

**The Experience of Co-Morbidity: An Interpretative  
Phenomenological Analysis: Living with Chronic Pain and  
Traumatic Stress**

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## Abstract

There are few qualitative studies exploring co-morbidity and specifically the experience of living with chronic pain and traumatic stress. In addition existing research has focused on the relationship between chronic pain and post-traumatic stress disorder (PTSD) but has not considered the impact of complex post-traumatic stress disorder (CTPSD) on co-existing chronic pain.

The aim of this study was to explore the individual's unique experience of living with co-morbid chronic pain and traumatic stress. This study also supports a wider formulation by exploring CPTSD as a construct, acknowledging the diversity of symptoms beyond the diagnostic criteria of PTSD. Five participants were interviewed about their experiences. Interpretative phenomenological analysis (IPA) was used to analyse the data.

An IPA analysis revealed six superordinate themes: 1) "Every day is just such a struggle"; 2) Isolation; 3) The relationship between chronic pain and traumatic stress; 4) Chronic pain and traumatic stress change the relationship with the self; 5) Ways of coping with chronic pain and traumatic stress; 6) Moving forward; learning to adjust and live with chronic pain and traumatic stress.

The super-ordinate themes highlight the everyday reality of living with this co-morbidity, suggesting that co-morbid chronic pain and traumatic stress do not exist as separate isolated symptoms but are impacted by individual, relational and social factors. The results also highlight the complex interrelationship between chronic pain and traumatic stress.

Implications for policy and clinical practice include raising awareness and providing access to effective care pathways for clients who live with this distressing co-occurrence. An integrated treatment approach is required to address the meaning and multi-dimensional nature of living with this co-morbidity. Recommendations are made for further research in this area.

# Chapter 1

## 1. Introduction

It is apparent that an increasing number of people live with combined physical and mental health conditions with health care services under increasing pressure to address the management of co-morbidity. As identified by Valderas et al. (2009), co-morbidity has a significant impact on the quality of health care, mortality and the individual's quality of life and functioning.

My interest in the area of co-morbidity developed whilst working as a psychological therapist in a physical health setting. I was working predominately with people who live with chronic pain. It became increasingly apparent to me working in this area that many people experiencing chronic pain also experienced traumatic stress. This co-morbidity seemed to create significant and enduring distress for people as well presenting challenges for us as health care professionals to provide treatments and interventions aimed at improving quality of life.

In order to formulate my research question I started by returning to my earlier experiences of co-morbidity. I first encountered the term co-morbidity as a nurse. My understanding at this stage was purely based on the idea that co-morbidity exists as the presence of more than one distinct condition in an individual. Although I recognised that co-existing conditions complicate the clinical picture, I did not really appreciate the meaning and the psychological impact of living with co-morbidity from the individual's perspective. Medically the management of co-morbidity relies on compartmentalising into a symptom based approach. Although important, such an approach neglects the complexity and interplay between the conditions and how the individual themselves views co-morbidity. As highlighted by Meyers (2015): "a single definition ignores how episodes of distress come to shape the expression and management of other disorders for the individual in unique ways."

Training as an integrative psychological therapist and working in health psychology highlighted the importance of working with the unique subjective experience of the individual. For me co-morbidity as a concept raised questions and tensions between the medical model versus the humanistic and relational values of Counselling Psychology. It was my intention, based on the values of Counselling Psychology, to explore co-morbidity in its wholeness, honouring the uniqueness and multiple levels of the client's experience within the totality of their life situation. I believe the reflexive nature inherent in Counselling Psychology practice encouraged me think about the importance of bridging the gap between science and practice and the value therapeutically of holding multiple perspectives.

By adopting interpretative phenomenological analysis (IPA) as the research methodology, I was concerned with developing deeper subjective understanding about what it means to be a human being living with co-morbid chronic pain and traumatic stress. A phenomenological perspective acknowledges that there is no one objective truth, rather truth is based on the individual's subjective experience of the world and co-created in relationship with others. Therefore exploring the conflicts and context of each individual situation as well as holding in mind the idea of potentiality is integral to the research process. It was Heidegger (1962) who drew our attention to the 'thrownness' into which we arrive in the world. This is also explained by the sciences of chaos and complexity theory (Miller, 1999; Masterpasqua, 1997) supporting the idea of a postmodern self; interactive and negotiating an ever-changing world. From a research and therapeutic perspective, my belief is that chaos and complexity theories invite an openness to staying with a process that is often messy and unpredictable, subtle and unique, where change emerges in "stable and unstable" forms (Miller, 1999, p. 355).

There is a paucity of existing research exploring the qualitative experience of physical health comorbidity and specifically comorbid chronic pain and traumatic stress. As psychologists we know that patients attending pain clinics often come to us when all other specialists have been unable to treat the pain, adding to the sense of helplessness and hopelessness experienced by clients and sometimes clinicians. This research project aims to develop insight into the unique ways that prolonged and or repeated exposure to trauma shapes an individual's experience of pain.

Ultimately it is about finding ways to improve the lives of those individuals who live with this prevalent and distressing co-occurrence, acknowledging that there are “no one size fits all” answers. Therefore I have selected a qualitative, phenomenological research method, which importantly gives the participant a “voice” (McLeod, 2003) in the research process; making the invisible, visible, and addressing the complexity of a life dominated by pain and psychological trauma.

As I embarked on this research study it was with a strong belief in the importance of listening to the voices of people who live with chronic pain and traumatic stress. My reasoning was that a phenomenological stance into their experiences would open up an area which in many ways remains a mystery, with the relationship between chronic pain and traumatic stress still poorly understood.

This thesis contains the narrative of five individuals living with chronic pain and traumatic stress. Their fascinating contributions have opened up new and exciting areas, creating alternative perspectives that will greatly inform our understanding of chronic pain and traumatic stress as co-occurring conditions.

### 1.1 Research Question

How do people living with co-morbid chronic pain and traumatic stress understand and make meaning out of their experience?

### 1.2 Background and Rationale

Chronic pain has been described as a “public health crisis” by the Institute of Medicine (2011), revealing that more people are suffering from pain than from diabetes, cancer and heart disease combined. It is estimated that 14 million people live with chronic pain in England alone (Bridges, 2012). Morris (2003) states that chronic pain is the “invisible crisis at the center of contemporary life.”

The 2008 Chief Medical Officer report states that 25% of pain sufferers lose their jobs and 16% of sufferers consider their pain is so bad they sometimes want to die (Donaldson, 2008). Chronic pain is also associated with an increased mortality risk independent of socio-demographic factors (Department of Health, 2012). The Department of Health (2012) now recognises chronic pain as a long-term condition in its own right and alongside this it has also been highlighted that attending specialist pain services improves quality of life, with 76% reporting improvements in pain-related quality of life (National Pain Audit, 2012). In 2016 David Clark, Professor and Chair of Psychological Therapies Programme, announced plans for further expansion of the Improving Access to Psychological Therapies Programme (IAPT) by focusing on anxiety and depression in the context of long-term physical health conditions and medically unexplained symptoms. The implications are that physical and mental healthcare provision will be co-located, with psychological therapies integrated into existing medical pathways. Therefore clients will be increasingly able to access an IAPT service in their area in addition to any existing secondary or tertiary care services.

In addition to the increased awareness around chronic pain, studies have identified that chronic pain shares several co-morbidities. These co-morbidities include depression, anxiety, sleep disturbances, fatigue and neurocognitive changes (Dahan, Van Velzen and Niesters, 2014), reducing the quality of life for the individual. The current study is concerned with a growing body of evidence suggesting that a high percentage of people who live with chronic pain also live with some form of traumatic stress (Sharp and Harvey, 2001; Asmundson et al., 2002; Beck and Clapp, 2011). Importantly the research literature highlights the fact that individuals living with chronic pain and traumatic stress experience greater physical and psychological distress than those presenting with only one of these conditions (Geisser et al., 1996). To date much of the research in this area is quantitative, based on observing symptoms and attempting to establish 'cause and effect' relationships.

A qualitative approach is about moving beyond the obvious and exploring the unexplored, thus acknowledging the complexity and variability of experiences that form the client's subjective reality. The rationale as stated by Goethe (cited in Smith,

Flowers and Larkin 2009, p. 31) is “the particular eternally underlies the general; the general eternally has to comply with the particular.” From this perspective a focus on the detail of the individual will also move us closer to what is generally significant.

My intention in the current study is to take a holistic view of the client, recognising that pain and trauma cannot simply be reduced to isolated symptoms of the mind or body but is experienced through a mutual interplay of both. With reference to Seligman’s (1998) argument that psychology should focus more on positive mental health rather than on pathology, I want to remain open to the idea that individuals living with chronic pain and chronic trauma can with appropriate support mobilise their own potential for self-healing. I aim to bring an understanding about how individuals experience the co-morbidity in order to develop some insight into an individual’s strengths, resilience and coping mechanisms and focus on an identity based on functionality.

This study is based on the client being the most important variable in effective therapy (Bohart and Tallman, 1999, p. 288). This is supported by The NHS Plan (2000) which focuses on discovering ways in which patient participation can influence the quality of health care, therefore leading to patient -centered services. As clinicians we need more understanding about the meaning behind the experience; the beliefs, expectations and factors that maintain the problems, so that we can move towards interventions that are “user-led” (Smith, Flowers and Larkin 2009, p. 162). Levine and Phillips (2012, p. xiii) emphasize that:

the real power of most pain-treatment methods to bring lasting results lies not within the methods, but in their unique application in alignment with each individual’s needs, beliefs, personality and experience.

Drawing on my own clinical practice with this client population I have discovered many challenges to working effectively. For example some clients view psychology as a “*last resort*,” or they identify a referral to psychology as an indication that their pain is “*not real*” or it is “*in my head*.” Issues around poor timing of referral, waiting lists and lack of information about the role of health psychologists can sometimes be identified. In addition the physical symptoms of pain and side effects of medication

add further complications in relation to non- attendance. In my experience many people have been struggling with these overwhelming and co-occurring symptoms for a considerable length of time, creating maladaptive ways of coping which inevitably leads to problems with engaging and adjusting. Improved access, earlier referrals and a greater awareness of the importance of integrated physical and psychological health would support healthier coping strategies and adjustment.

Equally successful interventions are not just about selecting a particular treatment approach and fixing a problem but actively involving the client in a process self-discovery and psychological flexibility. Therefore for me the significance and strength of this research is based on listening to our client's experiences and how they make sense of what has happened to them. It is about honoring the uniqueness of their story and their journey so far as it is embedded within their social and relational history. When, as therapists we begin to understand our client's inner world we are better placed to be fully present, to attune to their needs and to work with our client's collaboratively as "co-therapists" (Bohart and Tallman, 1999).

### 1.3 Definition of Terms

#### *1.3.1 Chronic Pain*

The definition of pain provided by the Oxford English Dictionary covers both physical and emotional pain. Firstly pain is defined as a "highly unpleasant physical sensation caused by illness or injury," and secondly as "mental suffering or distress." Interestingly the word pain is derived from the Latin word "paena", which literally means the suffering inflicted for a crime or offence via a punishment. The French word for pain is "douleur" derived from the Latin word "dolar," meaning grief and distress.

Pain is a universal experience, serving a protective and adaptive function for our species. Although most of know what it is like to experience pain it can be difficult to articulate and to understand another person's subjective experience. Pain is fascinating in its uniqueness to each individual. It holds different meanings for different people and can be influenced by past experiences and individual differences such as age, gender, culture and social context. People react and cope in varying ways to the experience of pain.

For clarity I refer to the accepted definition of pain as defined by the International Association for the Study of Pain (IASP) where pain is described as:

An unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage, and pain is always subjective. Each individual learns the application of the word through experiences related to injury in early life. (Merskey and Bogduk, 1994, p. 210)

Chronic pain has gradually emerged as a distinct phenomenon in relation to acute pain (Department of Health, 2012). The definition of chronic pain is pain which persists past the normal time of healing (Bonica, 1953). Chronic pain as defined by the British Pain Society (2003) is “continuous, long-term pain of more than 12 weeks or after the time that healing would have been thought to have occurred.”

In addition to the definition of chronic pain provided by British Pain Society (2013), Brennstuhl, Tarquinio and Montel (2015, p. 301) draw attention, to the many diverse forms that chronic pain takes. They note that this is demonstrated by the number of nosological descriptions containing imprecise criteria such as “a pain disorder associated with both psychological factors and a general medication condition.” As Brennstuhl, Tarquinio and Montel (2015) point out, DSM-5 acknowledges this complexity by proposing that pain should be seen as “a complex somatic syndrome.”

To conclude, McCaffrey’s definition of pain recognizes that, "pain is whatever the experiencing person says it is, existing whenever he says it does" (McCaffrey and Pasero, 1999, p. 17).

For the purpose of this study chronic pain is non-malignant or non-cancer pain.

### *1.3.3 Traumatic Stress*

The term 'trauma' originates from the Greek word meaning a 'wound'. The word trauma has become frequently used in modern western societies to describe a deeply distressing or disturbing experience.



Trauma is defined as “exposure to actual or threatened death, serious injury, or sexual violence” and includes directly experiencing the event, learning that the event happened to a close family member/friend, or experiencing repeated/extreme exposure to aversive details of the event (APA, 2013). This is the current definition of post-traumatic stress disorder (PTSD) in DSM-5 (APA, 2013). Importantly this definition recognises that exposure to a traumatic or stressful event is required as a diagnostic criterion. It is also important to highlight that the current diagnosis of PTSD has expanded to account for the varying expressions of distress as a result of a traumatic experience.

Despite these changes and the clinical utility of the PTSD diagnosis, it is still apparent that the current definition is not broad enough to fully capture the psychopathology associated with exposure to chronic developmental stressors. (McDonald, Borntreger and Rostad, 2014). Within this study my aim is to acknowledge that many patients present with a high prevalence of developmental disruptions and exposure to interpersonal trauma as well as single event trauma. This has particular relevance in terms of the enduring and unique symptom presentations that move beyond or are separate from the PTSD criteria.

For the purpose of this study I have chosen to refer to the construct complex post-traumatic stress disorder (CPTSD) first proposed by Judith Herman (1992). Currently CPTSD does not exist as a diagnostic category in DSM-5, although this had been a recent consideration. Considerable research continues to support and develop this construct. Essentially CPTSD addresses the multiple or prolonged traumatic or stressful experiences during childhood. Courtois (2004) expanded complex trauma experiences to cover “other types of catastrophic, deleterious, and entrapping traumatization occurring in childhood and or adulthood” (Courtois 2004, p. 412). CPTSD has also been used interchangeably with the concept Disorders of Extreme Stress, Not Otherwise Specified (DESNOS).

Individuals exposed to chronic trauma are known to experience alterations in six areas of functioning (Pelcovitz et al.,1997): 1.regulation of affect and impulses; 2. attention or consciousness; 3. self-perception; 4. relations with others; 5. somatization; and 6. systems of meaning. A review of neurobiological evidence

(Ford, 2009) supports the symptom constellations above by illustrating the impact of early childhood trauma on the brain processes. What is evident is that more in depth and sophisticated models of post-traumatic distress are needed to keep pace with neurobiological advances.

Within this research dissertation I use the term 'traumatic stress' to encompass the complex trauma histories and symptom presentations consistent with terms CPTSD and DESNOS.

### *1.3.1 Co-morbidity*

The definition of co-morbidity rests on the "presence of more than one distinct condition in an individual" (Valderas et al., 2009, p. 358). From this Valderas et al. (2009) consider four areas that underpin co-morbidity. These are: 1) the nature of the health condition, 2) The relative importance of the co-occurring conditions, 3) the chronology of presentation of the conditions and 4) expanded conceptualisation. By integrating the four constructs, the complexity of co-occurrence is recognised and can be viewed from alternative perspectives. Secondly, and with specific reference to the term 'expanded conceptualisation', Valderas et al. (2009) address the importance of recognising the whole person. In this way co-morbidity is not just concerned with diagnostic terminology but also with capturing the individual complexity; acknowledging the cultural, social and relational background within which our lives are embedded.

## Chapter 2

### 2. Literature Review

#### 2.1 Overview

The purpose of this literature review is to provide a synthesis and critique of the existing literature investigating co-morbid chronic pain and traumatic stress, which will allow me to situate and present the contributions made by this study. The papers selected vary in terms of methodology and include research that explores different and interesting aspects of chronic pain and traumatic stress. Within the review there is a focus on exploring pain and trauma as separate entities. The intention is to illustrate the wealth of knowledge and methodological approaches in these areas integral to our evolving understanding and ongoing research in the field of comorbidity. Finally, I will reflect on the limitations of existing research in order to present the rationale for the current study.

In order to complete the literature review I have searched a number of sources, including the TRIP database, NICE evidence, the Cochrane Library and the Healthcare databases, as well as relevant books in this field. The search was not static: I gathered information gradually over time as new areas and studies emerged.

#### 2.2 The History and Theoretical Understanding of Pain

There has been a gradual recognition that chronic pain is a complex, multifaceted experience, influenced by “the meaning of pain to the person, and beliefs, attitudes and expectations” (Turk and Okifuji, 2002). This understanding has paralleled the significant changes in our understanding and perception of the meaning of pain. Tracing the theoretical understanding of pain therefore provides an opportunity to explore scientific advances and contrasting views and meanings about pain.

##### *2.2.1 A Physiological Understanding of Chronic Pain*

Physiological pain based theories date back to the 17th century. Early beliefs suggested that pain resulted from excess activity of certain nerves but these were not necessarily pain specific. This was referred to as the ‘theory of intensity’.

Descartes et al. (1664) was the first to trace a pain pathway and introduced the idea of pain as specific sense, the 'specificity theory'. At this stage we are introduced to the idea of mind-body dualism, leading later to pain being considered to be either organic or psychosomatic.

In 1894 Max Von Frey proposed that the type of nerve ending determined the nature and intensity of the pain experienced. In essence this explanation of pain is based on information travelling from the periphery to the higher centre, where it is received by a 'pain center' before travelling back down and creating a motor response. These linear models of pain did not allow for pain to be altered by attention or psychological factors such as past experiences. Equally these early theories could not be sufficiently used to explain the concept of chronic pain.

Following on from 'specificity theories' the literature goes on to describe 'pattern theories'. Essentially this adds to the linear concept of pain but introduces the idea that pain intensity can be modulated through touch, pressure or vibration (Todd and Kucharski, 2004).

Fortunately our understanding of pain has developed over the last few decades from a linear, dualistic explanation into a multi-dimensional model. With this increasing complexity psychology has become more involved in the pain field. In particular, Donald Hebb, a psychologist, and George A. Bishop, an American physiologist, were key to initiating this change, based on Hebb's treatment of pain outlined in his book *The Organisation of Behaviour* (1949). Ronald Melzack was Hebb's student and in conjunction with Wall, the Gate Control Theory of Pain (Melzack and Wall, 1965) was introduced. This theory illustrated the fact that there was not a simple relationship between nociception and pain experience.

### *2.2.2 The Gate Control Theory of Pain*

In brief the Gate Control Theory (1965) highlights the brain and spinal mechanisms as active systems; filtering, selecting and modulating inputs. The theory proposes that the neural impulses that potentially signal pain from the peripheral nervous system are subject to a number of modulations in the spinal cord by a gate mechanism in the dorsal horn, before the experience of pain is transmitted to the

central nervous system. The Gate Control Theory was revolutionary and generated an abundance of research which ultimately led to further advances in our quest to understand and explain chronic pain.

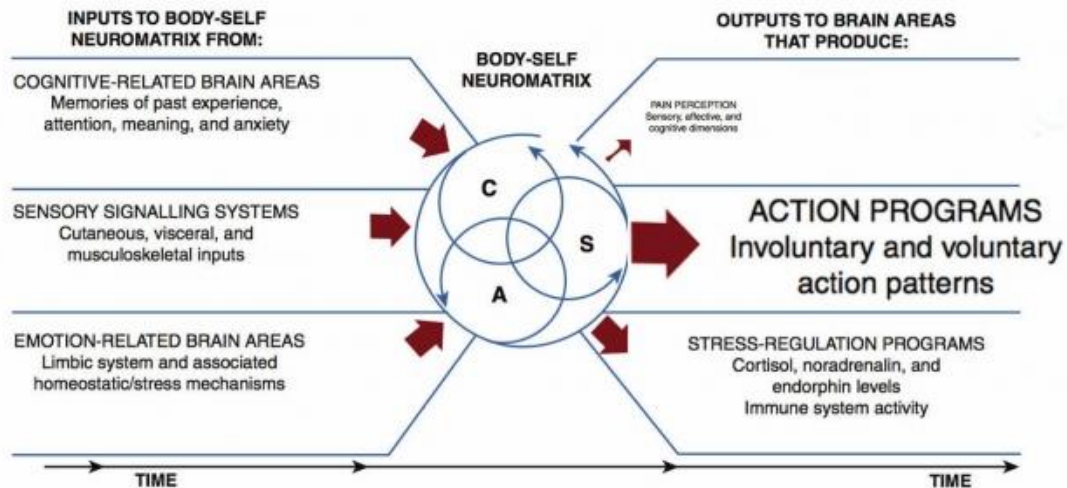
Building on the Gate Control Theory of pain, Melzack and Casey (1968) identified three dimensions or factors that contribute to the experience of pain and motivate actions to relieve pain. They labelled these dimensions the *sensory discriminative*, the *motivational affective* and the *cognitive evaluative*. From this emerged a fresh approach to studying and understanding pain and for the first time physical and psychological aspects of pain were accounted for.

However the Gate Control Theory (1965) was not able to explain phenomena such as phantom limb pain (Melzack, 1989), and contradictory evidence such the denial of pain despite injuries or, conversely, severe pain produced by a mild stimulus. All the evidence pointed to a need to look to the brain in order to understand pain more fully.

### *2.2.3 The Neuromatrix Theory of Pain*

Melzack proposed that all perceptual experience originates in the neural networks of the brain. Patterns of activity are generated in a widespread neural network by peripheral stimuli but equally this could occur in the absence of peripheral inputs. Melzack (2001) labelled this as the 'neuromatrix' and identified the fact that repeated processing of nerve impulses through the neuromatrix creates a characteristic pattern of the whole body-self, referred to as the 'neurosignature'.

An important aspect of the Neuromatrix Theory of Pain is therefore that pain is determined by multiple influences: emotional, cognitive and sensory input (see Figure 2.1, below).



**Figure 2.1** Factors that contribute to the patterns of activity generated by the body-self neuromatrix. (C=cognitive, A=affective, S=sensory) Adapted from Melzack (2005, p. 91)

This continuously evolving understanding of pain has identified the physiological mechanisms by which psychological factors may predispose, contribute and or maintain the experience of chronic pain.

With the Neuromatrix theory we have a framework which is influenced by genetic and sensory factors and modulated by the powerful stress system and the cognitive functions of the brain. In this way Melzack (2001) highlights the importance of understanding the relationship between pain and stress. In particular by focusing on the stress response in relation to pain mechanisms, Melzack (2001, p.1380) concluded that “the puzzle of pain is vastly expanded.”

### 2.3 Traumatic Stress

Alongside the theoretical and scientific advances in the area of pain, trauma has also been a subject of increasing interest. Early understandings of traumatic stress date back to World War 1, where symptoms of psychological distress were attributed to the exploding shells during combat. The term “shell shock” was used (Bentley, 2005) but the inadequacy of the term was questioned with a belief that it did not explain the mental effects of the war experience for many soldiers (Scott, 1990).

More than a century later the psychological importance of trauma continues to be recognized (Modlin, 1983), with a vast literature relating to combat trauma,

imprisonment, rape, kidnapping, natural disasters and accidents (Kardiner, 1941; Lindeman, 1944). The modern study of psychotraumatology can be traced back to 1980 with the advent of a comprehensive diagnosis of PTSD. The result for individuals suffering with the distressing symptoms has been a concise description and labeling of the condition, leading to treatment and a commitment to further research in this area.

In this respect the diagnosis of PTSD has been extremely useful, although equally PTSD as a diagnostic construct has attracted some controversy. Criticisms include failure to recognise that an individual is embedded within a social and cultural world. Aho (2009) makes reference to DSM-IV, writing, "it proceeds exactly as a scientist would: detaching a thing from its background so that it can be seen more clearly and objectively" (Aho, 2009, p. 137).

More specifically the limitations of PTSD as a diagnosis have increasingly received attention in relation to the construct of complex post-traumatic stress disorder (CPTSD). The suggestion is that a single diagnosis of PTSD does not adequately address the complexity of symptom presentation observed in survivors of prolonged trauma (Resick et al., 2012). Furthermore, post-traumatic stress disorder still tends to focus around single or major events such as victims of terrorist attacks and soldiers returning from duty. In fact research indicates that individuals are more likely to have been exposed to a number of traumatic events rather than a single trauma (Kessler, 2000).

The reality is that exposure to chronic trauma such as early childhood abuse and neglect produce a range of symptomology that includes not only the symptoms associated with PTSD but also disturbances in affective and interpersonal self-regulatory capacities such as anxious arousal, dissociative symptoms, aggressive or avoidant behaviours (Cloitre, et al., 2009). These symptoms are associated with CPTSD (Herman 1992). The term CPTSD has also been used interchangeably with the concept of Disorders of Extreme Stress, Not Otherwise Specified (DESNOS). At present, despite growing support, CPTSD is not a diagnostic category. The literature calls for further research in this area (Resick et al., 2012).

Experiencing trauma can have a distressing, life changing effect, both on our self-concept and how we view the world. Herman (1992) referred to traumatic events as those events that "overwhelm the ordinary systems of care that give people a sense of control, connection and meaning" (p.33). It is important to acknowledge that this is a complex field that requires looking beyond the DSM diagnostic criteria and symptom clusters. In an article written by Thompson and Walsh (2010) they present trauma as an "existential injury" recognising that both the psychological and social dimensions are disrupted. Within this article they call for existentialist philosophy "to offer fuller and more empowering understandings of traumatic experiences (p.387).

Increasingly research exploring traumatic stress has drawn on mixed-methods and qualitative approaches, in order to understand individual trauma experiences within a social and cultural context. In a qualitatively dominant nested mixed-methods study, La Row (2015) aims to develop a better understanding of the lived experiences of survivors of the genocide against the Tutsi in Rwanda. A gap is identified in the literature in terms of appreciating cultural influences on trauma based symptoms. The rationale being, that PTSD and DESNOS offer poor construct validity in non-western cultures. The findings within this study indicated symptoms extending beyond the diagnostic criteria for PTSD, paving the way for a greater consideration of cultural difference.

### *2.3.1 Trauma, the Body and Pain*

It has been understood for more than a century that traumatic stress has a physiological basis. Van der Kolk (2014, p. 21) writes "trauma is not just an event that took place sometime in the past; it is also the imprint left by that experience on mind, brain, and body." As noted by Van der Kolk (2014), "the body keeps the score." Following a review of the literature, D'Andrea et al. (2011, p. 378) identify that, "trauma sets the stage for ongoing psychological and physical distress, which can mutually affect one another." They go on to propose that the body's stress response is elevated either through conscious or nonconscious triggers and suppression of emotion as a coping strategy also generates a stress response.

Equally, Karp (2014) talks about the, "activating" symptoms of PTSD, which include re-experiencing and hyperarousal, as being "consistent with a state of high emotional



and physiological stress" (p.728). If prolonged, this state of hyperarousal leads to the general adaptation syndrome (Seyle, 1950) used to denote the exhaustion phase of the body under enduring stress. More recently the factors that place unacceptable physiological demands on the body have been referred to as allostatic load (McEwen and Stellar, 1993). Importantly this concept has been increasingly linked with the development of disease and disability (Seng et al., 2006).

The concept of allostatic load and allostasis can also be usefully thought of as a psychological as well as a physiological phenomenon. In essence an individual suffering with PTSD makes adaptations in order to cope with intrapsychic conflicts; defenses are used as a result of dysfunctional systems in PTSD. The chronically distressed individual "uses more maladaptive defenses to hold at bay the disruptive breakthrough of trauma" (Lindy and Wilson 2004, p. 127). Maladaptive responses continue to be reinforced through the interplay between mind and brain, with the intrapsychic structures being connected to the neurophysiological, neuroanatomical and neuroendocrine structures. In this way the relationship between biology and psychology is established.

In terms of understanding the relationship between traumatic stress and chronic pain, empirical studies have demonstrated that at a biological level, PTSD may increase pain sensitization due to dysregulation of the stress response system (Anderson et al., 2012; McLean, 2011). Research has revealed that the hypothalamic-pituitary-adrenal (HPA) axis is just one of many systems activated following physical and psychological threats (Ehlert et al., 2001). In the following section I will consider how psychoneuroimmunology as an integrative field has succeeded in drawing together a number of causal links between chronic pain and traumatic stress.

### *2.3.2 Psychoneuroimmunology*

Within the field of psychoneuroimmunology there have been some key findings that are relevant to the study of chronic pain and traumatic stress. As early as 1919, a study was published suggesting that negative emotions could have an impact on the immune system of patients with tuberculosis (Ishigami, 1919). Researchers are continuing to understand that stressful events may bring about changes to the

immune system (Seegerstrom and Miller, 2004). It has been suggested that prolonged exposure to elevated cortisol levels can influence the sensitivity of receptors on immune cells and dull the anti-inflammatory potential (Siraux et al., 2005). In a review by Thaddeus and Heim (2011) the authors identify that immune changes may play a role in the development and severity of PTSD symptoms. In addition, some of the negative effects of adapting to stress have been identified as atrophy of muscle and bone, suppression of the immune system and impairment of tissue growth. It has been suggested that these factors form the conditions for the development and maintenance of chronic pain (McEwen, 2001; McLean et al., 2005).

Chronic stress-induced hypocortisolism has received significant attention also and has been associated with pain somatization disorders such as fibromyalgia, chronic fatigue syndrome, chronic pelvic pain and temporomandibular disorder (Ehlert, Gaab and Heinrichs, 2001; Tak and Rosmalen, 2010).

#### 2.4 A Review of the Research Related to Chronic Pain and Traumatic Stress

A review of the literature shows a growing interest in the relationship between chronic pain and traumatic stress. A few early studies identified comorbidity between physical symptoms and PTSD (McFarlane et al., 1994; De Loos, 1990; Van der Kolk, 1996). Although it was Beckham et al. (1997) who proposed that chronic pain and PTSD were intricately linked as opposed to distinct disorders.

Two significant studies in this area were the first to draw our attention to the overlap between the conditions and to the lack of research in this area (Sharp and Harvey, 2001; Asmundson et al., 2002). These studies addressed the co-occurrence of chronic pain and PTSD providing valuable explanations about their relationship in terms of prevalence and symptomology. With reference to prevalence, the presence of chronic pain was demonstrated in 20-80% of trauma cases and PTSD documented in 10-50% of chronic pain cases.

The findings from these early empirical studies have generated theoretical models to account for the co-occurrence. For example, Sharp and Harvey (2001) described

the mutual maintenance model, whereby they propose that the two disorders are linked by seven specific mechanisms. It is worth outlining these mechanisms as they continue to influence current research. Briefly the first of these mechanisms is "attentional biases," where painful stimuli serve as constant reminder of the trauma. Secondly "anxiety sensitivity" as a symptom of PTSD, maintains chronic pain and PTSD through an individual's beliefs that the pain is harmful. The third mechanism is focused on "persistent reminders of trauma," chronic pain may provide a reminder of the trauma and trigger arousal and other PTSD symptoms. The result is the maintenance of a connection between the physical sensation and the trauma. This leads to the fourth process which is "avoidant coping style," in an effort to prevent the pain sensations and trauma memories that trigger the arousal response. "Depression and reduced levels of behavioral activity" form the fifth response. The sixth factor is identified as "pain perception," which is heightened by anxiety and in turn leads to increased distress and disability. Finally the seventh mechanism is named as "cognitive resources." It is expected that the cognitive demands required to manage chronic pain and PTSD are depleted, such that the ability to develop adaptive strategies to manage are compromised.

The seven factors proposed by Sharp and Harvey (2001) demonstrate the interdependence of chronic pain and PTSD, with cognitive, affective and behavioral aspects contributing to, maintaining or exacerbating the symptoms of the other. The authors also identify a number of points of intervention at which treatment could be aimed. Otis, Keane and Kerns (2003) provide further support for the co-occurrence with the recognition that mechanisms such as fear and avoidance, anxiety sensitivity, and catastrophizing, may maintain both conditions. More recently, Vachon-Preseau et al. (2013) have also suggested that chronic pain could be maintained by negative emotions and stress.

The second pivotal study in this area was published by Asmundson et al. (2002). They proposed a shared vulnerability model emphasizing the role of trait anxiety sensitivity in understanding the co-morbidity between chronic pain and PTSD. In this model Asmundson et al. (2002) emphasize anxiety sensitivity as contributing to an individual's vigilance during a stressful event. The suggestion is that an individual holds a disposition towards becoming fearful with fear of the anxiety symptoms

based on the fact that there may be harmful consequences. Elevated anxiety has been suggested as a predisposing factor to developing chronic pain and PTSD. Further studies provide empirical support for anxiety sensitivity as a relevant variable in adults with traumatic stress and chronic pain (Lopez- Martinez, Ramirez-Maestre and Esteve, 2014).

The studies reviewed so far have undoubtedly made a significant contribution in terms of raising awareness of the co-morbidity and developing models to begin to elucidate this complex interrelationship. Further quantitative research has continued to elaborate on these earlier models (Beck and Clapp, 2011). Longitudinal studies have continued to support the strong link between chronic pain and PTSD by identifying processes leading up to the development of chronic pain and PTSD (Sterling and Kenardy, 2006; Zatzick et al., 2007). It seems that despite significant contributions to this area, the true depth and complexity of comorbid chronic pain and traumatic stress has been neglected to date with an overreliance on isolated symptoms that have become decontextualized.

In particular, the existing literature so far has focused predominately on the diagnostic criteria of PTSD with reference to acute traumatic experiences, such as motor vehicle accidents or military combat (Wald et al., 2010; Beckham et al., 1997). The DSM-IV Field Trial for PTSD conducted between 1990 and 1992 revealed that exposure to chronic trauma produces a range of symptomology that is dependent on developmental stage, social context and origin of the trauma and is not captured within the PTSD diagnosis (Roth et al., 1997). Within this review it is my intention to address this niche by representing the complexity of and continuum of traumatic experiences in relation to our understanding of the co-morbid conditions.

The literature identifies that particular types of trauma are more likely to create the mutual interdependence between chronic pain and traumatic stress. Notably a study by Sachs-Ericsson, Kendall-Tackett and Hernandez (2007) examined the connection between abuse in childhood and chronic pain in adulthood. The study revealed more pain in those adults who had reported child abuse. A number of other studies have identified an individual's predisposition for pain and contributing factors such as trauma in childhood (Shofferman et al., 1993; Tietjen et al., 2009). Furthermore a

study by Lee (2010) examined the relationship between childhood abuse and stress reactivity and neurobiological development. The author conducted a systematic review of the literature and demonstrated significant associations between childhood abuse and a diagnosis of fibromyalgia in adulthood. Lee (2010) also noted that childhood abuse may be one of the etiological factors that could lead to abnormal brain development, affecting stress reactivity and therefore potentially leading to the onset of fibromyalgia.

