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Section A: Preface

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in Counselling Psychology, City University, January 2015.

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THE FOLLOWING PARTS OF THIS THESIS HAVE BEEN REDACTED FOR DATA PROTECTION/CONFIDENTIALITY REASONS:

pp 232-247: **Interview transcript.**
pp 248-261: **Coded interview transcript.**
pp 299-333: **Section C. Professional practice clinical case study:** A case of complicated grief and Fibromyalgia.

Section A: Preface

This section aims to provide the reader with the overview of the submission for the 'top up' doctorate in counselling psychology. It will reflect the three main characteristics of the activity of the counselling psychologist, namely research, practice and the process by which the two become intertwined. The research component (section B) represents the main element of this portfolio and describes the undertaking of a substantial piece of research exploring the 'lived experience' of chronic pain. An interpretative phenomenological stance was adopted in the conducting of this research whereby the main researcher, supported by his research supervisor, set about recruiting a number of participants to take part in a series of interviews exploring their experiences of living with persistent pain. As there is already a small corpus of qualitative literature that has shared these same ambitions, consideration was given as to what might make the current study different or how, by appealing to an alternative aspect of these experiences, a fresh perspective might be achieved. The decision was therefore taken to feature participant artwork as a primary aspect of the research. The participants recruited were able to provide graphic pictorial representations of their experience of living with pain. The images, although unique, all seemed to share particular qualities and in some instances there was an amazing degree of parity in form, colour and style. Highlighted in these was the frequent graphic depiction of red, pointed, mutative stabbing structures, as well as climatic references and depictions of dark brooding clouds, which served to reflect both the intensity of the pain experience, as well as the inclemency of pain and its psychosocial impact. A number of participants also provided images which seemed to

reflect the portrayal of ‘multiple selves,’ again a powerful indicator of the disruptive impact of pain and how its impact had disturbed both a cohesive and chronological sense of self. The artwork, alongside the commentary, provided a unique insight into the subjective phenomenological experience of pain and a rich gestalt, from which the researcher was able to make interpretations and inferences grounded in the material provided by the participants themselves. The thesis represents one aspect of the values held by the counselling psychologist, who seeks to engage in activities which aim to raise ‘the profile of the subjective experience into a more primary position in the research literature’ (Smith 2009 et al.). In following this agenda and promoting this particular aspect in the research, the researcher hopes to have responded to these values by both ‘revealing’ aspects of a condition, which in its ‘invisibility’ has come to represent one of the greatest challenges to the chronic pain sufferer (McGowan et al. 2007), as well as providing a ‘voice’ to a silenced population, whose external appearance may not match their internal state. It is also tentatively suggested that other researchers investigating similar conditions may too benefit where an amorphous quality represents a feature of the condition and its obscurity has proven to be detrimental to the client.

The following element of the portfolio (section C) aims to draw its focus more discreetly on another activity of the counselling psychologist and explore the aspects and activity of the therapeutic relationship. The format that this will take will be in the representation of a client study and process report. Once again chronic pain will provide the context in which this client study took place and I will present the case of Brian, a client of mine, who had been struggling with significant physical difficulties, as well as the complexity

of a complicated grief. The case study will explore both of these conditions in light of the available research and treatment protocols and consider how both of these conditions appear to have become fused with one another in the context of Brian's distress. The process report will provide an account of how the therapeutic relationship as an intervention, was able to provide a valuable space in which Brian was able to begin to make sense of this interconnectedness, but also consider how some aspects of his distress around the loss of his young wife had developed into maladaptive behaviours, which in turn seemed to have escalated his physical decline and further compromised his sense of low self-worth. The case study will conclude with a meta-analysis which will reveal that the discreet moment to moment exchanges between therapist and client reveal aspects of the therapeutic relationship as a whole and that this provided the means by which Brian had the opportunity to be heard, validated and valued, an experience that he appeared to have been deprived of in earlier relationships.

The final element of this portfolio (Section D) will aim to be a critically reflective account of the emerging role of psychology generally in the context of chronic pain. This review will firstly establish the principal philosophical positions that exist within the different treatment contexts, revealing that although purported to be the model which best fits the needs of clients living with chronic pain, the Biopsychosocial model (Engels, 1977) remains very much in its infancy and an emerging tradition. The prevalence and pre-eminence of the medical model still very much represents and maintains its authority when it comes to the treatment of pain and managing the tensions that exist between the two epistemologies, which may represent a primary task and challenge to the role of the

psychologist who comes to work in these contexts. The critical review will follow a perspective which aims to identify how psychology has not only influenced the treatment of those with chronic pain in the past twenty five years but will indicate which directions this passage is likely to take in the coming years. It will serve to highlight that technological advances and the emerging role of social media, may itself come to reflect aspects of these coming changes and provide a truly 21st century approach to the 'problem of pain'

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Section B: A Portrait of Living with Chronic Pain- an Interpretative Phenomenological Analysis.

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Abstract

Chronic pain is a mysterious and challenging problem that affects a significant number of people in a significant number of ways. Perhaps one of the greatest challenges of these conditions is the highly subjective nature of pain, coupled with the apparent absence of any observable abnormality. In this study Interpretative Phenomenological Analysis was adopted in order to gain access to elements of these subjective experiences and in response to its 'invisibility', a creative approach was also incorporated into its design. Seven working age female participants were recruited and invited to share aspects of their pain experience through both narrative accounts and pictorial representations. Participants' images and their accounts of them provided a rich gestalt which communicates a range of difficulties in a single cohesive image, which in turn also served to compliment the other themes identified in the study. Participants' unanimously found this feature of the study facilitative as well as cathartic and it is suggested that these positive experiences may also hold a significant clinical value. The current study supports that, by adopting multimodal methods as a means of exploring lived experience, a potential opportunity has arisen which could help to bridge the 'gap' between what is 'seen' and what is 'felt.' It is suggested that in the development of ever more creative means of approaching the 'problem of pain,' art and art therapy may be considered for its potential in helping patients to reveal aspects of their difficulties in order to be both better understood and supported.

Chapter 1: Introduction and overview of chapters

This thesis aims to contribute to the corpus of literature currently defining chronic pain conditions and explore the impact that living with these conditions evokes for the individual. This research will therefore follow a qualitative rationale, with a focus on the specific rather than the general. It aims to privilege the subjective accounts and testimonies of its participants, in order to arrive at a deeper understanding of the 'lived experience' of chronic pain. The aims of the current study will hopefully be achieved through the employment of a particular qualitative research methodology; Interpretative Phenomenological Analysis (IPA) (Smith, 1996) which aims to provide an 'insider's perspective' (Conrad, 1987) detailing how the lives of those living with these particularly challenging conditions are shaped by the persistence of their pain. The efficacy of these accounts will be complemented by the inclusion of participant 'art work' which, in conjunction with the accompanying testimonies, aims to provide an alternate 'lens' from which to illustrate a further aspect and dimension of the 'lived experience' of chronic pain.

With the primary aim of the study established, the purpose of this activity will be demonstrated across a series of chapters. Initially, a much broader approach towards the problem of pain will be undertaken, with the intention of examining the relevant theories surrounding this multifaceted phenomena and how they have come to be portrayed in the corpus of literature that currently defines these conditions.

The aims of the study are threefold. Firstly, in an effort to both demonstrate a consciousness and consideration of these very concerns and their clinical implications, the current study will aim to privilege the individual subjective accounts of its participants, acknowledging that these 'voices' rarely appear in the corpus of literature which currently defines these conditions (Smith, Flowers, & Osborn 1997). Secondly, the aim is that this research will help to raise the profile of patients' subjective experiences to a level commensurate with the mainly positivist voices that currently dominate the corpus of literature defining these conditions. Finally, the closing aim is that if both the above aims are achieved, then this may ultimately augment and secure both an enhanced understanding and empathic response to the profound needs of those 'silenced populations' living with these invisible conditions.

Chapter 2: The literature on pain

As indicated, a primary focus of this chapter is to provide an overview of the 'context' of chronic pain. This overview will initially explore the relevant literature on chronic pain in order to reflect the differences between acute and chronic pain, before moving on to consider the problem of pain from the vantage points of global, societal and individual perspectives. These explorations will follow a qualitative rationale from which, it is argued, a forum has been provided in which the individual 'meanings' of living with chronic pain can be more fully appreciated and their clinical worth better represented. A

detailed examination of these meanings and the themes in which they are represented will be presented as a sub-section of this chapter.

Chapter 3: Methodology

The third chapter will discuss in greater detail the design, philosophy and methodology of the particular qualitative methodology employed in the current study. Interpretative Phenomenological Analysis (IPA) (Smith, 1996) is the chosen method of analysis and the reason why this, rather than another qualitative model, or indeed a quantitative approach will be discussed.

Chapter 4: Method

In the fourth chapter the mechanics of how this piece of research developed and progressed will be detailed. Included in this will be a description of how ethical approval was sought, and how participants were approached, selected and ultimately recruited. A description of the interview format will be described, as will how the various stages of IPA were used to arrive at the current findings.

Chapter 5: Results

The fifth chapter will present the findings from the current study in its results section, which will further reflect the dynamics of chronic pain and aims to contribute something new to the corpus of work currently defining these conditions.

Chapter 6: Discussion

The discussion, which will follow, will consider the current study's findings in parallel and in context with those found previously. It will ask if anything new has been learned from the current study and how these insights might assist in the design and direction of future research, or indeed consider what the study may offer to the clinical arena.

Conclusion

Thematically, all of the above chapters in this study will be linked by the shared aims of the study and of the research method adopted. It is hoped that having a clear purpose and following this procedure will be advantageous in preserving the integrity and value of the testimonies obtained, and thus the study's primary objectives will be met. The secondary aim is that these contributions will further help to augment and support an improved understanding of the 'lived experience' of chronic pain.

Chapter 2: The Literature on Pain

In this chapter the relevant literature pertaining to the current study will be discussed. This will illustrate chronic pain's elusive and obscure status. This status is conceivably achieved through chronic pain having both ubiquitous yet distinct characteristics, perceived across the physical, psychological and behavioural dimensions. The impact of chronic pain will also be explored from the consequences it induces, which are identified across the individual, social and global divides.

2.1 Acute Pain

The phenomenon of pain is ubiquitous. It has been defined as 'an unpleasant sensory and emotional experience, associated with actual or potential tissue damage, or described in terms of such damage' (Merskey & Bogduk, 1994, p.210). It is an experience that all but a very few people, i.e. those born with a very rare condition called congenital analgesia, are familiar with. Pain is almost universally acknowledged as an unpleasant sensation and presents itself as an experience which most of us would rather not have to endure. However, in its unpleasantness, it performs an essential task which carries with it both virtuous and valuable contributions to our evolution and indeed to our survival as a species.

Pain is an experience which is implicated in our most basic emotions and cognitions and forms the basis of a number of our most important learned behaviours. We all learn through the experience of pain not to touch the hot stove, or that a leg is broken. Pain under these circumstances provides an important and necessary function, or a 'biological utility' (Gatchel & Epker, 1999, p. 413) designed to alert us to an external or internal threat and that some action needs to take place in order to preserve the organism from further harm. Under these circumstances pain has been referred to 'not as the enemy, but the loyal scout announcing the enemy' (Brand & Yancey, P.20. 1997).

Pain, as our 'loyal scout', can therefore be considered an essential system in which the momentary discomfort that we associate with it is more than outweighed by the benefits we derive from it, and the protection or warnings that it provides. However, these same accolades, utility and identity cannot necessarily be attributed to the condition which now becomes the central focus of this study, chronic pain. In this condition the principle function of pain as a warning becomes redundant, and pain and injury become largely independent of each other. Instead of pain being the 'loyal scout announcing the enemy', pain itself becomes that enemy.

2.2 A portrait of chronic pain

Chronic pain is very much a mystery. It has been defined as 'a pain that is often (but not always) elicited by an injury, but worsened by factors removed from the original cause, usually lasts a long time, and is not explained by underlying pathology'(Turk & Okifuji,

2002 P 7.). It is a phenomenon that has been baffling researchers and scientists alike for centuries (Todd, 1984). Even the definition suggests something of its enigmatic status, in which it declares its ambiguities, contradictions and anomalies. Chronic pain reflects one of the medical world's greatest challenges, that regardless of the tremendous advances in medical science, the seemingly simple goal of alleviating a person's pain, the most basic medical act and human right, remains defiantly elusive (Butler & Moseley, 2013).

2.3. Chronic Pain; a biological basis

The precise reason as to why an acute pain becomes chronic is largely unknown. Though as yet there is no conclusive proof, a number of theories have been presented in order to explain the persistence of pain, which are biologically complex and thus beyond the scope of the current study. However in brief, a growing body of evidence supports that through the interaction and continued involvement of a number of activities within the body's central nervous system, a system wide 'sensitisation' can occur (Straud & Smitherman, 2002; Baranauskas, 1998). This sensitisation is considered to be the result of an increase in the excitability of neurons within the central nervous system, so that normal inputs begin to produce abnormal responses. Prolonged or strong activity of these neurons leads to the continued transmission of normal signals throughout the body as 'pain signals' thus engaging the body's own inhibitory system, which attempts to inhibit or cancel out these pain signals (Dubner & Ren; 1999). However, due to the sensitisation of these neurons and their increased synaptic strength, the inhibitory system is brought even more into focussing on these pain signals. Paradoxically this then leads to the

development of a ‘feedback loop failure’. In this ‘failure’ the endogenous pain modulatory system has now itself become embroiled in the continuous occupation of pain perception. This leads to ever more increased levels of reported pain, in response to relatively minor infringements, as the inhibitory pain system continues to perceive these threats as real and on-going, interpreting and amplifying these messages as painful ones. This process has perhaps quite appropriately been referred to as ‘wind up’ (Graceley, et al. 2003). This term offers quite a literal expression of how, with the continuing occupation and activity of these systems becoming literally ‘wound up,’ it renders them both confused and unreliable in their ability to discern the accuracy of these messages.

With such a dynamic system in which ‘hard wiring’ and ‘sensitisation’ occurs, the impossibility of effectively being able to untangle or restore these systems to their original or normal functioning is just that, an impossibility. Indeed, when considering a condition which best demonstrates this, the curious phenomenon of phantom limb pain must be a powerful contender. The mechanics of this condition further supports that as part of the activity of the central nervous system, a ‘hard wiring’ within the brain’s somatosensory cortex can and does remain active and activated, regardless of the presence, or not, of a limb. Those who experience a loss of a limb or an amputation commonly report a partial, or in some instances a full range of sensations and perceptions of that missing limb, sensations which almost certainly can and often do include pain (Melzack, 1989). This phenomenon points to the permanence of the physical topography of the body being imprinted in the brain’s architecture. However, it is not just the somatosensory cortex in which the pain experience is implicated. Recent advances in

neuroimaging have now established that there are multiple pain centres in the brain, rather than a single area, as had previously been thought (Descartes, 1644). These include the thalamus, the parietal lobe, the limbic system and the cerebral cortex, all of which relate to different areas and responsibilities, such as motor function, memory, emotion and cognition. This is another indication of just how dynamic the experience of pain is, and furthermore how many levels are involved in our perception of and response to it.

2.4 The landscapes of chronic pain

Chronic pain can affect any part of the body, at any age and can affect men and women in equal measure (Andersson, 1999; Borkan et al. 2002). It does not discriminate between the old and young, with a sizeable minority of cases now being diagnosed in children, and an estimated incidence of between 45 and 80 percent in the old (The National Pain Audit, 2012). In a recent assessment of the national impact of chronic pain (Chief Medical Officer Annual Report, 2009), it was revealed that over a third of all households in the UK include someone who is living with persistent pain. Furthermore 1 in 5 people in the UK will, during their lifetime, go on to develop significant problems with pain or be diagnosed with a chronic pain condition. The problem of pain continues to escalate and having already been referred to as being *the* '20th century medical disaster' (Waddell, 2004), it has now been recommended by both the International Association for the Study of Pain (IASP) and the European Federation of IASP Chapters to be recognised globally as 'a major health care problem, and a disease in its own right'. (European Federation of IASP Chapters 2004).

The global impact of this major health care problem is also an economic one. The cost of back pain alone is equivalent to more than a fifth of one country's total health expenditure and 1.5% of its annual Gross Domestic Product (Maniadakis & Gray, 2000). In Sweden, the cost of pain represents three times the total cost of all types of cancer (Phillips, 2009). In terms of the UK economy, it has been reported that each year some 4.9 million work days are lost due to back pain alone, and that the economic impact of these figures essentially equate to a loss to the UK economy of £12.3 billion annually (Maniadakis & Gray, 2000). These figures underscore that just as chronic pain can affect people at any age, it will often affect them during their most economically active years (Collen, 2005). The results of this further help to secure its position, just behind mental illness, of being the second most common reason in the UK for claiming incapacity benefit (Chief Medical Officer Annual Report, 2009).

The economic impact of pain represents only one dimension of the range of difficulties associated with these debilitating conditions. Pain is now the commonest symptom in most medical settings (Merskey, 1980) and the second most common complaint of psychiatric patients (Delaplaine et al. 1978). Indeed, many people who live with pain also have to contend with what is referred to as a dual diagnosis, with sufferers experiencing both a physical and a significant mental health problem. 49% of people who live with chronic pain are also able to achieve a diagnosis of depression as a co-existing symptom of their condition (Chief Medical Officer Annual Report, 2009). Patients with chronic pain also report a host of other negative emotional consequences such as

helplessness, hopelessness, frustration, anger, guilt and anxiety. (Camic, 1999; Caudill 1999; Hardin, 2004; Leo, 2003; Otis, Cardella & Kerns, 2004; Shealy, 2003). Often accompanying these mood disorders are the significant concerns around suicide and evidence supports that pain is often cited as a reason for, or contributing factor in suicide attempts (Fishbain et al, 1999). Indeed, in a recent study conducted with chronic pain patients it was reported that 16% felt that at times their chronic pain and its associated impacts were so difficult for them, that they had either contemplated, or indeed attempted to take their own lives (Hardin, 2004).

Curiously, although there is a good awareness of both the profound impacts that chronic pain presents to the individual and to society, there currently remains no national strategy for its assessment or diagnosis, or any incentivised outcome measures designed around its optimal management. Indeed the medical response to this problem goes nowhere near to reflecting the magnitude of the problem. In a recent audit it was revealed that for every 32,000 people suffering with chronic pain there is only one pain specialist in a principal position to treat them (Chief Medical Officer Annual Report, 2009). Further, for those fortunate to receive help, only 30% were able to access what has been suggested as being the minimum recommended standards of care deemed necessary for these complex conditions. The remaining 70% fall into a model of treatment deemed to be incompatible with the profound needs of this population. (The National Pain Audit, 2012). Evidently, these circumstances reflect the need for a comprehensive review of health provision for those living with chronic pain, and indeed this has voluminously been called for throughout the literature (Arnau et al. 2006; Chief Medical Officer Annual Report, 2009;

The National Pain Audit, 2012). Sadly, these reviews have not influenced practice in any substantive way and chronic pain continues to reflect a dimension of healthcare in which the proliferation of certain assumptions and myths continue to influence both the treatment of these conditions and the poor outcomes with which they are associated.

The European Federation of IASP Chapters identified that ignorance, or a lack of knowledge or even awareness of pain was a significant barrier in the effective treatment of chronic pain. This was borne out in the UK's recent Pain Proposal (2010) in which it was identified that healthcare professionals training in chronic pain equated to less than 1% of the medical school curriculum (Donaldson et al. 2009). The same proposal found that less than half (46%) of physicians surveyed were confident in knowing what to do if a patient still complains of pain after treatment. This matched almost identically with the 45% of patients who felt that their pain was not adequately managed (Pain Proposal patient and PCP surveys, 2010). These discrepancies go some way to highlight just one of the many 'paradoxes of pain management' (Fagerhaugh & Strauss, 1977) where the significant ambiguities surrounding these conditions, and the lacking in a common strategy at even the most basic level, renders these conditions effectively invisible within the environs of the NHS (Pain Proposal). Indeed this deficit can be measured most comprehensively by the lack of appropriate provision of what is now considered to be the most effective treatment for those living with persistent pain, a multidisciplinary pain management service (Alaranta et al. 1994; Harkapaa et al. 1988; Mitchell & Carmen, 1994). Although hailed as the most effective treatment protocol for chronic pain management the actual presence across health care of these types of service remains

patchy at best. The national pain audit (2012), which is perhaps the most comprehensive insight into the current state of the nation's scale and response to the problem of pain, identified high variations in both referral and waiting times, coupled with the high variations in standards, reflecting a huge discrepancy on a national level in the availability of these services. 28 Primary Care Trusts (PCT's) appeared to offer no such services at all, with one provider claiming that it would paint its service in a bad light if it returned data on its own lack of provision. The services that did return data revealed a fairly low presence of both psychology and physiotherapy, suggesting that the majority of patients were not in receipt of truly multidisciplinary services. The audit committee found this lack of provision concerning, as they pointed out that psychological distress has long been recognised as a consistent accompaniment of chronic pain, both as precursor and more importantly as a consequence.

On an individual level these concerns perhaps highlight the fact that the variance that exists from person to person in their ability to manage pain may in fact be linked to differences in service provision from location to location. This concern was in fact highlighted by virtue of the decision to include patients in the audit, as a number of these patients, who had consented to completing an earlier series of questionnaires, ended up contacting the auditors to say they had had no treatment in the last six months, raising ethical concerns on the part of the audit organisers. This concern was addressed through the governance processes and the conclusion was that delays in expected treatment were an important issue to highlight. However, while this guidance on referral to treatment standards was published, it appears that the lack of provision remains a problem, with the

majority of these patients being re-referred back for conservative treatments. The scale of the National Pain Audit and this small facet of it (patients contacting researchers) seems to reflect an important feature of patients' desperation, confusion and a lack of confidence or involvement in their treatment pathway. It is just these dynamic concerns which, had the patients not contacted the researchers, may have been lost in the scale of the audit. However we are reminded that it is just these features that shape the meaning of an illness or a condition to the sufferer. Whereas a quantitative study, such as an audit is particularly useful in reflecting the scale of the problem, in order to provide a voice to those singularly affected by these conditions increasingly there becomes a need for a very different methodology and approach.

2.5 Pain is….. 'What the patient says it is'; Qualitative findings

The British Pain Society endorses the position that above all else, 'a person's self-report remains the most reliable measure of pain we have' and therefore 'the best and most fitting definition of what pain is is whatever the experiencing person says it is' (Margo McCaffery, P.11. 1968). In order to achieve an 'embodied' account of what the person says it is, a shift is needed from the general to the specific, from the objective to the subjective and as an incentive of the research method, from the quantitative to qualitative (Osborn & Smith, 2006, Snelgrove & Liossi, 2009, McCracken, 1998). Fortunately, it has been in just this area where the compatibility and relevance of research methods that follow this qualitative rationale have established their value.

A number of qualitative studies (Smith & Osborn, 2007; Hellstrom, 2001; Snelgrove & Lossi, 2009; McGowan, 2007; Slade et al. 2009; Holloway et al. 2007; Walker et al. 1999; Vroman et al. 2009; Osborn & Smith, 1998; Schlesinger, 1996) have attempted to help capture and reflect the lived experience of chronic pain. Themes that have emerged from these types of enquiries reveal some of the tremendous psychosocial impacts faced by people undergoing significant, forced transitions and demonstrate just how complex and diffuse the dynamics are, which are implicated in the various relationships that exist between an individual's pain, their body and their concept of self (Smith & Osborn 2007).

In Smith and Osborn's paper (2007), which sought to explore the psychological impact of chronic benign low back pain, participants described this as an 'assault' causing an internal split in which they described the existence of two separate selves; one referred to as the 'self with pain' the other as the 'real me.' The paper managed to capture and reflect the seemingly inexorable task of participants' attempts to assimilate and manage these 'two separate selves,' and how these efforts were themselves maligned by the often negative properties contained by the 'self with pain' and its contaminating effect on the valued 'real me'. Participants, in an effort to preserve the preferred self and maintain, revive and extol the virtues of this past 'real' self, fought desperately to keep the two separate selves apart. Ultimately, they recognised the futility of these efforts, realising that in fact this earlier 'part' of themselves had now ceased to exist in any real sense and had potentially been lost forever.

Hellstrom (2001) was able to develop this theme and illustrate these 'different selves' by using 'patterns' to represent perceived past and present self-conceptions. These were viewed as being both separate and extraneous from the self, whilst at other times being 'engulfed' by them. This theme of 'engulfment' was also present in the work of Kugleman (1999) who described the malevolence of pain as being like a possession "so complete that it leaves no aspect of life untouched" (Kugelman, 1999, p. 1670) and 'so intractable' as to 'possess' the participants' past, present and future selves. Indeed, many of the participants described being unable to see their own futures as being anything other than a 'pain-full' one, in which their expected selves were besieged by low ambitions, vulnerability, fear and perpetual loss. The true jeopardy of this could be identified in papers by Sofaer-Bennett et al. (2007) and Walker et al. (1999) who saw that these powerful themes essentially instigated and operated a self-fulfilling prophecy. These foresaw that participants dispossessed of anything like a positive possible future self, were increasingly likely to descend into further degrees of chaos, fear and ultimately obliteration.

These nascent fears are matched, and to some extent fuelled, by a corollary of other difficulties including a loss of function, status and role, further reflecting aspects of the chaotic accounts of participants whose lives and identities are perceived as being 'under attack'. It has been suggested that many of these dynamic concerns are activated through individual interactions with others and significantly the influence of the health care system. Much of the qualitative literature refers to this context as shaping the 'meanings'

that individuals ascribe to their condition (Fagerhaugh & Strauss, 1977; Thunberg et al. 2001; Busch, 2005; Van Huet, 2009).

The first negative accounts appear as a consequence of the lack of success associated with their treatment. Participants describe the psychological consequences of having their hopes raised by the prospect of an operation believed to offer the prospect of a 'cure', only then to have these hopes and expectations dashed when the procedure fails (Miller, 1993). There seems to be some suggestion that these failures become a theme in themselves, with many patients describing that, having been unsuccessfully treated, they come to inherit and imbue the same contradicting and anomalous status of their pain (Slade et al 2009. Holloway et al. 2007, Vroman et al, 2009). Patients describe that when the treatment failed to help them that they, themselves were regarded as the incongruity, perhaps articulated as the 'non-conformist' or the 'treatment resistant patient' or at worst the 'hypochondriac'. Patients felt that they had been on the receiving end of this type of speculation, i.e. that the problem, uncorroborated by visual or physical evidence may not in fact be physical, but psychological.

Pain as a true conversion disorder, where psychological distress manifests itself as a physical ailment, is considered to be exceptionally rare in the present era (Coen & Sarno, 1989; Merskey & Buhrich, 1975). However there is still much evidence to suggest that these conclusions are continuing to be reached with those living with chronic pain, further implicating that clinicians may still be applying an acute care model to a chronic condition (Deyo et al, 2009). The consequences of these activities could again be

identified as yet another paradox of pain management, (Fagerhaugh & Strauss, 1977) in which the activities of health care are seen as mirroring an implicit ideology at the expense of the individual. A consequence of this can be identified in the 'under treatment' of a significant health problem, leading to even greater degrees of chronicity, as well as an implication in the degree to which a patient engages, or more appropriately disengages in their treatment pathway (Van Huet, 2009;Hooker & Kaus, 1994). In a paper by Snelgrove and Liossi (2009), this disengagement was described as a reaction to the perception of being 'given up on' or continually being 'passed from one consultant to another,' leaving patients with the impression that no one wanted them, and that they were an inconvenience or a 'problem patient'. McGowan's et al's study (2007) explored the consequences of these experiences further whilst focusing specifically on the accounts of women with chronic pelvic pain. Her participants reported that due to the apparent invisibility of their condition they described a disengagement and withdrawal of concern by their carers, which seemed to be replaced with scepticism. This, coupled with the symbolic power of the doctor, had left them feeling both disenfranchised and disempowered, ultimately leading these women to become alienated from their own bodies.

Participants' negative experiences were not limited to the social arena, or to just the health care context. Indeed, in their efforts to 'fit' in and retain their 'normal' status, participants described experiencing further misunderstanding and alienation across a broad range of social contexts. This theme was highlighted by both Slade et al. (2009) and Holloway et al. (2007) and was identified and presented under the title of 'stigma'.

Drawing on an observation by Goffman (1963, 2009), who referred to stigma as a 'discrediting trait', stigma came to be encountered in virtually every dimension of a sufferer's life, often resulting in further alienation due in part to the accompanying disbelief and disempowerment it evoked (Walker et al. 1999). In the work arena, participants described a sense that they were being scrutinised and disbelieved by work colleagues, where it was insinuated that as their pain was invisible the sufferer was actually acting up their condition and pursuing secondary gains. Stigma in this case left them feeling that they were viewed as someone who was lacking in moral incentive to improve and instead held a preference to a life of benefits (Vroman, 2009). Participants' objections to these claims were particularly difficult, as former employers and colleagues were reported to have ostracised and avoided them, making it extremely difficult to challenge these colleagues or their perceived conclusions. Finally, this discrediting trait even pursued them into their own home lives and family. Once again a lack of understanding prevailed as shown in Schlesinger's work (1996), in which women's experiences of intimacy, sexuality and pain were explored. However, this time it was not the medical professional but the sufferer's own partners who struggled to believe what could not be seen. This disbelief, coupled with participants' own body confidence issues had had a significant impact not only on the participants' self-esteem, but significantly contributed to a severance of connection between themselves and others (Osborn & Smith, 1998). These themes further contributed to a growing sense of isolation and difference, and resulted in their being sucked further into the 'undertow of illness' (Fagerhaugh and Strauss; p.115).

Isolation was another significant theme and featured in a study conducted by Slade et al (2009). Here participants reflected on the causal link between their often self-imposed isolation and the corresponding feelings of shame, guilt and embarrassment. Importantly, in addition to these powerful motivating forces, the perceived disbelief of others, attributed to a lack of diagnosis and the invisibility of their condition, had made the decision to withdraw from social engagement all the more appealing. Invisibility was again highlighted in Smith and Osborn's paper (2007) but presented sufferers with a paradox. On the one hand they sought for an improved understanding, but the achievement of this would heighten their anxiety that they were needy and as such communicate their vulnerability. This activity held the potential to further usurp the former preferred self, and replace this with the ever-increasing dominion of the self with pain.

Interesting parallels can be drawn between these stories of patients and the perspectives of the Health Care Professionals (HCP's) who also feature in these challenging narratives. Indeed, in an illuminating study conducted by Thunberg et al. (2001), it was the health care professionals themselves who were interviewed and asked to consider what they felt were the particular challenges faced whilst working with patients diagnosed with chronic pain. The results of this study suggested that along with a palpable sense of professional ambiguity, reported as a lack of common strategy, these patients were perceived as being both guarded and hostile towards them whilst in their numbers they appeared like 'never ending beads on a necklace'. The Health Care

Professionals' described feeling particularly paralysed by the limited successes, the pressures of work and the tremendous needs of the patients with whom they worked. This revealed a further dimension of the chaos of chronic pain and lent support to the permanence and ubiquity of such themes as vulnerability, disempowerment and fear as being fused and found within many differing contexts of chronic pain.

Amongst the predominantly 'negative' accounts found in the qualitative literature are the occasional accounts that do not follow this trend. In an important study conducted by Van Huet. (2009), participants were able to reminisce on many of these themes, but from the vantage point of having 'moved through' them and having arrived at a place of acceptance of their pain and their situation. Van Huet's participants had all been recruited following their attendance on a Pain Management Programme and it appeared that their attendance had been instrumental in mobilising many of the changes they felt had occurred as a result. Participants' accounts reflected that an acceptance of their pain had been achieved as a result of having undergone a 'grieving' process, which the programme had given them both the opportunity and permission to do. Importantly, these experiences happened in parallel and in relation with others involved in the programme and that sharing these experiences had helped normalise their experience. Importantly, it was identified that an agent in perpetrating this shift had been developed through the positive engagement of the clinicians who had delivered the programme. Participants described the importance of their 'being believed' and that the HCP they encountered on the course were amongst the view who held this position towards them. This belief had

seemingly helped them to lower their guard and subsequently engage with the material more earnestly.

These accounts endorse that alongside the accounts of 'chaos' so commonly associated with living with these conditions, alternate narratives do exist. Perhaps not surprisingly the experience of 'being believed' is fundamental and crucial in the identification of this narrative as much as it is key to mobilising patients' engagement with their treatment and the positive outcomes associated with this commitment. These desired outcomes are perhaps mirrored by an increasing drive within the wider context of healthcare in which the patients' experience (Barry et al. 2000) is more closely examined. The purpose of understanding the patients' experiences as they move through the various health care settings is a considered attempt to improve these experiences and the outcomes with which they are also closely associated (Ong & Richardson, 2006). This movement is being supported by findings from both the qualitative and quantitative camps (Hellstrom, 2001; Hooker & Kaus, 1994; John et al. 2009, Thompson et al. 2008), in which HCP have been seen to contribute to fostering a stronger motivational force in promoting positive health behaviours, the outcomes of which are identified with much higher reported 'quality of life' scores and much lower levels of reported disability (Busch, 2005; Benjamin, 1989; Hooker & Kaus, 1994; Heapy, et al. 2006; Prochaska Norcross & DiClemente, 2005). Qualitative research methods are critical in maintaining this focus on 'patient experience' and have consistently highlighted the 'meanings' of illness to the individual and importantly how the meaning of illness is itself shaped through the individual's experiences of health care.

2.6 Chapter Conclusion

This chapter has attempted to refer the reader to the 'context' of chronic pain. This context has been explored first from a biological basis. It has provided some insight as to the profile and nature of chronic pain and perhaps why, when an acute pain becomes chronic, it becomes a *different* health problem within a *different* set of needs. A significant shift in recent years to explore the 'subjective' experiences of individuals has helped obtain a better understanding of what these differing needs may be as well as helping to establish how human and social structures play their roles in the development and 'meanings' given to such conditions (Houston & Mullan-Jensen, 2011).

These incentives are consistent with the values held by a number of qualitative methodologies, which have been able to endorse and represent the value of the 'multidimensional lived realities of participants living with conditions which would remain impoverished and inadequate if viewed along a single dimension' (Mason, p.12, 2006). Importantly, each year the volume of these types of study grows, ensuring that these voices take their rightful place alongside the mainly positivist and disembodied voices which had previously dominated the literature, and as such this has equally helped to challenge the dominance of the traditional biomedical paradigm to the treatment of pain.

In the current study, alongside the participant voices, participant 'art work' will be privileged, in which an attempt will be made to transform the 'lived experience into a textual expression' (Van Manen, p.104, 1990). The purpose of this is itself described as an attempt to gain direct access to, and illustrate something of, the unspoken 'essence' of the phenomenon of pain. As such this method is considered to be a complement to getting as close as possible to the topic under investigation. Equally this method is also representing a challenge to the dominance of the spoken word, be it quantitative or qualitative, as being the principle vehicle for the expression and interpretation of meaning.

Chapter 3: Methodology

3.1 Overview

In this chapter I will introduce the chosen method of analysis, a brief description of its philosophical underpinnings and why it was selected as the chosen method of research for the current study. It will also be demonstrated how the methodology selected has particular compatibility with the values and principles of counselling psychology, and further how these values are consistent with the considerations of the Biopsychosocial Model in being considerate of an individual's wider social and cultural context. Finally, a specific feature of this study is its visual component. A justification for this will be explored, as will what visual representation has to offer qualitative research methods, as well as the wider corpus of literature currently defining these conditions.

3.2 Interpretative Phenomenological Analysis

Qualitative methods of analysis have increasingly been responsible for providing crucial insights and an 'insiders' perspectives' (Conrad, 1987) into the study of particularly complex phenomena. The participants from such studies provide the context and a

unique vantage point from which to make sense of meanings, perceptions and interpretations of their experience leading to a deeper understanding of a particular phenomenon. Interpretative Phenomenological Analysis (IPA) (Smith, 1996) is one such form of phenomenological inquiry. It is particularly concerned with exploring and communicating the 'life worlds' of its participants and particularly effective at providing both clarity and insight into how they make sense of major life transitions from the meanings that they attach to them (Smith, 2004).

IPA has its theoretical roots in phenomenology, hermeneutics and idiography, which reflect a philosophical commitment to exploring and understanding human experience (phenomenology) through the process of interpretation (hermeneutics), whilst maintaining a consciousness and sensitivity to the particular contexts in which these experiences emerge (idiography). IPA was developed as a research method in its own right by Smith (1996) as both an alternative and complementary approach to the more established quantitative and qualitative methodologies in the field of psychology. As mentioned, IPA's philosophical underpinnings and guiding principles identify it as a research method that is particularly interested in exploring the roots of human experience. In its efforts to get as close as possible to a particular phenomenon, it acknowledges that the accounts and testimonies of those who are living with or going through a particular phenomenon can provide a unique and valuable vantage point from which to report on this, and reflect something of the sheer complexity and richness of the human experience.

Helped by an inductive, iterative stance, with a focus on the particular rather than the general (De Visser & Smith, 2006), IPA places the centrality of participants' narrative accounts at the heart of its enquiry. It has measures to ensure that this presence is maintained and privileged throughout the various stages of the analysis. IPA is therefore said to be a bottom up, rather than a top down form of analysis, which is in keeping with an idiographic commitment and ensures that the richness of the accounts are not lost as one moves toward a higher order level of analysis.

These values are clearly represented in IPA's philosophy and commitment to phenomenology and hermeneutics, in that 'it follows an inductive process which invites the researcher to 'bracket' their own preconceptions, scientific and theoretical assumptions' (Larkin, et al. 2006: pg.108). It is both sensitive and responsive in the data gathering and analysis to allow for participants unique stories to emerge in their own way. In its efforts to get as close as possible to experience, IPA acknowledges that the experience is firstly interpreted by the individual, who in their sense making communicates this experience to the researcher, who in turn is then involved in an interpretation of their own (Smith, 2003). In this way IPA can be described as operating on a double hermeneutic, the implication being that in the researcher's attempts to reflect the experience under investigation, they have an important role in that interpretation.

This double hermeneutic in fact represents another hallmark of IPA's particular methodology and reflects that it is purposely interpretive. The process of interpretation in IPA relates to the field of hermeneutics, which is literally defined as the theory and

practice of the interpretation of the meaning of texts (Rennie, 1999). The interpretive activity is itself developed alongside a consciousness of the wider and shared context of the individual, as well as a number of additional participants within a study and ultimately the wider context of the study itself. To that end, it requires the researcher to engage in a degree of interpretation in order to balance these divergent and convergent needs. This balance is achieved through a continuous process of engagement, interpretation and validation, sometimes referred to as the hermeneutic circle (Moran, 2002; Smith & Osborn, 2007; Smith, Flowers & Larkin, 2009). This process of careful interpretation and validation is adhered to throughout the life of the study and is finally represented as the 'hard won insights' (Moran, 2002), which although more general, can still be transparently traced back to the original utterances of participants engaged within the study.

With both this idiographic commitment at its core and the very exhaustive process of analysis that IPA adopts, it is both a measure of practicality and suitability that IPA studies tend to focus on a relatively small number of participants, with sometimes an analysis of just a single case being presented. IPA itself makes no real claims to generality beyond the scope of the study itself, but by selecting a few accounts over the many, it may have just as much to offer as a Randomised Control Trial (RCT). Indeed with a condition as multifaceted as pain it is appropriate to have caution in interpreting the findings of an RCT, whereas one may have much more confidence in the outcomes of a qualitative study in being able to capture and reflect the dynamics involved in researching a phenomena as complex as the pain experience. In addition to this, methods

of research which aim to focus specifically on complex phenomenon or under researched groups (Quin et al. 2009) perhaps have both the potential and a responsibility for making powerful contributions to achieving a more equal society. This, it is argued (Liamputtong, 2010), is achieved by qualitative researchers providing a 'voice' to those whose accounts may not have been represented if following a positivist methodology.

