A qualitative service evaluation of the usefulness of a group based Acceptance & Commitment Therapy programme for Chronic Pain

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ABSTRACT

Background

In recent years *Acceptance and Commitment Therapy* (ACT) has gained increasing status as a promising approach to treating chronic pain physical functioning and psychological well-being. The basic premise of ACT as applied to chronic pain is that while pain hurts, it is the struggle with pain that causes suffering. This approach aims to restore effective and adaptive functioning for an individual within a context of continuing pain so that the individual can live a more vital and meaningful life.

There is a growing empirical support for the effectiveness of ACT however research has relied on self-reported quantitative outcomes, focused on addressing changes in pain intensity and the physical and psychological impact of chronic pain. There appears to be a gap in the literature on the exploration of the experience of attending an ACT programme for chronic pain from the patient's perspective.

Aim

This study sought to explore the experience of attending an ACT programme for chronic pain within an outpatient NHS hospital setting. Furthermore the study sought to explore the modulating factors influencing clients learning and understanding of the construct of acceptance from the perspective of the participants. Additionally, the experience of attending a group based ACT intervention was explored.

Methodology

A qualitative methodology was chosen for the project. The study used a purposive sample of twelve participants, who had all attended the Luton & Dunstable Hospital ACT 8 week outpatient programme for chronic pain. The participants were interviewed through the use of a semi structured interviews, and the transcripts were transcribed and then analysed using Thematic Analysis. Identified themes were further organised using the tool of Thematic Network Analysis.

Results

Three global themes emerged from the analysis of the data. The first global theme encompassed the participant's pre-programme expectations and this theme highlighted the participant's feelings of hope and hopelessness prior to attending the programme. The second global theme demonstrated the on-going process of living with chronic pain and highlighted the benefits and barriers to adopting and ACT based approach to chronic pain. Finally the third global theme addressed the experience of a group based intervention and included the positive and negative aspects of this experience for the participants.

Clinical Implications & Conclusion

Based on the results of this study a number of clinical implications were highlighted in relation to the future development of ACT programmes for chronic pain. These included suggestions in relation to engaging participants in such programmes. Notably, timing issues, validation of physical symptoms, and consideration of the potential barriers to acceptance and understanding of the benefits of adopting and ACT group based pain management approach were discussed.

CHAPTER 1 - INTRODUCTION

1.1.   Overview

The introduction to this study first orients the reader to the position of the researcher and why this topic area was chosen. The concepts of pain and chronic pain are presented and some key psychological factors related to chronic pain are outlined. This is followed by an introduction to the treatments for chronic pain including some of the theoretical underpinnings of these treatment approaches. There is a vast amount of literature available on the treatments for chronic pain and a full review of its entirety is beyond the scope of this project. An overview of the Acceptance and Commitment Therapy (ACT) approach to chronic pain is provided followed by an introduction to the key concepts within the ACT philosophy. A review of the empirical evidence for ACT for chronic pain discusses the findings of quantitative outcome studies and makes enquiries about the need for a qualitative understanding of the experience of adopting an ACT approach to chronic pain management, which appears to be limited in the literature. Finally the rationale for this study and its clinical relevance and aims are outlined.

1.2.   Literature Search Strategy

Identifying relevant information was an on-going and iterative process. A systematic literature search was conducted over a period of 12 months, in order to ensure thorough coverage and reduce the potential for bias within selected literature. In summary, the preliminary stage focused on a limited set of key terms (e.g. Chronic Pain; Acceptance and Commitment Therapy (ACT); pain management programmes; CBT, Mindfulness Based Cognitive Therapy, Contextual Cognitive Behavioural Therapy), in the databases Psych Info, PubMed, Medline, Scopus, Web of Science, Science Direct and Google Scholar. References from generated articles were followed up and a list of relevant key search terms developed, alongside additional inclusion and exclusion criteria. Researchers in the field were contacted to source further references if articles were not accessible freely on the internet (for

example, articles in submission or in press). An additional literature search was carried out following initial stages of analysis to explore areas that had arisen, and search terms were expanded to incorporate these.

The Serenity Prayer

God grant me the serenity
to accept the things I cannot change;
courage to change the things I can;
and wisdom to know the difference.

--Reinhold Niebuhr

1.3.   Statement of Position

Self-reflection allows a researcher to acknowledge their own values and existing theory in order to more adequately represent the experiences of their participants (Elliott, Fischer, and Rennie, 1999). Additionally, the importance of "owning one's perspective" is well recognised in the development of good qualitative research. Whilst qualitative researchers accept that it is not possible to set aside their own beliefs, values and perspectives throughout the process (Webb, 1992), by being transparent, my aim is that the reader will recognise both the personal and theoretical position underpinning this study.

1.4.   How I Came to this Study?

In many ways this research study chose me. I initially started clinical training five years ago, however following a near- fatal car accident during my first term, I was left with significant physical injuries which forced me to temporarily terminate my chosen career path and undergo a rehabilitative process which was to change my life forever. During this time I battled with pain, on many levels, and although the physical scars healed, the emotional struggles and pain continued.

I am now in the position whereby I am able to look back over the past five years and reflect on the changes I have faced. I have been blessed with a son, and am now nearing the end of training. My choice of research topic therefore seemed an obvious one, as my journey this far has been full of challenges; however, by accepting and maintaining a commitment to myself and my family I have been able to live my life despite chronic pain.

My experiences throughout Clinical Psychology training and previous employment in conjunction with my personal values and experience have led me to favour social constructionist and constructivist ideas in research. Pain can mean so many things, to so many different people, and the experience of pain is essentially an individual, internal experience, known only to the person in pain (Davis, 2000).

1.5.   Understanding Acceptance

Acceptance does not imply a blind pursuit of activity and uncompromised lifestyle in spite of pain, but features behaving in chosen ways with pain, thus achieving a full and satisfying life (McCracken, 2005a). Acceptance acknowledges pain, and suggests that pain has been incorporated into a person's life and that life could be lived regardless of pain.

The research questions posed within this study grew from an interest in the response of individuals with chronic pain to this alternative approach to managing chronic illness. Current pain management interventions are based on the accepted pain paradigm that "pain is an unpleasant sensory and emotional experience associated with actual or potential tissue damage" (IASP, 1994). However although this definition acknowledges that there is an emotional component to pain, it says nothing of how emotion fits and/or interacts into the individual experience of pain. It also fails to convey the way pain shifts and changes the landscape of a person's world.

Chronic pain changes the foundations of a person's life, because the pain creates new and qualitatively different life conditions. In my final year of training I have chosen to work in an outpatient pain clinic, and this experience has provided me with an insight into the way that pain can affect the every aspect of being-physical, social, psychological, financial and even

spiritual. Some people reach acceptance, whilst others find that the limitations in their daily life make difficult the move towards acceptance. I have seen people in disbelief, frustration, anger and confusion as it became known to them that a cure was not possible to free them from their pain.

I became interested personally and professionally in alternative approaches to pain management such as acceptance and commitment therapy, and began to frame research questions around the experience of adopting this alternative approach. I retained the belief that ACT can be useful for some chronic pain sufferers but was also open to the likelihood that therapy will not be useful to everyone. My main position was one of curiosity; if ACT was helpful to the participants in this study, why and how is it so, and if it is not helpful why and what could help?

Transition is a complex process of intense personal development, characterised by the idea of moving on. By starting and ending my clinical training through the lens of chronic pain, I feel empowered to pursue a life I want to live despite my pain, and hope to be able to use my personal and professional coping strategies, which will be further informed through this research, to help others in pain.

1.6. What is Pain?

Pain is a subjective and multifaceted experience that impacts upon emotional, social and physical functioning (International Association for the Study of Pain, 1986). In 1968 McCaffery *wrote 'Pain is whatever the experiencing person says it is, existing whenever he says it does'* (McCaffery & Pasero, 1999, p. 17). This statement has been influential in emphasising the subjective nature of pain and the reliability of patients' report of pain.

The subjective and multifaceted experience of Pain suggest a definitive definition is problematic, but that most commonly ascribed is the IASP (1986) definition as: *"an unpleasant sensory and emotional experience associated with actual or potential tissue damage".*

Pain can be identified within two broad categories; *acute* and *chronic.* Acute pain has a short duration and can be linked to an identified cause (Renn & Dorsey, 2005). Chronic pain, persisting beyond the point of tissue healing, however, is believed to have no biological purpose (Merskey & Bogduk, 1994).

The definition of *Chronic Pain* (CP) suggested by Clinical Standards Advisory Group (CSAG, 1994) is *"intermittent or continuous pain that persists past the time when healing is expected to be complete".* Melzack and Wall (1996) have further noted that CP requires duration of at least six months for it to be recognised as *chronic.*

There has been an explosion of research on CP over the last fifteen years, with significant advances in understanding its etiology, assessment and treatment (Gatchel, Peng, Peters, Fuchs, and Turk 2007). CP can be seen as a complex biopsychosocial problem (British Pain Society, 1997), consisting of sensory, affective and evaluative components (Melzack & Wall, 1965). It can be caused by a number of physical conditions including arthritis, trauma, and disease (Morley, Eccleston, and Williams 1999). However, a single physiological explanation is not available for many chronic non-malignant pain states and up to one third of CP patients will have no objective findings of organic disease (BPS, 1997).

1.6.1. Prevalence rates and impact of chronic pain

UK epidemiological research has shown that CP affects 10-20% of adults in the general population (Blyth et al., 2001). Like many other chronic conditions, CP cannot always be cured, and complete, lasting remission of pain is rarely achieved (Turk, 1990a). This can lead to prolonged duration, with a recent study finding almost 60% of sufferers had lived with pain for up to 15 years, (Breivik, Collett, Ventafrida, Cohen, and Gallacher, 2006). Therefore, CP can be seen as a prevalent health concern and has been shown to contribute to considerable costs in terms of healthcare, lost work, productivity and disability compensation (Gatchel & Okifuji, 2006).

For many individuals CP has significant adverse impacts on psychological distress such as depression and anxiety, (Bair, Robinson, Katon & Kroenke, 2003), and sufferers are four times more likely to be diagnosed with anxiety or depressive disorder (Gureje, 1998; Breivik et al., 2006). The subjective and invisible nature of pain can serve to isolate sufferers, with

many perceiving that colleagues, employers, family and doctors are unsympathetic to their pain (Breivik et al., 2006).

Relationship difficulties and problems with emotional functioning (Breivik et al., 2006) have also been recognised within CP sufferers, with one in four patients stating their ability to maintain relationships and sustain an independent lifestyle was compromised (Breivik et al., 2006). CP therefore represents a serious problem, not only for the individual (Sprangers et al., 2000), but also the systems of relationships surrounding them.

1.7. Psychological Factors of Pain

There is growing recognition that pain is a complex perceptual experience, influenced by a wide range of psychosocial factors, including beliefs and expectations, social and environmental context, as well as biological factors (Turk & Okifuji., 2002). Bigos, Bowyer, and Braen (1994) further suggest that psychosocial factors play a crucial role in the transition from an acute episode of pain to a chronic experience.

Understanding of the experience and response to pain can be enhanced by consideration of psychological constructs such as the concepts of beliefs, self-efficacy, stress, adjustment and locus of control. These shall now be considered below.

1.7.1. Beliefs

There is a growing body of evidence to support the importance of patient's beliefs in CP (Jensen & Karoly, 2001). Beliefs about the meaning of symptoms, the patient's ability to control pain, the impact of pain on the patient's life, and worry about the future, have been shown to play a central role in CP, and psychological functioning and response to treatment (Tota-Faucette, Gil, Willilams, Keefe, and Goli, 1993).

Crombez, Vlaeyen, Heuts, and Lysens (1999) suggest that in CP, pain-related anxiety and fear may actually accentuate the pain experience. Fearful patients attend more to signals of threat and appear less able to ignore pain-related information (Crombez, Vervaet, Lysens, Baeyens, and Eelen, 1998). Furthermore, Mayer and Gatchel (1998) have argued that

patients with CP often demonstrate prolonged protectiveness and passivity, largely induced by fear. The result is likely to be a decrease in mobility, muscle strength and cardiovascular fitness and ultimately an increase in disability.

The fear avoidance model (Vlaeyen & Linton, 2000), reinforces the impact that appraisals and cognitions have on the pain experience. According to this model, if certain bodily movements are feared and avoided, problems such as increased pain arise due to the lack of movement and de-conditioning in that area of the body (Lohnberg, 2007).

Therefore, fears, pain-related anxiety, and concerns about harm and avoidance appear to modulate the CP experience. Notably, interventions which incorporate the reduction of pain related fears/anxiety and maximise adaptive functioning have been found to be beneficial for individuals with CP (Lohnberg, 2007).

It is important to recognise however, that premorbid individual differences may contribute to the process whereby fear and beliefs contribute to the experience of CP. Negative affectivity and anxiety sensitivity have been demonstrated to be associated with elevated symptom reporting in CP patients. Furthermore, individual variability can also be attributed to prior learning history in some CP sufferers (Turk & Okifuji, 2002).

1.7.2. Self-efficacy

Self-efficacy appears to play an important role in perception of and adjustment to pain and subsequent disability. Evidence suggests that self-efficacy is important in the control of pain (Lorig, 1990), adaptive psychological functioning (Spinhoven et al., 2004), disability (Lorig, 1990) and treatment outcome (O'Leary, 1990).

Bandura (1977) defines self-efficacy as "a personal conviction that one can successfully perform certain behaviours in a given situation". From this perspective therefore, self-efficacy is thought to be central in determining how people think, feel and act. In terms of thinking, a strong sense of competence facilitates cognitive processes and performance. In terms of feeling, a low sense of self-efficacy is associated with depression, anxiety, and helplessness. Self-efficacy levels can therefore enhance or impede the motivation to act.

Behaviour change is facilitated by a personal sense of control (Bandura, 1977). Therefore it may be argued that if a person believes that they can take action to solve a problem instrumentally, they become more inclined to do so and feel more committed to this decision. This was identified in social learning theory, derived from the ideas of stimulus response theory (Rosenstock, Strecher, & Becker, 1988), in which self-efficacy is posited as fundamental to behaviour change.

Over the years, the notion of self-efficacy has been adopted as part of most health behaviour theories. Becker and Rosenstock (1987) have incorporated it into their Health Belief Model, reinterpreting self-efficacy as being "barriers" to action. Maddux and Rogers (1983) have incorporated self-efficacy as one major determinant of *intentions* in their Protection Motivation Theory.

A large body of research has examined the role of optimistic self-beliefs as a predictor of behaviour change in the health domain. Both outcome expectancies and efficacy beliefs play influential roles in adopting health behaviours, eliminating detrimental habits, and maintaining change (Schwarzer & Fuchs, 1995).

However despite the awareness of the influence of self-efficacy on health promotion and treatment, understanding with regards to what motivates people in chronic pain to manage it is limited (Main & Booker, 2000) and more complex cognitive processes are therefore evident before the consideration of behaviour change.

1.7.3. Stress

The impact psychological stress has on the physical body is well recognised. As human beings our bodies are geared towards survival, and when we are stressed or become anxious the secretion of cortisol and adrenaline prepares the body to respond to danger. However, if cortisol is secreted when such a state is not required but is due to the likes of psychological stress, anticipatory anxiety or pain, then there is too much or too little of it in our systems. This then in turn weakens the immune system, slows down healing and the ability of the body to repair itself. This has been implicated in many conditions, including chronic heart disease, hypertension, diabetes and rheumatoid arthritis (Gardner-Nix, 2009).

This fits with diathesis-stress formulations of pain, and in particular with the model of coping suggested by Lazarus and Folkman (1984), in which appraisal is seen to be influenced by personal and environmental characteristics. Furthermore, magnification and ruminative processes such as catastrophisation could be related to primary appraisal processes where people could focus on and exaggerate the threat value of the pain (Sullivan et al., 2002).

Consideration of the coping style of an individual with chronic pain can therefore provide an insight into their motivation to seek treatment and furthermore their ability to engage in interventions and their ability to adjust to living with chronic pain.

1.7.4. Adjustment

The concept of adjustment to pain involves a successful individual learning process to mental functioning and the ability to carry out "normal" physical and psychosocial activities (Jensen, Turner, Romano, & Karoly, 1991). Complex relationships exist between individual pain appraisals, coping strategies and adjustment to CP. Jensen et al. (1991) suggest that identifying individual factors that promote adaptive functioning when living with pain is important.

Gatchel et al. (2007) note that there are adjustment differences seen in people with CP. Some function adaptively whereas others may not. CP does often lead to inactivity, emotional suffering and depression, but this is not always so (Gatchel et al., 2007). Various dimensions of adjustment considered relevant to CP include: pain behaviour, self-reported pain severity, activity level, physical strength and mobility, medication use, health services utilisation, employment status and depression.

Smith, Lumley, and Longo (1999) investigated the relationship between cognitive and emotional constructs and their relationship to adjustment in chronic pain patients. Emotional coping was found to be a more robust predictor than cognitive coping, and self-efficacy was found to be a particularly robust predictor of adjustment, predicting reduced sensory pain, affective pain, physical impairment and depression.

Therefore cognitive and emotional constructs could be considered to play a key role in understanding adjustment for some chronic patients.

1.7.5. Locus of control

The term *locus of control* refers to one's sense of the origins of events or circumstances. Rotter (1954) describes an external locus of control as the belief that life circumstances are influenced by chance and fate, and that the individual has little control over events. This is in contrast to an individual with an internal locus of control, who is able to maintain agency over their own actions, believing that they have the ability to act and make a difference. Research suggests that if adverse life situations are accompanied with an external locus of control, passivity, hopelessness and isolation can occur (Mikulincer & Segal, 1990).

Chronic pain patients who display an external locus of control, report greater depression and anxiety, feel helpless to deal with their pain and often rely on maladaptive coping strategies, such as resting and eating.

Additionally, Mikulincer and Segal (1990) suggests that individuals who believe that they have no control over events tend to adopt passive emotion focused coping strategies which may result in depression and apathy and reduced motivation to actively seek resolution.

Therefore locus of control could be seen as an important factor to consider in the understanding of the motivation in chronic patients to either seek treatment or not.

1.8.   Health Care Seeking Behaviour

Individuals vary greatly both in levels of anticipatory concern for discomfort and their tolerance of it. According to Robinson, Wicksell, and Olsson (2004), people with little tolerance for pain and discomfort are more likely to seek help with the aim of reducing unpleasant feelings. However, short term alleviation of discomfort can reinforce a low tolerance for pain, stress and discomfort and increase the control exerted by anticipatory worries about them (Robinson et al., 2004).

These differences highlight the question of why some people feel they are sick and work, while others feel sick and do not. Linton (1995) showed in a study of pain and stress symptoms and sick leave among health care workers, the differences between those who

worked and those who were on sick leave was related to distress tolerance, coping strategies and belief about symptoms.

Therefore it appears that how a person reacts to the symptoms, rather than the symptom itself that determines health seeking behaviour and disability (Linton, 1995).

1.9. Treatments for CP

1.9.1. Traditional medical interventions

The experience of CP often prompts a search for understanding that initially focuses on diagnosis and treatment recommendations to eliminate the pain. However, CP patients often undertake a vigorous quest to find a "cure", and when initial attempts are unsuccessful; this search can often dominate a person's life (McCracken, Carson, Eccleston, 2004; Keefe, Rumble, Scipio, Giordino, & Perri, 2004).

Caudill (2002) argues that western culture has given rise to a "quick fix" attitude of using medications to alleviate problems. This approach is aimed to reduce or eliminate pain at the treatment of tissue pathology level. It may be argued that this has come at the cost of people learning self-management strategies to improve their lives, and has led to the frequent assumption that medicine has all the answers (Caudill, 2002).

Most traditional medical treatments for CP aim at reducing or avoiding pain sensations. Kazdin (1995) defines avoidance as "the performance of a behaviour which postpones or averts the presentation of an adverse event". In the scope of CP, avoidance entails any attempt to reduce the pain including but not limited to avoiding activity, treatment seeking and taking medication (McCracken, 1998). High levels of avoidance have been found to predict greater disability (Crombez et al., 1999), diminished physical capacity (Geisser, Roth, & Robinson, 1997) and lower pain tolerance (McCracken, 1998).

Research has shown that avoidance behaviour by CP clients is harmful to them. For instance, clients who reduce physical activity in an attempt to avoid pain may end up with

increased pain as a result of deconditioning that leads to muscle weakness (Dahl & Lundgren, 2006; Grinstead, 2008).

The use of analgesics, surgeries and procedures to control pain have been reported to be of limited benefit (Siddall & Cousins, 2004) and despite conventional healthcare utilisation, nearly half of patients with CP report that their pain is *not* under control (Rosenzweig et al., 2010). In recent years several meta-analyses evaluating the established pain treatments used today (Morley et al., 1999) have shown that these medical treatments, which may be effective in *acute* pain, are not effective with *chronic pain*, and may in fact; be causing further problems such as substance abuse and avoidance of important activities, (Morley et al., 1999). Furthermore one Swedish study concluded that of all established medical treatments offered today, the best treatment a primary care physician could give a patient with CP was *nothing.*

For some patients with CP, the unending pursuit of new treatments can reinforce a message that pain must be reduced in order for meaningful functioning to be restored, which is not necessarily true (McCracken, 2005a). Additionally, the cumulative effect of recurrent failures of treatment to achieve pain relief often include feelings of defeat, confusion and dismay, and these experiences can further exacerbate pain-related difficulties, (Baker, Reddish, Robertson, Hearnshaw, & Jones, 2001).

These findings and limitations of traditional western medicine thus reflect the complex pathophysiology of the condition, as well as the profound contribution of psychosocial factors to the perpetuation of pain and suffering (Keefe et al., 2004). Multimodal approaches to conceptualising CP and its treatment are now forefront in the field of pain management (Gatchel et al., 2007).

1.9.2. A biopsychosocial approach

In contrast to the medical perspective, there is growing support for a biopsychosocial approach to understanding and treating pain. A biopsychosocial view provides an integrated model that incorporates mechanical and physiological processes as well as psychological and social-contextual variables that may cause and perpetuate CP (Turk & Okifuji, 2002). Furthermore a biopsychosocial model views illness as a dynamic and reciprocal interaction

between biological, psychological and sociocultural variables that shapes a person's response to pain (Turk & Flor, 1999).

Not all pain develops into CP, and not all people who develop CP become disabled. The subjective nature and assessment of pain makes can make it difficult to ascertain what proportion of disability can be attributed to actual physical impairment and what portion can be attributed to other factors such as emotional and cognitive responses (Turk & Okifuji, 2002).

The biopsychosocial model focuses on both disease and illness. With *disease* defined as an objective biological event involving the disruption of specific body structures or organs systems caused by anatomical, pathological or physiological changes. In contrast *illness* refers to a subjective experience or self-attribution that a disease is present. Thus, illness refers to how a sick person and members of his or her family live with and respond to, symptoms of disability.

The distinction between disease and illness is analogous to the distinction that can be made between *nociception* and *pain.* Nociception involves the stimulation of nerves that covey information about potential tissue damage to the brain. In contrast pain is the subjective perception that results from the transduction, transmission and modulation of sensory information.

Loeser (1991) originally formulated that *suffering* could be classified as the emotional responses that are triggered by nociception or some other aversive event such as fear or depression. *Pain behaviours* [1] are overt communications of pain, distress and suffering.