Given these developmental findings it is important to note at this point that in a recent study Anderson, Elklit and Brink (2013) proposed attachment insecurity as a vulnerability factor for both pain and PTSD. The study also suggested that attachment insecurity may be a predisposition to problems with adjusting to pain. Anderson et al. (2013, p. 80) went on to identify hyperarousal as being the "strongest mediator between the attachment dimensions, pain and somatization."

The most striking aspects of the co-occurrence, are the notably higher levels of pain and distress (Geisser et al., 1996) increased levels of disability (Sherman, Turk, and Okifuji, 2000) and life interference (Turk and Okifuji, 1996) in comparison to those who live with either pain or PTSD. More recent empirical studies also continue to confirm that individuals managing and experiencing chronic pain alongside a background of trauma experience more severe symptoms and increased levels of distress and disability (Wald et al., 2010).

Despite the significant contributions of existing research studies, there seems to be an overreliance on purely quantitative measures, neglecting the subjective experience of individuals who suffer with this co-morbidity. In this sense very little is conveyed in terms of the meaning of co-morbidity to the person. The research tells us little about the individual experiences and importantly the impact of living with these conditions on daily basis.

A study by Taylor, Carswell and de C Williams (2013) was one of the first to use IPA as the methodological approach to explore the relationship between chronic pain and PTSD. More specifically Taylor et al. (2013) focused on the interaction of persistent pain and the re-experiencing of traumatic events in torture survivors. Whilst this

study provides an important contribution in terms of understanding and highlighting the relationship between chronic pain and PTSD, and the impact of contextual factors on the individual, the focus is concerned with victims of single or major event trauma. More specifically the study by Taylor et al. (2013) does not explore the individual's experience of living with complex trauma and co-existing chronic pain.

Within the current study my intention was to provide a wider formulation by exploring CPTSD as a construct. Importantly it was about recognising that PTSD as a diagnosis does not fully capture the symptom constellation and psychopathology associated with exposure to chronic developmental stressors. This is relevant in terms of acknowledging the high prevalence of developmental disruptions and interpersonal trauma that co-exist in individuals who also live with chronic pain.

The current study aims to consider the unique and diverse symptom presentation associated with CPTSD and explore with the use of IPA, how this is subjectively experienced by individuals who also live with co-occurring chronic pain. To date there are no studies in this area that have addressed this complex co-morbidity from the individual's perspective.

## 2.5 An Integrated Developmental Approach Towards Understanding Pain and Traumatic Stress

In view of the fact that current understanding recognises mind-body interaction it seems questionable, as suggested by Greenberg (2009) that any illness is "purely" physical or "purely" psychological. Although challenging, creating the connection between mind and body is vital if we are to expand on our understanding of chronic pain and traumatic stress and think in a more integrated way about this co-occurrence.

I continue by exploring an integrative developmental approach applied to the field of somatoform pain and alexithymia. An approach which I consider is also relevant to the current study.

### 2.5.1 Somatoform Pain

Somatization has been defined as the expression of emotional distress through physical symptoms (Barsky and Klerman, 1983). It is a chronic disorder defined by multiple medically unexplained symptoms with poor response to treatment (Mai, 2004). Somatoform pain is one of the main symptoms of the somatization spectrum disorders (Rief, Hessel and Braehler, 2001). In a review of the clinical research Landa et al. (2012, p718) highlight the importance of integrating “multiple levels of inquiry” in order to understand the etiology of somatoform pain. The review draws on evidence from developmental neurobiology, cognitive-affective neuroscience, psychoneuroimmunology, genetics and epigenetics, alongside clinical and treatment studies. Landa et al. (2012) also establish a connection between somatization and alexithymia.

### 2.5.2 Alexithymia

Alexithymia had been previously been considered a characteristic of somatization, although it has been more closely linked with psychopathology (Taylor et al., 1997) and increased presence of depression. Alexithymia literally means 'a lack of words for feelings,' (Greek *a* [lack] and *lexis* [word] and *thymos* [emotion]) (Sifneos, 1973; Greco, 1998, 131-58).

The study of alexithymia elucidates the relationship between emotional regulation and the impact on the body. In a quantitative study Gulec et al. (2013) highlight that emotional abuse and emotional neglect predict alexithymia and somatization. Shibata et al. (2014) have reported that alexithymia contributes to an increased risk of several chronic diseases and health conditions. Alexithymia should be viewed as a potential factor that may contribute to the development and maintenance of chronic pain.

A recent questionnaire based study (Saariaho et al., 2015) explored the occurrence of alexithymia and early maladaptive schemas in a sample of chronic pain patients. The findings indicated the presence of early maladaptive schemas, increased pain intensity, disability and depression in comparison to non-alexithymic patients. This study clearly indicates that psychological factors have an effect on the subjective

experience of pain and much of what is happening inside our bodies is out of conscious awareness.

## 2.6 The Evolution of Psychological Theories of Pain- Integrating Pain and Trauma

Psychological theories of pain date back to Aristotle (384-322BC) who described pain as a 'passion of the soul'. Other famous physicians who regarded pain as an emotion include Avicenna in the 11th century and Spinoza in the 17th century. Thomas Sydenham, known as 'The English Hippocrates', believed the concept of hysteria to be predominately psychological and pain was potentially a feature of this. Equally Benjamin Brodie (1783-1862) alluded to the idea that certain pain presentations could not be attributed to physical sources. Early in the 20th century Freud also proposed that pain could be generated by the mind, in the absence of injury or disease. He went on to propose that pain could be understood as a way of punishing the self and as such he identified the mental processes of repression, aggression and guilt to explain this concept. Pain could therefore be understood as a way of communicating emotions such as anger or anxiety, at a subconscious level. In his book, 'The Hidden Psychology of Pain' Alexander (2012) provides evidence to support the unconscious conflicts described so avidly by Freud.

The relationship between pain and emotional states was further supported by Thomas Szasz in the 1950's. Szasz (1957) believed that pain represented an unconscious form of aggression towards others and that by suffering pain, feelings of guilt could be relieved. George Engel (1977) added to this by introducing the concept of the 'pain prone personality', whereby individual's behavior is self-punitive. The inference is that many individuals suffering with chronic pain have led "painful lives" and struggle to express emotional pain (Miller, 1993). Although there is no evidence to support the idea of the 'pain prone personality', there is evidence to suggest that individuals who experience psychological trauma earlier in life have a greater disposition towards developing chronic pain in adult life (Jernbo et al., 2012).

Psychoanalysis as an approach reflected the notion that the greater part of the mind was out of conscious awareness. This concept remained prominent for many



decades. However the focus of psychology changed with the rise of behaviorism and in particular the work of Skinner (1904-1990), followed by the inclusion of the cognitive aspect (Bandura, 1977). Eventually the emergence of Cognitive Behavioural Therapy (CBT) gathered momentum in the 1980's with the work of Ellis and Beck. CBT emphasized the influence of conscious thoughts, feelings and behaviours. In this way psychology became relevant to understanding pain through conscious awareness of factors such as psychological stress which overtime disrupts the body's homeostasis.

I complete this section by reflecting on the third school of thought in psychology, which has also had a considerable impact on our understanding of pain. Humanistic psychology represented a radical change in thinking. In particular humanistic values recognized the uniqueness and potentiality of human beings. This represented a move away from a mechanistic mind-body split, towards a holistic view of the self, concerned with an increased awareness of intrapsychic, interpersonal and biological processes. Essentially in relation to chronic pain, the belief is that mind and body interact and function as a dynamic whole.

The literature clearly reveals that psychology has a significant and pivotal role to play in understanding the experience of chronic pain and traumatic stress both at a conscious and subconscious level. It was Melzack and Wall (1965) who proposed that the perceptual experience of pain is influenced by the history of the individual, the meaning they ascribe to the pain-producing situation and their state of mind at the time. It is these factors that play a role in determining the function of pain pathways in the central nervous system, so that pain becomes a function of the whole individual based on the cumulative impact of past and present experiences; social and cultural contexts.

In many ways we have come full circle as the Neuromatrix theory potentially supports the contribution made by Freud and his predecessors, with the notion that emotions, thoughts and behaviors are instinctively driven by factors operating at a subconscious level. Taylor (2008, p.52) supports this concept by proposing that:

psychological vulnerabilities to pain, which are largely unconscious can be

embedded in the neuromatrix waiting to be activated by some pertinent life event.

I believe that this is an exciting area that demonstrates firstly that Cartesian mind-body dualism has been replaced by the notion that 'mind' and 'body' work together but provide different levels understanding about the human condition. Secondly there is a need for integration of theories at multiple levels. In this way a more comprehensive and detailed understanding of chronic pain and traumatic stress can be achieved.

### 2.7 Limitations of Previous Research

Throughout this literature review I have referred to a wide variety of literature sources and developments within the field of chronic pain and traumatic stress both as a co-occurrence and as separate fields. The intention was to demonstrate the significant advances in these areas both from a psychological and physiological perspective. With the rise of neuroscience there has been a recognition that a more integrated view of human beings can offer a deeper view that the role of emotions both physically and psychologically. Claxton (2015, p.112) talks about “how the brain has evolved to help increasingly complicated bodies coordinate their interlocking subsystems.”

However, current research examining the co-existence of chronic pain and trauma is predominately quantitative in approach and appears to be mainly concerned with PTSD rather than a chronic trauma presentation. Undoubtedly quantitative studies have provided significant evidence and explanations of a direct causal link between chronic pain and PTSD, facilitating both clinicians and patients to understand how these conditions maintain each other and what might predispose an individual to being susceptible to chronic pain and PTSD. Research in this area has raised awareness in terms of assessment, treatment and theoretical development, providing a foundation from which further research can be generated.

Arguably the studies looking at pain and trauma have limited themselves to symptom presentation, with the process of symptom production and maintenance as the focus.

In this way quantitative research could be criticized for offering a simplistic, disembodied and symptom based understanding for what remains a complex, unique and multidimensional experience. Snelgrove and Lioffi (2009) suggest that a:

simplistic model of biomechanical dysfunction does not allow for beliefs, feelings and social context that may all have an impact on the experience of pain and disability.

It must be remembered that pain and trauma intersect with other aspects of daily life as well as one's internal and external view of body self and identity. Our culture, race, religious beliefs and relational histories all influence the way we react and cope with pain and trauma.

One of the most prominent features of modern society is the medical pathologising of conditions and the scientific organisation of life (Illich, 1976). This creates clear distinctions between health and normality or healing and curing. "Health suggests wholeness, completeness, and balance" (Aho 2009, p. 5). Hans-Georg Gadamer writes that "health is concealed, elusive, and enigmatic (Gadamer, 1996, p. 112). There is the potential to explore and expand upon our understanding of health and disease by attending to individual experiences and meanings.

### 2.8 The Current Study

The current study aims to complement and build on existing research in this area by exploring the implicit and idiosyncratic aspects of living with both chronic pain and chronic trauma. Individuals who suffer with chronic pain and traumatic stress try to make sense and understand what is happening. By examining the client's subjective experience of the interrelationship between the two, I will develop an understanding about how these co-morbid experiences contribute to and shape their experience.

## Chapter 3

### 3. Methodology

Within this chapter I aim to discuss and reflect upon my reasons for selecting a qualitative research methodology and specifically interpretative phenomenological analysis IPA (IPA; Smith, Flowers & Larkin, 2009). I will begin by exploring the emergence of qualitative methods in healthcare before moving on to examine some of some of the key philosophical and theoretical underpinnings defining this approach. What I aim to offer to the reader is a sense of the richness and unique contribution that can be made by adopting IPA as a methodology.

#### 3.1 Qualitative Research in Psychology

Psychology in general has previously been dominated by quantitative methods based on positivist and post-positivist research paradigms (Ponterotto, 2005). This empirical approach has fostered important advances in medicine with success evident in terms of improved health outcomes and longevity. However over time the dualistic nature of the biomedical model, with its separation of body and mind has been criticised for neglecting the human dimension of suffering (Engel, 1980) and ignoring the possibility that the subjective experience of the patient was amenable to scientific study.

There has increasingly been a flourish in interest towards qualitative approaches which are concerned with gaining a detailed understanding of an individual's response to living with chronic illness as demonstrated by this study. Fundamentally qualitative methods all share the common aim of contributing to and enriching our understanding of a particular phenomenon in question and generating new insights (Willig, 2001).

### 3.2 The Design of the Study

The research presented is exploratory in nature with an emphasis on understanding the lived experiences of individuals who live with co-morbid chronic pain and traumatic stress. A qualitative approach, concerned with discovering and generating meaning was selected as the most appropriate methodology.

With reference to the research question below, I will clarify the ontological and epistemological perspectives of IPA.

How do people living with co-morbid chronic pain and traumatic stress understand and make meaning out of their experience?

#### *3.2.1 Ontological and Epistemological Positions*

Ontology is concerned with what can be known and how knowledge exists. With reference to the current study my ontological position is constructivist-interpretivist based on a belief that there is no one objective truth, but instead multiple realities exist (Lincoln and Guba, 2000). Essentially constructivism-interpretivism emphasises that an individual's reality is subjective and influenced by their interactions with the historical socio-cultural environment (Gergen, 1994).

Consistent with this ontological position I have chosen to engage with the individual voices of people who live with co-morbid chronic pain and traumatic stress. My understanding is that the lived experience is real to the person experiencing it.

The ontological stance taken has epistemological implications in terms of the choice of qualitative approach to the research. Epistemology is the theory of knowledge and asks the questions how we know what we know and what are the ways of knowing. There are a number of different epistemological positions in relation to qualitative research including realist, contextual and constructionist.

IPA has its theoretical roots in critical realism, (Bhaskar, 1978) and the social constructionist tradition. Critical realism acknowledges that there is a real world that exists independently of our perceptions, theories, and constructions. At the same time it is accepted that our understanding of this world and the meanings individuals attach to their experiences are inevitably based on our own construction of reality.

The social constructionist paradigm illustrates how human behaviour, speech and language reflect these individual differences in meanings and experience. As such interview data becomes a useful source for accessing and understanding uniqueness.

As an approach IPA is interesting in that it combines interpretative, psychological and idiographic concepts. The approach is phenomenological in that it seeks an insider perspective on the lived experience and interpretative in that the researcher's personal views and beliefs are acknowledged. I will move on to explore each of these in more detail.

### *3.2.2 Phenomenological Philosophy*

Qualitative research methods have been inspired by phenomenological philosophy. The aim of phenomenology is to explore 'lived' experience. Experience in a phenomenological sense, includes everything that we live through or do; our sensory and emotional experiences, our thoughts and imagination. The real potential of this methodology is the ability to achieve a thorough understanding of the participant's subjective experience and meanings, "to capture as closely as possible the way in which the phenomenon is experienced within the context in which the experience takes place" (Giorgi & Giorgi 2003, p. 27).

However phenomenological philosophy is diverse and has developed in different directions, with varying interests and emphases informing the methodology (Langdrige, 2007). In order to trace the progression of phenomenology, I will draw on key figures and their contributions which are relevant to my understanding and engagement with IPA.

Phenomenological research originated from the ideas of Edmund Husserl (1859-1938) in the early 1900s. Husserl (1927) challenged the view that empirical science was the only means to achieve an understanding of the world. Instead he was concerned with establishing a science based on describing and understanding phenomena as it occurs. Husserl's famous and frequently quoted phrase "a return to the things themselves," emphasises his belief that conscious experience is at the core of phenomenological philosophy. Husserl defined experience as a "system of

interrelated meanings which are bound up in a totality of the “lifeworld.” He did not believe it was possible to separate individual experience from the outside world. In this way, unlike scientific approaches focused on studying isolated variables, it becomes possible to acknowledge that what can be known changes depending on the context and individual differences between people.

Consequently the aim of phenomenological research is to study and understand lived, unique experiences as they are encountered. As such, the researcher works towards these rich, in depth descriptions by drawing on a set of methods. Husserl (1927) was particularly influential in developing concepts that could be integrated into qualitative research methods. In particular he was concerned with developing a “phenomenological attitude,” in order to attend to the phenomena in question. The term “intentionality” was used by Husserl to explain that our consciousness is always directed towards something. My understanding of this concept is that individuals cannot think or feel without thinking or feeling something. Giorgi and Giorgi (2003) talked about this as the “essence of consciousness.” Intentionality therefore focuses on the way consciousness emerges; the relationship between a person’s consciousness and the world as all important. In addition Husserl identified the importance of the researcher suspending preconceptions; putting aside prior knowledge or judgements so that the focus is on reaching the heart of the participant’s experience. The term “bracketing” was used by Husserl (1927) to illustrate this concept and through a process of “phenomenological reduction” he believed it was possible to reach a deeper, “transcendental understanding.”

The phenomenological attitude described by Husserl created much controversy concerning its application in research practice. Martin Heidegger (1889-1976) a student of Husserl’s, was concerned with phenomenologically developing a deeper understanding about what it means to be a human being. Unlike Husserl, Heidegger’s opinion in relation to bracketing was that;

understanding is never without presuppositions. We do not, and cannot, understand anything from a purely objective position. We always understand from within the context of our disposition and involvement in the world” (Johnson, 2000, p.23).

In his seminal work, *Being and Time* (1927/1962), Heidegger introduces the ontological dimension of human existence. He uses the term “Dasein” which literally translated means “there-being” or “being-in-the-world.” With “Dasein” Heidegger emphasises that human beings are embedded in the world and always in the process of “becoming,” there is no fixed point of knowing, rather our past, present and future continue to have an influence. He stressed that our understanding, what it means to “be” cannot be separated from our “thrownness” into an existing world of objects, culture, history, language and relationships. In this sense Heidegger rejected Husserl’s epistemological mind-body dualism (Lavery 2003) and instead addressed the complexity, diversity and dynamic nature of being in the world, while still holding and describing the uniquely important aspects that shape us as individuals.

For Heidegger, phenomenology means making sense of what is appearing. In his writings he also makes it clear that appearance has a “dual quality” in that “things have certain visible meanings for us (which may or may not be deceptive), but they can also have concealed or hidden meanings” (Smith, Flowers and Larkin 2009, p. 24). This provides a real sense of what phenomenology is about and how this understanding can be translated into the practice of IPA.

Essentially Heidegger argued that all description is always already interpretation and every form of human awareness is interpretative. In line with Heidegger’s thinking, the researcher enters the world of the participant with prior understanding and the interpretation of data becomes a cyclical activity, engaging with the data and reflecting on possible influences. In this way “bracketing” becomes a reflexive ongoing process.

Merleau-Ponty (1908-1961) also shared Heidegger’s view of “being-in-the-world” but his attention placed embodied experience as central to understanding the human situation. He uses the phrase “flesh-of-the-world” to capture the idea that we live and engage with the world in a bodily way. Merleau-Ponty’s *Phenomenology of Perception* (1962) represents a significant shift from being concerned with the temporal aspects of bodily experience to the spatial qualities of our existence.



Merleau-Ponty identifies that "to be a body is to be tied to a world" (Merleau-Ponty 1962, p148). Merleau-Ponty argues that our body not only connects us to the world but is central in all lived experiences and integral to understanding ourselves. The interconnectness of our bodies is central to our being and can be demonstrated by amputees who experience phantom limbs.

In addition Merleau-Ponty (1945/1962) makes the distinction between the "subjective body" and the "objective body." The subjective body is seen as the lived body that inhabits the world in a way that is particular to the individual. In contrast he describes the "objective body" as one that is observed and objectified by another. In this way the body becomes a "contained, material, biological thing" to examine (Finlay 2011, p. 55). Equally we can objectify our own bodies, particularly when our body fails us in some way and we focus our attention on parts of the body. As the researcher this is an area of particular importance and interest; understanding the "body-world of illness" (Finlay 2011, p32) and developing a sensitivity to bodily expressions and experiences.

### *3.2.3 Hermeneutics*

Hermeneutics is the name given to describe the process of interpreting the meaning of texts (Rennie, 1999). The interpretative orientation of IPA relies on the ideas of three hermeneutic theorists; Schleiermacher, Heidegger and Gadamer (Smith, Flowers and Larkin, 2009). I will briefly outline the contributions made by each in order to understand how they have influenced IPA as methodological approach.

Schleiermacher was a theologian and one of the first to propose a detailed and systematic interpretation of texts, involving a linguistic and psychological analysis. His aim was to bring together the meaning of the text while gaining insight into the author's intentions. Schleiermacher was also concerned with attending to the shared context within which the meaning is produced. In addition and relevant to this study Schleiermacher saw the process as both creative and intuitive and he advocated drawing on a number of different skills. His theories opened up the potential of interpretation to look beyond the obvious and achieve meaningful and even unexpected analyses. He explained that with a detailed, comprehensive and holistic

analysis it would be possible to achieve “an understanding of the utterer better than he understands himself.” (Schleiermacher 1998, p. 266).

Heidegger continued to build on Schleiermacher’s theories of interpretation by combining his understanding of phenomenology with theories of hermeneutics. From Heidegger’s position interpretation was an inevitable part of being-in-the-world. He insists that understanding is always modified by our prior experience of the world or “fore-conceptions.” Rather than bracketing preconceptions, Heidegger suggests that the researcher acknowledges these and make sense of them. Heidegger explains that understanding emerges from giving priority to the phenomena to be interpreted rather than attending to the preconceptions. Equally what Heidegger proposes is that as we analyse the data these “fore-conceptions” may come to be known more clearly.

The dynamic process of moving between the whole text to parts of the text and then back to the whole is referred to as the hermeneutic circle. It is an iterative process, challenging us as researchers to move beyond the obvious, to the hidden, unknown or unexpected phenomena.

Finally in relation to hermeneutics I refer to Gadamer (1990/1960) and his work *Truth and Method*. His perspectives are aligned with those of Heidegger’s in that he continues to emphasise the idea that lived experience is both a way into the interpretation of the text as well as a potential obstacle to understanding it. In the following quote, Gadamer is also clear about the importance of allowing the text to speak for itself, rather than being influenced by preconceptions.

“The important thing is to be aware of own bias, so that the text can present itself in all its otherness and thus assert its own truth against one’s own fore-meanings.” (Gadamer 1990/1960, p. 269)

Gadamer appears to place more emphasis on historical context, so that the past is always part of the present. He identifies the fact that we are born into traditions and in terms of interpretation this conditions our understanding. He also attends to the

importance of language in that language is the means by which understanding is achieved.

In my opinion the dialogue between each of these theorists offers an insightful way to approach the interpretation of the text in relation to IPA. Each has a unique contribution to make and each helps us to move towards the essence of the phenomena.

Smith, Flowers and Larkin (2009, p. 37) concisely summarise the interdependent relationship between phenomenology and interpretation; “Without the phenomenology, there would be nothing to interpret; without the hermeneutics, the phenomenon would not be seen.” Specific to IPA Smith and Osborn (2003) refer to the “double hermeneutic” whereby “participants are trying to make sense of their experience; the researcher is trying to make sense of the participants trying to make sense of their world” (Smith and Osborn, 2003, p. 51).

#### *3.2.4 Idiography*

Idiography is concerned with a focus on the particular, the distinct experience of particular individuals in particular settings in which the experiences occur. It is also revealed in the depth and detail of the analysis. This offers a contrast to the ‘nomothetic’ adopted predominately by psychology, where generalizations are made about human behavior based on studying groups or populations.

Having considered the philosophical and theoretical considerations underpinning IPA, I move on to consider the application of this approach.

### 3.3 Interpretative Phenomenological Analysis: Application to Practice

Interpretative Phenomenological Analysis (IPA) is one of a number of approaches within qualitative research. IPA came into the spotlight and was developed and described by Jonathan Smith (1996, 2004). As a methodology IPA has flourished in health psychology (Smith et al., 1997) as well as attracting attention in related fields, namely clinical and counselling psychology (Smith, 2004). Furthermore, IPA has also been compared favorably with other qualitative research methods in terms of

integration of research and practice, which is in line with NHS commitment to 'the patient's agenda' (Reid, Flowers and Larkin, 2005).

IPA is a methodology in its own right concerned with detailed exploration of participants "lifeworlds" (Smith, 2004). Above all IPA is a process of discovery which is not possible with quantitative approaches. From this perspective IPA provides us with an exceptional approach for revealing unique individual experiences as well as shared experiences across participants. Importantly understanding how people feel about and attach meaning to the often indefinable areas of their life has implications for treatment interventions and coping strategies. In addition this method is also well suited to exploring chronic health issues over extended periods of time and adding to existing research studies.

IPA is concerned with the particular, distinct experiences of individuals as they are situated within particular contexts. Consistent with this, IPA recommends a small sample size of 5-10 as a typical example (Smith, 2004) to support creativity and prevent an overload of data to analyse. The strong commitment to idiography has however raised questions about the clinical utility and generalisability of IPA studies.

In order to understand individual meanings attributed to particular experiences, most IPA studies employ in-depth interviews; questions are exploratory and semi-structured. The use of the semi-structured, one-to-one interview supports a rapport between researcher and participant, offering "the space to think, speak and be heard," (Smith, Flowers and Larkin 2009, p. 57). Semi-structured interviews also provide flexibility for the researcher to explore areas of interest that emerge. At the same time the participant also has freedom to lead the direction of the study and discuss issues that they feel are important to them.

My experience is that IPA as a methodological approach is not prescriptive, rather there is a drive for creativity and reflexivity (Stige, Malterud and Midgarden, 2009) reflected not only in the collection of data but also with the analysis.

The process of analysis has been described as an "iterative and inductive cycle" (Smith, 2007) associated with a number of distinct processes. Specific information

about the analytic procedures for IPA can be found in several texts (Larkin, Watts and Clifton, 2006; Smith, Flowers and Larkin, 2009; Smith and Osborn, 2008).

It has been my intention in this section to introduce IPA and provide a sense of how a hermeneutic phenomenological approach has the ability to go only expand on existing knowledge. My aim has been to bring this study alive and convey something of the theory and practice involved. As the researcher I hope to have made transparent the relational, embodied and co-constructed nature of the research process as I see it and my own philosophical and epistemological position.

## Chapter 4

### 4. Method

#### 4.1 Introduction

This chapter focuses on the process of conducting the study, commencing with obtaining ethical approval and a description of participant recruitment with demographic information. To follow there is an outline of the format for collecting data, including the development of the semi-structured interview schedule.

Reference is also made to process by which participant confidentiality and welfare is maintained. I conclude with a detailed description of data analysis.

#### 4.2 Ethical Approval

The study required careful planning and implementation to comply with ethical guidelines. In particular the ethical issues relevant to this study include informed consent, confidentiality, reducing participant stress and harm, the right to withdraw and data management which will be discussed in more detail in section 4.5.

Ethical approval for the study was obtained from the Metanoia Institute and the East of England-Cambridgeshire and Hertfordshire NHS Research Ethics Committee (See Appendix 1).

In addition, my view is that ethics is an on-going process, not just about rules and procedures; ethical considerations are integral to the research process. As such ethical issues are embedded and referred to throughout the study and not limited a specific discussion.

### 4.3 Participant Recruitment

Participants for this study were recruited from the Department of Clinical Health Psychology at the Queen Elizabeth Hospital King's Lynn NHS Foundation Trust. In total 5 participants were recruited. This was the intended sample size, and considered normative for IPA (Smith & Osborn, 2003) where detailed analysis of each case is required. Participants were representative of the clients who currently attend the department for psychological therapy.

#### *4.3.1 Recruitment Process*

The participant recruitment process took place over a period of 6 months. Potential participants comprised of all clients referred to the Department of Clinical Health Psychology who met the inclusion criteria. The inclusion criteria for the study consisted of clients who had lived with pain for more than 12 weeks in accordance with the definition of chronic pain from the British Pain Society (2003). The length of time living with chronic pain was established during the pain triage assessment and with reference to the referring letter from the pain consultant or GP.

Complex trauma symptoms were assessed during the history taking based on four factors: 1) the chronic, pervasive nature of the trauma; 2) the early nature of the trauma, meaning occurring in early childhood; 3) maltreatment, referring to abuse or neglect; 4) within a care-giving relationship.

The Structured Interview for Disorders of Extreme Stress (Pelcovitz et al., 1997) (See Appendix 3) was also used to comprehensively assess the clinical presentation and phenomenology of complex trauma symptoms and to differentiate from a diagnosis of PTSD. SIDES is a 45-item instrument used to assess past and present functioning over six domains: 1) affect dysregulation; 2) disturbances in attention/consciousness; 3) disturbances in self-perception; 4) disturbances in relationships; 5) somatization; 6) disturbances in meaning systems. As identified by Pelcovitz et al. (1997) SIDES has been a valuable instrument in providing empirical evidence for the validity of the CPTSD construct.

As this was the first qualitative study to date, to explore the experience of living with co-morbid chronic pain and traumatic stress, there was no discrimination in respect

of gender, sexual orientation, ethnicity and cultural background, religion and religious beliefs or political beliefs. My intention was to remain open to the range of individual, social and cultural factors which may impact on the subjective experience of co-morbidity.

Participants were excluded from the study if they did not meet the inclusion criteria. They were also excluded from the study if they were experiencing significant mental health problems that required urgent referral to mental health services; for example engaging in high-risk situations such as self-harm, suicidality and risk taking.

To outline the process, all clients referred to the Department of Clinical Health Psychology receive an opt-in letter as part of the service. It is the responsibility of the client to contact the department and make an appointment to be seen for a pain triage assessment. Following a pain triage assessment, potential participants who met the inclusion criteria were selected for the study.

For clarity, the pain triage assessment is a routine assessment for all individuals who are referred to the Department of Clinical Health Psychology. The aim of the assessment is to determine the most appropriate interventions or referral pathway for each client. As part of the assessment the Hospital Anxiety and Depression Scale (HADS) and the Pain Self-Efficacy Questionnaire (PSEQ) are routinely completed. A comprehensive assessment of trauma experiences and symptoms are taken with clients presenting with a trauma history, with the additional use of the Structured Interview for Disorders of Extreme Stress (SIDES) (Pelcovitz et al., 1997).

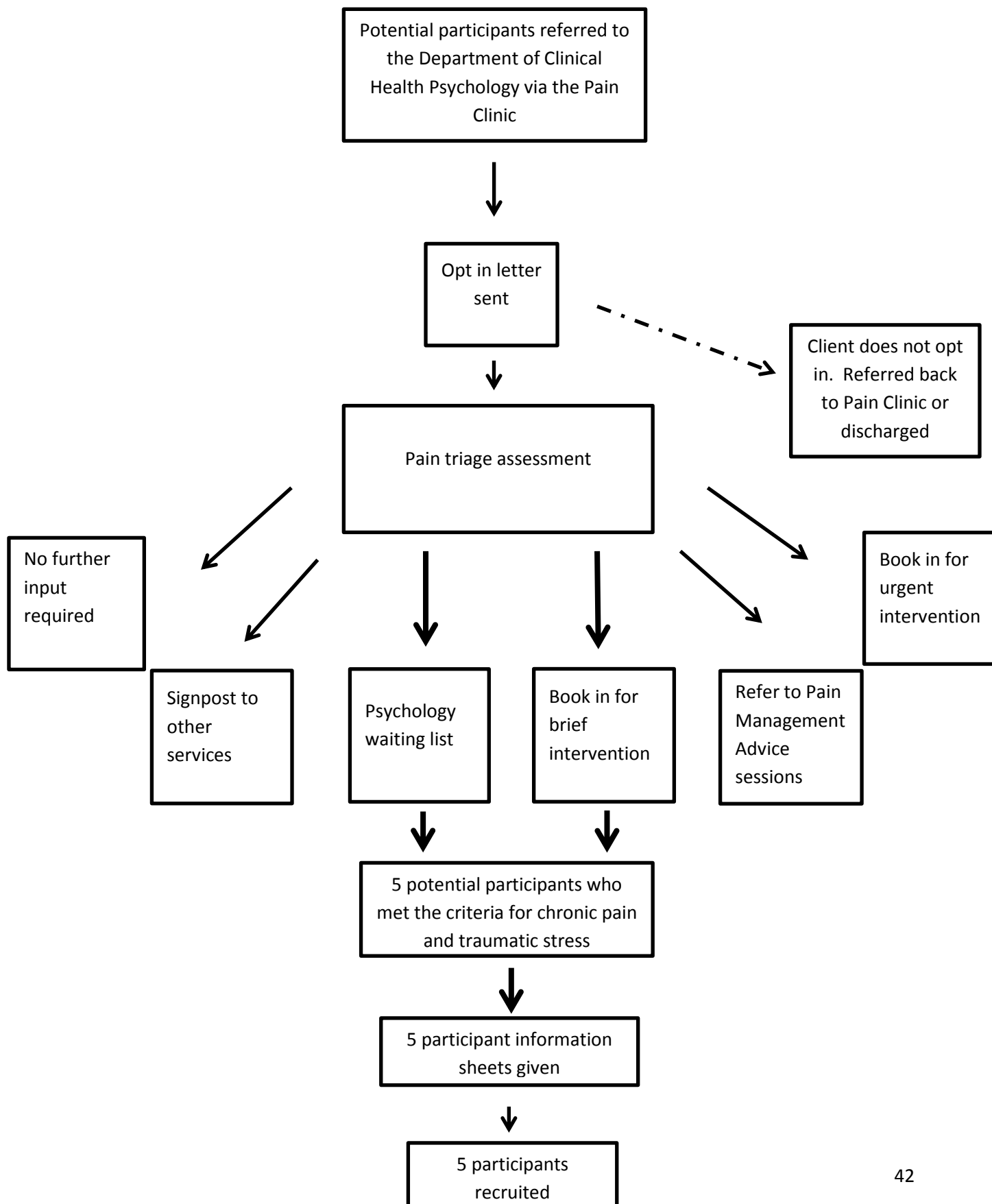
Following the pain triage assessment and in discussion with each client the process is either for the client to be seen for urgent intervention; to be seen for brief intervention; to attend the Pain Management Advice sessions; to be placed on the psychology waiting list; signposted to other services or no further input is required and the client can be discharged from the service.

Once the pain triage assessment had been completed and if the clients met the inclusion criteria outlined, a participant information form was given to potential participants with detailed information about the study (See Appendix 2.1). In total 5



participant information sheets were given out over 6 months and all 5 participants agreed to take part. For further details regarding the participant recruitment procedure see section 4.5.1. Of the participants taking part, three had been identified for the psychology waiting list and two for brief interventions following the pain triage assessment. After taking part in the study they returned to the agreed pathway, i.e. psychology waiting list or brief interventions list. No further participants were identified for the study once the first five participants had agreed to take part in the study. Figure 4.1 provides an overview of the recruitment process.

Figure 4.1 Participant Recruitment Process



#### 4.4 Introduction to the Participants

The participants in this study included three white British females and two white British males in middle adulthood, aged 42-64 years, who had been experiencing long-term chronic pain and traumatic stress. Table 4.1 contains an overview of participant characteristics.

**Table 4.1** Participant Characteristics

<b>Pseudonym</b>	<b>Age</b>	<b>Sex</b>	<b>Nationality</b>	<b>Duration of pain</b>
<b>Sarah</b>	<b>46</b>	<b>F</b>	<b>British</b>	<b>&gt;20 yrs</b>
<b>Lorraine</b>	<b>61</b>	<b>F</b>	<b>British</b>	<b>&gt;10yrs</b>
<b>James</b>	<b>42</b>	<b>M</b>	<b>British</b>	<b>&gt;25 yrs</b>
<b>Laura</b>	<b>48</b>	<b>F</b>	<b>British</b>	<b>&gt;25 yrs</b>
<b>Thomas</b>	<b>40</b>	<b>M</b>	<b>British</b>	<b>&gt;20 yrs</b>

I will briefly introduce each of the participants without compromising anonymity and confidentiality. The intention is to provide the reader with some background information and also to support the idiographic element of IPA.

