates down through my body and especially my legs it will go up and down, up and down, like a weird sensation
[Kate, T3]

Besides the lightning bolts and waves, she also drew ants to describe the feeling of crawling on the skin, a knife to illustrate the suddenness of her shooting pains and a black-centred flower to illustrate dull aching pain radiating out, which are all typical fibromyalgia symptoms, many of which we saw earlier in other participants' pain drawings.

This was the first time that Kate had drawn any symptoms, so it marked a breakthrough on her slow but steady path towards metabolising the reality of her illness. She still admitted to having thoughts about the illness not being real, but now she was ironic about it: *"I suddenly think, Oh actually, are you really ill? [laughs]"*.

When reviewing the three pain drawings together (Figure 10, Pain) Kate confirmed that the changing subject of the drawings could indicate her finally starting to come to terms with pain:

I think I was more focused on the negative in this one [T1], that I can't fly, you know? That's it, I can't fly and it's all about what I can't, whereas in that one I've just been hit by train [T2], I can't do anything, whereas that one [T3], well, there's my pain, but it's not going to ruin my life completely, if that makes any sense [...] I think I'm in a better, in a so much better place than I was [Kate, T3]

In her third drawing, the physical pain was finally appearing (*"there's my pain"*) and her life would continue despite it (*"it's not going to ruin my life completely"*), so Kate was indeed in a *"better place"* than she had previously been. At the beginning of the study, her focus had been on what the pain was leading her to lose and on her efforts to resist the changes it was causing; at the second timepoint, she had experienced a sharp halt and was somehow starting to face the reality of her condition; at the third timepoint, although joking about still not believing she was ill, she had in fact started to integrate the pain into her life and to trust that she could have a life despite the pain. By describing it for the first time in a drawing, Kate was finally expressing acceptance of her pain.

This sense of acceptance is made more explicit in Kate's third Self drawing (Figure 10, Self T3), where she is smiling and standing under a bright sun, between five colourful flowers and a large snail. Her frame of mind is clarified by words: *"snail's pace"* below the snail and, next to the figure, *"acceptance," "peace," "listen to my body,"* and *"make memories"*.

During her third interview, Kate appeared more at *"peace"* compared to previously, she described herself as *"happy"* and with *"no dark clouds."* The impression was that she had finally settled into her life with pain, accepting the change of rhythm it entailed, as suggested by the snail in her drawing (*"snail's pace"*). When asked about her expectations for the future,

however, it became obvious how deeply rooted her old ways were and how difficult she was still finding it to adapt:

my brain always churning forward [...] before I got ill that was what my brain was like and I think I need to enjoy, enjoy the little things, I need to definitely live in the moment [...] I'm trying to learn to stop my mind from racing [...] I think I've got to stop and just focus on listening to what's going on inside [...] and then plan a future after... not plan a future... Do you know what I mean? Just plan... Not even make a plan, but try to get well and then I can think about working and what I want to do with my life [Kate, T3]

Kate drew a contrast between how she used to be and how she was now, exactly as she had done in her second interview where she had finally “*stopped to smell the roses*” (Figure 10, Self T2). She described how projected into the future she used to be (“*my brain always churning forward*”) and then, using expressions such as “*I think I need to...*” and “*I am trying not to...*” she listed a number of ‘good’ behaviours she aspired to, including living in the moment, stopping her mind from racing, focusing on listening to what was going on inside and so on. The quote above illustrates how hard it was for Kate to bridge the gap between theory and practice. While listing her resolutions, she slipped into her old ways by suggesting she needed to “*plan a future.*” Then she immediately corrected herself by saying that she should just try to “*get well*” before thinking about working. There is a tension evident between Kate’s active nature, the thoughts still inhabiting her mind and her newly acquired normative idea of what those thoughts should be from a CP self-management perspective. Living in the limbo represented by CP, where she could not plan her life and had to contemplate the possibility of never returning to work again had been and still was difficult for Kate. She was making efforts to change and, judging from her drawings and her words, she had made progress, but her narrative and her representations of Self continued to have an aspiring quality.

Summary. Over the course of the study, Kate had been striving to come to terms with the changes that her condition entailed. It had been a slow process of adaptation that was still ongoing: the difficult emotions that she had struggled with initially had partly subsided and she had adjusted her focus inwards (“*listen to my body*”). She was also looking ahead in terms of family life (“*making memories*”) and trying not to look ahead as far as her work was concerned. Over time, her drawings became more positive and less performative, to reflect her slow journey towards accepting her new life and pain.

Lauren's journey: from raging to being real

Lauren's trajectory was a complex one: at the very start of the study she was wrapped up in anger towards herself and her body. The PMP was a breakthrough for her: she became more open and understanding of her body and emotions, and more focused on her own needs. This change led her to face issues that she had been ignoring for many years. The changes in her pain and Self drawings trace her path towards being more truthful with herself and others.

	PAIN	SELF
TIME 1		
TIME 2		
TIME 3		

Figure 11. Lauren's drawings of her pain and Self- larger format drawings in Appendix D.8

Time 1. Lauren's first pain drawing shows her from behind, with her arms folded in front. She has a black left leg and a red exploding star at the base of her spine, with yellow waves radiating upwards, to her hips and down her right leg (Figure 11, Pain T1). Having no sensitivity in her left leg, Lauren described it as "dead" and a "waste of skin". The pain she described in gruesome terms:

it's almost like somebody's putting their claws in the base of my spine and just ripping it apart. I feel like I am being strangled at times [...] it overpowers you and you feel almost suffocated by your own pain [Lauren, T1]

Lauren's language was aggressive ("waste of skin") and she saw the pain as external and violent ("somebody" was ripping her back and she was "being strangled" by "it"). As she observed when reflecting on her drawing, she did not see the pain as an integral part of her body nor of her identity:

It's almost that I've drawn somebody else, it's not me, but I know it's me, because that's my pain, that isn't me, that's my pain, there's a difference [Lauren, T1]

Lauren was distancing herself from her pain, desperately trying to defend her identity from it. The first interview had been upsetting for Lauren, she had cried a lot. She had also recently failed to come off morphine, which had made her angry. As indicated by the large dark cloud and wave of zeds over her head, her concentration and sleep were problematic. Although apparently simple, Lauren's first picture of her pain conveys her intense physical and psychological suffering.

Her first Self drawing (Figure 11, Self T1) sheds additional light on Lauren's distress. It contains two versions of her. On the left, she is facing the viewer, standing in crutches before three pleading unhappy children. She appears unstable and sad, with a black downward grimace, a broken heart and fumes radiating from her head. The figure on the right is a sideways view of her on a wheelchair, holding two happy children in her lap. Here, the heart is whole, her pink lips are smiling and there are musical notes in the air, suggesting serenity. Lauren said that on crutches she was "wobbly" and therefore unable to pick up her grandchildren, which made her sad and angry with herself. In the other figure she was happy because, despite the wheelchair, she could hold and cuddle the children. Although the drawing might suggest that the wheelchair was her preferred option, she seldomly used it because it evoked complex feelings:

instead of being like that [crutches], I make myself be that [chair], why struggle when there's no need? I've been given this stuff to use for quality of life, so damn well use it, stop being so stubborn. But as much as I am saying that to you, at the same time, when it actually comes to using it, I hate it, I absolutely hate it. It's a godsend because I have had some really great days out with the family [...] but I do feel like I'm slowing them all down [Lauren, T1]

Lauren did not like using the wheelchair because it made her feel like a burden to others. She tried to encourage herself to use it, but her words were harsh ("make myself," "damn well" and "so stubborn"). These aggressive and self-deprecating expressions reveal an inner conflict and negative emotional state: Lauren hated herself for not being what she thought she should be, and the fumes from the head of the first figure illustrate this rage. At the same time, she was

exhorting herself to see the positive (“*it’s a godsend*”). The inclusion of two versions of herself in the drawing reflected her struggle; the first figure represented her frustration and sadness and the second figure, with its red smile, was an injunction towards having a more positive outlook: “*there’s always a positive for every negative, turn it around, turn that frown upside down, start smiling*”. It felt as if Lauren were attempting to free herself from her negative emotions by forcefully fighting them and herself. The assistive devices represented an unwanted identity:

that’s not how I see myself [...] I’m not in the mirror with my crutches, I’m sitting on the end of my bed doing my makeup with the mirror and I’m normal, and I’m okay, and no one can take that away from me. The minute I turn away from that mirror, the crutches come in [...] I don’t look at myself and I walk away and I’m fine. That’s not what I see, that’s not who I am, that’s who I am... [covers the wheelchair with her hand] [...] I’m not that stubborn that I won’t, it’s just that it shouldn’t be there, my own two legs should be there [Lauren, T1]

Both the crutches and the wheelchair symbolised an identity that Lauren could not accept and, although she used them for the sake of being mobile, she resisted them to preserve the identity that she could not renounce. Lauren refused to recognise assistive devices as a part of her, yet, in the image of herself, she drew them both. When saying that she was not “*that stubborn*” to not use the assistive devices, her tone was again expressing her anger. Lauren was angry at herself for having to use assistive devices, but equally angry at her own refusal to use them: a catch-22 with profound existential implications.

The children in Lauren’s drawing were her grandchildren, whom she described as “*her world*”, giving her “*purpose*” and representing her “*future*”, in contrast to her own physically contracting world. Talking about their outstretched arms in the drawing she said:

this is when it all catches me off-guard or one of them says, “Nanny, can we?” and I say, “Do you know what? I really can’t today”. It’s the look on their faces, I hate it! I don’t feel like I’ve let them down because they do understand, it’s me that doesn’t like it, it’s me that has the anger, it’s me that feels I have restricted them or I’ve let them down [Lauren, T1]

In this quote, Lauren said she didn’t feel that she’d let her grandchildren down and immediately after said the opposite. Although she described her family as “*fabulous*” and “*one real good unit*”, suggesting that they were a strong source of support, Lauren felt guilty about not being able to care for them and often declined invitations to go out with them to avoid “*slowing them all down*.” Lauren was blaming herself for not living up to a physical standard, and was pre-empting her family’s presumed objections by choosing not to participate in their life. This choice, as in a vicious circle, was leading her life to contract further and increasing her anger towards herself.