The Gate Control theory (Melzack & Wall, 1965), a revolutionary theory has formed the basis for the biopsychosocial model of pain. The pain gate theory has been adapted over the years and one of the current models of pain perception, the pain neuromatrix theory (Moseley, 2003) has extended the suggestion that pain can persist due to alterations in the nervous system. When pain has become chronic, various changes are thought to occur along this pathway. For example, neurons can reduce their threshold to firing in response to

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[1] i.e. those things that people say or do when they are suffering or in pain, such as avoiding activities or exercise due to fear or re-injury

stimulation and in some cases will fire in the absence of peripheral stimulation. Essentially pain can start to occur, even though there is no tissue damage detected (Woolf, 2007). The emphasis of this theory on a neural circuit helps to explain the individual and contextual dependent nature of pain. The question remains what it is about the social context that activates the pain-control system.

As highlighted earlier in this chapter, a person in pain may develop appraisals which attribute meaning to the pain which subsequently influencing behaviours. Turk and Okifuji (2002) posit that these appraisals are influenced by the beliefs a person develops over their lifetime and on the basis of these beliefs a person in pain may chose to ignore the pain and continue working, walking, socialising and engaging in previous levels of activity. Or they may chose to leave work, refrain from activity and assume a sick role. The interpersonal role is shaped by responses from significant others that may promote either the healthy or active response or the sick role.

Therefore, the biopsychosocial model advocates a shift to a more inclusive perspective of a person's pain, and it allows for consideration of how psychological structures and personalities, social and familial environments and attitudes, can impact on wellbeing (Turk & Okifuji, 2002). The biopsychosocial model has also been instrumental in the development of cognitive-behavioural treatment approaches for CP and the heuristic approach to the management of CP-the interdisciplinary pain management programmes.

1.9.3. Pain management programmes (PMPs)

The British Pain Society describes treatment or management of pain, regardless of cause to be a "basic humanitarian right" (BPS, 1997, p.5) and a "fundamental objective of any health service" (BPS, 2008). Recommended treatments include medical interventions such as surgery, medication, nerve blocks, stimulation and physiotherapy, as well as psychosocial interventions including psychotherapy, education and rehabilitation programmes (BPS, 1997). Whilst rehabilitative and physical treatments can be helpful, when problems associated with pain are more complex and adversely affect quality of life, Pain Management Programmes (PMPs) based on cognitive behavioural (CB) principles are the recommended "treatment of choice" (BPS, 2007, p.1; NICE, 2009).

PMPs differ from other pain treatment, in that pain relief is not the primary goal (BPS, 1997). Instead, they aim to reduce disability and distress by combining physical, psychological, and practical aspects of pain management to improve quality of life (BPS, 1997, 2007). Problems are formulated in terms of the effects of persistent pain on physical and psychological wellbeing, rather than as disease/biological damage, or as deficits in personality/mental health (BPS, 2007). Specific components include education on pain physiology and psychology, self-management, goal-setting, identifying/changing unhelpful beliefs, relaxation techniques, and changing unhelpful habits (BPS, 2007). They should be delivered by a specialist multidisciplinary team (MDT) in either inpatient or outpatient settings (BPS, 2007). The BPS (2007, p.8) recommends that PMPs are delivered in group format in order to "normalise the pain experience, to maximise possibilities of learning from other group members".

The efficacy and effectiveness of PMPs has been demonstrated in a number of systematic reviews and have consistently been found superior to single-discipline treatment of CP. They have been found to reduce pain and drug intake, increase perceived control and self-confidence and improve quality of life (Williams et al., 1996; 1999; Morley et al., 1999; Guzmán et al., 2001; van Tulder, Koes, & Bouter, 1995; Hoffman, Papas, Chatkoff, & Kerns, 2007). Patients who participate in PMPs are more likely to return to work (Watson, Roach, & Urmston, 2004) and report an improvement in activity compared to those who do not (Morley et al., 1999; Guzmán et al., 2001).

Hoffman et al. (2007) carried out a meta-analysis of PMP interventions for chronic pain. They provided support for psychological interventions in reducing self-reported pain, pain-related interference, depression and disability. The study also demonstrated that multi-disciplinary group based programmes were superior to active individual treatment programmes at improving work-related outcomes at both short and long term follow up.

Therefore the empirical support for group based PMPs suggests that a multidisciplinary approach to pain management is beneficial for many people with CP. Consideration of the psychologically orientated treatment approaches provides further elaboration of the processes which may contribute to the successful outcomes shown within PMPs and furthermore factors which may impede the process.

1.10. Psychologically Oriented Treatment Approaches

A large volume of research exists demonstrating the efficacy of psychological treatments for CP (e.g.Hildebrandt, Pfingsten, Saur, & Jansen, 1997). The general consensus amongst researchers however, is that psychological treatments for CP are most effective when incorporated with other treatment modalities (Morley et al., 1999).

1.10.1. Cognitive Behavioural Therapy

The cognitive behavioural perspective introduced in 1983 emphasises the role of attributions, efficacy expectations and problem solving. Cognitive Behavioural therapy (CBT) soon became the standard treatment for CP patients, contending with the psychological distress and disabilities. CBT, incorporating both cognitive restructuring (Clark, 1995), and operant and respondent learning (Fordyce, 1976), reinforces techniques to alter behaviour and therefore helps individuals to manage their pain conditions. CBT for CP represents a wide variety of interventions including education, relaxation, skills training and goal setting (Turk, Meichenbaum, & Genest, 1983).

To date there is good evidence that a CBT approach to CP works reasonably well. Three meta-analyses indicate relatively good outcomes of cognitive behavioural approaches to pain (Hoffman et al., 2007, Morley et al., 1999, Ostelo et al., 2008). Despite sound evidence that CBT-based treatments are effective, a systematic review carried out by Morley, Eccleston, and Williams (2009) reported only moderate effect sizes for patients with CP.

Despite the growing supportive evidence base for CBT for CP, there are a number of concerns raised by authors in relation to the model. Eccleston, Williams, and Morley (2009) argue that CBT has become a catch all term for a broad combination of techniques that are often applied in the absence of a clear and well integrated theoretical framework.

A key assumption of the cognitive approach is that specific cognitive *change* techniques are fundamental to the achievement of adaptive behaviour (Clark, 1995). However, this hypothesis has not held up under empirical scrutiny within the more recent pain literature. Vowles, McCracken, and Eccleston (2007) found that achieving cognitive change is not necessary to achieve positive treatment outcomes in CP. There is also persuasive evidence from a number of studies which indicate that coping strategies encouraged through CBT

such as distraction techniques, activity pacing and cognitive restructuring are only weakly related to emotional and physical functioning (see Vowles & McCracken, 2010 for reviews). This is important to consider as such components are considered crucial for interdisciplinary treatments interventions for CP (Main, Sullivan, & Watson, 2008). Therefore the literature on CBT for CP appears somewhat incongruous.

Although CBT has documented efficacy, the processes underlying treatment effects remain still unclear (Keefe et al., 2004; Morley, 2004). CBT as an organised approach has traditionally placed significant emphasis on the importance of changes in the context of thoughts and beliefs in the treatment process (e.g. Clark, 1995, DeRubeis, Tang, & Beck, 2001). This is true in CP related applications as the central roles of catastrophic thinking, cognitive coping styles and beliefs about pain are frequently emphasised (e.g. Turk & Rudy, 1990b; Vlaeyen & Linton, 2000).

However, some authors have more recently argued that treatment may not need to focus on the semantic meaning of thoughts and beliefs to be effective, but rather may focus on the *way* in which thoughts and beliefs have their impact on functioning (Hayes et al., 1999b; Segal, Williams & Teasdale, 2001). Furthermore consideration of how these thoughts and beliefs can impact on psychological adjustment to CP is questionable.

Person-related factors such as self-efficacy, readiness to change and perceived pain control have influenced treatment outcomes using CBT (Nicholas, Wilson, & Goyen, 1992; Turner, Holtzman, & Mancl, 2007). Furthermore, potential external moderators that may influence CBT effectiveness have included: the number of sessions of CBT individuals received, therapists' skill and competence using CBT approaches, and group versus individual delivery (Vlaeyen & Morley, 2005).

The challenges raised in relation to the effectiveness of CBT interventions for CP have led to the awareness that there is more to CP than the symptoms of pain and the reactions to pain. Furthermore, Longmore and Worrell, (2007), note that there is little empirical support proving that the "agent of change" causing improvement in mood (and impact of pain) is cognition. Notably, it is clear that other factors need to be considered within the interventions for CP.

1.10.2. Third wave approaches

In recent years there has been a growing interest in alternative "*third wave approaches*" to manage clinical health problems. Mind-body medicine is receiving increasing recognition as one alternative. Mind-Body medicine is defined by a range of therapies intended to enhance the minds capacity to improve bodily function and symptoms. Within this umbrella term, *Acceptance and Commitment Therapy* (ACT) has gained increasing status as a promising approach to treating CP, physical functioning and psychological well-being (Hayes, 2004). ACT shares a resemblance with other acceptance and mindfulness based approaches[2], and it is linked with the field of behaviour therapy. An emerging body of research suggests that an ACT approach is beneficial for a wide variety of human suffering[3], including CP (Hayes, 2004).

1.11. Acceptance and Commitment Therapy (ACT)

The basic premise of ACT as applied to CP is that while pain hurts, it is the struggle with pain that causes *suffering*.

According to Burch (2008), the experience of pain or suffering can be distinguished as two elements. *Primary suffering* can be seen as the actual unpleasant sensation in the body at the time of injury. *Secondary suffering* can be considered as the resistance to the physical, emotional and mental experience.

Burch (2008) reinforces that chronic pain is an *experience* and as mentioned earlier in this chapter, that experience is deeply personal and the way a person experiences their pain is influenced by many factors including; emotions, beliefs, attitudes and past experiences.

This distinction between the two levels of suffering can help individuals to identify the resistance that may cause secondary suffering and ultimately an individual's relationship

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[2] such as Dialectical Behavioural Therapy (DBT), (Linehan, 1993), and mindfulness-based cognitive therapy (Segal, Teasdale & Williams, 2004), mindfulness based-stress reduction (Kabbat-Zinn, 1990)
[3] Controlled trials have shown ACT to be effective in the treatment of, panic disorder (Eifert & Hefner, 2003), depression, (Zettle & Hayes, 1986), generalised anxiety disorder (Orsillo, Roemer & Barlow, 2003), psychosis (Bach & Hayes, 2002), and work-site stress (Bond & Bunce, 2000).

with their pain, which is one of the assumptions of an ACT, based approach to pain management (Dahl, Wilson, Luciano, and Hayes, 2005).

The ACT approach aims at the restoration of effective and adaptive functioning within a context of continuing pain (Hayes, Strosahl, & Wilson, 2003). The clinical goal of ACT includes the general loosening of verbally based influences on behaviour, the strengthening of present-focused awareness, and increasing flexibility in responding to aversive experiences, so that this responding is more congruent with a vital and meaningful living (Hayes et al., 2003).

The primary goal of ACT according to Hayes, Luoma, Bond, Masuda, and Lillis (2006) has recently been more broadly defined as *"psychological flexibility"*. Treatment aims to enable pain sufferers to flexibly respond to pain, distress and related experiences in a particular way, such that struggling with these experiences decreases with frequency, options for living well with them are maximised, and, ultimately, that one's behaviour is in accord with one's goals and values. Therefore a focus on the reduction of the suffering associated with CP is a key component of ACT interventions.

In contrast to CBT and other models focused on reducing pain severity, the ACT model is based on the theory that attempts to change certain aversive internal experiences, such as CP, are likely to be futile at best and at worst may contribute to increased distress and interference (McCracken, Vowles, & Eccleston, 2005b; Robinson et al., 2004). The objective of the ACT model in relation to CP is to improve awareness and non-judgemental acceptance of all experiences, both positive and negative, to identify valued life directions and appropriate action towards goals that support these values. The mechanism of acceptance is believed to improve functioning and decrease interference of pain with value-driven action, in contrast to control-oriented treatments such as CBT (Hayes, 2004).

In order to outline the ACT approach to CP, it is helpful to first give a brief overview of the conceptual and theoretical basis to the approach.

1.12. ACT Philosophy

1.12.1. Conceptual and theoretical underpinnings

Functional Contextualism

ACT is part of the behavioural analytic tradition and applies a behavioural model of human suffering. It is an approach grounded in functional contextualism (Hayes, Brownstein, Zettle, Rosenfarb, & Korn, 1986), which at its core views psychological events as on-going interactions in and within historically defined and situational contexts (Hayes et al., 2006). Removal of a client's problematic behaviours from the contexts that participate in that event is thought to miss the nature of the problem and avenues for its solution. Therefore from this perspective no thought, feeling, memory or action can be viewed as inherently problematic or pathological, rather it depends on *context.*

Painful thoughts and feelings will function very differently in contexts where they are held to be objectively true and as something to be avoided, compared to contexts in which they are 'accepted' and not held to be objectively true (Hayes et al., 2006). In the latter context, the thoughts and feelings will have far less of an impact. They may still be painful, but they will not be harmful and they will not hold someone back from valued living (Harris, 2009). According to this philosophy, it is possible to go beyond trying to alter the form of thoughts or feelings to influence overt behaviour to changing the context that causally links these psychological domains (Hayes et al., 2006); that is, the relationship one has with their thoughts and feelings.

Relational Frame Theory

The theoretical basis of ACT is rooted in Relational Frame Theory (Hayes, Barnes-Holmes & Roche, 2001; Fletcher & Hayes, 2005), a contextual behavioural approach to human language and cognition that has growing empirical evidence. RFT is derived from functional contextualism (Gifford et al., 2004; Pepper, 1942), and the basic premise of RFT is that human behaviour is largely governed through networks of mutual relations called *relational frames*. These relations form the core of human language and cognition and allow learning to occur without direct experience (Hayes & Smith, 2005). For example a child does not need to touch a hot stove in order to be taught verbally that it can burn. Humans are able to arbitrarily relate objects in the environment, thoughts, feelings and actions (essentially

anything) to other objects in the environment, thoughts, feelings and actions in virtually any possible way. RFT asserts that humans suffer because they are verbal creatures and that people increasingly live inside the world of language and move away from the world of direct experience. Problems can arise when these processes are applied to every thought or memory (Hayes & Smith, 2005).

In relation to CP, RFT can help us to understand the relations that CP sufferers have with their pain and how their cognitions are related to the context within which they occur. ACT was developed in order to help patients change the context in which behaviour occurs.

Experiential Avoidance

Experiential avoidance is considered to be the attempt to avoid or escape the form, frequency or situational sensitivity of events such as thoughts, feelings, memories or physical sensations including pain (Hayes, Wilson, Gifford, Follette, & Strosahl, 1996). Experiential avoidance has been found to predict poorer outcomes in a broad range of areas including chronic pain (see Hayes et al., 1996, for review). Extensive research has shown that experiential avoidance (the act of avoiding an experience due to a feared outcome) doesn't reduce pain; it actually may serve to increase pain (Gutierrez, Luciano, Rodríguez, & Fink, 2004). As an example, trying deliberately to avoid thoughts of pain is likely to be unsuccessful because the rule being followed will a) remind the person of these very thoughts and b) may contain memories, worries or verbalised consequences that may themselves be painful. Additionally, avoiding pain can make pain and possible signs of pain, more relevant.

Avoidance of feared or painful situations has been shown to strengthen the underlying relational frames in patients with chronic pain leading to psychological rigidity (Hayes et al., 1999b). The focus of ACT is to help people to break the cycle of experiential avoidance in order to be more psychologically flexible and thus more able to adjust to their living their lives despite pain.

The assumption behind the application of ACT to CP can be considered to be that it is not merely the severity of pain or other symptoms in isolation that influences patient functioning, but also psychological relationships between these symptoms and behaviour

which need to be addressed within an ACT intervention. It is argued that most people with chronic pain have altered their life in some way to accommodate their pain, in some ways to avoid the experience of pain. But if avoidance of this nature causes suffering, which causes more pain, which causes more suffering, this endless cycle can draw people into a difficult battle.

Being able to see the difference between pain and suffering and developing an awareness of the impact of "response" to pain is argued to be at the heart of the ACT approach to chronic pain. Acceptance can be seen as the act by which you allow yourself to willingly engage your pain (Hayes et al., 1999). ACT seeks to improve functioning for people with CP by modifying the impact of pain and other symptoms through acceptance and mindfulness methods.

1.12.2. The model of change underlying ACT

Psychological Flexibility

Psychological Flexibility is defined in part as the "ability to act effectively in accordance with personal values and goals in the presence of potentially interfering thoughts and feelings" (Hayes et al., 2006).

There are six core processes in the ACT model of change that promote psychological flexibility and these are illustrated in the ACT hexagonal model of change (see Figure 1). Each core process occupies one point in this diamond shaped model and every one of these core processes represents a healthy psychological skill (Hayes et al., 2006).
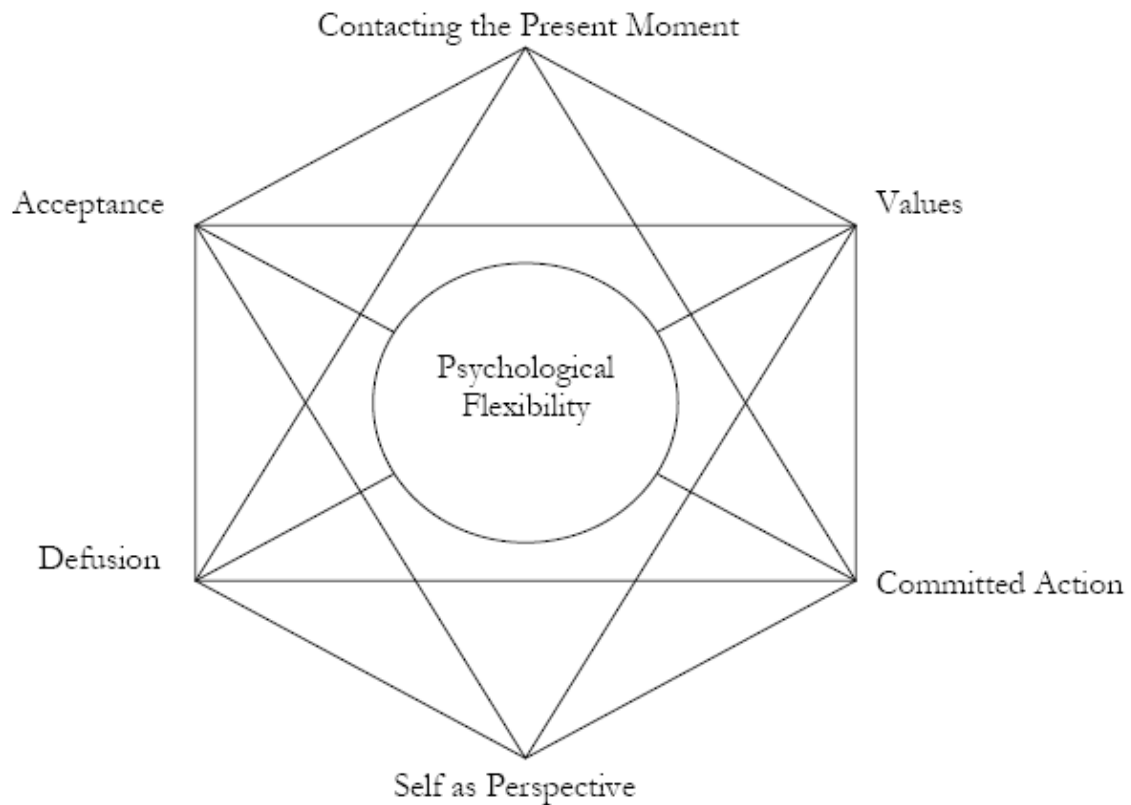
Figure 1: The ACT hexagonal model of change (Hayes et al., 2006).

The six core processes in the ACT hexagonal model of change, and techniques used to address them will be briefly described below.

Acceptance

Acceptance as a core construct and process of ACT means that one is fully and truly connected to what appears as a life event in any given moment without judgment and resistance (Hayes & Strosahl, 2010). It does not mean tolerance or resignation, but rather involvement of an open mind in the life experience as it appears. In the treatment of CP, patients learn how to experience and accept intense feelings about their suffering and somatic sensations of their pain without judgment or fear or harm (Robinson et al., 2004).

Defusion

According to the ACT model, the struggle with pain is seen as a form of *non-acceptance,* and the intensity of suffering depends on the extent of the clients *fusion* with thoughts and feelings associated with pain (Hayes & Strosahl, 2010). *Fusion* is the extent to which the client believes the pain-related thoughts e.g. "I can't do anything useful or enjoyable

because of my pain" and "I have to get rid of my pain before I get on with my life". The aim of ACT is to help the client to develop greater psychological flexibility in the presence of thoughts feelings and behaviours associated with pain. Through the process of cognitive *defusion,* clients are encouraged to not act upon their thoughts and feelings and to realise that are able to learn to observe and separate themselves from their thoughts. Cognitive defusion does not mean to counter, negate or deny their experiences of or thoughts about pain. Rather, defusion is an acquired skill enabling them to observe thoughts as they come without judging or paying attention to them (Dahl & Lundgren, 2006). It involves looking at their thoughts instead of looking from them (Hayes et al., 2003). Defusion does not eliminate bodily pain, but it may help to eliminate the suffering the client is experiencing (Dahl & Lundgren, 2006).

Self as Perspective

This is the position from which one observes their actions. Clients are encouraged to observe themselves as somewhat independent from the thoughts and feelings that arise in their minds, thus allowing them to better able to defuse from or not identify with harmful thoughts or feelings (Dahl & Lundgren, 2006). When this is maintained, it is believed that this can support a person to make more valued choices in life.

Values

Values refer to what gives meaning to individual's lives. They represent what people want their lives to be about and are directions, not outcomes or goals (Hayes & Smith, 2005). Clients with CP are encouraged to do what they value and to make a choice between what they value most in their lives and their desire to control their pain. The aim is to empower clients to live a meaningful life and to help them to not allow their pain to occupy all their attention (Dahl & Lundgren, 2006). This is done through the use of mindfulness techniques, metaphors and experiential processes.

Committed Action

Committed action means to choose a goal and then follow the path to reach that goal. For clients with CP, ACT suggests that clients follow the goals in the presence of the pain. Clients are encouraged to mindfully accept the experience of pain using behavioural strategies to control the pain if necessary, and then to continue their committed action based on their

values, instead of giving into the pain (Dahl & Lundgren, 2006). A committed action intervention during therapy can help a client to get "their lives back on track" (Bach & Moran, 2008), therefore leading to a more satisfying way of life.

Contact with the Present Moment

This means to stay in the experience of the "here and now" (Harris, 2009). This can be seen as a key component underlying the ACT approach, to be able to develop the ability observe what is occurring in the environment in any given moment and how to identify what is present, for example their pain, without evaluating or judging (Hayes & Strosahl, 2010). Mindfulness training is used as a strategy to help clients with CP achieve this neutral awareness of the present moment.