##### *4.4.1 Sarah*

At the time of interviewing Sarah was 46 years old. She described suffering with back pain following a fall in her twenties. Over the years the pain has gradually become widespread. She emphasized that during the last few years the pain has become much worse and her mobility has deteriorated to the extent that she uses crutches and sometimes a wheelchair.

Sarah outlined a long history of physical and psychological trauma starting as a child and continuing into early adulthood.

#### *4.4.2 Lorraine*

Lorraine was aged 61 years at the time the interview took place. She outlined a history of chronic back, knee and hip pain dating back more than ten years. At the time of interview she explained that she was considering knee and hip surgery.

Lorraine described having a difficult childhood. As an adult she was involved in an abusive relationship. More recently she talked about being subjected to a form of bullying.

#### *4.4.3 James*

James was 42 years old at the time of interview. He identified a long history of back and shoulder pain following an accident. James described the pain as unpredictable with sudden spasms of pain disrupting his ability to work and carry out activities of daily living.

James talked about a succession of difficult and traumatic life events dating back to his late teenage years. These include serious road traffic accidents and adverse relational experiences.

#### *4.4.4 Laura*

Laura was 48 years of age at the time of the interview. She outlined a long history of chronic back pain dating back to young adulthood. Laura believes the back pain started as a result of heavy lifting in her job. She informed me that the pain became more widespread following two road traffic accidents several years ago.

Laura discussed a significant traumatic event in her early adulthood against a background of relational trauma.

#### *4.4.5 Thomas*

Thomas was 40 years old when interviewed. He discussed a long history of chronic knee pain, starting in his late teenage years with the gradual onset of back pain. Thomas told me that he now walks with crutches and is unable to work.

Thomas discussed developmental disruptions growing up. As a young adult he reported experiencing emotional and physical abuse.

## 4.5 Procedure

### *4.5.1 Consent*

Potential participants who met the inclusion criteria described for the study were contacted in writing asking if they would like to participate. The participants who agreed to take part in the study received a full written explanation of the study including the rationale for the study, the selection criteria and potential risks and benefits involved with taking part (See Appendix 2.1). As the researcher I included my contact details within the Department of Clinical Health Psychology should participants wish to discuss any aspects of the study at any stage of the process.

In line with the British Psychological Society's 'Ethical Principles for Conducting Research with Human Participants' (BPS, 2010), all participants were asked to sign a consent form before the interview and were informed of their right to withdraw at any point within the study up to and including the final writing up stage. A full copy of the consent form used can be found in Appendix 2.2.

### *4.5.2 Confidentiality*

Due the depth of information gathered from each participant, confidentiality was a particular ethical consideration. Participants were informed that the interview materials would be treated, with respect, as 'sensitive material'. Confidentiality falls under the category for potential 'harm to participants', with the following points being particularly relevant to confidentiality in this study:

#### Transcription of interviews:

As the author I transcribed all interviews and I was the only person who had access to the audio recordings. Data was stored according to relevant regulations; all information was stored in a locked filing cabinet within a locked room. Part of the transcription process involved anonymising any potentially identifying information such as locations, comments or names. Pseudonyms were given across each

transcript. A table with participant's pseudonyms and demographic information was compiled. See Table 4.1.

### Dissemination of Data

Full details regarding dissemination of data were included within the Participant Information Sheet (see appendix 2.1). Full permission was also obtained while taking informed consent, to use verbatim quotations in the final write-up of the study.

#### *4.5.3 Data Collection*

Data was collected in the form of semi-structured interviews (see appendix 2.3). Smith et al. (2009, p. 56) suggest that "IPA is best suited to a data collection approach which will invite participants to offer a rich, detailed, first person account of their experiences". The questions were therefore constructed so that the participant could talk about and reflect upon their experiences freely and as the researcher I could enter the participant's life-world. The interview questions started with, "Please can you tell me about ...". In this respect the construction of an interview schedule served as a guide only. Preparing the interview questions was an evolving process with input from my research supervisor and shaped by my progression through the research process.

The interviews were face-to-face and took place in the Department of Clinical Health Psychology at a date and time that was convenient to the participants. Each participant spent one session with the researcher. The interviews varied in length from between 60 minutes to 90 minutes. See Appendix 2.3 for a full copy of the interview schedule.

Kvale and Brinkmann (2009) suggest the process of interviewing be viewed as a "craft" with the person of the researcher being integral to the quality of the data produced. The interview in the present study started with an introduction about my role as the researcher and a brief outline of the format of the interview. I believe this created a space for the participant to feel more relaxed and informed about what was expected of them before the audio tape recording commenced. It also provided an opportunity for participants to ask questions. Once the tape recording started the definitions of chronic pain and traumatic stress were provided, followed by a brief

summary about the participants' history of pain and traumatic stress that had been captured during the pain triage assessment.

My aim throughout the interview was to create an atmosphere that would encourage participants to talk freely about their experiences in an unrestricted way. As the researcher I wanted to adopt a stance that was facilitative and curious, remaining completely present with each participant and paying attention to the subtle, non-verbal gestures and nuances of body language as well as the verbal content.

As the researcher I was aware of the potentially distressing nature of the material that may emerge during and after the interview process. At the end of the interview participants were given time to talk about their experience of taking part.

Participants who took part in the study also had access to psychological therapy following the interview, should they experience any distress as a result of the interview. Within this study all the participants declined this offer. All participants who took part in the study would return to the pathway according to the outcome of the pain triage assessment.

Each interview was audio-taped, transcribed and served as data for the study. All the participants were invited to read the transcripts following the interview to add any further comments and to ensure that the data closely reflects the description of their experiences. This was not simply an ethical consideration but also one of research validity. Only one participant registered interest in doing this and then declined to attend an appointment.

#### 4.6 Data Analysis

The data was analysed using interpretative phenomenological analysis (IPA). The analysis closely followed the guide described in detail by Smith, Flowers and Larkin (2009). To provide clarity the process of data analysis is detailed in Figure 4.2.

**Fig 4.2** The process of data analysis based on the guidelines outlined by Smith et al. (2009)

<p><b>Step 1</b> Reading and re-reading</p>	<p>I immersed myself in the data by listening to the first recording several times before transcribing the interview.</p>
<p><b>Step 2</b> Initial note taking</p>	<p>I carried out a detailed line by line analysis of the text based on free association, unstructured commentary and noting areas of particular interest. My aim was to capture the meaning and importance of the experiences to the participant. Consideration was given to the use of language and context. Smith et al. (2009) identify three separate processes within this: <i>Descriptive</i> comments (describing content of what participant has said). <i>Linguistic</i> comments (a focus on specific use of language, such as metaphor, repetition or hesitancy) and <i>conceptual</i> comments (engaging with text at an interrogative level). I made notes which were documented in the right hand margin. I used normal text for descriptive comments, italic text for linguistic comments, underlined text for conceptual comments and red text for my countertransference responses.</p>
<p><b>Step 3</b> Developing emergent themes</p>	<p>At this stage my focus was to stay with the complexity whilst reducing the volume of data. The aim was to capture quality and content of sections of text and begin to notice interrelationships, connections and patterns grounded in the data. I then clustered phrases into emergent themes.</p>
<p><b>Step 4</b> Searching for connections across emergent themes</p>	<p>Once I had identified the emergent themes the next stage involved looking for connections across the emergent themes and mapping how they fit together. In order to do this I listed the emergent themes in chronological order</p>



	<p>on a separate piece of paper. I cut the list up so that each theme was separate. I used a large board to spread the themes on and started to group the themes together with similar meanings and themes in opposition at the opposite end of the board. At this point a significant amount of pruning took place, as I started to develop themes relevant to the research question and discard themes that were not relevant. I continually compared the themes with original transcript to ensure the analysis was representative of the participant account.</p>
<p><b>Step 5</b> Developing superordinate themes</p>	<p>The development of superordinate themes took place through a number of different processes. Identifying patterns across themes, <i>Abstraction</i>. <i>Subsumption</i>, where the emergent theme becomes superordinate theme, <i>polarisation</i>, (identifying oppositional relationships between emergent themes), <i>contextualisation</i> (attending to temporal, cultural and narrative themes), <i>numeration</i> (frequency with which a theme is discussed), <i>function</i>, (determining function of themes for the individual) (Smith et al., 2009). In addition I compiled participant's phrases to support the superordinate themes. Bringing it all together involved producing a table of superordinate and sub-themes for each participant.</p>
<p><b>Step 6</b> Moving on to the next case</p>	<p>I moved on to the next case, repeating the process. As the researcher I held in mind the importance of approaching each case with an open mind, trying to "bracket" previous themes in order to maintain individuality</p>
<p><b>Step 7</b> Looking for patterns</p>	<p>The final step involved a cross case analysis. This involved looking for similarities and differences across</p>

across cases	cases, identifying connections and revising themes. With each of the five boards of participant themes I was able to lay them out and identify connections across these themes that could be grouped into broader super-ordinate themes with sub-themes illustrating the super-ordinate theme. At this stage super-ordinates theme were re-named as a deeper understanding of the data emerges (Smith et al., 2009). A master table of superordinate and sub-themes was produced. (See table 5.1)
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Drawing on my knowledge and practice of psychotherapy I was able to move to a deeper analytical and interpretative space by attending to unconscious dynamics and meanings that emerged which participants themselves might have been unaware of. Dilthey (1894/1977) identified that lived experience may also be outside of immediate conscious awareness but could be brought into awareness.

As I analysed the participant transcripts I noted my countertransference responses in red text in the right hand margin. This allowed me to connect with my subjective affective and bodily reactions.

Throughout the data analysis process I also referred to Finlay (2011). She encourages researchers to “stop and linger” and stay with sections that resonate, “embracing an attitude of wonder.”

To ensure validity the data analysis process involved continually checking and questioning the themes, by returning to the transcript. I used verbatim extracts to support the validity of the themes and capture the richness of parts of the text. In addition the inclusion of raw data ensures that readers have the opportunity to form their own interpretation of the material (Willig, 2001).

A second person was asked to read the transcripts for each participant once the emergent themes had been identified. This was to ensure that the most relevant

data had been retained with sensitivity and openness to the meanings within the data. She was a psychologist who knew of the research but was not directly involved and therefore would not compromise the validity. Each transcript was read independently by the psychologist. At this stage she felt that the emergent themes represented a clear and consistent analysis of the participant accounts. A further check was carried out to support the validity of the superordinate and sub-themes following the cross-case analysis. There was general agreement by the psychologist that all the themes were representative of the participant transcripts with no recommendations for changes or rewording of themes.

The research findings were then considered in relation to existing experiential knowledge, extant literature and woven into the narrative explanation.

#### 4.7 Demonstrating Validity and Reliability

The validity and reliability of qualitative research cannot be judged within the traditional frameworks of quantitative research. However it is still vital to ensure the quality and trustworthiness of qualitative research (Cohen, Manion and Morrison, 2011). No single set of standards have been established; instead qualitative research encourages “multiple standards of quality, known variously as *validity, credibility, rigor or trustworthiness*” (Morrow 2005, p. 250).

A number of researchers have suggested ways in which to ensure that qualitative research is of a good quality. Smith et al. (2009) favor the “four principles” approach of Yardley (2000: 2008). In this assessment of quality reviewers are asked to consider research from the perspective of: *sensitivity to context; commitment and rigor; transparency and coherence; and impact and importance*.

In terms of the present research study I refer to Yardley (2000: 2008) in order to discuss how I have demonstrated quality and trustworthiness within this research study in each of the four areas she suggested:

##### 4.7.1 Sensitivity to context

The methodological approach inherent in IPA means that sensitivity to context is integral to the study. This is key from the very beginning and continues through all

the stages of the research process both implicitly and explicitly. As the researcher I have been guided by ethical principles and procedures such as obtaining ethical approval; informed consent and maintaining confidentiality with each participant. I have used supervisory support to design the study and attended closely to the existing literature within this area. Throughout the study I have developed good systems of support with supervisors and colleagues.

At each stage I was aware of the importance of placing the participants at ease. I was conscious that researching this area of experience may be anxiety provoking. Therefore prior to attending the interview a full written explanation of the study was given in the form of a participant information sheet, assuring the right to withdraw from the process at any time (See Appendix 2.1).

I was sensitive to the clinical context of the interview and considered what meaning this might hold for the participant such as expectations around treatment interventions or issues of hidden power dynamics. The participants had previously attended the department for a pain triage assessment and therefore had an understanding about the role of the psychological therapist in terms of pain management.

Participants attended the Department of Clinical Health Psychology at a date and time convenient to them. Participants were sent an appointment letter for the interview with a map and parking details. In practical terms participants already knew the location and ways to access the department based on their physical limitations and pain. I was available to meet the participant on arrival to the department, introducing myself and provided clear explanations about each stage of the process.

At every stage it was important to me that the participants felt involved and experienced a sense of trust and autonomy with myself as the researcher and the research process. As the researcher I clear about my own interest and involvement with the study and my role within the department. Informed verbal and written consent was taken prior to starting the interview and participants were given the opportunity to ask questions. Participants were again clearly informed about their

right to withdraw at any stage. The interview process itself was clearly explained, including the process after the interview. Participants were informed that following the transcription they would be invited to read through the transcripts before they were analysed. Participants were advised that they would return to the pathway agreed following the initial pain triage assessment.

I recognised as the researcher I had a duty of care to ensure the emotional and physical safety of participants. Within this I attended to my roles and boundaries as the researcher and not a therapist. There was a debriefing for each participant at the end of the interview. Participants could receive support as documented on the Participant Information Sheet (see appendix 2.1) from another psychologist if they experienced distress or difficulties either during or following the research. None of the participants required this and all participants returned to the agreed pathway determined by the initial pain triage assessment. As the researcher I actively listened, valuing the participants 'voice', and showing empathy and respect for the sensitive nature of the material disclosed.

Sensitivity to context was also demonstrated explicitly through the writing up stage. I paid careful attention to the interpretations made using verbatim extracts to support the claims being made.

#### 4.7.2 Commitment and Rigour

Commitment and rigour was demonstrated through in-depth engagement with the study. This level of commitment started with choosing a topic and a research question, through to careful planning and gaining ethical approval, data collection and analysis and writing up. I have provided an audit trail to illustrate the research process (see all appendices). The quality and thoroughness of the analysis was achieved and strengthened by listening to the audio recordings multiple times to ensure transcription was accurate and to develop a closer relationship with the data. Reliability was further strengthened by a clear description of how the data analysis was conducted.

#### 4.7.3 Transparency and Coherence

I have demonstrated transparency and coherence by providing a clear description with diagrams and tables and appendices, of the individual stages of the research process, including the recruitment process, the construction of the interview schedule and the process of analysis. In writing up the research study I have clarified the rationale for the study, situating the study within the context of existing research.

Demonstrating coherence has involved stepping into the position of the reader to ensure there is a fit between theory and method; the rationale for the study is clear and consistent and the themes flow and are logical. This has been achieved through supervision with the redrafting of the writing up process.

I believe transparency and coherence emerges from developing an embodied self-awareness into my subjective and intersubjective processes throughout the research process. Finlay (2011) refers to “hermeneutic reflexivity” which encompasses a continual process of reflecting on interpretations and our own experiences in order to open up and expand upon our previous understandings. As I was immersed in each transcript I kept a reflective diary to record my personal feelings and responses to the data as advised by Bager-Charleson (2016). This enabled me to reflect on and understand my own experiences of the research process.

#### 4.7.4 Impact and Importance

I believe the study offers a significant contribution to the field of chronic pain and traumatic stress, enriching our understanding in this field. I also believe it is empowering to the participants and other individuals who suffer with this co-morbidity. This study will inform therapeutic practice and build on existing research in this area.

## Chapter 5

### 5. Findings

#### 5.1 Introduction to Findings

The focus of the study has been to explore the experience of comorbidity; namely participants unique experiences of living with chronic pain and traumatic stress. This chapter is concerned with presenting the findings in detail following an in-depth analysis of the transcripts.

Six superordinate themes emerged from cross-case analysis of each of the interviews. The sub-themes which made up the super-ordinate themes were mostly consistent across the participant's accounts. A small number of sub-themes were unique to particular participants. Where this has occurred it has been documented and discussed to ensure clarity for the reader.

Each of the six superordinate themes will be presented in turn along with the interrelated sub-themes. It is significant to note that the raw data from each participant contained rich descriptions of the experiences of living with chronic pain and traumatic stress. Quotations are used throughout to support and illustrate the themes in more detail. All quotations have been taken directly from the raw data.

The presentation of the findings is followed by a discussion in section 6 in which the researcher offers an in depth interpretation of the findings. Finally, the conclusions drawn from the study are presented in section 7.

A summary of the overarching and sub-themes can be found in Table 5.1.

Table 5.1 Master Table of Superordinate Themes and Sub-themes

Superordinate Themes	Sub-themes
<p>“Every day is just such a struggle”</p>	<ul style="list-style-type: none"> <li>• Overwhelmed by chronic pain and traumatic stress</li> <li>• Feeling out of control</li> <li>• The debilitating impact of chronic pain and traumatic stress</li> <li>• Loss of meaning and hope</li> <li>• Living with uncertainty; not knowing</li> </ul>
<p>Isolation</p>	<ul style="list-style-type: none"> <li>• Loss of connection with others</li> <li>• Experiencing delegitimisation and judgement from others</li> <li>• Invisibility and ambiguity</li> </ul>
<p>The relationship between chronic pain and traumatic stress</p>	<ul style="list-style-type: none"> <li>• Chronic pain and traumatic stress maintain each other: “It’s a vicious cycle”</li> <li>• “It’s a battle between the two”</li> <li>• Pain as a reminder of trauma</li> <li>• The body as a container for traumatic stress</li> </ul>



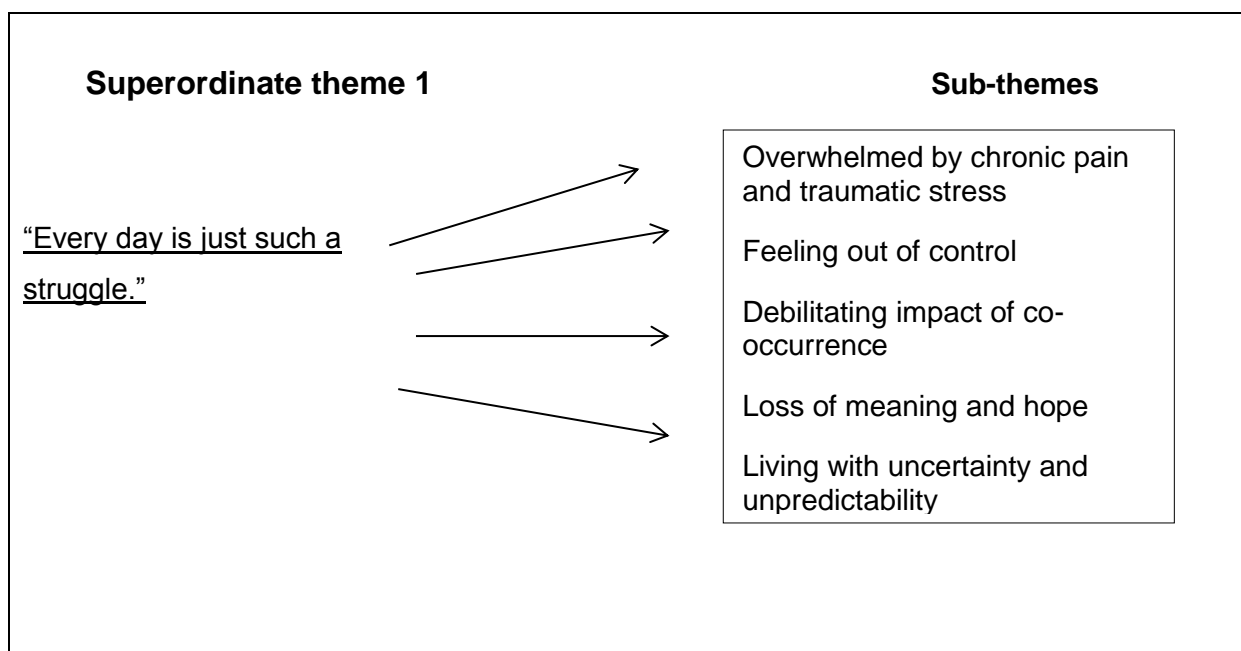
<p>Chronic pain and traumatic stress changes the relationship with the self</p>	<ul style="list-style-type: none"> <li>• “I’m a shell of myself”</li> <li>• Reflecting on changes to self over time</li> <li>• Gender identity and roles</li> <li>• A lack of self-compassion</li> </ul>
<p>Ways of coping with chronic pain and traumatic stress</p>	<ul style="list-style-type: none"> <li>• Surviving not coping</li> <li>• Feeling guarded: coping with anxiety</li> <li>• “I’m here but I’m not here”</li> <li>• “I just bottle it up”</li> </ul>
<p>Moving forward: Learning to adjust/live with chronic pain and traumatic stress</p>	<ul style="list-style-type: none"> <li>• The importance of feeling seen and valued as a person</li> <li>• Acceptance</li> <li>• “Having control over my life”</li> <li>• Resilience and determination</li> <li>• Holding hope</li> <li>• Compassion for self and other</li> </ul>

5.2 Superordinate theme 1: “Every day is just such a struggle”

The superordinate theme “every day is such a struggle” has been quoted directly from one of the participants accounts. This dominant theme represents the unique

set of personal struggles faced by the participants living with co-morbid chronic pain and traumatic stress. As the researcher I witnessed the struggle and suffering that all the participants faced every day and at times I noticed a strong pull to want to move away from the distressing nature of the material. For example Laura talked about her struggle just to be able to attend the interview: *“Every day is a battle to do anything. To come here this morning, yes I was up at 5 o'clock because I was in pain.”*

The theme “every day is such a struggle” is an abstraction of five sub-themes which capture the range of struggles that participants have to cope with every day. Each sub-theme will be discussed in turn below.



### 5.2.1 Sub-theme 1: Overwhelmed by Chronic Pain and Traumatic Stress

A clear theme to emerge throughout the participant accounts was the feeling of being overwhelmed by the constant unrelenting pain alongside the trauma. For some of the participants the pain was experienced as more disruptive. For other participants the trauma had a more negative impact on their lives. For all participants it was the interplay between the pain and trauma which really challenged

their ability to cope. Coping strategies are discussed in more detail in section 5. Lorraine offers an insight into how powerful pain and trauma are together when she refers to the co-occurrence as “forces.” There was a clear sense of the intensity and energy created by the interaction, leaving her feeling powerless both physically and emotionally. She also uses the word “sorrow” to illustrate the depth of her suffering and hopelessness as she reflects on the meaning of living with the co-morbid conditions.

In several of the accounts the inescapable nature of pain and trauma was evident. Laura says: “*You can’t never forget it no matter, you sit and relax and you can’t forget it’s not there.*” In referring to his pain James stated, “*it’s all pervading.*” Sarah also makes it clear that there is no escape from the pain, which mirrors her experience of the trauma: “*Ok, erm, well it, it is with me every mmm, every minute of every day.*” Pain and trauma overshadow her life: “*Umm, so obviously it is an ongoing, even with the, the pain meds it is an ongoing...struggle, ahh to do anything.*” Sarah elaborates further:

*Erm, I've fought it over the years, I have fought it and I've tried er but it always comes back and knocks me down again and I have to start up and on, on the ladder again and try and gain some self-confidence and (sighs) umm, (sighs 2secs). How else would I describe it, erm (sighs, 3 sec pause). I don't know, its, it's like a huge boulder that's there all the time and I try and ignore it, erm, but it's always there.*

In the above extract Sarah’s powerful use of imagery clearly captures the constant battle and pressure she has been under for “years”. The image created by the word “boulder” conveys the weight of the burden she has been consistently carrying. Similarly Laura describes feeling overwhelmed by the constant presence of pain and trauma in her life, “*it just feels like you're weighed down with the world on your shoulders.*” It was also the idea of the cumulative impact identified by Laura “*it has all built up and up and up.....*” As I sat with each of the participants I found their use of metaphors and the images really allowed me to understand how pain and trauma dominated every moment of their lives. At the same time I was aware of the

discomfort and distress I felt listening to the participant's accounts and my own feelings of helplessness and inadequacy emerged.

Participants went on to acknowledge that they could no longer cope with the psychological and physical demands placed on the self. Sarah describes her experience poignantly: *"It engulfs me, the pain and the psychological side you know."* In her acknowledgement of pain and trauma together Laura says: *"and putting the two together the pain overcomes the sort of like my get up and go sort of thing. So I don't cope with it both."*

James talks explicitly about the pain but implicit within this is the cumulative traumatic events he has also experienced: *"because it's constant (sighs) if it was one single event it wouldn't be too bad."* Again James reinforces the idea that it is the relentless and cumulative impact of pain and trauma together that overwhelms.

Lorraine reflects in more detail about on the on-going challenges she faces living with the co-morbidity. The anger and frustration is clear in her voice:

*It's no good you telling me you can deal with the two. You know because if there was a magic wand to get over, to get rid of the stress but you can't because it, you can't get it out of your head... You know it's erm, it's like having your leg cut off, you know your brain knows that that leg was there was always there.*

In the following extract Thomas draws attention to the cumulative and prolonged impact of pain and trauma. He reveals that he has reached the limit of the demands placed on him, both physically and psychologically:

*Er, the biggest one is not being able to cope with it anymore. Erm, where in the past, or being able to block out the pain, working through it and getting to the stage where you can't deal with it anymore and er, and then because you can't deal with the pain it effects your mental side of it. Where before you can block the pain, work through it, you can get on with your life, but it gets to a stage where there's too much of everything and it, it is a total breakdown*

*in your mental and physical ability, which I think is the hardest thing.*

What is interesting in Thomas's account is that he reveals how the pain and trauma compound each other, so that once he cannot cope with the pain he cannot deal with the "mental side." A more detailed discussion of the relationship between pain and trauma will be discussed in section 5.

Lorraine: "...umm, and so what with all the trauma that he threw back, it wasn't just what happened then it all came flooding back." Lorraine was clearly overpowered by the pain and trauma that never feels far away and leaves her "... thinking well I can't cope with this..."

### *5.2.2 Sub-theme 2: Feeling out of control*

This subtheme links with the previous subtheme; feeling overwhelmed but it also captures some of the additional struggles expressed by participants. Thomas in particular explained in some detail how pain and trauma have left him feeling emotionally out of control:

*Erm, emotionally it's ...(sighs)...it's lost control of your emotions, really there's, there's umm...short temperedness, frustration, not being able to be happy about things, it's, it's, it's like, it inhibits your ability to control your emotions in a normal, in a normal manner.*

Thomas describes his emotional distress. "All these feelings they're all, all in a big ball together." He goes on to add, "like erm, on the sun you get solar flares, yeah, yeah, and there's no controlling, which, where it flares out and that..." Thomas clearly illustrates how overwrought and out of control he feels with the use of vivid imagery. For Thomas feeling out of control is experienced as being trapped and powerless to effect a change in his circumstances:

*... because there's no control of it, because it overwhelms you.  
the two together, it's uh, you had the classic film where you've got the adventure and the walls are coming in and there's a little door at the end and the door's getting smaller. It's very much like that.*

Thomas identifies pain as more difficult to cope with but adds:

*....once I start getting stressed and worried and that, it, it is like a, going, a snow ball rolling down a hill...that gets bigger and bigger and bigger...  
.....and then that takes over.*

Thomas's use of the "snow ball" metaphor illustrates the way in which stress gathers momentum alongside the pain to create two uncontrollable forces. As the researcher I found it difficult to tolerate the devastating, uncontrollable impact that the co-occurrence was having for Thomas and indeed all the participants. Again as a healthcare professional I was faced with the reality of my own powerlessness and inability to control the destructive "forces."

Some participants identified feeling more in control when they experienced some respite from either pain or traumatic stress. For example Lorraine noticed: "You know you can't, if you take stress out of a situation...you'll find that the pain is easier to deal with..."

The constant struggle and loss of control with pain and trauma led some participants to feeling suicidal. One participant reported attempting suicide and two participants reported contemplating suicide as an escape from the constant struggle and suffering. Thomas talked openly about his reasons for attempting suicide:

*Erm....(pause) as I say, attempted suicide but that was not all just pain related. Some of that was the, the mental side of it....with being bullied and being picked on etc..etc..*

In the above extract Thomas clarifies that his suicide attempt was related to the pain and the cumulative traumatic events that he had been exposed to.

Lorraine talked about her struggle to keep going and identifies suicide as a "way out:"

*The two together is umm, if you allow it to, it er, you'll look for a way out, you know erm, and for somebody to say they don't think that then they are fooling themselves.*

Similarly Laura recalls: *"I was there on the edge with the pills, with the glass of water thinking, I'll take these, that'll be the end of it. All my worries will be gone."*

Suicidal thoughts or intentions offered these participants a way of escaping the pain and distress they experience every day. It could also be seen as providing a sense of control when it felt like all other choices had been taken away.

### *5.2.3 Sub-theme 3: The debilitating impact of living with chronic pain and traumatic stress*

Living with chronic pain and traumatic stress was associated with a number of debilitating consequences. Sarah offers a sense of just how debilitating the pain and trauma are together when she describes the *"ordeal"* she goes through everyday just getting out of bed *"It's almost impossible some days to ....do everyday things ..."* Sarah goes on to add:

*I suppose, like, like you know, you just it. It is so many things that I used to be able to do and I mean I do try and focus on what I can do...., umm but it's not every day that you've got that, that I feel strong enough mentally to be able to force myself to do it and force through the pain.*

What is evident from Sarah's quotation is not just the wide ranging loss of activities and functioning but also the loss of mental strength that is debilitating. The repetitive use of the word *"force"* in relation to the pain and the trauma powerfully highlights her ongoing struggle. Sarah appears to be reflecting on the gradual deterioration of her physical abilities which seems to parallel a deterioration in psychological ability to cope. She is also offering an insight into how physically and socially active she used to be. Sarah also identified her struggle as a no win situation: *"But that creates more pain, if I, if I overdo things it creates more pain..."*

Within all the narratives it was apparent that quality of life and choices had been taken away. For me the accounts were a reminder of just how vulnerable we are as human beings. Activities that were previously taken for granted were questioned for example when James said, *“how much is that going to cost me.”* The use of the word *“cost”* emphasizes how restrictive his life feels. James emphasizes: *“It’s almost impossible some days to.....do everyday things ...”* James’s account indicates that the debilitating impact of pain is also related to his heightened sense of fear and anticipation when he says: *“But literally is, it can be that bad where, you have to think about opening a door.”* James reiterates:

*The best word I could use is debilitating, erm, an image...ahh...again it varies (sighs) at its worst it literally, it’s somebody in the foetal position, just covering up trying to hide from it.*

The image of a *“foetal position”* is a powerful image illustrating the disempowering impact of pain and trauma which might not be captured with words in the same way. As the researcher this image really allowed me to understand and empathise with James’s fear and vulnerability. He moves on to talk about *“covering up”* and hiding from the pain. As he is talking I have a real sense of how he needs to protect himself in response to the trauma as well as the pain.

Living with the debilitating effects of the co-occurrence impacts not only the individual but their wider social network. Thomas describes how the co-morbid conditions have led to him becoming more reliant on other people with a loss of independence:

*So no, even though they say like ok you could do this, you could do that, you can volunteer for this, you’re like ....you put it into practice. I can’t deal with day to day activities. No, the getting up, the making sure you’re clean and presented. If it weren’t for my wife, I wouldn’t be ...*

This quotation illustrates Thomas’s frustration with other people’s lack of understanding about physical and psychological decline. He also goes on to



emphasize that without the support of his wife he would struggle with activities of daily living.

Participants discussed feeling guilty because of not being able to function independently and watching others struggle. Thomas talked openly about his loss of independence and his role within the family. The extract below contains a real sense of sadness and loss:

*Umm, you get upset because you can't do things, you get upset because you can't cope with dealing with things... You get upset seeing your wife, struggling not being able, you see, upset because you can't play football with your kids.*

Several of the participants identified the co-occurrence as having an impact on their work and social life. James discusses how difficult it has been for him to continue to work, *"I don't function to the best of my abilities all the time which again..."* The loss of optimal functioning was accompanied by negative self-appraisal. This will be discussed in more detail in section 5.5.

Lorraine talked about the consequences related to her loss of functioning: *"Cos, things, the more disabled you get the more erm, smaller you, the world's smaller."* Clearly there is a feeling of life closing in as she recalls with sadness giving up activities that she used to enjoy. In what also feels like a defensive move to protect herself from the loss and sadness Lorraine denies herself any chance of pleasure by isolating herself.

*I've now accepted that I wouldn't be going dancing and that took me a long while to, because I was always dancing, so then that was, I wouldn't go anywhere.*

On the surface it appeared that Lorraine had accepted her physical limitations, although there was an element of resentment in the tone of her voice. It seemed that participants were not only struggling with the loss of their physical bodies but also the loss of social interaction and activities.

The chronic conditions affected the individual, those around them and the way they engaged with the social world. There was also a distinction between past and present self and loss of meaning and purpose which will be explored within the next subtheme, "Loss of meaning and hope."

#### 5.2.4 Sub-theme 4: Loss of meaning and hope

Many of the participants spoke about their struggle with loss of meaning in their lives and loss of hope for the future. For Sarah life was experienced as an existence:

*Erm, ooh for a number of years I feel as if I don't have a life, I feel I just exist every day to get through the pain and get through the effects of what I went through, umm, because of the anxiety etc... yeah, I feel I exist.*

While reflecting on his future Thomas said: *"It isn't getting any better, if anything it's going to get worse."* There is a real sense of hopelessness and loss of purpose as he goes on to add:

*Yeah, er whereas my purpose in life, yeah it's we, we strive to be the best in the area we are in, everybody does. I don't "oh I'm happy being here," "yep ok but you're you've strived, you've reached where you want to be, I not haven't, I'm able to yeah, it's impossible for me to do what I do and I was good, I was very good at what I did.*

In the above quotation Thomas talks about the importance of having a purpose and achieving your potential, at the same time he questioning the meaning and purpose in his life. Many of the participant accounts contained loss and mourning for a life before the pain and trauma. There a clear sense of the pain and trauma reducing lives to misery and emptiness.

Similarly Lorraine talks about her loss of motivation and questions the purpose of her life in the future:

*Erm, there doesn't seem to be any umm, there's no goals anymore, they've gone, you know you can't say well I'll work towards that, I'll work towards this, that, that's gone now. Erm and I've come to accept it in a way, erm but just let that emotion go.*

Thomas appears almost tormented as he says:

*Yeah, so you can see the pit below you, you can see where your life was and you're ...stuck in the middle because you don't know where, what's what's available, where you're gonna go.*

In the preceding quotation Thomas uses clear images to express his confusion and fear about his future. *"It's, it's limbo again."* It feels as if he is struggling to hold on to his life and not fall into the "pit."