Lauren’s first interview was distressing and tearful. Her pain and Self drawings and her narrative show her under fire from aggressive pain and self-hatred, not accepting her disability and feeling guilty with her family for not meeting her own standards of care towards them.

Time 2. Lauren's second pain drawing resembles her first but is richer in detail (Figure 11, Pain T2). It shows her again from the back, with black leg, red star at the base of her spine and thunder bolts running up. This time, her arms are extended outwards, with pain marks on the left arm and hands. Also, the cloud on the head is smaller than before. The most important difference is a legend on the right explaining the types of pain: numbness, pins and needles, pain and worse pain. The added details are matched by an unemotional description, with none of the previous dramatic tones:

just don't have feeling in the leg, that's never going to come back, the pain in the spine is just as bad, it radiates up the spine, as last time [Lauren, T2]

When Lauren compared her new drawing to her earlier one, she noticed the visible hands and the new marks on the arms, and tried to explain the difference:

this is all extra [hands], so yes, the pain has got worse, in that short time, but I don't know: has it got worse or is it because [...] I thought all this was part of that, so to me that was just a case of it's all pain and it's just radiating everywhere, no need to draw it on. [...] perhaps [it was] too much to take in, or perhaps I didn't want to look at it that far [...] that's probably just the fact that, "Oh my God, that looks disgustingly awful, I don't want to draw any more on there, because that looks bad enough, it makes me look like I'm a right pain-freak, I don't want to do any more of that." Whereas this is acceptance, this is real. I thought that was real, that's what I had accepted, this is real [Lauren, T2]

This quote is pure hot cognition: realisations were unfolding for Lauren as she spoke. Initially she thought that the pain had worsened, then she suggested having previously omitted the extra pain for the sake of simplicity, then she wondered whether the omission was to make the drawing more bearable. At each turn, Lauren was digging deeper in a crescendo of truthfulness. Seeing her pain on paper during the first interview had been upsetting for Lauren. After the interview, she had recreated her drawings at home, discussed them with her husband, and ripped them up, as if in a ritual. In her second interview, comparing the drawings enabled a reflection on how her relationship with the pain had changed. Where initially she had been overwhelmed by the pain and by internalised stigma ("I am a right pain-freak"), she now felt that she was accepting the pain. The intervening PMP had had a normalising effect:

the whole thing [PMP] was just so real it was frightening to see everybody go through those emotions and the anguish and the reality of what that [pain] does to you on a daily basis: it closes you down, makes you feel less than a human [Lauren, T2]

Meeting other sufferers and learning about CP had been a terrifying experience but also a liberating one: through other people Lauren could see how she had "closed down" and felt "less than human", a strong expression that matches her self-hatred from T1. Through the emotion of others, Lauren had come face to face with her own emotions and become more "real". The result was a "more honest drawing" of her pain, with an open posture, to match her change in attitude.

At the second interview, although her drawing of pain was fuller and apparently worse, it reflected a new era for Lauren in which, having abandoned her previous resistances, she was more open, more transparent and ready to face her many physical problems.

The sense of openness is also at the centre of Lauren's second Self drawing (Figure 11, Pain T2), a window with open shutters radiating light and labelled as "*ME – opened doors to all possibilities*". Above the window there is a large heart, big red smiling lips and a bright yellow sun; below there are eight little well-characterised figures, each representing one of her grandchildren. The drawing feels expansive and joyful and the texts reinforce the positive message. This is Lauren's description:

Before I was kind of not coping with anything, trying to be positive, but not quite coping [...] this is me breaking the doors open and saying, basically, without being rude, bugger the negativity! Let's just do what we can do, day-to-day, so not looking too far ahead [Lauren, T2]

Lauren's drawing was a positive and emphatic affirmation of herself, of her determination to cope with her situation and of her desire to break loose from the past by being open like a window to new possibilities. It was also a pragmatic declaration of an intent to realistically live life day-by-day.

As mentioned earlier, by bonding with other PMP participants, Lauren had seen herself differently:

[at the end of the PMP] we didn't look at each other like strangers any more, we didn't look at each other as a problem or a disability [...] we went in looking like that, we came out looking at ourselves like human beings and I think moreover we came out laughing at the face of adversity [Lauren, T2]

Lauren's previous perception of herself as disabled and all the accompanying self-hatred and negative emotions had dissolved through contact with other people who were in a comparable condition. She no longer felt like a "*problem*" or a "*disability*", she felt "*human*" again. The radiating window and the "*positivity*" label in her drawing illustrated this new expansive outlook.

As previously, Lauren's drawing featured her grandchildren, representing her family. She described one of her daughters as "*an absolute rock*," the source of comfort and support, and the main provider of the "*with help*" underlined in red in the drawing. However, Lauren's relationship with her other daughter was strained:

when I first started using a stick she used to walk three paces behind me because she was embarrassed [...] where my disability is concerned and the pain levels I am in, she won't see it, because she doesn't want to see it, because she doesn't want to have to deal with it [Lauren, T2]

Lauren's description of her daughter's embarrassment and attitude to her disability were both intense and painful, the only negative note in an otherwise overly positive narrative. They made a dent in the idyllic picture that Lauren had been presenting of her family and provided insight into the origin of Lauren's previous sense of guilt and resistance to using assistive devices. Although she did not say more at this stage, this revelation was a tangible sign of the new openness and honesty with herself that Lauren was claiming. Family remained central to Lauren's world and she knew that to be helpful to them she needed to be well psychologically:

it's not about what I can give other people, it's now about what I can do for me that makes me happy, so that I can then radiate that out to the rest of them [Lauren, T2]

In order to “radiate” as the window was doing in her second Self drawing, Lauren needed to focus on her own needs and develop her own happiness, symbolised by the big heart and smile. This was a substantial change from her previous narrative of guilt and anger towards herself. Assistive devices, appearing in miniature form in the second Self drawing, were finally being seen as a tool that could allow Lauren to spend time with her grandchildren.

Lauren’s new openness had affected many areas of her life. At the end of the interview, she offhandedly added something that was a strong hint of the things to come:

I wasn't open enough to say to you, to my own doctors, that this is all going on, because obviously I have that thing with my bowels as well where I am still constipated as heck [Lauren, T2]

Lauren had not discussed her constipation with me or, more importantly, with doctors, but this was about to change with devastating effects.

The PMP had been pivotal in bringing about a change in how Lauren felt about herself and her pain. Her drawings were more open, she was being more real and determined to face whatever life would bring her way.

Time 3. At the start of her third interview, Lauren was very downcast. As she worked her way through the drawings, particularly comparing new and old ones, her mood improved. Her third picture of pain (Figure 11, Pain T3) was surprisingly similar to her second: an image of her from behind with wide open arms and legs, her body covered in marks and a legend to explain the different types of pain. The cloud on the head was still there, but notably smaller. In addition, on the right, there was a miniature sideways view of the same figure with a large green ball on the belly, representing a bloated bowel.

Lauren had suffered from severe constipation most of her life. Whenever she had raised the issue with doctors, she had been told that it was caused by the morphine she took for pain relief. After the PMP, Lauren had demanded that the problem be investigated, leading to a diagnosis of prolapse and a prescription of strong laxatives, waiting for surgery. The laxatives caused incontinence which was very distressing. Initially, Lauren addressed her anger at the doctors who “*should have listened to me a long time ago*”, but as she talked, her anger turned towards herself, because she “*didn't make them listen.*” She associated her previous inability to make herself heard to her attitude towards her body:

they [CCPS] gave me the encouragement to go and make myself clear, whereas before I wouldn't have done, because I would have just thought [...] it's my back that is causing this [...] they made me realise that, no, there is something else wrong, there is something underlying and, actually, yes, I should be taking more notice of my body. And that was the crux of it for me [...], when he said, “listen to your body, feel the pain and work with it, don't allow it to beat you, you be the boss of it.” And from that point on I strived to do exactly that and the bowel then reared its ugly head, but it was always there, but that was one point that I

just couldn't get around, always pushed it to the side, because nobody listened anyway, what's the point? [Lauren, T3]

The CCPS staff had told Lauren to “listen” to her body, “feel” the pain and “work with it”. In other words, she had been encouraged to be receptive to the signs that her body was sending, to accept them and to collaborate with her body. This was a message of integration, in contrast with Lauren’s earlier efforts to separate herself from her pain and her body. Lauren thus decided to make her voice heard with doctors about her constipation. The positive effect of this newfound integration was particularly evident when reviewing her older pictures:

I feel clearer in my mind, maybe that's why the fuzziness is smaller [...] it's gotten smaller over time, that's amazing! [...] the pain has stayed the same I think, it's just that the coping with it has changed [...] I have learnt to cope with it more and I am now ruling it more than it rules me [Lauren, T3]

Although the pain was unchanged, Lauren’s attitude towards it was different, she felt she was “ruling” her pain and this was affecting both her clarity of thought (reflected in the smaller mark over her head) and her level of exhaustion (reflected in the lack of zeds in her third drawing).

Lauren’s third Self drawing (Figure 11, Self T3) is surprisingly similar to her pain one. She appears as a full standing figure covered in pain marks and with a detached head floating on a cloud a short distance above the body. There are tears on her face and cartoons to word her thoughts. As mentioned earlier, Lauren’s mood at the start of the interview was low:

I feel like I've gone three paces back, I just feel like I was in a really good place the last time I saw you and suddenly it's all gone out of the window, I just feel like I need a break. [Lauren, T3]

In the picture, “give me a break” and “three paces back”, appearing as “1→2→3” below her, illustrate how Lauren was demoralised by the constipation setback, feeling she had regressed. However, unlike before, she now had the ability to cope. Talking about her detached head in the Self drawing, she said:

I am very real now [...] this isn't dismissing it, this is just taking myself off and giving myself half an hour's break from the reality, being somebody else in my mind [Lauren, T3]

Lauren’s being “real” that had started in her second interview, was continuing, and included the ability to temporarily abstract herself when reality became overwhelming. She would mentally cut off from her body and travel with her fantasy to a happier place and time, gaining some respite. This technique had been inspired by her love for reading:

I can read that book 5 times, because I'll be a different character each time and I don't get fed up reading it and then the sixth time [...] I am reading it as the outsiders looking in and that's what I try to do with my body. I try to be a different character maybe, somebody I'd like to be, like [...] 21 years old again [...] So it's a silly game that I play, but it's one that stops me becoming depressed and down in the doldrums [Lauren, T3]

What Lauren described was a visualisation technique of the kind used in hypnosis. In order to cope, she was self-hypnotising herself, taking her mind away from reality, and this was allowing her to keep her depressive mood at bay. Part of being “real” was pretending to be somebody else and also allowing herself to cry, as the detached head was doing.