3.3 Why IPA?

Although all qualitative methods can be considered to share similar ambitions, it is the subtle differences in both the guiding principles and the methodology that IPA adopts that made it particularly suitable in meeting the aims of this study. IPA is particularly concerned at getting close to the participants' cognitive and affective reaction to what is happening to them and how they make sense of these experiences. This differs from other qualitative approaches that follow a discursive approach (e.g. Discourse Analysis), which may be more focussed on the linguistic resources that participants draw on in order to provide accounts of experience (Smith, 2011). This distinction is made even clearer by considering the divergent motivations for each approach in the researcher's commitment to phenomenology. Whilst Discourse Analysis focuses on the obvious and hidden meaning of texts to explore how and why these meanings vary across contexts and cultures, IPA aims to get closer to the root of experience by gaining insight into the experience itself. Therefore a researcher coming from a Discourse Analysis approach may not be quite as motivated towards pursuing this same ambition and is perhaps more

interested in, or concerned by, how a person constructs their own reality. In this way a researcher coming from this perspective may adopt a focus on the examination of participants' accounts by attempting to identify the constructing apparatus involved in the narration of life events (Smith, 2011).

Grounded Theory (GT) is another qualitative research method that could be considered as sharing similarities with IPA (Glaser and Strauss, 1968). However, again subtle differences in the purposes of both approaches set them apart. In GT, the sample itself is selected on theoretical grounds and the recruitment process is not dictated by homogeneity (Brocki & Wearden, 2006) as it is with IPA, but by the incentive to reach saturation. This subtle but important distinction can also be identified in how the activity of the researcher differs in achieving the aims of the study. In GT the researcher is attempting to reach saturation in order to fulfil the aim of trying to account for a particular phenomena (Willig, 2013), whereas IPA's motivations and activities are perhaps dictated by an effort to 'examine the nature or essence of that phenomena' (Smith, 1995) in isolation of an agenda. As such, each methodology might be better suited for alternative purposes. Whilst IPA's purpose is to gain a greater insight into the individual psychological worlds of its participants and therefore a greater insight into the phenomena itself, in GT the insights are attempting to reflect more of a social process. Therefore if the purpose of enquiry is to gain insight into a sociological process, GT might be far better suited as a means of enquiry, whereas if one is attempting to illuminate a particular phenomenon through exploring psychological processes then IPA may be deemed more suited to achieving these outcomes.

The subtle differences in principle and method explained, as well as IPA's compatibility with the motivations and guiding principles of Counselling Psychology (see next section) ultimately brought the researcher to conclude that IPA would be the most appropriate method of analysis for achieving the aims of the current research.

3.4 IPA and Pain

Although IPA has been employed across a wide range of phenomena, a consistent feature of interest has been in the area of health and health related transitions. Chronic pain itself has proven to be a fairly popular subject for IPA (Smith 2011) and has featured in at least ten studies. Naturally the question may present itself as to why qualitative methodologies in general, and IPA in particular is considered to be particularly well suited to these types of inquiries. IPA has consistently offered the researcher an opportunity to explore in depth the 'meanings' that individuals associate with their experience of living with a chronic condition (Reid, Flowers & Larkin, 2005). An extension of this has helped identify that the experiences of healthcare are paramount in shaping these 'meanings', the importance of which is demonstrated by the acknowledgment that these contexts have a direct influence on the associated levels of distress and disability (Skevington, 1995) and therefore reveal themselves to have just as much potential to harm as to heal.

A further asset provided by IPA has been its ability to provide a 'voice' to those living with chronic pain. It is apparent that this voice has often been swallowed up or drowned

out with the dominance and supremacy of the obdurate medical model which continues to prevail, as does the dominance of the mainly positivist and 'disembodied' accounts which have thus far largely accounted for this phenomena.

3.5 IPA and Counselling Psychology

IPA has not only been used across a broad spectrum of physical health conditions but has also been used extensively in examining the experience of mental health issues (see for example Howes et al. 2005; Newton et al 2007; Carradice et al. 2002; Roose & John, 2003; Swift & Wilson, 2001). These studies have again helped to shed light on the 'meanings' of living with a mental health problem, the process of change and recovery, the institutional context of certain kinds of experiences and the cultural understanding of mental health issues. Once again these studies have thematically linked outcomes to a number of recommendations in clinical interventions.

The thematic links and clinical interventions would also be of particular importance to the Counselling Psychologist who, for a number of reasons, might also find IPA a particularly appealing method of analysis or a 'natural' choice from which to consider exploring the 'lived experience'. IPA offers the Counselling Psychologist a clear conceptual framework within which research can develop and from which the CP is well equipped to evaluate and engage with these findings congruently within the scope of their own clinical practice. This is made possible by both CP and IPA sharing a number of

similar aims and guiding principles, foremost of which is the shared goal of elevating the understanding of the subjective world of the self into a primary position in psychology (Smith et al. 2007). These aims are expressed by IPA's commitment to phenomenology and demonstrated in its efforts to privilege the accounts of its participants in such a way that it is possible to enable that experience to be expressed in its own terms (Smith, 2007 p32). These values are consistent with those of the CP who equally attempts to privilege the subjective experiences, feelings and meanings that individuals ascribe to a phenomenon, and is motivated to accept these subjective worlds of the client as meaningful and valid in their own terms (Woolfe et al, 2003). In addition IPA is particularly attractive to the CP as it has sensitivity to the consideration of the social and cultural contexts in which participants live, making it especially compatible with both the Biopsychosocial Model of health (Smith, 1996; Smith et al. 1997) and the values of the CP

3.6 A creative approach towards achieving the aims of the study

Although the primary researcher has described his awareness of a number of studies which share the same or similar aims and ambitions as the current study, with a phenomenon as universal and subjective as pain, there remained much scope from which to explore and better understand this phenomenon. Indeed, a feature of this conviction could be identified in the current study's ambition to contribute something fresh to the corpus, articulated as the belief that subtle adjustments in the manner in which the subject itself was approached could result in bringing about something completely original. In

the current study this belief was reflected in its efforts to explore how participants not only articulated their accounts of living with chronic pain verbally, but how they illustrated these experiences of living with chronic pain through a visual representation (i.e. art work).

In IPA's commitment to getting as close as possible to the essence of experience, it is unfixed on the methods or approaches used in which these contributions can be made. Recently, an increasing number of mixed methods, as well as more creative approaches have been employed in order to provide different and differing perspectives on particular phenomena or themes. Thematic analysis of Poetry using IPA (Shinebourne, P 2011) as well as other forms of creative approaches, such as participant artwork, has provided a fresh perspective on achieving ever more 'embodied' accounts of a particular phenomenon. Indeed studies which have provided a 'pictorial turn' (Mitchell, 1995) to its participants may also provide an opportunity for them to illustrate some of the aspects of their experience that may prove difficult to express verbally. Cross et al. (2006) suggest that as people rely upon their 'visual sense more than any other to understand their worlds,' art may therefore afford the social researcher who is interested in understanding the relationship between people, discourses and objects an opportunity to:

'Focus on …the visual meanings that she or he seeks to understand (as they) will often live at the intersection of these different areas of interpretation, rather than being revealed in any one approach'. (Pink, 2006: p31).

Pink (2006) suggests that visual interpretation might be a complement to, or an additional resource for the researcher attempting to understand the lived experience of his/her participants. Indeed in his study (Pink, 2006) participants, all of whom had sustained a spinal cord injury, were invited to illustrate how they saw themselves and how they saw their spinal cord injury. The images created and the analysis of these images followed Rose's (2001) critical visual methodology framework. Both the images and the analysis challenged what might have been predicted under the circumstances. Over half of the participants in the study did not portray themselves as paralysed at all. A notable absence of a wheelchair in which they were sitting suggested that the self they recognised was not as others saw them. This perhaps is an interesting parallel to the problems reported by pain patients, who were frustrated by the apparent invisibility of their own conditions and how this contributed to their experience of stigma. However, in Pink's study participants uniformly saw themselves as being 'more than a disabled body'. Within their artistic representations this was captured under the title of 'floating heads and faces'. This theme reflected that for participants, the body was something they had a desire to eliminate, or the part of themselves that they wished would disappear. With the request for participants to draw their spinal cord injury the results were even more intriguing. Although most participants represented this in an anatomical fashion, drawing their spines, and the point at which their injury occurred, others drew no such concrete representation. Instead, many participants reflected these injuries in the form of metaphor or abstractions of emotion, with one participant drawing themselves as an imperfect flower positioned next to a perfect flower, with petals missing and weeds littered around its base. In this abstract illustration a single image conveyed a strong sense of emotion and feelings about their

injury, with the use of different colours to reflect different emotions and the contours of these coloured lines reflecting the ups and downs of living with spinal cord injury.

3.7 The research question and the utility of art as a form of expressing the lived experience.

IPA has been particularly successful at focussing on the lived experience of chronic pain and has represented the chaotic experiences of stigma and loss as well as the very real concerns around identity and identity change. In the current study the primary aims of the research questions reflect an attempt to build on these findings. However it also hopes that by providing and prompting participants to engage with the visual interpretation, 'an analytic lens upon the social intersection between 'what is seen' and 'what is felt' (Cross et al, 2006) may also be expressed. It is argued that by providing an artistic outlet participants' may have the opportunity to provide an account of this phenomenon at an even more rudimentary level, which, due to its subjective nature may have incommunicable aspects. Also in its adulteration by the modulating effect of cognitive or affective interpretation it may lose some of its true essence. Art may also allow a participant to engage with the subject at a deeper level, or in a more creative way and therefore alongside the valuable affective or cognitive responses, it may invite an even greater intuitive or instinctive response to the research question 'What does living with chronic pain mean to you?' The intention of the current research and the research question is to integrate participants' cognitive, affective and visual interpretations of their

experience in order to arrive at a more complete account of this particular phenomenon. In the first instance, this study aims to conduct an analysis of the visual imagery in its own right in the participants' accounts of their experience of pain and it will also attempt to pursue how, having created these images, the participants were guided or prompted in their elaboration by these same images.

Chapter 4: Method

4.1 Overview

In this chapter an outline will be provided of the particular procedure that was undertaken and how this progressed throughout the life of the current study. Firstly, a description of a self-interview will be given and the purpose for which this was carried out. A description will then be made of how the recruitment and selection process was carried out and what considerations were made in order to arrive at a fairly homogenous sample. As the study was seeking to recruit patients from within the NHS, some description will be given as to the measures taken to ensure both confidentiality and patient safety. Finally, it is considered most helpful to demonstrate the analytic process adopted by the study therefore a small section of transcript will be taken and analysed in accordance with IPA guidelines.

4.2 Self Interview

The procedure of IPA necessarily involves a number of stages which require careful progression in order to preserve the integrity of the accounts of its participants at each of these various stages of the analysis. In order to uphold the core values shared by CP and IPA, the researcher considered the appropriateness of examining his own beliefs, thoughts and feelings about this phenomena in order to remain as reflexive as possible

and to ensure that the primary researcher remained considerate about performing his primary task of researcher.

A self-interview helped to explore and identify any personally relevant themes that the researcher may have had towards the study. It helped in developing a mindful approach towards the potential encroachment or contamination by personal agendas of the data that might emerge from the participants in the study. This measure took the form of a sensitive self-reflective process of self-interview, probing ideas, thoughts, hopes, fears, criticisms and confusions about the participant group selected and indeed what expectations the researcher may have had about the participant interviews. What emerged from this process was the concern that past experiences of working in this context had shaped the researcher's own assumptions and beliefs as to what he might anticipate and that his being aware of this might skew the interpretation of the data. Notes of these assumptions were recorded in light of this activity, along with a set of questions which might be based on the researcher's past experience in order to remain conscious of these potential traps.

In reviewing my own self-report, it was clear that I was informed by my own clinical practice in this area, in terms of identifying themes that appeared to be relevant to the therapeutic relationship. I was aware that themes like resistance and acceptance often emerge as important and that in my role as therapist, I would be likely to respond to these themes by attempting to provide the conditions whereby these transitions could be supported and facilitated. My role as researcher however required that I bracket off these

inclinations in order for whatever emerged for the participant to do so without impingement or without the agenda of the therapist shaping the interview. I was also conscious of themes that I had identified in my own clinical work, which related to clients' efforts to maintain the expectations made of them or that they hold themselves. I am conscious that this often manifests in their behaviours, which will often take the form of their pushing into their pain, or trying to ignore their pain. I have identified in my therapeutic work that what often underlies this behaviour are the strong motivational emotions, which include guilt or shame, and that in my therapeutic stance I aim to facilitate the process of self-determination by illuminating these processes and their potential consequences. Again in my role of researcher I identified that I would have to hold back on these inclinations, in order for the participant to express more fully the penalties associated with following these motivations. The self-interview therefore was seen as having been a powerful cautionary activity that helped to orientate my position of researcher rather than therapist, and allow for the participants' experiences to emerge unadulterated by the functions and activities that might be central in a therapeutic relationship.

4.3 Selection and recruitment of participants.

The working research question in this study was "What does living with chronic pain mean to you?". Accordingly participants were selected on the basis of their being drawn from a fairly homogenous group and their ability to answer this enquiry both in verbal

and in visual terms. A homogenous sample in IPA is important for partly practical purposes and partly interpretative ones. It is usually more practical to gather participants from a single context or setting, coupled with the economy gained from focussing on a fairly small sample. Equally, by pursuing a purposive homogenous sample who find the research question meaningful, participants come to represent a perspective rather than a population (Smith, 2009). This perspective acknowledges that it is one of many and encourages the investigation of numerous perspectives to help build up a fuller picture of a phenomenon. Also by grouping participants together into as uniform a collective as possible one is able to examine in greater detail the variability that arises within the group by analysing the pattern of convergence and divergence.

4.4 Ethical issues and Confidentiality

Prior to interviews taking place ethical issues and ethical approval was sought so as to ensure both the confidentiality of participants and to ensure that their involvement would not result in adverse reactions. It would be likely that in sharing their accounts and experiences of living with chronic pain, participants may inadvertently reveal details about themselves or others, which may pose difficulties in maintaining confidentiality. To that end it was necessary to devise a system that sought to anonymise identifiable details of both participants and anyone else named in their interview. It was made clear to participants that this would be to ensure confidentiality. This was detailed in the recruitment information and was expressly considered through each stage of the

interview process and the analysis of its content. Pseudonyms would be used as well as additional measures such as deletion, to remove any details that could possibly reveal any identifiable persons discussed during the interviews. Participants were also reminded of their right to withdraw from the process at any stage without having to give a reason, and that once interviews were collected they would be held under strict security measures and deleted upon completion of the research. Participants were reminded of the limitations of confidentiality and that if there were any concerns which suggested either a danger to themselves or others, then the researcher would be at liberty to share these concerns with relevant parties, such as the participant's GP, particularly if there were concerns around suicide.

It was considered likely that in a participant's disclosure of information about their experiences of living with their condition, there was a risk of them becoming emotionally distressed. With this risk identified it was deemed appropriate to make provisions for this eventuality and therefore details would be made available of how a participant might be able to access emotional support following their interview. This information would be disseminated both orally and in written form. It was further considered that there was equally a possibility that in their involvement with the study, participants may in fact experience a positive therapeutic benefit, from which they may feel psychologically supported in their attempts to make sense of their personal worlds.

Ethical approval was sought and granted by submission and interview with the local NHS Ethics Committee (see Supplementary Material Section). An amendment was made to

this ethical approval with the request to include participants' artwork as a method of research. The same ethics committee also granted this.

4.5 Selection Criteria

In the current study, criteria were developed in order to arrive at a fairly homogenous sample. This criteria included participants' involvement with a community based chronic pain service, that they were all white British women falling within a specific working age group living in the south east of England, and most prominently, that they satisfied a diagnosis of having a chronic pain condition. Beyond these fairly broad conditions, a few further considerations and specifications were initially sought, so as to arrive at an even more homogenous sample. Factors such as the length of living with the condition, the age at which their condition began, whether or not they had been, or were currently in receipt of conservative (interventional) procedures, or indeed the degree to which they had had prior exposure to pain management approaches (non-interventional) were all considered as being further factors in helping to identify desirable participants for achieving homogeneity within the study.

The reasons for seeking participants who had had no exposure to pain management beyond the conservative were twofold. Firstly, an attempt was made to recruit participants who had developed their own 'natural' means and methods for coping with their pain. The intention here was to capture and reflect as purely as possible participants' own psychological flexibility in relation to living with their chronic pain condition, which

is the focus of the current research. Secondly, the primary researcher was mindful that if the participants were in receipt of on-going interventions this might skew an engagement with self-management. This is because generally a secondary care context may yield a much stronger representation of the Medical Model, in which they may have found themselves to be more a passive recipient rather than an agent in their own self-care. This again is a dimension that the current research wished to explore.

Interestingly, no discrimination was made as to what particular pain condition participants had. Although this has been an exclusion criterion elsewhere, this was deliberately avoided in the current study, as the ambition of the research was not to pre-suppose that any one condition should take precedent. It was intended that the experience of having persistent pain be the significant variable, and how the person has come to live with chronic pain the inquiry. In supporting this position it was immediately apparent that the conditions with which participants presented were so broad and diverse that achieving homogeneity along these lines would have been an overly demonstrative process anyway, which would not necessarily been relevant in terms of meeting the aims of the study. The researcher was however satisfied that homogeneity was achieved based on the lines of age, sex, ethnicity, geography and indeed the context in which they were seen.

4.6 Recruitment Process.

Participants were initially recruited and made aware of the study through their attendance at a community pain education session. The pain education session is devised as an introduction for new patients coming into the community service and an opportunity to introduce some very basic education around pain management. It is expected, and is indeed common that up until this time the majority of these patients would have had next to no pain management consultation. Their previous treatment would have generally oscillated between a Secondary Care setting, where the Medical Model is much more pronounced, and treatment from their GP, which may have largely consisted of a regime of medication management. For the majority of patients, attendance at a one off pain education session could therefore be expected to be the first experience of pain self-management and as such an opportunity to introduce people to a different philosophy towards the treatment of their pain, more closely aligned to a Biopsychosocial approach. Attendees to these groups were given information about the study via the distribution of the recruitment sheet upon their arrival.

In order to avoid any possible coercion during this recruitment phase, a member of staff not directly involved with the study had been asked to hand out these recruitment sheets to all attendees at the pain education session. The recruitment sheet outlined the study and the intention to select participants from a number of such sessions. The recruitment sheet outlined the design of the study, and the inclusion/exclusion criteria. It further asked the reader to consider if they found that they fitted the desired demographic and

invited them to consider whether or not they wanted to participate in the study, to explore their experiences of living with chronic pain. If participants had a desire to share their stories they were asked to indicate their interest by leaving their details on a separate sheet, whereupon they would be contacted by the chief researcher at a later date with a view to arranging an interview.

Following these declarations of interest the chief researcher was then tasked with contacting those who had indicated that they would indeed be interested in taking part in the research and arrangements were made for them to attend a GP practice close to their where the education session was delivered, in order to conduct these interviews. The number of participants initially being sought for the study was eight. However from this very first attempt at recruitment, the number of people wanting to share their stories far exceeded that figure. Therefore the sample ultimately had to be obtained on a first to be contacted basis.

4.7 Description of participants and researchers

Ultimately seven participants came in to interview. They were all woman whose ages ranged from 35 to 52 and all were white Caucasian. On average they had had pain for 11.8 years, and none had had it for less than six years. Most had some history of unsuccessful medical interventions and investigations. All but one had no prior exposure to any ‘pain self-management’ approaches and had detailed their health care up until their

referral to the community pain service, as being shared between Secondary Care and their GP. The basic demographics of participants are represented in the table below:

Pseudonym	Age	Yrs. with pain	Relational status	Children	Employed
Claire	36	8	Married	1	No, ex nurse
Fran	52	15	Married	1	No, ex lab assistant
Gill	38	6	Single, Lives with parents	0	Yes, part time vet assistant
Julie	50	12	Married	2	No
Rebecca	46	21	Married	3	No
Sarah	42	8	Single, lives alone	4	No, ex publican
Zoe	38	13	Single, lives alone	0	No

(Figure 1 Participant profile)

The main researcher (Kirkham) for the study is a Chartered Counselling Psychologist, with five years post qualification experience, all of which has been in the delivery of individual and group based pain management to patients experiencing unremitting chronic pain. The supervisor (Smith) has extensive knowledge of conducting research himself, as well as experience of conducting numerous qualitative studies on the subject of living with chronic pain. This role in the study was to both supervise and validate the findings of the principle researcher.

4.8 Data Collection: Interview Preparation and Procedure

Participants were invited to attend a venue local to them (GP practice) in order to participate in the study. They were greeted by the chief researcher in the practice waiting room and led to the room in which the interview was to be conducted. Participants were asked to read the participant information sheet and the consent form and, if happy with both and wanting to proceed, to sign both. The researcher then explained that, as a method of expression, participants would be offered a blank sheet of A3 paper as well as a range of materials (crayons, pencil, paint) from which they could freely choose to illustrate their experience of living with chronic pain. As a cue, a laminated card with titles such as, ‘What does your pain look like?’ and ‘What does living with chronic pain mean to you?’ was offered. It was explained that participants were free to use or disregard this cue card as they wished.

Participants were asked if they had any questions and reminded of their right to withdraw at any stage should they wish to. If they were still willing to continue the researcher explained that they would now be left for a period of about fifteen minutes, which provided an opportunity to create their images in privacy. Should the researcher be needed he would be available just outside the room. Participants were then left and upon the researcher's return to the room a digital tape recorder was switched on and the interview proper began.

The interview schedule followed a semi-structured approach, which was considered to be the most appropriate method of obtaining rich detailed material. In the book by Smith, Flowers and Larkin (2009) it was pointed out that "…semi-structured interviews and qualitative analysis are especially suitable where one is particularly interested in complexity or process, or where an issue is controversial or personal" (p. 10). By utilising this approach the researcher was in a position to both ask questions and assist the participant in exploring personally relevant themes in greater detail that therefore increased the likelihood of obtaining in depth relevant data from the participant. Each interview began in the same way, by asking the participant to explain what they had drawn and what it meant to them. This was then followed by the interview process as detailed above. Interviews lasted between 45 minutes and 70 minutes. The style of interview was left as open as possible for participants to engage with, and to answer the research question as they saw fit. The role of the researcher was to ask clarifying questions, or to enquire about any particularly valuable or pertinent comments. The full interview schedule questions are provided below:

What does living with chronic pain mean to you?
What does your pain look like?
What are the particular difficulties you experience with your pain?
How do you manage your pain?
How does your pain affect those around you?
What has been your experience of treatment for your condition?

(Figure 2 Interview schedule)

The researcher was careful to be considerate of the participants' level of distress and therefore the probing of specific topics was done in a sensitive way. Further, due to the specific needs of participants engaged within the study, the researcher actively encouraged participants to move around and to take care of their physical needs as necessary throughout the interview.

4.9 Data Analysis

Analysis of the transcripts followed the IPA procedure outlined by Smith et al. (2009). The first step in this process involved a verbatim transcription of the recorded interview. This transcript then underwent a detailed reading and re-reading. The transcript was then split into three columns. The first stage was intended as a free flowing capturing of thoughts, ideas, images and feelings as they emerged in the reading of the transcript and these initial thoughts were captured in the right hand column. When this was completed a move towards a higher order conceptualisation of themes began. These higher order themes were captured in the left hand column. It is appropriate to provide an example of

how this process evolved and included below is a sample section from *Julie's* transcript, in which she reflects on her experience of achieving a diagnosis for her condition and the resulting struggle with acceptance:

Emergent themes	Transcript lines 138-158	Initial notes
Defiance of others prognosis of her condition Desire to prove others wrong, harbouring non acceptance Fear of disability Problems with acceptance Wheelchair and identity Psychological impact of pain diagnosis Anger victim/victimisation Feelings of guilt Conflicting aspects of the self, good vs. bad	*Going back to the diagnosis, they told me what my condition was and that I would end up in a wheelchair, have problems breathing and that would probably be my demise, if you like, and I thought, 'no, I'm not going to be stuck in a wheelchair', I'm going to do everything I can to prove them wrong, I don't know, its defiance, I'm not going to accept that, some people would accept I'm going to be in a wheelchair and sit down in the house all day, I did go through that, it's taken me 11 years to get where I am now, I went through a terrible terrible depression, very moody, anger at your family as well, I mean they've done nothing wrong, they've been really marvelous, but I think it's like like those two parts of me, a good part and a bad parts and they're just trying to fight each other; the good part is who I was before all this diagnosis and the bad one is the one that says you've*	Diagnosis as death sentence Defiance emerging, fear of disability Difficulties in accepting the fate expected of her Emphasis of terrible, suggests severity of depression Anger with family Describing self as two parts, good vs. evil, is this old vs. new, internal conflict Seeing all the good as existing before diagnosis, power of diagnose causing

	got to sit down, you can't do that, you've got to accept what's going to happen.	internal split Acceptance as 'bad part of self'

(Figure 3. Sample transcript taken from participant 6 Julie: Transcript lines 138-158.)

After completing the first interview a validation of emergent themes was undertaken. This process of validation involved the researcher's supervisor auditing the findings. Subsequent to this validation the first transcripts returned 144 separate emergent themes, from which subsequently a movement of these into 'higher order categories' or super-ordinate themes was then completed Again in an attempt to demonstrate this process and in the case of *Julie,* this activity ultimately produced a table of five super-ordinate themes with 15 clustered themes:

Super-ordinate Themes	Themes
Pain; perception and *fantasy*	Illustrating the landscape of pain Pain as resident Perception and fantasy
Me vs. pain; living in conflict with the self	Split aspects of the self Me vs. pain: internal conflicts
Psychological impact of pain;	Depression and pain Anger and frustration Loss of autonomy
Belonging and being separate from others	'Becoming' and 'being' different Contaminating others; the systemic impact of pain Being understood and misunderstood Empathy and belonging
Constructing a new self 'with' pain	Acceptance and pain Reclaiming independence Working with pain

(Figure 4 super-ordinate themes and the constituent clustered themes)

This same process of evaluation, validation and audit was then applied to all subsequent interviews. Upon completion and validation of the final interview the next stage involved a cross case analysis. As with all other stages of the analysis this stage is an iterative process, in which a continuous process of crosschecking was maintained in order to remain true to the principals of IPA.

4.10 Cross Case Analysis

The cross case analysis involved a comparison and consolidation of themes identified across transcripts which helped in the construction of a number of over-arching themes, under which already identified sub- themes across transcripts coalesce and are contained.

Master Themes	**Themes**
Representing Pain	**Representing torture violence and persecution (Zoe, Gill, Fran)** **Representing heat and destruction (Zoë, Gill, Fran, Claire, Rebecca)** **Representing the oppressive malignancy of chronic pain (Zoe, Gill, Rebecca, Sarah, Claire)** **Representing relief (Zoe, Fran, Rebecca, Claire)** **Representing aspiration, hope and change (Zoe, Fran, Gill)**

	Representing self and others (Fran, Claire)
<u>Pain and the self</u>	**The identity of pain (Rebecca, Sarah, Fran, Gill)** **Past, present and future selves (Zoe, Gill, Fran, Rebecca, Sarah, Claire)**
<u>Pain and relationships</u>	**Erosion of the social self (Zoe, Gill, Fran, Rebecca)** **The systemic impact of pain - becoming a burden (Julie, Rebecca Sarah, Gill, Claire.)** **Invisibility of pain -a barrier to compassion. (Claire, Sarah, Julie, Gill)**
<u>Coming to terms with pain</u>	**Acceptance. (Claire, Julie, Zoe, Gill, Fran)** **Living *with* pain. (Julie, Rebecca, Fran, Gill)** **Pain: a vehicle for growth -. (Zoe, Fran, Sarah, Rebecca)**

Figure 5: Table of Master Themes and the constituent sub-themes

These themes represented the study's main findings and will be reported in the results chapter below.

Chapter 5: Results

5.1 Overview

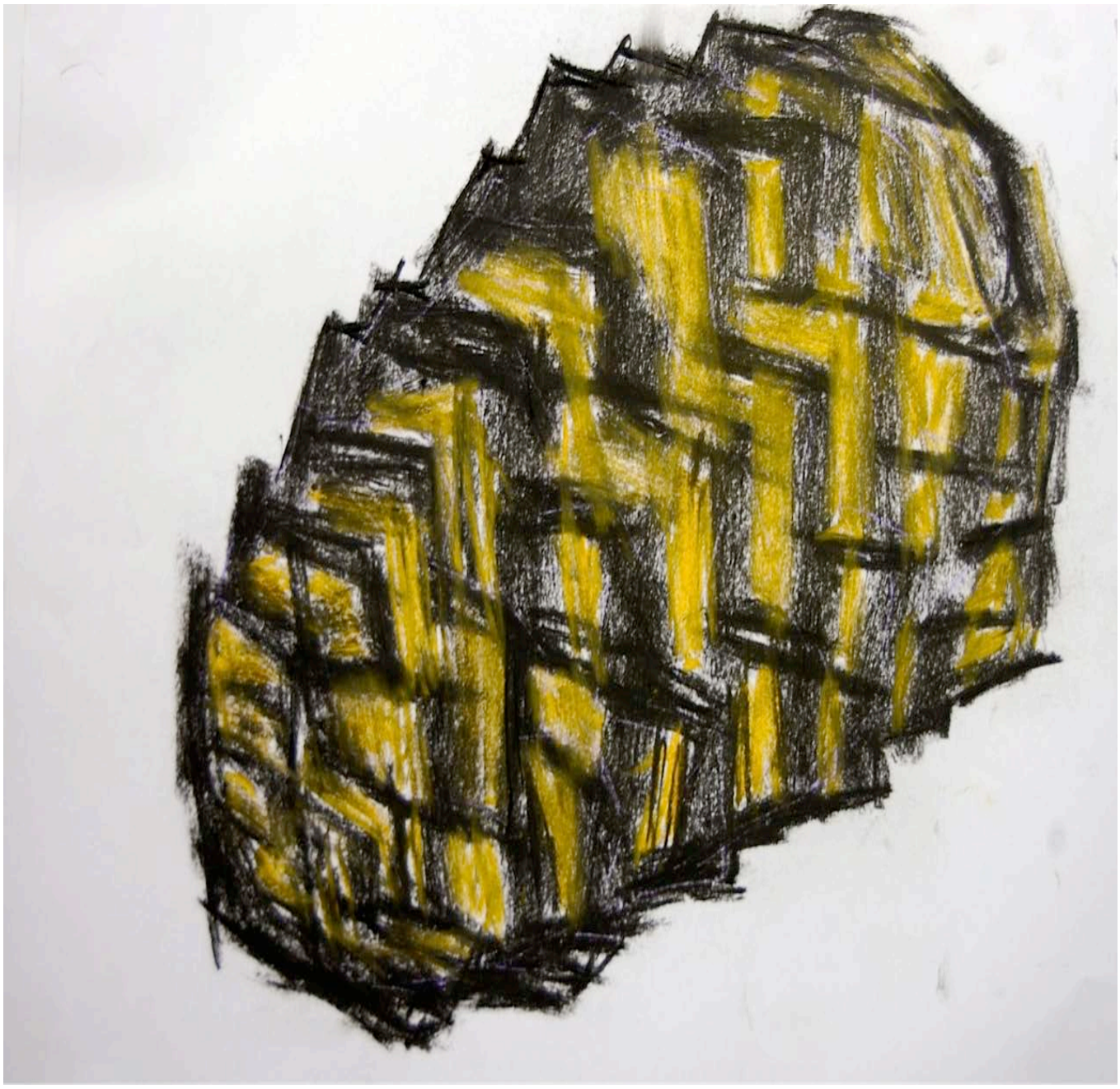
In this chapter the results from the current study will be presented. The analytical process resulted in establishing four Master Themes, comprising 14 sub-themes. These themes illustrate participants' experiences of living with chronic pain. Each Master Theme will be briefly described followed by its constituent sub-themes. These sub-themes will in turn be supported throughout by the corresponding quotes of participants. The format that participant quotes will take will be uniform, with quotes being indented into the page, placed in italics and with participant name and the line number in which the quote originates following. Due to economy of space the quotes selected are presented as strong but not untypical quotes relating to the theme being discussed. A full disclosure of supporting quotes, which comprise each sub-theme, can be found in the appendices.

5.2 How the participants represented their pain

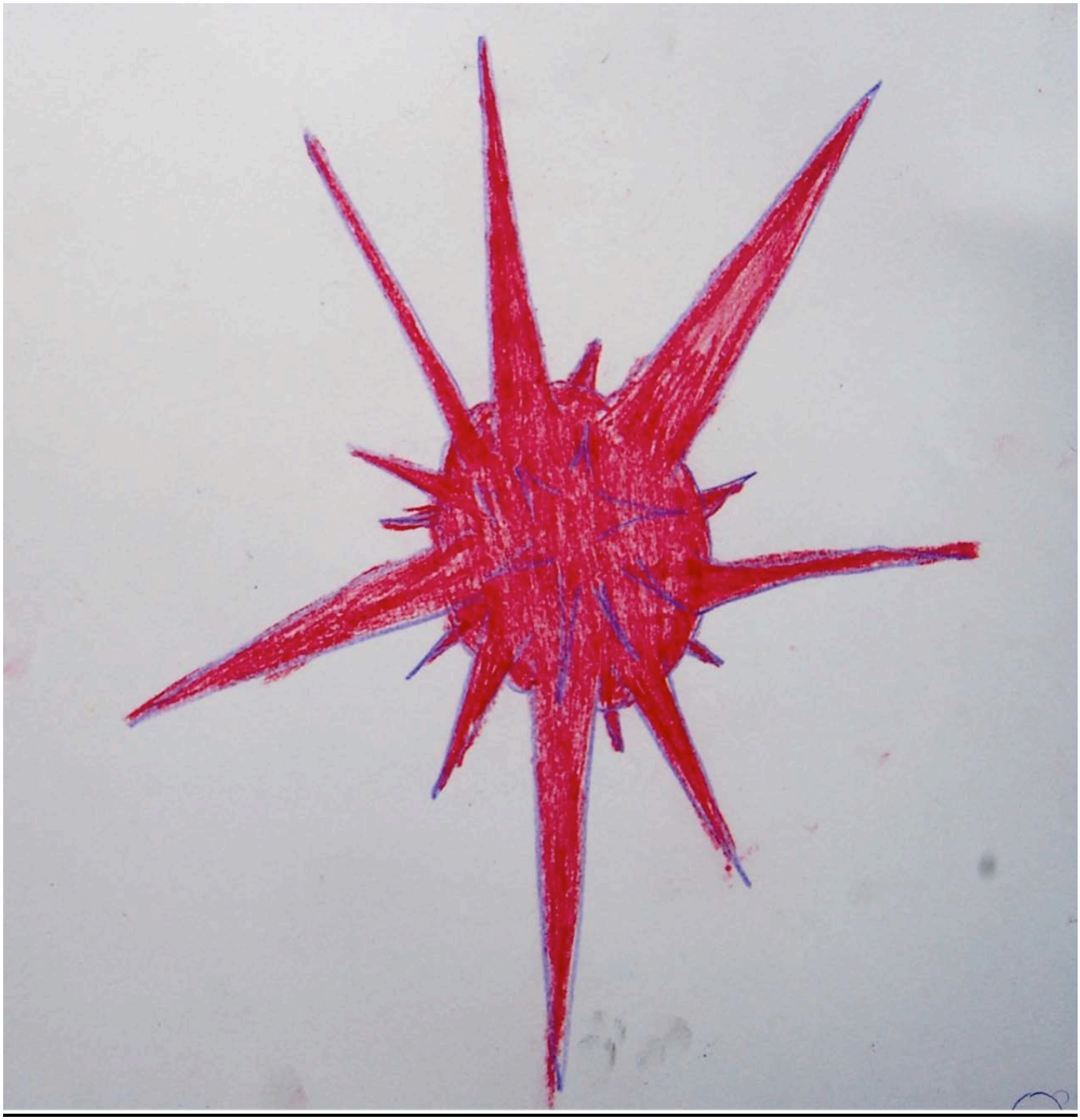
The experience of pain is idiosyncratic and private. Certainly, one thing that was shared by all participants in the study was the frustration of their external appearance not matching their internal state, thus making it impossible for others to comprehend what difficulties they were experiencing. It was perhaps for these same reasons that in the current study, participants responded so well to this opportunity of representing their pain in visual form. Indeed by engaging with and creating artistic impressions of their

experiences of pain, all the participants were able to demonstrate powerfully and with immediacy their internal perceptual worlds, indicative of how they themselves visualised and perceived their experience of living with pain.

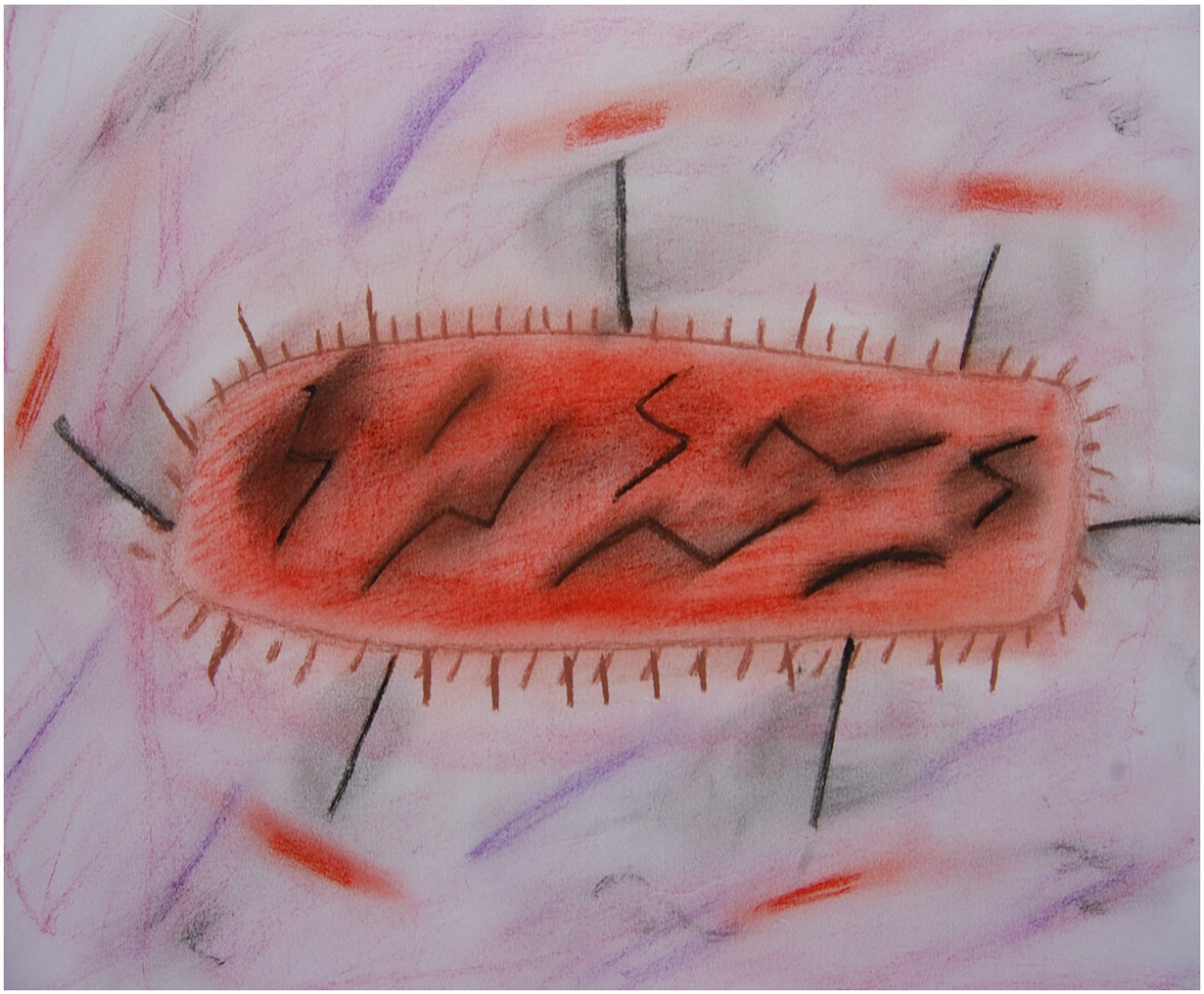
Below, all eight images will be presented (one participant drew two images). This will be followed by an analysis of the similarities identified across participant images. These images were also instrumental in the development of, and support given to a number of subsequent themes that are explored further in this chapter.