Thomas talks about loss of meaning and purpose. He feels he has nothing to offer other people: *"People needed my advice and my abilities, that's no longer...everybody needs to feel needed, in a way, even if it's in the work place, socially, at home."* Thomas is clearly questioning his usefulness and place in the world when he says: *"You can't put anything back into it."* This also relates to gender identity which will be discussed further in section.

Similarly Lorraine's account contains regrets that she could have achieved more with her life. Although Lorraine is able to reconnect with positive aspects which have given her life meaning:

*Um, sometimes I think ah, what a waste of a I, what a waste of a life, but you can't say that, I've got two sons and I don't regret, you know, but umm, in a lot of other things and I'm thinking, it could have been so, I could have done so much more and course now that I'm in pain I can't do and I sometimes, I wouldn't say I think oh whatta, why me, I don't use that.*

Within the narrative accounts participants reminisced about their previous lives, clinging to past aspirations and sharing regrets and missed opportunities. Lorraine

talks about loss of aspects of her life she previously enjoyed: *“Umm, yes I look at clothes but I’ve got to, I think well, what’s the point because I wouldn’t wear them anyway so I’ve lost all that.”*

James talks about missed opportunities and regrets. *“And it’s just kind of ok, and that again it’s always having your hopes dashed.”* In the following extract James reveals the extent of his loss and reflects on missed opportunities; it had always been his dream to jump out of an aeroplane:

*I should have done it when I had the chance but (sighs) but yeah it’s just kind of everything, it (sighs) it actually, almost have you have to re-evaluate your whole life and again being from a more physical, physically active kind of family it doesn’t help because all my cousins are off doing their hundred mile bike rides....And triathlons and running marathons and ...*

This description above indicates the degree of impairment caused by the pain but also the psychological impact of having to “re-evaluate” your “whole life.” James is also constantly reminded by others of a lifestyle which he continues to miss. For him the sudden loss of physical capabilities has been traumatic in itself as he struggles with feelings of lost identity and shame. There is also a heightened sense of his vulnerability which relates to feeling let down by his physical body.

#### *5.2.5 Sub-theme 5: Living with uncertainty; not knowing*

The sub-theme living with uncertainty and unpredictability highlights the context within which the participants negotiated their day to day lives. Thomas expressed his fear about the future: *“Where am I going to be”... “It’s again, not knowing what’s going to happen to you.”* Lorraine revealed: *“...I don’t go, I don’t look into the future...”* The prospect of looking forward to the future created fear for Lorraine who had watched her mother suffer with Alzheimers. Related to this Lorraine shared her fears around ageing: *“I think it is you know and I think as you’re getting older you, you’ve really got to talk about getting old you know and I don’t want to do that.”* Lorraine’s own physical deterioration as well as her mother’s had become a constant reminder of her own mortality.

For many of the participants there was uncertainty in terms of the trajectory of their physical condition which impacted psychologically. James talks about living with uncertainty in relation to chronic pain as having “*no end point.*” He goes on to add: “*Which again doesn’t help because, again it’s nice to know you’re heading towards an outcome.*” There was a sense of James not having control or being able to plan.

Laura spoke about her struggle with not knowing in relation to her diagnosis and treatment. She is also sharing her expectations that medicine has all the answers and the potential to cure. It seems as Laura is placing the autonomy for her care in the hands of medicine and the frustrations she describes below could also be understood as projections from her past adverse relationships:

*...even with all these new pain killers and different treatments and things it's still there and I do get frustrated when I go and see the surgeon and say, well look there must be something that I can take or something you, can say to me, you've got...*

For participants such as Laura living with the physical uncertainty became a reminder and repetition of her trauma experiences where the clinicians unresponsive reactions replay patterns of past relationships whilst awakening a need for responsive and caring relationships:

*But they say oh well it could be this or it could be that and you...can't really focus on...I think if I knew what it was I may be able to deal with it better.*

In contrast Sarah’s account reveals that her diagnosis offered certainty and reassurance in what has been a chaotic and traumatic life. There was also a sense that Sarah felt validated and seen as a person:

*...with my health but you know somebody giving me a list and saying right well you know, this is connected to and there was only box that I couldn't tick so...*

For James living with the unpredictability of his pain related to the unpredictability of his trauma experiences: *“It, yeah, you know it might hurt a little tiny bit...You also know it might bring you to tears.”* It also feels as if James lives in a persistent state of anticipation and uncertainty related to his experience of pain and trauma.

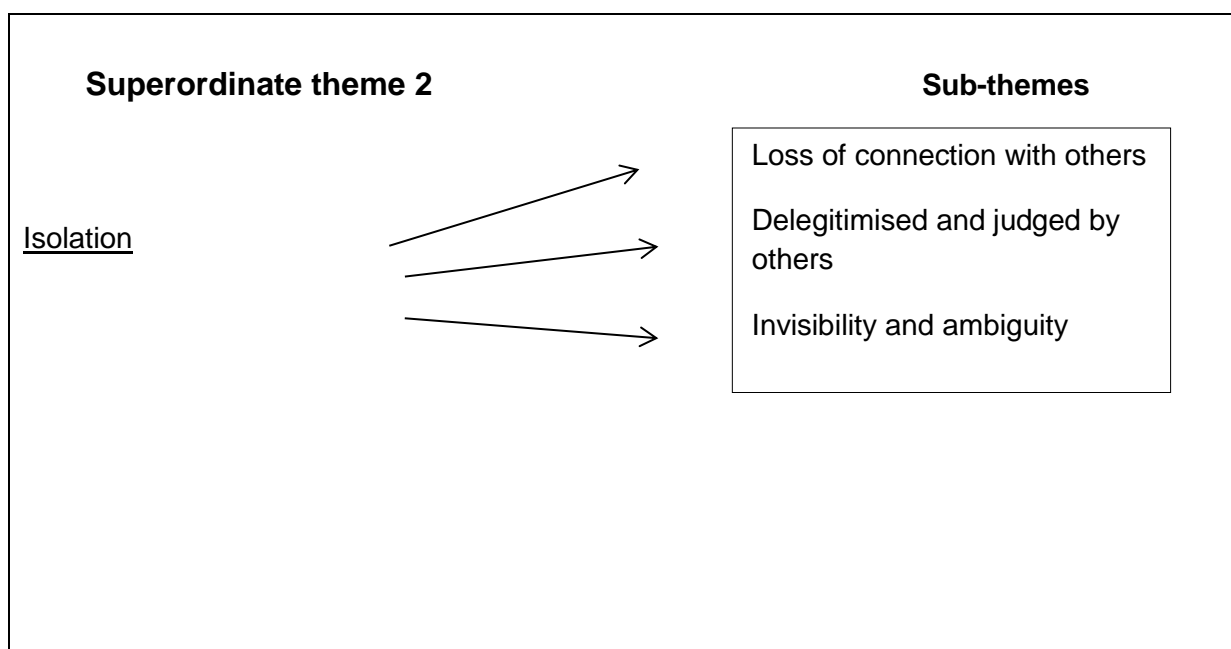
### 5.3 Summary

The theme: “Every day is such a struggle” has highlighted the challenges faced by all participants on a number of different levels. Many of the struggles were not concerned solely with the overwhelming nature of co-morbid conditions but the problems participants encountered in the social world and the feelings loss of control and agency.

Participants talked with distress about the destructive nature of pain and trauma and the loss of purpose and meaning in their lives. In turn this made them question their place in the world. The narratives therefore reflected the simultaneously personal and social dimensions, drawing attention to the individual’s sense of ‘being in the world.’

### 5.4 Superordinate theme 2: Isolation

For all participants living with chronic pain and traumatic stress had left them feeling isolated. Within this superordinate theme several sub-themes emerged which captured the different aspects of isolation experienced. These were labelled: Loss of connection with others; Delegitimised and judged by others; Invisibility and ambiguity.



#### 5.4.1 Sub-theme 1: Loss of connection with others

Loss of connection with others was a particular difficulty faced by most of the participants. Lorraine shared her experience: *“You become very isolated, even if you’re in a room where there’s a lot of, there’s, there’s other people you can still feel very isolated.”*

For some participant’s loss of connection was experienced in their immediate world of family and friends. Sarah described how the pain and trauma had created a loss of intimacy with her partner:

*I...I know that, but not, not being able to be as close as I’d like us to be and that’s, that’s there’s a huge circle with that, there’s the pain but there’s obviously also the stuff that happened when I was a child that also makes me want (sighs).*

Sarah talked about how pain and trauma continued to reinforce each other and maintain loss of connection. She adds that even when she is not in so much pain, *“I’ve gotta deal with the psychological side.”*

Sarah describes this as a “*huge circle*” suggesting that the pain and trauma link and continue to maintain her sense of isolation. Sarah went on to discuss why she has become isolated and the emotional impact this had had:

*Scared of being amongst people, umm, I am, I am improving, I'm, I'm getting there but (sighs) er there's days where I can't stop crying and I think that is, that is a mixture of the pain but it's also the emotional impact of what I've lost*

Her account contains a deep sense of the fear and distress which continues to maintain her isolation.

Lorraine appears resigned to being isolated: “*I think that's why you tend, you know when you you're you end up like this you become very isolated.*”

James identifies his isolation to be a consequence of directing his anger and frustration towards other people. He describes himself as: “*...not very nice person to be around outside work.*” “*It's made me a nightmare at times, I don't react well...to....I'm quicker to anger.*” James is clearly blaming himself for the loss of his close relationships. Towards the end of his account James adds:

*Erm, keep hold of your friends because again I would imagine it's, oh to be honest I know I've done it to a point as well. Keep, as I say keep your friends because it, it does make you want to push people away.*

Sarah talked about “*...really, erm tut, feeling isolated and feeling that you're on your own dealing with things doesn't help.*” This highlights the distress and struggle coping with the co-morbidity alone. Laura comments: “*You, you soon find out who your friends and family are when you are rock bottom...And there wasn't anybody.*”

The quotations also identify the fundamental need for support and empathy for people who live with comorbidity.



In addition isolation was experienced by Lorraine as having a cumulative impact. “*You know, umm, that you become more on your own*” and Thomas captures the impenetrable nature of isolation: “*...it’s more like a steel ball, yeah, you can’t get out and people can’t get in...*”

As a consequence of isolation Thomas experienced a loss of self-confidence in social interactions. This continued to reinforce the isolation: “*I’ve dealt with people on a regular basis due to my work and everything and not having social skills anymore is quite, quite hard.*”

Lorraine’s experience is: “*I’ve been left on one side.*” Thomas also attributes his loneliness to others lack of understanding and the expectation that people are not prepared to support you:

*And that’s that’s the thing people don’t understand. Er so, it, it is easier being on your own sometimes, unless you can find somebody who has strength and and the love to actually be there for that person whatever happens.*

#### 5.4.2 Sub-theme 2: Delegitimised and judged by others

Participants encountered very specific and delegitimising experiences in a number of contexts. For Thomas: “*it’s very much like leprosy in a way, in both ways, you don’t want to be with people and people don’t want to be...with you.* The use of the word “*leprosy*” suggests he believes others view him with revulsion and avoid contact. There is also a real sense of shame attached to his disturbing description of himself.

The participant accounts contained clear examples of experiencing social judgement. James and Thomas identified how loss of physical abilities becomes a reflection on gender identity and your place in society. Thomas says: “*it does go back, very much back to our basic survival instincts. You can’t provide, you’re no good to me.*” Thomas’s account becomes tinged with anger as he articulates his struggle and the stigma with not being able to work due his mental and physical health:

*And people don't understand that neither, it's not my, it's not my fault. I haven't done anything...wrong...And to have that worry, you're not working, that causes a hell of a lot of stigma, stigma. People automatically put you in a box, yeah...*

Lorraine feels discriminated because of her age as well as her physical limitations: *"The more disabled you get, people tend to go away, they tend to back off. I dunno what they think we're gonna ask them to do."*

Lorraine reflects on her conversations with others:

*Erm, or if we want, if we're going out you know, does that mean we have to take that wheel chair, does that mean I have to push you. And I'm thinking well if that was you, I would do it if I was able to do it, you know, umm and I just think now over the last few years I've just found that umm, we've become more selfish, more umm, perhaps because there's more people, now or perhaps it's just my age, you know that I'm aware of umm, or is this how you are with older people.*

The preceding account has an air of cynicism. Lorraine expresses feelings of rejection and a lack of kindness and compassion in others. She reveals how she would have liked to be treated by referring to how she would treat others if the situation was reversed. In addition she feels discriminated for her age. She identified this as a challenge alongside coping with chronic pain and traumatic stress. As she is speaking I am aware of my own feelings of anger rising as a result of the unnecessary distress caused by others lack of understanding and compassion.

*You know and thinking oh what are these at then, then all of a sudden your thinking ooh hang on this person's younger than me so there is a thing you know that gradually society is saying, you're not worth it and gradually and if you're in a lot of pain and really down, you're thinking well if they're all saying it, if it's all in the papers....*

Lorraine felt marginalized and undermined by others attitudes, leading her and some of the other participants to question their place in the world.

In the following quote Lorraine seems to expressing her struggle to cope with the judgement and rejection from others, both with friends and family and society as a whole:

*You know but it's all that they've just got to keep putting you down and it seems to of been that's all, it seems to have just run through and umm, when you're younger and you're in a lot of pain you can do something that will take that off.*

Again Lorraine emphasizes that she is not only coping with co-morbid chronic pain and traumatic stress but growing older is met with social exclusion:

*You get to a certain age, I'm sorry but you walk on the gravel, walk on the gravel, you know, it's not just ourselves that are putting you know saying what are we worth.*

Similarly Laura identifies the lack of compassion from others; not feeling valued or cared for:

*I just can't, I've just had enough of the day, so no I don't go out, I don't socialise but I'm fine with that..... I'm happy with that. I'd, I'd rather be like that than having people say, oh come on, you know, pull yourself together. That is the worst thing that somebody can say to you.*

Lorraine expresses her anger about people's attitudes in general: *"Doesn't matter what drugs that you take, erm, we're not very nice people."*

Pain and trauma seemed to undermine the participant's experiences of being in the world. A key factor running through Lorraine's account was coming to terms with an aging body alongside the challenges of coping with the impact of living with the pain and traumatic stress. Lorraine felt judged by society in relation to her physical

limitations and her aging body. James and Thomas experienced stigma related gender identity and roles. Feeling judged and delegitimized by family, friends and society intensified feelings of isolation and added to their struggle to cope with the chronic conditions.

In the following quotation Lorraine recognizes that having the support from others would be beneficial: *"...cos obviously it's better to have somebody with you..."*

Likewise Thomas added: *"I think the biggest bit of advice I could, I, I give is, is there are people who are starting to underst, understand it with it and don't try to cope on your own."*

Unsatisfying relationships with healthcare professionals also created feelings of isolation. Thomas in particular identified that services should be tailored to meet the needs of individuals living with co-morbid pain and trauma. Participants described not feeling listened to or understood by healthcare professionals which for some of the participants linked into past trauma at an implicit level.

Lorraine adds: *"but yeah just somebody to sit and say well, just what's going on, what do you think? And you know, not a lot. "let's see what we can do," how I hate those words."*

When talking about her experiences with healthcare professionals in the above quote, Lorraine expresses her frustration about not feeling seen as a unique individual with a mind of her own. Instead she is made to feel belittled and insignificant. This is a repetitive theme going back to her childhood that has now been played out her clinical encounter. The participant's projections of anger and frustration highlight the importance of the clinician's ability to identify, cope with and contain these responses. Ultimately what these accounts demonstrate is the importance of really feeling listened to.

Lorraine's opinion in terms of medical assessments and treatment is, *"...close the book..."* Essentially she is suggesting the importance of moving away from a 'one size fits all' approach and really listening and seeing the person in front of you.

Lorraine recalls an incident when she felt delegitimised by a healthcare professional:

*“Er the nurse she said, “read that board.” I said “I can’t see the board.” She said, “well try a bit harder and you’ll manage it.”*

Expectations were shattered by not feeling seen or valued by the very people who should be there to support them. Again for some of the participants this may have been reminiscent of their early attachment experiences.

However some participants such as Lorraine reflected on positive experiences with the healthcare professionals and a feeling of validation as a human being:

*... because I’ve been told by a couple of doc, you know doctors that I’ve I’ve seen, just don’t say that and don’t think it because at the moment, at this particular time there is nobody worse than you...*

#### *5.4.3 Sub-theme 3: Invisibility and ambiguity*

Participants experienced a constant struggle to validate their symptoms with others which compounded the isolation they faced. Participants felt they were not really believed, particularly in relation to the pain. Thomas shared his experience:

*“Invisibilty, yeah. It’s very, very frustrating that people like, well, what’s wrong with you...”* Participants talked about how difficult it was to describe what cannot be seen and this seemed to reinforce the feelings of isolation.

This was apparent within the interview when James struggled to capture his experience of pain in words, *“Yeah, its...I’m trying to think how, hasn’t an easy way to describe it (sighs).”* James adds *“it is quite isolating, pain, I find pain a very strange thing in as much as it’s very hard to articulate it (sighs).”* James goes on to explain:

*“Yeah, that’s, say there, there is, um it is quite, it is quite isolating, pain, I find pain a very strange thing in as much as it’s very hard to articulate it.”*

James clearly found it difficult to describe and share his own subjective experiences:

*But you can’t actually say (sighs) there is no way to say to somebody this is what it feels like because one it isn’t very nice and two, everybody feels pain differently which is part of the problem...*

It appeared that words were not enough to capture the unique and complex nature experience of pain as Thomas makes clear: "... it's you can't just put it into a few words." Lorraine also supports this: "But you know you can look and everybody is different." Lorraine's comment is a reminder about the importance of respecting and understanding individual subjective experience.

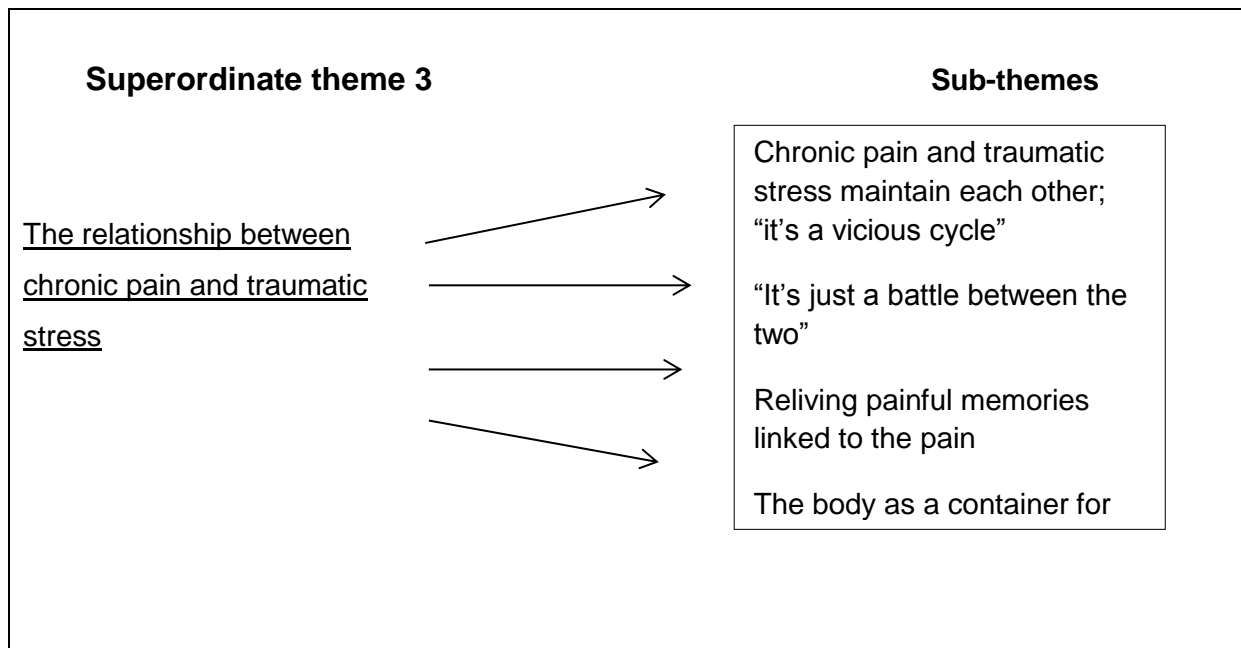
Thomas talks about the invisibility of chronic pain that makes it difficult to cope with: "Invisibility, yeah. It's very, very frustrating that people like, well, what's wrong with you....(laughs)." This also links back to Thomas's childhood experiences of not being able to articulate the distress he was suffering. As the researcher my experience was that the trauma also remained invisible and isolating both within the social contexts of the participants lives and within the interview itself.

### 5.5 Summary

Chronic pain and traumatic stress separated the participants from others and from society as a whole leading to feelings of isolation. This theme is important because it highlights the impact of isolation on the participant's ability to cope with co-morbid health conditions. Unrealistic expectations from others and a lack of understanding were sources of distress for the participants. Providing more information and increasing awareness, are possible ways of authenticating the suffering that people experience. It was also clear that trauma experiences are not just about what is explicitly experienced but the isolation may also come from what has been missing developmentally for some of the participants in terms of insecure attachment experiences (Bowlby, 1969).

### 5.6 Super-ordinate theme 3: The relationship between chronic pain and traumatic stress

All participants described and experienced interactions between chronic pain and traumatic stress. There were many ways in which the relationship between chronic pain and traumatic stress emerged; from a general belief in there being a link between the two: "they're definitely partners," to identifying specific interactions and maintaining factors. Overall the theme highlights the complexity and multidimensional nature of the co-occurrence.



*5.6.1 Sub-theme 1. Chronic pain and traumatic stress maintain each other: “it’s a vicious cycle”*

All of the participants described interactions between pain and trauma and the recursive process within the two. For example Sarah recognises: “*Yeah, some days it’s difficult to separate the two.*” James highlights his experience as “*... an ever descending cycle because the pain effects everything which causes a stress in itself.*” James goes on to clarify:

*Yeah its well actually I don't know if ever descending is probably the right word. It's a vicious cycle would probably be a better because stress causes the pain which then causes more stress which causes more pain.*

The use of the term “vicious cycle” suggests there is no escape for James. He goes on to explain what this feels like for him: “*You can't almost let yourself go almost.*” and when I reflect back to him what hard work that feels his response is: “*Yeah, it is and it does it makes, again it's, it's part of the vicious cycle because it's stressful.*” He adds: “*...you're going into every situation almost thinking about it... And thinking how not to do things instead of going in with a positive frame ...*” There

is clearly no respite for James as he maintains a constant state of hypervigilance which has a negative impact psychologically. He adds:

*But you also (sighs) you go into a, into a social situation or a work situation almost thinking, going in I mustn't get angry with these people, I mustn't get frustrated with these people*

James talked in detail throughout about his experiences of not being able to relax: “*just having to be switched on.*” It feels as if he is constantly hyper-vigilant, living with a chronic state of tension held in his body and mind as he emphasizes his battle to contain unwanted emotions with others.

In the following extract James goes on to confirm and elaborate on his experience of the link between chronic pain and traumatic stress:

*Umm, there is a link and I, best way of describing it, they feed off each other...Umm, the more stressed you get the more pain you have...But of course the more pain you have the more stressed you feel because your ... body's on edge ...Because you constantly feel on edge...*

James captures not only the interaction between the co-occurrence but also the idea that the two together maintain and make each other stronger.

Equally as Sarah is talking about the physical abuse she endured, she explicitly links the increase in pain with the traumatic experiences she was subjected to: “*...and really the pain started to escalate from there. I mean, it had always been there since the accident...But it just started to, to, to get worse and worse, umm.*”

Similarly Thomas supports the way pain and trauma, “*magnify each other:*”

*You put the two together and it's like tenfold, because the pain increases the stress and the stress increases the pain.... Yeah and then you're being hit from all sides. But it's like being stuck in a canoe without a paddle (laughs)...And you've got a hole in the bottom (laughs).*



In the passage above Thomas identifies the cumulative and constant burden of pain and stress. He provides a sense of what that feels like when he says, “*hit from all sides.*” Again he specifies that it is being physically and mentally assaulted by the pain and trauma together that is so debilitating. It is also apparent from Thomas’s narrative that he feels he is sinking; trapped in a cycle of pain and trauma without the resources to escape.

Thomas emphasises that the constant presence of pain against a background of trauma creates a vulnerability in terms of his resources for coping:

*Being in constant pain you are worn down. I think that's the hardest one, being physically worn down and when you're physically worn down, your brain does not function in the manner it, it should.*

Sarah also confirms her experience of pain and trauma as being a “*vicious cycle.*” She also emphasizes how it is the pain that depletes physical and emotional strength which mutually maintains the co-occurrence:

*Erm, before the acc, first accident and that fight was huge in me every day to survive and things (sighs) with the chronic pain erm, it's almost as if it chips away at the strengths that I had, it, it just er (pause) it is a vicious circle though, I will admit that, it is...*

Lorraine also supports the interaction between pain and trauma when she says:

*... so it's like with anything else, the more umm trauma that's going on the more in pain, anything that's all stress related... You know you can't, if you take stress out of a situation... you'll find that the pain is easier to deal with....*

The interaction and maintenance between pain and trauma is clearly highlighted by Sarah in the following extract when she talks about the fear created by both the pain and trauma:

*You know I'd take myself off walking or I'd go walking with other people like N [husband] or the girls or erm. So yeah it has impacted hugely on and it makes, it makes the anxiety worse because of the pain, you know. I, I not only get anxious now because I'm going to be somewhere there's a lot of people, but I get anxious because ah am I going to be able to am I cope...physically going to need N [husband] to come and get me?*

It evident, not just from Sarah's explanation above but with all the participants, that pain and trauma together add layers of suffering and heighten feelings of anxiety. In essence this makes it feel impossible for participants to cope and move on with their lives.

#### *5.6.2 Sub-theme 2: "It's just a battle between the two"*

This sub-theme builds on the interaction between the pain and trauma with some participants explicitly or implicitly referring to a conflict between the two. Laura states: *"It's two worlds battling against each other, that's how it feels."* She elaborates on her experience of the "battle" between the two in the following extract:

*But yeah the pain, the pain, makes you feel...Well you physically can't do something because of the pain and then you mentally think I've gotta get this done like filling all this paperwork and stuff in. That's been a nightmare because there's been days when I felt such in pain and my fingers won't go and I'm trying to write forms out and then you get stressed you get headache and then mentally I think I can't do this. And then part of me is saying but you've gotta get it done, you've got to do it and it's just a battle between the two.*

Similarly Laura offers a clear description of how pain and trauma work against each other:

*Yeah, that's the only word I can describe it. They do grate or grind against each other, yeah it's like one's turning one way and one's turning the other and the friction in the middle is...feels like that's me in the middle... And to*

*you're trying get everything to work the same way and it don't it feels as if one's going backwards and one's going forwards and visa versa and ...*

The use of the words “grate” and “grind” suggest the friction between the two. Laura also portrays herself as powerless; caught in “*the middle*.”

When asked which of the two Laura experienced as most disruptive, she highlighted the trauma:

*But (sighs) yes it's been the trauma that's turned everything upside down. The pain has been like an additive I suppose. If I hadn't have had the, the, the pain maybe I'd have coped better with the, my world being turned upside down, I don't know, whether in all, in a strange sort of way that's kept me going as well, the pain.*

Laura’s account also acknowledges that her pain has distracted her from the emotional pain of trauma and in some ways has helped her keep going.

For James pain was experienced explicitly as a battle but it felt as if the trauma was always implicit within his narrative and part of the battle: “*Yeah, it would literally, you, you'd fight it all day...Umm.*” For James part of the battle is trying to suppress emotions and cope with the anticipatory anxiety in relation to his pain: “*(sighs) it also, it also puts you on guard because when you are dealing with people you're almost fighting the urge to get angry.*” The interaction and conflict between the pain and trauma is evident in James’s narrative.

### *5.6.3 Sub-theme 3: Reliving painful memories linked to the pain*

For some of the participants the memory of the trauma was relived as a consequence of the pain. As James identifies, “*...the actual pain in itself isn't so much of the problem, it's the thought of the pain.*” James adds: “*...there is always something there saying this is hurting, this is...umm, (sighs) this is gonna hurt and automatically you flinch, its...*” For James the thought of pain appears to be a trigger for trauma memories. He experiences fear and anxiety around the unpredictability of pain which links with the unpredictability of the trauma:

*But again it's, it's, not knowing that actually I find the hardest, is sometimes (sighs). I'm trying to think how to best describe it. The best way of describing is, im, imagine opening a door that you know has got somebody wired up to the current but will only give you an electric shock fifty percent of the time... And every time you open that door you know you've got to open the door...but you're not quite sure how much it's going to hurt you....*

The vivid torture metaphors within James's account present a clear illustration of the intense fear and anxiety he experiences around the unpredictability of the pain. The threat of the pain is as overwhelming as the pain itself, continuing to keep his body in a constant state of hyper-vigilance. *"It, yeah, you know it might hurt a little tiny bit. You also know it might bring you to tears."* The psychological and physical demands placed on self are clear as pain and trauma are experienced as powerful and destructive forces working together: *"...it's kinda like Chinese water torture, it's the drip, drip, drip effect..."*

It is clear that for James he experiences the pain and trauma as taking over his life. He feels constantly under threat and unable to switch off his habitual response to the threat:

*It...it's again it's almost all, all pervading because all, not all of you can think about but there is always something there saying this is hurting, this is...umm, (sighs) this is gonna hurt and automatically you flinch, its...*

James continues to make the link between pain and trauma; literally the psychological trauma is explicitly perceived as physical trauma with a wound to the skin: *"The best way was where I imagine somebody sitting on your shoulder, occasionally sticking a needle into you (sighs)."* The pain becomes an enemy at work, inflicting pain from the outside in an erratic way and continuing to keep the trauma memories alive. The sudden shock of the trauma continues to be replayed in James's experience of pain when he says: *"Because the pain would suddenly rush up and go bang."*

Other participants also seemed to relive the trauma through the pain. Sarah talks about the destructive attacking nature of pain in the same way as trauma has been destructive and attacking: “...it's a killer, it really is a killer...”

Lorraine identifies the pain as a direct result of the trauma: “*There was a trauma there... that I ended up with all this pain.*”

*And although I feel now as though I've achieved, I've got my little bungalow, I've still got them other thoughts in my head that I can't shift...Because it's been going on for so long....and it....To me I'd, I wished I could just say you know, give me a tablet or give me a, something to say it's all gone.*

#### 5.6.4 Sub-theme 4: The body as a container for traumatic stress

For many of the participants the body comes to the forefront and is experienced as a ‘container’ for the traumatic stress. Within the interview James identifies how his body becomes a focus for attention:

*And again you're back to everything you do you have to think about. So I'm sitting here doing it now (sighs) Ah as you probably won't be able to tell from the tape recording (laughs) actually sitting here now I talk a lot with my hands.*

The above quotation reveals just how constantly aware James was of his intrusive painful body during the interview. His movements appeared restricted and there was a noticeable bracing of his body as a way of preparing and protecting himself against the unpredictability of pain. As the researcher I was aware of holding anxiety and tension within my own body. I had a real sense of James’s subjective experience of living with pain and trauma. Theoretically James provides a clear description of the lived experience of trauma being ingrained and stored within his body and brain over time.

As James is describing his experience of pain there is also a sense of the trauma invading his body:

*Umm but again it's, because it's all pervasive and it does invade every single, again partly because of where it is because it's tied in because it's my shoulder it's tied into your neck...(sighs) And it's my dominant hand.*

Laura also made references to the physical impact of the trauma: *"...it just feels like you're weighed down with the world on your shoulders."*

In her descriptions of the pain Sarah's body has become as a container for disowned aspects of past trauma: *"Er (Sighs, 2secs) burning, er, stabbing, if I try to lay on my hips or there's any kind of pressure on my hips it's like a stabbing pain."* In her descriptions of the pain it feels as if she is recalling the trauma events in her past. Both the pain and trauma have been an assault on her body, with physical pain continuing to reinforce emotional pain.

Although Sarah described coping by trying to *"block"* the traumatic experiences, separating the physical and emotional pain, it was clear that in an embodied way the trauma revealed itself as tension in her body and the rigidity of her posture. In a way the pain represented a barrier to emotional and relational connection: *"I can't, I can't even bear anyone to touch the knee and the right hip it's that that bad but..."*

Undoubtedly the pain and the body for Sarah, becomes a way of expressing unconsciously what cannot be expressed consciously. Her suffering is contained within the rigid musculature and stooped posture of her body. Sarah's experience of traumatic stress is concerned not just with the traumatic events that were inflicted on her but also with what was missing (Totton 2015, p156). For Sarah the lack of secure attachment figures and attuned responses is embodied in her loss of vitality and relational disconnection. The developmental trauma she experienced may be out of conscious awareness but emerges through bodily expressions. There is sense of unfinished business and incomplete emotional expression.

Thomas talked about all his emotions being *"held inside."* He goes on to recognize:

*Yeah it, it, it, it's like anything if it gets too much it's gonna, yeah doesn't matter if describe it as a dam, you cope with it, then suddenly the water*

*flushes over. Volcano, another perfect example, lays dormant and then suddenly when that goes bang.*

In the above extract Thomas vividly captures the impact of suppressed emotions on his body and mind.

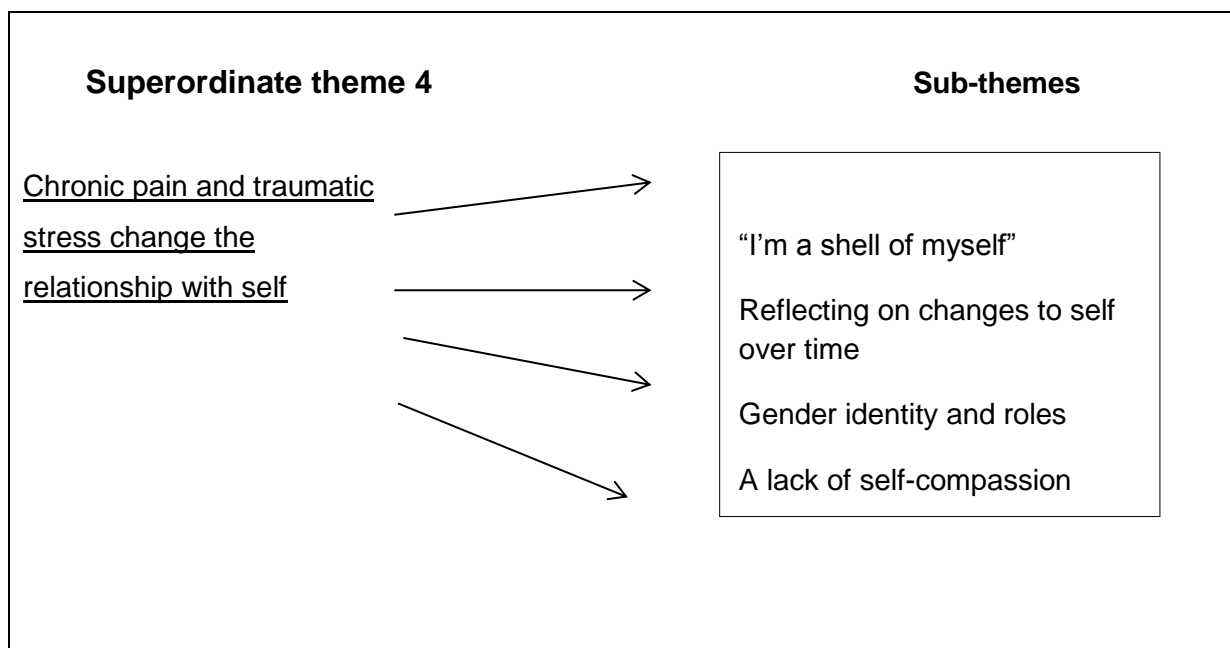
### 5.7 Summary

This superordinate theme draws our attention to the relationship between pain and trauma. All the participants identified an interaction between the two and the sense of being caught up in a “*vicious cycle*.” Pain and trauma could be identified as maintaining and in some cases exacerbating each other. It was evident that the prolonged and cumulative nature of the co-occurrence impacted on the mutual maintenance and the participants coping resources.