The ACT hexagonal model of change can be divided into two parts (see Figure 2). The first is *Acceptance and Mindfulness* and the second is *commitment.* The two units together form together the processes of ACT. Acceptance is specified as the willingness to accept the situation for what it is. Mindfulness is referred to as being aware of the situation, living in it and not letting the thoughts you have influence how you perceive a situation. Finally commitment is characterised as the ability to let your own values guide your actions, not your thoughts, (A-Tjak & De Groot, 2008).
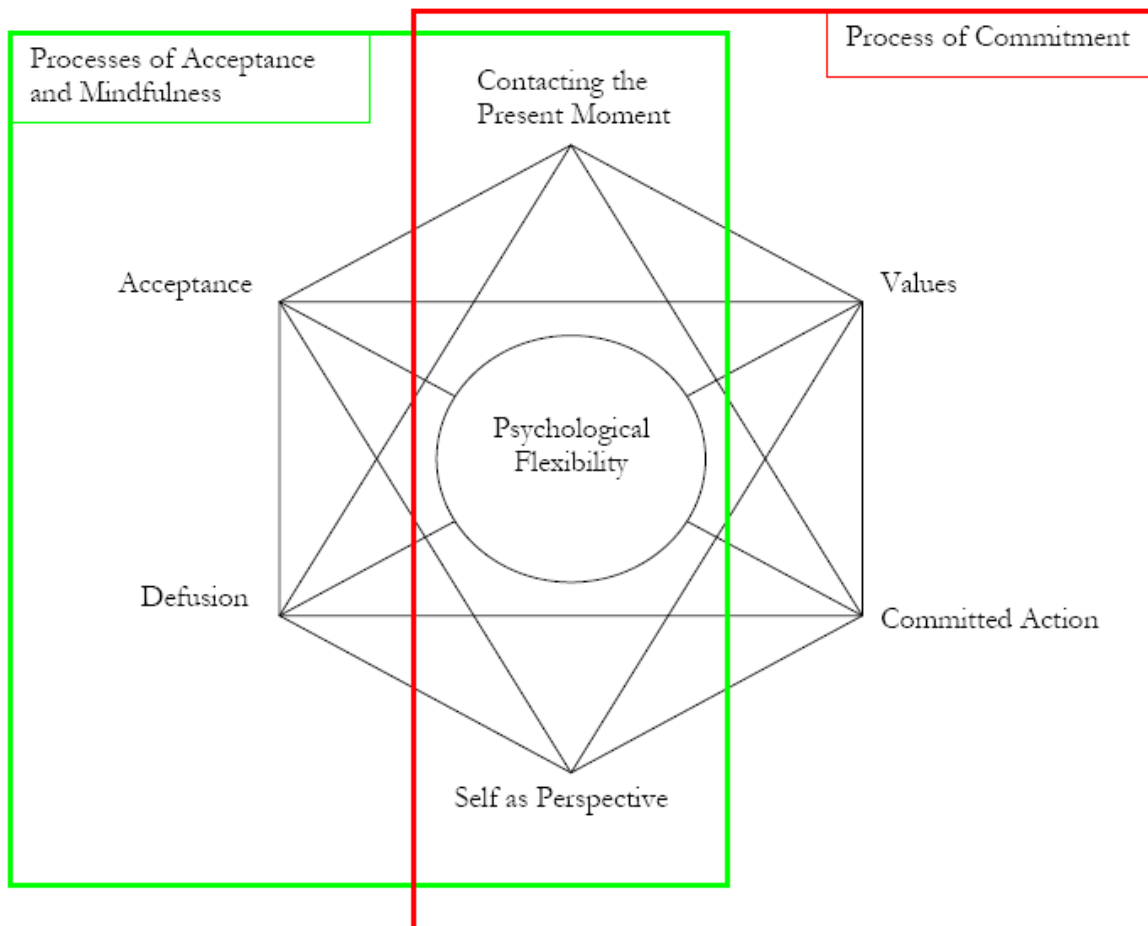
Figure 2: The ACT hexagonal model of change divided into two parts (Hayes & Strosahl, 2010).

1.13. Empirical Support for ACT

A growing number of studies support the effectiveness of ACT in a diverse range of clinical populations including CP. A series of early treatment outcome studies found that ACT programme participants, with various self-reported CP conditions demonstrated significant changes in pain intensity, medical symptoms, psychological symptoms, coping ability and inhibition of daily activity by pain, most of which were superior to standard medical care alone (Dahl, Wilson, & Nilsson, 2004; McCracken et al., 2005b; Vowles et al., 2007). Furthermore, following an ACT model has been found to facilitate significant improvements in the mental as well as the physical aspects of CP (Sephton et al., 2007).

Some studies have examined the effectiveness of ACT by using one or two core processes of ACT in the treatment of CP, such as acceptance (McCracken, 1998; McCracken & Eccleston, 2003), value-based action, (Vowles & McCracken, 2008; Branstetter-Rost, Cushing, & Douleh, 2009) and psychological flexibility (McCracken & Velleman, 2010). Hayes et al. (2006) carried out a meta-analysis including 32 correlation studies. Three studies from the analysis found that psychological flexibility was linked to lower rates of psychological disorder and in comparison to alternative treatments, cognitive defusion techniques were found to be more effective in reducing discomfort and believability of negative self-thoughts.

A Swedish preliminary randomised trial evaluated the effectiveness of the ACT intervention for CP compared to medical treatment as usual (MTAU), (Dahl et al., 2004). The purpose of the trial was to reduce sick leave and medical utilisation of the participants (N=19). The ACT group was provided with additional training in four ACT processes: acceptance, cognitive defusion, values, self as perspective. Results showed significantly lower use of sick leave and fewer medical treatments than the MTAU group only after four weeks treatment and six months follow up.

Johnston, Foster, Shennan, Starkey and Johnson (2010) carried out a randomised two group study design to evaluate the effectiveness of the ACT based self-help book. The researchers concluded that the clients who used the self-help book demonstrated decreased anxiety and improvement in quality of life. Large effect sizes were found in acceptance, quality of life, satisfaction with life, and the values attributed to illness. A medium effect size was shown in reports of the participants overall reduced pain ratings (Johnston et al., 2010). However, further study of the *influence* of the processes affecting the behaviour change in the self-management of people with CP has been recommended (Johnston et al., 2010).

1.14. How does ACT compare to other therapies for chronic pain?

Other studies have compared ACT used for CP with other therapies including CBT (Vowles et al., 2007, 2009). Vowles, Wetherall, and Sorrell (2009) evaluated the effectiveness of ACT in

two preliminary trials of an outpatient group based intervention. Their research supported the feasibility of ACT and suggested that effectiveness rates compare favourably to CBT.

Wetherell et al. (2011) carried out the largest randomised controlled trial of a group based ACT intervention for CP in a treatment seeking sample. They found that when added to usual care, both ACT and CBT can improve pain interference, depression and pain related anxiety in patients with CP. Notably; CBT was found to be more credible and had higher expectations for improvements at the outset. However, ACT was rated more satisfactory than was CBT and therefore participants were found more likely to remain engaged in a treatment that they found enjoyable.

Improvements were maintained over a 6 month follow up period which is consistent with other investigations of acceptance based pain treatments that have examined maintenance of gains over 3-7 months (Vowles & McCracken, 2008; Wicksell, Olsson, Bond, & Melin, 2008). Therefore these findings suggest that a brief course of acceptance based treatment can have a lasting impact on chronic pain.

In a meta-analysis carried out by Veehof, Oskam, Schreurs, and Bohlmeijer (2011) looking at acceptance based interventions for CP, it was highlighted that acceptance based therapies so far have small to medium effects on physical and mental health in CP patients that are comparable to CBT. They noted that a promising new direction is therapies that integrate ACT with behavioural therapy (Vowles et al., 2009).

Although CBT has proven to be an important contribution in CP management, there is much that is unclear with regards to the process of change (Morley, 2004). More insight into the processes underlying the ability for individuals to use an ACT approach to pain management is needed to help clinicians to tailor interventions accordingly.

1.14.1.   Empirical considerations

Review of ACT intervention studies have identified some shortcomings, including small sample sizes, lack of medical and psychiatric diagnostic evaluations, non-manualised treatment components and no control for possible therapist effects (Ost, 2008).

Many authors question the ability of traditional psychological self-report measures to capture changes ascribed to acceptance and this may contribute to some ambiguity in reported findings. One of the challenges identified in the literature is that there are no clear outcome measures to determine success in the treatment of CP (Connor-Smith, Compas, Wadsworth, Thomsen, and Saltzman, 2000). Some authors have argued that the wide variety of measures used makes integration of the research of the treatment effectiveness a challenging task (Turk & Okifuji, 2002).

Ost (2008) carried out a systematic review and meta-analysis of third wave behavioural therapies including ACT. According to these studies: 1) ACT is better than treatment as usual conditions (Hayes et al., 2006; Ost, 2008; Powers, Sive Vording, & Emmelkamp, 2009). However, more evidence is needed in order to determine if ACT is better than established treatments for chronic pain (Levine & Hayes, 2009; Powers et al., 2009).

Levin & Hayes (2009) have argued that all future studies of ACT must fully integrate quantitative and qualitative data and the exclusive use of self-report inventories may expose trials to significant response bias. Furthermore no studies have explored *qualitatively*, the experience of attending acceptance based pain management programmes to the author's knowledge to date.

Wetherell et al. (2011), suggest that ACT and CBT are both efficacious treatments for CP however future research should focus on the mechanisms underlying the treatment effects. Research until now has focused on the measurable aspects of mindfulness and ACT, rather than the subjective experience for users, (Wetherell et al., 2011).

1.15. Luton & Dunstable Hospital ACT programme for chronic pain

An outpatient Pain Management Programme has been running at the Luton & Dunstable Hospital since August 1999, based on recommendations by the British Psychological Society (1997). The programme was originally delivered as a Cognitive Behavioural PMP intervention and was managed and delivered by a multi-disciplinary team of healthcare professionals with experience in pain management rehabilitation, comprising of; Consultant

Clinical Psychologist, Consultant Anaesthetist, Clinical Nurse Specialist, Occupational Therapist and Physiotherapist.

Over the past three years the programme has been adapted and the approach has incorporated the ACT model of change to help individuals with CP (Hayes & Strosahl, 2010). Within this framework, learning to live as best as possible with pain is the overarching desirable treatment outcome. Ownership of pain and personal choice to live a valued life despite pain are key strategies utilised within the programme (Dahl & Lundgren, 2006). Clients are encouraged to learn new ways to relate to pain and are taught to modify their routines and improve their functioning. The emphasis is to increase client's sense of self efficacy and control and reduce the feelings of helplessness and hopelessness as is often the experience of a person suffering with CP (Caudill, 2002).

The goal of treatment is not necessarily to improve the pain, but rather to increase psychological flexibility and enhance adjustment to pain, and reduce the negative impact of the suffering that arises from behavioural avoidance of pain. This is in contrast to "functional restoration" programmes which tend to focus on physical conditioning and management of symptoms (Stanos & Houle, 2006).

The desired outcomes for the programme can be seen in Figure 3. The cycle of acceptance and commitment illustrates the key processes which are hoped that clients attending the programme will be able to achieve and aspire towards.

Values
(The life direction I choose; what I want my life to be about)

Commitment & Flexibility
(Choosing to take action consistent with my values, carrying my passengers with me; taking heed of them when it works to do so; thinking and living more flexibly)

Acceptance and Being Present
(Embracing my experience in the here and now fully and without resistance. Accepting my pain and living in the present)

The Acceptance & Commitment Cycle

Growth & Contacted Barriers
(Moving forward in the direction of my values without avoiding the pain and discovering new pleasures and abilities as I watch my life grow)

Mindfulness & De-fusion
(Non-judgementally observing my pain and its consequences. Seeing my thoughts as thoughts, my feelings as feelings, untangling "me" from them)

Figure 3: Desired outcomes for the Luton & Dunstable ACT programme for CP[4]

In contrast to the acceptance and commitment cycle, the control and avoidance cycle, Figure 4, illustrates the struggles that clients with CP often face. The negative downward spiral often results in a vicious cycle and the clients suffering endures.

Control & Avoidance
(Looking for immediate "solutions" proposed by my mind, often with the agenda of controlling or avoiding my pain and the associated thoughts, feelings and sensations; making deals with my

Life Restriction & Loss
(My life shrinks; I lose vitality and contact with my values and become more preoccupied with my pain)

Words, Words, Words
(Endless fearful predictions and evaluations about my problems; I lose contact with the present moment and start living in my head)

The Control and Avoidance Cycle

Relief and Struggle
(Temporary relief and the illusion that control and avoidance may work soon and the constant desire to get the solution soon gives way to "this isn't working" and the battle ensues and values are lost)

Entanglement
(Buying into my thoughts; being defined by my pain and the pain taking control)

Figure 4: The control and avoidance cycle which is often experienced by people with CP[5]

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[4] This diagram is adapted from Hayes and Smith (2005). Get out of your Mind and Into Your Life. The New Acceptance and Commitment Therapy; New Harbinger, Oakland, CA.

The Luton & Dunstable Hospital ACT programme for CP is suitable for people with pain of longer than 6 weeks duration that has not been resolved by medical intervention and meets the inclusion criteria (see Chapter 2 - Method). The programme is contracted by the hospital to provide intervention for people with chronic pain referred by hospital medical consultants, consultant clinical psychologists, specialist physiotherapists and specialist nurses. Referrals are either accepted or signposted to a more appropriate service, such as mental health services, drug and alcohol services or specialist inpatient pain management programmes.

After an initial assessment, the facilitators provide selected group members with an information package containing standard group contract and consent forms, guidelines about confidentiality, and rules about attendance, withdrawing, termination, and safety. Full session plans and an information folder are given to the participants upon attending the first group session.

The group based programme lasts for 3.5 hours per week for 8 consecutive weeks and clients are invited to a follow up approximately three months post programme. The size of the group has ranged from 12-18 group members dependent on referrals and taking into account drop outs. For details of the weekly session plans please refer to Appendix 1.

Meditation and mindfulness meditation are introduced to clients to facilitate acceptance during each session, as from an ACT perspective, mindfulness skills (i.e. the ability to be present in each moment in any activity) are considered to be a key to cognitive defusion (Walser & Pistorello, 2010).

Research has shown that flexibility and mobility are key elements to successful pain management (Egoscue & Gittines, 1998). Experiential exercises, reviews, homework and discussions are also part of each session. Moderate movement exercises taken from yoga and Tai Chi or simple stretching to promote increased blood flow through the body are also offered each week during the session.

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[5] This diagram is adapted from Hayes and Smith (2005). *Get out of your Mind and Into Your Life. The New Acceptance and Commitment Therapy*. Oakland, CA: New Harbinger.

Participants are also encouraged to speak up and contribute during the sessions and to share their experiences at the start and at the end of each group in order to promote group cohesiveness and facilitate clarity of the material covered (Corey, 2008).

1.16. Rationale for this Study

Outcome research shows that the majority of clients undertaking ACT programmes for CP make significant improvements, however an understanding of why and how this treatment approach works relies on generalisations and assumptions derived from other interventions and standardised self-report questionnaires. Research into client's experience of therapy has been gaining increasing importance over the last two decades (McLeod, 2001). Information from client's accounts of their experience is vital to our understanding and yet is overlooked in research (Paulson, Everall, & Stuart, 2001).

Paley & Lawton (2001) have raised concerns that in the current NHS climate, the focus on evidence-based practice is moving us towards a search for premature implementation of certain techniques, models or ways of working which seek to condense therapy into uniformity rather than exploring possible disparity. They further suggest that there is a need for more qualitative research that taps into the unique experiences of therapy for participants.

To the authors' knowledge, no study has qualitatively investigated the experience of attending an ACT programme for CP. Qualitative research aims to "understand and represent the experiences and actions of people as they encounter, engage and live through life situations" (Elliott et al., 1999) It therefore provides an appropriate alternative methodology through which to achieve this study's aim. Furthermore, a qualitative exploration of participants' experiences of change following a pain intervention based on ACT may add to specific understanding of what people perceive as useful, and to what they may or may not attribute change.

1.17. Aim

The aim of this study is to qualitatively evaluate the Luton & Dunstable Hospital ACT programme for CP. This will generate an understanding of the experience of attending an ACT programme for CP within an outpatient NHS setting. The study aims to also provide an insight into how this programme can influence treatment outcomes and further service development.

This qualitative service evaluation aims to explore in depth the participants' learning experiences with respect to the construct "acceptance". This also involves an exploration of the potential significance of acceptance in enabling them to better manage chronic pain psychologically, in order to lessen its impact on suffering. Finally, the experiences of the participants with the group setting of this intervention will also be explored.

The main exploratory questions for this study are as follows:

1) What was the motivation for clients undertaking the ACT programme for CP?
2) What have clients learnt from attending the ACT programme for CP?
3) What is the clients understanding of acceptance?
4) What were the challenges the clients faced whilst attending the ACT programme for CP?
5) What was the experience of attending a group based programme for CP?

CHAPTER 2 - METHOD

2.1. Overview

This study aims to gain an understanding of the experience of attending an ACT programme for Chronic Pain (CP) from the clients' perspective. The review of literature identified a gap in the research for qualitative studies investigating the experience of attending ACT pain programmes. Therefore it was decided that a qualitative approach would address this gap in the current literature and add to the exiting evidence base.

A rationale for the choice of method, recruitment and data collection strategy, as well as the analytic procedures which followed, are presented in this chapter.

2.2. Design

Given the aim of this study was to evaluate an established ACT programme for CP, a qualitative research approach was particularly suited to this study to help identify barriers and facilitators to change (Starks & Brown, 2007).

Qualitative research can be described as a formal process of inquiry, characterised by a flexible emerging design and providing an insight and understanding of the meaning of phenomena from the participant's perspective (Dempsey & Dempsey, 2000). Furthermore, Sandelowski and Barroso (2003) suggest that qualitative research findings can contain information about the subtleties and complexities of human responses to illness and its treatment. This could therefore be seen as essential to the construction of effective and developmentally and culturally sensitive interventions.

2.3. Epistemological Positioning

Methodology can be described as conducting research with reference to a set of principles, evolving from particular epistemological assumptions which guide decisions in several areas throughout the process. This following section will outline the perspective typically taken in the field of enquiry, followed by that of the current study.

2.3.1. Dominant traditional perspective – positivism and quantitative methods

The development of evidence-based practice in the NHS is based on a largely quantitative hierarchy of the quality of research evidence (Eccles & Mason, 2001). The NICE guidelines view meta-analyses of randomised controlled trials (RCTs) - group designs where participants are randomly allocated to the treatment of interest or a control group of no treatment or a placebo- as the "gold standard" (P. Richardson, 2003). Research designs relying on quantitative data and statistical generalisation are considered by their proponents to be 'scientific' (Robson, 2002), and to fit with the scientist-practitioner model within clinical psychology. This type of design employs the same methods and processes as the traditional medical model research paradigm – principally positivism - in studying both the natural and the social world (Kolakowski, 1972).

Positivism assumes that science quantitatively measures independent facts about a single apprehensible reality (Healy & Perry, 2000). It sees the goal of knowledge to describe objective experience by experimental observation and measurement. By eliminating confounding variables it formulates generalisable cause and effect laws.

2.3.2. The emergence of an alternative perspective – relativism and qualitative methods

Some researchers are of the opinion that the NHS research quality hierarchy has to date virtually ignored qualitative research, which has rejected positivism and its quantitative research rules in favour of 'Relativism' (Robson, 2002).

Despite receiving criticism and lack of priority in the NHS, qualitative research has grown in recent years, and when well conducted can be considered as "scientific" as quantitative (Nicolson, 1995). Its relativistic, constructivist ontology posits that there is no objective

reality since each of us experiences from our own point of view and therefore sees a different reality (Krauss, 2005). It criticises quantitative research for fuelling a "...fantasy of prediction and control" (Banister, Burman, Parker, & Tindall, 1994), arguing that this is misguided, particularly in relation to social phenomena. It may be argued that psychological research will always contain an interpretative component (Banister et al., 1994). No amount of rigour in experimentation, sophisticated statistical survey methods, or large-scale psychometric testing enables understanding of, for example, what it *feels* like to have a physical or emotional problem (Lewis, 1995).

Psychological therapies theory and research has traditionally operated in the positivist paradigm, for example CBT focuses on the treatment of behaviours associated with medical classifications e.g. Pain. However, the main agent of change in CBT is the subjective, interpreted world of the client, i.e. the cognitions behind the behaviours that are diagnosed as symptomatic (D. M. Clark, 1998).

Many qualitative researchers believe that the best way to understand any phenomenon is to view it in context, without which understanding of social phenomena is incomplete. They see all quantification as limited in nature, looking only at one small portion of a reality that cannot be split without losing the importance of the whole. Maxwell (2002) argues that knowledge is established through the meanings attached to the phenomenon; researchers interact with the subjects of study, cannot therefore be value free and objective, since enquiry changes both researcher and subject (Coll & Chapman, 2000; Cousins, 2002; Krauss, 2005), explicitly placing the researcher within the research process. Therefore researchers are expected to include personal connections or judgements which may have impacted on the research process (Elliott et al., 1999).

2.4. Why a Qualitative Approach?

Whilst accepting and acknowledging the importance of a positivist stance, a qualitative methodology allows for consideration of the complexities of thoughts and meanings, and an exploration of the experience of applying an ACT model of change to CP. This research also

has an exploratory purpose, to seek new insights, ideas and hypotheses for future research within this field and to inform clinical practice in pain management settings.

Adopting a qualitative approach to evaluate the experience of attending an ACT programme for CP, therefore, provides a more flexible and fluid approach to understanding people's behaviour and the understanding and interpretation that they give to their behaviours (Rice & Ezzy, 2000). Furthermore, this type of research enables access to areas not amenable to quantitative research (Pope & Mayes, 1995), such as the participants own perspectives on what is meaningful to them.

2.5.   Rationale for Semi-Structured Interviews

Qualitative data for this study was collected through use of semi-structured interviews with each participant, ideal for exploration of issues that may be too complex to investigate through quantitative measures (Burman, 1994). Semi-structured interviewing is an open and flexible research tool, combining structured and open-ended questions, encouraging a collaborative approach helpful for people experiencing reduced concentration levels.

2.6.   Reasons for Using Thematic Analysis

Thematic analysis is used as a coherent way of organising or reading interview material in relation to specific questions. Often seen simply as a tool to use across different methods (Boyatzis, 1998; Ryan & Bernard, 2000), it has also been considered a method in its own right (Braun & Clarke, 2006). One advantage is its flexibility and as a research tool it can potentially provide a rich and detailed account of data (Braun & Clarke, 2006). Unlike other methods, it is essentially independent of theory and epistemology, and compatible with both essentialist and constructionist paradigms. It was therefore selected as the most appropriate method for analysing the semi-structured interview data for this study.

The flexibility of this research analysis method has attracted an "anything goes critique" in some cases (Antaki, Billig, Edwards, & Potter, 2002). This research therefore used the clear procedures outlined by Braun and Clarke (2006).

2.7.   Other Qualitative Methods

Qualitative methods such as Interpretive Phenomenological Analysis (IPA) or Grounded Theory might have been appropriate for this type of exploratory study. IPA is attached to a phenomenological epistemology (Smith & Osborn, 2003) and takes an idiographic approach (McLeod, 2001), focusing on meanings ascribed by individuals. As such, this is an inductive approach, not testing hypotheses, and avoiding prior assumptions. Grounded theory is also inductive, with a theory constructed from the data (Charmaz, 2006).

IPA was not considered an ideal approach for analysis in the current study because it comes with a specific interpretative, hermeneutic and idiographic tradition attached to it (Smith, 2004), whereas thematic analysis is an a- theoretical approach (Braun & Clarke, 2006; Boyatzis, 1998) and can be used flexibly within different frameworks.