After seeing her current drawing in the context of her previous ones, Lauren's tone became chirpier and how she described her current state became more positive.

I just feel like I've been thrown back, but when you put this whole lot together [all drawings], I haven't been thrown back, I haven't gone back those three footsteps, I just felt like that, it's just another thing to deal with and I will. So, yes, I've coped with the major pain, I can cope with that, there's got to be a positive outcome and if it's a negative one, I will deal with it
[Lauren, T3]

Learning to manage her CP gave Lauren the confidence to cope with her constipation and even the prospect of a negative outcome (i.e. permanent colostomy bag), was acceptable.

A notable feature of Lauren's third Self drawing, compared to the previous two, is that for the first time the main focus is her, with her pain and her coping strategies, while her family are no longer represented visually, being instead listed in one of the bubbles alongside many occurrences of "PAIN". Family was on her mind, possibly as a preoccupation, but did not occupy as much space as in earlier drawings. She was finally representing herself as a full figure, over the whole page. When I brought this to her attention, she confirmed that she had drawn herself as a whole figure to make the representation "real" and added:

I'm not that useless article that I thought I was here [T1], going to land up in three years' time in a wheelchair, totally stupid, can't do anything, no, that's not me at all, this is me [T3], looking forward, thinking things through correctly, having the right expectations for me and my pain levels, not overdoing it all the time, not trying to be the person I think I should be, be the person I am [Lauren, T3]

Lauren's new Self was "thinking things through," having the "right expectations" and, importantly, being who she was. This was a major change in narrative: Lauren seemed to have reconciled with herself. The key to understanding her change was her difficult relationship with her eldest daughter, who was in denial about Lauren's illness and triggered feelings of guilt:

If there's a law in the world, I should be doing that for my daughter, I should be allowing her to go out and have fun [...] I should just accept that. No, I shouldn't. I'm human too and I have my needs [...] Mum's changing for the better, she's not a doormat anymore, she's a human being [...] Mum doesn't feel guilty anymore [Lauren, T3]

Lauren had been sacrificing her own health on the altar of her daughter's needs, acting as a "doormat" because she was obeying a higher "law in the world." Lauren's self-loathing during her first interview was connected to the guilt she was feeling for failing her duties as a mother and as a grandmother. Over time, as she had learnt to accept her condition and its limitations, she had found the strength to focus on herself and claim her right to be who she was with her daughters. The PMP and the CCPS had been pivotal in this process, because they had made Lauren feel supported and encouraged her to live happily within her limits. Her last drawings were of her "real" Self with pain, tears and a clear mind, psychologically stronger and determined to live her life to the full.

Summary. Looking across all of Lauren's drawings one might conclude that her pain and her general situation had worsened. In reality, from a state of angry denial and suffering, Lauren had

become increasingly aware of her body, open with herself and in her drawings to being “*real*,” and ready to be at the centre of her own life, challenging others, if necessary.

Discussion of the positive but complicated trajectory

While outcomes in the first upward and positive trajectory group were exceptional in terms of speed and magnitude, and participants in the second negative or unchanging trajectory group did not progress at all, participants in this positive but complicated trajectory group had a positive outcome, but their path was not linear, and was characterised by setbacks. As a result, they can be positioned somewhere between the two ends of the positive/negative outcome spectrum.

At T1, Gillian and Kate were finding it difficult to understand and believe what was happening to their body. Their initial pain drawings reflected these difficulties, with Gillian's inventory of "*weird*" symptoms and Kate's disbelief in the reality of the truncated wings constraining and trapping the 'true' nature of her butterfly. Lauren, on the other hand, initially played down her symptoms, to distance herself from her pain, in a manner similar to Alison from the negative or unchanging trajectory group. The pain representations of the women in this group reflect a common experience among CP sufferers, who describe feeling distant and alienated from a body which is perceived as constraining and unreliable (Lempp et al., 2009; Miles et al., 2005; Snelgrove et al., 2013).

The sense of body alienation has repercussions on CP sufferers' sense of identity (Hellstrom, 2001; Osborn & Smith, 2006; Toye et al., 2017), as illustrated by the first Self drawings of participants in this group. Gillian drew multiple versions of herself and talked of not being able to reconcile with the inactive, confused, jealous and angry person that she had become. Kate was putting on a brave face while struggling with negative emotions, mourning her lost professional identity and questioning whether she still had value in the world. Lauren drew herself with crutches and a wheelchair in front of her pleading grandchildren, but she was fighting the identity symbolised by the assistive devices and hating herself for not fulfilling her family duties. Issues of identity associated with difficult feelings, particularly of anger, had emerged in other trajectory groups as well, for instance with Monica resisting the pain to save her Self or Alison's feeling useless and angry at losing valued activities, but the women in this trajectory group seemed to exemplify these issues more clearly.

Qualitative studies have highlighted how, challenged by pain and trapped in a body they cannot recognise, sufferers fight to retain their old identity, but are unable to be who they once were and struggle to adjust to who they have become, an experience that well-encapsulates what was happening to Gillian, Kate and Lauren (Hellstrom, 2001; Osborn & Smith, 1998, 2006; Smith & Osborn, 2007b; Toye et al., 2013b).

The ways in which identity issues were represented and described by participants in this group can be explained using different models. For instance, all the selves in Gillian's first Self drawing are pain-related in some way: she is lying and sitting because of pain, angry and

envious because of pain and crying and affected by brain-fog because of pain. According to the pain-self enmeshment model by Pincus and Morley (2001), elevated distress results from an overlap between pain, self and illness schemas. With pain having taken over all spheres of Gillian's life at T1, there no longer seemed to be a separation between her pain, her condition and who she was as a person and this was causing her great distress. Kate's difficulties in accepting the loss of her professional identity to pain could be explained through a motivational model of pain, where pain's disruptive impact is attributed to its interference with the valued daily activities that define one's sense of Self (Crombez et al., 2012; Vlaeyen et al., 2016). Having been profoundly invested in her profession and no longer being able to work, left Kate without a recognisable sense of identity. Finally, according to Self-Discrepancy Theory (Higgins, 1987), distress occurs when there are substantial differences between who you believe you are, and who you would like to be, or believe you should be, with actual-ideal self-discrepancy in CP sufferers associated to depression and psychological distress (Waters et al., 2004). This model resonates with the conflict in Lauren's first Self drawing, between an undesirable actual self on crutches, a desired self not needing assistive devices to ambulate, and an ought self who should accept assistive devices and happily sit in a wheelchair with her grandchildren.

As the women in the first upward and positive trajectory had done, all three women in this group embraced their time in the CCPS and PMP as an opportunity to change how they managed their pain. They listened to what was said and did their best to apply the strategies that were recommended, however, their path towards integrating the pain into their lives turned out to be more turbulent compared to participants in the upward and positive trajectory.

Just after the PMP, at T2, Gillian and Lauren appeared much better than they had been at T1, but their positive trajectory came to an abrupt halt at T3, when Gillian had a flareup and Lauren faced new physical problems unrelated to CP. Kate's disruption had occurred earlier, at T2, when she also had to contend with a pain flareup. For all three women, the setback came as a shock, but it was also an integral part of their journey towards learning to manage their pain. After feeling better at T2, Gillian had regained control of family matters but the associated stress had triggered a flareup. Kate's flare-up was the consequence of her difficulty pacing herself and her ongoing disbelief in the reality of her pain. At T3, having grown closer to her body, Lauren had finally made her voice heard with doctors, raising medical issues that had laid dormant for years. Flareups and other disruptions are common in CP and the purpose of self-management techniques, particularly pacing and mindfulness, is to provide PMP participants with the tools to contain such events.

Pacing is a way of regulating activity levels, through rest or moving at a slow but steady pace (Nielson et al., 2013). Comparing pacing-only interventions for fibromyalgia patients, Racine et al. (2020) concluded that pacing encourages movement in sufferers who have stopped their

activity because of pain, while encouraging those who move too much to slow down and adopt a more regular pattern of activity. In either case pacing produces better physical outcomes.

Gillian ascribed her change between T1 and T2 to having been very rigorous in her pacing (*“doing one thing a day”*). At T3 Lauren talked about *“not overdoing it all the time,”* suggesting that she too was practicing some form of pacing. In contrast, at T2, Kate was still misinterpreting slight improvements as signs of recovery and was surprised to be having a flareup. Pacing requires staying focused on the present and the discipline to not over-exert oneself when feeling better, an attitude that clashed with Kate’s tendency to project herself into the future in the hope of getting her life back on track. The snail (*“snail’s pace”*) in her T3 Self drawing suggests that pacing was still work in progress for her. In an IPA study by Andrews et al. (2015), participants with a tendency to be overactive, like Kate, ascribed it to pre-morbid patterns of behaviour and enduring self-concept, while for those who, like Gillian, adopted pacing, it was a challenging but fruitful strategy, which increased function and gave a sense of control over pain.

Mindfulness aims to encourage detachment from thoughts, and physical and environmental circumstances by bringing awareness to one’s breath, without judgement (Darnall, 2019). Each PMP session ended with a body-scanning, relaxation or mindfulness exercise. Tai-chi, that all three participants in this trajectory group practiced, is known to increase mindfulness levels (Chen et al., 2021). Mindfulness is associated with significant improvements in depression and both physical and mental health-related quality of life (Hilton et al., 2017), with positive effects on pain intensity and quality of life lasting over six-months (Bjornsdottir et al., 2018).