In some cases the trauma experiences continued to be relived through the pain. What was also clear was the way the body became a container for the traumatic stress.

### 5.8 Superordinate theme 4: Chronic pain and traumatic stress change the relationship with the self

This theme emerged as an important aspect of the participant’s experience of living with chronic pain and traumatic stress. It was clear from the participant accounts that the combination of chronic pain and traumatic stress disrupted a more valued, coherent sense of self. Participants reflected on a past and mostly preferred self as they struggled to assimilate their current experiences within the social context. Participants were also concerned about the impact of their unwanted self on those around them and were often critical or punishing of themselves because they felt unable to fulfil previous roles or expectations.



#### 5.8.1 Sub-theme 1: "I'm a shell of myself"

Participants described a loss or a change to their sense of self. *"It is, it is almost like a, a bereavement"* [Sarah]. Thomas states: *"...I'm a shell of myself, it's made me ...very much like an empty shell..."* Whilst Sarah emphasises: *"it's broken me."* What is striking about the participants descriptions is just how destructive pain and trauma have been in stripping away the self.

As James speaks the shock and disruption to his self-concept is immediately apparent: *"Er, literally have an event that changes everything, to have to re-evaluate is not, I don't know, again it doesn't help your self-worth."*

A loss of self-esteem and self-worth were commonly reported amongst the participants:

*And it (sighs) it er, it erodes your self-worth almost. I think that's a say because you don't feel good about yourself and because you're constantly thinking what's when's the next episode gonna be almost [James].*



In the passage above James uses the word 'erode' to suggest a gradual and cumulative loss of self-worth over time. What is also evident is the destructive and combined impact of the pain and trauma together, with pain triggering the memory of trauma creating anticipatory anxiety. The reader is left with the idea that it is the constant cyclical nature of the co-occurrence that continues to destroy his self-worth. In a similar way Thomas's description captures the idea of the self gradually becoming fragmented: *"it feels like you're being knocked down brick by brick by brick."*

Likewise Sarah reveals just how pain and trauma have changed her as a person:

*Yeah, erm, depression, anxiety, no self-esteem, no self-confidence (sigh).  
Erm, I've fought it over the years, I have fought it and I've tried er but it  
always comes back and knocks me down again and I have to start up and  
on, on the ladder again and try and gain some self-confidence and (sighs)  
umm, (sighs 2secs). How else would I describe it, erm (sighs, 3 sec pause).  
I don't know, its, it's like a huge boulder that's there all the time and I try  
and ignore it, erm, but it's always there.*

Within Sarah's narrative you can hear her determination and constant struggle to preserve some sense of self. However there is also a feeling of hopelessness about her situation, as if she is fighting a losing battle. This is evident when she says: *"it's like a huge boulder that's there all the time."* In her use of the word "burden" Sarah conveys the just how much pressure she is under coping with co-occurring chronic pain and traumatic stress.

Sarah does reveal that she could maintain some sense of self when she was coping with the trauma alone. The quotation below illustrates that it is the additional burden of the pain that debilitates the self.

*...as I say when, when there wasn't any pain there was a huge  
part of me that was so strong and ...I could achieve things even if they were  
difficult and even if they did make the anxiety worse I still achieved them...*

Shame emerged throughout the participant's accounts: *"Hmmm, just makes you feel worthless, you don't feel like you are anybody..."* [Sarah]. Sarah holds a negative inferior view of herself. The depth of shame experienced is also evident in Sarah's narrative:

*Hubby's tried for years, we've been together nearly fourteen years umm, to make me see, that I'm a worthwhile person to be around (becomes tearful). don't see it...*

Sarah goes on to say: *"...I couldn't, I couldn't look in the mirror when I met N [husband] I couldn't do it."* This quote illustrates how ashamed she feels and how destructive and disruptive this has been for her and her relationships. The entrenched nature of her shame suggests that the pain and trauma together continue to threaten the self, making it impossible to move towards a place of self-respect.

The participants expressed how their self-concept had deteriorated leaving them with unwanted and undesirable aspects which they found uncomfortable and distressing to negotiate within the social context. James shared his experience within the present moment of the interview:

*Say you probably noticed now why I'm not concentrate on you I'm ...all over the place...Whereas ten years ago, (sighs) I'd have been fully focused on you...Nothing else in....almost nothing else in the room would have mattered.*

James goes to add: *"... it's again it's another building block to not making you feel good, feel happy about yourself."*

#### *5.8.2 Sub-theme 2: Reflecting on changes to the self over time*

The temporal aspects of living with the co-morbid conditions became significant as participants reflected on changes to the self over time. James's narrative contains an awareness of the speed of time passing when he says: "Time flies." He appeared

to be expressing a fear around his future, as time had passed and he was still struggling with the pain and trauma.

James connects into past memories of himself and identifies the qualities in himself then that he found desirable:

*When I was younger I used to be a casino dealer. I used to deal black jack...And my boss used to love me because I could literally be in room, room three four hundred people, have two people in front of me and not know the other room existed for hours which was good for his profits....And now (sighs) I wouldn't be able to concentrate like that for more than about two minutes.*

James goes on to talk about the impact of pain and trauma his sense of self over time:

*Erm, I'm not as outgoing as I was, I'm definitely not as confident as I was, which again annoyed me because I'm one of my great strengths in life was, there was always (sighs), I could cope with most things say... And it's, that doesn't make, make you feel good about yourself...*

James moves between reflecting on a past, preferred self which he experienced as strong and able to cope, to his present self which feels vulnerable and undesirable. James goes on to explain:

*And it is, it's kind of (sighs) it's almost self-diminishing, almost because again it's back to the split personality, it's more, one of my great strengths was I could concentrate on something, I could literally block out a room.*

It seems as if James is identifying two selves; a good and a bad self when he refers to having a “split personality.” Within this there appears to be a struggle to maintain the good self in the face of pain and trauma.

Similarly Laura reflects nostalgically on the person she was before the co-occurrence:

*I used to be, erm, very outgoing, umm. I used to have loads and loads of friends, always used to be out and about. I'd do anything for anybody. You know I'd, if I had a last pound in my purse I'd give it to somebody if...*

Laura provides an image of a sociable, self-confident, compassionate person, before the pain and trauma. As she continues she refers to the pain and trauma disrupting the person she was: *"But it's changed me an awful lot and yeah all these things are just piled up on top of each other and ..."*

Laura continues by recalling a photograph of her younger self which due to the degree to which her self-concept has been affected by the pain and trauma, she cannot identify as being her:

*Of being....you know looking at a photograph of me when I was 16, 21, whatever and thinking I wasn't happy then or, or, or when I was 16 before then, you know. I was a feisty little so and so, who wouldn't put up with any bullshit from anybody. I would soon give them a clump or a mouthful or you know and then looking at me then when I was..., the pictures of when we were married and all this, that and the other. I think no, this, just a different, that's not me there.*

The above passage suggests two selves; the young self before the pain and trauma and the present self. There is almost a sense of disbelief and shock as Laura recalls the picture of her past self and reflects on her present self. She refers to the positive aspects of her past self: *"...just have that mental, that mental state of being able to deal with things..."* There is almost a sadness and despair as Laura goes on to say: *"But no, I can't get that, I can't find the old me. I love to find the old me somewhere but I don't know where it's ..."* The loss and alienation from her past and preferred self is evident. It is also apparent that Laura is able to connect into and draw strength and hope from the idea of getting *the "old fight to come back just to be (sighs) just so I could (sighs) just be normal."*

Laura then goes on to talk in more detail about how the trauma has dominated her life but pain has taken away some her resources to cope more effectively. She is suggesting that with some of her “old self” back she could cope more effectively:

*I think because of the pain, I can't, I can't deal with things because I'm in too much pain. I think probably that stops me but then I'm, (sighs) if I've not got me back, my old self back, I just think I haven't got that, I'm battling against trying to find my old self and battling against the pain and putting the two together the pain overcomes the sort of like my get up and go sort of thing. So I don't cope with it both.*

In the extract below Sarah offers a view of herself as anxious and vulnerable following the pain and trauma. This is a complete contrast to the person she was:

*Scared of being amongst people, umm, I am, I am improving, I'm, I'm getting there but (sighs) er there's days where I can't stop crying and I think that is, that is a mixture of the pain but it's also the emotional impact of what I've lost...Umm, I was always very, very active.*

Sarah is clearly mourning the loss of her previous self and offering some insight into the person she used to be. This change was, in part, the result of the physical activities she engaged in and in part the loss of relational connection with people. Sarah's experience is of being emotionally and physically fragile but her sadness and loss is clear when she adds: “*You still want to do, in your mind you still want to do things.*”

There were also differences in how the participants perceived the changes to their self-concept had come about. Sarah recognises that the loss of positive attachment figures and the impact of developmental trauma had resulted in a loss of self:

*I feel that I lost a huge part of who I was when they went. Erm, I don't know, guess the events in my childhood and growing up was very (sighs), I don't know it stopped me developing...*

Similarly Lorraine provides an insight into how her identity has been undermined and “oppressed” by others from a young age:

*... you know, erm and I would say erm, I, it is oppressed, you know, pushed down, you know erm. I remember as, as a teenager, you know, you leave school, you make friends and I remember my father saying to me, once when I'd come in, is get down of the horse and come down to the class that you belong to, ah...*

It is possible that the messages from past difficult or traumatic experiences become internalised to maintain a negative self-concept. This makes it difficult for Laura to draw on healthier aspects of the self in order to adjust to living with pain in addition to the trauma. Laura provides a sense of how destructive these messages have been: “...it just sticks in my head that I'm useless.”

Our identity connects us with past, present and future. The narratives offer an insight into how pain and trauma have disrupted this self-continuity over time. The participants were left feeling insecure and uncertain about how to negotiate and assimilate some of their pain and trauma experiences into a coherent sense of self.

### *5.8.3 Sub-theme 3: Gender identities and roles*

The participants talked about what provides them with their sense of identity. For Sarah caring for others had formed part of her identity: “... *looking after people and that was, that was me, that was who I was...that's what I'd always done.*” Sarah goes to explain how work provided her with a sense of achievement and it was important for her self-worth to feel she could contribute financially. Now she is left with feelings of guilt and inferiority.

The male participants discussed their inability to engage in activities which they felt defined their gender identity and responsibilities. In the early part of James's narrative, when talking about his work situation, James is quick to say: “*Cos, if you can't actually do anything, its, you may as not as well not be there.*” It is important for him to feel he is fulfilling his role at work in order to feel valuable and worthy.

As James continues it becomes apparent that from an early age his identity was clearly defined by his physical activities and his physical body was his way of expressing himself emotionally: “... *I used to do judo and we used to work a lot with our hands, we would think nothing of going to cutting down trees...*”

James continues to explain how his identity has been defined by his physical capabilities:

*I don't like standing right at the front, but row three and again (sighs) part of my self-confidence was, I was strong enough and physically able enough to actually control the crowd almost...I could stand in row three and everybody in front of me wouldn't get crushed because I could roll the crowd, I could move it and now just the very thought of standing there fills me with dread almost.*

Again within his work situation James is suggesting that physical impairments and visible displays of pain or emotion may be seen as a sign of weakness:

*And that's you (sighs) I don't know if it's a macho thing or just one of those things, when you shake somebody's hand you don't want to see them flinching in pain.*

So it feels that for James living with chronic pain and traumatic stress have left him feeling inferior and shamed by his loss of function and an inability to fulfill what he believes are socially expected roles and rules. James is struggling with a new, unwanted self which he considers is socially undesirable.

Participants also struggled in terms of how they perceived others evaluated them. Within the interview James is clearly feeling threatened and hurt by others comments:

*...I would go and see an osteopath every month or so and our osteopath always used to say she'd never met a (surname) who couldn't pick up their*

*end of the piano....and then it got to the point as, well I've now met one (sighs). It's like, oh, (sighs) which is just a glib comment...*

Thomas also expressed concerns about the impact of pain and trauma on his family responsibilities: *"You get seen for...it goes back to the caveman thing, like you provide, yeah. When you no longer provide, so what use..."* Again Thomas emphasizes feeling less of man because he is unable to provide for his family. He continues: *"...it does go back, very much back to our basic survival instincts. You can't provide you're no good to me."* Clearly Thomas is expressing loss self-worth relating to gender stereotype and society's expectations.

Thomas's frustration is clear in the next quote as he asks: *"Well who's going to employ me."* At points like this within the narrative, it feels as if his developmental experiences are being played out in the present as the past critical introjects surface. Thomas seems to have placed high expectations on himself which could relate to the developmental trauma: *"Very much a case of having to always prove myself."*

The following quotation reveals Thomas's frustration but also loss of hope and opportunity to fulfil his family and social roles:

*Plus I have a family, huh, and it's like well that potential's gone. It's, it's not, there the people who I knew, who worked within the industry aren't there anymore, they have moved on, they had their, reached their potential or they've gone different routes, so...*

At times within the narrative Thomas seems to connect emotionally in and out of his own self-identification with pain and trauma. This appears to be his way of managing and expressing his own feelings of shame around gender identity: *"...So half the problem is we are more active. We do, do more and when that's taken away it's hard for people..."*

The participants seemed to experience pressure from others to return to or fulfil previous roles, as well as their own internal struggle to maintain some sense of coherence and connection with their past self:



*Also means you kind of think, do I want to put myself in a position where something could happen that you don't, wouldn't necessarily want to happen and you end up in a fight or something. It's not, you just kind of think is it, we're back to the, as I said at the start, the, the cost benefit.*

For all the participants living with chronic pain and traumatic stress becomes a reflection of the self interpersonally and intrapsychically as they negotiate the roles and responsibilities within the interpersonal and social realms of their lives.

#### *5.8.4 Sub-theme 4: A lack of self-compassion*

Participants talked in a punishing and critical way about themselves, almost adding another layer of suffering and shame. Laura reveals her lack of self-compassion when she says:

*I feel it was my fault. I should have been stronger, and said right, make a choice, this is your family as well, but I didn't so, I think that's my fault. I look back and I think it's my fault I didn't say nothing, it's my fault I didn't do nothing. So I don't know, I just like I say. I blame myself.*

Laura repeats over and over again “*it's my fault.*” This process seems to be internalised forming a negative self-concept. She explains: “*I cry a lot, I get frustrated, I get angry, but with myself not with anybody else.*”

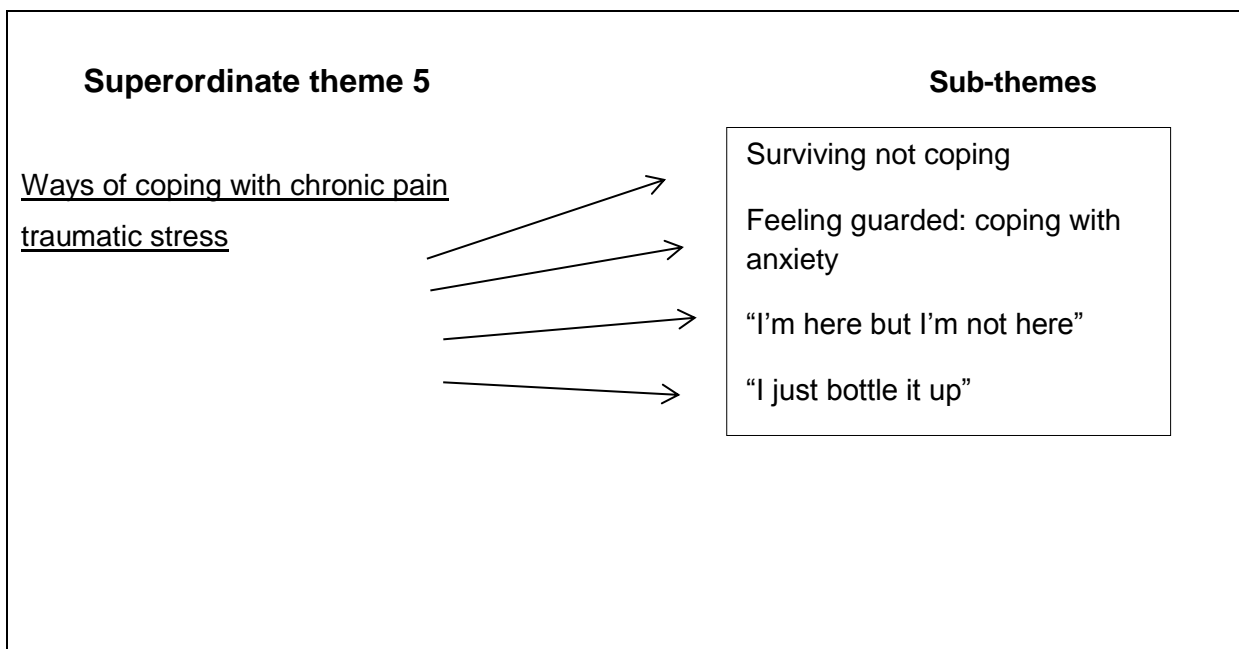
Equally Sarah seems to experience a lack of self-compassion in the way she pushes herself “*through the pain.*”

### 5.9 Summary

The participant narratives revealed that their pain and trauma experiences involved more than a loss of function. Pain and trauma separated the participants from their desirable sense of self, leaving them with a self-concept that felt unwanted both to themselves and others. The experience of living with pain and trauma was seen as a threat to identity and disrupted the participant's ability to connect with their own body and self in a compassionate way.

### 5.10 Super-ordinate theme 5: Ways of coping with chronic pain and traumatic stress

The narratives reflect the various ways the participants coped with the distressing and enduring experiences of living co-occurring chronic pain and traumatic stress. The subthemes within this superordinate theme reflect personal coping processes and ways of managing as a result living with chronic pain and traumatic stress. Some of the sub-themes were taken as direct quotes from participants in order to capture the participant's experience of coping more closely.



#### *5.10.1 Sub-theme 1: Surviving not coping*

This sub-theme emphasizes that coping with chronic pain and traumatic stress was very much about survival strategies for the participants: *“I think it’s more like you, you survive. It’s not coping.”* [Thomas]. James talks about coping by trying to *“maintain some semblance of...say almost sanity would be (laughs)...Normality would be a ....yeah.”* The ways of coping reflect the participant's efforts to maintain some form stability despite feeling overwhelmed coping with chronic pain and traumatic stress.

Nearly all the participants spoke about coping by avoiding or isolating themselves from people. James *“Yeah, you kind of almost avoid people....”* Laura stated: *“So I*

*cut myself off completely from everybody...Which was, actually, was easier than what I thought.*” Laura’s total disconnection completely from others is a way of protecting herself from painful emotions; almost a survival strategy. It is also possible to speculate from what Laura has said that her habitual way of coping with difficult and overwhelming life experiences has been to isolate herself. Isolating herself from others offers a kind of safety in response to the trauma and the pain.

Equally Sarah maintains a sense of safety and manages her anxiety by avoiding people: “Umm, it’s made me, (sighs 3 secs), scared, scared of going out.” Sarah goes on to explain: *“Erm, the anxiety just goes up and up and up and up, erm and I try and remove myself from the situation, erm or I switch off.”* In this quote Sarah is talking about coping with her constant fear of danger related to past trauma. It is as if the memory of trauma has become frozen in time leaving her alert to threat. Sarah goes to reveal some awareness about her coping strategies:

*...(sighs) um, I tend to be quite (pause 2 secs) detached I suppose from people, um, (2 sec pause) even the closest to me there are days where I can't deal with it.*

Relational disconnection also robs Sarah of the support and help she desperately needs from others. Sarah also explicitly refers to the pain making, *“that gap that...much wider.”*

Other participants also described similar experiences. Laura emphasizes: *“I don't want, I'm not ready for that closeness of somebody being...”* Again Laura maintains relational distance as a way of maintaining safety following the traumatic overwhelming events in her past. Lorraine talked about finding it easier to cope alone: *“I just find that I can deal with pain but if I'm left to do what I want to do, go at my own pace.”* Trauma experiences are implicit within Lorraine’s narrative; others have let her down and her expectations of being ignored or shamed are never far away. This is also echoed by Laura who says *“Yeah, it's easier for me just to be on my own and just cope with my day.”*

In what appears to be a recursive and reinforcing self-protective coping mechanism Laura states: *“But now I, I like my isolation now.”* Over time repetitive coping strategies have potentially blocked her ability to adjust and adapt in healthier ways. Her life is constricted and overshadowed by trauma as well as pain. James also identifies a similar pattern: *“You just become more insular, it's the best way to describe it, is you just become more and more insular.”* It is apparent that Laura and James have become trapped in a vicious cycle of avoidance in order to survive the unbearable symptoms of trauma and pain. At the same time there was an acknowledgement from James that, *“You need to interact with other people to keep yours, to keep yourself human almost.”*

For some of the participants the pain was a way of maintaining some form of relational connection that felt perhaps less shaming or threatening. There appears to be a tension between feeling safer isolated from others and a longing to be with others.

#### *5.10.2 Sub-theme 2: Feeling guarded: coping with anxiety*

For James in particular, his experience is one of feeling physically and emotionally *“guarded.”* The pain he has is a result of the trauma. The anxiety he feels is linked with fear and danger, which he cannot seem to switch off. He describes the “not knowing that actually I find the hardest:

*If you're going into every situation almost thinking about it...  
And thinking how not to do things instead of going in with a positive frame ...  
...of mind you're almost going into everything with a negative frame of  
mind...Which again say is stressful, which again causes more pain...  
Which again, makes you even more guarded.*

In the above extract James is constantly preparing his body for danger in order to manage his anxiety. In appearance James's body appears rigid as a way to protect and 'armour' him. James himself is aware of the cyclical nature of his coping mechanism when he adds: *“You can't almost let yourself go almost.”* It feels as if for James, there is a real fear associated with letting go but at the same time constantly being in fight or flight mode is distressing.

James continues by expressing his struggle which is manifested in distancing in his interpersonal relationships. The muscular rigidity also separates him from himself and others in the interests of coping:

*But it's just, but again it's caused almost a barrier. I know I am withdrawn. knowing oh I've got to break down these little barriers...  
...to get everything moving but then think well I've actually got another one on top of it ...*

It feels as if James really wants to break down those barriers but equally there is a fear with losing this defensive strategy.

Laura emphasises how difficult it is to move on and adjust: *"You can't seem to move on, you. I suppose I'm too scared to move on."* Her comments suggest the pain and fear she lives with in her daily life.

In contrast Thomas talks about experiencing a sense of respite by managing his stress. Using relaxation he is able to reach a more peaceful place and he notices his pain can be eased although he only experiences this fleetingly:

*...if, if you can get to a more peaceful place and you can put the stress aside for a while...and then...it...your pain is eased a bit you can then try to focus...but that doesn't happen very often.*

Lorraine also reveals a healthier, less guarded way of coping when she talks about laughter as a medicine: *"I think it helps, it, it's like a medicine isn't it."*

### 5.10.3 Sub-theme 3: "I'm here but I'm not here"

The participant narratives contained examples of not only relational disconnection but also a disconnection from the self, their body and their actions. Thomas describes experiencing a gradual separation from himself and his body:

*... the person who was there before all of this is...slowly being overtaken by everything else which has happened yeah, it's a bit like umm, the film The*

*Body Snatchers, yeah, (laughs)...I'm your body, I'm here but I'm not here*

Similarly in describing a stressful experience alongside coping with the pain James reveals a dissociative quality to his experience; feeling like his body is not his own could be a way of distancing himself from the pain:

*... and, yeah, just um, almost surreal experience, it's like looking at it, almost as if you're looking at it from, as an outsider and looking at everything going on and thinking, you really doing this. (Both laugh). I don't know if that's how other people feel normally, it was...very, just the pain, just made everything that more difficult.*

Again Laura talks about her experience of coping with the overwhelming impact of the trauma: *"A part of me was looking in on. I felt as though sometimes there was two of me and one was looking on thinking why are you letting him do this to you."* Laura's experience is of detaching herself from her body, almost freezing as a means of coping with the terrifying traumatic experiences. There also appears to be a lack of self-compassion for the distress she was going through.

The participant's ways of coping also emerged within the interview itself. For example there were points during Sarah's when her presence was experienced as missing in the room. This was evident in her speech, punctuated with sighs and pauses and lacking in vitality, as struggles to articulate her experiences: *"(pause), I've lost the thread again, I'm sorry."* It was also experienced on a visceral level by the interviewer; holding and sensing Sarah's anxiety.

#### *5.10.4 Sub-theme 4: "I just bottle it up."*

Some of the participants had learnt to hide or minimize the distress they experienced. Sarah reflects on how she coped with the psychological and physical pain inflicted on her:

*I had to cope every day looking after them with the abuse going on to me. (Sighs) umm, I couldn't let, allow myself to think about things that happened in the past, cos I wouldn't of been able to look after them and I had to, I, I*

*couldn't. ...*

The above extract reveals Sarah's need to disconnect herself emotionally in order to care for her children. She continues by explaining how she coped with the traumatic events:

*I used to put them behind doors in my mind...And when the door started to open and I started to open and I started to think about them I used to shut the door again.*

Sarah went to elaborate: *"But I find the days where I try and block things out is the nights where the recurring nightmares and the dreams and ..."* The trauma emerges in some intrusive form, despite Sarah's attempts to 'block' it out.

In the same way James described masking his distress in social situations:

*... But, it was (sighs) very painful but it was also quite difficult because, one of those, it was one of those situations where you kind of had to hide it, because I was almost a, an interested on looker in the situation.*

James's account also offers a disembodied view of self when he refers to himself as *"an interested on looker."*

The extent to which James suppresses his pain and distress is clear when he says:

*"Umm and it just gets to the point, point where you kind of either have to remove yourself or literally you go bang."* In a further example James mentions:

*"...everything's fine and...." Went home and when it finally was allowed to come out, literally curled up in a ball and cried (sighs)."* James describes a powerful release of suppressed pain and emotions. There is a primitive, almost regressive quality to his description. From his account it appears that he inhibits his pain and emotional expression until the intensity becomes unbearable, coping instead by presents a false self. James also uses the word "allowed" which suggests constraints on emotional expression, possibility linked to past critical introjects.

Laura talks in a self-deprecating way about the way she has coped: *“But I bottled that up and that really winds me up.”* She moves on to announce:

*Yeah, and I and I should let fly, my cousin said to me, we, she, you know you should say something. I said yeah but my dad's elderly, he wo...he, he's slightly losing his memory. I said he won't remember...*

Laura is clearly struggling to assert herself and tolerate interpersonal conflict when she says: *“One day I'll get my turn to say something but until I shall just bottle it up.... like I normally do.”*

Lorraine reflects on her passive way of coping formed by repeated early experiences during her childhood:

*Erm, growing up I was never umm, I can't see, all I could see is that I was, I was a watcher, rather than erm, saying anything. I was aware of things going on but not aware, so you can block out, you know read a book, I think because we were always told, we were brought up you know, don't sit there doing nothing, read a book, but I could lose myself in books.*

There is sense of Lorraine renouncing her own subjectivity. She has focused and organised her life around the service of others: *“So I had to look out for him, I looked at, so I think that's always been me.”* Lorraine goes on to say:

*I would, I would never voice, I would say, voice an opinion, but when it come to arguments or anything verbal or fights something would just, as if it all went over my head, but it didn't go over my head. So when it come to anything that was going on, umm, I just stood there and took it, or sat there and took it.*

The above passage highlights Lorraine's passive coping strategies growing up; watching but never having a 'voice'.



James also spoke about finding it difficult to negotiate his needs alongside the needs of others. Whilst reflecting on a stressful experience James recognized “.....*after that, really looking back I probably should have cancelled, I think I...*”

In contrast to the other participants Thomas talked about communicating his distress by getting angry, venting his emotions in contrast to bottling them up. Thomas stated: “*You get angrier quickly, yeah.*” “*And then all the emotions get together, you get short-tempered, you get, get, you become withdrawn because you can’t do these things.*”

Towards the end of Laura’s account she acknowledges the importance of emotional expression:

*Doesn't matter if you sob your heart out for an hour, two hours, it's better than keeping it bottled in and, and not being able to ...you , you get, you get really really angry and you wanna perhaps break a plate. If you've got a spare plate go and break it and sweep the mess up and put it in the bin, if it makes you feel better do it.*

### 5.11 Summary

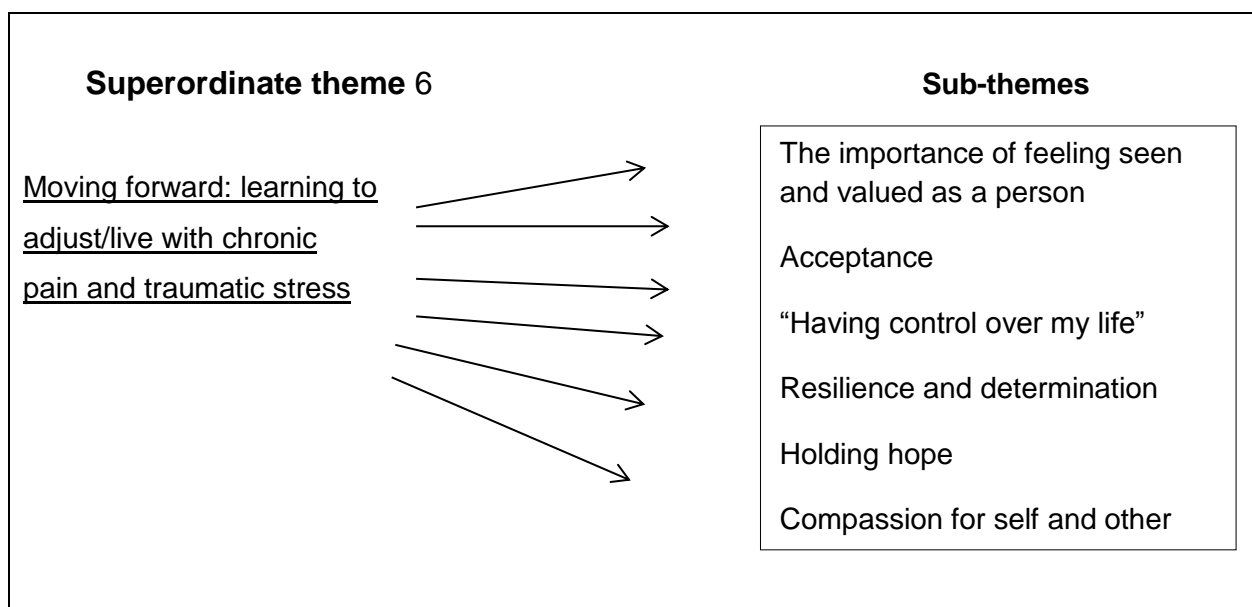
Chronic pain and traumatic stress were experienced as threatening and unbearable for the participants. Participants described various coping strategies to manage the distressing symptoms of pain and trauma. All participants described detaching themselves from others and themselves. Embedded within the narratives some participants spoke about adaptive coping strategies. For example Lorraine spoke about her religious beliefs as being a source of great strength. These will be discussed in more detail in the next section.

### 5.12 Superordinate theme 6: Moving forward: learning to adjust/live with chronic pain and traumatic stress

This was a particularly important theme to emerge from the participant accounts. The findings illustrate that despite living with chronic pain and traumatic stress all the participants were able to identify ways that they could begin to move forward with their lives in a meaningful and valued direction.

In some cases the interview itself was seen as a beneficial. Participants started to acknowledge their own strengths, resources and resilience which allowed them to consider the possibility of moving forward with their lives despite the struggles they faced.

The six sub-themes discussed in detail below were aspects of the participant's experience that enabled them to think about adjusting and moving forward with life.



#### 5.12.1 Sub-theme 1: *The importance of feeling seen and valued as a person*

The aim of the study and the intention within the interview itself was for participants to really feel heard and understood. Throughout participants were encouraged to reflect and give voice to their experiences. Within the interview Lorraine's surprise is clear as she announces, *“I'm coming out with different words that I wouldn't have thought of now you know.”* This suggests the importance of having a reflective space. The participants talked about the value of being seen as a person and recalled the negative impact of feeling delegitimized. For all of the participants living with chronic pain and traumatic stress had been about feeling excluded and unworthy.

Having a voice and feeling validated allowed the participants to begin to move forward. For Thomas the relief was clear as he said “...yes it's good that people are starting to understand...” beginning to adjust and move forward with their lives. In fact within the interviews themselves participants identified the importance of having a voice and a space where they could talk about their experiences

Equally Thomas confirms the importance of really being seen for the person you are: *“I have, I'm, I've been very lucky. I've found somebody who sees me still for the person I was before...”*

When asked what could be done to support people living with the distressing co-occurrence, Lorraine responded with:

*I think people, you have to sit and you have to listen, like you're listening to me now and I'm sort of telling you what I think. You can sit and listen to, so you can say well I can't listen to everybody but yes, erm you can listen and you can take in what they say but not all of us are gonna c, its what, you've gotta a book, not you particularly, you know. You've got a book and this is what the book says you should do..... close the book...*

Lorraine had experienced disappointment and a loss of faith in medicine. The above extract captures the importance of being seen as a unique individual; really listening and entering the client's world and letting go of a 'one size fits all approach'.

Sarah felt seen and validated as person following her diagnosis: *“You know, if, if you, if you see what I mean umm, to actually know that there's..... There's been a reason behind it all.”*

Lorraine found it cathartic to talk about her experiences when she actually felt really listened to:

*Umm, whereas now, like talking to L you know, then I'd say well actually she listened to me, I feel better when I was going home and when she said you might be, I might get a letter, and so when you rang I spoke to you and*

*I'm thinking why not you know, because I'm not the only person that's like this, I'm not saying that, you know, there are people that have had worse life than me but pain and depression, you know, it needs to have something done*

Lorraine identified feeling listened to and being able to talk about the traumatic events as a turning point for her to be able to move forward with her life: *“Say this last talking to, you know and it's just because it's all started to come out and you're thinking hang on I can start dealing with this now and...”*

Talking was seen by Lorraine as a vital aspect of managing the stress related to coping with co-morbid health conditions: *“You can erm, I think if you get really stressful, well I know. I know that even speaking to my friend. If you're really stressed it does help to talk.”*

In contrast Thomas highlights his surprise at feeling overwhelmed by receiving too much help all at once from healthcare professionals:

*Erm and I think that was, that was one which took me by surprise, actually having too much help, you can't cope.....with where you have to be, where you were going, all the different appointments and that, that can...*

Thomas's experience highlights the risk of non-engagement with healthcare professionals and interventions if individuals are overwhelmed with too many services at once. His account also draws attention to how uneasy he feels receiving support after so many years of feeling he was coping alone.