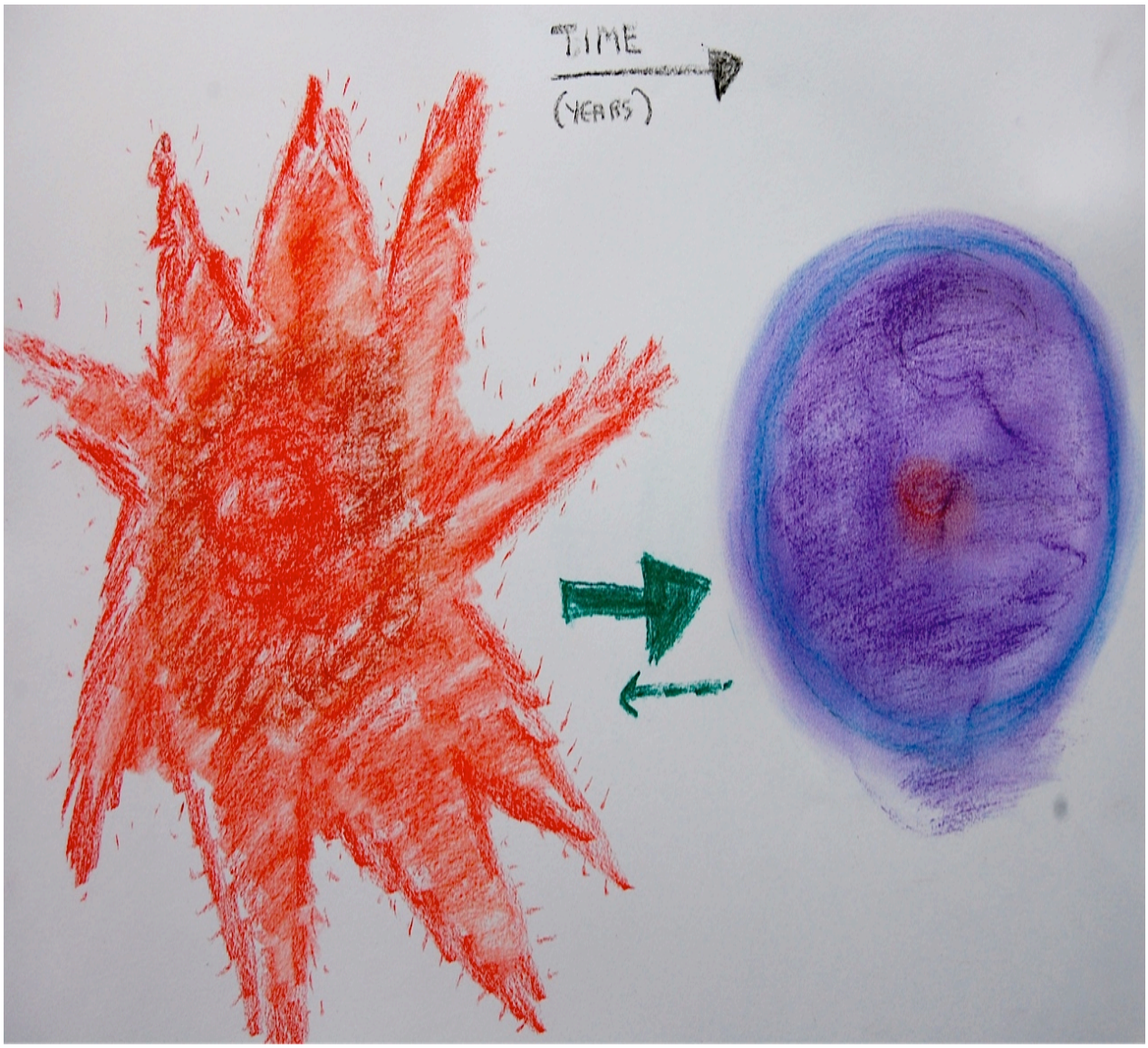
Zoe’s image 1



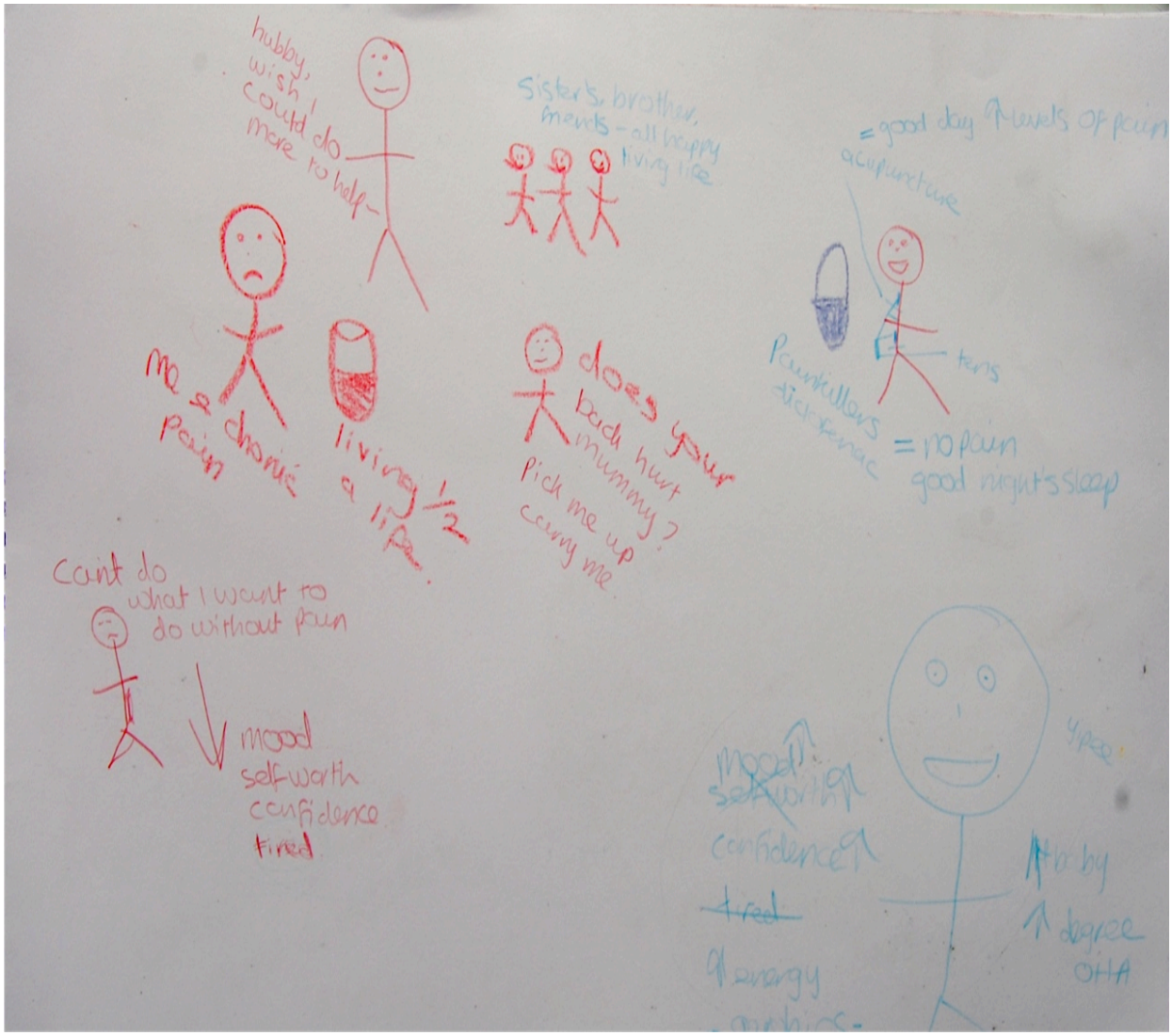
Zoe's image 2



Gill’s image

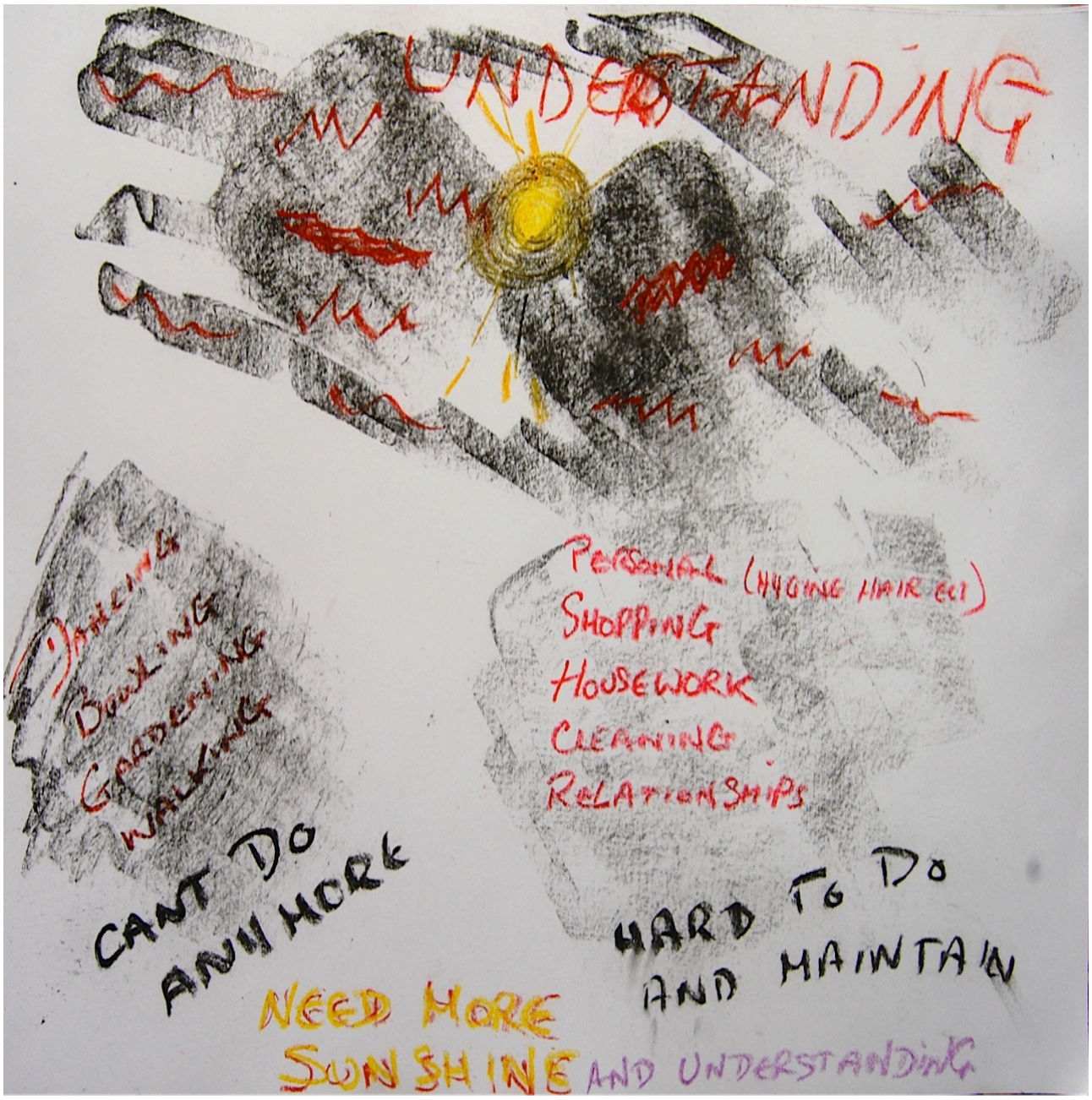


Fran’s image

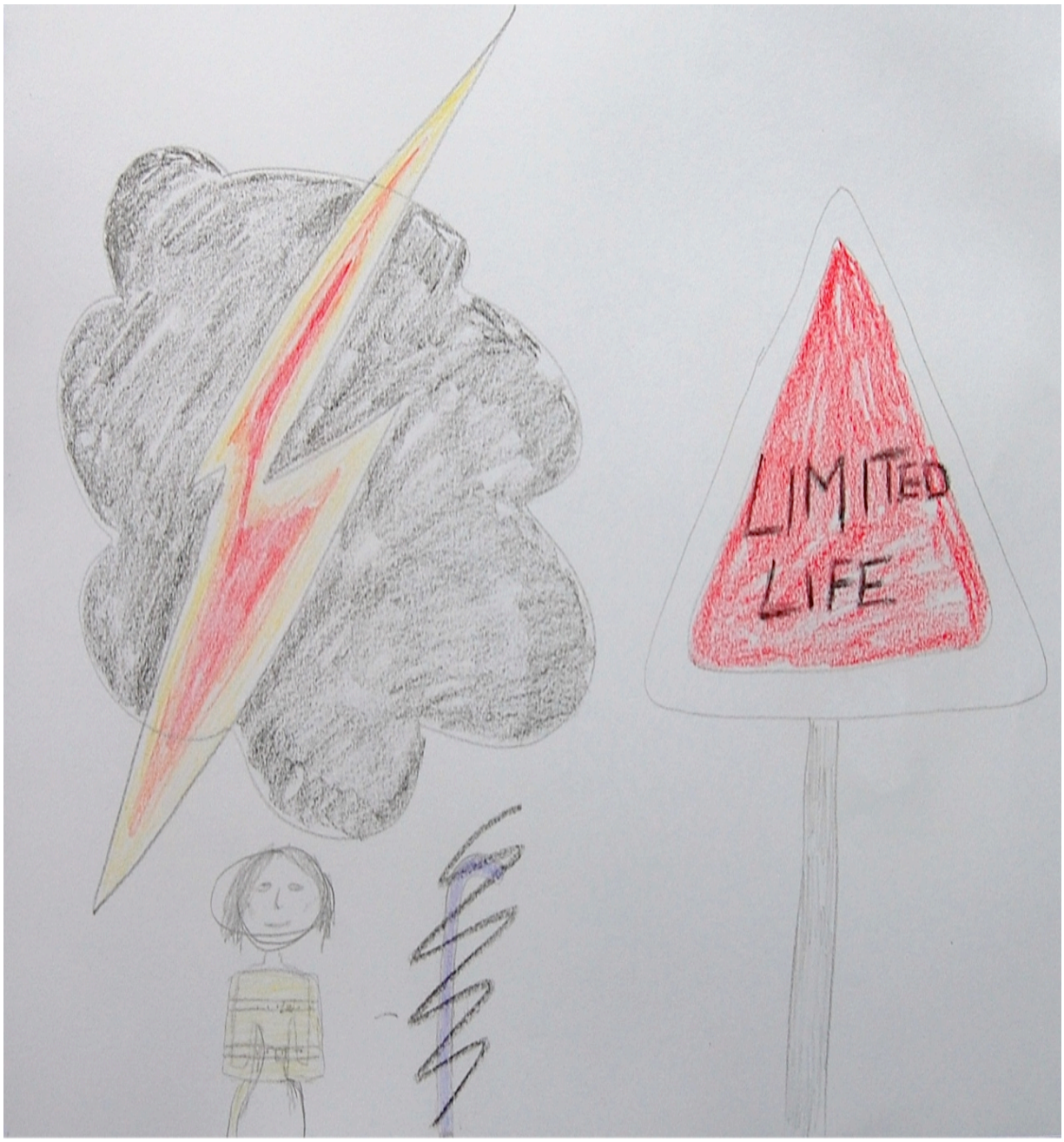


Claire's Image

Rebecca’s Image



Sarah's Image



Julie's image

5.3 Representing pain

Viewed in isolation the images that participants created provoke a powerful emotional, if not visceral reaction. They convey with immediacy a sense of disturbance, oppression and discomfort. What makes these images all the more persuasive is the almost morphic resonance they share. Despite the fact that they were all drawn independently of each other, with no participant seeing any other participant's image, several of these images emerged with some rather compelling similarities.

In order to examine the textural symmetry in these images, an analysis will take place that will look specifically at these shared properties in an attempt to identify themes that reveal particular aspects of living with the phenomena of pain. A powerful symmetry was identified in a number of participants' images, with the recurrence of a series of specific structures and features, as well as the repeated illustration of climatic conditions to reflect internal states. The purposeful selection of a very particular set or palette of colours which participants used further illustrates different aspects of both the sensory quality of their pain, and the affective and psychosocial consequences of living with these types of conditions. The validity and value of these recurring themes and the symbolic utility of colour was also supported by the dynamic use of metaphor across a number of the participants' transcripts. Metaphor provided a powerful utility to participants by helping them to further expound on the dimensions of their images, as well as helping to create a bridge across the obscure intersection that exists between what is seen and what is felt.

5.31 Representing torture, violence and persecution

The tone of the images as well as the metaphors used depicts the degrees and dimension of suffering. Participants described the ongoing assault of pain and its violent, persecutory intent. This theme was represented most clearly in Fran's, Gill's and Zoe's pictures, which all depicted an odd, recurring, irregular shaped form, penetrating and mutating. All three refer to the textural quality of this structure in their images and refer to its felt malignancy as possessing threatening, violent and tortuous implications. Gill's image almost consumes the page and her use of metaphor describes how she perceives her gut pain:

> *I used to say to people, 'if you can imagine swallowing a rugby ball covered in spikes and that's gone through and that's how it feels.* (Gill, 19-36)

Gill's metaphor conveys a very clear sense of how she both perceives what she 'sees' in her body and what she tells others in order to help them see it too. The language used tracks the path of swallowing, and going through, referencing her pain as being something which she has been forced to ingest, rather than it coming from within. The unpalatable reference to the swallowing of a rugby ball provides a sense of scale and adds to the degree of discomfort, as does the reference to it being 'covered in spikes.' The spikes add a sharp contrast to the smooth exterior of a rugby ball and imply the destructiveness and piercing malignancy of her pain. Zoe's own description of her head pain shares a curious resonance with this description as she too remarks upon the

association of rubber and spikes. Zoe's description however is even more direct in capturing the violence she associates to her pain:

> *You know it's like rubber, but with really sharp spikes on it and that's how I see it, it's like that, it feels like that, it's like my eyeballs exploding like you want to do that, (pulls at eye socket) (Zoe, 85-89).*

Zoe's image and description powerfully communicate the desperation of her situation. The image she drew and the contradictory qualities of her pain are made all the more distressing in the supporting quote of the perception of an exploding eyeball from which, in its harshness, fantasies of self-harm emerge. Perhaps what makes this threat all the more pronounced is that the accompanying image Zoe has drawn shares an uncanny likeness to a medieval mace - like weapon, known either as a Morningstar or a flail. Interestingly the brutality of this particular instrument of violence is achieved, to varying degrees, through a combination of blunt force trauma and puncture, both of which seem to resonate with the curious duality of the rubber covered in spikes as described by both Gill and Zoë. Fran's image also contains the flail-like image and once again themes of violence are used to reflect the sensory quality of her pain:

> *It's eating away at me, like fire, like destroying the very tissue and these bits are like sparks flying off, where it's all out of control and is raging, it's burning away (Fran, 654-658)*

Fran's image depicts her pain as a swirling, raging thing. Interestingly she refers to its destructive quality by referencing yet another form of punishment or torture, immolation. In this case her pain is described as eating away at her, burning and out of control.

The destructive and aggressive impact of pain is also reflected through participants' use of metaphor that, in the numerous references to torture and violence, appears to be employed to express both the hostile sensory quality of pain, as well as its perceived brutality:

> *I've got different pains, I've got the cycling shorts of pain and the guillotine, the guillotine is normally right across but from the back, through my chest, through the top of my lungs and it feels like a sharp blade right across me, I get that all the time with this, and I've got the same thing, the guillotine feeling in the neck and I've got the scaffolding pole. It feels just the size of the scaffolding pole, that thick, which goes through the top of my head, at an angle and it feels like it comes out here somewhere and what else is there, guillotine, and then there's the ball, it feels like I've got a big brass, like a massive chain around my neck, with one of those big balls like a big gold brass ball, where the chain goes round but the ball's so big it's right there, sat right on the back of my neck and I feel that all the time pretty much, it's smooth, but it is heavy and it hurts, like I've got a weight. (Zoe, 372-388)*

Here Zoe reflects on her legions of pain and her own distinct nomenclature for them. The implication throughout seems to be that her body is being violated by an array of different methods of torture, causing maximum distress. Her first metaphor, the 'cycling

shorts of pain' reflects the restrictive, pressurised nature of her pain, which curiously is restricted to a particular quadrant of her body, mimicking what might be experienced by the permanent wearing of cycling shorts. She adds texture elsewhere to this metaphor by adding that these shorts are perceived as internal, with the 'Lycra' experienced as 'fire in every sinew', again a phrase that is shared almost identically by Fran. Zoe's subsequent descriptions of her other pains seem to employ and conjure up even stronger references to both archaic and antediluvian methods of torture and penance. Perhaps the most obvious of these is her reference to her chest pain, which she describes as being 'like a guillotine', with the bisection being through her lungs. Another reference she makes is to one of impalement, in which she describes the shaft as thick as a scaffolding pole literally staking her through the top of her head, down and out through another part of her body. It seems clear that Zoe herself has considered the symbolic reference she is making to the nature of her pain:

> *It's ludicrous and torture, the word torture, that that's something to do with, it's dark, it's almost it's punishment, its torture, (Zoe, 195-197)*

This reference to pains' torment captures the malevolence of her pain. She goes on to describe one further pain, her neck pain, as being like bearing a brass ball with heavy chains, 'sat on the back of my neck'. She is once again able to offer both texture and substance to this burden, *"it's smooth, but it is heavy"*. Traditionally the burdening of a ball and chain was both a punishment but also a penance for a crime and yet again this

reference seems to have been considered by Zoe's as a possible explanation to her suffering:

> *Sometimes it feels that I must have done something wrong, not necessarily in this life. (Zoe, 141-142)*

The implication of this statement is that nothing she can think of in her own life could have provoked this degree of pain and therefore her suffering could only be explained as penance or karma from a previous incarnation, as this seems the only viable explanation for the degree of suffering with which she has to contend. The connotations of violence, hostility and assault were also identified in Julie's transcript, in which the metaphor she arrives at to best describe her pain is that of an assault:

> *The only way that I could describe it to someone is on a really bad day, it feels like somebody's got a hot knife and they're just sticking it in your back. (Julie, 709-712)*

This metaphor is particularly powerful, as it clearly demonstrates dissociation between herself and her pain, with the pain being represented as an external threat being inflicted by an unseen attacker, and therefore her pain is experienced as an assault. Interestingly, the reference to being stabbed in the back is usually a colloquial reference to betrayal and in this case the betrayal is not from within her body, but by somebody or something external, which is inflicting this punishment upon her. Julie's image and her metaphor actually seem to draw together a number of properties and themes present in a number of

participants' transcripts, i.e. the climatic/emotional conditions, the sharpness of pain and the punishment or persecution motif, as well as the sense of isolation and limitation and loss. This is perhaps depicted succinctly by the traffic sign which suggests what she believes the future has in store for her.

5.32 Representing heat and destruction

Participants also chose a specific set, or palette of colours to further represent different aspects of the sensory quality of their pain. Red was amongst the predominant colours used by participants and featured in no less than five images as a powerful means of illustrating the sensory alarm associated to participants' pain.

> *Well, I used red because it's quite a hot pain; I think you'll find that pain always seems to be hot for some reason. (Rebecca, 403-404)*

> *I've chosen red…pain ... inflammation burning (Claire, 43-47)*

> *The colour red signifies the anger and the heat from the pain, represented by the strong red colours flaring out. (Fran, 13- 16)*

Participants' choice of red appears to be an attempt to capture something of both the energy and activity of pain, but also and more specifically, its 'heat'. Rebecca refers to pain as always 'being hot for some reason' and in her image the figure on the right is

drawn encased in a red aura to reflect this. Claire also associates the inflammatory sensation of her pain as a burning, mirroring Rebecca's incarnation, and drawing herself in her image entirely as a red figure, or a series of red figures, emphasising this temperate aspect of her pain. Fran's arthritic pain is also described as a heat, but she also describes this heat as 'anger' with the sparks flying in her image representative of the sort of fiery discharge emitted in welding, or some other process in which intense heat is employed. The anger she describes fuses the heat of her pain with a particular affect, which best communicates the destructive quality of her pain and its being experienced as out of control. Zoe, in her second image also chose red. However the meaning of this colour has different connotations to her and is much more allied to the symbolic quality of this colour and its curious similarity to a textural representation of her pain:

> *It's symbolism maybe, I don't know, but that is when I get this pain right in there (points to eye socket) for no reason it will just happen, a lot and that, that is that is that and it's the right colour it's the right colour it's spot on, it's like whoopee cushion colour and that's as good as I can do it and it looks a bit messy because of pastel, but that's the right colour (Zoe, 75-85)*

Zoe describes the accuracy of the colour she has selected to depict her head pain. However her association to this colour is itself a reference to the colour of a child's toy which carries a texture she closely associates to a property of her pain. Although Zoe's reference is much more diffuse than the other three, colour still affords her a powerful

means of accurately illustrating how she perceives her pain not just as a visual reference, but a textural representation of her pain.

5.33 Representing the oppressive malignancy of chronic pain

In a further attempt to define the textural, sensory and affective dimensions associated with their pain, it was considered particularly relevant that in no less than five participants' images, black was used extensively to convey something of the oppressiveness and malignancy of pain, as well as an expression of the negative affect participants associated with these conditions:

> *I've got a confession to make, I broke your black! ….. black, because it's bad. (Gill, 19-32)*

Both Gill's image and the apology for pressing so firmly that she broke the researcher's pastel, stress the emphasis she was placing on the impression of her pain. Gill stresses that black emphasises the 'badness' with which she associates her pain. Gill's reference is supported by her image in which an almost viral like shape appears. She then goes on to describe its penetrative presence, in which the black spurs emanating from the shape seem to be spreading and infecting the surrounding tissue. Here she describes the implications of pain's felt malignancy:

Sometimes when it's at its worst it is horrible, probably all of this (points to picture) would just be black, just black. (Gil, 79-81.)

Her description of how the image would change if she were not trying to present a 'balance' implies further allusion to a contaminator in which the carbuncle she carries has the potential to get much worse. Zoe similarly has considered that her own pain has a malevolent quality, and this is defined more clearly in relation to its proximity to the 'light' in her picture and again its contaminating, obfuscating reach:

I don't quite know how to say it, but that it is, it's like a crunchy black horrible shell on it, like it is covering up all the light and that's how I see it, it's like that's the pain kind of, it's that feeling, crunchy feeling, that's the best I can articulate it. (Zoe, 48-66)

Zoe's attempt to describe the image of her pain evokes something rather macabre**.** The light, which is something she refers to elsewhere as her 'hope', is being covered over by the 'crunchy black horrible shell' of her pain. She includes a further textural reference in her description, with the word 'crunchy' portraying brittleness, and her reference to 'black shell' further evokes an insect-like quality. Indeed the two colours that Zoe has primarily chosen, black and yellow, reflect a primitive scheme that nature itself selects to declare a threat and her image itself also appears to carry a remarkable likeness to a wasp's body. The use of black to illustrate pain's threatening or obfuscating quality is also represented by Julie, who describes her pain as being likened to storm clouds.

To me it's just like a big thundercloud, black thundercloud, it's there all the time, but sometimes you don't notice it, until it actually starts to rain, that's how I feel about it. (Julie, 24-28)

The use of the thunderclouds and rain conjure up the archetypal image of the 'personal rain cloud' that gathers above the head to symbolise either a character having a bad day or being particularly depressed. Julie's image is perhaps the clearest reference to this, with her personal dark cloud singling her out and a bolt of lightning charging through these dark clouds. Interestingly, the dark cloud trope and its symbolic utility were identified in half of the participants' images, suggesting that participants' attempt to illustrate the meaning of living with chronic pain to them was inseparable from the emotional impact of these conditions, as Sarah seems to imply in the following quote:

Black, it's like blackness. It's like darkness. I love the light ,and bright things, my home is light and bright, everything is, I don't like dark things, I don't like dark rooms, I like things that have got colour, but the pain is like having this dark cloud come over and it can make you feel miserable, dark clouds are miserable and it makes you feel….. Absolutely and completely useless. (Sarah, 418-424)

Sarah's description of her pain as a blackness coming over her conveys a sense of oppressiveness. This also has similarities with the 'covering up' that Zoe described, as does the reference to obscured light. Sarah goes further to liken this experience to the

gathering of dark clouds and describes an emotional state with which she associates this image. Although not directly referred to as ‘depression’, a sense is achieved that the feelings associated with the statement ‘absolutely and completely useless’ does imply a hopeless affect. The association of depression being a feature of chronic pain is also referred to by Zoe, whose depression is likened to a further state of environmental and climatic inclemency:

> *Depression to me is like being, you know, one of those grey days and you just walk outside and it's still, it's warm so it's like there's no temperature, it’s not cold and it's not hot and you can be walking through a grassy field on a hill and there wouldn't be a rustle and there's a coat of cloud, all the same colour and it's like, there's a lid on the world, it’s that feeling, something like that, it's that feeling nothing is moving. (Zoe, 224-230)*

The symbolic utility of red and black to convey both sensation and affect conferred a powerful means for participants to illustrate a range of imperceptible experiences in a highly visual and stylised way. Red was used to express pain’s fiery and destructive connotations, whereas the association of black was referenced to either the malevolent or obscuring quality of living with a chronic condition. However these were not the only colours that participants employed to represent different aspects of living with pain.

5.34 Representing relief

As a counter to these virulent and repressive colours, blues and purples were used by a number of the participants to reflect the tensile quality of their pain. Specifically, this was employed by Claire and Fran in their images, with the use of these colours offering a contrast to the fiery destructiveness of pain and malevolent oppressiveness represented by the use of reds and blacks prevailed elsewhere. Here blues and purple stood out as an attempt to depict either the relief from their pain, or an indicator of change.

Claire reflects on the tensile quality of her pain and how she has chosen to depict this in her image:

> *That's quite weird actually to associate, pick those colours (Claire, 48-52)*

Where she had chosen red to depict the inflammation and burning she associates with her pain, she states that she has chosen blue for the opposite connotations that the property of this colour holds for her:

> *Blue, because it's soothing (Claire, 48)*

Blue in Claire's image is employed to depict certain adjuncts which bring about this change in the sensation of pain. A TENS machine can be identified as do the words 'pain killers' and 'acupuncture', both of which are written in blue and therefore are

representative of the relief from her symptoms. This image has parallels with Fran's, in which again a palette of blues and purples was used to demark and define a further tensile dimension of her pain. A clear distinction is made in how her perception of it appears to have become subsumed by the relieving hues of blue and purple, which she describes as a smoother calmer feeling:

> *With the passage of time and I'm talking about it's taking me about 15 years to get where I am now, living with this chronic pain, this ultimately is where I like to be, there is still this core of pain in the middle, which is still quite sore and I have to live with, but the colours of purple and blue is like everything has calmed down from the red and blue and purple and I'm not angry anymore, so these spiky feelings have gone and it's a much smoother calmer picture here, (Fran, 16-26)*

Fran describes a qualitative change in the perception of her pain. She reflects that this shift has come about over the passage of a decade and a half and is represented here by the depiction of two shapes set to represent this tensile change of her pain. Her reference to blue and purple further reflect a tensile quality of her pain and indicates a shift in the perception of her pain brought about as a result of its longitudinal attendance. This shift or recalibration was something that a number of the participants were able to demonstrate and once again it was through the application of quite a different and distinct palette of colours and symbolic structures that this shift was most clearly defined.

5.35 Representing aspiration, hope and change

Participants' use of yellow suggested an attempt to depict and offer an alternative angle on an aspect of living with their pain. This colour was adopted by a number of participants and appeared to be fused with their predilection for maintaining some semblance of optimism and hope in an otherwise bleak climate. In both Sarah's and Rebecca's images this colour was employed symbolically and represented as sunshine. This offers something of a counterweight to the oppressing dark clouds and perhaps represents participants' attempts to convey something of their aspiration of change and hope amongst the more disturbing and bleak landscapes:

> *Yes because you know everybody needs sunshine in their life (Sarah, 44)*

> *Well light at the end of the tunnel, it's a, I think just showing that things change things are changing, so I suppose you could call that change, (Rebecca, 391-393)*

> *I think the gold is that it's trying, I think its saying, this is going to sound so weird, that I think it's giving me hope (Zoe, 49-50)*

The optimism communicated in these three short passages conveys an important aspect of living with chronic pain. Both Sarah and Rebecca are referring to the presence of sunshine in their images. Although quite small and remote in Rebecca's and obscured in Sarah's, they are both representative of participants' ambitions to keep a beacon of hope

glowing as a resource to cope with the consequences of living with persistent pain, and a further reference to their aspirations or belief that their outlook might change. Rebecca points to her sunshine and makes the comment that it represents 'light at the end of the tunnel', and as such represents her hope that the future will be more optimistic than her past. Zoe's reference to hope also perhaps offers a counterpoint to the web of black lines in which she finds herself enmeshed. Indeed her reference to the light being gold seems to imply a wealth attached to her experience, which introduces another theme which will be explored further on in this chapter.

5.36 Representing self and others

Another key feature identified in both Rebecca's and Claire's images were their references to others. In Claire's image she includes her son and her husband and in Rebecca's image the two primary figures drawn are surrounded by others, family and friends. The inclusion of these other figures reflected participants' efforts to demonstrate the systemic impact of pain, and those in the participants' lives who also suffer as a consequence of pain's contaminating influence. The representation of these figures introduces an important theme which is expanded further in this chapter. However it is important also to highlight that in some of the images there is an attempt to illustrate not just others, but aspects of themselves. A number of participants, including Rebecca, Claire and Fran make explicit reference to temporal aspects of self and represent these in their images. These references are indicated by either a dual self, as appears in both Fran's and Rebecca's images, in which the past is separated from the present by the

population or lack of it depicted around her, or indeed the use of colour to stylise the difference she feels existed in the character of the images. Equally Claire's image carries similar connotations using colour to emphasise difference. However the different shapes and colour in Fran's image perhaps best illustrate the noticeable difference she identifies between past and present and configurations of self.

5.4 Pain and the self

This title has been chosen for this theme in an effort to reflect changes to participants' personalities and identities, and their ideas about the self with pain. Participants described the process of living with pain as bringing about an internal conflict between mind and body, in which their efforts to maintain their past activities, interests and aptitudes became compromised by the interruptive influence of their pain. The participants also described that their pain brought about further division, in temporal terms in which their past and present selves were divided by their pain. This division and discord ultimately brought about how participants came to describe their relationship with pain and the type of character or persona pain itself inherited through participants' engagement with it. Significantly, it was found that the identity that pain came to assume had a bearing to how participants' responded to its permanence in their lives

5.41The Identity of Pain

Alongside the representation of pain that participants made using colour and form, a number of participants made references which implied a far more complex relationship with their pain. These references to relationships and the identity of pain were as dynamic as the images, with participants alternately objectifying their pain as an amorphous non - thinking entity, whilst at other points implying that their pain, through its permanent attendance, was a subsuming, consuming force, with which a daily war was waged. This war was fought along the psychological as well as the physical dimension. Participants associated this ongoing acrimony with the degree to which they suffered as a measure of the malignancy of their pain's intention to consume them. Curiously a number of the participants had considered these implications and in an attempt to reduce the degrees of suffering with which their pain was associated, sought to revise the meaning of their suffering and sought also to re-conceptualise the identity of their pain.

In introducing the theme, Rebecca described the permanence of her pain as having a claustrophobic quality:

> *But it doesn't ever go, some days you can push it a little further, some days it's quite claustrophobic and other days it's like walking round a huge bubble gum bubble, you can push it a little bit further away than you did yesterday, another day you can't push it any further than here (places hand in front of face) when*

you feel like that, it's almost an indicator, I can push it this far today, so I can do this and today I can't. (Rebecca, 226-232)

In this passage Rebecca describes the degree to which she is able to distinguish the influence of the ‘bubble’ of her pain, in which she is held captive. This expression shares a resonance with Zoe’s 'whoopee cushion' reference and the restrictiveness of the Lycra shorts. For Rebecca the restriction of her pain serves as a psychological guide, which she then translates into a physical manifest or an indicator of the potential she is afforded for a particular day. Rebecca develops the encapsulating influence of her pain further and it appears that her own identity is both implicated in, and divided across multiples levels on the outside, and foremost is her pain:

I suppose it might even be a bit more like Russian dolls, because this person inside this person, inside the pain, so it's a bit like Russian dolls and it would be really nice to get that glue from the outside of the pain one, and pull it apart. (Rebecca, 422-426.)

Rebecca’s analogy to Russian dolls is a powerful one. She describes how she has a sense of her constitutional self, tantalisingly close but ultimately unattainable and inaccessible. She describes her pain as occupying the outermost shell and her desire to pull this apart suggests her sense of entrapment. However the pain is ‘glued’ suggesting the degree to which her pain and these circumstances are undeviating. Rebecca likens this situation to that of being trapped in a body that doesn’t feel like it belongs to her:

It's a bit like that in every fat person is a skinny person trying to get out, and every person with pain as a person not in pain inside, it's still me in here, I think that's how it feels, it's still me; but I can't get out.(Rebecca, 431-434)

Her sense of entrapment is most palpable here. She describes her experience as being like a skinny person trapped in the body of a fat person. Not only does this describe the possession of her pain, but her plight. Her reference to 'it's still me in here, but I can't get out' seems a desperate, far off cry from a self which has been usurped by her pain. The ever-present proximity of her pain is psychologically suffocating and a sense is achieved that the link to her constitutional self is tenuous at best. Similarly this theme also seems to be present in Sarah's account of her pain, indicating once again the close and influencing proximity of her pain from which, in its unexpected withdrawal, she is afforded a degree of impermanent liberty:

Some days it will almost leave me alone and then and then I think, oh yeah right we'll go and do something, come on mum, we'll go shopping and it's almost like, this thing comes back and makes me pay for it, you know. (Sarah, 542-546)

This statement implies a predatory association with her pain as she describes her pain making her 'pay for it' if she is foolish enough to be lured into a false sense of security by its sudden departure. The consequence of this is felt when she's inspired by its absence to engage in normal activities, (socialising, shopping), only for her pain to return

and wreak its terrible revenge on her for living ignorantly of its dominion. A similar association is also commented upon by Fran whose image, as well as her explanatory comments, likens her pain to having predatory connotations which she associates with the activity of a dormant virus:

> *It's like a dormant virus in your body that will, you may have had an illness by it, the illness would have gone, but the virus will sit there waiting for an opportunity to arise when the body is weak. (Fran, 740-744*)

There is a resonance here between Fran's words and Gill's image in which both seem to illustrate a sense of threat, as well as contagion. Fran refers to her pain as being like an 'opportunist' waiting for the ripe moment to 'arise' and take over when her guard is down or when her body is weak, very much like a virus. This new viral identity and its proximity are also supported by Fran's image within which the 'core of pain,' as she describes it, is situated at the centre of her contemporary image, indicating both the proximity and the permanent threat that it affords. Gill's description of her pain also follows this internal 'dis-ease' and specifically her consciousness of her 'guts' within which her pain resides and of which she is especially made aware:

> *I don't think, oh what's my gut doing, you just wake up and you just know you've got intestines, which with other organs, obviously you've got them, but you don't, you're not aware of them. (Gill, 816-818)*

Gill's anatomical terms demonstrate an acute attention to the different parts of the body of which her pain has made her aware. This internal world is normally expressionless and silent. This appearance or 'dys-appearance'(Leder, 1990), in which the body only 'appears' when a problem becomes apparent, seems to be a permanent concern too her and this is something which Julie also considers, her own ever present awareness and how she has come to objectify her pain as a thing, or more accurately as 'it'.