At T3, all participants in this group talked of having learnt to listen and understand their own body, which resonates with the mindfulness concept of being aware of the present moment, including the ability to attend to bodily sensations (Harrison et al., 2017). Gillian, whose body had initially felt alien to her, was very confident about what to expect during her flareup. Lauren’s constipation problems were finally being addressed because she had observed what was happening to her body and confronted doctors about her symptoms. Kate included *“listen to my body”* in the list of good practices in her Self drawing. In a mindfulness-based CBT RCT for people with CP and comorbid depression, participants receiving the intervention showed a significantly higher ability to control their distress by consciously attending to and not ignoring uncomfortable body sensations, a practice which also mediated the intervention’s positive effect on depression (de Jong et al., 2016). These findings confirm that mindfulness can increase body awareness and improve the emotional response to pain, which could explain why Gillian’s and Lauren’s increased sense of being in tune with their body was associated with a stronger sense of control and, in the case of Lauren, empowerment in her relationship with HCPs.

The disruptions experienced by all three women in this trajectory group were part of their evolving relationship with their bodies in pain. Their individual trajectories illustrate how

teachings on pacing and mindfulness, two cornerstones of the PMP they attended, had been received, acted on and integrated at different degrees, with the effect of improving their connection to their bodies and their ability to self-manage CP.

This evolution can also be understood in terms of growing acceptance, a construct within the ACT psychological flexibility model discussed earlier in relation to the upward and positive trajectory group.

Initially Gillian's pain had been difficult for her to understand, let alone accept; she had drawn her pain on disjointed body parts and drawn herself expressing anger for the life changes caused by pain. At T2, after practicing mindfulness and pacing, her body appeared whole in her pain drawing, and she sounded serene in recognising that resuming her previous lifestyle was no longer an option. Over time she had come to accept both her pain and its impacts on her life. Lauren expressed her acceptance by producing increasingly "*real*" drawings of pain and being more "*open*" about its impacts. Kate, who had originally resisted acceptance, took longer to adapt, but by T3, when she drew her pain symptoms and included "*acceptance*" in her Self drawing, she was starting to let go of her struggle with pain (Hayes et al., 2006).

Although pain acceptance has been found to reduce suffering and increase functioning (Vowles et al., 2009), general acceptance, defined as the acceptance of the psychological experiences that accompany pain, presents stronger negative correlations with depression and psychosocial disability than simple pain acceptance (McCracken & Zhao-O'Brien, 2010). In fibromyalgia, which both Kate and Gillian suffered from, general acceptance is a significant predictor for the physical and psychological aspects of functioning (Trainor et al., 2019).

The general acceptance construct seems closely linked to the issues with identity raised by CP. When, at T1, Gillian and Lauren were refusing to accept their pain, they felt disconnected from their bodies and from their former selves. After the PMP, they grew closer to their bodies in pain, the pain was not less, sometimes it was even more, but the chasm between Self and body (Osborn & Smith, 2006) was reduced and they expressed acceptance of what was happening to them. As they became more accepting of their body in pain, they also became more serene, as if Self and body were being integrated and a new Self was developing as a result. This interpretation is corroborated by other qualitative studies where, after a PMP, participants have talked of developing a new self 'with pain' (Mathias et al., 2014) or where acceptance has been associated with an altered and more-flexible self-identity and openness to change (Casey et al., 2019). Kate was on a similar journey but possibly at an earlier stage of this process. Having left work just before joining the study, her experience of loss of Self was more recent. She struggled more than Gillian and Lauren to accept the pain and at T3 there was still a discrepancy between her positive drawings and the difficulties that transpired from her narrative.

Compared to the journey of the women in the upward and positive trajectory group, the experience of Gillian, Lauren and Kate was less outstanding and possibly more common. They

progressed over the course of the study, but their path was challenging and far from linear: each in her own way, they were coming to terms with their pain, becoming more attuned with their bodies and able to deal with the downturns that having CP can cause. As they integrated pain into their lives, they also accepted the changes to identity that CP can require. Their complex and somewhat slower process of change offers an exceptionally nuanced account of the links between pain, change, acceptance and identity.

Chapter 9 – Concluding discussion

Key findings from the study

In terms of understanding CP, this study's findings suggest that, after referral to a CCPS and participation in a PMP, experience can vary greatly: some participants embrace the opportunity to make substantial changes to their life; others do not engage and continue to suffer, especially psychologically, and struggle with CP; others absorb the CP self-management teachings and embark on a slow process of acceptance and integration of pain into their lives. In all cases, the experience of CP and responses to support from HCPs to manage CP emerge as being profoundly idiosyncratic and deeply embedded in the context of each person's lifeworld.

The experience of participants in this study resonates with some well-established theoretical models, namely self-compassion and components of the psychological flexibility model that underlies ACT, and the findings illustrate in a unique manner the situatedness of such models, with the different constructs combining and concurring to explain each individual's evolving experience.

This study breaks new ground methodologically by introducing new ways of investigating the evolution of the CP experience, which will be transferrable to many other empirical contexts. The drawings of pain confirm the power of the imagery associated with CP in conveying the physical and psychological impacts of the condition. Self drawings, used here for the first time in combination with pain drawings, illustrate how participants feel about themselves in relation to their condition and their life more widely. Together, the drawings are an effective tool to elicit in participants pre-reflexive and reflexive insight into their experience, achieving a rare depth during interviews. Amongst other things, the drawings make explicit what is implicit and allow participants to break free from rehearsed narratives about themselves and their condition. The drawings and their metaphors also talk to the researcher and the viewer directly, resonating emotionally and physically and integrating the narrative.

The novel longitudinal design, combining interviews and drawings, allows for a nuanced account of temporal progression and participant trajectories. The longitudinal sets of drawings illustrate the trajectories and are also, importantly, powerful research tools. The opportunity during the interview for participants to compare drawings, enables them to retrace the timeline of their experience, reviewing what has been through the 'objective' eye of the drawings, that represent unchanging windows onto the past. For the researcher, drawings and reflexive narratives facilitate a shift from an asynchronic view of time as a series of snapshots to a diachronic view of time as fluid and processual.

Considering the three trajectory groups together

My study stemmed from a desire to explore how being referred to a pain management service and attending a PMP can affect the relationship with pain and the sense of self of people with CP. I chose a longitudinal design, gathering data at three timepoints (with T1 and T2 before and after PMP participation, and T3 six months later) to be able to closely capture short-term and medium-term changes resulting from the PMP. At the start of each interview, participants drew an image of their pain and one of themselves, and the interviews revolved around current and, when available, previous drawings. The aim of the drawings was to help participants express difficult aspects of their experience, and to reflect on the pain and its impacts on them and their lives more widely.

The results illustrate in detail how the experiences of CP sufferers can idiosyncratically evolve, with some participants embracing self-management and change, and others not. The results are also very informative in methodological terms because they demonstrate the value of using IPA longitudinally to achieve insight into temporal processes and they show how drawings of pain and Self can illustrate transformation, adding depth and understanding to the narrative of participants.

At T1, all participants were in a dark place, perceiving their pain as an aggressive, oppressive and sometimes baffling agentic force. Some were resisting the pain, others were overwhelmed by it, all were suffering greatly, both physically and psychologically, for the impacts of pain on their life. The Self drawings conveyed depressive moods, anger, and a sense of isolation from others that completed the bleak picture offered by the pain drawings.

At T2, and then at T3, each of the 8 participants' response to the PMP and the CCPS delineated a trajectory, with three different trajectory groups resulting from the overall analysis:

- The first group, which includes Jane, Monica and Olga, had an upward and positive trajectory, with the pain and Self drawings showing a clear positive evolution. During the study they experienced a radical and outstanding change for how they were able to regain control over their pain and agency in their lives, which made them feel better in themselves and reach some sort of normality.
- The second group, which includes Helen and Alison, did not improve at all: their pain and Self representations worsened, they made no attempt at self-manage their pain and were locked in static identities and relationships, with a pain that seemed to become worse.
- The trajectory of the third group, including Gillian, Kate and Lauren, was also positive, but less linear and complicated by specific circumstances. Although their drawings showed disruption and deterioration at times, they all embraced self-management practices and were on a path towards gaining a better understanding of their body, integrating pain into their lives and gaining some sense of control over it.

When discussing the experience of participants in relation to literature in the previous trajectory group chapters, I focused on the aspects that I considered central to the journey of participants in each group. However, some of these aspects were relevant for participants in other trajectory groups as well. For example, pacing (Nielson et al., 2013) which was discussed in relation to participants in the third trajectory group, was also listed by Monica from the first group as a tool in her last pain drawing and mentioned by Alison from the second group as something she was refusing to do.

The psychological flexibility (PF) model (Hayes et al., 2006) is the most useful to understand a number of the processes occurring for all participants. One of its constructs is acceptance (McCracken & Zhao-O'Brien, 2010), which is relevant in different ways for different trajectory groups. For participants in the first group, acceptance was manifest by them putting their pain back into its place through a process of empowerment (Biguet et al., 2016); for participants in the third group, who had struggled more with the challenges of CP to identity and body alienation, acceptance was a gradual process which progressed hand-in-hand with gaining an understanding of their bodies (Harrison et al., 2017). In contrast, Alison and Helen, from the second group, did not express any acceptance because their focus remained on finding a biomedical or miraculous solution to their pain.

Related to the PF model was also the ability of participants in the first group to challenge their self-concept and commit to making life changes reflecting their personal values (Feliu-Soler et al., 2018). Similarly, techniques such as mindfulness, used in ACT interventions to help participants develop PF, helped participants in the third group to bridge the mind-body gap (Harrison et al., 2017). In contrast, Alison's and Helen's inability to overcome their maladaptive coping strategies were signs of psychological inflexibility (Van Damme et al., 2008). The shift towards prioritising their own needs over the needs of others evident for the women in the first group, and in Lauren as well, is linked to self-compassion (Edwards et al., 2019), also a construct gaining increasing traction in the psychology of CP.