### *5.12.2 Subtheme 2: Acceptance*

Some participants such as James appeared to be moving towards a place of acceptance; rebuilding their identity and thinking about moving forward in a valued direction. In the following quotation my understanding is that James is more accepting that chronic pain will be a part of his life but at the same time he can see a way forward by focusing on what he can do. He appears more relaxed and optimistic as he says:

*Yeah, say, much as I'd like my pain to go away, you've kind of gotta get your head round it is gonna be there. It is gonna be part of your life so you've got to carry on with it and do .....find things you can do.*

Similarly Laura notices: *“But yeah, I can, I can, when I take my killers, yes it doesn't take all the pain away but after 18 years I've learnt to like live with the pain as best I can.”*

### *5.12.3 Sub-theme 3: “Having control over my life”*

In order to move forward with their lives some of the participants, for example Laura, recognised that it was important, *“to sort of get that, get that feeling back of being in control.”*

Participants discussed the unique ways in which they tried to establish a sense of control in their lives. Lorraine identifies how she regains a sense of control in her life when she describes how she manages her pain. *“Put it into boxes and deal with one at a time. That's easier for me but I can do that.”* In a similar way Laura says:

*And I just think you have to, you can't, solve everything at once, you have to deal with one thing and it might take you 10 years to sort out one thing but you just have to keep going.*

For Laura feeling in control is about experiencing a sense of freedom to make choices and move forward with her life in a healthier way:

*I'd just like to get in the car because I don't live far from the beach just to be able to get in my car, drive to the beach get out and go for a walk along the beach and just feel like the weight of the world has gone off my shoulders and feel happy and contented and ... and it's my choice that I'm there and it doesn't matter what time I get back or I haven't got to be back a certain time I can suite myself.*

Lorraine used positive affirmations to regain a sense of control in her life: *“As they say don’t look back, don’t look forward...”*

#### 5.12.4 Sub-theme 3: Resilience and determination

During the final part of the interview participants were able to reflect on their own self-determination and resilience. Participants were able to identify aspects of themselves or review past accomplishments which had been lost through living with co-morbid chronic pain and traumatic stress. Laura’s determination became apparent when she talked about the importance of attending the research interview:

*...this might help me so I've got to be here and that's the only thing that I, you know, as much pain as I was in and still in, I kept thinking I've got to go, I've got to go.*

James emphasises:

*...enjoy the little things, almost enjoy the little victories (sighs). It, it does kind of, on a, on a positive thing, it does make you enjoy certain things more I suppose, you do appreciate things you do, do.*

Likewise Laura spoke proudly about her experience of being a mother despite the pain and trauma: *“Yeah, all, I think of all the worse times and there were some really gritty and horrible times I just think that I have achieved bringing him up...”*

Lorraine identifies her determination to make the most of her life by recognising that others are worse off:

*A lot of people have got nothing and thinking how your life is so good, you know, so make the most of it. You want to say that. Just enjoy your life and do it one day at a time.*

Laura draws strength and determination from adversity when she says: *“And if you give in, the person who's bullied you or upset you or, the people they're, they're winning, they've won and you can't have that.”* Laura’s advice to others

was....."keep battling it." It feels as if Laura is making a more authentic connection with herself and her determination and self-worth is returning.

Laura goes on to add:

*And I feel I've, I've taken, I'm not rock bottom anymore, as much as I have days when I cry and I get upset and silly things remind me of what's going on. I know I'm not rock bottom anymore, I'm better than that.*

When asked what else would be important in terms of supporting others who live with co-morbid chronic pain and traumatic stress Laura added:

*And I just think you have to, you can't, solve everything at once, you have to deal with one thing and it might take you 10 years to sort out one thing but you just have to keep going.*

James added: "Don't let it take over your life, keep fight, almost keep fighting it."

Similarly Sarah said:

*... if I stopped trying then I wouldn't get out of bed..... I wouldn't, erm. I think that, that, that fight, or part of that fight in me has always been there, erm.....otherwise I don't think I would have come through... the childhood the way I did, erm, I'll have to stand up.*

Sarah talks about the advice she would give to others:

*Even on the hardest days, don't give up, erm, (sighs). Don't give up trying To do things, don't give up, er, (pause). (Sighs) erm, finding different ways erm of distraction...*

Lorraine seems to be connecting with her own determination, recognising that in some ways on she can make the choice to move forward with her life:

*...it's just all built up from there, you know doing this. I really gotta get back*

*to it, I think when you're in a lot of chronic pain the only person that can deal with it is you. People can give advice but at the end of the day you've got to think hang on this is me...*

#### 5.12.5 Sub-theme 4: Holding hope

The importance of holding hope; having a reason or purpose to go on, allowed participants to contemplate a better future for themselves. Holding hope became a turning point for Laura:

*If you stop, even if you're on your own and you've got no dependents or anything you, you've got to think that you are worth something and no matter what that other person has taken away from you or done to you, I am still me and one day I will get the me back. I may not get it all back, but, I will get I know I will get part of me back.*

Laura goes to explain: *"I think it's my turn now maybe, perhaps there's hope after all. First time I've said that for a long time."* In the following quote Laura seems to capture the importance of having hope:

*It could be a worse day, but it might be a better day and then you think, sort of think about the day before and you think well yesterday I was, you know, couldn't do this, today I've done it, gives you a little bit of achievement.*

Laura maintains a future focus when she says, *"I'll get there one day.* She also seems to be holding hope in the following statement:

*And it might take a shock of something to happen to me or it might just Happen overnight, I don't know but one of these days I'm gonna wake up hopefully and think, you know what, this is my day for me.*

Sarah is also hopeful in outlook when she says: *"...and just get a few things back ....that I feel what I've lost..."*



Lorraine also draws hope and strength from her spiritual beliefs. She talks about religion lifting her mood: *“You know, erm, if I get really, really down like, like last year it got to the stage and I’m thinking right, I’ve gotta get above this...”*

In discussing the support and strength she draws from religion Lorraine acknowledges:

*I wouldn’t say to, I’d, I’d, I wouldn’t say to someone you should try that but I felt better when I got home...Erm, it was something that I needed, it was very umm, uplifting for me.*

For Thomas some of his hope was related to improvements in medical advances and understanding: *“But it is getting better in the last few years, there’s been quite a large break through, through from what I can see...”*

#### 5.12.6 Sub-theme 6: Compassion for self and others

What also emerged during the narrative accounts was a sense of self-compassion and self-worth. Laura is clearly feeling self-compassion when she says: *“And now I can see that it wasn’t my fault.”* It is also evident when Laura declares:

*This is the new me, I’ve had them thoughts before and thought, when I’ve had a horrible day and I’ve gone to bed thinking tomorrow will be better and you get up and it’s no better you think. Why the hell am I bothering but you’re a person you’re somebody.*

Laura’s self-compassion and positive affirmation of self is acknowledged in the following extract:

*Yeah, maybe it’s my turn to sort of have a life really, umm. Even if I’ve still got the pains and the aches and pains, just to be able to, I don’t know really, go through days without feeling guilty about things or, umm you know, worrying about things, silly things; should I have done this, should I have done that. If I could just get some days or when my head is clear, if that*

*makes sense.*

Lorraine talks about how she is able to feel compassion for others because of the experiences she has been through:

*Erm, because of the way the pain and everything else I will feel for somebody else. I can erm, help that, another somebody else, say with this friend when she's, she would say she's in, she's about the same as me as far as pain and umm, I will feel for, I know what she's, what she's thinking and what she's feeling.*

In the above quotation there is a sense of resonance and shared experiences. Sarah also seems to experience compassion for others by drawing on her own distress when she says:

*...however hard that happens to be, erm...the one thing I try and say to myself when it's particularly bad day is that I know that there is an awful lot people in this world that suffer more than I do, erm, in a lot of ways so.*

Lorraine talks about how adverse experiences have made her more self-aware and aware of others:

*I think that always, I've always had that. I've always been aware but umm, I think it's because of the way I've been treated and how I've noticed how other people are.*

### 5.13 Summary

This theme captures the potential to move forward with life despite living with chronic pain and traumatic stress. The value of nurturing relationships is recognised in order for participants to develop a sense of self-worth and self-efficacy. Hope and resilience and the potential for growth are also identified.

## Chapter 6

### 6. Discussion

#### 6.1 Overview

The aim of this study was to gain an in-depth understanding of the experience of co-morbidity; living with chronic pain and traumatic stress. This was achieved by analysing semi-structured interviews using Interpretative Phenomenological Analysis (IPA). This chapter will explore the key findings of the study in relation to the research question and the current literature in this area.

#### 6.2 Reflecting on the Research Question

This section will focus on linking the initial research question posed to the findings outlined in chapter 5.

The research question was:

How do people living with co-morbid chronic pain and traumatic stress understand and make meaning out of their experience?

A broad range of themes emerged from the analysis; six superordinate themes and twenty six sub-themes were identified (See table 5.1). These themes provided a clear picture of how the participants understood and made meaning out of their individual experiences.

There was a variation in the contribution of each participant to the superordinate themes. However the sub-themes secured a connection to the master themes. The narrative accounts highlight the deeply complex and individual experience of living with chronic pain and traumatic stress. This supports Meyers (2015) view that "there is no one picture of co-morbidity" (p. 1129). New intersubjective meanings of

chronic pain and traumatic stress were created as the participants shared their experiences.

### 6.3 Superordinate Theme 1: “Every day is just such a struggle”

Sub-themes:

- Overwhelmed by chronic pain and traumatic stress
- Feeling out of control
- The debilitating impact of chronic pain and traumatic stress
- Loss of meaning and hope
- Living with uncertainty; not knowing

This superordinate theme with related sub-themes illustrates the overwhelming struggle and wide ranging distress faced by all the participants. Consistent with this study Wald et al., (2010) have suggested that individuals managing and living with chronic pain alongside a background of trauma experience more severe symptoms and increased levels of distress and disability

It was clear that the participants in this study were not just coping with isolated symptoms but they were also negotiating the significant disruption to the relational, social and cultural context of their lives. So far little attention has been given to the significance of social factors in the study of co-morbid chronic pain and traumatic stress. Research in the area of chronic pain (Dysvik's et al., 2005) has identified that the major stress caused by living with chronic pain is not health-related but due to the impact of family life and social activities. In this study it is evident that these personal and social struggles all contribute to understanding the meaning of living with co-morbid conditions. Van Deurzen (1997) supports these findings by stating “as human beings we are complex bio-socio-psycho-spiritual organisms, joined to the world around us in everything we are and do” (p. 94).

For most of the participants these struggles were interrelated and continuous leaving them feeling overwhelmed and powerless to effect change both physically and psychologically. There were descriptions by the participants of feeling beaten or defeated by the “*force*” of the two conditions together. ‘Mental defeat’ as identified in

this study has been highlighted as an important cognitive construct for predicting symptom severity and treatment outcomes in people who live with post-traumatic stress disorder and depression (Dunmore, Clark and Ehlers, 1999, 2001; Ehlers, Maercker, and Boos, 2000; Ehlers et al., 1998).

The findings clearly demonstrate that the participants in this study experienced an existential form of mental suffering which expands on the more specific symptoms of PTSD and depression. By adopting a phenomenological approach this study has revealed that participants living with chronic pain and traumatic stress experienced a loss of meaning, motivation, fear and guilt leading to feelings of mental defeat.

In the present study, the feelings of mental defeat are clearly connected to a loss of control and helplessness in relation to the constant struggle to cope with pain and trauma. Some of the participants talked about suicide as a way out of the constant struggle. The results of this study suggest that feelings of helplessness could be linked to suicidal thoughts and intentions, with suicide as way of experiencing a sense of control. Existing studies focused on chronic pain have identified suicide as a way of escaping from the pain (Hitchcock, Ferrell and McCaffrey, 1994; Seers and Friedli, 1996; Thomas, 2000). In the current study it appeared that the distress caused by chronic pain added the feelings of helplessness and therefore increased the risk of suicide.

Consistent with other research in the area of chronic illness (Gregory, 2005) Thomas elaborated on the adverse impact that chronic pain and traumatic stress has had on his role as a parent. Participants talked about having to re-evaluate their whole life as they negotiated existential losses. Lost dreams and regrets formed part of the struggle, with participants no longer able to imagine how their hopes and dreams could fit into their lives.

The present study captures the participant's unique struggles as they negotiate living with uncertainty in terms of their physical and psychological health and with the uncertain world around them. It is clear from the results of this study that the unpredictability of pain and lack of feeling safe in their bodies could be linked to trauma experiences for some of the participants. Sadavoy (1997) writes that

psychological trauma heightens the sense of mortality and physical vulnerability. In addition trauma research highlights the struggle to cope with the unpredictability of being in the world and experiencing a loss of security (Stolorow, 2007).

For Lorraine her fear around physical deterioration was not just linked to the pain but to the aging process. She had witnessed her mother's physical and mental decline and this had not only heightened her fear of dying but the suffering that can accompany this. The perceptions we have about aging have been highlighted as an important factor in this study, which has been identified as interfering with pain treatment (Clarke et al., 2014).

The findings within this superordinate theme draw attention to the fact that lifeworld experiences for people who live with co-morbid chronic health conditions need to be given priority and explored in more depth. Turk and Okifufi (2002) also identify the importance of individual's beliefs about chronic pain; the meaning they attribute to the symptoms of pain, their sense of control over the pain and the impact of pain on their life and future. It was evident that participants in this study were confronted and struggling with the existential issues of our existence; death, freedom, isolation and meaninglessness, (Yalom, 1980).

#### 6.4 Superordinate Theme 2: Isolation

Sub-themes:

- Loss of connection with others
- Experiencing delegitimation and judgement from others
- Invisibility and ambiguity

The narrative accounts portray the lived experience of chronic pain and traumatic stress as a solitary struggle. Within the analysis it became apparent that relationships were affected with participants describing feelings of disconnection, loss of intimacy and loneliness. This was labelled under the sub-theme "Loss of connection with others." It was evident that for some participants isolation could be connected to early insecure attachment experiences which continued to impact on

adult relationships. Sarah in particular suggests that her developmental trauma has created feelings of emptiness and isolation with chronic pain adding to and maintaining the isolation. In this way developmental trauma can be understood as a deficit (Borgogno, 2007) in that the child who was not loved or validated enough continues to experience something as missing.

In this study isolation can also be seen as a way of coping with the demands of pain and trauma. The participants appeared to shift their focus inwards towards the body, to manage the physical and psychological demands placed on them, and away from the outside world.

This study also highlights the role of sociocultural contexts in shaping distress and reinforcing feelings of isolation. Most participants felt quite strongly that they had been delegitimised or stigmatised in some way because of the co-occurrence and the expectations placed on them by society. They talked about a change in their experiences as social beings, with pain and trauma creating a form of difference and feelings of discrimination from others. Discrimination has been supported by earlier studies (Hahn, 1983) with a recognition that this is a major problem faced by people with disabilities in interpersonal interactions. More recent research studying the narratives of participants living with chronic pain also supports the delegitimising social discourse (Lavie-Ajayi et al., 2012).

The use of the word "*leprosy*" in Thomas's narrative account highlights the revulsion he believes others experience towards him and the difficulties to challenge or change this. This was equally echoed by Lorraine who felt that it was not just her physical limitations but her age that marginalised her from society. Some participants experienced isolation as having a cumulative impact with descriptions of a loss of self-confidence and an increase in social anxiety.

Consistent with this study McParland et al. (2011) suggest that perceiving injustice can have a negative impact on physical and psychological health for those living with chronic pain. In this context research suggests that the psychological pain related to social exclusion activates particular areas of the brain which are also activated during physical pain (Panksepp, 2003; Eisenberg and Lieberman, 2004). Such

results again suggest the negative impact of social factors and the links between pain and traumatic stress. Therefore support and assistance with enabling people to maintain or establish new relationships is vital to improving quality of life.

Generally participants in this study felt others treated them with a lack of kindness and compassion which reinforced feeling of worthlessness and shame in them. Some of the participants described patronizing encounters with healthcare professionals which reinforced rather than allayed feelings of worthlessness. Similarly with this study, Roth and Batson (1993) demonstrated that for some participants negative experiences with healthcare professionals had impacted on the participant's attitudes towards seeking healthcare.

The present study demonstrates the importance of social support networks to promote well-being and a sense of belonging. Human beings are social creatures with neurobiology supporting the fact that our brains are socially motivated (Cozolino, 2006) to seek out and maintain relationships for physical and psychological well-being. Extensive research has been conducted to demonstrate that insecure attachments (Bowlby 1969) create dysfunctional internal working models (Brisch, 2002) which can lead to enduring disturbances in interpersonal relationships.

It could be hypothesized that living with co-morbidity triggers the social engagement system described by Porges (1995). In the struggle for everyday survival participants needed to distinguish between those who would protect and those who would attack. Pain both physical and psychological can be understood as a warning of danger with survival mechanisms of 'fight' and 'flight' (Cannon, 1932) being triggered. Fundamentally our means of achieving homeostasis and regulation is dependent on our interpersonal interactions (Siegel, 2007).

Theories of motivation (Lichtenberg, 2011; Panksepp, 2012) demonstrate the intersubjective context of our lives and the unique hierarchical needs that emerge when needs are not met. Equally Heidegger (1962) highlights the importance of the social context and our interconnectness, as 'Being-with-others,' or 'Dasein' (Heidegger, 1962). As demonstrated in the present study, the participant accounts



suggest that isolation exacerbates the negative impact of living with the co-occurrence. Research supports this by identifying that coping alone with chronic health problems is difficult without emotional and practical support (Heckman and Westefeld 2006).

Isolation for the participants in this study was also related to the hidden nature of chronic pain and traumatic stress. The 'invisibility of pain' has been identified in previous pain research (Thomas, 2000) as an important theme. Participants in this study wanted to feel credible in the eyes of others but found it difficult to articulate their experiences in a clear way to people. What is particularly prominent in this study and consistent with studies of chronic pain is the ambiguous nature of pain itself with the external presentation revealing little about the internal world of the sufferer.

In support of the findings of this study, McGowan et al., (2007) highlight the frustrations individuals feel and the barrier this represents to understanding the lived experience of chronic pain. With this in mind, Kirkham, Smith and Havsteen-Franklin (2015) identify their research as the 'next step', by asking individuals to draw their pain and discuss the images produced. In relation to the current study it was often the images and metaphors used by the participants that offered a powerful and deeper insight into the individual's subjective experience of living with chronic pain, helping to make visible what was previously invisible. Equally although often not referred to explicitly, traumatic stress was also experienced as an invisible presence (Sorsoli, 2010) and again some participants found it difficult to articulate their experiences.

The findings within the current study demonstrate the importance of feeling seen and understood. A biomedical construction of pain and traumatic stress neglects the co-constructed meaning in relationships; the 'enactive' framework of embodied intersubjectivity (Fuchs and De Jaeger, 2009). Existing research emphasises the importance of studying the social context in pain populations, with Alschuler and Otis (2013) demonstrating that veterans who reported clinically significant levels of PTSD were receiving more punishing or delegitimising responses to pain than those veterans found to have sub clinical levels of PTSD. Therefore the present study

highlights the importance of a systemic perspective in understanding how social and relational experiences shape beliefs and behaviour related to living with chronic pain and traumatic stress. With the introduction of the biopsychosocial model there has been a greater emphasis on the importance of adopting an integrated view in relation to pain (Turk & Flor, 1999). Pain and suffering can clearly be understood as a multifactorial, complex process, (Engel, 1980; Gatchel et al., 2007; Turk and Okifuji, 2002), with psychological factors becoming integral to understanding and managing chronic pain.

### 6.5 Superordinate Theme 3: The relationship between chronic pain and traumatic stress

Sub-themes:

- Chronic pain and traumatic stress maintain each other; “it’s a vicious cycle”
- “It’s just a battle between the two”
- Reliving painful memories linked to the pain
- The body as a container for traumatic stress

All the participants identified a relationship between chronic pain and traumatic stress. Some of the participants were clear that the relationship between the two conditions felt impossible to separate, emphasising the bi-directional nature of the co-existing conditions. Feelings of being trapped in a “vicious cycle” were common descriptions, providing an insight into just how distressing the co-occurrence is to cope with. The participants were also quite clear that the two conditions together continued to reinforce and exacerbate their symptoms of pain and stress over time preventing any hope for improvement in the quality of life.

Exploring the relationship between chronic pain and PTSD is not new. Papers have been published suggesting a connection between the two conditions in terms of maintenance and vulnerability (Sharp and Harvey, 2001; Asmundson et al., 2002). Consistent with the findings of this study Taylor, Carswell and de C Williams (2013) use a qualitative approach to address the complexity of this co-morbid relationship whilst recognising the impact on the everyday lives of individuals. The present study

offers a wider formulation by exploring CPTSD as a construct acknowledging the diversity of symptoms beyond the diagnostic criteria of PTSD (LaRow, 2015).

In terms of symptom presentation it was clear from the detailed accounts that the participants lived in a constant state of hypervigilance and hyperarousal. James in particular identified feeling “*switched on*” all the time and Thomas talked about his brain not functioning in the “*manner it should.*” These findings have biological support. Baliki, et al., (2008) identify disruptions to the resting state of the brain in people who suffer with chronic pain. Karp (2014, p. 728) also highlights the “activating” symptoms of PTSD as re-experiencing and hyperarousal. Alongside this and as already discussed in the previous sections the participants were clear about how difficult and distressing it was to negotiate the symptoms of chronic pain and traumatic stress alongside the social and relational aspects of their lives.

The present study illustrates the mutual maintenance and experiences of exacerbation between the co-existing conditions. This can be attributed to the prolonged and cumulative impact of pain and trauma. Thomas reveals constantly feeling “*worn down.*” This appeared to be most destructive, depleting the participant’s physical and emotional strength to cope which further added to the feelings of vulnerability. What differed in the accounts was the emphasis placed on which condition participants felt was most destructive.

The results of this study expand on quantitative research in this area by providing insights from the participant’s subjective experience into how they believe the co-morbid conditions are maintained. Some participants were clear that the trauma “turned everything upside down,” creating feelings of vulnerability which then impact negatively on the pain. Similarly D’Andrea et al., (2011, p. 378) note that trauma “sets the stage for ongoing psychological and physical distress, which can mutually affect one another.” I believe understanding this complex interplay and maintenance between the biological, social and psychological elements, as vital for supporting clients to break the “*vicious cycle*” and begin to cope more effectively with this co-occurrence.

The participant accounts recognise that traumatic stress creates a sense of vulnerability in terms of the experience of, or coping with, chronic pain. Some of the participants clearly refer to insecure attachment relationships. This finding is well documented in the literature. Meredith, Ownsworth and Strong (2008) provide support for insecure attachment as a vulnerability factor in terms of adjusting to chronic pain. Landa et al. (2012) offer a developmental theory of somatoform pain with a particular focus on somatic reactions to stress. The authors demonstrate that patients with somatoform pain have a high rate of insecure attachment, interpersonal difficulties and problems with affect regulation. They go on to propose a shared neural system underlying physical and social pain. Equally van der Kolk et al., (1996) drew attention to the fact that individuals who suffered interpersonal traumas experienced significantly more somatic symptoms than individuals who were subjected to disasters such as earthquake or fire. This is explained as the ongoing impact of an early sub-optimal environment affecting the development of body systems, including the neurobiological development of the brain and the immune system.

The sub-theme “it’s a battle between the two” captures something of this ongoing battle and the interactions both at an intrapsychic and interpersonal level. The participants described the friction between the co-existing conditions which left them feeling powerless and defeated as discussed in section 6.3. Despite the “*battle*” Laura identifies how in some ways it has been the pain that has kept her going by distracting her from the emotional pain of the trauma. It is possible to speculate that pain is a definable sensation that takes attention away from overwhelming emotions (van der Kolk, 2014). The potential for the full expression and integration of fearful states (Kutsko, 2014) is prevented, therefore maintaining the vicious cycle of pain and trauma. This presentation is consistent with the concept of alexithymia where a lack of emotional language fails to capture internal emotional states (Sifneos, 1973).

For some of the participants there was a definite trigger and connection between trauma memories and pain. James emphasised that it was not the pain itself but rather the “*thought of the pain*” linked to the trauma memory. This finding is consistent with an existing qualitative study in this area (Taylor, Carswell and de C Williams, 2013) where the authors identify a predominately “unidirectional” link from

memory to pain. James in particular spoke in detail about his anticipatory anxiety around pain which continued to reinforce a state of hypervigilance. He used vivid and violent imagery suggestive of torture which he continued to re-live in a cycle of re-traumatization and fear. Consistent with the findings of this study Gil et al., (2005) identify the role of trauma reminders in triggering arousal and other symptoms related to PTSD. In addition Anderson et al. (2013, p. 80) have identified hyperarousal as being the "strongest mediator between the attachment dimensions, pain and somatization."

As cited by Gatchel et al. (2007, p. 599):

Emotional distress may predispose people to experience pain, be a precipitant of symptoms, be a modulating factor amplifying or inhibiting the severity of pain, be a consequence of persistent pain, or be a perpetuating factor.

For many of the participants their bodies had literally become a container for unwanted traumatic experiences, with references made to "*burning*" or "*stabbing*" sensations. In some cases the painful body became the dominant focus during the interview with visible displays of pain and tension. Reich (1972) [1945] referred to this tense bodily presentation as "armouring." The literature in this area (Levine, 1997) suggests that the mind appears to store the shocked feelings in the body as they are too overwhelming to cope with in the moment of trauma. In this way IPA can facilitate access to the parts of the self that are hidden, but clearly these unconscious dynamics can shape how we construct and process our experiences.

Van Manen (1998) points to how sickness, unlike physical well-being draws attention to our bodies, reminding us that our body is central to our experience of being-in-the-world. In the present study pain separated the participants from others as well the experience of feeling separated from their own bodies. Participants were constantly reminded and aware of their intrusive and restrictive bodies. Merleau-Ponty (1968, p. 131) captures the sense of separateness and togetherness of our bodies with his reference to "connective tissue of exterior and interior horizons."

## 6.6 Superordinate Themes 4: Chronic pain and traumatic stress changes the relationship with the self

Sub-themes:

- “I’m a shell of myself”
- Reflecting on changes to self over time
- Gender identity and roles
- A lack of self-compassion

The participant accounts are consistent with studies in this area suggesting that chronic conditions can impact negatively on the self over time (Helstrom, 2001; Osborn and Smith, 1998). Participants clearly described a loss or fragmentation of the self and a sense of struggling to regain some form of identity (Henare, 2003). Sarah linked her profound sense of emptiness and shame to her early adverse attachment experiences.

The results of this study demonstrate that the self cannot be seen in isolation but as part of a relational and social context which takes into account how past experiences are internalised and emerge in the present (Schoore, 1994). It appeared that pain alongside the trauma continued to reinforce negative self-schema (Young, Klosko and Weishaar, 2003). Participants referred to their loss of self-worth and self-confidence and made reference to the negative impact on their relationships.

In understanding and making meaning out of their experiences of living with chronic pain and traumatic stress some participants reflected on changes in self-concept over time. Participants spoke about battling and feeling hopeless about maintaining some form of self-concept. Sarah revealed that she could maintain some sense of self when she was coping purely with the trauma. The depth of shame was evident throughout the accounts and supported by existing qualitative accounts in the area of chronic pain (Smith and Osborn, 2007).

Within the narrative accounts some participants reflected on a changed self over time. Participants described a past, valued self and an unwanted present self. Smith and Osborn (2007, p. 527) validate these findings by highlighting in their study

the participants reference to a past “preferred self” and an “unwelcome” present self. More specifically Laura reflected on the “*old me*” with a sense of nostalgia and an expectation that if she could connect into aspects of the “*old me*” this would support her to move forward with her life. The participants were clearly struggling to reconcile with the loss of their old selves and come to terms with an unwanted self, defined by limitations and altered responsibility. It is clear from the participant’s responses that negative aspects of the self and pain become ‘enmeshed’. (Pincus and Morley, 2001) resulting in a loss of self and a loss of autonomy.

It was evident within the participant’s accounts that chronic pain and traumatic stress had prevented the participants from engaging with activities which they considered defined their gender roles in society. This clearly posed a threat to identity. The loss of perceived status and social roles through chronic conditions has been well documented in the literature (Charmaz 1983). For the male participants in particular, the body with impairments seemed to be a negative reflection of the self both intrapsychically and interpersonally. In addition self- criticism then formed a significant part of the participant’s current self-concept. Lawrence and Lee (2014) suggest that self-criticism represents an internalised attachment relationship that the participants have with themselves.

Again these findings are relevant because as Bowlby (1973) identified, the attachment system becomes activated through intra and interpersonal relationships. Therefore maladaptive self-critical responses continue to be reinforced.

The current study recognises the self as intrinsically embedded within a historical and social context. In essence the participants in this study were faced with the cultural and social expectations, challenging their identity and role in society. In terms of rehabilitation it is my impression that interventions should focus not only on the physical and psychological symptoms but also the distress related to a diminished sense of self, where individuals are left feeling alienated and detached from areas of life that once provided a sense of meaning and purpose.

#### 6.7 Superordinate Themes 5: Ways of coping with chronic pain and traumatic stress

- Surviving not coping

- Feeling guarded: coping with anxiety
- “I’m here but I’m not here”
- “I just bottle it up”

The findings of this study detail mostly maladaptive coping strategies by the participants as they attempted to defend themselves from unpleasant thoughts, emotions and bodily sensations and maintain some sense of “*sanity*.” This is compatible with existing research in this area; people with chronic pain and PTSD employ a greater use of maladaptive coping strategies than those who live with chronic pain alone (Alschuler and Otis, 2012). It is also evident that maladaptive pain coping strategies in people who have PTSD lead to poorer pain related outcomes (Geisser et al., 1996).

In addition this study demonstrates that unhealthy coping strategies continue to maintain the “*vicious cycle*” between chronic pain and traumatic stress. This is consistent with more recent evidence recognising that maladaptive coping strategies mediate the relationship between PTSD and pain, with an increase in pain severity and interference (Morasco et al., 2013).

Fear was a prevalent response within the accounts leading to participants isolating themselves as a way of managing high levels of anxiety. The participants coping responses were around minimizing the perceived threat in terms of triggering trauma or pain memories. Anxiety emerged as a prominent factor in the comorbidity of chronic pain and traumatic stress, this is supported by numerous studies in this area (Sharp and Harvey, 2001; Asmundson et al., 2002; Lopez- Martinez, Ramirez- Maestre and Esteve, 2014). Sharp and Harvey have also identified avoidant coping as a means to prevent the pain sensations and trauma memories that trigger the arousal response. In a recent review (Sueki et al., 2014) discuss the role of associative learning or ‘conditioning’ and protective behavioral responses in the presence of actual or perceived threat.

James in particular used vivid torture imagery within his narrative to express the intensity of his fear in relation to the memory of trauma and pain. He used the word “*guarded*” to capture the fear associated with the physical movements of his body



which in turn triggered trauma memories. James appeared to be stuck in survival mode. From a biological perspective van der Kolk (2014) emphasises that the 'fight' and 'flight' mode is activated but the stress hormones are not utilised due to immobility either from fear or pain. This is worthy of consideration as researchers have identified that prolonged exposure to elevated cortisol levels may bring about changes in the immune system (Seegerstrom and Miller, 2004). It has been suggested that these changes may play a role in the development and severity of PTSD symptoms (Thaddeus and Heim, 2011). In addition maladaptive strategies used to cope with stress have been identified as providing the conditions for the development and maintenance of chronic pain (McEwen, 2001; McLean et al., 2005). Again the findings of this study illustrate how maladaptive coping strategies may support the maintenance of chronic pain and traumatic stress.

The sub-theme, "I'm here but I'm not here" emerged from participant descriptions of separation or strangeness of one's own body and feeling detached from reality. As the researcher I also experienced some of the participants as disconnected in the room, through their loss of concentration and energy. This type of response occurs through the defense of dissociation and was used by some of the participants as a primary defense to protect them from being overwhelmed with trauma and physical pain. Within the narrative accounts it was possible to speculate that for some of the participants, dissociation as a coping response originated during early developmental experiences due to disruptions in the early attachment relationship (Lyons-Ruth, et al., 2003).

In addition the adverse early experiences described by some participants led me to consider the lack of cohesion between the self and the body, suggesting that it is difficult to experience a sense of "wholeness" (Kreuger, 2002). The findings offer some insight and explanation into the experiences of disconnection from one's body as well as from reality. Dissociation as a coping strategy can be understood as having developmental origins and therefore becomes a habitual in terms of managing overwhelming fear and minimizing movement. In this way both psychological and physical pain can be numbed.

Many of the participants in this study were dealing with unresolved past traumas. They spoke about coping by trying to “*bottle up*” and conceal their thoughts and emotions. Participants in the study recognized how difficult it was to change these poor coping strategies which in turn prevented more adaptive ways of coping. Costa and Pinto-Gouveia (2013) draw attention to the fact that our bodies are constantly trying to self-regulate and trying to control these responses can interfere with healthier patterns of regulation (Neff, Kirkpatrick and Rude, 2007). The literature also highlights that it is not the coping strategies themselves but the rigid and inflexible use of coping mechanisms that leads to problems (Kashdan, et al., 2006).

To summarise the findings illustrate how participants are employing defensive coping strategies in an effort to maintain self-cohesion when confronted with the demands placed on them by living with chronic pain and traumatic stress. Existing qualitative studies in the field of chronic pain highlight the “unremitting demands of pain’ over a long period of time results in a narrow range of coping strategies and ‘enmeshment of self and pain” (Snelgrove, Edwards and Lioffi 2013, p. 135).

This study draws attention to the importance of understanding the origins and the purpose of unhealthy and rigid coping strategies so that clients can be supported to develop healthier ways of coping with the co-occurrence. Lindy and Wilson (2001) refer to allostasis as a useful way to understand defensive strategies that are used to maintain self-cohesion and affect dysregulation. The authors also highlight how the intrapsychic and biological components interact continuing to reinforce this “maladaptive allostatic state” (p138).

This struggle to control the symptoms of pain and trauma witnessed in the narrative accounts became so all encompassing that some of the participants had neglected other valuable and important aspects of their lives. However the findings of the present study also demonstrate that mood was not consistently negative. Some participants did detail periods of laughter and happiness and integrated positive coping strategies such as religious or spiritual beliefs. This is an area that is not widely discussed in the literature but acknowledges the resilience and resourcefulness of individuals when faced with adverse situations. This will be discussed in more detail in the following section.

Within this study IPA supports the individuality of responses and recognizes the complexity of coping with co-morbid conditions. As clinicians the findings of this study demonstrate the importance of listening to people's appraisals and the meanings and coping strategies they employ. Therapeutic interventions based on a compassion focused approach could facilitate a reintegration of mind and body so that individuals can engage with rather than avoid painful and experiences and move forward with their lives in a valued direction. Current research suggests that individuals may achieve better overall adjustment to chronic pain if they reduce avoidant coping and move towards acceptance (McCracken and Eccleston, 2005).