> *'It' is always there, it never goes away, so I think that's probably why I labelled it 'it'. I never realised I labelled it until I was talking to you, but yeah it's always there, it doesn't go away It's just there, just lingering in the background. (Julie, 239-247)*

The ever present awareness of 'it' has parallels with Gill's awareness of her gut pain and Fran's dormant virus. For Julie her awareness of this permanent threat, lingering in the background, personifies the predatory nature of her pain and in response to its attendance she describes how she is drawn into a conflict with 'it':

> *I think there's a little bit of a fight going on in there as well. (Julie, 230- 231)*

Julie refers to her pain in adversarial terms and clearly this bleak co-existence is forged under formidable circumstances. Indeed this seems to be implicated not just by her, but by a number of participants who consider the inevitable and ongoing conflict of living with pain:

> *Every day it's a battle, because every day it hurts and every day you get up and you throw the pills down your throat and it's almost like every day you start from scratch. (Rebecca, 216-218)*

And:

> *A battle, oh yeah, always a battle, always a battle, don't you have battles with yourself, I have battles with myself all the time, I have battles with myself about what I should do and what I want to do, you know. (Julie, 599-602)*

Both Rebecca and Julie describe the continuing conflict between mind and body, in which Rebecca describes no progress being made and every day starting with the same routine and her preparing for yet another day of battle. This theme of permanent conflict is also articulated by Julie, who describes the protagonists as being represented by the parts of her which reflect 'what I should do' and 'what I want to do'. This split between mind and body seems to imply that she regards her pain as the enemy and her mind the resource. However the careful ordering of 'should' coming before 'want' does suggest a subtle transition, in which she may be acquiescing to the demands of her body (her pain) and that this consideration must come first, before her own wishes and desires. Fran adds texture to this passage by reflecting on this process and how she used to purposely push herself into her pain in a desperate attempt to maintain her integrity:

> *I suppose there was a lot of frustration, I was trying very hard to carry on, in the physical sense, that I always had, but then it felt there was a conflict, my body was saying no, but my mind was saying 'yes carry on'.* (Fran, 154-158)

Fran seems to refer to her body in this passage as representing the drain and her mind the resource. The resulting disparity and tensions that exist between these two dimensions causes a split. Zoe endorses this split in the following passage:

> *I need to lay down, even if I don't want to, my mind never wants to, to be honest, but the lower back does. (Zoe, 619-620)*

Zoe's keen and active mind is unable to be complemented by her body which cannot follow the same compulsion. This clear division between mind and body results in her ongoing frustration for these concessions which she appears to have had to make in order to cope. Fran, in this next passage, also reflected upon the conflict in which she found herself caught up:

> *It was like an inner conflict, I was fighting myself, because I wouldn't accept what had happened, so I continued to go to work, I would push myself beyond my limits, just to prove to myself and other people that I could still do it. (Fran,* 168-172)

Fran referred to an inner conflict in which she found herself at war with herself. She indicates this being as a result of her unwillingness to accept that her body was failing her. She also seems to infer that these efforts were an attempt to preserve her integrity as well as others' opinions of her. Sadly this motivation only resulted in an exacerbation of her symptoms:

> *So I struggled for quite a few years, of pushing myself and the condition got worse and worse and worse. (Fran, 176-178)*

Fran's 'worse and worse and worse' repetition seems to imply both the degree and the severity to which she was prepared to push things, and certainly the 'quite a few years' implies this too. Claire and Gill also described a similar process with their pain, in which the motivation to continue to push into their pain was a conscious decision, with the intention of maintaining a sense of 'normality':

> *Or you just keep pushing your limits, you think I will just do this, you know it can cause pain but you just do things anyway as you want to be normal. (Claire, 132-144)*

> *Everything was just about when the pain goes, I'll go back to normal* (*Gill 453-454)*

It appears that Fran, Gill and Claire all share similar motivations to try to carry on as 'normal', the implication being that their identity is under threat. However their efforts to maintain this sense of normality appear only to bring about more pain and suffering and perhaps, ironically, an even greater sense of being abnormal. This distinction was made even more apparent around participants' anxiety with any sort of walking aids or wheelchairs. Temperamentally they knew these aids could help them, but their connotations carried far too great a risk to their identity and it being replaced with disability:

> *I've got a wheelchair, and I hate and I refuse to use it, it does come on holiday with us and things, but it very rarely gets used because that's it taking over me, that's a bit of a battle between me and the wheelchair, it's probably a psychological one,(Rebecca,195-199)*

Rebecca's battle is indeed a psychological one. She describes a refusal to allow her pain (her body) to 'take her over'. One gets the sense that her wheelchair is a symbol of her pains' domain and although its use might enable her to do things that physically she is unable to do (go on holiday), its use comes at a significant psychological cost. Importantly this fear matches with the anxieties of both Fran and Gill, who equally reflected on their own conflicts with pain and how they ultimately provoked a greater degree of suffering than perhaps the original motivation to push on provided them with esteem.

Participants' fear of disability, being taken over and loss seem to promote the escalation of conflict, and further ossification as to the identity of their pain as the enemy. This seems to be implicated in Julie's own need to visualise a character of defence:

> *There is a, there is like a little soldier in there fighting this blackness, some days the blackness wins, some days the soldier wins. (Julie, 514-516)*

Julie's defending character, which she refers to later as *'my little knight in shining armour' (Julie, 873)* is a fantastical visualisation intending to portray her psychological resistance to the identity and malevolence of her pain. Again there might be parallels here with the imagery of torture expressed by Zoe and the heroic figure of salvation being contextually appropriate to these types of assault. The reference to battles, winning and losing all designate the ongoing war within her and the themes of assault and oppression describe an adversarial relationship with pain. However, not all participants described such enmity.

During their interviews, Rebecca and Zoe described their own evolving relationship with their pain, having arrived at a position in which it was able to be conceptualised in ways less like an adversary, more like a companion:

> *A companion because it's always there, but not that sort of companion you would want, that you choose to have as a companion. (Rebecca, 506-508)*

And:

I'm not saying we are friends me and pain, but we're definitely companions, I would say. (Zoe, 574-576)

Curiously, both Rebecca and Zoe use the exact same phrase to describe this unique bond, a companion. By itself this is a curious phrase, as a friend is usually a companion, but in this case a companion is not necessarily, as Zoe points out, a friend. However by describing pain as a companion it does imbue it with a human or relational quality. A companion is often referenced as a relationship in which two or more individuals have travelled together for a long time. This certainly seems to be the implication in Zoe's quote, which depicts that her pain and her self have become bound to each other and are now inseparable. Fran equally describes this companionship and this is indicated with the curious but seemingly necessary ritual she partakes in each morning:

Every morning I wake up, I can feel the pain and I sort of talk to it, as if it were…., and I say okay, I know its first thing in the morning and it's hurting sort of, thanks very much, I don't want you there, I've got things to do and I just carry on, and I don't try and focus on too much then, I've given it its lecture to go away, and I don't want to keep thinking about it being there.(Fran, 588-596)

Fran talks about a process in which she describes the importance of acknowledging her pain as if she were acknowledging a person. She emphasises that in making this acknowledgement to her pain she is more able to shift her focus away towards other concerns. She trails off before she settles on an identity for her pain ('as if it were…')

but later thanks her pain and describes herself as giving it a lecture. These activities describe an evolving relationship, one in which the nagging persistence of her pain cannot be ignored, and it appears that her response to it is how one might refer to an attention seeking, needy child, who must be placated or acknowledged lest they continue to repeat their demands. Zoe also described her relationship and the identity of her pain as having attained certain characteristics or traits. In her case however her pain does not carry the same adversarial or exasperating connotations and her arrival at a figure of an educator or a teacher, where she has assumed the role of pain's pupil, presents quite a contrasting identity for pain to have achieved:

> *It's definitely teaching me something, there's something and maybe can't quite put my finger on it, because I don't know yet, you know, maybe in another kind of few years, I would be able to give you more insight, but I'm still learning about this.(* Zoe, 594-597.)

Referring to her pain as a teacher demonstrates a reframing of the meaning and identity of her pain, not as cruel and meaningless, but as important and educative. This re-imagining seems significant in her ability to engage with her pain in a way which, if her pain was infused by wholly negative characteristics, she may not have been able to do. Pain as a companion or indeed a resource is a sentiment echoed in Rebecca's closing statement, where she suggested that its presence and permanence was now almost so entirely integrated into her own identity that it is persuading and reassuring of her continued existence:

I think it would feel really weird to wake up and not feel any pain, I think I would think I was dead. (Rebecca 508-509)

Pain's identity is of particular importance. The terms used appear to have an influence on how participants interact with their pain and respond to it being in their life. A number of participants described this identity as having only malevolent qualities and correspondingly their response to these encroaching characteristics is one of resistance and defence. However Zoe and Rebecca have described a maturing relationship with their pain. They were also able to describe a resource state in which an alternative meaning can be attributed to their ongoing pain, to which a completely different set of responses can develop.

5.42 Pain and Past, Present and Future Selves

A number of participants make explicit reference to temporal aspects of self and represent these in their images. These temporal aspects are referenced by participants as representations of their 'old selves' or their 'former lives or lifestyles'. Claire's, Fran's, and Rebecca's images were particularly clear in conveying the delineation between two quite 'separate selves,' one in which the past and present were side by side and the distinction in form, colour and population reflected aspects of the perceived differences. Interestingly many of the participants could identify a specific point in time in which their identities first began to undergo this split and transformation. Indeed this reference

is made explicit in Rebecca's image which depicts two separate characters, both of whom she reports as representing different parts of herself at two separate points in time:

> *Well it's probably a before and after, this is like 1990, this is now, so it's before and after I hurt myself, so my different lifestyles I suppose. (Rebecca, 4-6)*

It seems clear that Rebecca considers the division in her 'lifestyles' as having occurred in 1990, as a result of the 'hurt' she experienced. She describes the picture as a before and after snap shot, indicating and accounting for the change and difference she feels. Her image too is populated by very different characters, with the 'former self' being surrounded by people and activities and the person she is now being somewhat isolated, save for one individual and the outline of a car and house. Zoe too located and considered the dividing point in her life and how this division was represented as a single event, in this case at the point when she fell down the stairs, and how this event divided her life almost categorically into good and bad dimensions:

> *I led a totally pain-free, totally pain-free life and now... I was at the age of 25 when all that happened and I'm now 38 and you know, if I really sit and go 'oh the last 13 years of my life have been miserable and it's slowly taken away everything I had' really, in my eyes, to be honest, …not everything, because I've still got family and friends, but you know my relationship, my career. (Zoe, 169-173)*

Zoe begins by reflecting on her pain-free existence and then refers to the last 13 years of her life as being a miserable erosion of the important features of her former life. Interestingly, Zoe changes direction mid-sentence to acknowledge perhaps the permanent and consistent features in her life represented by 'family and friends'. However, the emphasis is placed on what 'belonged' to the person she was at 25, which now no longer exists. This point in time acts as a reference for her as the beginning of the end of a part of her life. Zoe gives a strong account of what it is she misses about her old life:

> *I feel like I haven't had a lay in in 13 years and that I used to love as a teenager, kind of Sunday; getting up dinnertime at one o'clock in the afternoon and I cry for that, I feel, my heart aches for what I used to be like, how before all that, you know, rolling over in bed, most people it's easy it's nice isn't it? I can't, every time; it's an event for me. (Zoe, 189-195)*

Zoe's loss is profound. This powerful account of the 'taken for granted' represents a way of life which is now closed to her and for which she holds a great deal of nostalgia and affection in its passing. The difference is made starker by the easy recognition of warmth, comfort and security one achieves from the image she describes, held against the stark reality of the effort required for her simply to roll over in bed. She uses the phrase 'most people' and seems to include the researcher in this with the question 'nice isn't it? These off the cuff remarks actually represent a further distinction she feels between her situation now and the pleasures of the past, which remain only as a memory. Claire is another participant who reflects on her former life and her desire for this to be achieved again:

This is who I was, perhaps before I reached 25 and this is what I want to be again (Claire, 505-506)

Claire's hope that she can again become who she once was suggests that the qualities she had belonged to a former self. Indeed this indication seems to be made clearer in a further statement she makes about her contemporary self:

I just, I don't feel like the person I was, I think I've always had quite a low self-confidence, but I just feel like half, now. (Claire, 334-336)

Describing herself as 'half' suggests that she no longer feels like a 'full person' and the use of the past tense again demarcates this person she 'was' as no longer existing. All that remains is the fading memory and the deficit serving to remind her of how she feels about herself now. Sarah too reflects on the losses from her former life and its implications:

You can't do the things that you want to do. I loved to dance, I've got a bowling ball and shoes that I've had made for me and I can't use them, because I can't bowl any more. I love my garden, I could go out and do a bit, but then I pay for it two days, because I'm in so much pain, so I have to have someone to come and do it for me, which takes half the pleasure away, I get the pleasure from seeing it, but I don't get the pleasure from doing it, you know, (Sarah, 116-124)

Sarah's comments are reminiscing on the life she used to have. It's clear that previously her wide and diverse interests reflected an individual who was very active and sporty and whose interests and social life were combined, and her life was directed to pursue these passions. The loss of pleasure she describes reflects the impact of these losses in her current circumstances as she now admits that:

> *Everything I do is based around my pain. (Sarah, 260-261)*

Sarah pauses to reflect on this reality, with an almost profound sense of surprise:

> *God that's awful isn't it, that's dreadful. To base your day on how much you hurt. (Sarah, 252-253)*

This reflection suggests the degree to which her old or former life is completely removed from her, and that accommodating her pain is now almost so familiar that she herself is surprised by how harsh these circumstances sound when spoken aloud. Gill also reflected on this discrepancy, and her having to accommodate her pain as having contributed to her losing not only certain pursuits and activities that interested her but a part of her own identity:

> *It's difficult to describe, it affects your confidence as well, I felt a little bit like I'd lost a bit of my identity (Gill, 450-451).*

Both Gill's 'little bit of my identity' and Claire's 'half now' reflect a discrepancy existing between the self now and the past. Both also cite confidence and self-confidence in the same sentence, suggesting that confidence was fused with their former identities and that neither has been able to feel the same degree of confidence about their contemporary selves. Identity and division is also very much a theme for Julie, who is able to reflect on what she sees as the two different parts of her self, co - existing but in conflict with each other:

> *I think it's like there's two parts of me, a good part and a bad part and they're just trying to fight each other; the good part is who I was before all this diagnosis and the bad one is the one that says you've got to sit down, you can't do that, you've got to accept what's going to happen. (Julie, 152-158)*

The theme of conflict and identity Julie describes reflects different aspects of the self co-existing, one good and one bad. Importantly, Julie denominates the word 'bad' to be representative of, and reflect the part of her which is urging caution and restraint. Conversely, the 'good' is defined by who she was before her pain and as such, represents parts of herself which claim providence and which seem to be being assaulted by the 'bad' foreign invader. Claire also employs a similar methodology to further delineate the 'separate selves' in her image. She indicates that the different palettes of colours, red and blue are an attempt to represent her present and future self:

I'm still this person here and I'm trying to get away from here and I want to be all blue and happy. (Claire, 445-447)

This 'person here' representing her contemporary self is presumably unhappy as she has depicted her using the red palette. Equally the sad face symbolically represents the emotional affect of her character. Her aspiration to be all blue and happy is fused with being pain free. Most tragically she demonstrates the improbability of her achieving this state by asking the primary researcher if it would be ok to draw it:

I want to be this happy person, I want to be pain-free, can I draw it? (Claire, 495-496)

Claire at this point proceeded to outline a figure in the bottom right hand corner of the picture, surrounded by the fantasy of how different this imagined future self's life might be. When asked about this 'pain-free self' she describes that just the process of imagining such a situation evokes an almost palpable sensation:

I feel liberated, (laughs) you can almost sort of imagine it happening, it just feels good it makes me feel happy (Claire, 520-522)

Defining oneself in these absolute categories polarises how participants' past, present and future identities appear to exist almost independent of each of other and have very different outlooks and affects. Pain's devastating ability to corrupt the

contemporaneous self and lance great swathes of the individual's identity reveals more fully its destructiveness. This theme will be developed in the next section, to include the surfeit erosion and contamination of the individual's social self, demonstrating the potential of pain to not only adversely affect the individual with it, but those around them.

5.5 Pain and relationships

Participants' conflicts and difficulties around themes of identity appear to be made even clearer in the context of their relationships with others. For many of the participants their social life, or lack of it, reflected yet another area of their lives in which the split between mind and body, past and present was made all the more palpable. Participants described these circumstances being evoked in situations where an awareness of others' expectations of them was identified. Their difficulties in living up to them, coupled with their own, often quite critical internal locus of evaluation, coalesced to further define aspects of an unwanted identity. Participants' consciousness of these themes provoked an incentive to maintain an appearance of normality, which was strongly predicated and articulated through participants' anxiety that they should not be treated any 'differently'. Participants' anxiety was perhaps most evident in their efforts to preserve their own integrity, whilst being vigilant to their perhaps even greater fears of 'contaminating' others.

Becoming a burden represented a significant concern to all participants with some going to extraordinary lengths to avoid this. Sadly, these efforts often only resulted in further discomfort and suffering, and a magnification of the very things they were attempting to conceal. Conversely, participants also talked of their own frustrations with others who were often seen as having a lack of compassion, understanding and empathy with them. Participants reflected on these experiences as being influenced by the diaphanous nature of their condition, the barrier this represented to others' comprehension of it and the associated compassion that this might then offer. Consequently these obstacles led towards even further losses of legitimacy and even greater levels of misunderstanding and social ostracism.

5.51 Erosion of the social self

The consequences of pain's interruptive nature can be identified in the growing sense of abnormality and difference described by participants and their inability or difficulty in meeting them. As a consequence there is a growing sense of their 'opting out' of social engagements in order to avoid the psychological consequences, reflected through these numerous disappointments. Sadly, this cessation only contributes further to a growing sense of isolation and an increasing estrangement from others as participants' social selves slowly became eroded.

Gill introduced the theme of social loss as she reflected on and questioned the responsibility of her pain for her own social decline:

> *I don't really have any social interaction with anybody and I think, I mean, I don't know maybe if the pain hadn't have been there, I would have had the impetus to do things, to meet people, but having the pain, I have just never had the…I don't know. (Gill, 773-775)*

She seems to convey a sense of hopelessness in reflecting on the state of her social life, implying perhaps that pain may be responsible for this. She describes a loss of impetus to engage with others, which if 'it' (her pain) wasn't there she suspects she would be able to achieve. She seems to be searching for a word before she trails off and we can suspect it may be 'energy' or 'inclination'. However it is perhaps more telling that she trails off, as this seems to convey a disengagement and lack of dynamism when reflecting on this aspect of her life. She reflects on these circumstances further on and considers how the nature of her pain prevents her from pursuing social engagements, and she also considers her worthiness as a partner.

> *Being abdominal it has the fact that sometimes you're going to the toilet quite frequently and it is, I can't go out for meals so you think, 'who they heck is going to want to go out with me' (Gill, 696-698)*

The change in social outlook is something that Claire too had observed in herself as she considered the interruption caused by her pain and how this has made her very self-conscious:

> *You just you don't feel like you're talking to people properly, you can't relate to people properly, my brain just, you know, like at work and writing reports you just feel like my brain is always thinking or not thinking about the pain, just distracted and I can't think clearly about what I'm saying maybe. (Claire, 347-352)*

Claire supports the statement made by Gill by reflecting on the machinations involved in being 'present', something which clearly is no longer taken for granted or accomplished with ease, but is an effort in itself. She describes the sense of staccato when in a social situation, becoming a laboured effort in which she is pitted against the divergent distraction of her pain, which is permanently demanding of her and constantly drawing her attention inward. The statement that her 'brain is always thinking or not thinking about the pain' offers a curious tautology which implies a permanent receptiveness to the ubiquity of pain, which necessarily offers only a tenuous commitment to other matters, including the ability to communicate and be sociable. Perhaps Claire's concluding thoughts on this offer a powerful proclamation of this fact:

> *I've just lost that natural ability to talk. (Claire, 376)*

Claire's loss is profound and absolute. She has lost what was taken for granted, the free flowing of ideas and thoughts and the ability to effectively communicate them. With this goes a further loss of aptitude and potency, which becomes a further abnegation of her social self. Zoe too reflected on the predicament of managing her pain in social situations, as having resulted in her uniform disappointment, anxiety and embarrassment. This has become such a problem for Zoe that when an invitation was made she experienced a visceral reaction to it as a conditioned response:

> *I tend not to make a lot of social arrangements and every time someone says 'oh we've got a party coming up in six months, or six years' my stomach turns. I feel sick, nervous, just because, I know that I am going to feel too ill to go. (Zoe, 433-437.)*

What seems significant here is that talking from experience, she is utterly convinced that her pain will rout and ruin any chances of her being able to relax and enjoy herself, regardless of when, or how distant in the future it may be. Further, the impact of pain appears to be made more auspicious in a social context in which others are different to her and perceived as 'well'. Zoe is acutely aware of her 'difference' and feels nervous and embarrassed by it. It seems that exposure to these experiences has brought her to the position of concluding that in order to avoid the discomfort it is better to avoid social arrangements almost altogether. Interestingly, when she is with others the predominant emotion she

feels is embarrassment, whereas on other occasions she talks of a more hostile emotion. This was illustrated on a recent visit to the 'bookies', which has come to be one of the few social activities she pursues, but one too which her pain comes to dominate and impose a curfew upon:

> *That's what annoys me; I can't have half an hour's fun, standing around talking to some people, some real live people, 'oh my God', do you know what I mean, it does feel like that sometimes. (Zoe, 368-371)*

Zoe gives credence to the theme of annoyance as she appeals to God regarding the apparent unfairness of her situation. These experiences of embarrassment and annoyance coalesce to form a powerful reference from which to consider future engagement in social situations and from which Zoe seems to have made a commitment to withdraw and retreat. Rebecca further illustrated this theme with a failed attempt to go shopping. The embarrassment and frustration this event caused resulted in her self-imposed exclusion and offered a further dimension of erosion of her social life:

> *I had to ask people to take me places and because, I didn't want to have to keep asking people, I didn't, and then I didn't do it and then I didn't go out, one day I thought, I'm going to go out on my own and I found a taxi and I went downtown and I went to go in Marks & Spencer's and I couldn't push the door, but wouldn't ask somebody to open the door for me, because as far as I was*

concerned, I should be able to open a shop door, but they were so heavy that I couldn't, so I was so frustrated that I went round the corner back into a taxi went home and didn't go out again for another month. (Rebecca, 336-345)

Rebecca's story highlights a significant theme for the entire participant selection. In it she highlights a vicious circle, within which her social decline developed. Many participants had similar accounts to tell, in which their efforts to challenge the imposing legislation of exclusion orchestrated by their condition and take back control of their lives proved to be futile. Unfortunately, these noble efforts tended to result only in further confirmation of the anxiety that their bodies would deny them fulfillment of these wishes, and that these 'failings' had come to vouchsafe their vulnerability and add to the sense of alienation and 'difference'. The social decline experienced by participants is both broad and specific. Indeed, hearing from Rebecca again, she offered a challenging example of how the process of her social decline became paralleled on the home front, where for three years she was bed bound, upstairs, living on the fringes of her family life:

I could hear things and people would say do you need this, do you need that but it was if, not as if I wasn't there because I was there and, but almost like I'm sitting there and sometimes I'd shout out, and somebody would say do you want so and so, have you got whatever it is and carry on, so it would almost be as if

you were passing in the street it didn't, it sounds awful, it didn't feel like a family for a while. (Rebecca, 118-124)

This devastating passage illustrates the process of becoming estranged from her family. She describes her interaction with them almost as inconsequential, as if they were 'passing in the street', and her reflection that for a while it did not feel that she was a part of a family is equally as potent. A sort of banishment metaphor can be drawn from her existence upstairs, in one room of the house, both physically and metaphorically removed and out of the way. Rebecca went on to state that it was only through a change in her geography and the building of an annexe downstairs that finally brought her back into a more central position within her family:

I think that the building of the room downstairs was what brought me into, and then I was then able to, because everything was down on the floor I was able to start to do things again, because I didn't have to keep going up and down stairs, it took a while, but I slowly moved from the bedroom to the living room, and then from the living room I started going to the kitchen, do bits and pieces, so sort of took back control of my life. (Rebecca, 133-139)

A parallel can be drawn between this account and the earlier account of her shopping trip. However the narrative this time is about a sequence of virtuous changes that bring about her reintegration and with it a gradual return to activities and an identification of her enhanced self-efficacy.

The social self appears as fundamental to participants' experience as any another aspect of their identity, and with its erosion participants' difficulties became further compounded. Participants' social erosion was complicated further by the acknowledgment that the profound impact of pain was not just confined to them, but held the potential to impact on others too. This acute awareness introduces yet a further theme, within which participants' efforts to protect others brings about its own set of unique consequences for them.

5.52 The systemic impact of pain, becoming a burden

Participants overwhelmingly reported on the negative impact of their pain not just on themselves, but on those around them. In both Rebecca's and Claire's images there were references to others. In Claire's image she specifically includes her son and her husband and in Rebecca's image the two primary figures drawn are surrounded by others, family and friends. The inclusion of these other figures reflected participants' efforts to demonstrate the systemic impact of pain, and those in the participants' lives who also suffer as a consequence to pain's contaminating influence. Unease develops about the contaminating potential of their pain and the sense of responsibility they claimed for their provoking these circumstances. Many participants referred to themselves as a 'burden', and any reliance on others was felt to be synonymous with a further loss of independence and the proliferating of an undesirable self. These themes were often identified in the

‘fine line’ participants walked between their own attempts to limit the impact of their condition on others, and at the same time needing their support (see next sub-theme). Relationships with partners, parents and children had become a constant source of *dis*-ease, wherein participants identified the ‘radiating’ effect of their pain, as introduced by Julie in this opening passage:

> *I don't want to disturb him and when I get up he gets up, because I'm not there and my son gets up, because he hears the dogs downstairs, it starts with me, but then it radiates through everybody. It affects everybody. (Julie, 258-262)*

In this passage Julie illuminates the responsibility she feels for affecting others. The disturbance she recounts begins internally and appears to fan out concentrically and as it grows it touches those around her. One can imagine the tortured futility of this scenario being played out every single night, where she is caught between her own suffering and desperately trying not to disturb her husband who is sleeping peacefully next to her, whilst her own pain incrementally rises. Inevitably this scenario ends the same way every night. Her pain becomes so great that she is no longer able to exercise choice and she simply must get out of bed, setting off the series of events she described earlier and further confirming her accountability for its creation. She describes this sequence beginning with her, and then moving to her partner, her son, even the dog is disturbed. Rebecca too reflected on the systemic impact of her

condition on those closest to her and recalled her observations and perhaps her guilt for how her circumstances have affected others:

> *Then when I hurt my back, and, it was always me who took them, wherever they wanted to go, so they then started, I need a tissue, thinking for me, I had a discussion with my younger daughter the other day about this, they felt that dad was at work and as I was the person that used to take them everywhere, so they suddenly decided that they wouldn't start going to parties, because it meant that they had had to find somebody else to take my place, or it proved quite difficult transporting them here there and everywhere, so their lives changed as well, not just mine, everybody's lives changed. (Rebecca, 48-57).*

Rebecca's comments illustrate the changes that occurred throughout her family after hurting her back. She accounts for others' actions changing as a consequence of her own physical limitations. Clearly, in reflecting on this she becomes upset and one can imagine it remains a source of constant distress to her as she perhaps blames herself for interrupting her daughters' social lives and consequently her not being able to provide a 'normal' upbringing for them. However, what appears particularly significant in this passage is the lack of apparent transparency about how roles were defined in the first place and how they came to change under the inauspiciousness of pain. These circumstances reflect that the individual roles of the family were unspoken and came with inherent expectations. The changing circumstances of her pain prompted individual family members to make their own adaptations to these changes. Again it is

interesting to note that there appeared to be no apparent attrition, resentment or indeed resistance. Her family does not blame her or appear to demonstrate any hostility towards her for their own losses. Rather the suggestion is that their losses went unspoken, as her daughters themselves chose to stop going to parties as transportation proved difficult. This passage perhaps communicates the strength of the family's bond to withstand these dramatic changes, and perhaps a measure of their love, as in an unspoken and dignified way the family adapts to its changing dimensions and realities. Indeed this concept is given further credence by the illuminating comment that it was only 'the other day' that these changes were first really spoken about.

Rebecca, like all participants in the study, raised the centrality of dependency as an ongoing concern. However some participants voiced these concerns more vociferously than others:

> *Ohhh, dreadful, I hate asking anybody for anything. (Sarah, 511)*

Sarah elsewhere declared herself as being both a stubborn and proud person, perhaps helping us appreciate why dependency provokes such strong responses from her. However Sarah herself shed more light on why experiencing herself as a burden feels so destructive and therefore why asking for help remains a challenge:

> *Yes, it's like that failure I suppose, because you can't do it yourself, and to ask somebody to do something that you would have three years ago not even*

thought about and it is sort of yeah it makes you feel a bit useless. (Sarah, 520-523)

Sarah reflects on the threat to her independence and the fear that by asking others to help she will be asked to confront her own dependency. She is also aware of how she might perceive herself as coming across if she were to ask for help:

Yeah, it's a very fine line between telling someone how you feel and coming across as somebody who whinges. (Sarah, 334-335)

This 'fine line' captures succinctly the tightrope that Sarah walks in attempting to maintain her independence, whilst staving off the undesired mantle of appearing to others, as well as to herself, as needy or as she might phrase it, a whinger. However these efforts invariably fail and in her efforts not to impact on others or appear weak she invariably pushes into her pain, rather than asking for help. Ironically these noble intentions result in bringing about the very same circumstances she was hoping to avoid, as having pushed into her pain she finds herself increasingly disabled:

If you push yourself too hard one day, for two days afterwards you can't do anything (Sarah, 209-211)

This cyclical psychodynamic, whether it's fuelled by stubbornness, conscientiousness or indeed self-preservation, seems to draw the same consequences - increased suffering for

themselves and those around them. Although most participants showed an awareness of this, it seems that 'asking for help' represented the hardest obstacle to resolve. Gill's own anxieties about this are reflected by similar feelings of uselessness, failure and redundancy. In her efforts to avoid these she has effectively been brought back to where she started, having moved back in with her parents:

> *I've been back home for about five years now, so I'm 38 living with my mum and dad and obviously because I only work part-time, I don't have lots of money, so they really are supporting me financially, to a certain extent and you think they are in their 60s, my dad will be retiring in September and they shouldn't have to be supporting their child. (Gill, 326-333).*

Clearly Gill is not happy with the 'indignity' of relying on others, whom she sees as being vulnerable themselves. Her loss of autonomy is made starker in her identity of being '38 and living with mum and dad'. It seems clear that she may be a little ashamed of finding herself in this situation, but as she has indicated elsewhere, what choice does she have? Indeed the choice she has made is between her current situation and what she sees as the only other potential reality for her, represented as the benefits system, which she doesn't want to get *"sucked into" (Gill, 289).* Gill is attempting to manage her life, whilst trying to minimise the impact on anyone else. The illusion of choice perhaps highlights that in the two possible scenarios she imagines for herself, both have the potential to make her feel dependent. It is maybe only the degree to which she feels this burden, and to whom, which differs.

Participants' dependency seems clearly associated with a sense of failure or worthlessness, especially evoked when those with whom they associate appear to have their own vulnerabilities and needs. This seemed also to resonate with Claire who recognised that her own failure to respond to the inherited responsibilities perpetually drew her into an irresolvable paradox, in which she places unrealistic expectations on herself, and from which she feels unable to unhinge herself:

> *It feels like I should be doing that. I should be looking after them, because I'm the eldest, it's what I've always done, mum had always done, mum had always kept the family together and I just feel that now mum is not here, it's my job to do it, to keep them going. (Claire, 610-615).*

There are a number of difficulties here for Claire, not least of which is the perceived inherited responsibility of holding her family together, something which her late mother bequeathed to her when she passed away. Claire represented the figures of her husband and child in her image as well as providing her perception of their supporting narratives of helplessness and disappointment *'hubby: wish I could do more'* and *'child: pick me up carry me'***.** These images of others further convey the systemic impact of pain and to some degree the responsibility she feels for their disappointments. It also provides perhaps some of Claire's motivation for pretending to be normal, as her sense of worth seems to be hinged upon other people's expectations of her. However, her own struggle is fuelled by the guilt she

feels in not meeting these expectations and in fact proving to fall far short of them. The implication is that they (her family) are responsible for looking after her and that this invalidates her role as a mother, as she is the one who is dependent.

It appears that for some participants, relationships with others hold a mirror up to themselves and what is reflected is the experience of their own vulnerability. Indeed, Julie recounted how her son's consideration for her by opening the car door and assisting her only served to highlight this, something for which he was then subsequently attacked:

> *But then when my son done it 'c'mon mum get in' and I said 'I'm not an old woman I can do it myself' and he went 'oh sod you then, I'm only trying to help' and I bit my lip and I thought I shouldn't have said that, but it was different to what he would have normally have done and I don't want to be treated any differently.* (Julie, 669-677).

Julie describes here the difficulties with perceiving herself as a burden for others. However what this passage highlights is that this is felt to be most difficult when those closest to them behave differently towards them and this is reflected in their behaviours. The interpretation of Julie's neediness and vulnerability was hers and not her sons. Irrespective of this, his behaviour was 'different', which presented Julie with the opportunity to consider that in fact her needs were obvious and all her efforts and intentions to hide them had been futile.

5.53 Invisibility of pain - A barrier to compassion.

This sub-theme reflects the participants' frustration with the apparent invisibility of their condition and how one is judged upon appearance - an appearance which denies the internal constellations of pain. This dilemma, coupled with the inherent difficulties in effectively communicating their pain, represents an important factor in the sense of isolation as reflected elsewhere. It further ushers in a sense of dissillusion and frustration with others and often a growing sense of hostility towards them, particularly from those in positions of authority (the medical profession, the Department of Work and Pensions) who have come to represent, reflect and further define the margins of an indifferent world.

Claire introduced this theme by first sharing her experiences of others' misconceptions about her pain:

> *I think, people just think oh, it's just a bit of back pain, you'll be all right, or you're making it up, or it's all in your head, its mind over matter, definitely my family think like that. (Claire, 129-132)*

Claire's frustrations are clear in this statement. She reflects the doubts that others have about her own account of the dimensions and degree of her suffering. She suggests that even those closest to her, her own family, hold beliefs that her pain

is in fact imaginary and that she is therefore malingering. The unhelpful suggestion that it is ‘mind over matter’ is referred to in a derogatory way, perhaps suggesting the degree of other people’s misconceptions about pain and the belief that the mind can control it. Again Claire explains that her family hold these beliefs, which suggest that the limitations of people’s compassion are felt most profoundly when it is her own family that disbelieves her. The frustration of not being believed by others is a composite problem and something that Sarah too had encountered on many occasions:

> *But people don't understand that, they can't seem to get past… because you haven't got any sores on you, or you haven't got your arm in a sling, because there's nothing visual to see, then you're all right. (Sarah, 67-70)*

Sarah, like Claire, highlights the impossibility of being understood by others as there is nothing visual to justify participants’ complaints and therefore warranting a response of either understanding or sympathy. Claire indicates that, due to the apparent invisibility of her condition, and because she doesn’t come across as more physically disabled or diseased, others cannot ‘get past’ this absence and as a consequence they treat, or perhaps more appropriately, *mis*treat her accordingly. She has gone to lengths to consider that what non-sufferers are demanding of her is effectively beyond what is possible for her to reveal:

> *Yes, it's like saying there's magic in the world, show me. Prove it to me,*

do something to make me see. (Sarah, 81-82)

Likening her pain to magic is a powerful metaphor, as magic itself works along the principle of being fooled by the unapparent. In order for magic to work it relies on an investment on the part of the observer to be fooled, tricked or misdirected, whilst being delighted by the belief that they are witnessing something beyond their logical comprehension. As Sarah sees it, a demand is made for her to 'prove it' to them rather than for others to make the effort to divorce themselves from their preconceptions and expectations of what pain '*looks like'*. Sarah's position may, quite rightly, be one of 'Why should I, isn't it for you to believe me?'. In her frustration she may have come to live with managing judgments of others as a continued source of difficulty in managing her own condition. Interestingly, some of the participants did describe where and how non-sufferers had attempted to try and understand their situation. However, Julie was confident that no matter how quixotic these ambitions, their efforts are ultimately without comparison:

Unless you're talking to somebody else who's been through the same thing, I mean, all the goodwill in the world people go 'I know what you're going through', they don't. (Julie, 212-215).

Goodwill is apparently not enough in order to fully appreciate the reality of living with pain. Empathy's function seems to only extend to the emotional difficulties of the sufferer, but the physical domain inevitably remains outside the purview of

even the most earnest listener. Gill is another participant who remarked on the veracity of chronic pain as only meeting the deficit in others' comprehension. She recalled an incident with one of many GPs who, seemingly frustrated, imparts this advice:

> *One doctor just said 'look, you're just going to have to cope with things better aren't you', so then you feel like, you're doing this to yourself and you're thinking well why the heck would I do that and that sort of makes it worse and you just think 'am I a bit nuts that I would cause this pain'. (Gill, 530-536)*

The implication that she is not coping well or appropriately with her pain infuriates Gill. This encounter left her with the impression that she was perceived as exaggerating her condition, or perhaps more accurately underrating her capacity to cope with it. Either of these interpretations results in the same outcome, i.e. further mutability of her suffering and further alienation. The significance of this statement also demonstrates the symbolic power of the doctor and how the experience of being disbelieved by him served to provoke further division between her mind and body, with the implication that actually it was her mind (her self) rather than her body which was causing her pain. It seems that this encounter was a seminal one for Gill, through which the doctor's exasperation perhaps reflected that there was nothing more he could offer her. However Gill's own exasperation with her doctor may have mobilised her own defences from others' lack of compassion. Indeed this can be

identified with Gill's fantasy of how others might grasp what living with her pain is like for her:

> *In my sort of darker moments, where I suppose I don't think people are understanding, I think 'I'd like you to live my pain for a week and then see how you could cope with it'. (Gill, 900-904).*

Gill's 'darker moments' entertain the fantasy of her own suffering being inflicted on others. However, it would be entirely erroneous to suggest that this is only intended as a hateful punishment or as revenge. On the contrary it is perhaps much more intended as a means of communication, with the express intention to be better understood. Indeed looking more closely at this passage one can see that the onus is not on vengeful intentions but on 'coping'. This suggests it might itself offer a kind of approbation for Gill, as it might make others aware, not just of her pain, but what it takes or asks of her to survive it.

5.6 Coming to terms with pain

This last master theme offers a more hopeful insight into participants' efforts to come to terms with living with their pain. Participants talked about a slow return after years

spent in the wilderness of their pain, emerging into a landscape of acceptance. Acceptance appears to form the bedrock from which the construction of a 'new' self can be charted and old conflicts laid to rest. The language used by participants noticeably shifts away from the language of divergence, as found in previous themes, towards acquiescence and acceptance and beyond this, the seeds of growth appear to be sown. A noticeable shift is identified in participants' descriptions of how acceptance, whether desired or achieved, holds the prospect of a greater management of their pain, whilst also harvesting the potential for the next, hopefully more productive chapter in their lives. It would appear that through acceptance many of the participants found that their pain had come to achieve a different meaning in their lives. Its permanence had moved them toward a different path and trajectory which, whilst uncalled for and unexpected, was not entirely objectionable to some. Indeed, some participants saw their pain as becoming a positive force in their lives, assisting and promoting exploration of deeper personal parameters. Some saw it as being singularly responsible for obtaining a greater empathy with the universality of others' suffering and indeed encouraged a strong desire to help alleviate it. With this recalibration comes a sense of status, previously lost, which helps return a greater sense of esteem. Pain in this context has purpose and offers rapprochement for the sufferer, who no longer identifies themselves as a victim of their pain, but a survivor of it.