The position taken in this study is an evaluation of a service within the realms of a contextualised method. This is characterised by approaches such as critical realism, and lies between essentialism and constructionism (Braun & Clarke, 2006). This position acknowledges the ways in which "individuals make meaning of their experience, and in turn, the way broader and social context impinges on those meanings, while retaining focus on the material and other limits of reality, (Braun & Clarke, 2006). This is consistent with thematic analysis as it aims to extract the thematic content which emerges naturally from the data (Burr, 2003).

2.8.   Study Development

At the planning phase of this research the researcher was in liaison with the Consultant Clinical Psychologist who was the clinical lead for the ACT programme for CP at the Luton & Dunstable Hospital. The PMP is continually evaluated from quantitative analysis of outcome data. It was decided that a qualitative design and analysis would therefore add to this data

and was fitting to the initial idea of the exploration of the subjective experience of the clients attending the ACT programme.

2.9. Interview Design

Semi-structured interview is considered the exemplary qualitative method, offering a focused yet flexible form of data collection (Smith & Osborn, 2003). An interview schedule was drafted by the researcher and then reviewed by the clinical team. The final schedule (see Appendix 2) aimed to elicit an understanding of the motivation for attending the ACT programme, the learning outcomes, any aspects considered particularly helpful or unhelpful and the impact of a group based intervention.

2.10. Ethical Issues

Ethical approval for this study was granted by the Hertfordshire Research Ethics Committee and Luton & Dunstable Hospital Research Ethics Department. Relevant documentation is provided in Appendices 3 and 4. The research is in accordance with the British Psychological Society's Code of Conduct (2004), Ethical Principles and Guidelines for conducting research using human participants and the Good Practice Guidelines for the conduct of psychological research within the NHS (The British Psychological Society, 2004).The study initially sought approval for a mixed method design incorporating both qualitative and quantitative evaluation of the programme, however it was decided to pursue the qualitative evaluation of the programme for this study as the quantitative outcome measures were limited and incomplete.

2.10.1. Informed consent

Potential participants were initially sent a letter of invitation from the researcher and a written information sheet about the study (see Appendix 5). Participants were also sent an opt-in form (see Appendix 6) to return to indicate their interest in participating in the study. The participation information sheet also contained contact details of the chief researcher

and potential participants were invited to contact the researcher to find out further details about the study if required. The written information sheet provided clearly stated that participation was voluntary and the decision to participate would not affect the health care provided via the service.

All the participants who showed an interest to be interviewed, (having returned the opt-in form) were invited to participate in the study. Prior to carrying out the interview the researcher obtained written informed consent from the participants (see Appendix 7) in person. All participants were given time to talk about the risks and benefits of taking part in the study and the researcher reinforced that they had the right to withdraw from the study at any time. All participants were informed that a transcription service would be used to transcribe the recorded interviews, and participants were aware that the recordings would not be anonymised, but that the final transcripts would be.

2.10.2. Confidentiality

Participants were made aware that any data collected would be kept confidential, no demographic information would be taken off site, audio-recordings would be password protected and subsequent transcriptions would have any potentially identifying information removed. They were also made aware that the researcher knew only their names and contact details and had no access to their records and no knowledge of their histories. Participants were informed that any transcription services used would sign confidentiality agreements (see Appendix 8). Participants were made aware that research supervisors would have access to anonymous transcripts in order to help with the analysis. The limits of confidentiality were also discussed in person prior to receiving informed written consent.

2.10.3. Distress

The research methods adopted in this study was designed to produce minimal risks of harm to participants. Research suggests that participants find the process of reflecting on their experiences as therapeutic (Birch & Miller, 2000), however, the researcher is aware that CP is a distressing condition, and enquiries about CP and the ACT programme could have led to participants becoming distressed during the interviews.

The participants were reminded verbally and by written communication that they were free to withdraw and stop the interview at any time. Furthermore the researcher ensured that a member of staff from the multi disciplinary team involved in the ACT programme would be available for participants to meet with following the interview, if required. Support from staff at the interview site was therefore negotiated prior to the interviews being carried out.

2.10.4. Further considerations

It was anticipated that the individual interviews would last approximately one hour. For the participants who were experiencing CP, comfort was taken into consideration as it was considered a long time to be sitting in pain. Participants were therefore encouraged to use the interview room to stretch and stand up during the interview in order to facilitate a more comfortable experience of being interviewed.

2.11. Procedure and Data Collection

2.11.1. Context of the service

The ACT programme for CP has been running at the Luton & Dunstable Hospital since September 2010. The group runs on a rolling basis three times per annum for 8 consecutive weeks.

Originally the programme was based on the INPUT programme, developed by Michael Nicholas (1990) and Chris Main (2000) and was a cognitive behavioural approach to pain management, based on recommendations by the British Pain Society (1997). The following components supported by written materials were covered: education about pain, stress management, problem-solving, assertiveness, sleep, hygiene, coping strategies, employment issues and response prevention.

The ACT programme has since integrated acceptance and commitment based strategies within the original programme. Clients are introduced to mindfulness based meditative relaxation alongside a structured ACT schedule during the 3.5hr session every week. The content of the weekly sessions is based on manuals of application of ACT for CP sufferers, (Hayes et al., 1999b; Dahl & Lundgren, 2006).

Following recommendations by the British Psychological Society (1997), the ACT programme for CP has been run by a multi-disciplinary team of clinicians with experience in pain management rehabilitation, comprising consultant clinical psychologist, assistant psychologist, clinical nurse specialist, occupational therapist. The maximum capacity for the group is 18 clients. Inclusion and exclusion criteria will be explained further in the participants section.

2.11.2. Participants

The participants for this study had all attended the Luton and Dunstable ACT programme for CP. They had either been referred to the service via, consultant clinical psychologists or other health care professionals. In order to attend the ACT programme for CP the following inclusion and exclusion criteria is considered.

a) **Inclusion Criteria (to be met in full):**
- The pain has been fully investigated and treated and there are no further surgical or medical investigations or treatments indicated or planned.
- CP of at least 6 months duration, not associated with progressive disorder
- One or more of the following:
  - Reduced sense of control over life/loss of confidence
  - Reduced quality of life
  - Reduced fitness and activity levels
  - Distressed by pain
  - Sleep disturbance
  - Inappropriate use of analgesic medication
- Pain is the primary concern for the individual at this time
- English speaking

b) **Exclusion Criteria (indicating further investigation or onward referral):**
- Assessed to have acute signs or symptoms
- Assessed to have current or past history of significant psychiatric problems
- Assessed to be impaired by significant levels of depression, anxiety or anger, learning disability or other difficulty, which would affect ability to participate in an educational based self-management group

- Assessed to have alcoholism or dependency upon illegal drugs
- Assessed to have a significant medical condition that would compromise ability to participate in the programme
- Unable to attend the full programme

As the study recruited participants who has already been assessed to attend the programme and had subsequently attended the programme itself, all the participants in the study had met the inclusion criteria outlined above.

2.11.3.   Sampling method

Participants were selected using a purposive sampling method (Patton, 1990). Purposive sampling methods are more typically employed in qualitative research to obtain a homogenous sample which captures the range and diversity present within the target population. This is in contrast to quantitative research that employs a random sampling method to ensure that a representative sample is obtained from which findings may be generalised to the target population.

Chambless et al. (1996) propose that 9 case studies are required to provide sufficient 'evidence' for the efficacy of the intervention, however to allow for a reasonable dropout rate, a sample of 12-15 was aimed for.

The researcher initially selected a sample of twenty potential participants from a pool of approximately 47 participants who had already completed the ACT programme for CP. Participant selection was collaboratively identified with the consultant clinical psychologist co-ordinating the programme.

The 20 potential participants were all sent an information sheet about the study (Appendix 5) and an opt-in reply slip (Appendix 6) to return to the researcher if they were interested in being contacted to participate in the study. Out of a potential 20 participants, 13 participants returned the opt-in reply slip, expressing an interest in participating in the research. Of the 13 participants, 12 were finally recruited and were invited to be interviewed about their experiences of attending the ACT programme for CP. One potential

participant declined participation after the interview had been arranged as she explained she had later decided it was not possible for her to attend.

2.11.4. Flow chart

The following flow chart illustrates the procedure of recruiting the final sample of 12 participants.

```
┌──────────────────────────────────┐
│              47                   │
│  potential participants who have  │
│      attended the programme       │
└──────────────────────────────────┘
                 │
                 ▼
┌──────────────────────────────────┐
│              20                   │
│  purposive participants identified│
│      and invited to participate   │
└──────────────────────────────────┘
                 │
                 ▼
┌──────────────────────────────────┐
│              13                   │
│   interested potential            │
│   participants returned slips     │
└──────────────────────────────────┘
                 │
                 ▼
┌──────────────────────────────────┐
│               1                   │
│   participant decided not to      │
│      attend when contacted        │
└──────────────────────────────────┘
                 │
                 ▼
┌──────────────────────────────────┐
│              12                   │
│  Final sample of participants     │
│      invited to interview         │
└──────────────────────────────────┘
```
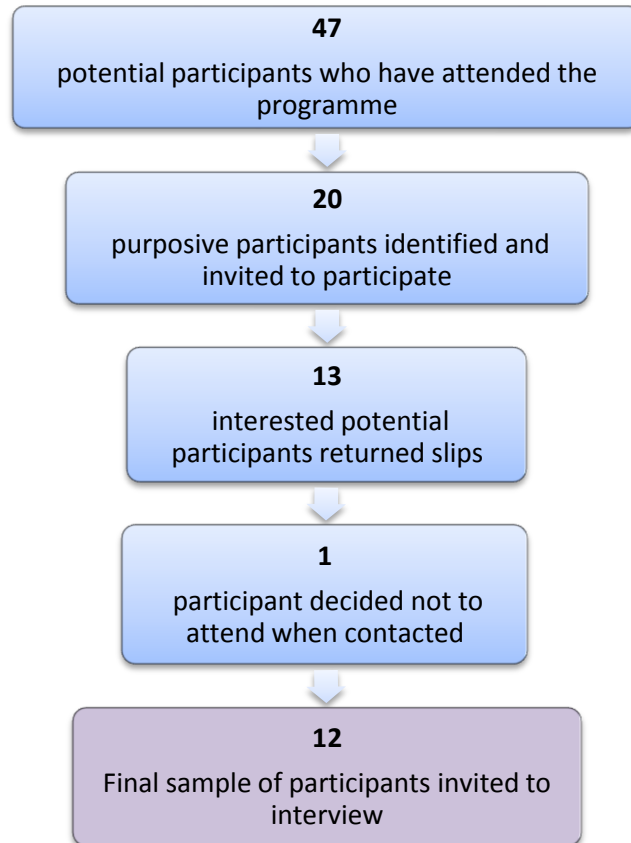
2.11.5. Sample of participants information

Certain demographic information for the final 12 participants who were interviewed for the study was collated and for the purposes of anonymity and confidentiality, alias names were used to protect the identity of the participants (See Table 1).

Table 1: Table of Participant Information

Name	Gender	Age	Ethnicity	Site of Pain	Date of Programme	No. of sessions attended
1. Linda	F	45	White/British	Back	Jan 2011	8/8
2. Sharon	F	40	White/British	Back/neck	Jan 2011	7/8
3. Jamie	M	39	White/British	Back	May 2011	8/8
4. Paul	M	48	White/British	Back/neck	May 2011	8/8
5. Annalie	F	42	White/French	Back/neck/legs	Jan 2011	7/8
6. Dave	M	51	White/British	Back/neck/legs	Jan 2011	7/8
7. Tracy	F	60	White/British	Back	Sept 2011	8/8
8. Sandra	F	56	White/British	Head	Sept 2011	7/8
9. Siobhan	F	48	White/British	Back/neck	Jan 2012	6/8
10. Ann	F	60	White/British	Head/neck/Shoulders	Jan 2012	8/8
11. Maria	F	57	Caribbean/British	Back/neck	Jan 2012	7/8
12. Jenny	F	55	White/British	Back	Jan 2012	6/8

2.11.6. Interviews

Interviews were conducted in the same outpatient department the participants attended for assessment to attend the ACT programme for CP. This helped to reduce any unnecessary anxiety for participants of travelling to an unfamiliar location. Participants were asked to allow for up to 90 minutes for the interviews. The first 10-15 minutes were spent to ensure the participants were fully informed about the study and had the opportunity to raise any concerns and ask questions. At this stage participants were given the opportunity to take more time to consider whether they wanted to participate and the confidential nature of the interview was explained. After they had agreed to participate and asked any questions, participants were asked to sign an informed consent form (see Appendix 6).

The interviews were conducted using a semi-structured schedule (Appendix 2). This was used flexibly in order to ensure an informal, conversational atmosphere that would facilitate detailed descriptions of participant's experiences of attending the ACT programme and allow exploration of areas of interest. The interview schedule was reviewed after each interview and refined where necessary. Interviews lasted between 35 and 60 minutes and were recorded using a digital voice recorder. At the end of the interview the participants were given a book, *The Happiness Trap,* by Russ Harris, as a token of thanks for participating in the research. This is a recommended text as per the ACT programme for CP.

Following each interview, a reflective diary was used to record reflections on the interview and any issues around content and process, aimed at increasing reflexivity.

Each interview was audio-taped and notes made. A transcription service was used due to time limitations but accuracy was verified by the researcher listening to tapes whilst examining transcripts and checking notes to avoid loss of context.

2.12. Data Analysis

As mentioned earlier in this chapter, thematic analysis was the method chosen for analysing the qualitative data in this study. Thematic analysis is a method for identifying, analysing and reporting patterns (themes) within data (Braun & Clarke, 2006). However, it often goes further than this, and interprets various aspects of the research topic (Boyatzis, 1998). Although thematic analysis is a widely used method, there is no clear agreement about what thematic analysis is and how you go about doing it (Attride-Stirling, 2001). Some authors have argued that it can be seen as a poorly branded method, in that it does not appear to exist as a "named" analysis in the same way as other methods such as narrative analysis and grounded theory. However, it may be argued that a lot of analysis is thematic, but is often claimed as something else (Meehan, Vermeer, & Windsor, 2000).

If it is unclear how a researcher went about analysing the data, or what assumptions informed their analysis, it is difficult to evaluate research and to compare or synthesise it with other studies and it could possibly impede other researchers carrying out related

projects in the future (Attride-Stirling, 2001). Therefore, clarity around the process and practice of this method is essential, and it is hoped that the next section will lead to more clarity around the process of the analysis undertaken for this study.

Researchers have traditionally tended to omit the "how" question from accounts of their analyses (Lee & Fielding, 1996) and some authors suggest that there is greater need for disclosure in qualitative analysis so that existing techniques may be shared and improved, and new and better tools may be developed (Attride-Stirling, 2001).

2.13. Thematic Analysis Procedure

The data analysis for this study initially followed the first three stages of a systematic procedure outlined by Braun and Clarke, 2006. In addition, the thematic analysis was aided by *thematic networks,* an analytic tool used to organise a thematic analysis of qualitative data (Attride-Stirling, 2001).

2.13.1. Stage One: familiarisation with the data

The first stage of analysis consisted of reading and re-reading the twelve interview transcripts. Both manifest and latent levels of data were coded on a paragraph by paragraph basis (for an example transcript see Appendix 9). Manifest levels of data refer to what was observable and stated by the participant, and latent levels of data refer to what was implicit (non-stated) content in the data.

An inductive coding method was used; therefore the themes arising from the data were strongly linked to the raw data, and were not heavily influenced by existing theories or research. Inductive coding was considered more suitable for the analysis of the data in this study in order to better explore the experience of participants, as this is an under-researched area.

2.13.2. Stage Two: generating initial codes

The second stage of the thematic analysis consisted of writing the initial codes from each paragraph in the transcripts. Codes refer to the "most basic segment, or element, of the raw

data or information that can be assessed in a meaningful way regarding the phenomenon"
(Boyatzis, 1998). The process of coding involves organising the data into meaningful groups
(Tuckett, 2005), however, this is different to the *themes* which are the broader units of
analysis.

At this stage, it became apparent that some of the codes had a degree of overlap and
merged to form overarching themes. These were typed with examples alongside them and
potential themes were identified. This stage involved a process of encapsulating the rich
content in the data, whilst identifiable examples that embodied the shared meaning of a
broader theme. This stage also highlighted divergent content and inconsistencies within and
across the data, which could be split into sub-themes.

2.13.3. Stage Three: searching for themes

The third stage involved sorting the codes into potential themes and collating all the
relevant coded data extracts within the identified themes. Visual representations were used
to allow the researcher to start to analyse the codes and consider how the codes may
combine to form an overarching theme. Thematic maps were drawn out in order to
negotiate the relationships between codes, which were then reconsidered and revised in
order to create a more cohesive understanding of the emerging theme. Different levels of
themes were identified at this stage, and this allowed for the creation of sub themes and
overarching themes. Data that did not appear to fit with the emerging themes were put
under the bracket of miscellaneous themes at this stage.

During this stage, the process of thematic networks was followed in order to structure and
review the themes generated from the data. This approach also provided an illustrative tool
in the interpretation of the text (Attride-Stirling, 2001).

2.14. Thematic Networks

Thematic analyses seek to unearth the themes salient in a text at different levels, and
thematic networks aim to facilitate the structuring and depiction of these themes (Attride-
Stirling, 2001). A more thorough explanation of this process will be outlined in the results

chapter of this study whereby the researcher will outline the step by step procedure and present the results at each stage of the process.

Essentially, thematic networks systematise the extraction of:

1) Lowest-order premises evident in the text (**Basic themes**)
2) Categories of basic themes grouped together to summarise more abstract principles (**Organising themes**)
3) Super-ordinate themes encapsulating the principle metaphors in the text as a whole (**Global themes**).

These are then represented as web-like maps depicting the salient themes at each of the three levels, and illustrating the relationships between them. This is a widely used procedure in qualitative analysis and parallels are easily found in grounded theory for example (Strauss & Corbin, 1990). Importantly the networks are only an illustrative tool in the analysis, not the analysis itself.

2.15. Providing Credibility Checks

Barker, Pistrang, and Elliott (2002), suggest that traditional psychometric criteria for evaluating reliability and validity in quantitative research may not be easily transferable to qualitative methods.

Employing an interpretive approach to data is particularly prone to subjectivity, therefore a number of safeguards were used to maximise trustworthiness and consider issues of quality and rigour (Elliot et al., 1999; Yardley, 2008). These were: data analysis checks by an independent assessor, transparency of thematic analysis making it verifiable, and "reflexive methodological accounting" (Altheide & Johnson, 1994) to make explicit the theoretical orientations and preconceptions of the researcher.

Some authors have stated that member checking may influence the researcher's interpretation of the interview (Whittington & Burns, 2005; Alexander & Clare, 2004). However, others have argued that it is a useful measure of credibility, which increases face validity within qualitative research (Barker et al., 2002; Elliott et al., 1999; Smith et al.,

2000). The value of qualitative research lies in its exploratory and explanatory power, which the researcher recognises is unachievable without rigour at all stages of the research process; from design, to field work to analysis (Attride-Stirling, 2001).

CHAPTER 3 - RESULTS

3.1. Overview

This chapter presents the results of the thematic analysis and thematic network analysis of the textual data from the 12 semi-structured interviews carried out. The first section of this chapter will consider the initial stage of the thematic network analysis; the process of generating themes from codes. The second section of the analysis and the generation of the organising themes will then be presented. Finally the global themes and overall thematic maps will be illustrated and outlined.

3.2. Thematic Network Analysis Stage 1: From Codes to Themes

The first step taken in the thematic network analysis of the data was to reduce the codes generated through the thematic analysis into themes as recommended by Attride-Stirling (2001). This was done on the basis of the guiding research questions and the salient issues that arose in the texts themselves.

The process of abstracting the themes involved reading and re-reading the text segments within the context of the codes under which they have been classified, which enabled the researcher to identify underlying patterns and structures.

Themes were then refined so that they were i) specific enough to be discrete (non-repetitive) and ii) broad enough to encapsulate a set of ideas contained in text segments. The researcher noted that themes are only visible through the manifestations of expressions in the data (Opler, 1945); therefore care was taken to consider these expressions which were noted as codes within the transcripts.

An initial 50 basic themes were identified from the 12 interview transcripts. All codes and themes initially generated at this stage of analysis were illustrated in a table showing the sequence of generating themes from codes (see Appendix 10). This table is divided into

three columns. The first column contains the codes that were used to inform the identification of the basic themes. The 50 basic themes are listed in the second column of the table and the third column of the table distinguishes the underlying notions the researcher felt was pertinent to the codes and themes at this initial stage of the network analysis. These underlying notions appeared to reflect the initial topic questions the researcher sought to investigate through the semi-structured interviews.

This identification of the underlying notions could be seen as a preparatory step for the next stage of the thematic network analysis. Themes were therefore sorted according to commonalities amongst the codes and the content area for these commonalities is distinguished in the underlying notions (see Column 3, Table 1, Appendix 10). Strauss and Corbin (1990) refer to these underlying notions as "concepts" which they propose link codes within the data to themes. These concepts group together themes which pertain to a similar phenomenon, and for this study they could be seen as being related to the topic questions.

The analysis at this preliminary stage therefore highlighted some interesting basic themes in relation to the evaluation of the ACT programme for Chronic Pain (CP). The second stage of the thematic network analysis allowed further exploration of commonalities, contradictions or differences within the data and allowed for the organisation of these basic themes into organising themes.

3.3. Thematic Network Analysis Stage 2: From Basic to Organising Themes

Once the initial basic themes were generated, these were arranged into clusters of themes of similar issues. The basic themes are the lowest-order theme that is derived from the textual data and on their own they say very little about the text as a whole. In order for a basic theme to make sense beyond its immediate meaning it needs to be read within the context of other basic themes. Together these basic themes represent *Organising Themes* (Attride-Stirling, 2001)*.*

The organising themes can be seen as more abstract and more revealing of what is going on in the texts, and their role is to also enhance the meaning of the broader theme that unites several organising themes. Six organising themes were identified within the data and within these organising themes a number of super-ordinate (basic themes) were considered (see Table 2).

For the purpose of arriving at a thematic analysis with a particular focus on the original topic questions, the themes which were not pertaining to these questions were not considered and taken any further. This therefore resulted in a partly selective thematic analysis whereby the original 50 basic themes were narrowed down to 24 basic themes (see Column 2, Table 2). It is important to note that the search for the organising themes was therefore in part governed by the topic questions.

The researcher chose to discard 26 basic themes at this stage as they did not appear to contribute to the organising themes owing to their duplication and repetition which is considered to be a process of extraction due to recurring regularities (Guba, 1978). This was achieved through a constant comparison method (Glaser & Strauss, 1967), which involved sorting the themes and arranging them in relation to similarities and differences by making comparisons across the basic themes.

Furthermore, the researcher chose to focus on generating themes that were pertaining to the topic questions which some authors identify as being a rich source of a priori themes (Dey, 1993). An a prior approach is considered to be the generation of themes from the researchers prior theoretical understanding of the phenomenon under study (Dey, 1993), and for this study the generation of themes related to the topic questions were selected to represent the organising themes.

Table 2: Organising and Basic Themes from analysis of 12 interviews

Organising Theme	Basic Themes
1. **Hope**	• 12. The Last Resort • 5. Receiving Validation
2. **Hopelessness**	• 11. When all else has failed • 10. Scepticism • 6. Feeling Misunderstood • 7. Being invisible • 13. Desperation
3. **Benefits of Acceptance**	• 33. I am not my pain • 36. Adjusting Expectations • 32. Being in the present • 24. Giving up the fight • 20. Willingness to try
4. **Barriers to Acceptance**	• 26. Fighting pain • 22. Cycles of emotions • 40. Societal Attitudes • 27. Employment Issues • 41. Struggles to focus on present • 42. Language
5. **Positive experience of Group**	• 45. Understanding • 44. Mutual support • 46. Increasing confidence
6. **Negative experience of Group**	• 47. De-personalisation • 48. Seeing others in pain • 50. Intimidation

The six organising themes and basic themes will now be presented, supported with quotations from the textual data itself.