#### 6.8 Superordinate Theme 6: Moving forward: Learning to live/adjust to living with chronic pain and traumatic stress

Sub-themes:

- The importance of feeling seen and valued as a person
- Acceptance
- "Having control over my life"
- Resilience and determination
- Holding hope
- Compassion for self and other

This superordinate theme and related sub-themes recognises that participants were able to consider adjusting and moving forward with their life despite the pain and suffering they were experiencing. The findings therefore support the concept of human potentiality and inherent movement towards growth and ultimately "self-actualisation" (Goldstein, 1939). The potential for participants to be empowered to cope more effectively and restore a sense of meaning to their lives is evident within the accounts. Such positive outcomes have been referred to as 'post-traumatic growth by growth Tedeschi and Calhoun (1995, 1996). This has important implications for formulation and treatment where it is equally important to identify the client's capacity for self-healing and focus on existing strengths.

The sub-theme, 'The importance of feeling seen and valued as a person', demonstrated the importance of relationships that are genuine, accepting and empathic (Rogers, 1961). Some of the participants in this study identified taking part in the interview as the first time they had felt able to tell their story and really feel listened to. This study emphasises the positive benefits of self-expression which has been supported within the field of narrative therapy (Mathes-Loy, 2012). In addition research has identified connections between narrative and self-development (McLean, Pasupathi and Pals, 2007).

A biological understanding of safety and danger also clarifies the importance of feeling seen and understood in terms of managing dysregulation and fear. Within the accounts participants indicated that there were very few people they felt they could turn to for genuine support. In general, healthcare professionals were not experienced as being empathic and the participants did not feel they were seen as unique human beings. For some of the participants the lack of understanding and validation replicated and reinforced early experiences of not feeling understood or seen by others.

As healthcare professionals the findings demonstrate the importance of developing a therapeutic alliance in helping people to adjust and adapt in a healthy way. As stated by Maguire (2012, p. 119) "...a rupture to one's humanity is healed by the mirroring of humanity in another's face; to be met as a human who is more than their pain." What was evident within this study was how when participants felt listened to and able to express themselves, they started to reflect on the importance of rediscovering and reconnecting with themselves and others. Herman (1997) supports this connection between the social and psychological dimensions.

The findings clearly demonstrate the participants recognising the potential within themselves to cope and adjust; re-discovering a determined and resilient sense of self. The sub-themes: "Having control over my life" and 'resilience and determination' capture these adaptive strategies. Interestingly research in the area of resilience has received increased attention (Sturgeon and Zautra, 2010; Zautra and Reich, 2011), although few studies have applied this concept to healthcare.

The current study supports the importance of resilience in living and adjusting to life with co-morbid conditions. Existing studies illustrate that some individuals exposed to adverse events demonstrate resilience, posttraumatic growth (Joseph and Linley, 2008) and the capacity for 'self-righting' (Duncan et al., 2010). A further study by West, Stewart, Foster and Usher (2012) recognises the value of resilience in terms of remaining positive, accepting help and learning to live with pain.

Hope emerged as an essential feature in this study in terms of adjusting to a future with chronic pain and traumatic stress. Participants were able to imagine a future for themselves coupled with feelings of self-worth. Studies confirm that hope has been associated with problem-focused coping (Taylor, 2000) and increased self-worth (Barnum et al., 1998). Both of which were apparent within the narrative accounts of the present study. For one of the participants religious and spiritual beliefs offered strength and hope despite suffering. These findings are compatible with those of de Castilla and Simmonds (2013) identifying positive changes in relation to religious and spiritual beliefs following trauma.

The findings presented in this study provide an insight into how people might cope with adjusting to living with chronic pain and traumatic stress and move towards a place of acceptance. The participants in this study were able to contemplate re-engaging with the meaningful aspects of their lives and begin to let go of rigid and inflexible styles of coping (Kashdan, et al., 2006). Acceptance of pain has been found to be a key factor in adjusting to life with chronic pain (McCracken, 2005). With acceptance lower levels of pain, psychological distress and physical and psychological disability have been reported (McCracken, 1998; McCracken et al., 1999).

As the narratives progressed some participants were beginning to develop a sense of self-compassion. The process of developing self-compassion has been described as a difficult but vital aspect of well-being (Lawrence and Lee, 2014). Problems with becoming self-compassionate have been linked to developmental trauma (Gilbert, 2010), relevant to the present study, where some of the participants had experienced adverse developmental experiences. Compassion focused therapy has been shown to have positive benefits for individuals suffering with PTSD (Lawrence and Lee,

2014). In comparison individuals have been reported to do less well with conventional Cognitive behavioural therapy, due to self-critical and shame-based systems (Rector et al., 2000). In addition the participants in this study revealed that coping with their own adverse life experiences had enabled them to begin to feel empathy and compassion not only for themselves but also towards others who had been through similar distressing experiences. (Lim & DeSteno, 2016).

## Chapter 7

### 7. Implications and Recommendations

Within this chapter I will reflect on the key findings of this study and the contribution made in relation to theory, policy and clinical practice.

#### 7.1 Contribution to knowledge

The findings expand on previous quantitative studies in this area providing an understanding about aspects of the co-morbidity that are clinically significant from the client's perspective, therefore generating a unique type of knowledge. As cited by Corbett and Milton (2011, p. 69) "a core epistemological theme within existentialism is concern for uniqueness and irreducibility of human experience."

The depth and diverse nature of findings from this study invite a greater appreciation of individual idiosyncrasies as well as a greater acknowledgement of the contributing and maintaining factors that could be overlooked from a purely symptomatic perspective.

This study calls for a broader model when considering the relationship between chronic pain and traumatic stress; a model that includes a range of individual, social and environmental factors as well as the meaning and impact of chronic pain and traumatic stress for the individual. Above all the present study recognises that living with the conditions does not exist in a vacuum; instead as demonstrated the impact of co-morbidity must be evaluated within the social context. This study highlights the co-created nature of living with co-morbidity. The participants in the study spoke about how their experiences were shaped in relationship to others. Adopting a qualitative phenomenological approach places importance on situating embodied personal experience in the context of meaning, relationships and the lived world. Van Deurzen (1997) has commented that we are social creatures, inhabiting a cultural world that we need to be part of.

In many ways the problems of managing co-morbid chronic pain and traumatic stress lie at the heart of our culture. The need for evidence based practice has led to

a focus on quantitative studies that restrict the potential to examine complex interactions (Coote et al., 2004). As the findings of this study suggest, science cannot provide all the answers into such diverse existential areas of human experience. In relation to pain Illich (1976, p. 143) has identified that modern medicine "smothers pain's intrinsic question mark."

As this study demonstrates the medicalisation of pain and trauma deny the existential responses and experiences of human existence. In addition physical and nonphysical aspects of the human experience may still be viewed as separate entities despite our expanding knowledge about how they interact. As healthcare professionals it is important that we can draw on all aspects of evidence to reach an integrated view of human beings. Neuroscientific evidence and psychotherapy are bridging the gap between mind and body to inform therapeutic practice (Greenberg 2009, p142).

## 7.2 Implications for policy and practice

Whilst exploratory in nature this study has implications for policy and practice. More than twenty years ago co-comorbidity was referred to as "the premier challenge facing mental health professionals" (Kendall and Clarkin, 1992) and it is evident from the literature that this concept continues to remain a challenge on many levels, for 21st century medicine (Sartorius, 2013). Previous studies in this area have highlighted the increasing prevalence of co-morbidity as a cause for concern (Sartorius, 2013). In addition co-morbidity has been found to be the norm in both mental and physical health disorders (Fortin et al., 2007; Gadermann et al., 2012) with a growing interest around co-morbid physical and mental health conditions (Carney and Freeland, 2002; Schmitz et al., 2009).

The National Institute for Health and Clinical Excellence (NICE) identified that the guidelines should take into account co or multi-morbidities in order to provide better care for people living with more than one chronic condition (Rawlins, 2012). It is also evident from the literature that despite the growing concern around the impact and management of co-morbidity, the concept lacks a good evidence base in terms of generation and integration of research into clinical practice (Boyd, Vollenweider and Puhan, 2012).



The findings of this study highlight the importance of policy makers and healthcare providers recognising and understanding this complex co-morbidity “so that the mental health needs of patients with physical illness will be properly dealt with” (Layard, 2012). In addition the lack of awareness and understanding by some clinicians and the public in general often left the participants within this study feeling marginalised.

This study aimed to redress the balance by exploring the lived experience of co-morbid chronic pain and traumatic stress from the perspective of the service user. The intention was to move away from pathologising and de-humanising the concept of co-morbidity to taking a holistic stance based on human potentiality.

Individuals living with this co-morbidity should have access to effective care pathways, including follow up appointments. Turk and Okifuji (2002) make an important point in that a diabetic would not be offered time-limited treatment and then be sent off to manage their own care. It is also important that pain clinics are not seen as a last resort but rather an important step on the care pathway. This can only be achieved with further education and training for healthcare professionals, employers and the general public.

There is currently a lack of recommended guidance for clients who live with this distressing co-occurrence. The narratives within this study legitimize the need for tailoring services to individual needs. The participants themselves identified the “*vicious cycle*” between chronic pain and traumatic stress which mutually maintains the two, preventing individuals from finding effective ways of coping and moving forward with life. The findings are also relevant to any healthcare professionals managing the complex needs of clients living with co-morbidity.

Other aspects for consideration include recognising that unlike PTSD, there are no current NICE (National Institute for Health and Care Excellence) guidelines on or Cochrane reports exploring the effectiveness of psychological and pharmacological interventions for CPTSD in the UK (UKPTS, 2017).

### 7.3 Implications for Clinical Practice

This study has a number of important implications for clinical practice:

This study recommends an integrative problem formulation and therapeutic approach in order to address the complexity and uniqueness of each client living with co-morbid chronic pain and traumatic stress.

- 1) In constructing an integrative formulation the following concepts should be taken into account to provide a holistic view of the client and inform treatment directions:
  - a) The importance of identifying immediate risk factors so that risk can be appropriately managed.
  - b) Assessment and formulation should include a past, present and future focus. A detailed account the client's early attachment history, such as early developmental derailments or relational trauma and evidence of subsequent or recent traumatic events that are impacting on presenting issues.
  - c) Potential diagnostic thoughts around trauma with reference to DSM-5.
  - d) Existential life issues may be present for clients who live with this co-morbidity. Exploring these may provide a balance in terms of not pathologising but recognizing that pain and trauma may challenge established systems of meaning.
  - e) A consideration of the social, political, cultural and economic contexts in which the client is embedded and how these may impact on the presenting issues.
  
- 2) The therapeutic relationship is central to the process of integrative therapy:
  - a) Emphasis should be placed on establishing collaborative relationships between the healthcare professionals and clients. Collaboration brings personal agency and choice into the therapeutic frame. It is important the client feels empowered in the therapeutic process as living with chronic

pain and traumatic stress can create feelings of powerlessness and helplessness.

- b) Empathic attunement is central to establishing the therapeutic alliance and can be experienced as a healing factor in itself. Implicit relational exchanges, including body-based communication support an empathic experience for the client. Body-based techniques also facilitate an exploration of aspects that are not always available to conscious awareness. Equally as therapists it is important to develop an awareness of our own bodily responses and their relevance to the intersubjective field.
- c) Working with implicit relational exchanges emphasises the co-created nature of the therapeutic relationship. The self is seen as constantly re-organised within the relational process.
- f) A focus on dysregulatory patterns as a result of traumatic experiences both recent or related to earlier experiences, so that new regulatory patterns can develop within the relational frame.
- g) Attending to the use of metaphors and images is vital in terms of understanding implicit communication processes between client and therapist. Important issues may be out of client awareness but can emerge through listening and sensitive interpretation. The use of metaphors and images may also be a way for the client to express what is too difficult to communicate directly. Staying with the metaphor can be a way of empathically attuning to the client and working within the 'window of tolerance' (Siegel, 1999).
- h) The importance of psychoeducation in terms of sharing information about what happens to the body in the context of living with chronic pain and traumatic stress. Understanding physiological arousal and the importance of working within the client's 'window of tolerance' can help to normalize responses. Psychoeducation can also assist clients to identify and communicate the links between their chronic pain and traumatic symptomology. This will enable them understand how stress 'takes root in the body' (D'Andrea, et al., 2011), placing more value on stress management and reduction as well as identifying maladaptive coping strategies.

- i) Recognising the importance of resilience and post-traumatic growth in living and adjusting to life with co-morbid conditions. Therefore moving away from pathologising a conceptualisation pain and trauma and focusing more on individual experiences can offer greater insights into post-traumatic growth.
- j) The importance of self-care, supervision and development opportunities for clinicians to prevent vicarious traumatization and burn out.

#### 7.4 Limitations and Suggestions for Future research

Reflecting on the research process has highlighted some of the limitations associated with this study and suggestions for further research in this area.

This study was one of the first to date to explore the lived experience of co-morbid chronic pain and traumatic stress using IPA as a methodological approach. The sample size was small, although consistent with the recommendations of IPA, with participants recruited from only one service. Therefore it cannot be assumed that the findings are representative of all individuals who live with co-morbid chronic pain and traumatic stress. However the fact that all participants spoke similarly about the meaning of living with the co-occurrence is suggestive of wider applicability.

It would be useful to replicate the study in the same location but with attention to age, class and ethnicity in order to explore the transferability of themes and create a stronger evidence base. The participant sample for this study represented the age groups from 40 years to 61 years of age, with an average age of 47 years, reflecting the absence of younger or older voices. All participants were of British nationality with a balance in relation to gender with two male and three female participants.

The participants in this study had lived with chronic pain and traumatic stress for many years. Therefore future research might also benefit from exploring individuals experiences of chronic pain and traumatic stress at earlier stages of their condition. For example individuals who have fairly recently developed chronic pain may have different experiences of living with co-morbid traumatic stress to individuals who have managed traumatic stress against a long period of chronic pain. In addition

longitudinal studies would be useful in order to follow clients through the intervention phase and follow-up stages. This would enable an exploration of the efficacy of psychological therapy on areas such as identity or coping strategies.

A further potential limitation of this study was the vast amount of data generated, which prevented an in-depth exploration within each of the superordinate themes. However the six superordinate themes emerging from this study offer considerable scope for more specific areas of co-morbid chronic pain and traumatic stress to be studied. Each superordinate theme could be taken individually to form the subject of further research in order to develop deeper insights into the experience and relationship of living with co-morbid chronic pain and traumatic stress. This would enrich understandings and meanings for clients and service users.

Finally exploring mental defeat and improving cognitive flexibility are exciting areas for development in terms of intervention strategies. Equally a more comprehensive study of posttraumatic growth in relation to living with co-morbidity is a potentially useful area for psychological therapy. Finally the findings from this study suggest that other co-morbid presentations would benefit from being studied from a qualitative approach.

### 7. 5 Final Conclusions

This study has presented an interpretative phenomenological analysis of the experience of comorbidity; living with chronic pain and traumatic stress. The focus has been to capture the experience directly from the individual “voice” of the participants (McLeod, 2003), listening to and remaining curious to each individual’s unique meaning. Essentially IPA offered the opportunity for participants to be “witnessed” in their experience (Finlay 2011).

Chronic pain and traumatic stress are distressing and potentially destructive physical and psychological conditions which I believe can only be fully understood by integrating multiple forms of knowledge. The aim of this study has been to explore the individual’s unique experience of living with chronic pain and traumatic stress, with a view to addressing the complexity and expanding our understanding and awareness of this co-morbidity.

Using IPA as a methodology has provided a valuable counterpoint to the prevalence of empirical studies in this area. Through in-depth analysis of participant transcripts a space has been created to talk about and understand chronic pain and traumatic stress in more diverse ways. The findings demonstrate the complexity of living with co-morbidity that cannot be understood in purely physical or diagnostic terms. Instead this study actively encourages people to think about co-morbid experience as a multidimensional construct. The symptoms of pain and trauma were undesirable but the greatest challenge for the participants arose as they negotiated the social context.

As qualitative studies in this area are few, it is hoped that this study has provided a novel contribution to the evidence-base which can be transferred to other co-morbid conditions.

## Chapter 8

### 8. Reflexive Statement

The dynamic and cyclical nature of IPA recognises the researcher's use of self within the study (McLeod, 2001). The aim of this chapter is to reflect on the personal, professional and philosophical influences at different stages of my research journey.

#### Research Area and Methodology

My past experiences of co-morbidity as a concept have originated from the medical model and a background in nursing, with labels and theoretical explanations shaping my understanding and management of symptoms. My intention within this study was to explore and expand on the existing representations of co-morbidity. I wanted to adopt a holistic approach based on my values as a Counselling Psychologist. Using IPA as the methodological approach enabled me to engage with and question the dominant discourses around co-morbidity and my own beliefs around the construction of this concept. Importantly and throughout the research journey I have reflected on my own sense of self and the personal and social experiences that have shaped me and the process of my research.

#### Conducting the Interviews

As I embarked on the interview process I was enthusiastic about the unique contributions that could come from engaging with the participants narratives. I also experienced anxiety around causing undue distress or discomfort to the participants engaging with the study. I was also aware of being in the unfamiliar role of researcher rather than therapist. Attending to my own feelings encouraged me to step into and attune to my participants experience of taking part in the study.

As I reflect on the co-created nature of the research process my thoughts were concerned with establishing a respectful and equitable relationship. The interview process was underpinned by my therapeutic values and practice; drawing on Buber's

(1923) concept of the 'I-Thou', to reveal the value and poignancy of an open authentic relationship.

I wanted participants to feel empowered and talk openly about their experiences. I recognised that my role as researcher within a medicalised setting and my position as a White British middle class female could have created feelings of powerlessness and inequality. As the researcher I was honest and open about my reasons for carrying out the research and my training and work experience in this area. My belief and stance throughout was that the participants are active in the research process and they are the experts in their experience of living with co-morbidity. I actively encouraged participants to talk about their reasons for participating and I wanted to challenge the idea that the researcher or clinician is the expert. I was also conscious throughout to convey a non-judgemental attitude of warmth and curiosity to enable participants to feel validated in their experiences and promote respect for diversity.

Throughout the interviews I was aware of both the participants and my own body based experiences. At times I experienced their painful bodies as a dominating presence within the room and a sense of unease that my own body was pain free. I noticed a resistance to staying present with the physical and emotional pain which led to my own feelings of helplessness and a need to withdraw. I believe that these feelings originated from my own developmental experiences of being the 'omnipotent helper;' wanting to fix and please others to maintain relational connections and placate my fear of rejection. This pattern continued into early adulthood and clearly influenced my choice of career as a nurse. On reflection I now realise that my medical background created false feelings of safety and naivety in my contact with people who are suffering. Through my training to become a psychological therapist I am now aware of my process and how this could shape the therapeutic relationship. My self-knowledge and awareness ensures that I am able to meet my client's needs now rather than my own.

Within the interview process I became acutely aware at points of holding tension and heaviness in my own body. Accessing tacit bodily sensations offered me a 'felt sense' of what it might be like to live with pain. At the same time many of the



participants shared their images and metaphors which again allowed me to share and understand the participant's experiences. The use of images and metaphors also supported the interactive nature of the interview process. Following each of the interviews I found myself reflecting in depth on the interview process. I found it helpful to keep a diary and share my experiences in supervision.

### Analysis

Within this study I have used IPA as a framework for understanding and really entering the world of client's living with chronic pain and traumatic stress. Although I have had some experience as a therapist within this field I was unprepared for the depth of engagement involved with the analysis of the narrative accounts. The voices of the participants and the struggles and challenges they faced living with chronic pain and traumatic stress really moved me. There were times when I was conscious of being confronted with my own fragility and uncertainty as a human being which enabled me to really empathise with the participant's experiences.

Using IPA as the methodological approach has enabled me to understand the individual experiences as they are lived within a social, economic, political and cultural context. Through the analysis I became acutely aware and saddened by the social and economic reality of living with this co-morbidity. My attention in particular was drawn to the constructions of power and inequalities in society. It was clear for that for the participants in this study they felt marginalised and oppressed by society. Through analysing the texts I felt able to bring the participant voices to the forefront and highlight issues of social injustice.

More specifically as a female researcher through analysing the data I developed an insight into the suffering experienced by the male participants in terms of loss of gender identity roles. This highlighted the importance therapeutically of exploring individual experiences around gender identity and acknowledging the distress and inequalities that stem from wider socio-political narratives.

On reflection I believe that part of the complexity around this research area includes an innate survival instinct to move away from pain and trauma. Therefore as healthcare professionals and with reference to my own experience both as clinician

and researcher, there is a resistance to stay connected with deeply distressing subjective issues. Arguably this explains the preference to focus on the quantitative as opposed to the qualitative.

In many ways IPA as a qualitative methodology is aligned with my values and practice as a therapist. I realise that both therapy and phenomenological research “involve a journey of evolving self-other understanding and growth” (Finlay 2011, p. 7). This was realized through the findings of this study as the participants found their voices and developed a greater self-awareness and understanding into their lived experiences. These shared experiences supported my own beliefs about the central importance of the therapeutic relationship within the process of therapy (Rogers, 1957). An optimal therapeutic environment can support and facilitate the client's natural propensity towards health and self-righting (Lichtenberg, 1992).

I embarked on this study with the intention of enhancing my therapeutic practice so that I would be better able to meet my client's needs. I completed this research with a stronger sense of what it means to live with co-morbidity, reinforcing my belief in the value of an integrated approach to psychological therapy for physical health conditions. This study has demonstrated there is a 'no one size fits all' approach. As human beings we are all unique. The outcomes of this study therefore remind me about the importance of formulation and re-formulation in terms of staying close to my client's experience as the process of therapy unfolds.

The research process has also enabled me to find my own voice as a therapist, sharing my knowledge, values and beliefs with others. As a researcher I have been able to draw on my medical background as a nurse and my psychological understanding as a therapist. I recognise the depth of understanding that can be gained by holding both experiences within the research process and in my client work. I have experienced a growing self-awareness and I feel more compassionate towards others and myself as we all negotiate the existential issues of life. I have come to understand the richness of slowing down, looking beyond the obvious and having the courage to stay with the unknown. This is where real change and growth takes place. I agree with Finlay, in that phenomenology is more than a research methodology “it's a way of being” (Finlay 2011, p. 12). Undertaking this research

and engaging with the participant narratives has reaffirmed my belief in the importance and rewards of psychological therapy in supporting individuals who live with co-morbid chronic pain and traumatic stress.

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## Appendix 1

## 1.1 Ethical Approval letter from Metanoia



13 North Common Road  
Ealing, London W5 2QB  
Telephone: 020 8579 2505  
Facsimile: 020 8832 3070  
www.metanoia.ac.uk

Samantha Williams  
9A Sandy Lane  
Denver  
Downham Market  
Norfolk PE38 0EB

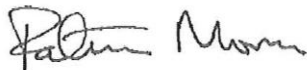
26<sup>th</sup> April 2013

Dear Samantha,

RE: *The experience of co-morbidity: An interpretative phenomenological analysis: Living with chronic pain and traumatic stress.*

I am pleased to let you know that the above project has been granted ethical approval by Metanoia Research Ethics Committee. If in the course of carrying out the project there are any new developments that may have ethical implications, please discuss these with your research supervisor in the first instance, and inform the Chair of the Research Ethics Committee, Dr Patricia Moran.

Yours sincerely,



Dr Patricia Moran  
Chair of Metanoia Research Ethics Committee  
Integrative Department

Registered in England at the  
above address No. 2918520  
Registered Charity No. 1050175

## 1.2 Research Ethics Committee letter

### NRES Committee East of England - Norfolk

Nottingham REC Centre  
The Old Chapel  
Royal Standard Place  
Nottingham  
NG1 6FS

Telephone: 0115 8839368

23 October 2013

Mrs Samantha L Williams  
Trainee Counselling Psychologist and Psychotherapist  
Queen Elizabeth Hospital, Kings Lynn NHS Foundation Trust  
Gayton Road  
Kings Lynn  
Norfolk  
PE30 4ET

Dear Mrs Williams

**Study title:** The Experience of Co-Morbidity: An Interpretative Phenomenological Analysis: Living with Chronic Pain and Traumatic Stress.  
**REC reference:** 13/EE/0284  
**Protocol number:** INTEG12/13-11  
**IRAS project ID:** 132354

Thank you for your letter of 20<sup>th</sup> October 2013. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 17 October 2013

#### Documents received

The documents received were as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering Letter	Letter from Samantha Williams	20 October 2013
Participant Information Sheet	3	23 October 2013

#### Approved documents

The final list of approved documentation for the study is therefore as follows:

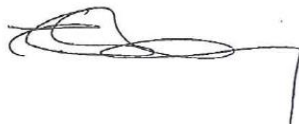
<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering Letter	Letter from Samantha Williams	10 August 2013
Covering Letter	Letter from Samantha Williams	20 October 2013
Evidence of insurance or indemnity	Social welfare Combined Insurance Certificate	10 December 2012
Interview Schedules/Topic Guides	1	01 April 2013
Investigator CV	Samantha Louise Williams	

Investigator CV	Dr Lucia Swanepoel	
Other: Metanoia Ethics Approval	Signed by Dr Patricia Moran	26 April 2013
Other: Letter from Dr Lizzie Davey		07 March 2013
Other: Co-Sponsorship Agreement	Metanoia Institute	13 June 2013
Participant Consent Form	2	01 September 2013
Participant Information Sheet	3	23 October 2013
Protocol	1	26 April 2013
REC application	132354/475543/1/159	09 July 2013
Response to Request for Further Information	Letter from Samantha Williams	01 October 2013

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

<b>13/EE/0284</b>	<b>Please quote this number on all correspondence</b>
-------------------	---

Yours sincerely



**Ms Tracy Leavesley**  
**REC Manager**

E-mail: [NRESCCommittee.EastofEngland-Norfolk@nhs.net](mailto:NRESCCommittee.EastofEngland-Norfolk@nhs.net)

Copy to: *Ms Kate Fromant*  
*Mrs Karen Lupton*

## Appendix 2



## 2.1 Participant Information Sheet

The Queen Elizabeth Hospital   
King's Lynn  
NHS Foundation Trust

The Queen Elizabeth Hospital  
Gayton Road  
Kings Lynn  
Norfolk  
PE30 4ET

[www.qehkl.nhs.uk](http://www.qehkl.nhs.uk)

Clinical Health Psychology  
Tel: 01553 613433  
Fax: 01553 613863

Minicom: 01553 613888  
E-mail: [keith.piper.sec@qehkl.nhs.uk](mailto:keith.piper.sec@qehkl.nhs.uk)

### Participant Information Sheet

**Project title:** The Experience of Living with Chronic Pain and Traumatic Stress.  
**Name of Researcher:** Samantha Williams (Trainee Counselling Psychologist)

You are being invited to take part in a research study. The following information has been compiled to enable you to be fully informed about why the research is being undertaken and what it will involve. It is important that you feel comfortable about your contribution and if any aspect seems unclear or you would like further information please feel free to ask.

Thank you for taking the time to read this.

#### What is the purpose of the study?

The purpose of the study is to explore your personal experience of living with chronic pain and difficult, stressful life events referred to as traumatic stress. The aim is to develop a deeper understanding about what these experiences mean to you and how your life has been impacted. The information from the study may be used to develop future support services and help others who live with similar experiences.

#### Why have I been chosen?

You have been invited to take part in the study because you are currently on the waiting list for psychological pain management interventions. We are hoping to recruit participants who, as well as having chronic pain have experienced difficult and stressful events in their lives and would like to share their experiences.

#### Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason.

Chair: Kate Gordon CB Chief Executive: Patricia Wright  
Patron: Her Majesty The Queen  
*The Preferred Hospital for Local People*



A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive

If you would be interested in taking part in the study please contact me, Samantha Williams, either in writing or by phone in the Clinical Health Psychology Department. The full address and telephone number is given at the end of this sheet. We have limited places in the study so we invite you to make contact as soon as possible. Everyone who volunteers will be written to informing them whether or not they have been selected for the study.

**What will happen to me if I take part?**

The process will consist of an interview that the researcher will have with each participant individually and privately. The interview questions developed will be a guide only and you will be asked to think about your experiences of living with chronic pain and stressful life events and talk freely in a way that feels comfortable to you. Importantly you will not be expected to talk about anything that does not feel comfortable to you.

If you decide to take part in this research study, the researcher will contact you to arrange a convenient date and time for you to attend. The study will involve one interview within the Psychology Department. It is estimated that the time required for the interview will be approximately one hour depending on the amount of information given. The interview will be audio tape recorded and then transcribed by the researcher. After transcribing the interviews, each participant will be given the opportunity to attend the Psychology Department for a final time in order to read the transcripts. The study is expected to last for up to one year.

**What are the possible disadvantages and risks of taking part?**

Taking part in the interview will take up some of your time. Talking about your experiences of living with chronic pain and stressful life events could potentially be difficult for you to talk about. We encourage you to only share as much as you feel comfortable with during the interview. There will be time at the end of the interview to talk through with the researcher about anything that you perhaps found difficult.

**What are the possible benefits of taking part?**

There are no specific, individual benefits in taking part. However, you may find it rewarding to share your experiences of living with chronic pain and traumatic stress. We hope that the information we gain from this research can be used to help others and develop future services.

**What happens when the research study stops?**

The results will be written up by the researcher. It will not be possible to identify you individually in this report. The report will be shared with people who work with chronic pain in the Clinical Health Psychology Department. Another copy of the report will be submitted to Metanoia Institute and Middlesex University, in the form of a dissertation, as partial fulfilment of the award of Doctorate in Counselling Psychology and Psychotherapy by Professional Studies. The results may also be published in academic journals. You will not be identified in any of these reports. If you would like to receive a summary of the results please indicate this on the consent form and you will need to provide your name and contact details.

**What if there is a problem?**

If you have a concern about any aspect of this study you should ask to speak to the researcher, Samantha Williams on 01553 613433 who will do her best to answer any questions. If you are distressed or having difficulties after taking part in the study support can be provided by psychologists within the Clinical Health Psychology Department. You can contact Dr Lizzie Davey on 01553 613433.

If you are harmed by taking part in the study there are no special compensation arrangements. If you are harmed due to someone's negligence, then you may have grounds for legal action but you may have to pay for it. Regardless of this, if you wish to complain or have any concerns about any aspect of the way you have been approached or treated during the course of this study you can do this through the National Health Service Complaints Procedure. Details can be obtained from the Complaints Department at the Queen Elizabeth Hospital. 01553 613890.

**Will my taking part in this study be kept confidential?**

All information which is collected about you during the course of the research will be kept strictly confidential. Any information about you will have your name and any other identifying information removed so you cannot be identified from it.

All data will be stored, analysed and reported in compliance with the Data Protection Act (1998). All data from the study will be kept in locked cabinet within a locked room in the Psychology Department. The data will be kept for three years after the study has finished. Audio recorded data will be taken to the Information Technology Department and physically destroyed by an external company according to trust policy. All paper data will be placed in a locked confidential bin within the Psychology Department and destroyed on site by the hospital.

**Who has reviewed the study?**

This study has been reviewed by the Metanoia Research Ethics Committee and East of England Research Ethics Committee-Norfolk.

**Contact for further information**

Samantha Williams (researcher and Trainee Counselling Psychologist): Clinical Health Psychology Department, Queen Elizabeth Hospital, Gayton Road, Kings Lynn, PE30 4ET. 01553 613433. Email: s.williams2@qehkl.nhs.uk.

**You will be given a copy of the information sheet and a signed consent form to keep. As the researcher I would like to thank you for taking part in this study.**

## 2.2 Consent Form

Samantha Williams.

Version 2, September 2013.

(To be printed on headed paper for participants)

### CONSENT FORM

Participant Identification Number:

**Title of Project:** The Experience of Co-Morbidity: An Interpretative Phenomenological Analysis: Living with Chronic Pain and Traumatic Stress.

**Name of Researcher:** Samantha Williams

Please initial box

1. I confirm that I have read and understand the information sheet dated .....for the above study and have had the opportunity to ask questions.
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason. If I choose to withdraw, I can decide what happens to any data I have provided.
3. I understand that my interview will be taped and subsequently transcribed.
4. I understand that relevant sections of my medical notes and the data collected during the study may be looked at by individuals from Metanoia and Middlesex University, from the BPS and HCPC regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.
5. I agree to take part in the above study.
6. I agree that this form that bears my name and signature may be seen by a designated auditor.

\_\_\_\_\_  
Name of participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Name of person taking consent  
(if different from researcher)

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

Samantha Williams.

Version 2. September 2013.

(To be printed on headed paper for participants)

\_\_\_\_\_  
Researcher

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

1 copy for participant; 1 copy for researcher

## 2.3 Semi-Structured Interview

Version 1. April 2013

Samantha Williams

### Semi-structured interview

The aim of this interview is to capture the experiences of living with chronic pain and traumatic stress that are important to you. I would like you to describe freely whatever comes to mind and it is important that you only talk about what feels comfortable for you.

I would like to start by briefly defining the terms chronic pain and traumatic stress that are used in this research study.

I will follow with a brief history and background of your chronic pain and traumatic stress that you gave during your Pain Triage Assessment. This will provide you with an opportunity to check and contribute to what you have already said.

### Tell me about your chronic pain-How do you experience it?

Emotionally?

Physically? (Somatic response)

Socially?

Think about it? (images, words)

### Tell me about your traumatic stress/difficult life events-How did you experiencethem/ it?

Emotionally?

Physically? (Somatic response)

Socially?

Think about it? (images, words)

**What is the experience of living with both chronic pain and traumatic stress like?**

Emotionally?

Physically?

Think about it? (Cognitive meaning, images, words).

**Has living with chronic pain and stressful life events impacted on you as a person?- How has it?**

Emotionally?

Physically?

Think about it? (Cognitive meaning, images, words).

**Has living with chronic pain and traumatic stress/stressful life events impacted on your relationships- How has it?**

Emotionally?

Physically?

Think about it? (Cognitive meaning, images, words).

**Has living with chronic pain and traumatic stress/stressful life events impacted on your social/work life- How has it?**

Emotionally?

Physically?

Think about it? (Cognitive meaning, images, words).

**How have you coped with chronic pain and traumatic stress in your life?**

Particular things that help?

Your own strengths?

Who helps?

**What is most difficult to cope with?**

Emotionally?

Physically?

Think about it? (Cognitive meaning, images, words).

**What is easiest to cope with?**

Emotionally?

Physically?

Think about it? (Cognitive meaning, images, words).

**Has chronic pain had an effect on your experience of living with traumatic stress?**

Emotionally?

Physically?

Think about it? (Cognitive meaning, images, words).

**Has traumatic stress had an effect on your experience of living with chronic pain?**

Emotionally?

Physically?

Think about it? (Cognitive meaning, images, words).

**Do you think there is a link between your chronic pain and traumatic stress- if so what is the link?**

Emotional?



Physical?

Think about it? (Cognitive meaning, images, words).

**What if anything has been positive about living with the pain and stress in your life?**

**What are your hopes/goals/expectations?**

**What advice would you give to anyone else living with chronic pain and traumatic stress?**

**Is there anything else that is important for me to hear and understand about your experiences?**

De-briefing

I would like to take some time to ask you about your experience of taking part in this interview and answer any questions that you have.

Thank you for taking part.