5.61 Acceptance

Participants' acceptance of pain was identified varyingly as a philosophical position from which to view their situation, a pragmatic shift in adjusting aspects of their life to accommodate pain, and as a developmental skill, within which pain management could be learned, considered and eventually practiced. It appears that for a number of the participants, acceptance had been achieved through either successive failure in portraying themselves as something which they patently could no longer be, or their desire to discontinue the charade. Acceptance also seemed to be achieved alongside the slow realisation that pain had become a permanent predictable presence in their lives and ultimately, in its familiarity, the fear it had provoked lessened over time. Equally participant's questioned the utility of anger and resentment, which many identified as part of their initial response to pain and the driver behind much of their own suffering. None of the participants however described acceptance as being easily achieved and all described it as having been a lengthy and in some cases ongoing process. Claire, who reflects on her own difficulties with acceptance, introduces this theme:

> *It's been a long slow process, especially because you don't want to accept that you got chronic back problems and of course you want it to get better, but then it's just year after year and it does kind of ebb and flow, but it's always there, it's never, it's never gone completely (Claire, 102-106)*

Claire's difficulties with acceptance are mobilised by the undesirability of having back pain and her desire to get better. However the permanence of her pain 'year after year' seems to erode this resistance. Indeed this seems to be indicated in her reflection later on:

> *I think I've kind of ruled out a cure, it would be lovely, but I don't think it's going to happen, (Claire, 423-424)*

Similarly Julie was able to reflect on her own 'slow process'. She further introduced the concept that there were perhaps distinct stages in the process of her own acceptance, which she could not circumnavigate but had to go through:

> *You have to go through these stages depending on who you are, how long it takes, I mean it's taken 11 years for me to get this far. (Julie, 184-190)*

In this passage Julie reflects on her pain journey and the 'stages' she has moved through in order to arrive at the position in which she finds herself today. In describing these stages she identified that initially her relationship with her pain was represented by anger, which ultimately presented a barrier that made it difficult to accept her condition. The theme of anger was not just directed towards her pain, but her family, who she saw as not looking out for her and consequently being partly responsible for the situation she found herself in:

I got angry, because if I had have had that diagnosed when I was younger, I wouldn't be where I am today, I blame my parents for that, because I thought they should have pushed my corner and they should have asked for a second opinion or something and I think that's where a lot of my anger comes from. (Julie, 124-130)

However Julie ultimately recognises that in maintaining her resentment the only person truly affected by this would be herself and that by letting it go she was able to accept her pain:

I think that anger is more an acceptance now, that you have to, you're angry because you are in this situation, angry because, I needn't be in this situation, if something was done further back down the line, I wouldn't be sitting here talking to you now, but 'If' is a massive word and it didn't work out that way and it's not going to go away, it is going to get worse, but I think it depends on you, you have to accept what you are, who you are, before you can move on and if you don't accept it, you've got this huge hurdle that you have to get over. If you don't get over that hurdle, no matter what you do, you're never going to go forward; you're just going to stay in this glitch all the time. (Julie, 751-765)

Julie acknowledges that maintaining an internal dialogue of anger and resentment had become a barrier to her managing her pain or indeed accepting herself.

Having assailed this enormous barrier it would appear that Julie has moved forward and resolved the perpetual ‘glitch’ in which she found herself.

Whereas Julie was able to identify anger as a barrier to acceptance, it would appear that for Zoe and Gill another strong emotion, in this case fear, may have been responsible for their own responses to pain, which again over the course of time has become modified. This theme is reflected in Zoe’s somewhat pragmatic, unconcerned response to her own pain:

> *Well it’s been there all the time, I'm not dead yet, so it can't be killing me, so just get on with it’ well not get on with it that ‘deal with it’. (Zoe, 482-484)*

Zoe reflects on the permanence of her pain and unlike Claire and Julie there appears to be an absence of affect and remorse in her own conclusions. Indeed the way in which Zoë refers to her pain is unapologetic. Whereas it seems clear she may have previously held strong feelings and fears towards it, it is clear that she no longer feels that way. Similarly an absence of affect was identified by Gill when she was asked to comment on what the interviewer found to be a terrifying image of her pain (the rugby ball covered in spikes), which clearly no longer provoked the same reaction for her:

> *I'm so used to it, if you like, so getting this onto paper, I've lived with this for a few years, so it's not scary to me anymore, or anything it just is. (Gill, 675-677)*.

The lack of anxiety in both Gill's and Zoe's accounts suggests that familiarity, or at least longevity have, over time, influenced their reactions to the threat posed by their pain. For both Zoe and Gill there appears to have been a confirmation that whatever their worst fears may have been about their pain, they have not been realised and perhaps as a consequence of this both have been able to conduct their lives in a less fearful way. For Zoe this is expressed as '*I'm not dead yet, so it can't be killing me, so just get on with it'* and Gill '*it's not scary anymore'*. Curiously, the last part of Zoe's passage commutes the 'get on with it' to a 'deal with it', which appears to acknowledge that it requires competence rather than ignorance to manage her situation. This is a reflection perhaps of her own acceptance arising out of an engagement with, rather than a disengagement from her pain. Modifying or exonerating previously held beliefs also seems an important theme in Gill's acceptance of her situation. Here she equated arriving at a position of acceptance with a re-assessment and a lowering of her expectations of being pain free:

> *I would equate it to, I do the lottery and winning the lottery would be marvellous, but I don't live my life as if I'm going to win the lottery and it's the same with the pain, it would be great if someone would suddenly think, oh we'll test you for this and it's this and we can cure you and I'll be pain-free, that would be marvellous, I would like more than winning the lottery, but I don't live my life as if they're going to do that anymore. (Gill, 152-162)*

In this extract Gill compares the chances of being pain free as being as unlikely as a lottery win. Importantly this extract seems to reflect the engagement with hope as an important vehicle in chronic pain. Curiously there is an assessment in Gill's extract which seems to imply that hope and hoping have both positive and negative qualities, the negative implication being that hoping for too much can lead one towards disappointments and distress and as such can itself be an even greater contributor to the amount of suffering in one's life. Although there is neither a total abandonment of hope for a cure, or indeed a lottery win, there is a much more realistic expectation of both. Perhaps Gill's realistic acceptance is also informed by her experiences elsewhere in her life:

> *So now I've just accepted that I'm not going to get a diagnosis, but that happens, I know that from working in the veterinary field, that people want to know, they want an answer, but in medicine we have a lot more questions than we do have answers. (Gill, 400-403)*

Working in a context where diagnosis isn't always achieved seems useful in Gill's assessment of her own situation. It appears that having undergone a range of fruitless investigations and explorations, she has accepted the limitations of medicine to provide an answer for her. Her diagnosis, or lack of it, may have represented a marker for her own acceptance in its relation to the continuation or cessation of hope. This had on the one hand mobilised a sense of hopelessness, but on the other perhaps provided a sense of closure. This stage of acceptance is perhaps reflective of how, through the eventual re-

assessment of pain as now being likely to be a permanent feature in sufferers' lives, a shift in responsibility occurs, from the physician to the individual. A concept that seems clear to Fran:

> *The pain is my responsibility to deal with, not somebody else's. (Fran, 375-376)*

Fran's statement is a claiming of her pain. With this statement she is taking responsibility away from both her family and the medical profession to do something about it. With her taking ownership of her pain she accepts that her pain is an intrinsic part of her self. Therefore in order to accept herself she *must* accept that her pain is now a part of who she is.

5.62 Living *with* Pain

This theme follows on from, or goes hand in hand with the previous sub-theme, suggesting that emerging as a chronic pain survivor is achieved through an acceptance of one's predicament and a desire to live in spite of it. Participants reported a 'working with' their pain as bringing about congruence, with pain becoming a constituent part of their new lives. There is an emphasis on how autonomy is negotiated, pain accommodated and independence achieved. On one level this construction is represented by the adoption of often quite pragmatic approaches to managing their condition and the refocussing of their efforts in the direction which would allow them to realise their potential, rather than their limitations. On another level a number of participants also described developing new

skills or returning to old ones in order to find renewed meaning in their lives, the results of which helped to promote a steady improvement in their self-efficacy, their self-esteem and to a greater degree their self-confidence. Consequently, as they found that their efforts to do things, but do them differently, were rewarded with success rather than failure, participants moved towards a more virtuous circle, rather than the erstwhile vicious one. This also invited them to engage with their pain in ways which they had previously been unable.

Julie introduced this theme with an alarming testimony in which she reflected on how her own road to living with pain was effectively inspired through her experience of hitting rock bottom:

> *I think a lot of it was when I went through the 'sorry for myself' stage and a really black stage where I could have taken those tablets and you think to yourself, 'well, what have I got to live for' and then you think 'well what have I got to live for' it's the same question in two different ways (Julie, 770-776)*

Julie's reflection that her pain had brought her to the brink of suicide, which she refers to as her 'feeling sorry for herself stage', is a difficult testimony to hear. However her appraisal of the same question having two different meanings is a crucial one. Her first effectively states that she is unprepared to continue living with all that pain has taken away from her. However the same question is then positively inverted to invite her to consider that by shifting her focus towards living *with* her pain she is able to identify the important things in her life and how precious and meaningful they are to her. This

decision to continue living *in spite* of her pain is perhaps further qualified in Julie's own conclusions of how her fortitude was augmented through this difficult experience and that this experience was in fact instrumental in helping her focus on living positively, regardless of her circumstances:

> *You're given one life, you can either sit down and just let everything get on top of you and just waste it away, or you can get off your backside and you can do something about it and that's what I've decided to do. (Julie, 487-492)*

Rebecca was another participant who was plagued by the same doubts and fears as Julie, but has also managed to find resourcefulness and a desire to live life in spite of her pain. For her the interview provided the opportunity to reflect on this:

> *I thought for a little while I couldn't carry on but you can, so it's quite interesting to think about sometimes, when you look back you think of what I'm doing now, how far I've come. (Rebecca, 579-582)*

Like Julie the changes in her abilities brought her to consider her purpose. However her commitment towards living a full life but a gentler path brought its own unique rewards:

> *So I started playing with computers and I taught myself how to use a computer and I taught myself how to use programs and I taught myself how to take a computer to pieces and put it back together again and build another one, …..Yes,*

> *I think it's quite satisfying and you think that just sitting around a computer is not really very satisfying, it's quite interesting, I learnt how to create a website and ran a website, I run three websites now. (Rebecca, 293-307)*

The shift from identifying with limitations to identifying possibilities was as helpful a process for Rebecca as it had been for Julie, who gave an account of her own achievements:

> *All I know is that I'm just taking it, each step at a time now. I've gone to college and I've got my level 2 math's and English I've done a cake course, computers, I've done health and safety I'm in the middle of the retail course at the moment, so I'm actually getting out and meeting people, doing things, for me. (Julie, 322-329)*

Julie's step by step progress has, over the course of a few years, brought about a number of achievements both academically and vocationally. Importantly, the achievements she has made all appear to be compatible with her current physical capabilities, something which she defines as 'doing things for me'. This reveals itself to be an important statement as it perhaps reflects that in her previous life this may not have always been the case. This is something that Rebecca too had considered in evaluating and arriving at imperative pragmatism in her approach to life:

I mean do I have to ride a bicycle? No, I don't have to ride a bicycle. Do I have to ride a horse? No, I don't have to ride a horse. It's things that I feel I have to do, that I do (Rebecca, 363-365)…..but I don't have too ride a bike any more, it's not a necessity, so I think a lot of the things I do now are necessities, or things that I really really want to do, whereas before, I would, I was probably run ragged…". (Rebecca, 369-372)

Rebecca reflects on a life now dictated by necessity as being consistent with her achieving an improved quality of life. This position has seemingly been arrived at through self-reflection, negotiation and reprioritisation. The strict adherence to this 'code' has seemingly helped Rebecca achieve and maintain important responsibilities and interests. Whilst others have had to justify their demands on her, importantly, activities which had defined a previous chapter in her life no longer claimed precedence, as they had received an unequivocal reckoning and were termed not 'a necessity'. Indeed living 'essentially' seemed to be an important justifications for Rebecca in order to maintain her sanity and her self, and her pain helped her consider her true priorities:

In one way it's (pain) taken this life away from me (points to picture) and then another way it's given me a new life and new focus, because I'm not doing 100 things, I'm doing 10 things. (Rebecca, 479-482)

The ‘ten things’ that remain for Rebecca are perhaps the most personally important and relevant to her and in their retention, have helped her identify her achievements. Indeed the activities and achievements of both Rebecca and Julie suggest an undertaking towards committed living, the rewards of which are revealed in the resurgence of their social life and the development of new skills, all reflected as a reprioritisation based around quality rather than quantity.

Fran is another participant who reflected on a similar process and having accepted that her pain was going to remain a permanent part of her life, she now found herself in a position to reflect on how she would like to design the next chapter of her life:

> *I've gone through this slow process of acceptance and where I am now and now it's time to do more, to actually go out and do more, but do different things from what I did before and so I've sort of come to a sort of crossroads and taken on a different path, a gentler physical path, but nonetheless it's still an onward movement, you know. (Fran, 442-449)*

There is an emphasis that although this process of acceptance has been a lengthy and diffuse journey for Fran it has been an important one. She reflects on her experience of arriving at a crossroads, at which she took an inventory and evaluation of her capabilities and limitations, and subsequently has set about living her life under more appropriate governance. A strand which draws both Fran’s and Julie’s stories together is the suggestion that acceptance and choosing to live full lives in spite of their pain is

acknowledged as an achievement for them. With Julie's concluding '*that's what I've decided to do'* and Fran's '*onward movement'* there seems also an acknowledgment of growth and attainment. Fran is perhaps further able to articulate that she had arrived at this crossroads as it was time, and that she herself had chosen to take a different path rather than feeling that her choice had been taken from her. Fran qualifies this path as being both physically 'gentler', but also 'different', which is encouraging as she doesn't denote it as subordinate to her former life, just 'different'. With this different path she is able to identify new strengths, desires and goals, which she is now contemplating and through which she wants to become more active. However these activities themselves are now more congruous to this different physical path that she is on. Gill also seemed to echo these same aspirations and desires to achieve a greater quality of life, something in which she recognised both difference and familiarity:

> *But I am now thinking I've got to get some quality of life back, it's not going to be the same as it was before, but, I do just feel like I'm becoming ME a bit more again. (Gill, 481-484)*

Gill's assessment that she is unlikely or unable to return to how things were before reflects a certainty that she no longer feels the needs to aspire to the things she knows she can no longer achieve. Again there is no judgement made as to the value of things now and in the past, just an acknowledgment of a difference. This shift in narrative perhaps reflects a renewed confidence in living with her pain as measured by her closing statement '*I'm becoming ME a bit more again'***.** Indeed this final reflection is fused with

both hope and the potential for further growth, which will be further explored in the final sub-theme.

5.63 Pain as vehicle for growth.

The engagement with pain was identified most powerfully by the way a number of participants were able to reflect on the fact that their pain's intrusion, and their response to it, had been instrumental in helping them develop and draw on resources they did not know they had. Seemingly this identification of their robustness also helped them to focus this 'new' skill on previously unexamined dimensions of the self, and challenge areas in their lives which, in their pre-pain days, they had been either avoiding or of which they were fearful. Many participants reflected on this curious development, the outcome of which had further resulted in changes in how they perceived their relationship with pain or indeed its purpose. Whereas pain had been referred to elsewhere as the agent in the individual's division and destruction, in the final theme, pain for some was now also referred to in both cohesive and constructive terms. A number of the participants went further, to describe this development in terms evocative of how a spiritualist might refer to the enlightenment they achieve through the process of their own suffering. There is evidence of this in a number of the participants' testimonies where pain has become fused and responsible for their own enlightenment and therefore pain, rather than being referred to as being

their curse, has become their salvation. Fran introduced this concept with an indication of her philosophy on her circumstances:

> *Sometimes we have to go through what we visualise as bad things, like pain disabilities, in order to grow and develop and that's how I think that pain is sometimes inflicted on people and I don't think you should apportion blame to anybody else, for your condition, I think that's, I think that, it's not exactly fate, it's not exactly rigid, you can do something about it, the pain comes to people, you can take two paths, you either accept it and learn from it and live with it and change your life, or you can just stay in this state, where you're angry and resentful, but that builds a negativity inside of you and hatred and blame and that isn't going to do any good, that isn't going to help yourself. (Fran, 103-117)*

Fran has come to draw meaning and significance from her perpetual suffering. She suggests that viewing pain as wholly bad is short sighted as, for her, she was offered a choice in how she came to respond to it suggesting that there were 'two paths' that she could have pursued. One was consumed by entrapment, negativity and resentment, the other offered her the opportunity to grow and learn from it. It seems that Fran's attitude towards her pain, or more broadly towards life, capture the utilitarian attitude from which growth and direction can be fostered. Sarah too reported a shift in her own outlook, suggesting what helped her rationalise her pain and further, how she achieved some recompense for it through fostering an attitude of gratitude:

It was always a feeling that you thought positively you can do what you want to do, if you've got a positive mental attitude and I think sometimes that gets me through the day, where I think to myself, well I have two legs and I have two arms and I'm a lot better off than some people. (Sarah, 283-287)

Sarah's gratitude for what she has, rather than what she has not, not only reflects a shift in her outlook but offers her a psychological asset in helping her get through the 'bad' days. This attitude and psychological asset is interpreted by participants in different ways. To balance and maintain this outlook against a backdrop of persistent pain is quite a feat, which becomes even more significant in considering how Rebecca, in the next extract, was able to explain that it was actually through her own physical suffering that she was able to identify a different type of suffering elsewhere in her life:

Because it's so all-consuming you can't ignore it and I think you then start to think about things that, maybe you shouldn't be ignoring. (Rebecca, 277-278)

Rebecca here is referring to childhood abuse, which she spent a large portion of her adult life avoiding confronting. She reflects that her lifestyle before her pain had provided an escape from the legacy of her abuse. Her abuse had been responsible for the creation of a false self in which she could hide from these aspects of her past. However when pain came into her life she found that she needed to draw on her inner resources to cope with it. In this process she effectively dislodged the disguise of her

abuse and was asked to confront it. Importantly, she is very clear about pain's instrumental role in both bringing about this exploration and in being a resource to cope with it:

> *The physical pain helped me to deal with the emotional pain. (Rebecca, 477 478)*

And:

> *I think it has been positive, in the fact that, it made me do that, or facilitated me doing that, it helped me to do it, because whilst I was looking at other issues, it helped me to look at everything. (Rebecca, 449- 451)*

Rebecca is able to evaluate her pain as having been a positive influence in her life. It afforded her the opportunity to focus on the hidden dimensions of her victimisation and ultimately facilitated both the confronting and redefining of herself. Perhaps in these circumstances pain has been responsible for helping her to differentiate between seeing herself less as a victim and more a survivor.

This above statement is particularly crucial in challenging the misconception of psychosomatic illness by indicating that the physical pain is not in fact a physical manifestation of emotional disturbance but in fact the reverse. This appears to have prominence not just for Rebecca but for a number of the participants, who reported

strength and emotional robustness emerging out of the context of physical pain. Fran supported this assertion with a declaration of her contentment with who she has become, as defined through her relationship with her pain:

> *I don't think I really want to be any different now. I've, its, it keeps me on the path I am on and I don't think, I don't think you can go back to how it was before, because if I tried to go back to where I was before, physically, then I wouldn't be growing in that direction. (Fran, 902-907)*

The value of growth for Fran is the defining feature of the path she is now taking. She acknowledges that the path back is blocked. Importantly she reflects that, even if it were not, she would not wish to return to a previous way of life. This is perhaps a testament to the growth that some participants ascribe to living with pain. Zoë too considered her path, her journey and the paradox of how, through her suffering, she had actually become a stronger person, and as a result, her strength had inspired her to help others:

> *It's really hard because I want to hate it. I want to hate it, 'course I want to hate it, you know, it's shackled me to…. But, has it…. it's let me meet people and help people, I know that I've helped a few people and I won't digress, but, I've helped a few people out that wouldn't have met me, if I hadn't have been in this situation I'm in and that's only so far and it has taught me, my mind is better, my mind is stronger and wiser and better, through everything that pain has given me, through the depression I suffered, through the knowing that I could easily fall back into*

that on a bad day but that I haven't, and that I do feel that my body may be weak but I have the mind…(laughs.). (Zoe, 663-674)

Zoe describes the curious recompense that's afforded her by her continued suffering. Not only does she consider herself to be mentally more robust now, but through her pain and suffering, the path that this has taken her on has enabled her to encounter and help others in desperate situations. She would never have met these people had her life continued on the trajectory it had previously taken. The importance of this recompense for Zoe is afforded prominence by her re-interpretation of her 'accident':

Yeah, yeah, because it's the one thing that would make me stop and look at my life wasn't it, how else would I have stopped the career and the lifestyle I was living, I wouldn't have done, I was doing well at work, I wasn't doing badly in my life as a person I mean, I had no reason to.. everything was brilliant at that point that I fell down the stairs, which is when, which is why I think 'did I want to fall down the stairs did I want to stop' I can't see that I would have done, I was great, I was earning loads of money, all the things that a young mid-20s person wants, I was in a great relationship, it was fantastic, why would I want to chuck myself down the stairs, even on a subconscious level, but maybe why, was for the bigger picture. (Zoe 288-301)

In this passage Zoe seems to question and challenge the person she was before, the values and the choices she had made. She re-frames the same things that seemed defining about

her in the first statement as now being almost a distraction from the ‘bigger picture’. Her language seems to adopt an affectionate nostalgia for what seems to be a reflection of the naivety of her former self, where she questions and perhaps introduces the concept of intervention as being responsible for the fall. She seems to add force to this concept as ‘even on a subconscious level’ she would not have wanted this. Her narrative seems to be alluding to the idea that ‘the fall’ was in fact a ‘push’ ordained by an influence beyond her. Curiously under this interpretation, the ‘fall’ then becomes an act of salvation ordained by a higher power and as a consequence her life has taken on a higher purpose. Indeed this appears to be powerfully evident in her closing statement, where the researcher posed her the question: Would you be without these insights and experiences if you could exchange it for a pain-free life?

> *Do you know what, no…. if I had a wish, I'd have thought it would have been to not suffer the pain, but then if you had one wish and it could be anything, would it be selfish just to look at yourself, maybe we should cure humanity of its pain, that's the person I am now and before I would have just ordered £1 million and thought ‘Fuck it, if I've got £1 million it doesn't matter does it’ so yeah, so no, I wouldn't be without it, which does surprise me because, it hurts and I don't really want it, but if it's meant to be, if it is my path and I’m meant to learn, then I’m meant to learn. (Zoe, 706-724)*

The value of existence here is not on material wealth, as she might have desired in an earlier incarnation, but spiritual wealth. Zoe sees ‘pain’ as a universal experience in

which everyone suffers in whatever form it takes. Her defining, unselfish wish then is to cure humanity of its pain rather than cure herself. This wish seems to reflect and contain both a sacrificial quality to it, but also a spiritual plea, where Zoe herself demonstrates transcendence beyond the body and earthly pleasures, which perhaps is what she hopes humanity might too resolve to attain.

Zoe, through her suffering, seems to have obtained an enlightened position, where her pain has become a catalyst, driving her in a more spiritual direction and away from her prior earthly material enthusiasms. Through this treatment her own perspective on suffering is viewed differently, through changed eyes, which rejects the notion of pain as a singularly sufferable phenomenon, to be endured and anathematised. It is replaced perhaps by viewing pain as a means to an end, a vehicle carrying her towards achieving her own spiritual enlightenment. Perhaps this was illustrated best through Zoe's own interpretation of what was being represented by the gold or yellow in her original picture:

> *I think the gold is that it's trying, I think it's saying, this is going to sound so weird, that I think it's giving me hope, I think it is horrible and I am having to suffer a lot of pain, but I see the gold, because it's like when I saw it, it was like, it was like a light underneath the dark crispy shell of pain and the way I saw it, it was, what I think is, you know, when you kind of interpret like a dream, the way I saw it as I was interpreting it as the gold is a good light of everything God, not God's, because, I'm not a goddist, I do believe there's something, but I don't really*

like the word God as such, but the power of the universe, the power that says that you can have, that you can get through it.(Zoe 49-62)

6. Discussion

6.1 Overview

This discussion aims aim to achieve three clear outcomes. The first is to provide a full account and overview of the main findings of the study. The second is more polygonal, as it seeks to engage in a process of mutual illumination, whereby the themes identified in the current study are intended to shed light on previous findings from the qualitative corpus, as well as identifying how previous findings may in turn serve to support and contribute to the findings of the current study. The final outcome aims to articulate how the findings from the current study may add something new to both the corpus and the clinical arena by supporting an argument for the potential therapeutic utility of incorporating art into clinical practice with chronic pain patients.

The discussion section will also address matters of rigour and validity, and consideration will be given to what measures were taken in both the undertaking of the research and the analysis of its findings. Finally, the discussion will make some critical and reflexive considerations. These will include possible criticisms, potential blind spots and limitations, as well as any particular recommendations that may be given for future studies investigating this topic. These reflections will also offer the primary researcher's own meditations and personal reflections on the study, which will include an account of how the researcher's own clinical work has altered as a result of the knowledge and insights gained from undertaking this study.

6.2 Summary of all themes

The current study returned four master themes with fourteen sub-themes. These themes were deemed to be representative of a number of discreet aspects of living with chronic pain, but as a whole reflected the confusions, fears, losses, chaos and hope associated with living with these types of conditions.

The first master theme focused on how participants attempted to represent their pain pictorially. These artistic representations offered participants a way of helping to make manifest what could seem an invisible and elusive condition. Through this external expression of their internal worlds, a deeply personal account was achieved of the sensory, psychological and social impact of chronic pain. Many chose to illustrate these experiences by incorporating bold shapes and structures into their images. These structures powerfully communicated both alarm and menace, which was further supported by the climatic references, which appeared in a number of the participants' images and were a further attempt to signify the inclemency and oppressiveness of their pain. The power of the images was further strengthened by the use of strong colours: red, red and black, yellow and black, which enhance both the sensory and emotive impact of pain. Participants' images were supported by the descriptions, which also confirm the sinister, malevolent and violent way in which they experience pain. Themes of relief and hope were also present and by their inclusion reflected another important feature of living with chronic pain. The value of creating these images was identified in numerous ways,

not least of which was in the support they provided to the development of other themes in the study. By way of an example Fran's image is a powerful contender as it contains a number of key elements in her own experience of living with pain and transformation which also shares an overlap with themes highlighted in other participants' accounts. In the appendix section (appendix 7) Fran's initial account, including her description and explanation, sets the tone for the rest of the interview and is able to capture an extremely complex dynamic in a simple and arresting form.

The second master theme described the impact of pain on the self and participants' descriptions were concerned with themes which reflected both division and enmeshment arising as a consequence of the uneasy tenancy of their pain. Themes in this section reflected the internal conflicts existing between participants' bodies (their pain) and their minds (the self) and the seemingly inexorable task of achieving homeostasis between the two. Further descriptions were given as to how this conflict had provoked further ruptures along the fault lines of the self, with further themes of division arising as a consequence of the ongoing battle with their pain. Participants artfully represented these powerfully dynamic themes in their illustrations, with the rendering of 'dual selves' or a 'self in duplicate' reflecting 'past' and 'present' selves, using stylistic changes in colour, content or proximity to others to further represent the themes of division and enmeshment. These 'alternate' versions of themselves were strong indicators of how the disruptive nature of their pain had ultimately resulted in profound instabilities to participants' sense of a cohesive and chronological self.

The third master theme extends the observation of the impact of pain on the self, but focused more discreetly on the social implications of living with pain. Participants reflected on the slow inevitable erosion of their social self, their manifest efforts to prevent this and their frustration with the futility of these efforts. Participants described the process of a systematic withdrawal as a result of their concerns about the impact of their pain on others, coupled with the distance provoked by the inability of others to comprehend or respond empathically to their difficulties. Participants' accounts contained numerous examples of how, due to the 'invisibility' of pain, a significant barrier had developed between themselves and others, which included family and friends, as well as health care professionals and benefits agencies that were perceived as being inconsiderate or discriminatory towards them. It was considered that the lack of understanding or compassion further justified both their growing intolerance and resentment towards others, as well as their disengagement from their treatment pathways. It was further identified that, as these circumstances also compounded both the sense of isolation and difference participants felt, and that this represented yet a further barrier to them in their ability to accept or work with their pain, this was perceived to be instrumental or responsible for their social decline.

Relief was finally achieved in the final master theme, which was able to offer a more positive and optimistic outlook on the experience of living with pain. Its themes acknowledged that, alongside the perennial difficulties described throughout, participants also demonstrated a desire and capacity for positive change in their lives. These themes are represented in the expressions concerning their slow but inevitable coming to terms

with their pain, followed by a slow re-engagement with meaningful activities, with others and their reintegration with society. 'Acceptance' was referred to as having been an important vehicle in helping to bring about this reunification and was further considered to be instrumental in helping to develop a greater sense of attunement in meeting their own needs. A number of participants felt that attending to their physical difficulties had in fact also been important in helping them attend to other areas in their lives which they may have previously been avoiding. With such a shift in conception, the 'meaning' of pain for these participants had necessarily altered somewhat and indeed this was revealed most powerfully in the final sub-theme, 'pain as a vehicle for growth', in which for some, pain was no longer viewed as the enemy, but as a companion.

6.3 Representing pain

The images produced by participants reveal a rich gestalt, which wordlessly communicates a range of complex dynamics and experiences associated with living with chronic pain. It was of particular note that although none of the participants in the current study had any access or exposure to any other participants' images or transcripts, many of the participants' images, as well as their accounts of them, shared both an uncanny resemblance and a considerable overlap. The most powerful symmetry could be found in the methods adopted to produce an actual pictorial representation of the physical experience of pain. A number of participants chose to represent this by incorporating bold shapes and structures into their images. These structures were often cylindrical with pointed or stabbing structures shooting from a core. Texture and contrast were added to

these images by participants' deliberate application of a specific palette of colours, infused with a particular sensory or emotive quality, which further help to define their beliefs about the intent of their pain. Black and red were by far the most predominant colours and their implications represented both the obscuring and malevolent quality of their pain as well as the associated sense of alarm and threat perceived as the hostility of their pain. Three of the images also adopted or represented climatic conditions, with dark brooding clouds or lightning bolts reflecting both the inclemency and intensity of their pain and its associated obscuring quality. In addition some of the images also contained a distinctly organic quality. Gill's image in particular was an attempt to reflect her pain as being like a reaching, mutative virus, which she described as being seated deep within her. She emphasised its viral like quality in the accompanying commentary, in which she described that, when at its worst, it is perceived as stretching out, contaminating the rest of her body, almost having a life of its own. Julie equally felt that the analogy of a dormant virus was particularly apt for her in order to reflect the equivocal nature of her pain. She clarified this with a reference to her pain as being rather devious, waiting to seize its opportunity to take over when she is weak or when her 'guard is down'. She went on to describe how she perceives that her pain lures her into a false sense of security, by temporarily diminishing, only to rise up once again and take over when she is unprepared for it. These accounts alongside their corresponding images help to reveal participants' skill at not only representing their pain and what it looks like to them, but how they each have come to imbue their pain with a particular set of characteristics to both capture and define its unique character. In the main they refer to their pain as being hostile, aggressive, cruel and manipulative and once again the characteristics are reflected

in their images. In her image Julie depicted herself as a target for violence with a lightning bolt crashing through the dark clouds, singling her out. Rebecca's and Claire's images also captured the oppressiveness of their pain, with Claire illustrating herself entirely in red, both a reference to her pain as having consumed her, as well as how this is also responsible for the degrees of separation and difference she feels from those around her. Rebecca also depicted herself as separated from others, encased within a red aura and above her head, the black rain cloud trope bears down, again a powerful indicator of the oppressiveness of her pain. In both her images, Zoe also attempted to capture and reflect the identity of her pain. The first reflected her pain as a mace like structure, which she adopted to represent the violence of her head pain and the second was the large wasps body -like structure, meant to reflect the sense of imprisonment she feels. Zoe herself also adopted a number of torture and punishment metaphors in order to accurately capture the horror and intent of her pain and further described that the crisscross of black bars in her image represented her sense of incarceration and the restraint it implicates for the yellow underneath, meant to represent her hope.

Interestingly, the images that participants produced and the accounts of persecution, assault, possession and contamination share a resonance with both images and accounts found elsewhere in the qualitative corpus in which pain, whether emotional or physical, is featured as a part of the participants' story. In particular a number of parallels could be drawn between the images found here and those in Shinebourne's images (2011) of 'addiction and recovery', which attempted to reflect participants' pictorial representations at different stages of their recovery. One image in Shinebourne's study (2010), which

stood out as having particular symmetry to two of the images in the current study, was entitled 'It looks like pain to me'. The image drawn was that of a flail like structure, similar to that which appears in both Zoe's and Fran's illustrations, and depicts an intimidating mace like weapon. Shinebourne's participant selected both a deep amethyst and black to illustrate her 'pain', again suggestive of the similar palette used to refer to the affective and sensory illustrations of living with pain found in the current study. Symmetry can also be found with Broadbent et al's paper (2007), exploring psychological and functional status in heart failure, in which participants were asked to draw images of their hearts both before and after heart failure. In the images both damage and anxiety were communicated powerfully through a series of explicit changes identified between the two time lapsed images. Several of the participants in this study chose to illustrate the perceived threat of contagion of their condition by escalating the size of the heart in the after image, with one participant also escalating the sense of threat by including a menacing, piercing knife in the area in which presumably the damage or disease was understood to have occurred. In other images included in Broadbent's study, participants' emphasised the sense of damage or threat by the shading of certain areas, or depicting engorged blackened veins and arteries in areas affected by their condition. This sense of threat and its depiction has clear parallels with the current study and when viewed in conjunction with each other, they suggest that certain archetypes appear to be repeatedly employed in order to capture how participants' themselves perceive or interpret their condition as well as the feelings they have toward it.

These observations and themes and their possible clinical implications will receive particular attention later on in this chapter.

6.4 Pain and the self

The accounts of the participants in the current study, as well as their images, add to the findings of previous studies, in which chronic health problems have been seen to profoundly disrupt and pose a threat to a stable, cohesive or positive sense of self (Gustafsson et al. 2004; Hellstrom, 2001; Hellstrom, et al. 1999; Osborn & Smith, 1998; Paulson et al. 2002; Smith & Osborn, 2007). The origins of these disruptions for many of the participants first emerged when they found themselves being drawn into an uneasy sort of conflict between the mind and the body, both of which appeared to be at cross purposes with the other. Fran's comment highlights this conflict and echoes the sentiment of the majority of the participants who struggled to maintain both the ambitions and expectations of their pre-pain selves.

> *It felt there was a conflict, my body was saying no, but my mind was saying 'yes carry on'. (Fran, 157-158)*

With the ongoing development of their pain condition, this sense of disruption and incongruity between mind and body grew exponentially, and contributed to further themes of division and loss in participants' lives. Participants mourned the loss of a familiar and predictable way of life, as the unpredictable nature of their pain had taken up more and more space in their lives. Participants' frustration and distress escalated and as they became increasingly conscious of the disparity between what they could and could no longer achieve, a growing disdain developed for what was viewed to be a marginalised existence and the propagation of a lesser-valued present self. The participants' pictorial representations capture aspects of this incongruity and iniquity and once again their value is highlighted in articulating these powerful dynamics in simple and arresting forms. Both Claire's and Rebecca's images capture separate figures to represent these alternate versions of 'old' and 'new' selves and the method by which they suggest the disparity is clarified by their accompanying accounts, in which these separate selves are described as holding different qualities, aspirations and values. Rebecca's first image is surrounded by people and animals, and is imbued with bright colours, remnants of a previous life, full of agency. In comparison her second image is much more muted and remote and perhaps suggests the lack of agency in her life now. Claire's image equally captures these multiple selves and in the very simplest of forms depicts alternate sad or smiling faces powerfully reflecting her internal emotional state in each situation. As if the image were not enough to indicate her sense of disappointment, Rebecca also provides two powerful analogies in her interview that served to highlight the themes of division and difference she felt about herself both now and in the past. She adopts the metaphor of *'Russian dolls'* as being a fitting representation of the diminutive status she

now holds in relation to the outer shell of her pain, beyond which rests her former life, no longer obtainable to her. She also refers to her sense of engulfment as being like *'a thin person trapped inside the body of a fat person,'* in order to further illustrate the sense of estrangement she feels from her 'real' self and the appropriated, lesser valued or dysfunctional self which has taken its place.

The perceived hostility of this takeover and the degree to which this is perceived as an ongoing threat builds on the findings identified in Smith & Osborn's study (2007) in which the psychological and existential impact of chronic pain was aptly referred to as an 'assault on the self' (Smith & Osborn, 2007). Smith and Osborn were able to demonstrate how pain had come to be perceived as being both offender and doppelganger and managed to capture participants' desperation in their attempt to cling on to an 'earlier' preferred incarnation of the self, which was perceived to be under attack. Participants' in Smith and Osborn's study identified the elusiveness of this aspiration and were conscious of how this preferred version of themselves had become lost in the miasma of their pain, with perhaps their own disappointment for this self, emerging and in the self-deprecating view being they now held about themselves. This view it was considered had in turn became projected out into the way in which they believed others also saw them to.

> *I am a nice person but the pain takes over and sucks it all out and leaves me miserable. If you didn't know me you'd think I was a miserable cow, so maybe I was a nice person and now I'm a cow (Lynette).*

A number of participants in the current study were equally as disparaging about their own efforts at maintaining the preferred self and equally as unflattering in their appraisal of the person that they had become. The apparent disdain for the person seen to be emerging in both Smith and Osborn's paper and the current study's findings was considered to be valuable in helping to make sense of the incentives that drive chronic pain sufferers' behaviours, which may outwardly may be perceived as being detrimental to them. Participants in both studies talk of the psychological and physical efforts they had employed to resist pain's advances, and recount the numerous situations in which they had intentionally pushed into their pain, or indeed tried to ignore it, believing that if they did not do this then they had effectively chosen to 'give up' and had let their pain win. This insight adds credence to a process outlined by McKee (1998) who referred to the phenomenon of 'body drop' where pain patients, in an attempt to maintain their integrity, had literally attempted to 'drop' the body as a means of separating it from the self, as it had become either dysfunctional or a burden to them. The participants in the current study had all at one time or another engaged in a range of behaviours which reflect a very similar process. However many of them also demonstrated a clear awareness of the futility of these motivations and the inherent jeopardy of 'acting out' on these fears. All the participants' identified that in their efforts to 'fight back' against their pain and to try to reclaim or retain this preferred self, these activities had invariably brought about even greater levels or disability and suffering for them and had only served to further cement the tenuousness of their grip on a former life that was perpetually slipping away.

The themes of division, enmeshment and loss of self found in the current study make a powerful contribution to the findings made elsewhere throughout the qualitative corpus. However it was considered that the inclusion of participant pictorial representations may have taken this observation one step further. The participants' images ground these concepts firmly in the data itself and its validity can be measured by their success at depicting these complex themes in simple and arresting forms that have both immediacy and clarity. Indeed the clear pictorial references made by Rebecca and Claire in their images of multiple selves captured a compelling statement attesting to the prominence of these themes in participant's lives a powerful reference for which the participant's themselves in their own analysis of their images are the ones who confer these interpretations.