3.4. Organising Theme 1: HOPE

The organising theme of "Hope" encapsulated the feelings of the participants prior to attending the Luton & Dunstable Hospital ACT programme for CP. The basic themes within this will now be presented.

3.4.1. "The last resort"

The search for a cure prior to attending the programme was a common theme expressed across many of the participant's interviews. It was noted by some of the participants that their pain would not necessarily be "cured" or "taken away", however, despite hearing this message at the beginning of the programme, a number of participants noted that they felt hopeful that the programme would be able to offer them something. There was a willingness to engage in the programme despite previous failed interventions, and this was also discussed in relation to the expectation of the programme itself.

The following quotations have been selected to illustrate the basic theme of "the last resort" within the organising theme "hope".

Table 3: Quotations from participant's about the basic theme "the last resort"

"As I say I've tried pain killers, I've tried acupuncture I've tried all sorts of things that so I wasn't expecting too much to begin with. So I went in with my eyes open rather than well this aint gonna work, I'll give it a go." *"I thought yeah I'll try anything…nothing ventured, nothing gained."*	Paul (Age 48yrs)
"I'd tried all the medications off the shelf and surgery was out of the question…this programme was therefore the last resort."	Sharon (Age 40yrs)
"This was very much presented as the end of the line and here I am	Sandra (Age 56yrs)

now, so this was my last hope if you like…"

3.4.2. "Receiving validation"

Some of the participants spoke about the search for validation and belief about their symptoms prior to attending the programme. It appeared that for these participants being accepted and "believed" by health care professionals such as the facilitators of the ACT programme for CP, meant that they felt that their pain was acknowledged and that this was a positive experience for them. This also provided a more hopeful outlook on their problems and their pain.

The following quotations illustrate the basic theme "receiving validation" within the organising theme of "hope".

Table 4: Quotations from the participants in relation to the basic theme "receiving validation"

"I needed someone to actually listen to me and believe that yes, I am in pain, listening is a big part of acknowledging that there is a problem."	Dave (51yrs old)
"Just being accepted and someone saying, "Yes. We know you are in pain. We understand you are in pain. We can't cure your pain, but we might be able to help you live with it". That made a big difference-just being accepted."	Linda (45yrs old)

3.5.   Organising Theme 2: HOPELESSNESS

In contrast to hope, a number of participants described the sense of hopelessness prior to attending the ACT programme for CP. This theme encapsulated a number of basic themes which will now be presented.

3.5.1. "When all else has failed"

For some of the participants, previous failed attempts to alleviate or "rid them" of their pain contributed to a sense of felt hopelessness prior to attending the programme. Other

therapies such as acupuncture and medication were cited as having been tried with short to relief, however, for many of the participants the awareness that a different approach to their difficulties was acknowledged during the interviews.

The following quotations have been selected to illustrate the basic theme "when all else has failed" within the organising theme "hopelessness".

Table 5: Quotations from participants reflecting the basic theme "when all else has failed"

"Having tried lots of other things predominantly via my GP I felt that it was just a short term thing that was maybe just helping with the pain for a little while but I knew it wasn't actually helping with all the underlying problems."	Siobhan (48yrs old)
"I'd had lots of other therapies before. I'd had acupuncture for different parts of body pain-which again didn't help-but it's only a short term solution to the problem"… "I just thought of it as being a physical thing you could just get rid of or you got you know there is lots more psychological issues to it that I hadn't appreciated before."	Sharon (40yrs old)

3.5.2. "Scepticism"

Some of the participants spoke about feeling sceptical and apprehensive prior to attending the ACT programme. This was expressed as a consequence of previous failed attempts to alleviate their pain which further exacerbated their sense of hopelessness regarding their problems prior to attending the programme. However, a few of the participants expressed a willingness to try the programme despite their apprehension and this further reinforced their desire to find a cure for their problems, when previous attempts had failed.

The basic theme of scepticism within the organising theme of "hopelessness" can be considered from the following quotations.

Table 6: Quotations from participants reflecting the basic theme of "scepticism"

"I thought here we go again, it was another tick box so I was a little apprehensive. But at the same time I'm a great believer in that the	Sharon (40yrs old)

body can do an awful lot if you allow it to, but you have to allow that pattern to happen."	
"The reality is that nobody can wave a magic wand and take your pain away… so you think well how is anything going to make a difference?"…"I was very sceptical you know as to whether it would work, But I was open minded you know and gave it a go."	Jamie (39yrs old)

3.5.3. "Feeling misunderstood"

A number of the participants expressed their feelings around the judgement they faced from others whom they believed misunderstood their difficulties and their pain prior to attending the programme. This is a common experience for people with CP and this was described by many participants in this study as difficult and challenging. Some participants also spoke about their own personal misunderstanding of their pain problems and this was described as contributing to further confusion and feelings of hopelessness but also a sense of desire to be rid of their symptoms.

The following quotations have been chosen to highlight the basic theme of "feeling misunderstood" within the organising theme of "hopelessness".

Table 7: Quotations from participants reflecting the basic theme of "feeling misunderstood"

"Family and friends…they don't seem to quite grasp what you've gone through and what you're going through at the time…you're complaining about pain all the while, your close ones get fed up of hearing it. It's like a broken record."	Annalie (45yrs old)
"The worst thing about pain is being judged…"	Paul (48yrs old)

3.5.4. "Being invisible"

The metaphor of being invisible was often used by the participants in this study to describe how they felt about their pain prior to attending the programme. This experience of others not being able to see the symptoms of their pain, was described to further reinforce the

feelings of being misunderstood by others and this was a common experience across many of the interviews.

The following quotations describe the basic theme of "feeling invisible" within the organising theme of "hopelessness".

Table 8: Quotations from participants reflecting the basic theme of "feeling invisible"

"People can't see the pain you are in and because they can't see the pain you are in, if you look healthy then there's nothing wrong with you, and outwardly-other than using my mobility aids-I don't look ill, but I have an awful lot going on inside that people don't see and more than just the pain side of it as well. I have many other conditions which I have to deal with on a daily basis."	Linda (45yrs old)
"I see myself with a disability, because it's hidden, no-one sees what you know what I'm really feeling. I'm sitting here now and I know how my body's feeling and of course you can't see, but I really wish I wasn't feeling like this."	Tracy (60yrs old)
"In society if you can't physically see something then actually we don't understand and we don't accept and we don't make considerations…"	Sharon (40yrs old)

3.5.5. "Desperation"

Several participants described the sense of desperation that they felt as a result of their CP experience, and this contributed to their feelings of hopelessness prior to attending the programme. Drastic attempts to alleviate their pain were seen as the only option to rid themselves from their pain prior to attending the ACT programme. Furthermore, some of the participants spoke about feeling emotionally low, angry and tired which they described as a manifestation of their felt desperation.

The following quotations have been selected to highlight the basic theme of desperation within the organising theme of "hopelessness".

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Table 9: Quotations from participants, reflecting the basic theme "desperation"

"I was going to bed and I was in pain, and waking up in pain the next day, it was a losing battle and I started to hate myself, I was getting more angry with myself, thought about committing suicide and this sort of thing…"	Jamie (39yrs old)
"When I was in hospital, not this time one of the first times, I was in bed and I was on oxygen and I was terribly ill and I just thought I'm too tired now. I'm going to sleep. If I wake up great and if I don't, I don't."	Ann (60yrs old)
"There was a stage when I couldn't give a monkeys and if I'd taken the car out and had an accident and I didn't really want to think it, but I was getting quite low."	Paul (48yrs old)

3.6. Organising Theme 3: Benefits of Acceptance

The organising theme of benefits of acceptance encapsulated in essence the feelings of the participants and the strategies they had benefited from since attending the ACT programme for CP. The basic themes within this theme will now be presented.

3.6.1. "I am not my pain…"

A number of the participants spoke about their ability to distinguish themselves as being separate to their pain, since attending the ACT programme for CP. This strategy was seen as a way of accepting their pain but also being able to focus on who they are, despite their pain. Some of the participants spoke about realising that there is more to them than their pain alone, and were able to reflect on this during the interviews. The basic theme "I am not my pain" was captured in the following quotations and can be considered within the broader theme of "benefits of acceptance".

Table 10: Quotations reflecting the basic theme "I am not my pain"

"This is part of me but this isn't as I've said, it's not who defines me. It really isn't. I've got this pain and I live alongside it. It's not a separate entity it's within you and you have to accept it. Not as my best friend but it's there and my body, you know I used to think 'god my body's awful' because it's not doing this and it's not doing that but actually my body is trying its best and it heals itself."	Ann (60yrs old)
"I try to see my pain differently to see that people aren't just their pain. You aren't just your pain, you're you and ok you've got pain but first and foremost you're you as a human being and an individual and yeah you might have to carry that around with you but just carry it around with you. Don't let it become you."	Siobhan (48yrs old)

3.6.2. "Adjusting expectations"

Many of the participants spoke about their ability to refocus their attention and energy on the tasks that they are able to achieve despite their pain, and they spoke about the impact this had on their confidence and self-esteem since attending the programme. It appeared that some of the participants were able to therefore adjust the expectations that they held for themselves since attending the ACT programme. By accepting their limitations, some participants explained that they felt more compassionate towards themselves which also contributed to a feeling of empowerment in being able to communicate this to others.

The basic theme of "adjusting expectations" is highlighted in the following quotations and is also considered within the organising theme of "benefits of acceptance".

Table 11: Quotations from participants reflecting the basic theme "adjusting expectations"

"I've learnt to accept what you can do and not what you can't. I try and be positive and if I can't do something one day then I say well there's another day and just limit myself to what I can do. I'm not afraid to say no."	Tracy (60yrs old)

"Before I used to think it was wrong that I couldn't do it and that I should be able to do this. I did used to beat myself up quite a bit …but now I just take each day as it comes and I don't beat myself up if what I did yesterday I can't do today."	Linda (45yrs old)
"I felt more empowered given the tools to feel that I could say to someone I can't do that."	Dave (51yrs old)

3.6.3. Being in the present

Being able to "be in the present" was discussed during the interviews as a further strategy that some of the participants had learnt whilst attending the programme. Some of the participants spoke about their recognition that prior to attending the ACT programme; they had been caught in a situation whereby their attention had focused on their past abilities/disabilities and concerns regarding future abilities/disabilities. It appeared that whilst attending the programme, many of the participants had been able to re-evaluate the perspective they adopt and were beginning to appreciate their present experiences in the life they are living. This subsequently enabled some of the participants to reconsider their values and negotiate a more meaningful quality of life, living for now.

The basic theme of "being in the present" can be illustrated within the following quotations within the broader organising theme of "benefits of acceptance".

Table 12: Quotations from participants reflecting the basic theme "being in the present"

"There is always a before and after, there's not a during and you're always thinking back to the past or in the future because you see yourself a bit into brackets really. Just in a waiting room, you are just waiting for something. But I've realised that while you're waiting you're not living."	Dave (51yrs old)
"I try to now put things from the past and things that have happened to me in an imaginary boat or bus or whatever and it allows me to think…its happened, you can't change it, not to beat yourself up over it and allow that to just pass and that actually each new hour of each	Sharon (40yrs old)

new day is a different opportunity to change things, to look at things differently, to deal with things, to cope with things."	
"A lot of the time I used to feel as if I just exist. Not living. I'm waiting for tomorrow, hopefully maybe I'll feel better tomorrow and I realised that this is not helpful."	Sandra (56yrs old)

3.6.4. "Giving up the fight"

A number of participants noted that since attending the ACT programme for CP, they had learnt to "give up the fight" with their pain. This was considered to be a strategy related to the concept of control and for many of the participants by accepting their pain and no longer striving to fight it and be rid of it, was a helpful strategy with desirable consequences. The notion of giving up the fight was therefore seen as a benefit of acceptance.

The following quotations illustrate the basic theme "giving up the fight" within the organising theme "benefits of acceptance".

Table 13: Quotations from participants reflecting the basic theme "giving up the fight"

"I accept my pain now I don't fight it…there might be the odd day when you slip back into the old ways but I try not to let the pain win, what I do instead of going into a 'sorry' mood so to speak, I just kind of now brush it off and say, Okay that's it and I just have to, I just have to manage it…no I'm not going to have you beat me anymore."	Maria (57yrs old)
"I try to be kinder to myself and that has possibly helped me to not fight quite so much. To acknowledge what I was doing rather than just keep highlighting what I wasn't doing which is always the downside of CP."	Sandra (56yrs old)
"I recognise very much more and more that when my pain is in the driving seat, it's controlling me and what I think I've found is a way of turning it down and being stronger again. The more you fight, the more stressed you become and I try not to get too stressed."	Paul (48yrs old)

3.6.5. "Willingness to try"

During the interviews some of the participants talked about the need for a willingness to engage in an intervention in order to appreciate the benefits. For some of the participants who had attended the ACT programme, there was an expression that change required a readiness to change in many ways, and this readiness was affected by how open minded or willing a person was to try and practice the strategies that were suggested during the programme such as the mindfulness meditation.

Willingness could also be considered as an inner confidence or motivation and therefore it was recognised that in order to continue to live life despite pain, a person must feel motivated to do so and this recognition appeared to have developed over the course of the programme for some of the participants interviewed.

The following quotations illustrate the basic theme "willingness to try" within the organising theme "benefits of acceptance".

Table 14: Quotations from participants reflecting the basic theme "willingness to try"

"You've got to be quite open minded and willing and you have to put quite a lot of effort in as well, you know the meditation cd's and that, I found it quite hard to get the time where my children don't interrupt and things like that - so you have to put the effort into it and if you are not willing then you are not going to get much out of it."	Jenny (55yrs old)
"…I've literally turned a corner and I know I've got a long road ahead of me to turn things around and to get to a point where I'm completely happy and you know settled with, you know what I'm doing and things but I now feel I can try, I didn't feel I could try before"… "now when I get up I'm more willing to have a go and make a cup of tea…it's just a matter of having a bit of patience with yourself and things around you."	Tracy (51yrs old)

3.7. Organising Theme 4: Barriers to Acceptance

In contrast to the benefits of acceptance, some of the participants noted their on-going difficulties since attending the ACT programme for CP. These themes could be considered as barriers to acceptance and will now be presented.

3.7.1. "Fight with pain"

Some of the participants talked about an on-going battle between the pain and themselves. The concept of fighting as it appeared in the accounts could be construed as involving both passive and dynamic elements. When fighting, some participants felt the pain would dominate their lives; however the control sometimes shifted between the pain and the person. Acceptance was considered as a possible "surrendering" to the pain which for many of the participants was a difficult position to consider since attending the ACT programme for CP. Furthermore, for some of the participants, the control passed between pain and the person, and whilst the person wished to be in control, the pain would be dominant at times since attending the programme.

The basic theme of "fight with pain" can be considered within the organising theme "barriers to acceptance", illustrated within the following quotations.

Table 15: Quotations from participants reflecting the basic theme "fight with pain"

"It's been quite hard to actually think of pain as part of me when I've been trying so hard to get rid of it. So it's very difficult, yeah, it's very hard to stop fighting and accept the pain, you know you're trying so hard to see it as the enemy."	Dave (51yrs old)
"For me the battle was as bad as the suffering, you're constantly not wanting to give into something, you're fighting it, you are not accepting it. When it's something that you don't want, you don't wanna be, it's really hard to accept that's how it's going to be."	Siobhan (48yrs old)
"I would hate to say the word acceptance because I don't like it but it is almost like accepting 'accepting', you know because it's been something I've been struggling with and battling with but I know I	Jenny (55yrs old)

need to accept it. It's not the big bad thing that it was and trying not to accept, was part of the battle."	

3.7.2. "Cycles of emotions"

Since attending the ACT programme, some of the participants recognised that the pain was only one component of their problems and that further emotions and struggles appeared to exacerbate their difficulties. For these participants, it was important to recognise these cycles of emotions as being almost a barrier to acceptance, as by accepting the pain, the other emotions were still present in their lives causing potential negative triggers and possible further pain. The notion that pain is a feeling but also an emotion was discussed and some of the participants talked about the difficulty in being able to accept their pain in view of the emotional impact it has on their lives, which they had come to realise since attending the ACT programme.

The basic theme "cycle of emotions" can be considered within the organising theme "barriers to acceptance" within the following quotations.

Table 16: Quotations from participants reflecting the basic theme "cycle of emotions"

"If you don't accept it, you end up being a recluse, staying in - I can't do this, I can't do that, and the more you can't do, the more you won't do it. I've been there. I've done that and it doesn't make you happy. You always feel like you are a nobody 'cos you can't do just what you want but you even feel lower. And the longer that goes on the harder it is to get out of it."	Tracy (60yrs old)
"Stress is a trigger and then if you get even more under pressure and then the depression, under more pressure, then that obviously aggravates it but again I think it's sort of this vicious cycle isn't it, you know you feel awful, you get depressed, so because you are depressed you feel even more awful and it just spirals - well it spirals out of control really."	Jenny (55yrs old)

3.7.3. "Societal attitudes"

The issues of society's attitude towards pain, and its influence on a person experiencing pain, were discussed during some of the interviews. These participants described experiences of being caught within the stigma of pain and the barriers they faced being accepted within society in view of their difficulties. There were some reflections on the age issues and that there is an expectation that if you are a younger person in pain then you "should" be able to return to work etc. This further contributed to the feeling of frustration, anxiety and negative emotions since attending the ACT programme, which could further exacerbate pain and therefore can be seen as a barrier in being able to accept their difficulties.

The following quotations highlight the discussion around the basic theme "societal attitudes" within the organising theme "barriers to acceptance".

Table 17: Quotations from participants reflecting the basic theme "societal attitudes"

"We talk about community spirit, we talk about, you know equal opportunities, everywhere you go everybody says "equal opps" and actually what is it? What are equal opportunities? How good are we on all levels of society at actually accepting people for who they are?"	Sharon (40yrs old)
"As a younger person…society…we do not tend to look at older people of having these issues rather than younger, and we don't cater…society doesn't quite cater in the same way for younger people with symptoms like that than they do for the older community, so that was a big barrier."	Jamie (39yrs old)
"People would turn around to me and say "oh you can't do, you can't lift this, you can't lift that", but I, I just tell people when they say that - "look I know how far I can go, so let me see, I won't overdo it". But half the time people don't even let me try."	Paul (48yrs old)

3.7.4. "Timing issues"

A number of participants spoke about the timing of attending the ACT programme for CP and explained that this was perhaps too late for them to receive such an approach. For some participants, receiving this intervention at this stage of their journey with pain was considered to be a barrier as they felt hopeless, having tried numerous failed interventions and therefore the expectation that this would not help was present.

The basic theme "timing issues" within the organising theme "barriers to acceptance" is highlighted within the following quotations.

Table 18: Quotations from participants reflecting the basic theme "timing issues"

"This kind of treatment should be at the beginning not at the end when you've run the gamut of everything else, taken all kinds of drugs which may in many cases made you worse. I know it's probably down to funding don't get me wrong, but to me that would have helped me a lot more 5 years ago. If only I could have had that then because its entrenched in me now, it's almost a learned response, you know?"	Sandra (46yrs old)
"I don't expect it to work in the blink of an eye because I've been in this situation for so long and habits are hard to break… it's too late to accept, I needed this earlier, then I wouldn't have spent all my energy trying to get rid of my pain"	Dave (51yrs old)

3.7.5. "Employment issues"

Many of the participants spoke about their own expectations about their work prospects and were reflective of the physical difficulties which they experience presenting as a barrier to returning to work since attending the ACT programme. These participants described being faced with the judgement of others expecting them to have returned to work, and furthermore the impact this had on their confidence and self-belief.

The following quotations illustrate the basic theme "employment issues" within the organising theme "barriers to acceptance".

Table 19: Quotations from participants reflecting the basic theme "employment issues"

"I know I'm not going to be able to ever work again because just doing a pottery class, even sitting for twenty minutes I've had enough. So how on earth can you do a job? I'm not going to be able to know what I'm like each day. So nobody's going to want you on those terms, let alone whether you can do it. 'Cos you know all this pushing people to go back to work, they don't understand what's happening within you when you are in pain."	Annalie (42yrs old)
"I'm continuing to try to prove to the system and still not being heard. I actually have said to my employers "you are listening, but you are not hearing what I'm saying because you are not accepting that I have told you I have a disability, I have limitations that prevent me from doing this", and no matter what you do they are not listening."	Sharon (40yrs old)
"I think it's "Oh you look fine. Why aren't you working?" There is no visible reason for you not to be in work. I mean, I left work through illness. So some of my old workmates that I see now say "are you working yet?" and I still say "no" and the response is "ooh" you know "been a long time."	Maria (57yrs old)

3.7.6. "Struggles with being in the present"

Another barrier to acceptance discussed during the interviews was the difficulty some participants faced with practicing the mindfulness meditation. Some participants spoke about the challenges they faced with focusing their attention on the present moment (as they were in pain) and therefore this was frustrating and made it even harder for some participants to accept their difficulties.

The following quotations illustrate the basic theme "struggle with being in the present" within the organising theme "barriers to acceptance".

Table 20: Quotations from participants reflecting the basic theme "struggles with being in the present"

"It was uncomfortable, we were all beginners and it was a bit thrown in the deep end. There was so much mindfulness and I couldn't do it and I think I got very frustrated and I just started to beat myself up about it. Being in the moment, I found I didn't want to be in the moment because in order to be in the moment I was more aware of my head pain."	Sandra (56yrs old)
"I think some other members found the meditation worked very well. For me, I really struggled and I'm still struggling, I fall asleep. Just listening to silence isn't for me"	Ann (60yrs old)

3.7.7. "Language - changing the name of the programme"

The final barrier to acceptance was a consideration of the name of the programme itself. For some participants the word "acceptance" was considered to be a resignation to the pain and they struggled with this concept. For others the suggestion that something more hopeful could be more usefully placed as a title of the programme.

The following quotations highlight the basic theme "language" within the organising theme "barriers to acceptance".

Table 21: Quotations from participants reflecting the basic theme "language"

"I hate the word acceptance and one of the biggest things I struggled with was the word 'acceptance'. I think it's a dirty word, for me acceptance was like giving in. It was just you know, that's it, that's how it's going to be. And I thought that they were telling me that I needed to accept what I've got and just kind of be grateful for what I've got."	Siobhan (48yrs old)
"I think you need a more positive name, it's an old-fashioned name as it's not actually about managing your pain, and it's about managing your lifestyle. You could call it 'live the life you want' or 'leading a	Ann (60yrs old)

better life with illness' as it's not all about pain. It could be chronic

illness and you show how to lead a better life"

3.8.   Organising Theme 5: Positive Experience of Group

When discussing the experience of the group based delivery of the ACT programme for CP, every participant mentioned the positive aspect of meeting others who understood their difficulties during the programme.

3.8.1. "Understanding"

The validation of other group members was reported by a number of the participants as being significant whilst on the programme, as experiences felt "normalised" within the group setting. Furthermore, the commonalities amongst group members enabled some participants to grow in their confidence and abilities as they reported that they felt comfortable amongst people who had similar problems to themselves.

The following quotations capture the basic theme "understanding" within the organising theme "positive experience of group".