## Appendix 3

## Structured Interview for Disorders of Extreme Stress-NOS (SIDES)

This instrument is meant to be given after the SCID-PTSD or the CAPS

=====  
 Name: \_\_\_\_\_ Age: \_\_\_\_\_ Sex: \_\_\_\_\_ Date: \_\_\_\_\_

Nature of traumatic experience(s) :

How old was patient? \_\_\_\_\_ Duration of trauma \_\_\_\_\_ Time since the trauma \_\_\_\_\_

**Instructions:**

What follows are descriptions of typical reactions someone could have after traumatic experiences such as you have had. Please indicate if you had similar feelings soon after the experience or as long as you can remember. After each reaction that you feel describes your behavior indicate how severely you felt that reaction in the past month. If the reaction is not one you feel describes you, enter a four, for not applicable, as the severity rating for the past month.

*NOTE: In view of the fact that some interviewees may be victims of interpersonal violence or other severe trauma very early in life, and essentially have no experience with pre-traumatic functioning, the preamble "after the experience" may not apply. Alternative wording (e.g. "as long as I can remember") is suggested where appropriate.*

### D) ALTERATIONS IN REGULATION OF AFFECT AND IMPULSES

**Ia. Affect Regulation**

1. Small problems get me very upset. For example, I get angry at a minor frustration. I cry easily.

"Was this true for you *after the experience*" or "Has this been true for you *for as long as you can remember*?"  Yes  No

"How true has this been for you *in the last month*":

- |  |   |
|--|---|
| None; not at all   | 0 |
| Sometimes I overreact a little   | 1 |
| Sometimes I get very upset, or everything upsets me more than it used to | 2 |
| Often I get extremely upset, have tantrums                               | 3 |
| Not applicable   | 4 |

2. I find it hard to calm myself down after I become upset and have trouble getting back on track.

"Was this true for you *after the experience*" or "Has this been true for you *for as long as you can remember*?"  Yes  No

"How true has this been for you *in the last month*":

- |  |   |
|--|---|
| None; not at all                           | 0 |
| I get momentarily upset                    | 1 |
| It keeps coming back to me hour after hour | 2 |
| I get completely consumed by it            | 3 |
| Not applicable                             | 4 |

3. When I feel upset, I have trouble finding ways to calm myself down.

"Was this true for you *after the experience*" or "Has this been true for you *for as long as you can remember*?"  Yes  No

"How true has this been for you *in the last month*":

None; not at all	0
I need to make special efforts to calm myself (e.g. talking, sports, listening to music)	1
I need to stop everything and focus all my energy on calming down	2
I need to resort to extreme measures, like getting drunk, taking drugs, or doing other harmful things to my body	3
Not applicable	4

#### Ib. Modulation of Anger

4. I feel angry most of the time.

"Was this true for you *after the experience*" or "Has this been true for you *for as long as you can remember*?"  Yes  No

"How true has this been for you *in the last month*":

None; not at all	0
I feel quite angry but I am able to shift to other matters	1
My anger gets in the way of doing things	2
My anger dominates my daily life	3
Not applicable	4

5. I have thoughts or images of hurting somebody else.

"Was this true for you *after the experience*" or "Has this been true for you *for as long as you can remember*?"  Yes  No

"How true has this been for you *in the last month*":

None; not at all	0
Yes, fleeting thoughts	1
I think about hurting people every day	2
I can't stop thinking about hurting people	3
Not applicable	4

6. I have trouble controlling my anger.

"Was this true for you *after the experience*" or "Has this been true for you *for as long as you can remember*?"  Yes  No

"How true has this been for you *in the last month*":

None; not at all	0
I snap at people	1
I yell or throw things	2
I actually attack people physically	3
Not applicable	4

7. I worry about people finding out how angry I am.

"Was this true for you *after the experience*" or "Has this been true for you *for as long as you can remember*?"  Yes  No

"How true has this been for you *in the last month*":

None; not at all	0
------------------	---

I have trouble confronting someone when they hurt me	1
I do not confront the person I'm angry at, but I show my anger in other ways	2
I do not let anyone know in words or actions that I am angry	3
Not applicable	4

**Ic. Self-Destructive**

8. I have been in accidents or near accidents.

"Was this true for you *after the experience*" or "Has this been true for you *for as long as you can remember*?"  Yes  No

"How true has this been for you <i>in the last month</i> ":	0
None; not at all	1
Occasional accidents causing harm or pain but not requiring medical attention	2
One accident or episode requiring medical attention	3
More than one serious accident or episode requiring medical attention	4
Not applicable	

9. I find myself careless about making sure that I am safe.

"Was this true for you *after the experience*" or "Has this been true for you *for as long as you can remember*?"  Yes  No

"How true has this been for you <i>in the last month</i> ":	0
None; not at all	1
I think about the risks involved in relationships or situations, but do it anyway	2
I take undue risks regarding the people I am with or places I visited	3
I keep company with people who I know could be dangerous; not taking measures to protect myself in dangerous situations	4
Not applicable	

10. I have deliberately tried to hurt myself (like burning or cutting myself).

"Was this true for you *after the experience*" or "Has this been true for you *for as long as you can remember*?"  Yes  No

"How true has this been for you <i>in the last month</i> ":	0
None; not at all	1
I hit or kick objects	2
I hurt myself deliberately (pinching, scratching, hitting, banging) without serious damage	3
I hurt myself deliberately in ways that cause serious physical damage	4
Not applicable	

**Id. Suicidal Preoccupation**

11. I have thought about killing myself.

"Was this true for you *after the experience*" or "Has this been true for you *for as long as you can remember*?"  Yes  No

"How true has this been for you <i>in the last month</i> ":	0
None; not at all	1
I was preoccupied, but had no plan	2
I made gestures or was chronically preoccupied with plans	3
I made one or more serious suicide attempts	4
Not applicable	



**Ie. Difficulty Modulating Sexual Involvement or Preoccupation**

12. I make active efforts to keep myself from thinking about sex.

"Was this true for you *after the experience*" or "Has this been true for you *for as long as you can remember*?"  Yes  No"How true has this been for you *in the last month*":

None; not at all	0
I try not to think about sex	1
I work very hard not to think about sex	2
I will not tolerate any thoughts about sex	3
Not applicable	4

13. It bothers me to be touched in general.

"Was this true for you *after the experience*" or "Has this been true for you *for as long as you can remember*?"  Yes  No"How true has this been for you *in the last month*":

None; not at all	0
It sometimes bothers me	1
It often or regularly bothers me	2
I simply could not stand it	3
Not applicable	4

14. It bothers me to be touched in a sexual way.

"Was this true for you *after the experience*" or "Has this been true for you *for as long as you can remember*?"  Yes  No"How true has this been for you *in the last month*":

None; not at all	0
Sometimes it bothers me	1
It often or regularly bothers me	2
I simply could not stand it	3
Not applicable	4

15. I actively avoid sex.

"Was this true for you *after the experience*" or "Has this been true for you *for as long as you can remember*?"  Yes  No"How true has this been for you *in the last month*":

None; not at all	0
I find myself making excuses	1
I try not to have sex	2
I don't have sex	3
Not applicable	4

16. I find myself thinking about sex more than I want to.

"Was this true for you *after the experience*" or "Has this been true for you *for as long as you can remember*?"  Yes  No"How true has this been for you *in the last month*":

None; not at all	0
I think about it too much	1
It distracts me from what I should be doing	2
I am obsessed with it	3
Not applicable	4





17. I find myself driven to engage in sexual activities without really feeling that I had a choice.

"Was this true for you *after the experience*" or "Has this been true for you *for as long as you can remember*?"  Yes  No

"How true has this been for you *in the last month*":

- |   |   |
|---|---|
| None; not at all                                | 0 |
| I feel the urge, but I do not act on it         | 1 |
| I feel compelled to, but I force myself to stop | 2 |
| I engage in compulsive sex                      | 3 |
| Not applicable                                  | 4 |

18. I am active sexually in ways that I know put me in danger

"Was this true for you *after the experience*" or "Has this been true for you *for as long as you can remember*?"  Yes  No

"How true has this been for you *in the last month*":

- |  |   |
|--|---|
| None; not at all   | 0 |
| I am a bit careless  | 1 |
| I talk myself into ignoring the danger or I only see the danger afterwards | 2 |
| I knowingly put myself in danger   | 3 |
| Not applicable   | 4 |

#### **If. Excessive Risk Taking**

19. I expose myself to situations that might be dangerous, e.g. I get involved with people who might hurt me. I go to places that are not safe. I drive too fast.

"Was this true for you *after the experience*" or "Has this been true for you *for as long as you can remember*?"  Yes  No

"How true has this been for you *in the last month*":

- |  |   |
|--|---|
| None; not at all   | 0 |
| I am a bit careless  | 1 |
| I talk myself into ignoring the danger or I only see the danger afterwards | 2 |
| I knowingly put myself in danger   | 3 |
| Not applicable   | 4 |

## II) ALTERATIONS IN ATTENTION OR CONSCIOUSNESS

#### **Ia. Amnesia**

20. There are parts of my life that I cannot remember, or I am confused about what happened, or I am unsure whether certain important things did or did not happen to me.

"Was this true for you *after the experience*" or "Has this been true for you *for as long as you can remember*?"  Yes  No

"How true has this been for you *in the last month*":

- |  |   |
|--|---|
| None; not at all   | 0 |
| There are a few memory lapses                                    | 1 |
| There are important gaps in my memory; there are missing periods | 2 |
| I have no memory for days, months, or years of my life.          | 3 |
| Not applicable   | 4 |

#### **Iib. Transient Dissociative Episodes and Depersonalization**

21. I have difficulty keeping track of time in my daily life.

"Was this true for you *after the experience*" or "Has this been true for you *for as long as you can remember*?"  Yes  No

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"How true has this been for you <i>in the last month</i> ":	0
None; not at all	1
At times, I have difficulty making or keeping track of schedules.	2
I regularly show up in the wrong place at the wrong time	3
I am unable to keep track of my daily life	4
Not applicable	

22. I 'space' out when I feel frightened or under stress.

"Was this true for you *after the experience*" or "Has this been true for you *for as long as you can remember*?"  Yes  No

"How true has this been for you <i>in the last month</i> ":	0
None; not at all	1
I am withdrawn at times	2
I go into my own world and do not let other people in	3
I feel like I stop existing	4
Not applicable	

23. I sometimes feel so unreal that it is as if I am living in a dream, or not really there, or behind a glass wall.

"Was this true for you *after the experience*" or "Has this been true for you *for as long as you can remember*?"  Yes  No

"How true has this been for you <i>in the last month</i> ":	0
None; not at all	1
I feel unreal at times but I can easily be brought back	2
I feel unreal a lot and have difficulty getting back	3
I regularly feel totally disconnected from my surroundings	4
Not applicable	

24. I sometimes feel like there are two people living inside me who control how I behave at different times.

"Was this true for you *after the experience*" or "Has this been true for you *for as long as you can remember*?"  Yes  No

"How true has this been for you <i>in the last month</i> ":	0
None; not at all	1
I am a very different person in different settings	2
It feels like different parts of me are in competition over how I should behave	3
There are separate parts of me that take control at different times	4
Not applicable	

### III) ALTERATIONS IN SELF-PERCEPTION

#### IIIa. Ineffectiveness

25. I have the feeling that I basically have no influence on what happens to me in my life.

"Was this true for you *after the experience*" or "Has this been true for you *for as long as you can remember*?"  Yes  No

"How true has this been for you <i>in the last month</i> ":	0
None; not at all	1
I do not take initiative in routine activities	2
At times, I do not bother to keep appointments, do not go out, do not return phone calls, do not take care of myself (e.g. my personal hygiene, shopping, eating.)	3
I simply do not bother to take care of myself	4
Not applicable	

**IIIb. Permanent Damage**

26. I feel that I have something wrong with me after what happened to me that can never be fixed.

“Was this true for you *after the experience*” or “Has this been true for you *for as long as you can remember*?”  Yes  No

“How true has this been for you *in the last month*”:

- None; not at all 0
- I feel wounded, but that I can get better 1
- I feel that parts of me are damaged but some parts of me still function 2
- I feel like I am a permanently damaged person 3
- Not applicable 4

**IIIc. Guilt and Responsibility**

27. I feel chronically guilty about all sorts of things.

“Was this true for you *after the experience*” or “Has this been true for you *for as long as you can remember*?”  Yes  No

“How true has this been for you *in the last month*”:

- None; not at all 0
- I feel more responsible than I need to for things that go wrong 1
- I blame myself for things that go wrong even when I had nothing to do with it 2
- I blame myself and punish myself for whatever goes wrong, even when I have nothing to do with it 3
- Not applicable 4

**IIId. Shame**

28. I am too ashamed of myself to let people get to know me. (How far did you go to hide from others? Did you avoid talking with people? Make up a cover story?)

“Was this true for you *after the experience*” or “Has this been true for you *for as long as you can remember*?”  Yes  No

“How true has this been for you *in the last month*”:

- None; not at all 0
- I make up stories to hide things I'm ashamed of 1
- I avoid letting most people know who I really am for fear that they'll get to know me 2
- I let no one get close to me to make sure they won't find out who I really am 3
- Not applicable 4

**IIIe. Nobody Can Understand**

29. I feel set apart and very different from other people.

“Was this true for you *after the experience*” or “Has this been true for you *for as long as you can remember*?”  Yes  No

“How true has this been for you *in the last month*”:

- None; not at all 0
- I feel quite different from people around me 1
- I feel different from others and distant, estranged or alienated from them 2
- I feel like I am from another planet and don't belong anywhere 3
- Not applicable 4

**IIIf. Minimizing**

30. I feel that other people made too big a deal of your having been exposed to potentially dangerous or violent situations.

“Was this true for you *after the experience*” or “Has this been true for you *for as long as you can remember*?”  Yes  No

"How true has this been for you <i>in the last month</i> ":	0
None; not at all	1
Minimal	2
Moderate	3
Severe	4
Not applicable	

\* (The following section (IV) only applies to victims of interpersonal violence. For others skip to section V).\*

#### IV) ALTERATIONS IN PERCEPTION OF THE PERPETRATOR

##### IVa. Adopting Distorted Beliefs

31. I sometimes think that people had the right to hurt me.

"Was this true for you *after the experience*" or "Has this been true for you *for as long as you can remember*?"  Yes  No

"How true has this been for you <i>in the last month</i> ":	0
None; not at all	1
They could not help it, they were mentally ill or drug addicted	2
I was pretty rotten; most people would have done the same thing if they had been in their shoes	3
I deserved everything I got	4
Not applicable	

##### IVb. Idealization of Perpetrator

32. I sometimes think that the people who hurt me are very special.

"Was this true for you *after the experience*" or "Has this been true for you *for as long as you can remember*?"  Yes  No

"How true has this been for you <i>in the last month</i> ":	0
None; not at all	1
They are better people than I am	2
They are very special people	3
They possess special powers that give them the right to do what they did	4
Not applicable	

##### IVc. Preoccupation with Hurting Perpetrator

33. I am preoccupied with taking revenge on the people who have hurt me.

"Was this true for you *after the experience*" or "Has this been true for you *for as long as you can remember*?"  Yes  No

"How true has this been for you <i>in the last month</i> ":	0
None; not at all	1
I think about it, but move on to other things	2
I think about it so much that it gets in the way of taking care of daily activities	3
Taking revenge dominates my thoughts	4
Not applicable	

## V) ALTERATIONS IN RELATIONS WITH OTHERS

### Va. Inability to Trust

34. I have trouble trusting people.

“Was this true for you *after the experience*” or “Has this been true for you *for as long as you can remember?*” Yes No

“How true has this been for you *in the last month?*”:

None; not at all	0
I am guarded and am suspicious of people's motives	1
People need to prove themselves over and over again before I let my guard down	2
I don't trust anybody	3
Not applicable	4

35. I avoid having relationships with other people.

“Was this true for you *after the experience*” or “Has this been true for you *for as long as you can remember?*” Yes No

“How true has this been for you *in the last month?*”:

None; not at all	0
I arrange to have lots of time by myself	1
I do not initiate contact with others. I do not make phone calls or write letters	2
I do not return phone calls, reply to letters. I stop conversations as soon as I can	3
Not applicable	4

36. I have difficulty working through conflicts in relationships.

“Was this true for you *after the experience*” or “Has this been true for you *for as long as you can remember?*” Yes No

“How true has this been for you *in the last month?*”:

None; not at all	0
I am quiet or avoid situations that might cause conflict, or I am easily hurt and offended	1
I have trouble hearing other viewpoints, or have difficulty standing up for myself	2
I quit jobs and relationships without negotiating, I threaten to sue people if they offend me, I can't stand it if people disagree with me	3
Not applicable	4

### Vb. Revictimization

37. I find that other traumatic experiences keep happening to me.

“Was this true for you *after the experience*” or “Has this been true for you *for as long as you can remember?*” Yes No

“How true has this been for you *in the last month?*”:

None; not at all	0
I find myself occasionally hurt in relationships	1
I repeatedly find myself hurt in relationships	2
I am seriously hurt by people I love or thought I could trust	3
Not applicable	4

### Vc. Victimizing Others

38. I have hurt other people in ways similar to how I was hurt.

“Was this true for you *after the experience*” or “Has this been true for you *for as long as you can remember?*” Yes No

- "How true has this been for you *in the last month*":
- |  |   |
|--|---|
| None; not at all   | 0 |
| People have told me once or twice that I am hurtful  | 1 |
| People have told me several times that I am hurtful, or I deliberately hurt people               | 2 |
| I seriously hurt or injure other people in ways that are similar to ways I have been hurt myself | 3 |
| Not applicable   | 4 |

## VI) SOMATIZATION

### Via. Digestive System

39. I have trouble with (circle item that apply), yet doctors have not found a clear cause for it.

- a) vomiting
- b) abdominal pain
- c) nausea
- d) diarrhea
- e) intolerance of food

"Was this true for you *after the experience*" or "Has this been true for you *for as long as you can remember*?"  Yes  No

- "How true has this been for you *in the last month*":
- |  |   |
|--|---|
| None; not at all   | 0 |
| I have had some trouble-did not require regular medical attention                  | 1 |
| I went to the doctor, and was prescribed more than one medicine without relief     | 2 |
| I had several doctor visits, hospital admissions, and/or invasive diagnostic tests | 3 |
| Not applicable   | 4 |

### Vib. Chronic Pain

40. I suffer from chronic pain (circle items that apply), yet doctors could not find a clear cause for it.

- a) in your arms and legs
- b) in your back
- c) in your joints
- d) during urination
- e) headaches
- f) elsewhere

"Was this true for you *after the experience*" or "Has this been true for you *for as long as you can remember*?"  Yes  No

- "How true has this been for you *in the last month*":
- |   |   |
|---|---|
| None; not at all  | 0 |
| Some trouble-did not require medical attention                                | 1 |
| Visited a doctor, more than one medicine without relief                       | 2 |
| Several doctor visits, a hospital admission, and/or invasive diagnostic tests | 3 |
| Not applicable  | 4 |

### Vic. Cardiopulmonary Symptoms

41. I suffer from (circle items that apply), yet doctors have not found a clear cause for it.

- a) shortness of breath
- b) palpitations
- c) chest pain
- d) dizziness

"Was this true for you *after the experience*" or "Has this been true for you *for as long as you can remember*?"  Yes  No

- “How true has this been for you *in the last month*”:
- None; not at all 0
  - Some trouble-did not require medical attention 1
  - Visited a doctor, more than one medicine without relief 2
  - Several doctor visits, a hospital admission, and/or invasive diagnostic tests 3
  - Not applicable 4

**VId. Conversion Symptoms**

42. I suffer from trouble with (circle items that apply), yet doctors have not found a dear cause for it.

- a) remembering things
- b) swallowing
- c) losing your voice
- d) blurred vision
- e) actual blindness
- f) fainting and losing consciousness
- g) seizures and convulsions
- h) being able to walk
- i) paralysis or muscle weakness
- j) urination

“Was this true for you *after the experience*” or “Has this been true for you *for as long as you can remember*?”  Yes  No

- “How true has this been for you *in the last month*”:
- None; not at all 0
  - Some trouble-did not require medical attention 1
  - Visited a doctor, more than one medicine without relief 2
  - Several doctor visits, a hospital admission, and/or invasive diagnostic tests 3
  - Not applicable 4

**VIe. Sexual Symptoms**

43. I suffer from (circle items that apply), yet doctors have not found a clear cause for it.

- a) burning sensations in your sexual organs or rectum (not during intercourse)
- b) impotence (males)
- c) irregular menstrual periods (females)
- e) excessive pre-menstrual tension
- f) excessive menstrual bleeding

“Was this true for you *after the experience*” or “Has this been true for you *for as long as you can remember*?”  Yes  No

- “How true has this been for you *in the last month*”:
- None; not at all 0
  - Some trouble-did not require medical attention 1
  - Visited a doctor, more than one medicine without relief 2
  - Several doctor visits, a hospital admission, and/or invasive diagnostic tests 3
  - Not applicable 4

**VII) ALTERATIONS IN SYSTEMS OF MEANING**

**VIIa. Foreshortened Future**

44. I feel hopeless and pessimistic about the future.

“Was this true for you *after the experience*” or “Has this been true for you *for as long as you can remember*?”  Yes  No

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"How true has this been for you <i>in the last month</i> ":	0
None; not at all	1
I get discouraged and lose interest in planning for myself	2
I don't see a future and go through the motions of living	3
I feel condemned and have no future left	4
Not applicable	

45. I don't expect I'll be able to find happiness in love relationships.

"Was this true for you *after the experience*" or "Has this been true for you *for as long as you can remember*?"  Yes  No

"How true has this been for you <i>in the last month</i> ":	0
None; not at all	1
I sometimes feel distant and disconnected from my loved ones	2
I go through the motions of relationships, but feel numb	3
I don't feel part of the human race, and cannot imagine ever loving anybody	4
Not applicable	

46. I don't find satisfaction in work.

"Was this true for you *after the experience*" or "Has this been true for you *for as long as you can remember*?"  Yes  No

"How true has this been for you <i>in the last month</i> ":	0
None; not at all	1
Sometimes it is a routine, but I can forget about my troubles by working	2
Work is a burden, and I have trouble keeping my interest up	3
I could not care less about my work	4
Not applicable	

#### **VIIb. Loss of Previously Sustaining Beliefs**

47. I believe that life has lost its meaning.

"Was this true for you *after the experience*" or "Has this been true for you *for as long as you can remember*?"  Yes  No

"How true has this been for you <i>in the last month</i> ":	0
None; not at all	1
Sometimes it seems pointless	2
I cannot think of a good reason, but I keep on living	3
I live in a huge void	4
Not applicable	

48. There have been changes in my philosophy or religious beliefs--or in, the religious beliefs or philosophical beliefs I grew up with.

"Was this true for you *after the experience*" or "Has this been true for you *for as long as you can remember*?"  Yes  No

"How true has this been for you <i>in the last month</i> ":	0
None; not at all	1
My beliefs have changed, but it was a normal progression of life	2
I am disillusioned with the religious beliefs I grew up with	3
I hate the religious beliefs I grew up with	4
Not applicable	



**SIDES Data Entry Sheet**

**Instructions:**

Translate raw scores from the SIDES into scores on this sheet by circling the appropriate choice, according to the following scoring system:

1. For all "Yes" and "No" answers on the SIDES, circle the same on this sheet. (For items #39 – 43, only one of the somatic symptom types must be circled for a "Yes".)
2. For all severity scores of 0 or 1 on the SIDES, circle 0 on this sheet.
3. For all severity scores of 2 or 3 on the SIDES, circle the same number on this sheet.
4. For all severity scores of "Not Applicable" on the SIDES, circle \* on this sheet.

<b>SCALE I ...</b>	1. Yes No Ia. 0 2 3 *	<b>SCALE I continued</b>	13. Yes No 0 2 3 *	<b>SCALE III</b>	25. Yes No IIIa. 0 2 3 *	<b>SCALE V continued</b>	37. Yes No Vb. 0 2 3 *
	2. Yes No 0 2 3 *		14. Yes No 0 2 3 *		26. Yes No IIIb. 0 2 3 *		38. Yes No Vc. 0 2 3 *
	3. Yes No 0 2 3 *		15. Yes No 0 2 3 *		27. Yes No IIIc. 0 2 3 *		39. Yes No VIa. 0 2 3 *
	4. Yes No Ib. 0 2 3 *		16. Yes No 0 2 3 *		28. Yes No IIId. 0 2 3 *	40. Yes No VIb. 0 2 3 *	
	5. Yes No 0 2 3 *		17. Yes No 0 2 3 *		29. Yes No IIIe. 0 2 3 *	41. Yes No VIc. 0 2 3 *	
	6. Yes No 0 2 3 *		18. Yes No 0 2 3 *		30. Yes No IIIf. 0 2 3 *	42. Yes No VIId. 0 2 3 *	
	7. Yes No 0 2 3 *		19. Yes No If. 0 2 3 *	31. Yes No IVa. 0 2 3 *	43. Yes No VIe. 0 2 3 *		
<b>SCALE II</b>	8. Yes No Ic. 0 2 3 *	<b>SCALE II</b>	20. Yes No IIa. 0 2 3 *	<b>SCALE IV</b>	32. Yes No IVb. 0 2 3 *	<b>SCALE VII</b>	44. Yes No VIIa. 0 2 3 *
	9. Yes No 0 2 3 *		21. Yes No IIb. 0 2 3 *		33. Yes No IVc. 0 2 3 *		45. Yes No 0 2 3 *
	10. Yes No 0 2 3 *		22. Yes No 0 2 3 *		34. Yes No Va. 0 2 3 *		46. Yes No 0 2 3 *
	11. Yes No Id. 0 2 3 *		23. Yes No 0 2 3 *	35. Yes No 0 2 3 *	47. Yes No VIIb. 0 2 3 *		
	12. Yes No Ie. 0 2 3 *		24. Yes No 0 2 3 *	36. Yes No 0 2 3 *	48. Yes No 0 2 3 *		
				<b>SCALE V ...</b>			

<b>SIDES Score Worksheet</b>				
<p><b>Lifetime Presence:</b> Using the criteria listed below, calculate the lifetime presence ("yes/no") of symptoms for each subscale. For example, if 2 of items 1-3 are present, write "yes". Calculate the current presence for the overall scale by following instructions below. Indicate "yes" or "no" in the space provided.</p>		<p><b>Current Severity:</b> Obtain a subscale score by averaging the items within each subscale. Place the average in the space provided. Total the subscale averages &amp; divide by the number of subscales within each scale. The average of the subscales comprises the overall current severity for that scale. Items scored with an "*" are not included in the calculations. Mark these items with an "*" (or 0?) as the score.</p>		
<b>SCALE I</b>	<u>Lifetime Presence</u>		<u>Current Subscale Severity</u>	
	Ia. 2 of items 1 - 3 _____	Ia. Average of items 1 - 3 _____	Ib. 2 of items 4 - 7 _____	Ib. Average of items 4 - 7 _____
	Ic. 1 of items 8 - 10 _____	Ic. Average of items 8 - 10 _____	Id. Item 11 _____	Id. Score for item 11 _____
	Ie. 1 of items 12 - 18 _____	Ie. Average of items 12 - 18 _____	Ie. Average of items 12 - 18 _____	Ie. Average of items 12 - 18 _____
	If. Item 19 _____	If. Score for item 19 _____	If. Score for item 19 _____	If. Score for item 19 _____
<p><b>Current Presence</b> (severity scores of 2 or higher on Ia AND presence of 1 of b-f) (yes/no): _____</p>		<p><b>Overall Current Severity:</b> (average subscale scores) Total: _____ + 6 = _____</p>		
<b>SCALE II</b>	<u>Lifetime Presence</u>		<u>Current Subscale Severity</u>	
	IIa. Item 20 _____	IIa. Score for item 20 _____	IIb. 1 of items 21 - 24 _____	IIb. Average of items 21 - 24 _____
	<p><b>Current Presence</b> (severity scores of 2 or higher on IIa. or IIb.) (yes/no): _____</p>		<p><b>Overall Current Severity:</b> (average subscale scores) Total: _____ + 2 = _____</p>	
<b>SCALE III</b>	<u>Lifetime Presence</u>		<u>Current Subscale Severity</u>	
	IIIa. Item 25 _____	IIIa. Score for item 25 _____	IIIb. Item 26 _____	IIIb. Score for item 26 _____
	IIIc. Item 27 _____	IIIc. Score for item 27 _____	IIId. Item 28 _____	IIId. Score for item 28 _____
	IIIe. Item 29 _____	IIIe. Score for item 29 _____	IIIe. Score for item 29 _____	IIIe. Score for item 29 _____
	IIIf. Item 30 _____	IIIf. Score for item 30 _____	IIIf. Score for item 30 _____	IIIf. Score for item 30 _____
<p><b>Current Presence</b> (severity scores of 2 or higher on 2 of a - f) (yes/no): _____</p>		<p><b>Overall Current Severity:</b> (average subscale scores) Total: _____ + 6 = _____</p>		
<b>SCALE IV: Do not score</b>				
<b>SCALE V</b>	<u>Lifetime Presence</u>		<u>Current Subscale Severity</u>	
	Va. 1 of items 34 - 36 _____	Va. Average of items 34 - 36 _____	Vb. Item 37 _____	Vb. Score for item 37 _____
	Vc. Item 38 _____	Vc. Score for item 38 _____	<p><b>Overall Current Severity:</b> (average subscale scores) Total: _____ + 3 = _____</p>	
<p><b>Current Presence</b> (severity score of 2 or higher on any of a - c) (yes/no): _____</p>				
<b>SCALE VI</b>	<u>Lifetime Presence</u>		<u>Current Subscale Severity</u>	
	VIa. Item 39 _____	VIa. Score for item 39 _____	VIb. Item 40 _____	VIb. Score for item 40 _____
	VIIc. Item 41 _____	VIIc. Score for item 41 _____	VIId. Item 42 _____	VIId. Score for item 42 _____
	VIe. Item 43 _____	VIe. Score for item 43 _____	VIe. Score for item 43 _____	VIe. Score for item 43 _____
<p><b>Current Presence</b> (severity scores of 2 or higher on 2 of a - e) (yes/no): _____</p>		<p><b>Overall Current Severity:</b> (average subscale scores) Total: _____ + 5 = _____</p>		
<b>SCALE VII</b>	<u>Lifetime Presence</u>		<u>Current Subscale Severity</u>	
	VIIa. 1 of items 44 - 46 _____	VIIa. Average of items 44 - 46 _____	VIIb. 1 of items 47 or 48 _____	VIIb. Average of items 47 - 48 _____
	<p><b>Current Presence</b> (severity scores of 2 or higher on 2 of a or b) (yes/no): _____</p>		<p><b>Overall Current Severity:</b> (average subscale scores) Total: _____ + 2 = _____</p>	

SIDES Summary Sheet			
Instructions: Copy scores from the previous page (Score Worksheet) onto the corresponding places on the SIDES Summary Sheet. * Scores of 2 or higher are clinically significant. *	Lifetime Presence	Current Presence	Current Severity
<b>I. Alterations in Regulation of Affect and Impulses</b>		—	—
Ia. Affect Regulation	—		—
Ib. Modulation of Anger	—		—
Ic. Self-destructive	—		—
Id. Suicidal Preoccupation	—		—
Ie. Difficulty Modulations Sexual Involvement Preoccupation	—		—
If. Excessive Risk Taking	—		—
<b>II. Alterations in Attention or Consciousness</b>		—	—
IIa. Amnesia	—		—
IIb. Transient Dissociative Episodes and Depersonalization	—		—
<b>III. Alterations in Self-Perception</b>		—	—
IIIa. Ineffectiveness	—		—
IIIb. Permanent Damage	—		—
IIIc. Guilt and Responsibility	—		—
IIId. Shame	—		—
IIIe. Nobody can Understand	—		—
IIIf. Minimizing	—		—
<b>IV. Alterations in Perception of the Perpetrator</b>		—	—
IVa. Adopting Distorted Beliefs	—		—
IVb. Idealization of Perpetrator	—		—
IVc. Preoccupation with Hurting Perpetrator	—		—
<b>V. Alterations in Relationships with Others</b>		—	—
Va. Inability to Trust	—		—
Vb. Revictimization	—		—
Vc. Victimizing Others	—		—
<b>VI. Somatization</b>		—	—
VIa. Digestive System	—		—
VIb. Chronic Pain	—		—
VIc. Cardiopulmonary Symptoms	—		—
VId. Conversion Symptoms	—		—
VIe. Sexual Symptoms	—		—
<b>VII. Alterations in Systems of Meaning</b>		—	—
VIIa. Foreshortened Future	—		—
VIIb. Loss of Previously Sustained Beliefs	—		—

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<b>SIDES Summary Sheet</b>			
<b>Instructions:</b> Copy scores from the previous page (Score Worksheet) onto the corresponding places on the SIDES Summary Sheet. * Scores of 2 or higher are clinically significant. *	<b>Lifetime Presence</b>	<b>Current Presence</b>	<b>Current Severity</b>
<b>I. Alterations in Regulation of Affect and Impulses</b>		—	— (Overall Severity)
Ia. Affect Regulation	—		— (Subscale Severity)
Ib. Modulation of Anger	—		— (Subscale Severity)
Ic. Self-destructive	—		— (Subscale Severity)
Id. Suicidal Preoccupation	—		— (Subscale Severity)
Ie. Difficulty Modulations Sexual Involvement Preoccupation	—		— (Subscale Severity)
If. Excessive Risk Taking	—		— (Subscale Severity)
<b>II. Alterations in Attention or Consciousness</b>		—	— (Overall Severity)
IIa. Amnesia	—		— (Subscale Severity)
IIb. Transient Dissociative Episodes and Depersonalization	—		— (Subscale Severity)
<b>III. Alterations in Self-Perception</b>		—	— (Overall Severity)
IIIa. Ineffectiveness	—		— (Subscale Severity)
IIIb. Permanent Damage	—		— (Subscale Severity)
IIIc. Guilt and Responsibility	—		— (Subscale Severity)
IIId. Shame	—		— (Subscale Severity)
IIIe. Nobody can Understand	—		— (Subscale Severity)
IIIf. Minimizing	—		— (Subscale Severity)
<b>IV. Alterations in Perception of the Perpetrator</b>		—	— (Overall Severity)
IVa. Adopting Distorted Beliefs	—		— (Subscale Severity)
IVb. Idealization of Perpetrator	—		— (Subscale Severity)
IVc. Preoccupation with Hurting Perpetrator	—		— (Subscale Severity)
<b>V. Alterations in Relationships with Others</b>		—	— (Overall Severity)
Va. Inability to Trust	—		— (Subscale Severity)
Vb. Revictimization	—		— (Subscale Severity)
Vc. Victimizing Others	—		— (Subscale Severity)
<b>VI. Somatization</b>		—	— (Overall Severity)
VIa. Digestive System	—		— (Subscale Severity)
VIb. Chronic Pain	—		— (Subscale Severity)
VIc. Cardiopulmonary Symptoms	—		— (Subscale Severity)
VId. Conversion Symptoms	—		— (Subscale Severity)
VIe. Sexual Symptoms	—		— (Subscale Severity)
<b>VII. Alterations in Systems of Meaning</b>		—	— (Overall Severity)
VIIa. Foreshortened Future	—		— (Subscale Severity)
VIIb. Loss of Previously Sustained Beliefs	—		— (Subscale Severity)

van der Kolk, Pelcovitz, Herman, Roth, Kaplan, Waldinger, Guastella &amp; Spitzer