6.5 Pain and relationships

This study supports findings identified elsewhere in the qualitative corpus (Slade et al. 2009; Holloway et al. 2007; Vroman, 2009; Mathias et al. 2014) that individuals living with chronic pain have to contend with a crisis around the self, which appears to be negatively influenced through their experiences with others, including those in the various health care contexts who represent a significant feature in their world. The participants in the current study articulated their difficulties with others whose disbelief and lack of compassion echoed those concerns described in a recent paper by McGowan, which illustrated this particular dilemma in its title 'How do you explain a pain that can't

be seen?' (McGowan et al. 2007). McGowan's paper emphasised the psychosocial consequences of living with chronic pain. It articulated the experience of participants whose journey through the various health care contexts and how they had come to feel 'disenfranchised' from their own bodies. The participants in McGowan's study had felt that, due to the anomalies arising between their own accounts of their pain and that of the doctors, whose authority was assumed to be unquestionable, this misalignment between the two, had effectively silenced them. This imposition represented a significant determinant to them in their distrust of the health care system and resulted in their eventual decision to withdraw from their healthcare pathway. The participants in the current study described undergoing similarly unflattering relationships with their own healthcare providers, who were alternately described as having 'given up on them', or who had questioned the veracity of their accounts. Gill herself was particularly embittered by her own experiences of her treatment in the numerous attempts she made to find the source of her abdominal pain. She described the litany of failed investigations to find the source for her pain and how as a result of this failure, suspicion had eventually developed as to whether her pain was in fact psychological rather than physical. She described how, as a result of this doubt, her own embittered fantasy developed whereby, in what she referred to as her 'darker moments', she either wishes or wills her own condition onto others 'just for five minutes' in order to help them more fully appreciate what her pain is like. There is amazing parity with Gill's comments and her desperate attempts to gain validation with those of a participant in a recent study by Mathias et al (2014). One of the participants from this study reflected on her own difficulties with the

invisibility of her condition being a barrier to compassion and as a result used an almost identical expression to Gill's:

> *Melany: I've often said, particularly to the family, I just wish you could feel it for 5-minutes, because you can't explain it to anybody.*

The similarities between the two accounts powerfully reflect how the invisibility of pain represents a significant barrier to compassion and how the resulting dismay of not being believed develops into both an intolerance and anger with others as well as a distance and separation from them. In the current study a particular focus of this anger was directed towards the Department of Work and Pensions, which came to represent the most tangible and yet faceless personification of these difficulties around disbelief and suspicion. Participants recounted numerous incidences of how their having to fill in benefits forms was a hated task, as not only were they often long, complicated and time consuming, but the experience of completing them often made them feel that they had no legitimate claim and that they had been targeted as malingerers looking for a hand out. Participants believed that they had to continuously justify themselves and many described their own feelings of shame and guilt about having to seek what they were rightfully entitled to. The majority of the participants also described how they had struggled on for years in agony in order to continue as they were often in jobs they loved, so as to avoid this outcome. The completion of these forms were therefore felt to be the crowning insult compounding their own sense of failure and further contributing to their impression of the world as being a hostile, uncaring place.

Participants cited a major contributing factor in these divisions between self and others was as the result of the almost total absence of any observable abnormality. This perennial frustration, and its consequence, is illuminated by Sarah, who comments on the perceived ignorance of others:

> *Because you haven't got any sores on you, or you haven't got your arm in a sling, because there's nothing visual to see, then you're all right, (Sarah, 68-71)*

Sarah's frustration clearly echoes the sentiments of the participants in McGowan's study, and they also share in the same sense of disappointment as participants in Dickson et al's Chronic Fatigue Syndrome (CFS) study (2007). Participants in Dickson's study felt that due to the equivocal nature of their own condition and the lack of any observable 'marker' for CFS, their condition had become delegitimized, they had been undertreated and the seriousness of their condition undermined. Although the current study deals with chronic pain rather than chronic fatigue there is clearly a shared sense that the 'invisibility' of both conditions had contributed to other people's behaviour towards them and the lack of understanding that was commonplace in both. Julie's image serves to further highlight the enormity of this feature in her difficulties by centrally representing it in her image and then almost entirely obscuring it with the familiar foreboding dark clouds, a powerful metaphor for both her sense of being misunderstood as well as a statement of her own obscured aspirations.

The current study was able to develop this theme further by making the observation that it was actually more of a bilateral process, which to some extent involved the participants themselves being complicit in obscuring their own pain from others. The majority of participants in the current study acknowledged that at the same time as they expressed a desire for their pain to be better understood, none of them were particularly keen to ask for help. Julie again articulates this best, and once again reflects her and many of the participants' dilemmas:

You do need help but you don't want to have to ask for help. (Julie, 428-429)

Participants in the current study reflected that as a result of their efforts to maintain the preferred self and the assumed independence this bequeathed, asking for help, or indeed saying 'no', even when this meant it might allow them to manage their pain better, was particularly difficult for them. It was considered that what may be being enacted by asking for help or refusing to offer it was participants' proximity to a sense of inferiority and helplessness, that all were at pains to avoid. This anxiety, coupled with the inevitable sense of guilt that emerged if they were unable to continue to put others first remained for many a real source of difficulty, which unless maintained only came to represent a further threat to their being able to maintain a positive image of themselves, as well as preserving it for others. As a consequence they consciously became complicit in the obscuring of their pain, by 'putting a brave face on' or 'gritting their teeth', effectively denying themselves and others an opportunity to better understand how they could be helped. This process was acknowledged in the findings provided in Slade's et al's study (2009),

in which a group interview focused on the needs of back pain sufferers. Slade's study identified that participants did indeed hold a strong desire for improved communication and understanding from health care workers, but they were equally keen that this support should enable them to maintain their independence. Participants expressed that they wanted to be 'asked' what their opinions were, to be 'understood' in terms of considering their life circumstances, 'listened to' by an empathic listener, and 'told' or given educational material and resources with which to cope better independently. These desires clearly find a parallel with the wishes and views of Julie's statement above and it was once again considered that the utility and application of art might be a particularly useful tool in supporting participants in both articulating their needs to others and maintaining their independence. Claire herself considered how the difficulties she experienced in asking for help may be offset if she felt able to share her image with her family:

> *I think, perhaps if I showed this to my family, they might understand a bit more, they might start to get it, (Claire 712-714).*

Claire's hope is that by sharing her experience and being able to represent it in this way, this may help in making a start towards involving her own family in a way in which she had previously struggled to do. Her image may then act as a helpful reference point from which she might be afforded the opportunity to articulate, without having to put it into words, what her concerns are and how those around her might begin to provide her with the support and understanding she so desperately wants.

6.6 **Coming to terms with pain (Acceptance)**

Participants' efforts to live a life of direct equivalence, maintaining the activities, interests and capacities of their former 'pre-pain selves' was consistently met by pain's copious ability to nullify and invalidate these efforts. These experiences contributed to further inequitable comparisons between themselves now and in the past, and further losses to esteem and autonomy.

There was however evidence that participants in the current study had contemplated that it may indeed be more profitable for them to find different ways of coming to terms with their pain rather than remaining in perpetual conflict with it. 'Acceptance' was articulated as the process by which these circumstances were brought about. Acceptance of pain is defined as a 'cognitive, emotional and behavioural response to chronic pain by individuals who recognise the futility of continued struggle to find a pain "cure" (Henwood et al. 2012). In the current study, a similar process is described and reflected as a dynamic process which revealed the participants' willful letting go of aspects of their past self, as well as detailing their movement towards working with their pain and self-acceptance. This process by and large represented an attitudinal shift, on which was based the assumption that by acquiescing to these measures, it would reduce the degrees of suffering that their conflict with pain had only contributed to. This attitude accurately captures and echoes the process of acceptance as described by McCracken and Vowles (2006), who refer to acceptance of pain as being a 'conscious cognitive process of

changing behaviour patterns so they are less tied to controlling the pain and are more directed towards elements of healthy living' (McCracken & Vowles 2006 P. 90). This change perhaps more formally represents the sentiments of 'integration' as described by acceptance-based therapies (Dahl et al. 2004; Hayes & Smith, 2005), which suggest that if sufferers could be helped to engage more positively with their pain, this perpetual conflict may be avoided and sufferers may come closer to accepting their pain as being 'a part' of who they are. There is much support for this in the literature (Geiser, 1992; Hayes et al. 2006; McCracken, 1998: McCracken & Keogh, 2009) with acceptance of pain being associated with lower pain intensity, less pain related anxiety and avoidance, less depression, less physical and psychosocial disability, more active time, and improved work status (Geiser, 1992; McCracken, 1998; McCracken & Eccleston, 2003: Vowles et al. 2007). Importantly there is also evidence of these themes and their positive consequences emerging in the current study, in which both the depiction of certain images, as well as the references made to integration, suggest a shift in this outlook and an integration of pain as part of the self.

Fran's image and her account of it in particular provide a compelling and insightful vantage point from which to understand these complex dynamic temporal processes of acceptance and her journey with pain. In her image she has captured two very distinct and separate structures, on the left the now familiar red, pointed, sharp structure, meant to represent the fiery and destructive quality of her pain *'raging and out of control'* and on the right a more subdued, darker, purple circle, suggesting a much more calmed down experience. Contained within this second image is what she refers to as the 'core' of her

pain. She helpfully provides signage to indicate the direction she has been taking and the scale of the two arrows suggest that although there is a greater movement towards this calming image, the smaller arrow indicates that it is always possible for things to turn back towards the more chaotic state. These images alongside the accompanying narrative provide both a concise and deeply personal account of her own processes across a number of years and how her pain and herself, which at one point were considered to be separate entities, have ultimately become fused, or enmeshed. This fusion is reflected in her image, as it is now difficult to see where she (the purple) ends and her pain (the red) begins, the implication being that they are seen as being part of the same whole.

Fran's success at accepting her pain as an essential and elemental part of herself is considered to be an achievement for her. However she is humble enough to recognise that this process is not yet, nor will it perhaps ever be complete. This is represented by the small imperfection at the bottom of her circular image, where there is a slight excess in her illustration. When questioned about this she explained that her initial impulse was to rub it out, but then that she decided not to. She reflected that she did not because this excess itself had meaning, as she explains: *"I was going to rub that out, but then I realised that nothing is ever perfect"*. Once again one can interpret this reference as reflecting an ongoing process for her, one in which her aspirations are both optimistic and realistic.

Fran's image and her account of the process of change and transformation provides an important counterpoint to the predominantly negatively correlated perceived process of

change, as can generally be found elsewhere in the qualitative literature. However hers is not the only account in the current study that details this type of transformation. Indeed it was identified in both Zoe's and Rebecca's accounts that accepting their pain had been instrumental in their coming to terms with it, but it had also been responsible for bringing about some quite unexpected and not unwelcomed changes in their own outlooks, values and beliefs.

6.7 Coming to terms with pain (Pain as a vehicle for growth)

The final theme on which the study reported is perhaps the most optimistic, hopeful and surprising. Its narratives are reminiscent of the accounts detailed in Frank's book (1995) The Wounded Storyteller, in which he describes the 'Quest narrative'. The plot of Frank's quest story reflects a process by which the sufferer has undergone something of a philosophical and psychological transformation. This transformation occurs as a result of the sufferer trying to make sense of their illness experience in an attempt to achieve a sense of purpose and renewed meaning in their lives. A number of the accounts by participants in the current study contain elements of this narrative, as do the images. Themes of hope, optimism or relief utilise a particular palette to reflect this shift in outlook. Zoe's image is a good example of this. At first glance, it appears reminiscent of a wasp's body, and contains both yellow and black, nature's own threatening palette, However further clarification is achieved with her declaration that the yellow is in fact gold, and as she refers to it, representative of 'the power of the universe' a symbol of hope and the belief that she can 'get through it'. An equally optimistic sentiment is

present in both Rebecca's and Sarah's images, in which a sunshine appears. Both describe this sunshine as representing a light at the end of the tunnel, and a belief that positive change is a possibility. The inclusions of these archetypal images of optimism and hope are reminiscent of themes that are again present in both Shinebourne's (2011) and Cross et al (2006) studies in which their participants are equally as keen to include similar elements of optimism in their images and accounts of living through adversity.

In the current study this finding represented one of the greatest surprises and it was striking how a number of the participants had reflected on the utility of their pain as being the principal vehicle for bringing about significant positive changes in their lives. Sarah, Fran, Rebecca and Zoe all reflect and share their thoughts on how, through the virtue of their confronting and coming to terms with great adversity, they had managed to piece together and make sense of other areas of their lives, which in their pre-pain days they had not paid attention to. Zoe is especially able to reflect on how her life previously was preoccupied with possessions and finances and the accumulation of 'stuff,' and that these vices, she realises only now, were a distraction to the real meaning of life. Her pain appears to be instrumental in this re-evaluation. As such the perception of pain has altered over the course of its occupancy, from something which was only feared and hated to something which has allowed aspects of herself to emerge and could be considered a resource to her. At one point she reflects on this dyad and describes her pain as being like a teacher and herself as pupil 'learning,' and that the insights that she has already gained have helped her to help others in difficult situations. She also describes pain as being a universal experience, whether it be physical or emotional, and that her

own wishes to be pain free if given the chance would take a secondary position behind her wishes that humanity can be cured of its pain. Rebecca reflections appear to be on a much more personal level. She describes how coping with her physical pain equipped her enough to be able to deal with the abuse she had experienced as a child, something that she had 'blocked out' through the distraction of her previously active life.

> *I think it has been positive, in the fact that, it made me do that, or facilitated me doing that, it helped me to do it, because whilst I was looking at other issues, it helped me to look at everything. (Rebecca, 449- 451)*

The reference to pain as being a positive influence on her life is shared in its sentiment by Fran, whose own reflections are that she too has learnt more about herself having lived with her pain and that her pain is aligned to her own 'growth':

> *I don't think I really want to be any different now. I've, its, it keeps me on the path I am on and I don't think, I don't think you can go back to how it was before, because if I tried to go back to where I was before, physically, then I wouldn't be growing in that direction. (Fran, 902-907)*

These accounts of growth and the accompanying images of optimism are important counterpoints to the unyielding accounts predominantly identified in both the quantitative and qualitative literature, representing the subjugation of those who live with chronic pain. Indeed, it was considered that there was no precedent for these themes and as such

their contribution here appears to have introduced something completely original to the corpus. This contribution however is considered to be of vital importance. These voices offer encouragement for those whose lives are affected by chronic pain and suggest that just as themes of division, conflict, torture and violence are staple features of the struggle of chronic pain, so too are themes of relief, change, optimism and hope.

6.8 Clinical implications and the value of patient artwork in examining the lived experience of pain

The degrees to which pain has profoundly disrupted participants' sense of a coherent self reflects a process described by Honkasalo (2001) who referred to chronic pain as having both transient and permanent features and in its vicissitudes reflected 'ambiguity par excellence'. This ambiguity has however always proven difficult to capture and therefore even more challenging to clinically utilize. The current study's decision therefore to incorporate participant artwork, although not intended to be presented as art therapy, may hold significant potential benefits in assisting chronic pain sufferers to articulate, or rather illustrate, the complex dynamics associated with living with chronic pain, as well as providing a template from which these images could form part of a therapeutic intervention in its own right.

To date the researcher has been able to identify only a very limited number of studies which have incorporated pain imagery as a feature as an aspect in their own research (Philips, 2011; Berna et al. 2011; Wintereowd et al. 2003; Jamani & Clyde, 2008). These

studies have all reached the same conclusions, that ‘in both their prevalence and their importance, images of pain represent an untapped resource in understanding the impact of these conditions on the individual’. It is of note however that none of these studies had chosen to involve the participant themselves in the art making process itself, instead asking the patient about the existence of pain related imagery, or alternatively inviting the patient to respond to or engage with images which have been previously produced by artists or photographers. It is also of note that although all could identify the potential benefits of developing art with chronic pain patients as a therapeutic intervention, this was not the intention of these studies either. The current study therefore believes it can make an important contribution to the development of these ‘next steps’ by both revealing the potential of including the participant in the image making, as well as offering an clear indication of how this feature can be harnessed in the clinical arena as a therapeutic tool to support chronic pain patients.

In the current study it was considered that the value of incorporating participant artwork held two levels. Firstly, it was considered that the act of art making itself held an intrinsic cathartic appeal and secondly it was considered that this appeal might help to shape the way in which elements of the art making process could be harnessed as a central part of a therapeutic intervention. In terms of its cathartic appeal, this conclusion was reached through both the direct observation and the response of participants to this element of the study. It was noted that the participants were able to articulate and comment on the process of constructing their art work at the same time that they were engaged with it. Gill stated that to begin with she had ‘no idea’ what she was going to

draw and that this had made her a little hesitant at the start of the interview, however by its conclusion she was both surprised and satisfied that she had been able to illustrate and talk at length about her difficulties and that it had been 'nice to get it out'. Rebecca and Claire also refer to a sense of relief, Rebecca stating she felt 'a weight has come off' and Claire believing that her image had inspired her to share it with other members of her family. The researcher noted that throughout the interview process, participant images acted as both a reference and an anchor for the interview and was also noted a persistent physical contact maintained with the images throughout, as if they were the first tangible evidence of their suffering and that these images had the potential to help them communicate what was particularly meaningful to them. The process of illustrating clearly came across as having been a surprisingly cathartic process for the participants, in which they have been able to represent a range of complex feelings, thoughts and experiences in a single cohesive image. This process reflects a reference made in Bullington et al's. paper (2003) who adopted the reference 'order out of chaos ' as a particularly apt statement to reflect the process of change and sense making that those living with chronic pain are undergoing in order to come to terms with their situation. It equally matches an observation (Guillemin, 2004) that through the use of visual material and the activity of expression, knowledge is produced and that this knowledge takes the form of sense making in which the visual product is an external representation of an individual’s internal world. With this in mind one can see the potential advantages and support generated for the development of this method as a therapeutic tool and a focus for a therapeutic intervention in which the involvement of art therapy may hold significant potential benefit.

Art therapy is a form of psychotherapy based on the belief that 'the creative process involved in artistic self-expression helps people to resolve conflicts and problems, develop interpersonal skills, manage behaviour, reduce stress, increase self-esteem and self-awareness, and achieve insight' (American Art Therapy association accessed online Nov, 2014). Art therapy has already demonstrated it wide ranging benefits in a range of health conditions (Wood et al. 2011, Appleton, 2001. Eaton et al. 2007) but as stated there are yet to have been any studies where chronic pain clients have been the focus of these enquiries where their images have provided the template from which the intervention develops. This deficit as previously stated has been widely acknowledged and further endorsement for the timeliness of art therapy with chronic pain patients has been made recently by Angheluta & King (2011) who stated that 'art therapy for chronic pain is a nascent area of study' (p.112) now ripe for further investigation.

In the current study it was considered that the images produced by participants hold a number of different features, which if working therapeutically might suggest to an art therapist a number of different directions in which the therapeutic work might progress. Firstly, an art therapist might be drawn towards specific elements of the images produced by the participants and enquiries might be made as to how their images reflect what is happening internally for them. They might enquire if in producing the images any conflicts or difficulties came up for them or any insights. The images could themselves also form the agenda for the therapeutic intervention, with the therapist making enquiries and eliciting the clients involvement, with questions such as 'What would need to happen

to blunt the edges on these spikes?' and 'How can we move you closer to this smoother image?', 'What does the distance between you and others represent?, How could we bring them closer?, What would need to change?. The patient could also engage in a process of transformative thinking, for instance by making enquiries along the lines of 'How would things be if we you were this image were in blue?' Claire herself suggested this in her own interview, where she had drawn a series of red stick figures, meant to represent her pain-full self. Towards the end of the interview when asked how she would like things to be she said that she would like to be *'all blue and happy'*. She then asks to draw a blue person and as she does so she comments on the freedom she feels as a consequence '*I almost feel liberated'*. This is a powerful demonstration of how, by engaging in an activity of transformational imagery, she has been able to alter her internal state.

There are other potential benefits for the client who engages in creativity as a means of management. Art therapy suggests that the process of creating art work itself can make valuable contributions to a client's self-esteem and self-confidence. The activity of art making may also provide a healthy distraction from being drawn into the pain experience, and again there is much in the literature to suggest that concentrating on and engaging in pleasurable activities is a valuable resource for pain patients. There is an additional consideration to make with the potential value of engaging in creative activities that relates to the often negative self-referential statements pain patients make about themselves. All forms of art making including painting, sculpture or poetry may be considered an important skill, valued by the client in how they then might come to define

themselves. The client may even come to view themselves in more favourable terms as a creator or an artist, rather than a burden or an inferior self, as they may have thought of themselves previously.

As a reflection of both the dynamic and temporal nature of these conditions and the therapeutic contract, an art therapist might invite the client to engage in art making at different stages of their treatment pathway, in order to reveal if the image, a reflection of their internal state, has altered and if so what does this reveal of how the client's experience of their pain may be changing. This may also serve to reveal an insight into the success, or otherwise of the therapeutic intervention, as well providing insight into the degree to which the client is coming to terms with their condition and the degree to which acceptance may be achieved.

The scope of incorporating art therapy into chronic pain as stated is in its infancy. The author knows of no service within the UK where an art therapist is employed as part of a multidisciplinary pain management service. However if the research is able to support the development of this role within a pain service the benefits may be diverse and long lasting. Art therapy would not be considered to be a particularly expensive intervention to develop, fits well within the framework of self-management, and is an innovative response to the management of long-term conditions. The benefits to patients and their families may be significant, if only in terms of one of the greatest perennial difficulties associated with living with chronic pain, namely the ‘invisibility’ of these conditions.

Art work and imagery may provide a very explicit means of challenging this problem and invite the chronic pain patient to represent their pain as they see it.

The current study was indeed fortunate in that it was able not only to generate some powerfully arresting images, but was able to provide the participants' own rich insights and accounts of these images and elaborate on the meanings of them. Participants' elaboration was both verbal and pictorial with participants at points developing themes and at others both editing and adding new components to their pictures as the interview progressed. Sarah provides a good example of this where her original image was amended at several points to include different aspects of her experience, most noticeably the inclusion of a new character who was drawn to represent her 'hoped for self ':

> *Claire: 'I want to be pain-free, can I draw it?'*
>
> *Interviewer: go ahead*
>
> *(Participant continues to draw herself in blue smiling)*
>
> *Interviewer: so tell me about this person here*
>
> *Claire: this is who I was, perhaps before I reached 25 and this is what I want to be again (Claire, 495-505)*

Each of the participants was asked to reflect on their experience of completing artwork as a part of the interview process. Without exception participants described this as having ultimately been a helpful experience. In fact value is added to this assertion with Sarah's

account in which she ponders what added value has been achieved by incorporating art into her interview:

> *I think you've asked me a lot actually and I think asking me to do that (points to picture) was a really good idea, I wouldn't have thought, about when you asked me to put things down, I hadn't got a clue, what I was going to do, at all. it just came out, so I suppose that's really quite good because, you're asking me to and when you write it down, it then becomes more, because, you see and what I was saying to you about seeing and understanding that people look at people see what they want to see. (Sarah, 650-658)*

In addition to the participants' comments on the images the researcher has an important role in managing the degrees of convergence and divergence for the study as a whole, especially as there are multiple unique images in which to identify commonality. Again, as stated previously, there are only a very few examples in the current IPA literature in which participant artwork, alongside the narrative accounts of a phenomena are presented for analysis. This lacking provides little in the way of a precedent to follow as to how this process of interpretation should be carried out or progressed. Previous studies have however benefitted both from Rose's (2001) critical visual methodology framework and may further benefit from Reavy's (2012) 'visual methods in psychology'. The current study however found that in its own interpretations for both images and narrative it benefitted from adherence to the particular analytic approach that IPA itself adopts. Indeed just as the starting point for an IPA study, including only transcripts, involves the

analysis of what the participants have actually said, where an image is concerned the starting point for analysis must also therefore begin with what words the participant themselves uses to describe their image. IPA as a methodology then follows a particular set of steps, in which the second step refers to "initial noting" (Smith, Flowers, & Larkin, 2009). With the inclusion of images this stage itself may require being broken down into three separate sub-steps. Firstly, the researcher should identify in the transcript when the spoken words relate to the image and create notes on the participant's analysis of their own image. Secondly, the analysis of the images and its themes can be developed by identifying areas in which contents, composition, balance, geometry, and other physical characteristics of a drawing appear. Thirdly the researcher may then go back to the transcript and make notes on other areas of the text that do not find a direct correspondence in the image. This may in turn help develop or generate other themes present within the study.

The three sets of notes could then also be developed into the next stage of an IPA analysis, which involves identifying emergent themes across the participants' transcripts, as well as supporting the researcher in reaching the final stage of the analysis, a cross-case analysis. The analytic approach in IPA also allows for the researcher's own impressions of these images. These interpretations can themselves provide a useful perspective in which links are made between images and narrative accounts of them. The researcher role at this juncture is in helping to balance the corresponding demands of divergence and convergence and acts as the bridge between separate life worlds which share a connection. These impressions themselves can provide a helpful insight as to the

effect that these images have on the researcher and how these insights themselves might help provide an account for other people's reactions. Having access to the researcher's own reactions and impressions as well as the participants' own accounts may yield some interesting data in relation to the closeness or distance of the researcher's own account from the author's original intentions.

The second key area in which the current research believes a contribution can be made to the clinical arena is highlighted around the themes of acceptance. Acceptance was represented in a number of different ways throughout the current study. It was evident in how the participants made inequitable comparisons with themselves now and in the past. It was evident in the images, which illustrated the existence of multiple selves rather than a single cohesive image. It was evident in how participants both moved away from others and struggled with their deficiencies in understanding their problems. Most significantly however participants' struggles with acceptance were identified in their conflict over control of their pain and how this conflict in perhaps the cruelest of vicious circles, or indeed the most verbose cyclical psychodynamic (Wachtel, 1977) associated with living with pain. Participants' desperate efforts to avoid the very thing that they feared the most, the loss of self, was both hastened and further assured through the very same behaviours endorsed to prevent it. It was however equally apparent that many of the participants had reflected upon the futility of these efforts and the resulting perpetuation of their suffering as a result of the activation of this vicious circle, and had sought to bring about changes. Many of the participants talked about their efforts or desire to come to terms with their pain, not to be at war with it, and to manage it more effectively. They also recognised that

this responsibility ultimately fell to them alone rather than the efforts of the Medical Model, and that in order to reduce their suffering they would eventually have to 'let go' of certain valued aspects of the past and try to embrace and work with change and their lives 'as is'. Consider Julie's own comments in relation to this:

> *You have to accept what you are who you are, before you can move on and if you don't accept it, you've got this huge hurdle that you have to get over. If you don't get over that hurdle, no matter what you do, you're never going to go forward; you're just going to stay in this glitch all the time. (Julie, 760-765)*

The glitch that Julie describes reflects her being 'stuck,' unable to move back to the person that she was before her pain and unable to move forward unless she is able to accept herself as the person she is now. Necessarily this process had involved a period of grieving and regret for the loss of a former 'self' and her willingness to let go of valued aspects of her former life. Doing so has allowed her to be less tied to competing with the past and attempting to control things beyond her current capabilities. It was considered that in supporting these efforts a particular strand of therapy may be particularly well positioned to acknowledge, respond and support patients in their response to these types of difficulties.

Acceptance and Commitment Therapy (ACT) (Dahl et al. 2005; Hayes & Smith, 2005) is a relatively new branch of therapy within chronic pain management and its value is identified in acknowledging a number of the particular dilemmas identified within the

current study and perhaps suggesting a course of treatment which may help assail these particular difficulties. The basic premise of ACT as applied to chronic pain is that while pain hurts, it is the struggle with pain that causes suffering. The intensity and degree to which the individual 'suffers' is very much dependent on the extent of the client's fusion with thoughts and feelings associated with the pain. Fusion is described as 'the extent to which the client believes the pain-related thoughts (e.g., "I can't do anything useful or enjoyable because of my pain" and "I have to get rid of my pain before I can do anything I value in life") and acts in accordance with these thoughts and related emotions' (Dahl & Lundgren P6). There are numerous examples of this across the participants' transcripts, in which negative evaluations of self and self-worth are interconnected with the participants' experience of pain, their attempts to control it and their avoidance of situations in which these narratives appear to be enacted. In the case of chronic pain, 'continuing attempts to control pain may be maladaptive, especially if they cause unwanted side effects or prevent involvement in valued activities, such as work, family, or community involvement' (McCracken et al. 2004). The treatment aims of ACT are therefore built on both identifying these values and helping a patient to develop a greater psychological flexibility in coping with thoughts and feelings associated with their pain and the suffering which these thoughts and feelings provoke.

The ACT therapist works by introducing the patients to five core processes. These are acceptance, defusion, contact with the present moment, values and committed action. Acceptance teaches the patient ways in which to embrace private experience in the service of chosen values. Defusion seeks to change the way one interacts with or relates

to thoughts by creating contexts in which their unhelpful functions are diminished. Contact with the present moment teaches patients to become increasingly aware of events as they occur but to assume the position of non-judgment, so as to experience these events in the 'here and now' rather than being pulled to the past or future. 'Values' asks that a patient identify that which they truly hold dear, that which at its essence is immutable regardless of circumstances. Committed action asks that the patient strive to achieve goals in accordance with their values. There is evidence, once again unbidden or untaught that some of these motivations have by themselves begun to emerge in participants' accounts and images. Fran, Gill, Zoe, Julie and Claire all talk about acceptance of pain as an ongoing process which has necessarily asked them to identify the particular values they hold and their committed efforts in both defining and working towards them. Rebecca perhaps most closely reflects some of these tenants of ACT without realising it, as she talks about her committed action to the things in her life she values the most:

> *I think a lot of the things I do now are necessities, or things that I really really want to do, whereas before, I would, I was probably run ragged, (Rebecca 370-372)*

It would appear that through a natural process the things that appeared to be important to her in her pre-pain life, and which she has been unable to maintain, have fallen away and instead revealed more acutely her core values, or her 'necessities' as she puts it. These 'necessities' or values reflect that family is represented as being the most meaningful

thing to her. This is further reflected in the explanation given for the presence of the sunshine in the top right hand corner of her image when asked what it represents:

> *Well light at the end of the tunnel, it's a, I think just showing that things change things are changing, so I suppose you could call that change, I now have another grandson, who's a month-old, although things aren't back to this anymore, they've almost found a plateau I suppose, although the pain is still always there, it's not getting me down quite so much (Rebecca 391- 396)*

The potential value for pain patients to be introduced to the core processes of ACT is that it may help them with the struggle through the miasma between resistance and acceptance which represents one of the greatest hurdles to the chronic pain sufferer. It is of particular note that all those participants who had identified core values and embraced the present moment reported an improved quality of life. It is perhaps even more telling in those accounts in which these processes not only helped them come to terms with and manage their pain, but were actually responsible for both their psychological and spiritual growth.

6.9 Validity

Throughout the life of the study measures were taken in order to ensure both rigour and validity. Initially all the interviews were subjected to further analysis by the study's

supervisor, who was able to provide both guidance and assurance that the findings were grounded in the interviews and could be traced back to the utterances of the participants. An additional measure taken to ensure validity was achieved by submitting extracts of the interviews to an IPA study group, who again were able to offer thoughts, assess findings and provide alternative interpretations of the text. The final measure followed a criterion set out by Smith (2011), in which papers were evaluated as to their sufficiency in meeting acceptable, unacceptable and good standards. Of those papers that focused specifically on the lived experience of chronic pain, 3 papers achieved a rating of good, 8 of acceptable and there were no unacceptable papers. This proportionately suggested that in following the rationale used to determine an acceptable or good paper, these papers would offer the researcher a reasonable guide and degree of confidence in assessing the validity of the current study. In establishing this guide, Smith set out that if the paper clearly subscribes to the theoretical principles of IPA, that it is sufficiently transparent so the reader can follow what was done, that it offers a coherent, plausible and interesting analysis and that the sampling is sufficient enough to demonstrate a density of evidence for each theme, then it is has achieved an acceptable standard. Using this criterion as a guide to evaluate the validity of the current study it is believed that the current paper abides by the values of IPA in that it can easily be identified as phenomenological, hermeneutic and idiographic in its examination of the individual accounts of those within the study. It contends that in conducting the analysis in conjunction with regular individual and peer supervision, the current study can declare that it believes it has been able to achieve both transparency and rigour and this is another measure of its validity. In meeting the criteria of sufficient sampling, it is suggested that for a sample of this size, at least three

participants be present within each theme. The current study had seven participants. From reviewing the results section it is possible to establish that in all cases at least 3 participants' extracts support the validity of each theme and in some cases four and five extracts support each theme. Having met this criterion it is suggested that both convergence and divergence have therefore been achieved. Following the rationale as set out by Smith, it is believed that the current research conforms to an acceptable standard. The assessment of what makes an acceptable paper become a good paper is its ability to offer three further considerations. They are: being well focused, offering an in depth analysis of a specific topic and that the data and interpretation is strong so that the reader will find him/ herself engaged and finds it enlightening. Given these criteria, it must be for the readers of the current study to judge whether this level has been achieved.

6.10 Critical and reflexive considerations and limitations of the study

At this point it is perhaps appropriate to consider some critical and reflexive considerations as to the development, execution and analysis of the study. In the developmental stage, it was important to consider not only the motivations that the primary researcher had to conduct such a study, but also the relevance of the role that the primary researcher held within the context in which the study was carried out. As a

Psychologist employed to work with individuals living with chronic pain, one has to consider and critically reflect on the potential dual roles that may have been present in both the interview procedure stage and during the data interpretation. The primary researcher reflected that during the interview stages, he could quite easily have found himself compromising his position and being drawn into a therapeutic stance towards his participants. The primary interviewer identified how, if working therapeutically, he would have pursued certain dynamics further, and perhaps enquired about certain themes more ardently. However this may have compromised the interview and jeopardised its findings. The researcher was able to reflect upon these experiences at the time and subsequently demonstrated reflexivity in maintaining his primary purpose. An example of where this restraint was employed was during one of the interviews where a participant was being particularly critical of herself and believing that she had little to offer others, except burden. As a therapist in this situation, I may have been inclined to challenge this assumption, and invite her to identify whether this was always the case, or if in fact she may be making unhelpful assumptions of what other people actually think. I might have also invited her to consider that due to the fact that pain had affected her emotionally, this may be influencing her thought processes, nudging her into a position where the appraisal of herself may be biased or skewed. As a researcher I was cautious to hold onto these therapeutic impulses, so as not to allow them to shift the agenda of the interview towards a therapeutic session and to allow the participant to express her views more fully, even if they may be perceived as detrimental to her.

Interpretation is another important consideration of the role of researcher and the process adopted by IPA is designed as organically as possible in order for reflexivity to exist throughout the life of the study. Therefore interpretation as an evolving process can allow for movement throughout this time. It also acknowledges that interpretation is by its nature subjective and therefore if another researcher was given the same material it is quite possible that different conclusions would be reached based on the subjective experience of the reader. To that end the conclusions reached by the study must remain tentative and be open and welcoming to other and alternative interpretations. A further consideration must be made in relation to the sample size itself. Obviously this study has a relatively small sample, as is typical with IPA. However the detail in the writing should allow the reader to make theoretical inferences about broader applicability. It was considered however that the degree of confidence in the broader applicability has been supported through what could be considered an advantage of the popularity of this topic in the qualitative literature. As previously stated no less than ten IPA studies have chosen to feature chronic pain as the focus of their investigations and the themes that have emerged from these studies share considerable overlap with those finding identified within the current study. The sheer volume of studies, coupled with the degree of confidence given for both their validity and rigour (Smith, 2011) serve to contribute to the increased confidence in achieving an ever more comprehensive and complete picture of the subjective experience of chronic pain. In addition to the contribution to the convergence between the current study and its predecessors it is believed that the current study may also help to shape the trajectory of future studies and the methods that might be considered at their disposal in any subsequent exploration into this uniquely subjective

phenomena. In light of this the hope remains that through the activity of subsequent studies picking up where the current study leaves off, a greater degree of confidence and assurance may be achieved into the mechanics of how research may be translated into clinical practice.

6.11 Conclusion

It is once again highlighted that this study represents a first excursion for IPA in using this particular approach for this subject. Importantly the contribution made here helps to establish a link between the pictures and the multilevel analysis by both participants and researcher in order to provide a coherence and confidence in the analysis and its results. The lasting impression that this process has made on the researcher has had a direct benefit to their clinical work. The researcher had not previously incorporated artwork in any form into their therapeutic work, but has, subsequent to the study, found it extremely beneficial to invite their patients to, capture or illustrate what living with pain 'looks like to them' if they so desired. The researcher reflects that by incorporating patient art into his clinical practice an enhanced awareness and understanding of the difficulties faced by his own patients has been achieved. It has also provided a valuable reference for the particular difficulties with which the client may be struggling, as well as an opportunity for them to articulate these concerns in a way, which feels personally relevant to them. This then reflects the primary researcher's final thoughts on the incorporation of creative means of articulating the pain experience. It is hoped that the current study may be

identified as having made a positive contribution to the approaches that may considered in helping pain patients to articulate the pain experience. It more formally hopes that the in the depiction of these powerful images alongside participants' accounts of them that they can be considered as providing support to the potential therapeutic utility of developing art therapy into clinical practice with pain patients. Thankfully the arena of chronic pain management is in somewhat of a renaissance and with recent developments adopting evermore innovative approaches, it is hoped that these conditions will lend themselves sympathetically to the findings of the current study and the potential therapeutic utility it serves to endorse.

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Version three: 29/11/2010
Appendix One

Participant information

Recruitment sheet about this research

Hello,

Firstly, thank you for sparing the time to read this information sheet about a piece of research, which aims to capture the experiences of people who live with chronic conditions.

My name is Jamie Kirkham and I am a Doctoral level psychology student looking into the impact that living in **chronic pain** has on people lives.

In my efforts to capture these experiences I am particularly interested in talking to you, if you:

1. Are female (sorry, no men this time)

2. Between the ages of 35 and 50

3. Have been experiencing chronic pain for more than two years.

4. Are **Not** receiving any hospital based treatment (e.g. injections/operations) for your particular pain problem, although you may have in the past.

5. Finally, you are still employed, part time or full, or have only recently stopped working (last 2 years)

If you feel you fit the above criteria and would like to share your own experiences, so as to better help others understand what living with chronic pain is like, then I would be delighted to hear from you.

What will my participation involve?

If you would like to participate, I would like to invite you to talk individually with me about your experiences, I should very much like to tape record our talk, so as to capture your experiences as fully and accurately as possible**. I would also like to offer the opportunity to use a variety of drawing/painting equipment to further help you to express your experiences**. I should remind you however, that, by talking and reflecting on your experiences you may at points feel distressed. If this occurs during the interview you will be reminded of your right to withdraw from the study.

You can expect the interview to last no longer than an hour and that it will be conducted at the [redacted], where you have come today for the pain education morning.

This study is separate from any treatment you receive within the service and the content of your interview will not form any part of your medical records, however, a brief note about your participation within the study will be added to your medical records unless you do not consent to this.

What will happen to the information I provide, or confidentiality

All the information that you provide will be kept in the strictest confidence. Following your interview measures will be made to ensure that any details

that may reveal your identity or those of third parties will be removed prior to any involvement in those auditing the research, or having access to your interview. Your recording will be stored in a locked cabinet and destroyed following completion of the research.

There are appropriate limitations to all confidentiality, which would include risk of harm to self and others, under these circumstances the researcher has a duty to inform relevant services should such a risk be identified

If you are interested in taking part in this research or require any further information, please contact me on [redacted] or the address detailed below, if you can leave me your details I will get back to you as soon as possible.

Contact Details:

Chief Researcher

Jamie A Kirkham
Chartered Counselling Psychologist
Psychologist for Chronic Pain

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Version three: 29/11/2010
Appendix Two

Living with Chronic Pain - An exploratory study

City University, School of Social Sciences, Northampton Square, London
Consent Form

Thank you for agreeing to participate in this study which aims to investigate people's experiences of living with Chronic Pain.

The interview that you are about to take part in will ask one central question:

What does living with Chronic Pain mean to you?

The interview will last up to one hour and will be digitally recorded. **You will also be invited to use a variety of drawing/painting equipment to help express your experiences**. Recordings will only be heard by myself, my research supervisor and other's involved in examining the project**, any art created will be made anonymous**. I also want to make you aware that in taking part in this study that any information you choose to share will be confidential. Further, measures will be taken to ensure that any details that might reveal your identity or that of others will be removed from the research or any future publications.

This confidentiality agreement complies with guidelines stipulated by the British Psychological Society (BPS) ethical guidelines.

Please also be aware that given the nature of this study, in talking about your experiences, you may be affected or reminded of challenging issues. You are reminded of your right to withdraw from the study at any point without reason.