Table 22: Quotations from participants reflecting the basic theme "understanding"

"It was lovely that everybody else there had an illness that caused them problems as I do, and that you could talk about it and laugh about it. And one girl when I first went said "well I've already thought you know when it all gets too much I'm going off to Switzerland" and I said yeah, I've thought of that but I've taken drugs and I just sick them up…and we actually laughed."	Ann (60yrs old)
"I wasn't the only one in the room with the pain, not the only one that likes to get up and move around when I'm in pain. But in a group where everyone else was like in pain and they were getting up and they were walking around, laying on the floor wherever they were comfortable, it gave me more confidence to say well I'm in pain and I'm just going to have to get comfortable and move around and they	Paul (48yrs old)

didn't mind at all."	
"I realised I was not alone, and that was very very important…actually being in a group where other people, okay they don't have the same pain as me, but they are in pain nonetheless. And they are experiencing the same frustration that I am, most of them have been through the same process I have, trying to find a solution of some sort"	Annalie (42yrs old)

3.8.2. "Mutual support"

Alongside the understanding of others in pain, mutual support was further considered to be a positive experience of being in a group setting. Some of the participants spoke about the mutual sharing of knowledge and insight about pain experiences which they explained helped them to feel supported, which they found helpful. The idea that the team accepted the group members for who they were was also seen as a positive experience and further reinforced the experience of feeling supported by others in the group.

The basic theme "mutual support" within the organising theme of "positive experience of group setting" is illustrated in the following quotations.

Table 23: Quotations from participants reflecting the basic theme of "mutual support"

"I prefer a group setting to one-on-one. Listening to what problems other people have as well, so you learn from each other. I didn't know if I would speak out but if you're with the right kind of group, you are all there for one common reason and I find that's what's helpful. And then you get each other to talk to now and again individually and support one another."	Jenny (55yrs old)
"There were 2 or 3 people there I really hit it off with, you know people in the same boat…I felt this acceptance of people accepting me as I am, you know."	Tracy (60yrs old)
"The team is very supportive in every way, they care about all aspects	Paul (48yrs old)

of you, and just not physically what you can actually do but mentally as well…it was just like a family group really at the end of it all."	

3.8.3. "Increase confidence"

It was noted by a number of participants that attending the group based programme increased their confidence and sociability. Since attending the programme some of the participants explained that they feel less isolated and have tried to continue to reintegrate within society, which was previously avoided. Coming to the programme appeared to have developed the social skills and confidence in the ability to carry out valued and enjoyable activities, despite their pain.

The following quotations highlight the basic theme of "increase confidence" within the organising theme of "positive experience of the group setting".

Table 24: Quotations from participants reflecting the basic theme "increase confidence"

"If I felt I was getting better over the weeks compared to others, I found that quite rewarding and you know that gave me a bit more confidence as well."	Siobhan (48yrs old)
"We had a chat, had a laugh and that sort of thing, we always kept in communication with each other and you meet, you meet some nice people, which is what it's all about, and you can have a smile and a laugh with them, instead of sort of going there and just being depressed all the time. It's meeting other people, which I did enjoy."	Jamie (39yrs old)
"Since coming on the programme I've been trying to socialise a bit more. But before that I used to be a hermit and I wouldn't, I wouldn't go out and spoil anybody else's fun you know. But I've been going out a bit now so, I go fishing even if I sit on the bank all day but I'm getting there."	Paul (48yrs old)

3.9.   Organising Theme 6: Negative Experience of Group

In contrast to the positive experience of the group based setting for the ACT programme, a number of participants highlighted the negative experience of the group. The basic themes in relation to the negative experience will now be presented.

3.9.1. "De-personalisation"

Some of the participants noted that they felt they were unable to talk about their more individual difficulties owing to the group based setting of the intervention. This left some participants feeling that they had been unable to address the more personal, psychological impact of their pain and felt that consideration could be given to this given this component of the pain experience during the programme.

The following quotations highlight the basic theme "de-personalisation" within the organising theme "negative experience of the group".

Table 25: Quotations from participants reflecting the basic theme "de-personalisation"

"We were a group and we were treated as a group and as a team, but it was left to us to try and interrupt the speakers to sort of say "well I've got a problem with this", and then you felt you were taking other peoples time as well"	Sandra (56yrs old)
"I thought it could touch a bit more on the personal side, because with pain comes quite a lot of other things, psychological problems. I thought maybe that could be covered in some ways."	Dave (51yrs old)
"Sometimes there were things that you wanted to say that were very personal to you but you felt you couldn't say it. First because it was very personal and maybe because it wouldn't apply to other members of the group and obviously the time is limited so you can't concentrate on every single one of us."	Annalie (42yrs old)

3.9.2. "Seeing others in pain"

A number of participants noted that they found themselves making comparisons between themselves and the other group members and noted that this was unhelpful as they therefore felt "undeserving of their place in the programme" as they felt that others may be worse off than they were. This led to them questioning the severity of their difficulties, which for some participants was a negative experience of being in a group. Furthermore, observing others in physical pain was seen to be an unpleasant experience overall.

The following quotations illustrate the basic theme "seeing others in pain" within the organising theme "negative experience of the group setting".

Table 26: Quotations from participants reflecting the basic theme "seeing others in pain"

"I also found it challenging watching other people, who are obviously struggling hugely, the one who in particular was in agony all the time, terrible headaches. It's difficult when you are in agony to think about doing anything, but doing nothing is not the answer either."	Ann (60yrs old)
"I saw some people that were in much more pain than I am and makes me feel a bit like a fraud, you know, what am I doing here? Is it really something for me? Maybe I'm taking the place of someone else?"	Tracy (60yrs old)
"One person caught my eye, she'd come and I could see she seemed to be in really bad pain with it, you could see this especially on her face. I could relate to what she was going through, but I still see I'm not too bad then because I'm not the only one."	Maria (57yrs old)

3.9.3. "Intimidation"

Finally, a couple of the participants spoke about the negative experience of certain group members "jeopardising" the group based programme by their actions; such as mocking the programme, and this was seen as form of intimidation in many ways. The feeling of intimidation was also expressed by one participant who noted that the size of the group (16

members) was too large and she did not feel confident enough to speak up during the weekly sessions.

The following quotations highlight the basic theme "intimidation" within the organising theme "negative experience of the group".

Table 27: Quotations reflecting the basic theme "intimidation"

"It is intimidating at first because I feel if I could have verbally participated a bit more, had that confidence, I would have got a little bit more out of it, but I don't feel confident enough in a group that is so big"	Siobhan (48yrs old)
"I don't think all the group were completely…into the group. I don't believe they all, some of them didn't believe it was going to work right from the very beginning. I got the feeling from some of them that it wasn't helping them, but they were going to do it anyway and ruined the experience for some of us"	Linda (45yrs old)

Once all the organising themes had been identified within the text, the final stage of the thematic network analysis was completed which involved identifying the global themes within the textual data.

3.10. Constructing the Networks: Identification of Global Themes

The Global themes can be considered as the core, principal metaphors that encapsulate the core points and organising themes generated from the text (Attride-Stirling, 2001). Global themes can be seen as super-ordinate themes that group together sets of organising themes, summarising the lower-order basic themes. Thematic networks are created by working from the periphery Basic Themes, inwards to the Global Themes and this can be illustrated as a web-like representation. Essentially, each Global theme will produce a thematic network and tell us what the texts as a whole are about within the context of a given analysis.

The following Global themes have been generated from the six organising themes to provide three overarching thematic networks of the data from this study (see Table 2 Appendix 10 and Table 28 below).

Table 28: The three global themes, six organising themes and 24 basic themes which were found to be representative of the data

Global Themes	Organising Theme	Basic Themes
Pre-programme Expectations	Hope	• 12. The last resort • 5. Receiving validation
	Hopelessness	• 11.When all else has failed • 10. Scepticism • 6. Feeling misunderstood • 7. Being invisible • 13. Desperation
Living with Pain: Outlook on problems	Benefits of Acceptance	• 33. I am not my pain • 36. Adjusting expectations • 32. Being in the present • 24. Giving up the fight • 20. Willingness to try
	Barriers to Acceptance	• 26. Fighting pain • 22. Cycles of emotions • 40. Societal attitudes • 27. Employment issues • 41. Struggles to focus on present • 42. Language
Experience of Group	Positive experience of	• 45. Understanding

Setting	Group	• 44. Mutual support
		• 46. Increasing confidence
	Negative experience of Group	• 47. De-personalisation
		• 48. Seeing others in pain
		• 50. Intimidation

3.10.1. Global Theme 1: Pre-programme Expectations

The Global theme *pre-programme expectations* were used to define the feelings that participants had pertaining to their pain prior to attending the ACT programme for CP. These feelings can be organised within the themes of hope and hopelessness and are representative of the basic themes discussed within this chapter.

The following figure illustrates the network for this Global theme and its component organising and basic themes for which it represents.
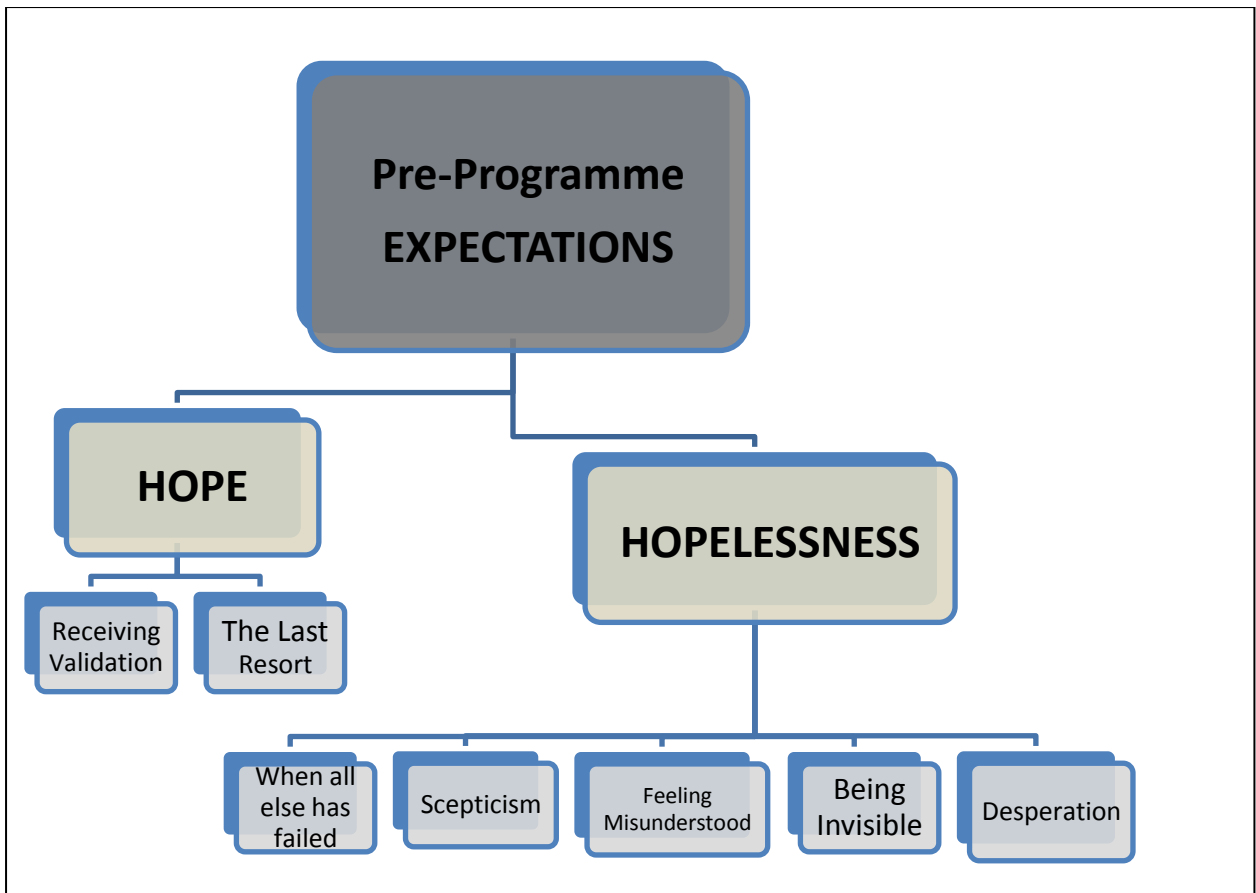
Figure 5: The thematic network for the global theme "pre-programme expectations"

3.10.2.   Global Theme 2: Living with pain: outlook on problems

The second Global theme was considered to be *living with pain: outlook on problems*. This theme was considered to be representative of the feelings of participants since attending the ACT programme for CP. The organising themes within this Global theme consider the factors facilitating and impeding acceptance for these participants, and are organised as benefits and barriers to acceptance.

The following figure illustrates the thematic network for this second global theme and its component organising and basic themes for which it represents.
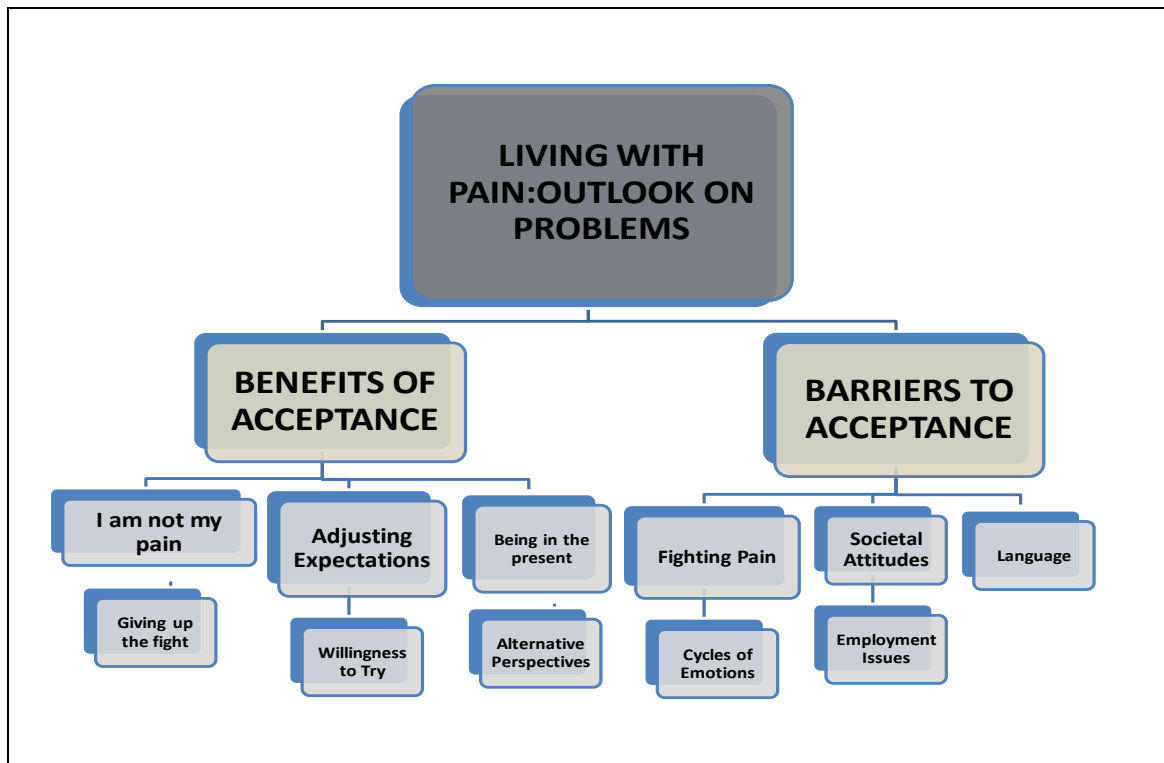
Figure 6: The thematic network illustrating the global theme "Living with pain: outlook on problems"

3.10.3. Global Theme 3: Experience of group setting

The final Global theme considered to be representative of the data was the *experience of the group setting*. This theme encapsulated both the positive and negative experience of a group based ACT programme for CP for the participants in this study.

The following figure illustrates the thematic network for this Global theme and the component organising and basic themes for which it represents.
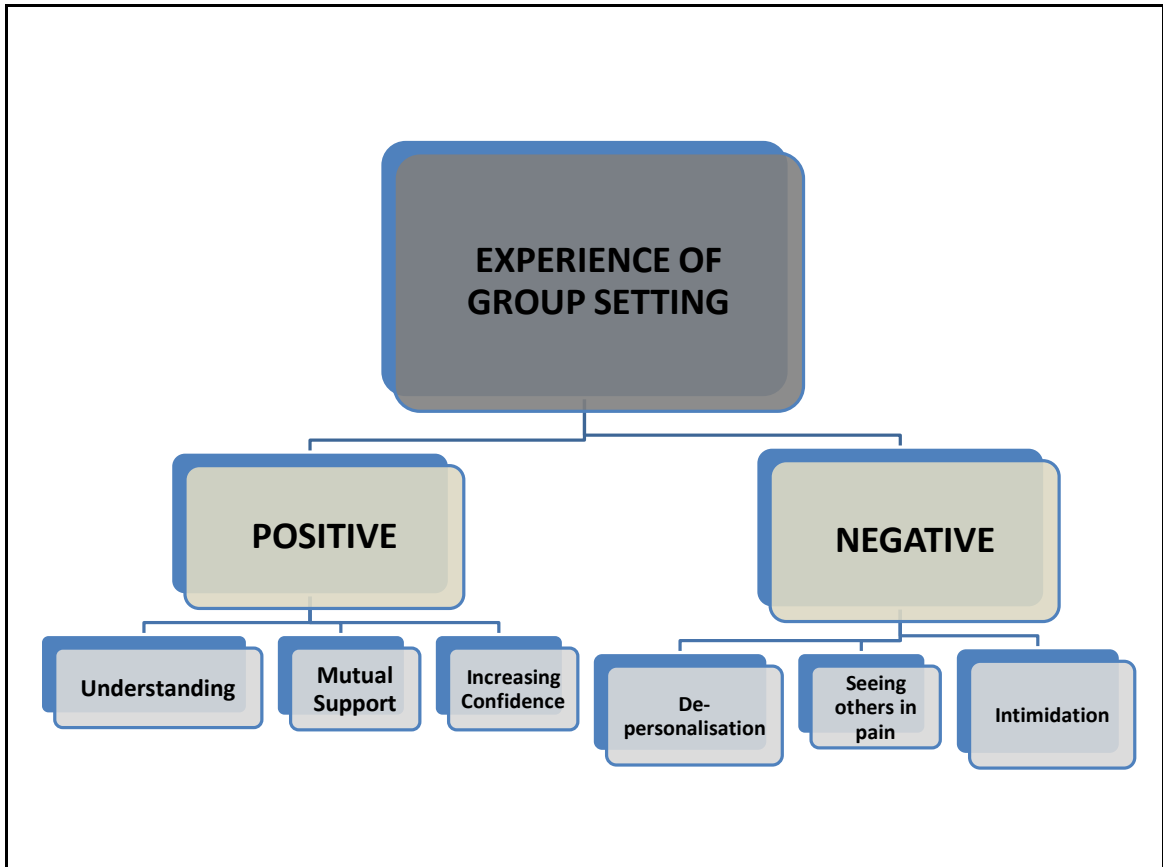
Figure 7: The thematic network illustrating the global theme "experience of group setting"

The results of this study have therefore highlighted connections within three global themes as illustrated by the conceptual maps above. The possible connections between these three global themes and further consideration of the organising and basic themes identifies will be discussed further in the next chapter.

CHAPTER 4 - DISCUSSION

This study sought to investigate a number of topic questions which included the exploration of the motivation for clients to attend the programme, the learning outcomes as a result of attending the programme, understanding of acceptance and experience of the group setting.

Through the use of thematic analysis and the tool of thematic networks, the results of this study have highlighted the following three global themes from the data;

1) Pre-programme expectations - *Hope vs. Hopelessness*
2) Living with Pain - *Benefits of Acceptance vs. Barriers to Acceptance*
3) Experience of Group Setting - *Positive vs. Negative*

The following discussion will interpret these three global themes and discuss their relevance for clinical practice. Furthermore, these findings will be discussed in relation to theory and existing research evidence base. Finally, the importance of the study, clinical implications of the findings, methodological issues and suggestions for future research will also be highlighted within this discussion[6].

4.1.   Pre-Programme Expectations - Hope vs. Hopelessness

One of the three global themes was the expectations of the participants prior to attending the programme. The results highlighted that the themes which arose around the expectations of the participants prior to attending the programme were divided. The organising themes of *hope* and *hopelessness* distinguished these differing experiences.

4.1.1. What factors contribute to a sense of hopelessness?

Overall some participants expressed that their sense of hopelessness was attributed to by previous failed attempts to alleviate their pain. Some participants noted that they had seen

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[6] Please note that themes highlighted in *italic* correspond with global, organising and basic themes presented in the results chapter.

several doctors, had numerous investigations and were at a loss to know why their pain could not be taken away. As a result this had left many of the participants feeling anxious, sceptical and apprehensive about the ACT intervention itself.

When comparing this finding with the extant literature it would appear that the theme of hopelessness could be attributed to beliefs such as anxiety. It is recognised that anxiety is a feature of CP, as for many sufferers there may be high levels of uncertainty about the future in relation to the course of the pain (Diamond & Coniam, 1997), the impact of the condition on their lifestyle, or the effectiveness of the treatment or intervention (Roy, 1992). There is also a link between pain and anxiety, with the anxiety of the pain being generated partly because of the "unknown unexplained symptoms". Anxiety may also become worse as the pain persists and short term expectations of relief fail (Wall, 1999). Therefore the experiences shared by some of the participants in this study resonate with the literature around the role that expectations may play for a CP sufferer. Hopelessness may be seen as a cause or a consequence of the previous failed attempts to alleviate their pain.

The results from this study have further highlighted that participants were often motivated to attend the ACT programme when all other interventions had been tried and exhausted. In Western cultures the dominant solutions to persistent pain are pharmacological methods and avoidance of pain provoking activity (Davies, Crombie, Macrae, & Rogers, 1992), and individuals in CP invest in searching for a cure. Despite these often unsuccessful attempts to "cure" their pain, individuals often persist in the continuation of these methods until they have exhausted the list of possible interventions (Viane , Crombez, Eccleston, Devulder, & De Corte, 2004). Subsequently this can lead to further distress, desperation and preoccupation with pain (Aldrich, Eccleston, & Crombez, 2000).

The participants in this study expressed the extent of their distress within their descriptions of their *desperation* to be rid of their pain prior to attending the programme. Some of the participants described thoughts of suicidal ideation and even amputation of their painful limbs. This finding has been reported by some studies where it has been stated that when pain is too much to bear, some patients seriously considered or even try to take an overdose to end the pain (see Tang & Crane, 2006, for review).

Morley et al. (2005) have noted that in participants for whom the elimination of pain was the primary or unobtainable goal, movement towards other goals was in many ways blocked, and this can lead to frustration, a sense of entrapment and depression. Furthermore, Tang & Crane (2006) found the presence of suicidal ideation in health anxious patients. Health anxiety may therefore have a role in augmenting the *suffering* experienced by patients with CP, perhaps by exacerbating other psychological factors associated with suicidality in CP, for example depression (Breslau, 1992), hopelessness (Hitchcock, Ferrell, & McCaffery, 1994), catastrophising (Edward, Smith, Kudel, & Haythornthwaite, 2006) and mental defeat (Tang, Salkovskis, & Hanna, 2007).