Overall, the three trajectory groups differed in whether and how they engaged with the CCPS. Those who did engage, experienced a process of change in which different psychological constructs came into play, depending on contextual and idiosyncratic factors. The constructs themselves have already been discussed extensively in the rich existing corpus of CP literature. What is special here is the sense of how the different biopsychosocial factors combine and concur to create a person's CP situation and how the stimuli of a CP intervention interact with the specifics of the person's life to bring about a change or for this change not to happen. As I shall discuss in detail in the next sections, the drawings contribute to make this account more vivid, in terms of the depth and reflection they enable for participants, and for their ability to resonate with the viewer and stimulate a deeper level of understanding of the CP sufferer's plight.

Considerations on the drawings and their metaphors

Although the pain and Self drawings were created and discussed separately in the interviews, often pain appeared in a Self drawing or participants represented themselves in their pain drawings, so both types of drawings could be considered aspects of a composite experience.

Wherever it appeared, pain was illustrated as a physical and/or emotional experience. Physical pain could be depicted as a body covered in vivid colours or under attack through implements, such as Olga's and Lauren's bodies covered with marks indicating pain locations, qualities and intensities. Other times the colourful pain marks appeared without a body, in abstract form (e.g. Monica's first pain drawing or Helen's last one). Physical pain qualities were also conveyed through metaphors, like Gillian's and Kate's inventory of pains, Olga's tooth in the lower back, or Alison's plug and socket. Where viewers have no CP experience, these metaphors allow them to imagine what the experience is like, drawing parallels with their own experience.

In other drawings, the psychological impact of pain was depicted. Examples from T1 were the weight above Jane's head, the wings in Kate's butterfly, and the monsters in Monica's and Helen's pain drawings. These 'psychological' metaphors allowed participants not only to communicate how they were feeling in response to the pain, but to ascribe an agentic will to the pain, at the expense of their own agency. So, for instance, Jane's weight was keeping her down and reducing her control over her life, Monica's monster was wilfully finding ways to victimize her and the truncated wings of Kate's idealised butterfly were preventing her from being who she wanted to be. These metaphors conveyed the emotions that accompany the CP experience: the sense of being under attack, crushed, restrained, overwhelmed and no longer in control of one's own life (Phillips et al., 2015).

All representations of pain served the purpose of conveying the unexplainable. The problem with CP is that it is invisible, unmeasurable, and its reality is often questioned, but it is also profoundly embodied and 'felt' both physically and psychologically. Pain metaphors helped to overcome the challenge of communicating the lived experience of pain.

In some pain drawings and in their Self drawings all participants represented themselves through a human figure. Some were basic stick figures or emoji-type faces, others were more elaborate, but the details were always important and telling. For instance, Olga's stick figures all had a characteristic stoop, an aspect of herself she disliked; Olga, Helen, Gillian and Lauren, even at their most distressed, clearly had their hair, which they described as attempts to preserve an identity despite circumstances. Identity was also associated with assistive devices, sometimes in a conflicted manner. For instance, whereas Alison at T2 simply drew herself with a stick, for Lauren at T1 assistive devices symbolised an unwanted identity. Olga's stick figures, allowed her to avoid representing the largeness of her body. These links between drawing appearance and identity resonate with findings from other (albeit few) studies that have used Self drawings

to investigate illness in adults. Cross et al. (2006), interviewing people with spinal-cord injury, found that only less than half drew themselves with a wheelchair and that many chose to represent themselves as a head or a face, to affirm having an identity that went beyond their disability. Lev-Wiesel and Hirshenzon-Segev (2003), using self-figure drawings with dementia sufferers, found that omissions of the eyes or of body parts were indicators of a desire not to see or be seen by others. Thus Self drawings offer valuable insight into the liminal space between the Self and the world (Cross et al., 2006).

Other aspects said something of how participants felt about themselves. Monica's Selves were small in comparison to her surroundings, highlighting her difficulty at prioritising her own needs, while Helen's first Self drawing occupied only half of the page. The relative small size of Self figures or parts of them is a key consideration when Self drawings are used in projective studies with children, where they are interpreted as signs of insecurity or depression (Dolidze et al., 2013). My participants interpreted their own drawings along similar lines.

Whether and how other people appeared in the drawings was also interesting to observe. For instance, Lauren's early Self drawings were full of her grandchildren, but in her last one she was alone, a symbol of how she had started to focus on her own needs. In contrast, in the various versions of herself of her first drawing, Gillian was always alone, while in her second and third, when feeling better, friends appeared, because she had returned to interact socially. Similarly, when starting to feel better at T2, Olga had represented family in her thought bubbles and Jane had included her son in her home. Boden et al. (2018), in their relational mapping interview, explicitly ask participants to draw themselves in relation to the other people in their life as a way of exploring the relational context of distressing or disrupting experiences. Thus drawings of oneself can help illuminate the social side of experiences.

Some representations of Self were literal, like Gillian's multiple Selves doing things and expressing emotions; other contained metaphors, ranging from simple ones (e.g. the sun to indicate serenity, a smile to indicate happiness, a grimace to show unhappiness or a cloud to indicate brain fog and depression), to more elaborate ones. For instance, Jane used hurdles to represent the daily obstacles she needed to overcome; Lauren used an open window to represent her new-found openness; Monica used a red suitcase to represent the problems she could not face yet; Kate was smelling the roses, to symbolise her appreciation for the small things in life; and Helen was crying in a cage, illustrating her feelings of isolation and a despair that she never expressed. As with pain metaphors, these metaphors served to communicate complex experiences and emotions in a concise and impactful manner, often offering a 'safe bridge' for emotions that were difficult to acknowledge (Shinebourne & Smith, 2010).

Drawings make explicit what is implicit, allowing the drawer to go beyond the limitations of linear narrative language (Boden et al., 2018). Especially since none of my participants had ever drawn their pain or themselves before and drawing was not a familiar form of expression for

them, drawing forced them to find new ways of describing a habitual experience, opening up new expressive avenues and stimulating new ways of thinking about their pain.

Some participants expressed surprise at their own drawings, suggesting that their rehearsed narratives had been disrupted (Reavey, 2020b). Drawings can also mediate access to pre-reflexive felt meanings, which can be blurred and fuzzy (Petitmengin, 2007). Some of Monica's and Helen's drawings had a hazy and instinctive quality and they spent time mulling over them exploring their possible meanings, suggesting that for them drawing had indeed been pre-reflexive. When artists with CP draw, they claim that the process allows them to express their inner voice (Reynolds et al., 2011). Drawings also talk to multiple sensory registers at once (Boden et al., 2018). Through colour, shape and texture, pain can be seen and it can also be felt and heard. Like in the pain drawings from the Kirkham et al. (2015) study, the red heat, the jagged thunderbolts, the explosions, the dark heavy weights and truncated wings resonate with the viewer physically and beyond the accompanying narrative descriptions. Representations of Self can be similarly impactful and able to directly communicate emotionally with the viewer (Helen's caged Self being a case in point), however, some images of Self needed more explanation to be understood, such as Lauren's detached head at T3, relying more on the participants' narratives.

The multisensory impact of all the drawings was enhanced by the use of metaphors, which in themselves have the ability to evoke perceptual and sensory images (Fainsilber & Ortony, 1987). Metaphors are particularly effective to communicate the inexpressible, especially strong inner emotional states (Fainsilber & Ortony, 1987; Shinebourne & Smith, 2010). When it comes to pain, metaphors allow the gap between the experience of one and the experience of another to be reduced because they can elicit in recipients a type of embodied simulation that can form the basis for an empathetic response (Semino, 2010). When the metaphors are communicated through a visual medium, the impact seems to be even stronger. For example, Gillian's inflamed legs in her first pain drawing resonate with me more strongly than her simply saying "my legs are on fire" would have. A possible explanation may be inherent in the metaphorical communication process. For Ricoeur (1978), interpreting metaphors entails bringing two incompatible concepts together so that they can be understood as a new concept through cognitive, emotional and visual assimilative processes. He theorises an imaginative (or iconic) phase, where the similarity and proportionality between the concepts is 'seen' and the metaphor acquires its new meaning. Since in a drawing the metaphor is already represented visually, this might facilitate the metaphor interpretation process. In other words, Gillian's visual representation of her legs on fire might have intensified the imaginative component of the metaphorical process, giving her metaphor more power.

Many of the pain metaphors in this study correspond to pain metaphors and representations reported in literature (Bullo & Hearn, 2021; Munday et al., 2020; Phillips et al., 2015), but some

of the stronger ones (e.g., Jane's third pain drawing with sharp teeth or Kate's constrained butterfly) were unique. In a sense, this made them more powerful because they have a surprising quality. Also special in this study is that nearly all pain drawings combined multiple metaphorical representations, illustrating the multifaceted impact of pain.

Self drawings have been used in studies investigating various health conditions (Broadbent et al., 2019), but, to my knowledge, no other authors have used them to research CP. Although when asked to draw their pain some participants include an image of themselves (Philips, 2011), being explicitly asked to make a drawing of yourself gives a specific focus to the act of drawing because it forces you to think about yourself, your situation and how others see you. In my study, drawings of Self widened the perspective offered by the pain drawings enabling aspects of participants' lifeworld beyond the pain to emerge. Self drawings raised issues of identity, sociality, embodiment, temporality, mood and project (Ashworth, 2016). When considered in combination with the pain drawings and the interview transcripts, they conveyed a holistic view of the experience of CP, providing context for the pain and illustrating in detail the interconnectedness between pain, identity and the lifeworld of sufferers.

Drawings allowed participants to provide a vivid and profound description of their pain and their experience in relation to it, with the variability of the drawings conveying the idiosyncratic and contextualised nature of the CP experience, which is a substantial contribution to the corpus of CP literature. Methodologically, this use of drawings to complement and guide the interview process proved to be an effective way of eliciting reflection and accessing a richer account of experience, particularly within a LIPA design.