If you are satisfied with the statements below, please sign before we begin the interview

- I have read the information sheet about this research.
- I am aware, I will be interviewed for approximately one hour and that my interview will be recorded and later analysed.
- I am aware of the main question that I will be asked.
- **I am aware that I may use paints/drawing equipment to help express my experience.**
- I am aware that I can withdraw my participation at any time without reason.
- I am aware that my identity and participation will be made anonymous unless I disclose information that may pose a risk to me or others.
- I give consent for the use of quotes taken from this interview to be used to in the current research and all future publications with the understanding that any identifying details will be made anonymous.
- I understand that the research data collected during this study may be looked at by other individuals from the research team, sponsor, and regulatory authorities or from the NHS trust, where it is relevant to my taking part in the research. I agree to give permission for these individuals to have access to my data

Interviewee
Signed _____ Print _____

Interviewer
Signed _____Print _____

Date_____

Version One: 4/04/2010
Appendix Three

Debriefing Information

We have come to the end of the interview. I would like to thank you for taking part in the study. I would be grateful if you could respond to the following:

- **That this research has been carried out in a professional and ethical manner.**
- **I am aware that the information I have given will be kept anonymously and that my interview tape and transcript will be destroyed on completion of the study.**
- **I understand I can withdraw my interview without reason.**
- **I have received relevant contacts should I need to access any support as a result of the interview.**
- **I have been invited to ask questions I may have with regards to the study.**

If you have any concerns regarding any aspect of this research and your participation in it, I remind you of the relevant contacts available as stipulated on the consent form.

Interviewee
Sign: _____ Print _____

Interviewer
Sign: _____ Print _____

Date: _____

MASTER TABLE OF THEMES FOR THE GROUP

A. Pain; perception and fantasy *(including participant artwork)*

Sub theme 1. Illustrating the pain experience

Zoë: I think it is horrible and I am having to suffer a lot of pain, but I see the gold, because it's like when I saw it, it was like, it was like a light underneath the dark crispy shell of pain and the way I saw it, it was, what I think is you know when you kind of interpret like a dream **52-56**

Zoë: the way I saw it as I was interpreting it as the gold is a good light of everything, God, not God's, because, I'm not a 'goddist', I do believe there's something, but I don't really like the word God as such, but the power of the universe, the power that says that you can have, that you can get through it **57-62**

Claire: pain ... inflammation burning and just yeah, and the blue because it's soothing, that's quite weird actually **47-48**

Gill: I suppose it's because, I'm so used to it, if you like, if getting this onto paper, I've lived with this for a few years, so it's not scary to me anymore, or anything it just is. **675-677**

Fran : Because, this is the color, I can see, it's almost like, I think I said to you before, my pain is in my spine my knees all my hands or wherever, the visualisation and these bits are like sparks flying off, where it's all out of control and is raging, its burning away, that's what all this spiky bits are, it's just burning, it's like the muscles are spasming and out of control **650-660**

Sarah: Black. It's like blackness. It's like darkness. I love the light ,and bright things, my home is light and bright, everything is, I don't like dark things, I don't like dark rooms, I like things that have got color, **418-421**

Julie: Well, the first one what does your pain look like, to me it's just like a big thundercloud, black thundercloud, **24-26**

Rebecca: Well I used red because it's quite a hot pain; I think you find that pain always seems to be hot, for some reason **403-404**

Sub theme2. Metaphors of chronic pain

Zoe: then there's the ball, it feels like I've got a big brass, like a massive chain around my neck, with one of those big balls like a big gold brass ball, where the chain goes round but the balls so big it's right there, sat right on the back of my neck and I feel that all the time pretty much, its smooth, but it is heavy and it hurts, like I've got a weight, like that **382-389**

Gill: I always used to equate it to, I used to say to people, 'if you can imagine swallowing a rugby ball covered in spikes and that's gone through and that's how it feels' **32-36**

Fran: so there is this feeling of swirling rage with spiky anger coming out, **12-13**

Sarah: No that's like the pain and these are the acute times, when I have like lightning strikes lightning bolts coming in and 'ooohh hard', you know **411-413**

Sarah : it's almost like you go through the day with gritted teeth,
248

Julie: some mornings you get up and it's all black and you can't see anything and other mornings you get up and you think it's a little bit overcast today, there's a little bit of sun at the end, that's how I sort of look at the day's **728-733**

Rebecca: but the inner nerves is excruciating, it's like having a raging toothache all the time, I think that's probably quite a good way of describing it, a magnified toothache. **409-411**

B. The 'pain matrix'

Sub theme3.Pain and the divided self

Zoe: well something changed in me, when all this happened **242-243**

Claire: I just, I don't feel like the person I was, I think I've always had quite a low self-confidence, but I just feel like half, now, **334-336**

Gill: yeah yeah, because before you just felt like, it was just pain, that was it was just pain, nothing else, I was just pain. **558-560**

Fran:, I suppose there was a lot of frustration, I was trying very hard to carry on, in the physical sense, that I always had, but then it felt there was a conflict, my body was saying no, but my mind was saying 'yes carry on' **154-158**

Julie: I think it's like there's two parts of me, a good part and a bad parts and they're just trying to fight each other; the good part is who I was before all this diagnosis and the bad one is the one that says you've got to sit down, you can't do that, You've got to accept what's going to happen. **152-158**

Rebecca: so it's, it's almost like another me, sometimes I feel like it's me inside this other person, there is this me (points to picture) and then there's this me (points to picture) Sort of there, it's all a battle trying to get out, strange, strange, weird thing to feel. **232-236**

Sub theme 4. 'Becoming' and 'being' 'abnormal'

Zoe: I feel like I haven't had a lay in in 13 years, and that I used to love as a teenager, kind of Sunday; getting up dinnertime at one o'clock in the afternoon and I cry for that, I feel, my heart aches for what I used to be like, how before all that, you know, rolling over in bed, most people it's easy it's nice isn't it? I can't, every time; it's an event for me, **189-195**

Claire: Or you just keep pushing your limits, you think I will just do this, you know it can cause pain but you just do things anyway as you want to be normal **132-144**

2 328-329
They're all just happily getting on with their lives, and living their lives

Gill: everything was just about when the pain goes, I'll go back to normal **453-454**

Fran: A feeling of being different from other people and not being able to join in in the same way I had and that went on for quite some time as well. **192-194**

Sarah :you see other people walking, around you know my friends and everything else, they base their day on their diary, or they based their day on their work pattern, or they based their day on their social network, if you like, but I don't, everything I do is based around my pain **257-261**

Julie: …but it was different to what he would have normally have done and I don't want to be treated any differently. **675-677**

Rebecca: I've got a wheelchair, and I hate and I refuse to use it, it does come on holiday with his and things but, it's very rarely gets used because that's it taking over me, that's a bit of a battle between me and the wheelchair, it's probably a psychological one **195-199**

Sub theme5. pain as resident

Zoe: but, this pain, even though I want it to go away and I pray and I'd beg for it to go away and I cry and hope that it will go away, I'd do anything for it to go away, **438-441**

Claire: it does kind of ebb and flow, but it's always there, it's never, it's never gone completely, maybe a couple of weeks, you go on holiday and it's really hot and nice and relaxed and you've not done anything but, it soon flares back up again and I think that's very hard to live with **105-110**

Gill: because I couldn't control what I ate, because that depended on the pain, whether I could eat or not, the pain would often be made worse through exercising, **470-473**

Fran : it's like a dormant virus in your body, that will, you may have had an illness by it, the illness Would have gone, but the virus will sit there waiting for an opportunity to arise when the body is weak. **740-744**

Sarah: some days it will almost leave me alone and then and then I think, oh yeah right we'll go and do something, come on mum, we'll go shopping and it's almost like, this thing comes back and makes me pay for it, you know. **542-546**

Julie:, 'it' is always there, it never goes away, so I think that's probably why I labeled it 'it' I never realized I labeled it until I was talking to you, but yeah it's always there, it doesn't go away **239-243**

Rebecca: A companion because it's always there, but not that sort of companion you would want, that you choose to have as a companion, **506-508**

B. *Pain and relationships*

Sub theme 6. erosion of the social self

Zoë: that's what annoys me, I can't have half an hour's fun, standing around talking to some people, some real live people, oh my God, do you know what I mean, it does feel like that sometimes, **368-371**

G**ill:** I don't really have any social interaction with anybody and I think, I mean, I don't know maybe if the pain hadn't have been there, I would have had the impetus to do things, to meet people, but having the pain, I have just never had the…I don't know **773-775**

442-447
:. I didn't go out, because you think, well I don't want to say to somebody that 'I will meet you next week' and then feel awful and then you keep letting them down, so you think well I'm just not going to bother even saying it and so I didn't really go out

Clair: you just you don't feel like you're talking to people properly, you can't relate to people properly, my brain just, you know, like at work and writing reports you just feel like my brain is always thinking or not thinking about the pain, just distracted and I can't think clearly about what I'm saying maybe, **347-352**

Sarah: I live by myself so there's no one there to talk to **305-306**

Julie: I mean none of my friends knew, but I knew and I just assumed that everyone else would notice, so that would make you withdraw in yourself and school discos and dances, I never used to go **410-414**

Rebecca: I could hear things and people would say do you need this, do you need that but it was if, not as if I wasn't there because I was there and, but almost like I'm sitting there and sometimes I'd shout out, and somebody would say do you want so and so, have you got whatever it is and carry on, so it would almost be as if you were passing in the Street it didn't, it sounds awful, it didn't feel like a family for a while, **118-124**

Rebecca: one day I thought, I'm going to go out on my own and I found a taxi and I went downtown and I went to go in Marks & Spencer's and I couldn't push the door, but wouldn't ask somebody to open the door for me, because as far as I was concerned, I should be able to open a shop door, but they were so heavy that I couldn't, so I was so frustrated that I went round the corner the back of a taxi went home and didn't go out again for another month. **338-345**

Sub theme 7; the systemic impact of pain, becoming a burden

Claire: I just feel like a bit of a burden to people and that they think, why can't you come out, why can't you, why can't you do this, **325-326**

Gill: I've been back home for about five years now, so I'm 38 living with my mum and dad and obviously because I only work part-time, I don't have lots of money, so they really are supporting me financially, to a certain extent and you think they are in their 60s, my dad will be retiring in September and they shouldn't have to be supporting their child. **326-333**

Fran : but she shouldn't be the center of everything and you shouldn't expect other people to give up their lives for you, just because you're suffering the pain, **364-368**

Sarah 151-154
I could feel absolutely awful and he'll say, you don't feel too good do you, and I'll say I feel dreadful and he says okay we'll cancel, so it has not only effect on you, but it has an effect on the other people around you as well

Julie: I don't want to disturb him and when I get up he gets up, because I'm not there and my son gets up, because he hears the dogs downstairs, it starts with me, but then it radiates through everybody. **258-262**

It affects everybody.

Rebecca : Then when I hurt my back, and, it was always me who took them, wherever they wanted to go, so they then started going, I need a tissue, thinking for me, I had a discussion with my younger daughter the other day about this, they felt that dad was at work and as I was the person that used to take them everywhere, they suddenly decided that they wouldn't start going to parties, because it meant that they had had to find somebody else to take my place, or it proved quite difficult transporting them here there and everywhere, so their lives changed as well, not just mine, everybody's lives changed **48-57**

Sub theme 8. Invisibility of pain, a barrier to compassion.

Zoë:, people might not believe me; if people see me, they only see me when I'm having a really good day. I stay away from everyone if I feel really bad, **448-451**

Zoë: Everyone sees me when I'm okay, if they see me they're going to expect, so they think I'm okay, because they only ever see me when I'm having a best day so, they don't see me really. **462-464**

Claire: I think, people just think oh, it's a bit of back pain, you'll be all right, or you're making it up, or it's all in your head, its mind over matter, definitely my family think like that. **129-132**

Gill:but sometimes it can get quite frustrating, because they're expecting you to do stuff and you think 'you know I can't do it I've told you this before' but then you're 'oh you're just being lazy' or 'you're doing this or you're doing that' **119-123**

Gill 900
in my sort of darker moments, where I suppose I don't think people are understanding, I think 'I'd like you to live my pain for a week and then see how you could cope with it'

Fran: it's a bit like bereavement, until you've experienced those feelings and emotions and the way that you go through those emotions and come out the other side, you can't understand what other people are going through **405-409**

5 81-82

P: Yes, it's like saying there's magic in the world, show me. Prove it to me, do something to make me see,

Sarah: but people don't understand that, they can't seem to get past… because you haven't got any sores on you, or you haven't got your arm in a sling, because there's nothing visual to see, then you're all right. **67-70**

Sarah: Yeah, it's a very fine line between telling someone how you feel and coming across as somebody who whinges. **334-335**

Julie: unless you're talking to somebody else who's been through the same thing, I mean, all the goodwill in the world people go 'I know what you're going through', they don't. **212-215**

D: Emerging as a chronic pain survivor;

Sub theme 9. Acceptance

fearlessness of pain through familiarity (1, 13, 482-484) but everything else has been 'well it's been there all the time, I'm not dead yet, so it can't be killing me, so just get on with it' well not get on with it that 'deal with it'

Zoë: however you want to see it, it's still a companion that you, if you are in a situation, where you can't get rid of it, it's definitely something you have to learn to live with, you have to learn to get on with it, even if you don't want to, that is my final thought whatever, however you think about what it is or why. **747-752**

Gill: I would equate it to I do the lottery and winning the lottery would be marvellous, but I don't live my life as if I'm going to win the lottery and it's the same with the pain, it would be great if someone would suddenly think, oh we'll test you for this and it's this and we can cure you and I'll be pain-free, that would be marvellous, I would like more than winning the lottery, but I don't live my life as if they're going to do that anymore. **152-162**

Fran: okay I've really got to slow down and acknowledge the existence of this problem I've got to modify my way of thinking so that I don't push myself to the point where my pain is so bad that I'm in a state of crisis' **184-188**

Julie: I'm never going to be free from it, but it's not going to get the better of me, so like that you've got no control but I think that's what I'm trying to grasp, trying to get control over it to stop it taking over my life I don't want that. **311-316**

756-762 Julie
'if' is a massive word and it didn't work out that way and it's not going to go away, it is going to get worse, but I think it depends on you, you have to accept what you are, who you are, before you can move on and if you don't accept it, you've got this huge hurdle that you have to get over

Sub theme 10. Constructing a new 'self with pain'

Zoë: my lower back was a huge affliction. There were several periods where I couldn't move for months and I feel, I don't want to be big headed, pretentious and say I've conquered that, because I haven't. And it can come and get me and I'm done for a few days, but I manage him, I manage it, that part, reasonably well, as long as I can do what I need to do, **608-614**

Gill: yeah, I still have the pain, it is part of my life, but it isn't everything that I'm about **629-630**

Gill: Yes, I feel more and more in control of it, rather than it being in control of me. I know that, things that they say it in the literature, so it might sound like I'm parroting it, but that is actually how it feels and that gives you confidence **549-554**

Fran: I've gone through this slow process of acceptance and where I am now and now it's time to do more, to actually go out and do more, but do different things from what I did before and so, sort of come to a sort of Crossroads and taken on a different path, a gentler physical path, but nonetheless it's still an onward movement, you know, **442-449**

Sarah: NO, that's wrong actually, I will reiterate that, you CAN control it, if I didn't, on good days, go out and do the things that I wanted to do and I take things easy, like I would every other day, possibly I could wake up the next day and not be in so much pain, as I would have been had I gone out and done what I wanted to do, so, **568-574**

Julie: All I know is that I'm just taking it, each step at a time now. I've gone to college and I've got my level 2 math's and English I've done a cake course, computers, I've done health and safety I'm in the middle of the retail course at the moment, so I'm actually getting out and meeting people, doing things, for me **322-329**

Julie 184-190

I think I have, people say 'Oh you have to go through stages', you do have to go through stages, you can't say Oh that's fine, I'll deal with it, your body isn't, your mind isn't going to do that, you have to go through these stages depending on who you are, how long it takes, I mean it's taken 11 years for me to get this far

Rebecca: I think you get into a bit of a mindset that it hurts, so I don't want to make it worse but, it doesn't matter where you are, it still hurts, so whether you stay home and hurt or push yourself a little bit and go out and hurt a little bit more it's still going to hurt, so it was, it, was what's it going to control me, or me it, it took me (large sigh) 10 years, 12 years to get to that point, you know who's controlling who. **167-173**

Sub theme 11.Pain as vehicle for growth; rapprochement

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Fran: I don't think I really want to be any different now. I've, its, it keeps me on the path I am on, and I don't think, I don't think you can go back to how it was before, because if I tried to go back to where I was before, physically, then I wouldn't be growing in that direction, **902-907**

104-106
what we visualise as bad things, like pain disabilities, in order to grow and develop and that's how I think that pain is sometimes inflicted on people

Fran pain accepted as change 4 35-40
I think that the reason being that, in my life its brought about change, which at first it difficult to accept, but over time I have realized that I can turn some negative things into positive things

Sarah: it was always a feeling that you thought positively you can do what you want to do, if you've got a positive mental attitude and I think sometimes that gets me through the day, where I think to myself, well I have two legs and I have two arms and I'm a lot better off than some people **283-287**

Julie: there is like a little soldier in there fighting this blackness, some days the blackness wins Some days the soldier wins. **514-517**

Rebecca: I think it has been positive, in the fact that, it made me do that, or facilitated me doing **449- 451**

that, it helped me to do it, because whilst I was looking at other issues, it helped me to look at everything.

Rebecca: Despite what the pain, I think I'm a lot more chilled than I used to be, **518-526**
a lot more relaxed, that sounds weird doesn't it, not that I can relax in the pain,
to me as a person I feel more relaxed, I'm not sure this person finds the necessity to
keep busy all the time, so that she didn't have to think about things, where as this
person can't be busy all the time, therefore thinks about things, I'm a lot more approachable,
apparently my friend thought I was a stroppy bugger

Value shift as a result of living in pain (1, 18, 714-722)Yes because if I had a wish, I'd have thought it would have been to not suffer the pain, but then if you had one wish it could be anything would it be selfish just to look at yourself maybe we should cure humanity of its pain, that's the person I am and before I would have just ordered £1 million and thought 'Fuck it, if I've got £1 million it doesn't matter does it' so yeah, so now, I wouldn't be without it, which does surprise me because, it hurts and I don't really want it,

Doubt creeps in
The role of ones beliefs about pain to deter from evil (1, 8, 314-317but nonetheless, I've got to believe what I believe, because if I don't believe that, then all I've got is that (points to picture) and the evil that it brings, because it does,

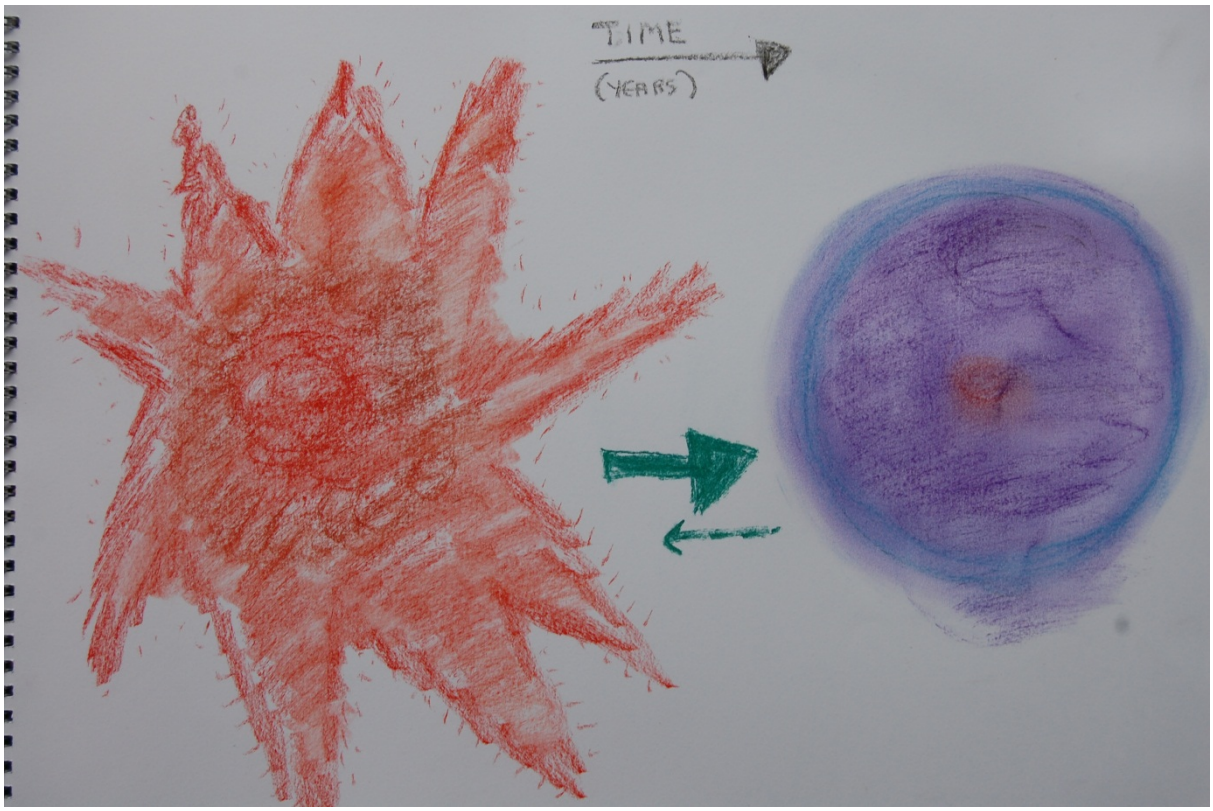
Identifying recurrent themes

sample?	Zoë	Claire	Gill	Fran	Sarah	Julie	Rebecca	Present in Over half
Pain; perception and fantasy	**yes**	**yes**	**yes**	**yes**	**yes**	**yes**	**yes**	**yes**
The 'pain matrix'	**yes**	**yes**	**yes**	**yes**	**yes**	**yes**	**yes**	**yes**
Pain and relationships	**yes**	**yes**	**yes**	**yes**	**yes**	**yes**	**yes**	**yes**
Emerging as a chronic pain Survivor	**yes**	**yes**	**yes**	**yes**	**yes**	**yes**	**yes**	**yes**

Appendix 7: FRAN providing a description and explanation of her drawing (line numbers 4-32)

Interviewer: If you can take me through what you've got here

Initially when, about I suppose 16 years ago, I started with the onset of the pain; this is how I would represent it. coarse pain, bright red, angry pain and this is how I reacted to it, like sharp spikes coming out of feelings of anger I suppose, of why has this happened to me now and it's taken away lots of things that I felt were very dear to me and things that were important in my life, so there is this feeling of swirling rage with spiky anger coming out, the colour red signifies the anger and the heat also from the pain represented by the strong red colours flaring out. With the passage of time and I'm talking about its taking me about 15 years to get where I am now, living with this chronic pain, this ultimately is where I like to be, there is still this core of pain in the middle, which is still quite sore and I have to live with, but the colours of purple and blue is like everything has calmed down from the red and blue and purple and I'm not angry anymore, so these spiky feelings have gone and it's a much smoother calmer picture here, this big arrow represents this is the way forward, this is what I'm ultimately aiming to achieve, but sometimes on bad days if I have a flare-up or something, it goes back, with the smaller arrow representing a move back to this feeling, that it's more of a physical feeling that I get, rather than a mental.



Supplementary Materials Contents Page

1. NHS application for ethical approval

2. Research and development notification form

3. Confirmation of Ethical Approval

The Chief Investigator should complete this form. Guidance on the questions is available wherever you see this symbol displayed. We recommend reading the guidance first. The complete guidance and a glossary are available by selecting Help.

Short title and version number: (maximum 70 characters - this will be inserted as header on all forms) living with chronic pain-an exploratory study

A1. Full title of the research:

Living with Chronic Pain: An Exploratory Study.

A2-1. Give details of the educational course or degree for which this research is being undertaken:

Name and level of course/ degree: PsychD , Doctorate top up in Counselling Psychology

Name of educational establishment: City University

Name and contact details of academic supervisor:

Address

Post Code E-mail Telephone Fax

Title Forename/Initials Surname Professor Jonathan Smith

Department of Psychological Science Birkbeck, Malet Street London WC1E7HX

[redacted]

Name and contact details of student:

Title Forename/Initials Surname Mr. Jamie Kirkham

[redacted]

A copy of a current CV for the student (maximum 2 pages of A4) must be submitted with the application. **A2-2. Who will act as Chief Investigator for this study?**

Address

Post Code E-mail Telephone Fax

3

DRAFT

Yes No

Integrated Research Application System **Application Form for Research**

The Chief Investigator should complete this form. Guidance on the questions is available wherever you see this symbol displayed. We recommend reading the guidanc

Short title and version number: (maximum 70 characters - this will be inserted as header on all forms) living with chronic pain-an exploratory study

PART A: Core study information

1. ADMINISTRATIVE DETAILS

A1. Full title of the research:

Living with Chronic Pain: An Exploratory Study.

A2-1. Give details of the educational course or degree for which this research is being undertaken:

Name and level of course/ degree: PsychD, Doctorate top up in Counselling Psychology

Name of educational establishment: City University

Name and contact details of academic supervisor:

Address

Post Code E-mail Telephone Fax

Title Forename/Initials Surname Professor Jonathan Smith

Department of Psychological Science Birkbeck, Malet Street XLondon WC1E7H

[redacted]

Name and contact details of student:

Address

Post Code E-mail Telephone Fax

Title Forename/Initials Surname Mr Jamie Kirkham

[redacted] [redacted] [redacted]

A copy of a current CV for the student (maximum 2 pages of A4) must be submitted with the application. 4

A2-2. Who will act as Chief Investigator for this study?

Student

DRAFT

Telephone 01304611674

Fax

A copy of a current CV for the student (maximum 2 pages of A4) must be submitted with the application.

A2-2. Who will act as Chief Investigator for this study?

Student Academic supervisor Other

A3-1. Chief Investigator:

Post Qualifications

Employer Work Address

Post Code Work E-mail *Personal E-mail Work Telephone *

Title Forename/Initials Surname Mr Jamie Kirkham

Counselling Psychologist

bsc joint major (psychology criminology) Psychotherapy Postgrad Diploma Counselling p

[redacted] St Augustines [redacted]

[redacted]

** This information is optional. It will not be placed in the public domain or disclosed to any other third party without prior consent. submitted with the application.*

A4. Who is the contact on behalf of the sponsor for all correspondence relating to applications for this project?

This contact will receive copies of all correspondence from REC and R&D reviewers that is sent to the CI.

Address

Post Code E-mail Telephone Fax

Title Forename/Initials Surname Mr Peter Aggar

City University [redacted]

[redacted]

A5-1. Research reference numbers. *Please give any relevant references for your study:* Applicant's/organisation's own reference number, e.g. R &

available): Sponsor's/protocol number: Protocol Version:

Protocol Date: Funder's reference number: International Standard Randomised Controlled Trial Number (ISRCTN):
ClinicalTrials.gov Identifier (NCT number):

DRAFT

Applicant's/organisation's own reference number, e.g. R & D (if

available):

Sponsor's/protocol number: Protocol Version:

Protocol Date: Funder's reference number (NOT IRAS ID)

Ref.Number Description Reference Number

A5-2. Is this application linked to a previous study or another current application?

Yes No

Please give brief details and reference numbers.

2. OVERVIEW OF THE RESEARCH

To provide all the information required by review bodies and research information systems, we ask a number of specific questions. T comprehensible to lay reviewers and members of the public. Please read the guidance notes for advice on this section.

A6-1. Summary of the study. *Please provide a brief summary of the research (maximum 300 words) using language easily understood by lay the website of the National Research Ethics Service following the ethical review.*

The aim of the intended study is to investigate the 'lived experience' of the chronic pain sufferer. The study aims to acquire an 'insiders perspective' by intervie chronic condition and then representing their experiences by utilising a qualitative method of analysis.

A6-2. Summary of main issues. *Please summarise the main ethical and design issues arising from the study and say how you have addresse*

The main ethical issues for this study are outlined below:

Given the subject material, participants may experience some emotional distress associated with reporting their accounts of living with their particular conditi manage this risk, participants will be reminded of their right to withdraw at any point in the process. They will also be invited to discuss any concerns or ask a given information about how to access psychological or any other necessary support. They will also be asked to share information about themselves that they

Another central ethical issues concerns confidentiality. The researcher will remove any identifiable data obtained through the interviews as well as anonymisi assured of anonymity. Limitations of confidentiality will also be set out prior to interview, i.e. if a risk to the client or someone else is identified.

3. PURPOSE AND DESIGN OF THE RESEARCH

A7. Select the appropriate methodology description for this research. *Please tick all that apply*:

Case series/ case note review Case control Cohort observation Controlled tria

Cross-sectional study Database analysis Epidemiology Feasibility/ pilot study Laboratory study

Case control Cohort observation

Full Set of Project Data IRAS Version 2.5

Controlled trial without randomisation

Cross-sectional study

Database analysis Ep

Other (please specify)

A10. What is the principal research question/objective? *Please put this in language comprehensible to a lay person.* To investigate participan

A11. What are the secondary research questions/objectives if applicable? *Please put this in language comprehensible to a lay person.*

The secondary research question will explore themes of acceptance and loss in the chronic pain sufferers life.

A12. What is the scientific justification for the research? *Please put this in language comprehensible to a lay person.*

Chronic pain is a major public health problem and has been described as having reached epidemic proportions in western society(Osborn, Smith 2006); it is th heart disease, diabetes and unemployment put together(pain coalition). Chronic pain often affects people during their most economically active years and a co cost of back pain alone in the UK was 12.3 billion in 2000. However the impacts of chronic pain conditions have a much more devastating effect on the suffer responsible for affecting and altering the sufferer's life, often beyond recognition.

Those in chronic pain often have had to leave work, sometimes relationships; self imposed isolation and financial insecurity, matched with feelings of helples decisions to direct their lives as they would like are taken from them.

What compounds the chronic pain sufferer's life further, is the difficulties in its treatment; as "chronic pain is a mystery which is unfolding as science provide differences in the way the nervous system responds to a painful stimulus may make the difference between a pain that lasts for a few days or for many years. management of pain is a challenge, both for the physician and for the person who suffers pain (Dr Joan Hester, president, British Pain Society). Until such a ti definition and understanding of pain must reflect "what the patient says it is" (Margo et al, 1986)

To that end, recent studies have begun to focus on the sufferers experiences living with their condition. Their have been only a handful of qualitative studies w pain for the sufferer. Emergent themes from this research have highlighted the impact on the sufferers sense of self and identity (Gustafsson, et al, 2004; Hells phenomenological experiences of patients who, living with their chronic condition, are able to move beyond and often between resistance and acceptance of t

This research aims to go some way in redressing this paucity. By utilizing an ideographic approach and positioning itself amongst the heart of this process, thi chronic pain and give voice to a silenced population.

A13. Please give a full summary of your design and methodology. *It should be clear exactly what will happen to the research participant, h language comprehensible to the lay person. Do not simply reproduce or refer to the protocol. Further guidance is available in the guidance note*

Potential participants will be identified following attendance and participation in a Pain Education Morning Course (run by the [redacted] Participation will be pursued in this manner as these clients will not be in psy7chological therapy with the chief investigator and this will therefore avoid any role confusion between therapist and researcher for the participants. The Chief Researcher will ask prospective participants following completion of the pain education morning, if they would like to take part in a research study investigating the experiences of those in chronic pain. Prior to making any decision, clients will be

DRAFT

A13. Please give a full summary of your design and methodology. *It should be clear exactly what will happen to the research participant, how many times and in what order. Please complete this section in language comprehensible to the lay*

Full Set of Project Data IRAS Version 2.5

person. Do not simply reproduce or refer to the protocol. Further guidance is available in the guidance notes.

Potential participants will be identified following attendance and participation in a Pain Education Morning Course (run by the [redacted] pursued in this manner as these clients will not be in psychological therapy with the chief investigator and this will therefore avoid any role confusion betwee prospective participants following completion of the pain education morning, if they would like to take part in a research study investigating the experiences o with written information, detailing the study and including research questions (See Recruitment information sheet, consent form and debriefing sheet, enclose

Following successful recruitment, participants will be offered a convenient location, time and date in which to conduct the interviews.

Interviews will be digitally recorded and last up to one hour. Participants will be given an opportunity to ask any questions or raise any issues during the inter

Following the interview, data will be transcribed and analysed using Interpretive Phenomenological Analysis (See below) procedures.

A14-1. In which aspects of the research process have you actively involved, or will you involve, patients, service users, and/or their c

Design of the research Management of the research Undertaking the research Analysis of results Dissemination of findings None of the above

Give details of involvement, or if none please justify the absence of involvement.

Participants will be interviewed regarding their experiences (as detailed above). ave ay ess given the opportunity to

4. RISKS AND ETHICAL ISSUES

RESEARCH PARTICIPANTS

A15. What is the sample group or cohort to be studied in this research?

Select all that apply:

Blood e Cancer

Mental Health Neurological

8

DRAFT

Oral and Gastrointestinal

Infection Inflammatory and Immune System

IRAS Version 2.5

Full Set of Project Data

Injuries and Accidents

Mental Health

Gender: Lower age limit: 18 Upper age limit: 80

Male and female participants Years Years

A17-1. Please list the principal inclusion criteria (list the most important, max 5000 characters).

Participants will be experiencing chronic pain for no less than two years. They would be patients accessing services falling within the [redacted] and w NHS Trust.

A17-2. Please list the principal exclusion criteria (list the most important, max 5000 characters).

Participants will not be included if they have severe or enduring mental health problems. If they lack mental capacity. participants will also be excluded if the is that these patients may have still be reliant on external influences and may not have matured in their own self management style and themes of acceptance

RESEARCH PROCEDURES, RISKS AND BENEFITS

A18. Give details of all non-clinical intervention(s) or procedure(s) that will be received by participants as part of the research protoco
and use of questionnaires.

Please complete the columns for each intervention/procedure as follows: ei1.Tdtsl ach pr of inter

2. If this intervention/procedure would be routinely given to participants as part of their care outside the research, how many of the total would be routine?

3. Average time taken per intervention/procedure (minutes, hours or days) ce 4.D ta ow w

Intervention or procedure

Participants will be invited to volunteer for the study face to face upon completion of the Pain education morning.

Participant Interviews

Interview Debrief: Giving Participants the opportunity to ask any questions relating to the study and thanked.

1 2 3 1 0 5M inutes

1 0 1Hour

1 0 10 m inutes researcher

4

Chief researcher

Chief researcher

Chief

A21. How long do you expect each participant to be in the study in total?

Up to one hour and fifteen minutes

9

A22. What are the potential risks and burdens for research participants and how will you minimise them?

DRAFT

Interview Debrief: Giving Participants the opportunity to ask any questions relating to the study and thanked.

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1 0 10 minutes

Chief researcher

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A21. How long do you expect each participant to be in the study in total?

Up to one hour and fifteen minutes

A22. What are the potential risks and burdens for research participants and how will you minimise them?

For all studies, describe any potential adverse effects, pain, discomfort, distress, intrusion, inconvenience or changes to lifestyle. Only describe research. Say what steps would be taken to minimise risks and burdens as far as possible.

It may be possible when discussing themes of the study that participants may feel distressed. Steps taken to minimise this risk include informing clients that th They will be invited to take a break at any point of the interview if they wish. If they experience any physical discomfort, they will be invited to move around

Participants will also be reminded of their right to withdraw at any point during the research process.

Finally, participants will be given information about relevant agencies and services that may be able to offer support for them if they wish.

A23. Will interviews/ questionnaires or group discussions include topics that might be sensitive, embarrassing or upsetting, or is it p occur during the study?

Yes No

If Yes, please give details of procedures in place to deal with these issues:

As above

A24. What is the potential for benefit to research participants?

This study may provide participants with the opportunity to contribute to our understanding of the processes involved in living with Chronic Pain and therefor

A26. What are the potential risks for the researchers themselves? *(if any)* No apparent risks identified.

RECRUITMENT AND INFORMED CONSENT

In this section we ask you to describe the recruitment procedures for the study. Please give separate details for different study group

A27-1. How will potential participants, records or samples be identified? Who will carry this out and what resources will be used?*For search of social care or GP records, or review of medical records. Indicate whether this will be done by the direct care team or by researchers a*

Participants will be identified on the basis that they have completed the Pain education morning and are therefore actively engaged in [redacted] service. The interview to discuss their experiences of living with chronic pain.

A27-2. Will the identification of potential participants involve reviewing or screening the identifiable personal information of patients,

Yes No

Please give details below:

A28. Will any participants be recruited by publicity through posters, leaflets, adverts or websites?

Yes No 10

If Yes, please give details of how and where publicity will be conducted, and enclose copy of all advertising material (with version numbers and dates).

Please give details below:

Full Set of Project Data IRAS Version 2.5

A28. Will any participants be recruited by publicity through posters, leaflets, adverts or websites?

Yes No

If Yes, please give details of how and where publicity will be conducted, and enclose copy of all advertising material (with version numbers and

When asked face to face, participants will be given written information regarding the research (See recruitment information).

A29. How and by whom will potential participants first be approached?

The Chief Researcher will approach potential participants upon conclusion of the Pain education morning.

A30-1. Will you obtain informed consent from or on behalf of research participants?

Yes No

If you will be obtaining consent from adult participants, please give details of who will take consent and how it will be done, with details of any s interactive material). Arrangements for adults unable to consent for themselves should be described separately in Part B Section 6, and for chil

If you plan to seek informed consent from vulnerable groups, say how you will ensure that consent is voluntary and fully informed.

The Chief investigator will give participants a consent form to read and sign prior to the interview. They will be given the opportunity to ask any questions ab

If you are not obtaining consent, please explain why not.

Please enclose a copy of the information sheet(s) and consent form(s).

A30-2. Will you record informed consent (or advice from consultees) in writing?

Yes No

A31. How long will you allow potential participants to decide whether or not to take part?

The recruitment and participation process will take place between receiving ethical approval and analysing the date. This period is expected to be approximate

A33-1. What arrangements have been made for persons who might not adequately understand verbal explanations or written informa needs?*(e.g. translation, use of interpreters)*

Any communication needs will be accommodated as necessary.

A35. What steps would you take if a participant, who has given informed consent, loses capacity to consent during the study? *Tick or*

The participant and all identifiable data or tissue collected would be withdrawn from the study. Data or tissue which is not identifiable to the research team ma

The participant would be withdrawn from the study. Identifiable data or tissue already collected with consent would be retained and used in the study. No furt on or in relation to the participant.

The participant would continue to be included in the study. – Not applicable. Informed consent will not be sought from any participants in this research.

Further details:

Participants will be given the opportunity to take part at a later date but within the proposed time frame.

Not applicable – informed consent will not be sought from any participants in this research.

Full Set of Project Data

Further details:

Participants will be given the opportunity to take part at a later date but within the proposed time frame.

CONFIDENTIALITY

In this section, personal data means any data relating to a participant who could potentially be identified. It includes pseudonymised number.

Storage and use of personal data during the study

A36. Will you be undertaking any of the following activities at any stage (including in the identification of potential participants)? *(Tick*

Access to medical records by those outside the direct healthcare team Access to social care records by those outside the direct social care team Electronic tran
personal data with other organisations Export of personal data outside the
allow identification of individuals Use of audio/visual recording d

Manual files (includes paper or film) NHS computers Social Care Service com

Private company computers Laptop computers

Further details:

A37. Please describe the physical security arrangements for storage of personal data during the study?

All data will be contained on an encrypted data recording device and stored in locked cabinet in the Chief Investigators home.

A38. How will you ensure the confidentiality of personal data? *Please provide a general statement of the policy and procedures for ensurin*

All participant details with be anonymised. This will include any potentially identifiable data.

A40. Who will have access to participants' personal data during the study? *Where access is by individuals outside the direct care team, p*

The chief investigator and research supervisor will be the only parties to have access to participants personal data during the study.

Storage and use of data after the end of the study

A41. Where will the data generated by the study be analysed and by whom?

The data obtained from the study will be analsysed by the Chief Investigator at his home address.

A41. Where will the data generated by the study be analysed and by whom?

The data obtained from the study will be analsysed by the Chief Investigator at his home address.

A42. Who will have control of and act as the custodian for the data generated by the study?

Post Qualifications Work Address

Post Code Work Email Work Telephone Fax

Title Forename/Initials Surname Mr Jamie Kirkham

Chartered Counselling Psychologist for Chronic Pain

BSc Psychology and Criminology, PG dip in the practice of Counselling Psychology and MSc Counselling Psychology.