 It is therefore important for clinicians and health professionals to carry out a rigorous assessment procedure when considering participants for engagement in an ACT programme for CP. Clear inclusion and exclusion criteria have been suggested for the Luton & Dunstable Hospital ACT programme for CP, (see method), however the participants who have been interviewed for this study have highlighted the extent of their sense of hopelessness and perhaps this could be further considered in view of attrition rates and barriers to acceptance.

4.1.2. What does it mean to have CP for the individual with CP?

One of the primary assumptions that arose from the literature review in Chapter 1, was that an individual's experience of chronic pain is often moderated by psychological factors such as beliefs and self-efficacy. The identification of the theme of hopelessness prior to attending the ACT programme provides an insight into the meaning that the participants in this study ascribed to their experience of having chronic pain.

Hellstrom (2001) explored the topic of what it means to the patient to live with CP and how this influences the functioning self in social and clinical contexts. People described a hopeless situation with an uncertain future, which was compounded by the perceived attitudes of hopelessness from health care workers. Some of the participants in this study echoed these feelings prior to attending the programme.

DeGood and Tait (2001) suggest that beliefs and personal knowledge about health provide a framework from which to make sense of illness and how to deal with it including decisions

about healthcare. Furthermore people's beliefs about the cause of their pain and the anticipated effects of treatment will also influence whether they take up a particular treatment and the likely outcome of the treatment (Walsh & Radcliff, 2002; Seers & Friedli, 1996). Beliefs have been shown to play an important role in the persistence of pain and how people adapt to it and notably, people with CP are also likely to be very sceptical towards an approach that is incompatible with their beliefs about their pain (Pincus & Morley, 2002b). When considering the findings of this study the theme of *scepticism* could therefore be considered to be attributed to the prior failed attempts for some of the participants to alleviate their pain.

Expectancies can be seen as thoughts with respect to the anticipated consequences and include thoughts about one's ability to control pain and the effectiveness of these coping efforts (Spinhoven et al., 2004). It is therefore useful to consider the impact that expectations can have on individuals prior to engaging in a programme such as the ACT approach and the adjustment to the intervention being offered.

4.1.3. What is the impact of others perceptions of CP?

Many of the participants in this study spoke about their distress within the basic themes of *feeling misunderstood* and *being invisible*. The concept of being invisible was related to the invisible nature of pain and how pain is often not overtly obvious to others who are not experiencing pain. Appearance affects how individuals feel about themselves and how others perceive and value them (McCall, 1990). Some of the participants in this study spoke about *feeling misunderstood* prior to attending the programme and this appeared to impact on their sense of *being invisible* and contributed to the organising theme of *hopelessness* before starting the programme. Notably, people with CP may have difficulties which are not immediately seen by others and essentially could be considered to be invisible to the outside world, however, this could be very visible and traumatic to the individual themselves (Salter, 1992).

It is important to therefore consider the impact that these feelings of being misunderstood may have on their relationship with their pain, themselves and others. Understanding how individuals experience their CP in terms of invisibility can have implications for both practice and research. The experience of having an "invisible chronic condition " can help clinicians

to facilitate a deeper understanding of the dynamic state of having CP and can be useful when delivering intervention programmes such as ACT, to improve coping mechanisms. Furthermore, Goffman (1963) stated that an individual is stigmatised by society when others can see the disability, however, Schneider and Conrad (1980) have implied that the state of being stigmatised is more dependent upon whether or not the individual chooses to see himself in that way.

Therefore consideration of how others see an individual's pain can further improve our understanding of the relationship between stigma, and self-image and chronic pain and thus allow consideration for these experiences when delivering interventions targeted to help individuals to live their lives despite their pain. The results from this study have further highlighted that others perception of CP can have a profound impact on the expectations that a person may have in relation to receiving an intervention i.e. fear of stigmatisation and misunderstanding, as these are possibly previously experienced.

Seers and Friedli (1996) concluded that the most important thing for people was that their pain was acknowledged as real by others and not just to be in their head. This supports the theme of *receiving validation* for many of the participants in this study, for whom this was a positive experience from the onset of starting the programme, fostering a sense of hope despite any pre-existing hopeless expectations and beliefs. It is important to be aware of these feelings and assumptions as this can be seen as crucial to individuals' engagement when at the stage of considering an intervention such as the ACT programme for chronic pain.

4.2.   Living with Pain - Benefits of Acceptance vs. Barriers to Acceptance

This sub-section addresses the research questions attempting to identify what participants learnt from attending the ACT programme for CP, their understanding of acceptance and the challenges they faced with the construct of acceptance.

The results highlighted that participants in this study oscillated between adopting the strategies that were provided through the programme, to struggling with particular aspects

of the programme in on-going process. The organising themes of *benefits of acceptance* and *barriers to acceptance* will now be explored further, and factors facilitating and impeding the process of acceptance will be discussed.

4.2.1. The process of acceptance

Some of the participants in this study described a number of strategies that were beneficial to them which they learnt as a result of attending the programme, including; adjusting their expectations about what they can and can't do, being in the present (mindfulness), giving up the fight with pain and being willing to try to engage in a valued life despite their pain. These findings can be conceptualised as the process of "redefining normal" (Hayes et al., 2005; McCracken et al., 2005). According to these authors, the process of acceptance involves establishing a new life in the context of their new reality. Risdon, Eccleston, Crombez, and McCracken (2003) identified in a community sample, the accounts of "redefining normal" as involving; acceptance, acknowledging limitations, empowerment, acknowledging there is more to life than pain, and relinquishing the fight against battles that cannot be won. Therefore some of the participants learnt experiences highlighted in this study, echo these findings.

However, a question which has been raised by some authors is the extent to which the concept of acceptance overlaps with other constructs such as coping, adjustment, adaptation, self-efficacy and cognitive restructuring (Nicholas & Asgari, 2006). Furthermore Gullacksen (1998) opposes the idea of acceptance and claims that none of the participants in her study ever accepted their pain, in fact they had only "learnt to live with it".

Notably, an ACT approach to pain encourages an individual to re-evaluate their relationship with their pain, and therefore a desirable outcome would be to be able to live with it, or to live a life despite it (Hayes et al., 1999). These arguments raise the important issue of the long term impact of "acceptance" and future studies should consider the impact of these benefits of acceptance at a later stage after completion of the ACT programme for CP. Questions this study has raised include the need to address what are the mediators and moderators of these benefits of acceptance and the longevity of acceptance itself?

4.2.2. What factors contribute to the process of acceptance?

As mentioned in Chapter 1, according to Hayes and Smith (2005), acceptance involves psychological flexibility, including being in the present moment and changing or persisting in behaviour in the services of chosen values. Consistent with this theory, the results of this study suggest that for many of the participants, acceptance represented an overall attitude towards the pain experience, involving the acknowledgment that their pain did not define who they are, and a willingness to engage in valued activities despite their pain. Furthermore, acceptance represented a foundation for improved adjustment; physically, socially and emotionally. The goal of ACT is not to change a person's cognitions, but rather to support them to accept their thoughts, emotions and physical experiences as they are in the present moment, in order to help them to navigate their behaviour towards a more meaningful life (Harris, 2009; Hayes & Strosahl (2010). The results of this study support this through the descriptions by some of the participants of being able to live a life despite pain.

McCracken and Gutierrez-Martinez (2011) explored quantitatively the processes underlying psychological flexibility for a sample of participants who had completed an ACT-based interdisciplinary group treatment for CP. Their findings suggested that improvements following the intervention result from an increase in a willingness to experience many varied psychological experiences. Their findings reflect that the suffering experienced by CP patients does not emerge solely from pain and pain avoidance, but as a consequence of general inflexible patterns of experiential avoidance (Hayes et al., 2006). This provides support for the broad applicability of ACT and its primary processes and adds to the growing body of research across a range of conditions including diabetes management (Gregg, Callaghan, Hayes, & Glenn-Lawson, 2007) and Epilepsy (Lundgren, Dahl, & Hayes, 2008) amongst others.

For some of the participants in this study, *willingness to try* to engage in previously avoided activities, despite their pain was described as a change in their approach and outlook of their abilities despite their pain. Some participants mentioned that they were able to look at their lives through a different lens, and felt empowered to try to do things that they had previously avoided due to pain. Among the functional goals in ACT interventions, willingness occupies a key position (Luoma, Kohlberg, Hayes, & Bunting, 2008). According to Harris

(2009), willingness means to make room for all experiences in life, bad and good and easy or difficult in order to live a meaningful life. Some authors suggest that in the treatment of CP, willingly engaging with pain supports acceptance of pain; being open to all that there is and to be able to actively participate in a valued life in the presence of pain (Dahl & Lundgren, 2006). It would be useful to consider further the long term ability to be willing to try activities despite pain and to sustain willingness over time in order to secure the benefits of the acceptance approach.

As previously mentioned in Chapter 1, the constructs of adjustment, coping and self-efficacy and locus of control could be seen as psychological factors and processes underlying the relationship that an individual has with their pain. Therefore consideration of the relationship between these constructs and willingness could also be explored further in future research.

4.2.3. Why can some people accept and others can't?

The results of this study suggest that for some individuals, psychological flexibility and ultimately acceptance of their CP was easier to comprehend and practice than others. The participants appeared to be a strongly heterogeneous group, each with a unique interpretation of what they found to be important learning outcomes as a result of attending the ACT programme. This heterogeneity amongst people in CP is consistent with what numerous researchers have found (Keefe, Beaupre, Gil, Rumble, & Aspnes, 2002; Main et al., 2008). It is useful to also consider the psycho-social factors such as educational level, socio-economic status, patient and professional beliefs (perceived control and self-efficacy), emotional state, coping strategies, social support, availability of community resources and access to health care are all thought to contribute to health outcome for individuals with CP (Shipley & Newman, 1993). Therefore the participants interpretation of the benefits of acceptance described within this study could have been influenced by a number of psycho-social factors which have not been further elaborated upon.

It has been proposed that self-regulation processes mediate between pain, disability and psychological adjustment for individuals with chronic illness including CP (H. Leventhal, E. Leventhal, & Contrada, 1998). According to Leventhal's self-regulation model, people's illness related cognitions derive from an implicit model of illness, based on illness related

beliefs, knowledge, experience and information from other people including healthcare professionals. The model suggests that the impact of CP will be mediated by a person's cognitive representation, including their perceptions of pain, perceived causes and consequences, and beliefs about curability or controllability. These will influence their emotional response, coping behaviours and appraisals of coping efforts.

Therefore the individual differences in the participants appraisal of acceptance based strategies to "cope" with their pain from this study could have possibly been influenced by these self-regulation processes. While shared cognitive representations may help to explain the similarities in people's response to CP such as quest to find a cure, individual differences may help to explain differences in emotional distress, levels of self-care behaviours and health outcomes. Furthermore Hampson, Glasgow, and Zeiss (1994) suggest that the extent to which people view their pain as chronic, and that treatments are important, influences their adherence to medical treatment and performance of self-management behaviours.

Additionally, relational frame theory posits that the ability for a person to accept their chronic pain can be attributed to the extent to which they view themselves "as their pain". It appears that the technique of cognitive defusion as presented during the ACT programme, allowed some of the participants to be able to detach themselves from the notion "I am pain" therefore further allowing the process of acceptance to engender an openness to redefine them, and reengage with valued activities despite their pain. Essentially living alongside their pain, but not being defined by their pain. Dahl et al., (2005) suggest that ACT provides a context in which language and thought is looked at rather than looked from, so that patients are able to let go of the struggle of unhelpful cognitions about pain. It therefore appears that cognitive defusion was a key process in enabling some of the participants in this study to adjust to their life with chronic pain which could have contributed to the reduction in the suffering that they may have experienced prior to attending the programme and adopting the ACT approach.

4.2.4. Issues of timing

A key finding of the study was that some of the participants felt that the timing of the ACT programme was too late in their journey with their pain and this could have been seen as a further barrier to acceptance. When comparing the theme of timing with the extant

literature, it has been suggested that the perceived time course of an illness may influence self-regulation, and therefore adjustment and self-management of chronic illnesses (Belgrave, 1990). Wallston (1993), carried out a review of on perceived control and rheumatic illness conclude that people with CP do not tend to view control over their health as strictly internal or external but as residing in both their own actions and what others do to and for them.

As previously mentioned in Chapter 1, factors such as locus of control may be salient in understanding what may facilitate and impede the process of acceptance. Cross-sectional studies show that stronger internal health locus of control beliefs are associated with greater life satisfaction and quality of life (Wallston, 1993). When a person believes that not only themselves but other people play an important role in the management of their illness, this may be particularly conducive to the development of a successful relationship between the health care professional and the patient.

Therefore consideration of the timing of an intervention and how this can influence a person's likelihood to engage and respond to the strategies offered is another factor which can influence the barriers to acceptance for a person with CP.

4.2.5. Living with uncertainty

The findings of the study highlighted the long term nature of the participants' difficulties with CP, and as mentioned previously this often resulted from successive previous failed attempts to alleviate their pain. Richardson, Ong, and Sim (2006) identified a dynamic relationship between thinking, responding and managing CP. Participants were classified as being optimistic, pessimistic or uncertain with regard to their pain and this influenced the cognitions and meanings that they attached to their pain.

Therefore, the uncertainty of CP with respect to pain relief could mean that constant effort to adjustment to this situation is required. Furthermore, this uncertainty may be compounded by not knowing whether the pain may last for another month or the rest of a person's life. Envisioning and planning for the longer term future may present as a dilemma for many individuals with CP, as this may be practically difficult due to the uncertainty but also because of the uncertainty, it may also be emotionally difficult because it requires

acceptance of CP as part of the future. Therefore further consideration of how individuals perceive and plan for their futures, given the underlying and pervasive uncertainty of the condition may provide further insight into the ability to accept their CP.

Peolsson, Hydén, and Satturland Larsson (2000) carried out a qualitative study and argued that living with pain was a dynamic learning process. Their participants described pain that was initiated, worsened and alleviated over a course of time. The participants developed learned behaviours as was seen necessary in order to negotiate balancing their "internal resources and environmental circumstances" in their management of pain. Therefore it may be important to consider the impact that the uncertainty about the future may have on the on-going approach individuals adopt to living with their pain, and thus could be seen as a further potential barrier to long term acceptance of CP.

Bullington, Nordemar, Nordemar, and Sjöström-Flanaghan (2003) used the term "meaning out of chaos" to illustrate the process of clients moving through diagnosis towards heightened self-awareness and finally taking responsibility for self-management. In this study the participants who appeared to have moved through the process were at a stage of active self-managements whereby they were willing to accept their pain and were pursuing activities within their limitations with adjusted expectations to live for the present. However, for some of the participants in this study, the experience of being unsuccessful in the process of self managing their pain and unable to accept their life as it was at present, will lead to persistently looking for a cure.

Therefore moving forward or getting stuck in the process could be seen as being contingent on time, aspects of the self and thinking about pain. Further exploration of the underlying impact of uncertainty of the future could provide more insight into the barrier of engaging with an ACT approach for chronic pain.

4.2.6. The pain battle

Many of the participants in this study spoke about the constant fight with their CP and the cycles of emotions that prevail as a consequence of the failed attempts to avoid or alleviate their painful symptoms. In contrast to those caught in the vicious cycle of being controlled by their pain, some of the participants talked about their ability to "give up the fight" and

identified that this was a helpful strategy for them in terms of gaining empowerment and control in their lives.

The consequences of either fighting the pain or surrendering the pain were discussed in terms of the long term costs and benefits. The ability to "accept" the pain and "give up the fight" could be understood in terms of the notion that it is the *suffering* as opposed to the pain itself which is cause of the difficulties experienced (Hayes et al., 2005). For some of the participants in this study, recognition of this was seen as a key process as part of the acceptance of their CP.

For some of the participants in this study, the struggle to make the changes in their life and not let the pain take over everything highlighted the battle of suffering, and the determination to ease their suffering. Suffering is one of the oldest human experiences (Copp, 1974), and can also be described as a struggle between hope and hopelessness (Rehnsfeldt & Eriksson, 2004). The participants described the experience of struggling with acceptance of their pain and this battle further exacerbated their pain experience and influenced their pain beliefs.

Tang and Crane (2006) carried out a qualitative thematic comparison between CP patients with high and low health anxiety. Compared to health anxious patients, non-health anxious pain patients did not link their identity with pain, nor did they see themselves as being "beaten" or "taken over" by the pain. Therefore perhaps psychological distance between self and pain and the ability to preserve mental autonomy from the grip of pain may be crucial for understanding how a person copes with the changes that comes with pain.

This idea is consistent with the pain enmeshment theory (Pincus & Morley, 2001), which posits that distress/disability in pain is viewed as a function of the overlap between the self, illness and pain schemas. It can also be linked to research in post-traumatic stress disorder and depression, where "mental defeat" has been identified as a cognitive construct that predicts not only symptom severity but also treatment response (Dunmore, Clark, & Ehlers, 1999, 2001).

As discussed in Chapter 1, cognitive fusion is particularly strong in CP patients. The longer people live with their pain, the more fused they and their self-identities are with their

thoughts about pain (Robinson & Riley, 1999). It is reasonable to presume that fusion is very powerful and persistent and hence cognitive defusion is not easy to achieve, requiring a lot of personal effort. Several research studies have documented that older women experience more pain, are more sensitive to pain, have more painful afflictions, and experience pain differently than individuals in most of the other population groups (Hoffmann & Asmundson, 2008). Thoughts, such as —'I am in pain', may lead to a strong identification with pain, as in —I am Pain (Robinson et al., 2004). The majority of participants in this study were older women and so the findings represent more the views of this particular group. Age may however be a factor to consider when looking at the individual differences in the participant's appraisals of the acceptance strategies provided within the programme.

4.2.7. Struggles with *language*

Another important theme constituting a barrier to acceptance was *language.* Some of the participants in this study objected to the use of the word "acceptance", instead preferring terms such as "coping" or "living" with the pain. Overall the rejection of the term; acceptance, appears to reflect the possible belief that acceptance equates with "resignation". Resignation, in turn, runs counter to the belief that a person can maintain hope for improvement in their pain while, at the same time be "willing" to experience pain in the pursuit of valued activities. Meaning that individuals ascribe to language is a strong precursor to their behaviour (Lachapelle, Lavoie, & Boudreau, 2008), therefore, health care providers and practitioners may find it easier to build a rapport with patients if they use the language preferred by the patients when considering the delivery of CP interventions.

Furthermore attributing acceptance to a form of resignation to the "pain" can be seen as impacting on the engagement and hope for the success of an intervention. Bendelow and Williams (1996) interviewed CP patients, who expressed the feeling that their lives were dominated by pain, and that there was no hope for the future as the pain would never disappear. Bendelow and Williams (1996) suggest the group displayed classic features of resignation, a term coined by Herzlich (1973). In this situation people dwell upon their condition, feel psychologically cut off or isolated from others; feel hopeless or depressed as a result of their condition and express the view that their illness has come to dominate their lives (Herzlich, 1973). Therefore for the participants for whom the fight with pain dominated

their experiences, apprehension about the acceptance based language could have influenced their reception to the theory of acceptance and may then have implicitly served as a barrier to implementation of the strategies proposed within the programme.

Some authors argue however that acceptance is not an act of resignation or surrender and that people who accept CP are not passive (Viane et al., 2004). Acceptance appears to be a complex construct that consists of several components. Although many patients may relate acceptance to giving up, recent studies have explicitly rejected this negative view (Risdon et al., 2003). Research has indicated that acceptance involves a search for a new identity, implying a re-evaluation of personal goals, values and life priorities (Branstetter-Rost et al., 2009). Furthermore McCracken and Eccleston (2003) have argued that acceptance is best conceived as halting the dominant search for a definitive solution of physical complaints and as a reorientation of attention towards positive everyday activities and other aspects of life.

It is reasonable to assume that despite acceptance of pain, the pain will sometimes interfere, and it is in this situation that the fighting is relinquished and a non-reactive openness and flexibility is adopted (Hayes & Wilson, 1994). For the participants in this study who were able to give up the fight with their pain, acceptance served as a tool to enable them to frame their lives in a more positive way and to live their lives despite their pain.

4.2.8. The stigmatisation of CP

Some of the participants in this study identified that societal and employment issues further contributed to the barrier to acceptance of CP. Some of the participants noted that they felt that often others judged them, and they described the experience of stigmatisation, which often fuelled a fear to return to work, and an apprehension of whether they would be accepted in society and within the workplace because of their CP.

The findings from this study have been found in other studies which have assessed patient perceived barriers to self-management for chronic illness in general and CP specifically. Jerant, von Friederichs-Fitzwater, Moore (2005) found both the physical (e.g. pain, fatigue) and emotional (e.g. depression) limitations associated with chronic illness, financial constraints, lack of family/social support, and inadequate communication with providers as common barriers to self-management for chronic illness.

A body of research is emerging suggesting that social responses to pain are related to patients' acceptance of CP (McCracken, 2005a). It has been found that "punishing" responses from significant others have a negative relationship with acceptance of pain, and that angry, irritated, frustrated and ignoring responses to pain behaviours are related to less activity engagement, less pain willingness and less total pain acceptance (McCracken, 2005a).These responses could be argued to shape a number of behaviour patterns in the individual pain sufferer. They could be seen as invalidating of the pain sufferers feelings, and may lead them to feel less accepted, and disbelieved.

It appears that these findings were similar to those experienced by those participants in this study for whom invalidation lead to additional consequences such as depression and low mood. It is possible that negative responses from others could add to the emotional pain experience and therefore lead to a greater likelihood of avoidance, and less likelihood of behaviour in the direction of acceptance, a process perhaps more akin to negative reinforcement than punishment?

Kleinman (1998) recorded that the victim of CP may sometimes be shunned and degraded, but also noted that the individual can either accept or reject the stigmatised identity. Scrambler (1988) argued that collective negative representations of the consequences of chronic illness can conspire to damage self-esteem; however it is clear that not everyone experiencing CP will feel stigmatised.

Given these suggestions it would appear that there are clinical implications for the social difficulties that appear to pervade the lives of some of the participants within this study. Pincus and Williams (1999) note that although the emphasis on pain management has continued to shift towards self-management, the most import outcome measure remains return to work, along with improvements in function and pain reduction. The findings of this study highlight the importance of addressing how to deal with the social situations that individuals with CP encounter during their daily lives, and the impact that the stigmatisation and judgment of others can have on the acceptance of their pain and how this may impede the ability in living a valued life despite their pain.

The findings from this study also support the view that listening and believing are important motivational aspects of the therapeutic process, (Jensen, Nielson, & Kerns, 2003), and that dealing with stigma and should be included as part of the ACT programme for CP. Societal attitudes and employment issues, whether real or feared, appear to be an important reason why some people with CP find it difficult to adapt to their situation.

4.3.   Experience of Group Setting - Positive vs. Negative

This sub section will consider the results of the study in relation to the research question addressing the participant's experience of the group based programme for CP.

4.3.1. What are the positive aspects of being in a group setting?

For the majority of the participants in this study the experience of attending a group based intervention was seen as positive. Participants noted that the mutual support and understanding they felt from fellow group members also experiencing CP or similar situations to them fostered a sense of positivity, and self-efficacy in their belief in them and their acceptance of their problems.

The socially supportive elements of being in a group with other people with CP has been seen to encourage feelings of belonging, reduction in isolation and promotion of respect for self and others (Martensson & Dahlin-Ivanhoff, 2006; Strong & Unruh, 2002). The majority of the participants in this study noted the *support*, motivation and socialisation that being in a group engendered. Furthermore, the sense of *being understood* and *feeling validated* appeared to reinforce the value of being "accepted" by the group facilitators as well as other group members.