Considerations on the longitudinal design

Longitudinal studies are concerned with capturing the evolution of experience over time and in context. IPA's phenomenological and hermeneutic roots make it a natural choice when investigating issues of temporality, and prospective and retrospective sense-making (Farr & Nizza, 2019). IPA's idiographic approach makes it particularly suitable for longitudinal research, where prioritising cases is considered important to capture the fluidity of time and contextualise change processes (Neale, 2021). Other studies have used a LIPA design to investigate the impact of CP interventions (King et al., 2016; Snelgrove et al., 2013) or have incorporated drawings from different timepoints in an in-depth IPA interview to gain additional depth (Shinebourne & Smith, 2011), but my study is the first to have combined the two by considering interviews with multiple pain and Self drawings in a LIPA design. Here, the pain drawings of each participant illustrated how their CP evolved, with the complementary Self drawings widening the view to consider their identity and lifeworld, while the interview narratives captured participants' sense making around the drawings and gave context to

participants' experiences more widely. Whereas single pain and Self drawings and the accompanying narratives were able to illustrate what was happening at a given timepoint, the sense of temporal progression and overall trajectory was only achieved when looking at each participant's complete set of drawings and the themes resulting from their three interviews.

The complete sets of pain and Self drawings were a crucial longitudinal sense-making tool for both researcher and participants. Comparing pain and Self drawings within and between timepoints enabled a nuanced account of change and continuity, greatly strengthening the idiographic focus of results. Comparing each set of pain or Self drawings as a gestalt, allowed for conclusions in terms of 'improvement' or 'deterioration.' Indeed, in the pain drawings of the first trajectory group, over time the pain occupied less space and pain metaphors became less aggressive, corroborating quantitative findings that the most brutal pain metaphors are associated with a higher degree of pain interference (Munday et al., 2021). However, in the other trajectory groups, things were not as clear-cut. In the pain drawings of the second group, the presence of pain visibly increased for Helen, while Alison's drawings became increasingly basic because she engaged less with the drawing process. In the third group, the transformation of images was even less easy to interpret visually, because it was linked to idiosyncratic events. Here the verbal data proved fundamental to gain a more nuanced account of the underlying processes. For example, Lauren's third Self drawing looks 'worse' than her earlier ones, however, when considered in the context of her trajectory and supported by her verbal narrative account and sense-making, it becomes an image of liberation. The interview data thus integrated the images and together narrative and drawings illuminated each other and the experience, leading to a more complete understanding. This process exemplifies IPA's hermeneutic circle, in which part and whole are inextricably linked and illuminate each other (Smith et al., 2009).

To appreciate the evolution of a participant's experience required the drawings to be considered in detail and in context. Saldaña (2002) recommends that longitudinal researchers focus their analysis on what increases, decreases or is missing over time. Accordingly, the appearance or disappearance of a body or a face in relation to the pain were often meaningful. Olga's pain stick figure transitioned from having an empty anonymous face when she was distressed at T1, to having clearly identifiable traits at T2 and T3, when she was feeling much happier, as if the reduction in pain had allowed her to 'find herself again'. In contrast, Helen disappeared from her pain drawings, which became increasingly abstract, conveying her growing sense of disarray.

Also interesting is to consider how pain conceptualisations evolved (King et al., 2016; Loftus, 2011). Gillian's pain metaphors transitioned from being a scattered inventory at T1, when she couldn't understand her pain, to being marks on the body of a recognisable figure at T2 and T3, when the pain had been understood and integrated into her life. There is similarity between the inventory of pain symptoms that was a starting point for Gillian and the inventory drawn by

Kate at the end. Having drawn equivalent metaphors at different times could reflect different stages in the path to acceptance of the two participants. At the beginning of the study, when Kate was still questioning the reality of her pain, she represented it as an ‘unreal’ butterfly. When she drew it as an inventory of symptoms at T3, she was starting to accept the reality of her pain. In contrast, Gillian, although still struggling to understand it, had already accepted the reality of her pain at T1. At T2 she progressed to integrate it into her life and represented it as part of her body, rather than a series of separate symptoms. The trajectories of the two women could be subsequent stages of a continuum, on which sufferers need to accept their pain as real, before they can start to understand it, a precursor to acceptance and integration. Of course, the two trajectories could also just be different ways of coming to terms with the change brought by CP.

For Lauren, who always represented her pain on her body, acceptance was expressed by her drawings becoming increasingly specific and detailed, while for Monica and Jane, later pain drawings were less about pain and more about how it was being managed (in the background by Jane and carefully balanced by Monica), suggesting an even more advanced degree of integration of pain.

When considering the Self drawings within their trajectories, different colour transitions can be observed. Jane’s drawings had the strongest transformation: her Self went from a dark stark drawing, to a soft very natural looking one. Kate’s, Monica’s and Olga’s last Self drawings were light and soft in comparison to their first ones. Gillian’s later drawings, even during a flare-up, included more natural colours compared to her first one. Interestingly, a distinguishing feature of the final Self drawing of all participants in the first group is the extensive use of green, which seems appropriate to represent the natural ‘normality’ that all participants in this group had gained by the end of the project.

Interpreting the visual evolution of the images was facilitated and complemented by a careful analysis of how the verbal accounts evolved over time, in relation to the drawings, but also independent from them. For example, Lauren’s initial rage against herself was mostly expressed verbally, by employing an aggressive language, while her first pain drawing did not reflect this aspect. Over time her narrative became more compassionate, and her pain drawings became “*more real*.” Thus, narratives and drawings brought different and complementary insight into Lauren’s evolving experience with CP: they completed, built on and illuminated each other. The understanding obtained from the drawings would not have been possible without the explanations provided during the interviews and interviews without the drawings would not have been as rich, insightful and communicative.

Whereas some longitudinal interview-based studies exploring a changing experience of CP already existed (King et al., 2016; Snelgrove et al., 2013), I have found only two other CP studies exploring drawings of pain longitudinally, both with limited drawing comparisons

across timepoints (Albert, 1999; Henare et al., 2003). Albert (1999) evaluated a psychosomatic group treatment gathering questionnaire data and pain drawings at 4 timepoints from 53 women with pelvic pain. Results were that the drawings “became more complex with more details” over time and that after treatment the pain was smaller in size and colours were milder (page 221), which matches some of my findings but leaves me curious to know and see more. The Henare et al. (2003) study shares more contextual similarities to mine: 14 participants were asked to draw the meaning of their pain at the start and at the end of a PMP programme and describe their drawings in an interview. Results are described as a journey from having lost oneself to pain to redefining oneself after the PMP, but only a few drawings are included to illustrate this transition. Despite the study being prospective longitudinal, using pain drawings and participant narratives like mine, there are some significant differences, because there are no Self drawings, no retrospective reflections on the drawings nor any idiographic results. Being CP the idiosyncratic experience it is, idiographic details are necessary to contextualise complex pain and Self-related processes. The concept of Self can be abstract, and the longitudinal sets of Self drawings allow insight into how it operates in practice within the lifeworld of participants.

The results from my study suggest that a careful analysis of how the drawings and narratives evolve contributes to understanding how the pain and Self experiences evolve. Pain and Self drawings act as maps for the journey of participants, prospectively illustrating their experience at each timepoint and retrospectively allowing participants, researchers and viewers to understand how the experience, in this case the relationship with pain, changes over time (Neale, 2021). Similarly, the comparison between the themes emerging from the textual analysis of each interview helps to identify and trace trajectories for the evolution of different aspects of the lifeworld of participants. It is through the textual analysis that the layered and cumulative nature of longitudinal findings is most evident (Neale, 2021). Whereas drawings are snapshots of specific moments, during the interviews, participants respond to their drawings, reflect on what is and has been, and verbally express their evolving understanding of their pain and personal journey. The longitudinal analysis of the interviews then enables the necessary shift from a synchronic to a diachronic reading of the data, so that processes of change and continuity can be considered and the fluidity of time can be revealed (Neale, 2021). Verbal accounts are a fundamental component of IPA’s double hermeneutic (Smith & Osborn, 2007a), where the researcher makes sense of participants’ sense making, and of the triple hermeneutic characteristic of multimodal studies, where the researcher makes sense of participants’ sensemaking around their drawings (Kirkham et al., 2015).

Drawings and narratives are therefore entwined, with change and continuity emerging from the longitudinal analysis of the drawings on their own, of the drawings considered alongside their accompanying narrative and from the narratives on their own. Details of the drawings are considered individually and as a gestalt, and, similarly, the contents, tone and linguistic features of the narratives are considered in detail and as a whole, with the two aspects, verbal and visual,

revealing facets of the complete human experience under investigation and its evolution over time.

Participants reflecting on the process

The use of drawings alongside interviews was a particularly innovative aspect of this study on which I invited participants to reflect at the end of each interview. All participants except Alison said they had enjoyed drawing and all of them commented on how the drawings had enabled them to obtain and communicate an unexpected depth of understanding about their experience.

In a multimodal design, drawings create a pathway towards feelings, enabling participants to access and express emotions more easily than using words alone (Kearney & Hyle, 2004). In my study, from the very first drawings, participants seemed surprised by the profundity of the drawing process (*“it’s amazing how many emotions you can pull up from a few drawings”*, Lauren T1). The drawings allowed them to explain their pain and articulate the difficult emotions associated with it, with the drawings revealing the multiplicity and complexity of such emotions (Reavey, 2020a). During the interviews there was a process of discovery that went beyond participants’ conscious perceptions (*“it kind of illustrates things that you maybe don’t realise,”* Jane, T1). Once available, the drawings were separate objects that could be interrogated and reflected upon. Thus the process of producing the drawings, the process of reviewing the drawings and the drawings themselves as products of that process added depth to participants’ understanding of their own emotional lifeworld (Lyon, 2020).

During subsequent interviews, the reflective value of the drawings became increasingly evident and fundamental in illustrating the unfolding of change processes and enabling such processes to be understood. Neale (2021, p. 217) talks of “retroductive logic”, where longitudinal data allows researchers to trace “backwards to understand the processes through which events and experiences unfold.” In this study, the longitudinal drawings were, primarily, a tool for participants to understand their own change. When given the opportunity, all participants spent many minutes musing on their sets of drawings, thinking about their journey and sometimes readjusting their interpretation of what had happened to them. A good example is Lauren at T3, who started her interview very low for having a health setback and, when reviewing her drawings, was reminded of her own resilience and her ability to overcome obstacles. Similarly, when Helen reviewed her set of drawings, she reflected on her inability to change, ascribing it to her lack of self-esteem, which she had not discussed before. This use of drawings speaks to the different planes of time enabled by longitudinal research (Neale, 2021): the possibility of exploring experience both prospectively and retrospectively. The presence of current and previous drawings offered participants the opportunity to turn their gaze into the past and reassess their present in a manner that would not have been possible without the drawings. The

drawings provided an account of the past which was complex and layered, seeping with emotional resonance (Reavey, 2020a).