[redacted] [redacted]

A43. How long will personal data be stored or accessed after the study has ended?

Less than 3 months 3 – 6 months – 6 12 months – 12 months 1 – 2 years over 3 years

○ ○ ○ ○ ○

A44. For how long will you store research data generated by the study?

Years: 1 Months:

A45. Please give details of the long term arrangements for storage of research data after the study has ended. *Say where data will be st*

The data obtained in the study will remain on an encrypted data stick and any written material will be stored in a locked cabinet at the Chief Investigators hom

INCENTIVES AND PAYMENTS

A46. Will research participants receive any payments, reimbursement of expenses or any other benefits or incentives for taking part i

Yes No

○ ○

A47. Will individual researchers receive any personal payment over and above normal salary, or any other benefits or incentives, for

Yes No

A48. Does the Chief Investigator or any other investigator/collaborator have any direct personal involvement

(e.g. financial, share holding, personal relationship etc.) in the organisations sponsoring or funding the research that may

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A47. Will individual researchers receive any personal payment over and above normal salary, or any other benefits or

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incentives, for taking part in this research?

A54-1. How has the scientific quality of the research be1e4n assessed?*Tick as appropriate:* Independent external review

Yes No

A48. Does the Chief Investigator or any other investigator/collaborator have any direct personal involvement (e.g. financial, share hol funding the research that may give rise to a possible conflict of interest?

Yes No

NOTIFICATION OF OTHER PROFESSIONALS

A49-1. Will you inform the participants ' General Practitioners (and/or any other health or care professional responsible for their care)

Yes No

If Yes, please enclose a copy of the information sheet/letter for the GP/health professional with a version number and date.

PUBLICATION AND DISSEMINATION

A50-1. Will the research be registered on a public database?

Yes No

Please give details, or justify if not registering the research.

if publication is achieved, it is likely that this will also be in electronic form.

A51. How do you intend to report and disseminate the results of the study?*Tick as appropriate:*

Peer reviewed scientific journals Internal report Conference presentation Publication on website

Other publication

Submission to regulatory authorities

Access to raw data and right to publish freely by all investigators in study or by Independent Steering Committee on behalf of all investigators

No plans to report or disseminate the results Other (please specify)

A52. If you will be using identifiable personal data, how will you ensure that anonymity will be maintained when publishing the results

All identifying features that could reveal the participant will be removed.

A53. Will you inform participants of the results?

Yes No

Please give details of how you will inform participants or justify if not doing so.

Participants will be given the opportunity to be sent a summary of the report upon completion.

5. Scientific and Statistical Review

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Review within a company

Participants will be given the opportunity to be sent a summary of the report upon completion.

Mr Jonathon Smith

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A54-1. How has the scientific quality of the research been assessed?*Tick as appropriate:*

Independent external review Review within a com
supervisor 0 ther

Justify and describe the review process and outcome. If the review has been undertaken but not seen by the researcher, give details of the boo
proposal for scientific rigour. As an expert in this chosen area, the supervisor has confirmed the utility of the above research question and the adequacy of the

The intended research has also been discussed and reviewed by the host institution and on the basis of nature and quality of the research question, the chief in

For all studies except non-doctoral student research, please enclose a copy of any available scientific critique reports, together with any related

For non-doctoral student research, please enclose a copy of the assessment from your educational supervisor/ institution.

A59. What is the sample size for the research? *How many participants/samples/data records do you plan to study in total? If there is more th*

Total UK sample size: 8 Total international sample size (including UK): 8 Total in European Economic Area:

Further details:

A60. How was the sample size decided upon? *If a formal sample size calculation was used, indicate how this was done, giving sufficient info*

In discussion with the Chief researchers supervisor who is an expert in this method of analysis, it was decided that in order to obtain meaningful qualitative da

A62. Please describe the methods of analysis (statistical or other appropriate methods, e.g. for qualitative research) by which the dat

The intended method of analysis used in this research will be Interpretive Phenomenological Analysis. The method and process used in this qualitative approa
later transcribed and analysed using IPA protocol. This protocol involves conducting a line by line analysis of the transcribed interview, whereupon explorato

treated to a thematic analysis, where further emergent themes in the data are identified, this process is conducted with each and every interview until emergen participants. This method of analysis therefore utilises a bottom-up approach which aims to use participants experience as the data with no hypothesis to test, that the results are generated singularly from what participants have actually said.

6. MANAGEMENT OF THE RESEARCH

A63. Other key investigators/collaborators. *Please include all grant co-applicants, protocol co-authors and other key*

members of the Chief Investigator's team, including non-doctoral student researchers.

Title Forename/Initials Surname

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A63. Other key investigators/collaborators. *Please include all grant co-applicants, protocol co-authors and other key*

members of the Chief Investigator's team, including non-doctoral student researchers.

Post Qualifications Employer Work Address

Post Code Telephone Fax Mobile Work Email

Title Forename/Initials Surname Mr Jonathon Smith

Professor BA (Cambridge) MSc (Sussex)
university of London, Malet Street, London WC1E 7HX [redacted] [redacted]

[redacted]

[redacted]

A64-1. Sponsor

Lead Sponsor

Status: NHS or HSC care organisation Academic

Pharmaceutical industry Medical device industry Other

If Other, please specify:

Commercial status:

Non-Commercial

Contact person

Name of organisation Given name Family name Address

Town/city Post code

Country

Telephone Fax E-mail

City University Peter Ayton School of Social Sciences, Northampton Square, L

EC1V OHB UNITED KINGDOM

[redacted]

Is the sponsor based outside the UK?

Yes No

Where the lead sponsor is not established within the UK, a legal representative in the UK may need to be appointed. Please consult the guidance notes.

Co-Sponsor

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Status: NHS or HSC care organisation Commercial status: Non-Commercial

Is the sponsor based outside the UK?

Yes No

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Where the lead sponsor is not established within the UK, a legal representative in the UK may need to be appointed. Please consult the guidance notes.

Co-Sponsor

Status: NHS or HSC care organisation Academic

Pharmaceutical industry Medical device industry Other

If Other, please specify:

Commercial status:

Non-Commercial

Contact person

Name of organisation Given name Family name Address

Town/city Post code

Country

Telephone Fax E-mail

[redacted]

[redacted]

[redacted]

[redacted]

Is the sponsor based outside the UK?

Yes No

Where the lead sponsor is not established within the UK, a legal representative in the UK may need to be appointed. Please consult the guidance notes.

A64-2. Please explain how the responsibilities of sponsorship will be assigned between the co-sponsors listed in A64-1 The NHS will be responsible for providing part funding of Doctorate programme, including time to conduct the study.

All other responsibilities will be with City University.

A65. Has external funding for the research been secured?

Funding secured from one or more funders External funding application
external funding will be made

A66. Has responsibility for any specific research activities or procedures been delegated to a subcontractor (other than a co-sponsor listed in A64-1) ? *Please give details of subcontractors if applicable.*

Yes No

A67. Has this or a similar application been previously rejected by a Research Ethics Committee in the UK or another

country?

Yes No 17

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Yes No

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A67. Has this or a similar application been previously rejected by a Research Ethics Committee in the UK or another

country?

Yes No

Please provide a copy of the unfavourable opinion letter(s). You should explain in your answer to question A6-2 how the reasons for the unfavo

A68. Give details of the lead NHS R&D contact for this research:

Organisation Address

Post Code Work Email Telephone Fax

Mobile

Title Forename/Initials Surname [redacted]

[redacted]

[redacted]

Details can be obtained from the NHS R&D Forum website: http://www.rdforum.nhs.uk

A69-1. How long do you expect the study to last in the UK?

Planned start date: 01/02/2010 Planned end date: 01/08/2012 Total duration:

Years: 2 Months: 6 Days:

A71-1. Is this study?

Single centre Multicentre

A71-2. Where will the research take place? *(Tick as appropriate)*

England Scotland Wales Northern Ireland Other countries in Europe

Total UK sites in study

Does this trial involve countries outside the EU?

Yes No

A72. Which organisations in the UK will host the research? *Please indicate the type of organisation by ticking the box and give approximat*

NHS organisations in England NHS organisations in Wales NHS organisations in Scotland

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HSC organisations in Northern Ireland

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A72. Which organisations in the UK will host the research? *Please indicate the type of organisation by ticking the box and give approximate numbers if known:*

NHS organisations in England

GP practices in Wales

Total UK sites in study: 0

A73-1. Will potential participants be identified through any organisations other than the research sites listed above?

Yes No

A74. What arrangements are in place for monitoring and auditing the conduct of the research?

The monitoring and auditing of the research will primarily be conducted by the Chief investigators supervisor, however their are opportunities for peer review

Also for the participants, opportunities will be made to confirm that their experience was that the research was carried out in a professional and ethical manne

A76. Insurance/ indemnity to meet potential legal liabilities

Note: in this question to NHS indemnity schemes include equivalent schemes provided by Health and Social Care (HSC) in Northern

A76-1. What arrangements will be made for insurance and/or indemnity to meet the potential legal liability of the sponsor(s) for harm *tick box(es) as applicable.*

Note: Where a NHS organisation has agreed to act as sponsor or co-sponsor, indemnity is provided through NHS schemes. Indicate if this appl sponsors, please describe the arrangements and provide evidence.

NHS indemnity scheme will apply (NHS sponsors only) Other insurance or inde

Please enclose a copy of relevant documents.

A76-2. What arrangements will be made for insurance and/ or indemnity to meet the potential legal liability of the sponsor(s) or employer(s) for harm to participants arising from the design of the research? *Please tick box(es) as*

applicable.

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Note: Where researchers with substantive NHS employment contracts have designed the research, indemnity is provided through NHS schemes. Indicate if this applies (there is no need to provide documentary evidence). For other protocol

authors (e.g. company employees, university members), please describe the arrangements and provide evidence.

Please enclose a copy of relevant documents.

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A76-2. What arrangements will be made for insurance and/ or indemnity to meet the potential legal liability of the sponsor(s) or emplo research? *Please tick box(es) as applicable.*

Note: Where researchers with substantive NHS employment contracts have designed the research, indemnity is provided through NHS scheme evidence). For other protocol authors (e.g. company employees, university members), please describe the arrangements and provide evidence

NHS indemnity scheme will apply (protocol authors with NHS contracts only) Other insurance or indemnity arrangements will apply (give details below)

Please enclose a copy of relevant documents.

A76-3. What arrangements will be made for insurance and/ or indemnity to meet the potential legal liability of investigators/collaborat

Note: Where the participants are NHS patients, indemnity is provided through the NHS schemes or through professional indemnity. Indicate if t evidence). Where non-NHS sites are to be included in the research, including private practices, please describe the arrangements which will be

NHS indemnity scheme or professional indemnity will apply (participants recruited at NHS sites only) Research includes non-NHS sites (give details of insur

Please enclose a copy of relevant documents.

A78. Could the research lead to the development of a new product/process or the generation of intellectual property?

Yes No Not sure

C. Sterilisation

Each record in this sub-section will populate an annex to the notification to the Competent Authority. It has been prepared to assist manufacture of the investigational device.

D. Summary of information for notifications to the Competent Authority

Information in the questions below will populate fields in MHRA Form PCA-2. When you have completed your application package, please sele PCA2 section and complete the documentation section.

PART C: Overview of research sites

Please enter details of the host organisations (Local Authority, NHS or other) in the UK that will be responsible for the research sites. *the research site is a primary care site, e.g. GP practice, please insert the host organisation (PCT or Health Board) in the Institution row and ins*

Research site Investigator/ Collaborator/ Contact

D1. Declaration by Chief Investigator

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PART D: Declarations

D1. Declaration by Chief Investigator

15. The information in this form is accurate to the best of my knowledge and belief and I take full responsibility for it.

16. I undertake to abide by the ethical principles underlying the Declaration of Helsinki and good practice guidelines on the proper conduct of research.

17. If the research is approved I undertake to adhere to the study protocol, the terms of the full application as approved and any conditions set out by review b

18. I undertake to notify review bodies of substantial amendments to the protocol or the terms of the approved application, and to seek a favourable opinion fr

19. I undertake to submit annual progress reports setting out the progress of the research, as required by review bodies.

20. I am aware of my responsibility to be up to date and comply with the requirements of the law and relevant guidelines relating to security and confidentialit with the appropriate Data Protection Officer. I understand that I am not permitted to disclose identifiable data to third parties unless the disclosure Wales, the disclosure is covered by the terms of an approval under Section 251 of the NHS Act 2006.

21. I understand that research records/data may be subject to inspection by review bodies for audit purposes if required.

22. I understand that any personal data in this application will be held by review bodies and their operational managers and that this will be managed accordin

23. I understand that the information contained in this application, any supporting documentation and all correspondence with review bodies or their operation

● Will be held by the main REC or the GTAC (as applicable) until at least 3 years after the end of the study; and by NHS R&D offices (where the research Practice on Records Management.

● May be disclosed to the operational managers of review bodies, or the appointing authority for the main REC, in order to check that the application has b

● May be seen by auditors appointed to undertake accreditation of RECs. ● Will be subject to the provisions of the Freedom of Information Acts and ma

to requests made under the Acts except where statutory exemptions apply.

10. I understand that information relating to this research, including the contact details on this application, may be held on national research information syste Data Protection Act 1998.

11. I understand that the summary of this study will be published on the website of the National Research Ethics Service (NRES), together with the contact po months after issue of the ethics committee's final opinion or the withdrawal of the application.

Contact point for publication*(Not applicable for R&D Forms)* *like to include a contact point with the published summary of the s*

information. We would be grateful if you would indicate one of the contact points below.

Chief Investigator Sponsor Study co-ordinator

Student Other – please give details None

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Chief Investigator Sponsor

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Study co-ordinator

Student Other – please give details None

Access to application for training purposes *(Not applicable for R&D Forms) Optional – please tick as appropriate:*

I would be content for members of other RECs to have access to the information in the application in confidence for training purposes. All personal identifiers

Signature: Print Name: Date:

..... *(delete as appropriate)* KHAM 20/02/2010

D2. Declaration by the sponsor's representative

If there is more than one sponsor, this declaration should be signed on behalf of the co-sponsors by a representative of the lead sponsor named at A64-1.

I confirm that:

1. This research proposal has been discussed with the Chief Investigator and agreement in principle to sponsor the research is in place.

2. An appropriate process of scientific critique has demonstrated that this research proposal is worthwhile and of high scientific quality.

3. Any necessary indemnity or insurance arrangements, as described in question A76, will be in place before this research starts. Insurance or indemnity policies will be renewed for the duration of the study where necessary.

4. Arrangements will be in place before the study starts for the research team to access resources and support to deliver the research as proposed.

5. Arrangements to allocate responsibilities for the management, monitoring and reporting of the research will be in place before the research starts.

6. The duties of sponsors set out in the Research Governance Framework for Health and Social Care will be undertaken in relation to this research.

7. I understand that the summary of this study will be published on the website of the National Research Ethics Service (NRES), together with the contact point for enquiries named in this application. Publication will take place no earlier than 3 months after issue of the ethics committee's final opinion or the withdrawal of the application.

Signature: Print Name:

Post: Organisation:

.....

D2. Declaration by the sponsor's representative

If there is more than one sponsor, this declaration should be signed on behalf of the co−sponsors by a representative of the lead sponsor name

I confirm that:

1. This research proposal has been discussed with the Chief Investigator and agreement in principle to sponsor the research is in place.

2. An appropriate process of scientific critique has demonstrated that this research proposal is worthwhile and of high scientific quality.

3. Any necessary indemnity or insurance arrangements, as described in question A76, will be in place before this research starts. Insurance or indemnity poli

4. Arrangements will be in place before the study starts for the research team to access resources and support to deliver the research as proposed.

5. Arrangements to allocate responsibilities for the management, monitoring and reporting of the research will be in place before the research starts.

6. The duties of sponsors set out in the Research Governance Framework for Health and Social Care will be undertaken in relation to this research.

7. I understand that the summary of this study will be published on the website of the National Research Ethics Service (NRES), together with the contact po than 3 months after issue of the ethics committee's final opinion or the withdrawal of the application.

Signature: Print Name:

Post: Organisation:

Date:

.....

(dd/mm/yyyy)

D3. Declaration for student projects by academic supervisor

1. I have read and approved both the research proposal and this application. I am satisfied that the scientific content of the research is satisfactory for an educational qualification at this level.

2. I undertake to fulfil the responsibilities of the Chief Investigator and the supervisor for this study as set out in the Research Governance Framework for Health and Social Care.

3. I take responsibility for ensuring that this study is conducted in accordance with the ethical principles underlying the Declaration of Helsinki and good practice guidelines on the proper conduct of research, in conjunction with clinical supervisors as appropriate.

4. I take responsibility for ensuring that the applicant is up to date and complies with the requirements of the law and relevant guidelines relating to security and confidentiality of patient and other personal data, in conjunction with clinical supervisors as appropriate.

Signature: .....

Date: *(dd/mm/yyyy)*

D3. Declaration for student projects by academic supervisor

1. I have read and approved both the research proposal and this application. I am satisfied that the scientific content of the research is satisfactory for an educa

2. I undertake to fulfil the responsibilities of the Chief Investigator and the supervisor for this study as set out in the Research Governance Framework for Hea

3. I take responsibility for ensuring that this study is conducted in accordance with the ethical principles underlying the Declaration of Helsinki and good prac supervisors as appropriate.

4. I take responsibility for ensuring that the applicant is up to date and complies with the requirements of the law and relevant guidelines relating to security a supervisors as appropriate.

Signature: ..... Print Name:

Post: Organisation:

Date: *(dd/mm/yyyy)*

RESEARCH AND DEVELOPMENT NOTIFICATION FORM

All research in the NHS must be carried out in accordance with the Research Governance
Framework. A summary of this framework can be found in the R&D policy, this can be
accessed via the Trust intranet. In order to comply with the requirements under the Research Governance Framework you must complete this notification form for each research project you intend undertake within the Trust.

Any notification forms should be sent via email to Ian Maidment [redacted]

Project title: Living With Chronic Pain-an exploratory study

Project number To be assigned by R&D group.

Chief Investigator Name: Jamie A Kirkham

Address [redacted]

Email: J[redacted]

Speciality: Psychologist for Chronic Pain

Name of Sponsor: City University

Does the Chief Investigator hold a substantive contract with the
trust (honorary contract not sufficient)

YES
If no please give the name and contact details of a Principal Investigator employed within the
trust

Is the project any of the following -
1. Student research. YES…… ……
2. Part of a commercial clinical trial. …… NO……
3. Part of a project with one of the research networks. …… NO……
Once the form has been received by the R&D office, the project will be assigned to a member of the R&D committee, who will guide you through the governance process and the documentation required by the committee.

National Research Ethics Service
[redacted]

Telephone: [redacted]
Facsimile:

08 November 2010

Mr Jamie Kirkham
[redacted]

Dear Mr Kirkham

Study Title: **Living with Chronic Pain- An Exploratory Study.**
REC reference number: **10/H1111/42**

Thank you for your letter of 14 October 2010, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Acting Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation (as revised), subject to the conditions specified below.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

For NHS research sites only, management permission for research ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Where the only involvement of the NHS organisation is as a Participant Identification Centre (PIC), management permission for research is not required but the R&D office should be

notified of the study and agree to the organisation's involvement. Guidance on procedures for PICs is available in IRAS. Further advice should be sought from the R&D office where necessary.

Sponsors are not required to notify the Committee of approvals from host organisations.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
Investigator CV		19 June 2010
Protocol	1	17 June 2010
Letter from Funder		06 August 2010
Academic Supervisor CV		11 August 2010
REC application		20 February 2010
Covering Letter		04 August 2010
Letter from Sponsor		06 April 2010
Interview Schedules/Topic Guides	2	04 October 2010
GP/Consultant Information Sheets		03 October 2010
Participant Information Sheet: (Appendix 1)	2	04 October 2010
Response to Request for Further Information		14 October 2010
Participant Consent Form: (Appendix 2)	2	04 October 2010
Evidence of insurance or indemnity		01 August 2010

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document *"After ethical review – guidance for researchers"* gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email [redacted]

10/H1111/42	**Please quote this number on all correspondence**

Yours sincerely

[redacted]

Acting Chair

Email: Sharon.Busbridge@nhs.net

Enclosures: "After ethical review – guidance for researchers"

Copy to: *Mr Peter Aggar*
Mr Peter Dodds

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Section C: Professional Practice Clinical Case study

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Section D: Systematic Review of literature/Critical Review: The emerging role of psychology in the context of chronic pain, a critical review of the literature.

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The emerging role of psychology in the context of chronic pain, a critical review of the literature

The aims and objectives of this critical literature review are twofold. Firstly it is the ambition of this review to explore the context in which health care for chronic pain problems has developed and consider how treatment for these problems has evolved over the last half a century. Secondly this review will seek to identify how the role of psychology in the management of these conditions has made a valuable contribution to both the understanding and treatment of these conditions and is argued to be of paramount importance in the future directions that pain management is expected to take.

In reviewing these objectives, it was considered both valuable and necessary to provide some context and background to these discussions by exploring the historical and contemporary perspectives of the medical world's understanding of these complex conditions and the treatment response to them. This initial focus will disclose how the 'traditional' Biomedical model's perspective and response to these difficulties has revealed itself to be 'inadequate and only moderately effective at best' (Turk et al. 2011) and that in the face of this inadequacy, increasingly a move towards a Biopsychosocial model of pain has been adopted. This model is now 'widely accepted as the most heuristic approach to both the understanding and treatment of pain disorders' (Gatchel & Okifuji, 2006; Gatchel, et al. 2007; Turk & Monarch, 1996). However and critically, this acceptance has not produced the sea change in the treatment of these conditions one might expect to see, and as this critical review will

demonstrate there remains widespread inconsistency and incoherence in achieving the much needed holistic vision of care necessary to support those living with the profound difficulties of chronic pain

The 'Medical Model' and the mechanical approach to the problem of pain

The treatment of pain, like the treatment of most health conditions, initially falls under the remit of the prevailing medical model, a model of treatment, the roots of which can be traced right back to the time of Rene Descartes (1644). Descartes' claim was that pain or illness was a phenomenon which, rather than having its origins arising from a spiritual dimension, actually had a physical or mechanical explanation. This was a bold departure from the prevailing beliefs held at the time. Until then the view held was that pain was divined as some form of chastisement and as such could only be cured through the sufferer's repentance and prayer or through the intervention of some 'witchdoctor like' character, who may have prescribed or inflicted some fairly barbaric interventions. Descartes' contrasting view was put forward at a time of great change and at the beginning of an evolving global scientific revolution, where the emerging philosophies of empiricism and positivism helped to usher in new ways of understanding the body. These views eventually gained greater and wider support, recognition and acceptance and in their development, effectively sowed the seeds of the Biomedical model, or as we are more familiar with it today, the 'Medical Model'.

The pre-eminence of this model has over the last 400 years, been largely unchanged or unchallenged. During this time the Medical Model has very much become firmly embedded within our cultural assumptions as being the most legitimate model of

health care and the most observable response to the health needs of our society. The validity and appropriateness of the Medical Model has helped to secure its position through both the authority and immutability of its epistemology. This epistemology is built upon the foundations of objectivism and positivism and articulated through the narratives of 'technical rationality' (Woolfe & Dryden 2003). It contends that there are discoverable laws or 'truths', which when observed or learnt can allow for the prediction and control of human behaviour and similarly can be relied upon to disclose the trajectory of an individual's health or illness (Woolfe & Dryden, 2003). In achieving these aims this narrative is supported by the interminable drive towards the measurability/ quantifiability of data and the derivation of statistical laws, uninfluenced by the prejudice of emotions or the variance of subjectivity.

In adherence to these rules and assumptions the Medical Model approach to pain is both mechanistic and reductive and remains consistent with the laws prediction and control. It contends that pain is a symptom of an underlying cause which in both its evaluation and its occurrence is directly implicated to the degree to which damage is occurring or has occurred. The treatment rationale would therefore be inclined to seek to identify this 'root cause' and in its identification apply a rationale that presumes that like 'a machine, it (the problem) can then be fixed, by either removing or replacing the ailing part, or destroying the foreign body that is causing the problem' (McClelland, 1987).

To some extent the suitability of this profile and rationale remains an entirely appropriate assumption, especially when considering pain in its acute context. However chronic pain neither follows this expected trajectory, nor does it conform to

these same rules of prediction and control. Indeed in its definition, chronic pain is alluded to as being outside this remit, as it occurs beyond 'the time that healing would have been thought/expected to have occurred' (BPS website, accessed 2014) and therefore has neither conformed to the expectations or efforts of the medical model. This incongruity appears to have been firmly established in a recent study looking at the efficacy of conservative measures for chronic pain (Lamvu et al. 2006). This study established that surgical options for improvements with chronic pelvic pain compared with non-surgical treatments, yield only a small percentage, around 15 %, of people having their situation comprehensively alleviated by conservative measures (Lamvu 2006. Moffett et al.1995). This very low figure is both a powerful representation of the limitations of the Medical Model for chronic pain and further an admission that once a pain becomes chronic, rarely will it go away by itself, or equally has it the potential to be 'cured' (Elliott et al. 2002).

The Biopsychosocial Model

The deviation from prediction and control in chronic pain reflects both an especially difficult aspect in the treatment of these conditions, as well as one of the greatest 'paradoxes of pain management' (Fagerhaugh & Strauss, 1977), whereby the current set up of the health system seems at odds with the demands of the condition, and a model that seeks to bring about restitution seems at odds with what can reliably be achieved with these types of difficulties. In the face of both this misalignment, and the growing concern about the 'epidemic' (Waddell, 2004) of chronic pain, it was indeed timely that in the 1960s and 70s an alternative 'Medical Model' emerged,

which sought to provide a fresh perspective on both the understanding and treatment of these types of complex conditions.

This 'alternative' model was spearheaded by George Engel (1977) and is referred to as the ‘Biopsychosocial’ (BPS) approach. Engels felt that the existing monocular approach to illness undermined the reality that pain is in fact very much a dynamic, subjective phenomenon, which he argued was better represented as a holistic concern, comprised of and arising out of a combination of unique influential factors surrounding that individual. This belief and the origins of the Biopsychosocial approach to chronic pain can actually be traced back a decade earlier to the ‘Gate Control Theory’ of pain, as presented by Malzack and Wall (1967). The Gate Theory was the first significant proposal to suggest that pain would be more accurately classified as a perception or an experience rather than just a sensation, and that this subtle reclassification implied that discreet aspects of the individual were themselves influential in the perception of that pain. This position was subsequently supported by and endorsed through the International Association for the Study of Pain (Merskey et al. 1979). However it was only after a significant number of studies had proven, without a shadow of a doubt, that indeed pain related disorders were the result of a complex interaction of physical, psychological and social factors, that the Biopsychosocial Model gained favour and began to be adopted in both medical and rehabilitation contexts (Gatchel & Turk, 1999; Gatchel, 2004;Turk et al. 2002).

Psychosocial factors in pain perception

The implication of the Biopsychosocial Model challenged the pre-existing views held about the understanding and treatment of pain, and argued that in order to provide a more meritorious response there was now a need to broaden the scope of the clinician's gaze to include those dimensions which had traditionally been left outside the domain of clinical relevance. The efforts over the next 25 years to examine more closely these other dimensions have been extremely valuable in developing a more comprehensive understanding of the mediating factors in chronic pain. Factors as broad as an individual's socio-cultural background (Adler & Matthews, 1994, Andersson et al. (1993), ability to access medical care (Thorn, 2004), and isolation (Macdonald & Leary, 2005) as well as the role of the family (Snelling, 1994) appear to be significant contributors to the chronicity of chronic pain and all are associated with poorer outcomes for patients (Harstall & Ospina, 2003; Otis et al. 2004; Miller & Kraus, 1990). In addition to these social factors a great many psychological concerns have also been highlighted as being either negatively associated with or a consequence to the impact of living with chronic pain. The individual's propensity to catastrophise and the degree to which illness perceptions were held and fear avoidance beliefs followed (Snelgrove & Liossi, 2009), as well as links between pain perception and hyper vigilance (Derch et al. 2002); the relationship between pain, mood, self-esteem and depression (Ploghaus et al. 1999; Burton, et al. 1995; Malzack & Wall, 1967, 1982; Adler & Matthews, 1994, Shealy 1995); and certain personality types (Sternbach, 1986) have all been equally identified as being significant influences on the adjustment or lack of it to chronic pain.

It is now agreed that in spite of the degree to which the biological concerns represent a key determinate in an individual's difficulties, it is these other factors which are both 'unrelated to' or 'removed from the original cause' which may actually have a greater determinacy on the degree to which 'disability' becomes a feature of an individual's condition (Main & Williams, 2002; Weisberg & Keefe, 1999). These 'psychosocial' indices of chronic pain have now become an increasingly important feature in shaping the clinical response to these types of conditions, as well as helping to inform those professions which might be best placed to respond to these types of holistic concerns.

A Multidisciplinary response to the treatment of chronic pain

There have been continuously calls throughout the literature (Arnau, et al. 2006, Donaldson, Chief Medical Officer Annual Report, 2009; The National Pain Audit 2011) for trusts to provide services, which reflect the needs of those living with persistent pain. Of all approaches to the treatment of chronic pain, none has a stronger evidence basis for efficacy, cost-effectiveness, and lack of iatrogenic complications than multidisciplinary care (Turk & Okifuji 1998). There are various forms of multidisciplinary teams (MDT), comprising different members and disciplines. However it has been suggested (National Pain Audit 2011) that in order to be regarded as offering a truly multidisciplinary service the involvement of at least two or more distinct disciplines must be present. The disciplines that comprise an MDT

largely reflect the aims of the Biopsychosocial Model and adhere to its vision of holistic care. Therefore alongside a surgical team the members of a multidisciplinary team may also include Psychologists, Physiotherapists, Occupational Therapist, and Clinical Specialist Nurses, often supported by other forms of complimentary therapies (Tai chi, acupuncture, Alexander Technique).

Focusing specifically on the role of the psychologist within a Pain Management service it is suggested that due to their training and background they might be particularly well positioned to respond to the profound psychosocial consequences of living with pain, as well as assisting in its management. Typically, a psychologist will be informed by and draw from a largely Cognitive Behavioral therapy (CBT) based approach adapted for chronic pain. Developed by Turk, Meichenbaum and Genest (1983), this approach endorses the view that an individual's cognitions, affect and behaviour (Keefe & Gil, 1986) are central in the development of a pathophysiology and therefore can influence the degree to which disability or chronicity becomes associated with their condition. Patients receiving this treatment are encouraged to both identify and explore their own unique resources, as well being introduced to a wide range of skills, such as thought and behaviour modification stress inoculation techniques and goal setting each designed with a view to help challenge the intransigence of negative thinking and the associated consequences to an individual's self-efficacy. The success of the introduction of these psychological approaches has on the whole been favourable, with a meta-analysis evaluating 28 Randomized Controlled Trials (RCT) in which CBT was adopted as a treatment protocol for chronic pain concluding that those receiving treatment which included CBT demonstrated a significant improvement, compared with those on waiting list (Boersma & Linton, 2002). More specifically, it has been shown that these

approaches and techniques can help decrease physical and psychosocial disability (Turner et al. 1990), decrease depression scores (Kleinke, 1991) and also anxiety scores (Turk et al. 2003). In terms of their longevity, positive outcomes have been identified as being maintained at 12 months (Bradley et al. 1987) and in some instances even longer.

Recently new developments in the psychological treatment of chronic pain have introduced 'third wave' approaches such as Biofeedback (Arena & Blanchard, 1996), Mindfulness (Kabat-Zinn, 1990) and Acceptance and Commitment Therapy (Hayes & Duckworth, 2006). A central feature of each of these newer approaches reflects the central role of the patient in the management of their condition and each modality's ambition strongly implies that their intent is not to change, cure or obscure the patient's pain, but instead help them develop ways in which they are able to change how their pain is experienced (Molloy et al. 2006).

The effectiveness of these new psychological approaches have achieved some considerable attention in recent years (Mindfulness: Rosenzweig et al 2010; Morone, et al. 2008; Acceptance and commitment therapy; Gutierrez, Luciano & Rodriguez, 2004 Bhatnager, 2011) and have lent further support to the appropriateness of non-interventional approaches in the treatment of these types of conditions. The accumulated evidence base for instance over the last twenty years for the efficacy of CBT interventions for reducing pain and improving physical and psychological functioning in adults and children with persistent pain (Eccleston, Williams, & Morley, 2009; Morley,2011; Ostelo et al., 2005; Palermo, Eccleston, Lewandowski,Williams, & Morley, 2010), and is considered to be comparable to that for other treatments (A. C. Williams, Eccleston, & Morley, 2012).

Curiously, although there is now a growing body of evidence supporting the development of the Biopsychosocial Model and the role of psychology in pain services is apparent, those services actually offering a truly 'multidisciplinary approach' are few and far between. The National Pain Audit, which is perhaps the most comprehensive insight into the current state of the nation's scale and response to the problem of pain, identified high variations in both referral and waiting times, coupled with the high variations in standards, reflecting a huge discrepancy on a national level with the availability of these services. 28 Primary Care Trusts (PCT's) appeared to offer no such services at all, with one provider claiming that it would paint its service in a bad light if it returned data on its own lack of provision. The services that did return data revealed a fairly low presence of both psychology and physiotherapy, suggesting that the majority of patients were not in receipt of truly multidisciplinary services.

The lack of provision of multidisciplinary services suggest strongly that what patients receive in these trusts is a model of care which may predate the development of the Biopsychosocial model and therefore does not match the complex needs of these conditions. What seems to be more troubling however is that in spite of the understanding that surgical intervention for chronic conditions yields demonstratively poor results, the enthusiasm for conservative approaches does not appear to have significantly diminished or abated. A powerful representation of this was reported in a recent study by Deyo et al. (2009) who recorded that in the last few years there had been a 629% increase in Medicare expenditure for epidural steroid injections, a 307% increase in the number of lumbar magnetic resonance images and a 220% increase in spinal fusion surgery rates. Similar figures also exist in the UK (Audit Commission, 2011) as do sadly the number of complaints by patients who declare that surgery

actually made their chronic pain worse not better. There has also been an increasing incidence of reporting post-surgical pain, where a chronic pain condition develops as a direct consequence of some unrelated procedure, as well as some additional unsettling findings which suggests that surgery itself is responsible for the onset and development of a large number of chronic conditions (Kalso et al. 1992; Keller et al. 1994). These sobering reports may invite some caution and cause for reflection as to the on-going efforts of the medical response to these types of difficulties and serve to highlight the reality that although a multidisciplinary team adopting a Biopsychosocial focus is espoused to represent the most heuristic approach to both the understanding and treatment of pain disorders (Gatchel & Okifuji, 2006; Gatchel et al., 2007; Turk & Monarch, 2002), those trusts that are actually providing this 'gold standard' of care to their patients remains woefully low.

At this time it would appear that the future of pain management is at a crossroads, clearly there is support for the value and validity of the Biopsychosocial approach, but this approach is often at odds with the dominance of the Medical Model, which it is clear continues to maintain its strong hold and authority over the governance of this particular problem. Nowhere is this more evident than in the current design of the British Pain Society (BPS), which represents the single greatest authority in the UK on pain matters. This organisation reflects in its ranks that those espousing a traditional biomedical approach significantly outweigh those who might be approaching pain from an alternative perspective. Both the current Chair and President are from a medical model background, and although psychology has its own working parties, its status and presence is not equal to that of its contemporaries. For

the role of psychology and the Biopsychosocial Model to take on a greater position within the development of the future of pain management, then psychology must position itself in alignment with this traditional approach, as well as evolving to capture and reflect its importance in shaping the future of pain management.

There is now more than ever a strong incentive for the efficacy of these interventions to be developed in order to reflect that not all psychological treatments are effective for all patients. Recently a drive towards matching interventions to patients based on a number of factors has been conducted. This was done to identify treatment responders (e.g., 30% improvement in pain severity, 20% improvement on a functional outcome) and then used regression analysis to identify the characteristics (predictors) of treatment response. For example, Thieme and colleagues (Thieme, Turk, & Flor, 2007) identified different pre-treatment characteristics associated with different response rates to CBT, relative to a treatment based on operant conditioning. This sort of matching is intended to enhance the efficacy of psychological methods, and to identify whom they are most likely to benefit. This approach reflects the evolving role of psychology and psychological methods in its attempt to get better results for those living with chronic pain and also reflects that achieving more reliable and accurate data may itself better support the future of psychological advances in pain management. This advance is clearly a good thing, but is not the only change occurring within the field of psychology in the context of chronic pain. Indeed, from looking at a number of recent studies there is a growing emphasis on how psychology is seeking to embrace and incorporate the advances being made in modern technology in order to better prepare and respond to the problem of pain and provide a truly 21st century response to this issue.

Future directions

In a recent review celebrating the contributions made by psychology to the understanding and treatment of people with chronic pain (Jensen & Turk, 2014), and considering the future directions that pain management might take it was hypothesized that a range of technical advances may assist pain management. It suggested that in the coming years sophisticated imaging procedures, technologically enhanced psychological pain treatments, and combined treatment might reflect an even more considered response to the management of chronic pain. A recent advance in imaging, for instance, such as fMRI have helped to identify specific regions of the brain associated with self-reports of pain. These images have been able to identify unique physiological responses in the brain, which are associated with the impact caused by chronic pain on the individual. It has been identified that specific areas of the brain that are associated with emotional responses, attentional foci, and processing of noxious stimulation (Apkarian, et al 2011, Seminowicz & Davis, 2006) are all illuminated. The clinical utility of identifying these areas was highlighted in the comparisons in activity in these areas both before and after pain treatments. These changes held particular significance as the 'pain treatments' that were referred to were all of a psychological nature, rather than pharmacological, thus providing for the first time observable evidence representing the effectiveness of these intervention to change brain structures and processes. It is suggested (Jensen, 2010) that there is much scope to develop this approach and combine treatments that actively target these areas in the brain in order to further enhance the value of psychological approaches to the management of these conditions.

A further strand in which pain management itself is evolving is in the field of genetics. Genetic variations have already been implicated in providing a partial explanation for sensory sensitivity, emotional distress, and inhibition and persistence of pain (Diatchenko et al, 2005). Once again it is suggested that the advancement is beginning to reveal hidden aspects of the mystery of chronic pain, to answer why two people, both whom may share identical conditions, may report totally different accounts of the degree to which pain is recorded as a symptom of their condition. Although nothing can yet be done to change a genetic code for being a 'high risk' patient, what the identification of these individuals may provide is the advantage of intervening earlier and in a more comprehensive way, so as to offset the potential pain related disability and suffering that is so much a part of these types of conditions.

Once again rapidly evolving technology and the ubiquity of social media have ushered in an array of web-based tools that are fast becoming a feature of the future of pain management. The advantage of these tools may have a particular value with chronic pain patients, who themselves may struggle with both the physical requirement and commitment demanded by chronic pain services. The advantage of these online tools, which themselves are underpinned by psychological approaches, has already been the subject of a large study conducted by Macea et al (2010). Macea identified no less than 11 studies in which web-based interventions had been developed and evaluated. The pooled effect size for pain reduction as identified across these separate studies identified a .29 effect size (95% confidence interval = (.15,.42),. Alongside this, other positive outcomes for web-based designs identified a reduction in pain behaviours, decreased depression and anxiety scores, greater capacity for

work, reduction in medication and reduction in physician visits. Although in its infancy, there are now an ever growing number of legitimate pain services that are either developing or turning to online resources as a means of providing further support to pain patients in a format which can accessed 24 hours a day from the privacy of their own homes.

The last half a century has seen much change in both the understanding and treatment of chronic pain conditions. Now more than ever the role of psychology represents a central feature in this development as suggested by Jensen and Turk (2014) in their conclusion that, 'psychologists have made and continue to make significant contributions to the science of relieving human suffering' (p. 115). It is believed that this time represents a "golden age" of pain study and that this, in real terms, represents an optimistic and hopeful forecast both securing the role of the Biopsychosocial Model and a vision of holistic care. Perhaps more importantly, for the treatment of those living with the debilitating conditions, it is an endorsement that the role of psychology will be at the forefront of this ascending narrative.

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