Drawings also have an empowering potential because participants take an active role in producing them and in analysing them (Fraser & al Sayah, 2011; Reavey, 2020a). When reviewing her complete set of drawings at T3, Jane said: “*with these pictures, it’s not me telling myself, yes, you can get through this, you can do it. I know I can do it because I’ve just, I’ve drawn it.*” The drawings revealed to Jane how far she had come, she considered them an inner confirmation of her progress and understanding. The empowering effect of visual representations of CP has also been observed during medical encounters where pain images have been found to act as transactional objects increasing patients’ amount of talk and emotional disclosure during consultations (Padfield et al., 2018). As I describe later on, one of the impacts of my study was the decision by the CCPS to invite new referrals to bring a drawing of their pain to their first clinical assessment, to aid communication about pain with clinicians.

A few participants, including Gillian, described the drawing process as “*cathartic*” and “*therapeutic*.” Rather than ascribing to the drawings a causal role in any change process, I interpret this to mean that the drawings, considered singularly and as sets, were valuable tools for understanding: they encouraged participants to think deeply about their experiences, revealing unexpected emotions, stimulating reflections and conveying in a succinct manner the complexity of their lives with and around CP, at single timepoints and over time.

The drawings were also at the heart of the analytical process: they were the starting point for the analysis and the common thread weaving findings together. They helped me to understand the experience of participants and explain it to readers. But beyond interpretations, even the simplest of drawings spoke for itself. The ability of drawings to resonate with viewers is part of their power in research. The pain drawings, with their colours and metaphors, trigger a cognitive and, more importantly, emotional response in the viewer, and the Self drawings do the same. For instance, looking through Monica’s three Self drawings one feels the claustrophobic quality of her apparent balance at T1, the wild and somehow liberating chaos at T2 and the suffering and joy of her ‘Little Me’ protected by her larger ‘me’ at T3. Although Self drawings are less immediate than pain ones, with help from Monica’s explanation of them, we understand and feel the magnitude of her change, the suffering behind it and its promise of a brighter future. All the drawings in this study, with their characteristic styles, bring the reader closer to participants: they become immediately recognisable and memorable, reinforcing the idiographic coherence of the results.

Study impact

This study illustrates the journeys of some women referred to a CCPS and PMP. Such services aim to help people with CP manage their condition by reviewing their medication, educating them on CP and its impacts, teaching them self-management techniques such as mindfulness and pacing, and offering opportunities to share experiences with fellow sufferers. The study results provide detailed insight into what can happen after PMP referral. CP self-management is not for everyone and does not work in the same way for all those that engage with it. Just as CP is a profoundly idiosyncratic experience, so are the practices through which it is managed. For the first group of women in my study, referral to the CCPS and all that ensued was empowering and transformational. From feeling hopeless and overwhelmed by pain, they were able to take back control over their lives and the results were outstanding. In contrast, the second group of women did not respond to what the CCPS had to offer. Although they participated in the PMP, they did not experiment with self-management and remained almost ‘stuck in a rut’ with their CP. Their situation did not improve and seemed to deteriorate: CP was and continued to be an adversarial experience deeply affecting their mood. Between these two extremes lies the third group: they experienced setbacks and their results were not outstanding, however, PMP participation still triggered a change for them that had the potential to extend beyond their time within the CCPS. They grew more confident about their bodies, more accepting of the new identity associated with CP and expressed agency in their determination to look after themselves.

The trajectories of all women in the study confirm that CP is more than a biopsychosocial experience, it is a profoundly idiosyncratic one, where different aspects of the lifeworld of participants come into play, in a “relational and emergent process of sense-making through the lived body that is inseparable from the world that we shape and that shapes us” (Stilwell & Harman, 2019, p. 659). Thanks to the level of detail inherent in a LIPA design, and the use of pain and Self drawings, the idiosyncratic sense-making of participants was contextualised within each person’s particular set of circumstances.

The study will be of interest to clinicians in different ways: at a more basic level, the drawings and supporting quotes provide an immersion into the difficult-to-understand experience of having CP, illustrating the complex balance of thoughts and feelings associated with it; the results are also a nuanced account of the dynamic interaction between the input that each participant received from the service and their responses, actions and sense making around the process; we see the impact of time and how change can unfold involving different aspects of participants’ lifeworlds or not happen at all; the different trajectory types illustrate alternative reactions to the stimuli offered by the CCPS, from the most responsive to the most resistant, with a range of experiences distributed along this axis. Finally, in the study, significant

theoretical constructs, such as acceptance or self-compassion, are situated and illustrated in all their complexity and interconnectedness.

We see, for example, how some participants responded to some stimuli from the CCPS and not others (e.g. Olga's focus on kitchen aids, other participants' adoption of daily mindfulness practices). We also see, for example, how the self-compassion construct can manifest in different ways for different people, and how it can be linked to mindfulness practices and acceptance of life with CP. This variability and idiosyncrasy make evident the difficulty of finding a 'one-size-fits-all' model for CP. So, on one hand we see the value of these models and their situatedness, and on the other we see the limitation of assuming that a model will speak to all CP experiences.

Some clinicians might be inspired to adopt drawings as a clinical tool. Unsurprisingly there is already a line of research about using images, particularly photos, to enhance clinical communication in CP (Padfield et al., 2018). As I mentioned earlier, after I presented my preliminary findings (Jane's case) at the CCPS staff and board of directors in 2017, they reviewed their procedures and invited new patients to draw their pain before their initial consultation. I am told [through personal communication with Jamie Kirkham] that a number of patients have responded positively to this invitation and that staff have been finding the pain drawings very useful to guide their initial conversations with patients. This was an immediate impact of my study for the CCPS, which could extend to other similar services.

Although my aim was not to evaluate the CCPS or the PMP as such, the study has nonetheless given insight into participants' journeys through the service and how they responded to the service's input. Trajectory types and case-level details on how the trajectories unfold can, as in my study, shed light on the mechanisms underlying change or lack thereof, a possibility that resonates with current discussions in literature on assessing efficacy of CP interventions.

As mentioned in Chapter 2, the disappointing results from RCTs of CP interventions have been ascribed to heterogeneity of intervention components, design and outcome measures (de C Williams et al., 2020; Morley et al., 2013), but also to the idiosyncratic nature of CP: different people have different pathways to change and statistics dilute results (Hayes et al., 2019). New approaches to measure CP outcomes are being pursued, such as monitoring change as it occurs through EMAs and adopting idiographic measures such as SCEDs (Chisari et al., 2022; Hayes et al., 2019; Jones & Hurrell, 2019; Vlaeyen & Crombez, 2020). These new approaches have been hailed as a paradigm shift (Morley et al., 2013) and highlight a general need to understand the context and temporality of change processes in CP. Longitudinal qualitative research has the potential to answer that need, particularly through LIPA designs which have a strong idiographic commitment. All qualitative longitudinal research requires a careful balance between case, process and themes (Neale, 2021). The eight *cases* in this study shared a journey that created opportunities for *processes* of change and continuity, where pain and Self, in the

drawings and through the narrative, acted as *themes*. After testing different ways of analysing and presenting results, looking for the perfect balance to achieve the aims of the study and tell the most compelling story, I settled on presenting individual case trajectories, in which the pain and Self themes were alternated and integrated. Case trajectories were grouped to allow wider process patterns and potential generalisations to emerge. The level of idiographic detail in the individual trajectories allowed findings to be contextualised and, consequently, for the importance of context in CP to emerge as a key finding from the study.

For instance, in the first group, both Jane and Olga achieved a new degree of control over their life, but for Jane this manifested as independence and ‘normality,’ while for Olga it manifested as being free from the burden of morphine and able to plan her future weight loss. In both cases, a clear future-orientation and sense of agency developed, but what each of them considered important was different, as were their life situations and the mechanisms through which they obtained a new wellbeing. LIPA studies, thanks to the focus on the particular which is a hallmark of IPA research and the fundamentally inductive nature of the analysis process, enable dynamic processes of change to be captured as they unfold and in a situated manner (Farr & Nizza, 2019; Neale, 2021). Thus my study results support the current and future adoption of LIPA designs, with or without drawings, for the evaluation of interventions, even within RCTs. Lastly, the drawings played a big part in allowing my study to reach the level of depth that it did and in conveying its findings. That pain drawings could contribute to a deeper level of understanding of CP using IPA is not surprising, particularly given the impact of the Kirkham et al. (2015) study⁵. The added aspects emerging from my study are the value of combining pain and Self drawings and the effectiveness of doing so within a longitudinal design.

Drawings of pain and their metaphors are rich and resonant and help participants explain their pain. Drawings of Self open up the lifeworld of participants, revealing what is important to them, how they see themselves and where they stand in relation to their social world. In general, drawings allow the expression of participants’ emotional life, they describe experience and can often even help participants understand experience. Particularly when the drawings are pre-reflexive, they are objects which can be carefully examined in the interview. The act of creating a drawing that then exists as a separate object creates a certain distance from the experience, which encourages reflection and can elicit unexpected takes on experience. Often reviewing a drawing during an interview will generate hot cognition, with the interviewer witnessing a participant’s response to their own drawing and the development of new understandings or even revised narratives. With drawings the quest for depth inherent in IPA’s hermeneutic stance can reach new levels of richness.

Then, in a longitudinal design, multiple drawings provide a temporal trace. The focus on change and continuity characteristic of longitudinal interviews is enhanced by reflecting on multiple

⁵ According to Google Scholar as of 22nd May 2021 this study has been cited 89 times.

drawings. Drawings are a testimony of the passing of time and their link to a specific moment can stimulate thinking in terms of change and continuity; they are an opportunity to look into the past through a window and compare the emotions they elicit with existing memories. Unlike memories, drawings are, by definition, unchanging, but can be reinterpreted by participants. During the analysis the researcher is then able to consider similarities and differences between the drawings, between different narratives and between narratives and drawings. So IPA's hermeneutic circles increase and, like a downward spiral, allow access to new and increasing levels of depth.

Evaluation of the study

To evaluate my study I shall refer to the seven criteria set out by Smith (2011) for good quality IPA, and to the criterion of temporal integrity proposed by Neale (2021). In the next paragraphs I discuss each criterion in turn and in the order that I think best helps assess my work.

- **The paper should have a clear focus**

My research question was very specific: it concerned the evolution of experience of CP and Self as represented in drawings when somebody is referred to a CCPS and attends a PMP. My focus was primarily on the drawings and longitudinal. The interview schedules were linked closely to the drawings and, in the analysis, I focused on aspects that appeared in the drawings and across timepoints, with the aim of uncovering the underlying processes of change and continuity. I refrained from pursuing aspects that were relevant to one timepoint only or that did not strongly link to the drawings. For instance, during her second interview, Kate discussed family issues which she had not discussed before nor later, and which did not appear in her drawings. Although family themes emerged from the analysis of her T2 transcript, the topic did not make it to her longitudinal analysis, nor to the final results.

- **The paper will have strong data**

The participants' drawings of pain and Self were strong data on their own. The interview procedure, where participants were left alone for 15 minutes with a choice of mediums and no distractions to create each drawing, contributed to the quality of the drawings, which were for the most part vivid and complex.

Then, during the interview, the drawings became for participants an opportunity to delve inside themselves, explaining, questioning and trying to make sense of what was happening to them. This resulted in strong verbal data, particularly in terms of retrospective reflections. The combination of visual and verbal data generated a powerful illustration of the complexity of living with CP.

I consider my relative naïveté to CP an advantage because it put me in a position of

openness and curiosity towards participants' experiences, increasing rapport and the depth of their narrations.

- **Sufficient space must be given to the elaboration of each theme**

Abundance of data was a challenge in this study and, as I explained above in terms of my focus, I had to be selective. However, given the importance of context for the experience of pain and Self in CP, I ensured that each case be given sufficient space for contextual factors to emerge and for the reader to feel immersed in the participants' lifeworld. The six drawings of each participant were described in turn, each accompanied by at least one quote that could illustrate the most relevant aspects of that experience at that time.

- **The paper should be rigorous**

The sheer volume of my data demanded a systematic approach to how data was gathered, analysed, stored and processed. Each case was analysed before comparing across cases, and, within each case, each timepoint was analysed before comparing longitudinally. The process was painstakingly detailed to ensure that all important aspects were covered and documented; the process was also experimental because no existing study had combined drawings with IPA interviews longitudinally; and it was also iterative, especially for the longitudinal and cross-case analyses, where multiple approaches were tried before the 'best' one was found. All attempts were documented, and all iterations and outcomes were discussed with my supervisor, for guidance and for triangulation.

In the final case-by-case writeup all participants are equally represented. Similarly, within each case, all drawings for that participant are described and discussed, one at a time, highlighting links between pain and Self at each timepoint and across timepoints.

- **The analysis should be pointing to both convergence and divergence**

The trajectory groups present convergence and divergence at the highest level: convergence within each group where participants have a similar trajectory, and divergence between groups where each trajectory group leads to a different outcome.

Convergence and divergence is then considered at every level below: between cases within a trajectory group, between the data for each timepoint within a case, and between the drawings and narratives at a given timepoint.

Also, when analysing participant assessments of their earlier drawings in T2 and T3 interviews, I paid particular attention to divergence and convergence with previous drawing interpretations, because incongruences were often a sign of important inner conflict (e.g. Alison's claim at T3 that her T2 Self drawing did not reflect her true mood at the time). Comparisons at all levels concerned both the experiences as described verbally and their visual representations.

- **The analysis should be interpretative, not just descriptive**

Although always privileging the interpretation of the drawings given by participants, especially for the more complex Self ones, I considered the style, artistic choices and metaphors of the drawings as meaningful. I observed the language used by participants to describe the drawings and their experiences and focussed especially on what the drawings and descriptions revealed of participants' emotional and psychological world. Issues of existential import, such as the impact of pain on identity, embodiment, life project and agency were of particular interest, as the means to a deeper interpretation of the data and of the experience more widely (Nizza et al., 2021). The longitudinal focus on processes of change and continuity required an interpretative effort to combine participants' perceptions of the temporal experiences with my inferences of the underlying processes based on the timepoint data.

- **The paper needs to be carefully written**

The need to clearly describe a complex analytical process and the need in the results to combine cases, timepoints, verbal data and drawings into a cohesive readable whole was a challenge that required multiple iterations to find the right balance between elements. For instance, in the results, I decided to present first the most positive trajectory group, followed by the most negative one and then the trajectory group that lied in between to emphasise the contrast between trajectories. Within each case, I integrated but systematically alternated the analysis of the pain and Self drawings, always clarifying what drawing I was discussing and clearly labelling each quote so that the reader would know exactly what was being said by whom and at which point of the study. I believe the outcome is a readable and compelling story, able to inform and sustain the attention of my reader.

- **The paper should have temporal integrity**

Temporal integrity is defined as "fidelity to the real-time flux and dynamism of the world" (Neale, 2021, p. 351). In my study, temporal integrity was an ongoing concern throughout all stages of the research process. For instance, in the T2 and T3 interview schedules, I aimed to gain a snapshot of the current moment, before eliciting a reflection on change by showing previous drawings. I wanted to be able to compare these views and capture dynamic temporal shifts in the analysis. Similarly, when writing up the results, I sought convergences between drawing components and narratives to convey the temporal flow, while cautiously teasing out causal connections to reconstruct processes of change and continuity. A practical example of this work is the analysis of Kate's trajectory, where her many visual and verbal professions of acceptance were combined with clues of her ongoing

difficulties in accepting, to illustrate how the balance between them slowly shifted over time.

Limitations of the study

Six of the eight women who took part in my study had a positive outcome, claiming that their time in the service and the PMP had been helpful in bringing about change. The inconsistent evidence on PMP efficacy (NICE, 2021) makes it difficult to assess to what extent the preponderance of success stories in my study reflects the CP population as a whole.

Some participants were lost to follow up (see Table 1 for details). Most of those dropping out after Time 1 had not been referred to the PMP or had failed to attend all PMP sessions, while those who dropped out after Time 2 chose not to continue with the study. It would have been interesting to understand the impact of not being referred to the PMP or the reasons for not completing the PMP, or what led those who dropped out before Time 3 to do so. Although the stories of Helen and Alison shed some light on what can go wrong, more insight could be gained on this aspect by hearing the stories of those who did not make it to the end.

Additionally, my pragmatic choice of recruiting participants from a CCPS could limit the portability of findings to people with CP who are referred to a different type of service or context.

It is increasingly common in studies such as mine to involve, during the design phase, people with the condition under study to gain their input on the proposed methods. My design was discussed and partly inspired by the previous work on CP using drawings by my contact in the NHS trust (Dr Jamie Kirkham), however, perhaps it could have benefitted also from the input of a patient group.

From a more theoretical standpoint, there are aspects of my study which could have warranted a discussion with areas of literature that I did not consider. For instance, I chose not to engage with the more general literature concerned with illness trajectories, illness and identity and identity and image. Instead, I remained focussed specifically on CP literature and was inductive in my approach to the discussion, so that I dialogued only with selected aspects and CP models most closely relevant to the experience of my participants.

Future directions

I can think of many ways to further develop this area of research.

It would be interesting to explore the experience of people who were still in work when referred to the CP service. I excluded those in work for reasons of homogeneity and because they were a

minority in the Kent service, however it would be interesting to compare their outcomes with my sample to understand the effect that PMP participation would have on this group.

Also, in the UK, the recent COVID-19 pandemic has accelerated the process of offering remote CP consultations and running PMPs online. One male participant in my study was lost to follow up because he had been diverted by the CCPS to an online PMP. When literature has compared the two modalities (Herbert et al., 2017) the only differences seemed to concern participant dropout rates. It would be interesting to use my same methods to explore the experience of participants attending an online PMP.

Finally, as most CP research, my study focussed on people who had obtained a referral to a CCPS, however, many people learn to self-manage their pain on their own or through informal groups and their voice is seldom represented in literature. This would also be a population whose experience would be worth exploring using my methods.

Methodologically, the use of Self drawings, alone and combined with drawings of illness has the potential to be applicable to many different fields. The first step I intend to take is to formalise and publish the methodology, so that it can be readily available to other researchers.

IPA using illness and Self drawings could be used to investigate the experience of other chronic conditions, particularly those which are known to have a life changing physical or psychological impact. For instance, I can imagine a longitudinal application to the study of breast cancer, or any other cancer for that matter, from diagnosis, through to treatment, recovery and discharge, as a way of exploring the profound transformations that this illness can cause in people.

Self drawings with IPA could also be used in a variety of other non-health related fields where issues of identity are particularly relevant, such as major life transitions. Again, the drawings could be used as a one-off or as part of a LIPA design.

Generally speaking, the combination of visual methods with IPA has the potential to be appealing to researchers in many different areas. Using drawings does add a level of complexity to an IPA study, both in terms of data gathering and analysis, but the rewards in terms of the depth can make it worthwhile.

Final words

This complex study has highlighted that different people respond differently to being referred to a CCPS and attending a PMP. Some embrace the opportunity for change and are able to transform their lives into a very liveable 'new normal.' Others are unable to do so and remain embroiled in complex lives of pain and distress. Others still have more complex journeys, where dealing with their pain brings to the fore previously ignored problems or requires a more elaborate process of acceptance or adaptation. Methodologically this study has demonstrated

how powerful longitudinal and multimodal applications of IPA can be to understand complex temporal processes. Drawings of pain have confirmed their ability to provide a vivid account of the difficult-to-describe experience of CP. Drawings of Self were an innovative approach to understanding the wider impact of CP, particularly in terms of identity and lifeworld. The longitudinal trajectories of both pain and Self drawings effectively complemented each other and with the interviews offered a detailed and insightful account of how the CP experience extends beyond the physical to all aspects of the life of sufferers.

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