According to Festinger's (1954) social comparison theory, social behaviours can be predicted largely on the basis of the assumption that individuals seek to have and maintain a sense of normalcy and accuracy about their world, particularly in times of uncertainty. Social comparison can therefore be seen as intrinsic in health care settings where anxiety levels and uncertainty about prognosis and outcomes leave patients feeling uncertain about their future. By being able to connect with other people who were in a similar situation to

themselves, the participants in this study were able to appreciate the opportunities for disclosure, empathic connections and shared goals and advice.

4.3.2. The challenges of being in a group setting

Notably, getting the "group mix right" was seen as difficult for some of the participants who attended the programme in this study. The results highlighted that some of the group members who dominated or were disruptive in the group had a negative impact on the experience of the group setting. Also the necessity of having one set approach within the group based programme was noted as being too prescriptive at times for clients whom often had diverse individual needs.

Therefore flexibility in the delivery of the programme in relation to personalisation of the approach was highlighted and it was recommended that this would further enhance the benefits of the ACT approach to those individual group members for whom it was pertinent to explore more salient personal issues. The researcher notes however that consideration of time and resources to do this needs to be taken into consideration.

It was also noted that for some of the participants, seeing other group members in significant pain resulted in them feeling uncomfortable and often lead to further comparisons regarding their position and level of discomfort within this group. This can be further seen as a form of cognitive fusion (Dahl et al., 2005), as the participants associated their experiences with those experienced by others. This led to some of the participants seeing themselves as being unworthy of having a place in the group and saw others as being in a worse situation than them. It is important to therefore consider the impact these negative social comparisons can have, for example they may carry the additional burden of a suppression to talk with others and further social barriers impeding their engagement in the programme being delivered.

4.3.3. The effectiveness of a group based ACT programme for CP

To be cost effective, many CP programmes are delivered in a group context. The group setting is believed to be the primary medium of change, benefitting from member-to-member interaction (Burlingame, MacKenzie, & Strauss, 2004), which promotes activities and feedback among its members. Furthermore, the group environment often models

experiences that assist members in fostering enhanced social interactions outside the group (Corey, 2008).

The effectiveness of group ACT based programmes has been demonstrated in some functional domains such as depression and quality of life (Vowles & McCracken, 2010), however it is noted that CP is a subjective experience mitigated by many factors, including social support, gender and influence of care interventions (Asghari & Nicholas, 2001). Therefore further exploration of the group processes in future research could shed light on the dynamics between and within group members attending ACT based CP programmes.

Robinson and Henry (1978) describes how group based interventions provide mutual help and support as information is shared, experiences are shared, ways of coping or of changing are shared. Robinson and Henry (1978) further notes that sharing benefits the members of a group because it involves deconstruction and construction. Deconstruction involves concentrating of whatever the common problem is, identifying it, admitting to it and thus bringing it out in the open. Once this has been worked through, the second stage can begin which involves sharing information about the practical ways of coping with difficulties. A third stage is perhaps the most difficult to de-stigmatise the problems. This involves changing self-perception, and being part of a group of individuals who are in the same boat contributes to this process. Groups can therefore aid the reconstruction of people's lives, enabling and encouraging a new way of living, a new way of seeing oneself and ones place in the world (Robinson & Henry, 1978, p.26). This fits with the underlying philosophy of ACT of being able to reduce the impact of the struggle and suffering that pain may present, in order to re-evaluate a meaningful life.

Therefore the ACT programme for CP appeared to foster the de-stigmatisation for many of the participants as they were able to find normalcy amongst other group members with similar conditions to themselves.

4.4.   Implications for Clinical Practice

The findings of this study have several important implications. According to Glasgow, McKay, Piette, and Reynolds (2001), identifying the barriers to "accepting" a particular model or intervention is helpful in the development and implementation of successful future self-management programmes for patients with chronic illness. Furthermore it is acknowledged that understanding CP sufferers from their own perspective may have important clinical implications (Walker, Holloway, & Sofaer, 1999). Self-management practices are believed to promote physical and emotional health, therefore health care providers should be aware of what interferes with or helps patients to engage in these activities or interventions. The barriers and facilitators identified in this study may apply, not only to the management of CP, but also to the care of patients with many other chronic conditions.

The serenity prayer highlighted at the very beginning of this thesis in many ways sums up the challenge of learning to live with pain. It also has resonance for the debate over acceptance based intervention versus pain management. There are complex issues that patients and clinicians face when considering treatment options (Walsh, 2009). It can be argued that the decision as to when or whether to take the route of acceptance or seek another test or treatment is often a personal one, specific to the individual and within the limits of available resources. But the question remains how can people choose acceptance if they are not offered tangible options from the onset? Furthermore, as has been discussed in 4.2.4., this study raises the question of whether acceptance based interventions should be at the end of the road of treatment, or integrated within medical treatment options?

These issues raised from this study highlight concerns about the current evidence based practice (Barker, 2009). By offering ACT based programmes as a last resort option to patients with CP can lead patients to feel frustrated and let down by the medical route, therefore finding this approach as "second best" (Barker, 2009). Clinicians running ACT based interventions may then find it harder to present the ACT model as a positive way of coping as a result of these pre-programme assumptions and expectations. However, by offering ACT programmes at an earlier stage in the process, this may result in fewer cure seeking appointments, savings through lower drug costs and patients may spend less time

and money on alternative therapies. The option of an earlier ACT intervention may not be right for everyone; however it may work better than the current "end of the road" referral system?

It is noteworthy that when an intervention might improve quality of life, emotions inevitable come into play (Ray & Hester, 2009). As identified within this study, hope and hopelessness appear to be prisms through which people with pain may see possible outcomes, and these same emotions may cloud their listening making it harder to receive the messages from an intervention when they eventually reach that stage in their journey with pain. There may be a further link between the constructs of hope and hopelessness and the themes of benefits and barriers to acceptance as identified within this study which could lead to further investigation.

Emerging literature in the areas of social science and medicine suggest the need for caution in accepting a "one size fits all" approach inherent in a medical-political climate which strives to derive clinical decisions and guidelines exclusively from within the positivist defines of "evidence base" (H. D. Hadjistavropulous & T. Hadjistavropulous, 2000; Harldorsen et al., 2002; Harrison, 2002). Therefore it is important to consider the factors which facilitate and impede interventions such as an ACT based programme for CP as what works for one person with pain may not work for another (Sanders, 2000).

More extensive research could consider other factors such considerations of the length of the programme to achieve beneficial and enduring outcomes. Further investigation of the composition of the group members and questions such as whether the programme should be homogenous in age?

A possible suggestion as a result of the findings of this study is that clients are offered an orientation session prior to attending the ACT programme for chronic pain. This could serve to provide clients a space to begin to foster an atmosphere of *creative hopelessness* (Hayes et al., 1999), i.e. addressing what treatments haven't worked and why? And furthermore, providing an opportunity for clients to review their own as well as others previous experiences, with a view to empowering the clients to generate a more hopeful outlook in adopting the ACT approach.

The arising notion that group members might experience cognitive fusion with other's experiences in the group provides another possibility of addressing this more explicitly within the sessions themselves. Perhaps identifying the impact that this may have on individuals suffering may also provide further consideration of the impact that chronic pain has on the systems around the individual with chronic pain. The integration of a family/friend session during the programme helps people to address these issues further and more openly within the group and systemically with those around the group.

Invalidation is a subtle process, which clients may not always be aware of and which clinicians may not routinely identify (Mountford, Corstorphine, Tomlinson, & Waller, 2007). Including questions about these more subtle experiences in the assessment of clients for ACT interventions may bring these issues to light and allow for them to be included in clinical formulations. Moreover, on-going consideration of how prior experiences of being *invisible* and *feeling misunderstood* prior to an intervention may impact on subsequent engagement in an ACT programme for chronic pain.

Safran and Muran (2000) have written about how developmental histories of emotional invalidation might lead to individuals experiencing an on-going sense of misattunement to their own feelings and developing a critical stance towards themselves and their own needs, which may impact on the therapeutic process and create a 'barrier to relatedness' (pg. 104). They outline the importance of a therapist remaining attuned to the relational aspects of the therapeutic encounter and discuss the ways in which the therapeutic relationship can be used to facilitate the working through of issues to do with relatedness. It may be that the process of relating to others and relating to the self can be understood and targeted during an assessment (Safran & Muran, 2000). With regards to focusing on relational processes in ACT specifically, Hayes et al. (1999) discuss the importance of the therapeutic relationship in ACT and state that sensitivity to the client is the most important aspect of being an effective ACT practitioner. This provides additional support for the above claims.

4.5.   Methodological Considerations

The use of qualitative semi-structured interviews in this study enabled the researcher to gain a better understanding of individuals personal perspectives on their pain, acceptance and group based ACT intervention. As noted by Hallberg and Carlsson (2000), this methodology is particularly valuable tracing developmental changes and in capturing the complexity of adaptation to CP. However, capturing this learning process relied on the retrospective account of their experience of pain acceptance, which may have been influenced by their present acceptance and current pain experiences.

Rothwell (1998) noted that science does not occur without a specific context, and that qualitative approaches are "bringing into light of something that is taking account of its context". Qualitative research which considers the subjective experience of those living with CP has increasingly been identified as providing empirical evidence across a number of personal dimensions. These dimensions include people's beliefs about pain, its impact on their lives and their experiences of attending CP management programmes (Keponen & Kiehlhofner, 2006; Parsons et al., 2007). However, few studies have examined the impact of CP beyond 12 months post CP intervention (Jensen, Bergström, Ljungquist, & Bodin, 2005). There is little research addressing how people live with CP on an on-going basis and this is a consideration for future evaluative research within the area of acceptance and CP.

One methodology issue commonly cited when qualitative research is used is its limited generalisability across groups. As qualitative research aims for a deeper understanding of a phenomenon, being able to generalise the finds to others was not the aim here. However, Curtin and Fossey (2007) have asserted that transferability should apply to qualitative research if "detailed descriptions of the participant's experiences are provided to enable the reader to make comparisons with other individuals and groups". It can be argued that through providing accounts of the salient features of the participant's experiences pre, post and during the Luton and Dunstable Hospital ACT programme for CP in this study, comparisons to other ACT based interventions for CP can be made in future research.

Evaluation of the effects of any treatment requires that it be adequately administered (Kazdin & Mazurick, 1994). Integrity of treatment implementation can be enhanced through

rigorous training and regular supervision of therapists with procedures such as direct observation, review of audio or video tapes or feedback. This study did not describe the procedures used to train the group facilitators or to evaluate the delivery of the ACT programme. Future research could consider this factor and furthermore interviews with programme facilitators could provide information about the experience of conducting a group based ACT intervention itself.

4.5.1. Reflexivity

To ensure reflexivity the researcher kept a diary during the interview process. Conducting the interviews with the researcher's knowledge and personal experience of CP came with both strengths and limitations. In terms of advantages, shared experiences can lead to better access to and a stronger rapport with participants, as well as a deeper, readily accessible shared frame of reference (Mercer, 2007). However from a critical perspective, the shared experience may have also meant that there may have been a degree of assumed knowledge during the interviews and the process of analysis (Platt, 1981). Despite the interviews generating rich data, it could be questioned whether this insider experience of CP could have influenced the questions the researcher chose to probe or follow and whether different questions or areas could have been explored from an "outsider" position?

Nevertheless, opportunities to reflect on the areas for exploration and questions to ask prior to starting the study were negotiated through discussions with the researcher's supervisors, therefore helping to raise awareness and curiosity about areas for the researcher to explore.

An alternative analytical tool might have been to use IPA or a narrative approach for this study, focusing on the lived experience of the individual (Crossley, 2000). However as a relatively novice qualitative researcher, the structure offered by thematic analysis was appealing to the researcher (Braun & Clarke, 2006). Accordingly thematic analysis provided the best methodological fit with the research questions aiming to provide a qualitative exploration of the experience of attending a specific ACT programme for CP, rather than an exploration of the lived experience of adopting an ACT approach to chronic pain. The findings from this study however could be used to generate further research within this area and has highlighted factors which may be further understood in relation to a longitudinal study of chronic pain and acceptance.

4.5.2. Validity and reliability checks

Although one needs to remain cautious about claims of transferability due to the nature and size of a sample, having a large data set for a qualitative study can broaden the claims that can be made from the findings (Smith, Flowers, & Larkin, 2009). The fact that common themes were found amongst the interviews perhaps increases the transferability.

Working with data from twelve interviews has been challenging. The rich data set led to dilemmas about which themes to privilege over others. In order to address this issue, the researcher has been careful in following recommendations for systematically managing larger samples and on-going dialogue with supervisors (Smith et al., 2009). Rigour and reliability of the interpretation was ensured by conducting audit trails with the principal supervisor. For example, basic themes and organising themes were checked by identifying that a sufficient number of quotations were sourced from the textual data in justifying these themes. Where those quotations were inefficient the researcher and principle supervisor together reviewed the inclusion of the themes and either revised the theme or removed them.

4.6. Limitations and Future Research

The findings from this study suggest that people with CP inter-weave multiple dimensions of their illness perceptions such as cause, consequences, chronicity, treatment efficacy and ideas about cure along with issues regarding relationships, self-expectations, and responsibility. The use of qualitative methods provided an opportunity to explore the factors which shape individuals perspectives on acceptance and their pain, thus enabling for further consideration and appropriate support to be provided within future ACT interventions.

Understanding client's attitudes is particularly important considering the findings of a systematic review of the evidence for a relationship between clients recovering expectations and health outcomes (Mondloch, Cole, & Frank, 2001). There is perhaps a need for health care providers to foster client's motivation to work towards achieving recovery goals, which requires an open and supportive dialogue between health care providers and clients (Mondloch et al., 2001).

This study did not seek to empirically evaluate the ACT intervention for CP, instead a qualitative exploration provided an insight into the experiences, beliefs and processes for consideration for a sample of CP patients attending one ACT based programme for CP. The researcher is aware that an empirical evaluation of an intervention requires clear operational definitions of concepts and procedures, and the identification of conceptually sound mechanisms that may account for changes produced by the intervention (Chambless & Hollon, 1998).

It is noted that caution should be taken when considering the evaluations of the participants of the study as the majority of them had attended 6+ out of a possible 8 weekly sessions; therefore, further examination of the missing sessions could be attributed to the aspects of the programme which they found more difficult to grasp. The qualitative experiences highlighted within this study could also be compared with the pre and post outcome measures completed by participants in future research.

To build upon the findings from this study it would be necessary to conduct a longitudinal study design to provide additional information about the nature of the transition of the individual's journey with acceptance as they move from the ACT programme onwards and the significance of factors such as relationships with health professionals, age, and social support. In future research, it may be of interest to select one of the participant's interviews or a particular global theme such as *pre-programme expectations* for further analysis in order to illuminate further general versus specific issues in relation to the experience of attending an ACT programme for CP.

Brown (2003) argues that knowing *what* treatment components people with CP believe to be important, is of little value without knowing, *why.* This study has served to provide a preliminary profile of a sample of CP patient's beliefs in relation to one ACT group based programme for CP. Future research could consider the underlying processes of change with a view to further the development of the provision of acceptance based interventions for CP.

Traditional pain management programmes and multidimensional rehabilitation for CP has received some criticism such as the length of the programme and the expense of travelling

and committing to the intensive weekly intervention (Thorsall et al., 2011). Recently self-help treatment packages for CP have been developed and meta-analyses show positive results for self-help interventions with internet format (Ritterband et al., 2006) and with therapist support (Burman, 1994). In a recent study, Johnston et al., (2010), evaluated the effectiveness of an ACT based self-help book, 'Living Beyond Your Pain', for persons with CP. The study showed that over a six week period, the participants who completed the book with weekly support improved in acceptance, satisfaction with life and level of function and decrease in pain intensity, depression and anxiety, however lack of a comparative group receiving treatment warrants further investigation into the use of self-help treatment packages.

Therefore future research could explore further the focus of the presence of therapist support within ACT based interventions. Therapist support has previously been seen to be beneficial in self-help interventions (Watkins, Wollan, Melton, & Yawn, 2008), however it would be of clinical interest to consider the role of the therapist in the ACT based programmes and furthermore to investigate the comparisons with manual-based self-lead ACT interventions for CP. This exploration could provide a valuable addition to the findings raised within this study.

CONCLUSION

This study has made an important contribution in qualitatively exploring the experience of attending the Luton & Dunstable Hospital ACT programme for chronic pain (CP). To the authors knowledge, this is the first study to conduct semi-structured interviews with participants who have attended an ACT programme for CP, and the results have identified some interesting findings in relation to the expectations that individuals have prior to attending the programme. Furthermore the role of acceptance whilst living with CP has been addressed and the experience of a group based delivery of the ACT intervention has been discussed.

These findings provide some insight into the processes which may underlie the ability for an individual with CP to accept their difficulties and embark on the journey of living a valued life despite their pain. However acceptance of pain and related problems appears to be a stumbling block for many. Furthermore CP appears to remain poorly understood by society and many health care professionals.

The results from this study support the growing body of evidence that Acceptance and Commitment therapy shows promising results in the treatment of chronic pain treatment (Hayes, 2004)**.** The ultimate goal of any research process is the production of an "insightful, relevant and responsive piece of work" (Nimon, Murray, Sandow, & Goodfellow, 1998, p. 115). This research thesis has provided an opportunity for people with chronic pain, to share their expectations, understanding and experience of attending the Luton & Dunstable Hospital ACT programme for pain. This insight can set a foundation for further research to elaborate on the themes highlighted and any possibly connections between these themes and longer term outcomes. Additionally the role that facilitators of such programmes play in this process could be explored further.

It is hoped that sharing their experiences of this specific ACT programme for CP, the participants have in turn helped others who find themselves in similar circumstances and those who are in a position to provide such interventions for individuals in the future.

REFERENCES

Aldrich, S., Eccleston, C., & Crombez, G. (2000). Worrying about chronic pain: Vigilance to threat and misdirected problem-solving. *Behavioural Research and Therapy, 38*(5), 457-470.

Altheide, D., & Johnson, J. (1994). Criteria for Assessing Interpretive Validity in Qualitative Research. In N. Denzin and Y. Lincoln (Eds.), *Handbook of Qualitative Research* (pp. 485-499). London: Sage.

A-Tjak, J. & De Groot, F. (2008). Acceptance & Commitment Therapy. Houten. Bohn Stafleu van Loghum.

Antaki, C., Billig, M., Edwards, D., & Potter, J. (2002). Discourse analysis means doing analysis: A critique of six analytic shortcomings. *DAOL Discourse Analysis Online, 1*(1). Retrieved from http://extra.shu.ac.uk/daol/articles/open/2002/002/antaki2002002-paper.html

Asghari, A., & Nicholas, M. K. (2001). Pain self-efficacy beliefs and pain behaviour: A prospective study. *Pain, 94*(1), 85-100.

Attride-Stirling, J. (2001). Thematic networks: An analytic tool for qualitative research. *Qualitative Research, 1*(3), 385-405.

Bach, P., & Hayes, S. C. (2002). The use of acceptance and commitment therapy to prevent the rehospitalization of psychotic patients: A randomized controlled trial. *Journal of Consulting and Clinical Psychology, 70*(5), 1129-1139.

Bach, P., & Moran, D. J. (2008). *ACT in practice: case conceptualization in acceptance and commitment therapy.* Oakland, CA: New Harbinger.

Bair, M. J., Robinson, R. L., Katon, W., & Kroenke, K. (2003). Depression and pain comorbidity: A literature review. *Archives of Internal Medicine, 163*(20), 2433-2445.

Baker, R., Reddish, S., Robertson, N., Hearnshaw, H., & Jones, B. (2001). Randomised

controlled trial of tailored strategies to implement guidelines for the management of

patients with depression in general practice. *The British Journal of General Practice,*

51(470), 737–741.

Bandura, A. (1977). Self-efficacy: Toward a unifying theory of behavioral change.

Psychological Review, *84*(2), 191-215.

Banister, P., Burman, E., Parker, I., Taylor, M., & Tindall, C. (1994). *Qualitative Methods in*

Psychology: A research guide. Buckingham, PA: Open University Press.

Barker, C., Pistrang, N., & Elliott, R. (2002). *Research Methods in Clinical Psychology: An*

Introduction for Students and Practitioners (2nd ed.). Chichester, United Kingdom: John

Wiley & Sons Ltd.

Barker, K. (2009). Explaining the successes and failures of a chronic pain management

course. *European Journal of Pain, 13,* 263–264.

Becker, M. H., & Rosenstock, I. M. (1987). Comparing social learning theory and the health

belief model. In W. B. Ward (Ed.), *Advances in health education and promotion, 2*, 245-

249. Greenwich, CT: JAI.

Belgrave, L. (1990). The relevance of chronic illness in the everyday lives of elderly women.

Journal of Aging and Health, *2*(4), 475–500. doi: 10.1177/089826439000200404

Bendelow, G. A., & Williams, S. J. (1996). The End of the Road? Lay views on a pain relief

clinic. *Social Science & Medicine, 43*(7), 1127-1136.

Bigos, S., Bowyer, O., & Braen, G. (1994). Acute low back problems in adults. *Clinical Practice*

Guidelines, AHCPR Publications for Health Care Policy and Research. U.S. Department of

Human Health and Human Services, 14(95-0645).

Birch, M., & Miller, T. (2000). Inviting intimacy: The interview as "therapeutic opportunity."

   Social Research Methodology - Theory and Practice, *3*, 189-202.

Blyth, F. M., March, L. M., Brnabic, A. J., Jorms, L. R., Willliamson, M., & Cousins, M. J.

   (2001). Chronic pain in Australia: a prevalence study. *Pain, 89,* 127-134.

Bond, F. W., & Bunce, D. (2000). Mediators of change in emotion-focused and problem-

   focused worksite stress management interventions. *Journal of Occupational Health

   Psychology, 5*(1), 156-63. doi:10.1037//1076-8998.5.1.156

Boyatzis, R. (1998). *Transforming qualitative information: thematic analysis and code

   development*. Thousand Oaks, CA: Sage.

Burch, V. (2008). *Living well with pain & illness: The mindful way to free yourself from

   suffering.* Piatkus.

Branstetter-Rost, A., Cushing, C., & Douleh, T. (2009). Personal values and pain tolerance:

   Does a values intervention add to acceptance? *The Journal of Pain, 10*(8), 887-892.

   doi:10.1016/j/pain.2009.01.001

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in

   psychology, 3*(2), 77-101.

Breivik, H., Collett, B., Ventafridda, V., Cohen, R., & Gallacher, D. (2006). Survey of chronic

   pain in Europe: Prevalence, impact on daily life, and treatment. *European Journal of Pain,

   10*(4), 287-333.

Breslau, N. (1992). Migraine, suicidal ideation, and suicide attempts. *Neurology, 42*(2), 392-

   395.

British Psychological Society Ethics Committee (2004), *Code of Ethics and Conduct*. London,

   United Kingdom: The British Psychological Society.

British Pain Society. (1997). *Desirable criteria for pain management programmes*. London,

United Kingdom: British Pain Society.

British Pain Society. (2007). *Recommended guidelines for pain management programmes for*

adults. London, United Kingdom: British Pain Society.

British Pain Society (2008). *Intrathecal Drug Delivery for the Management of Pain and*

Spasticity in Adults; Recommendations for Best Clinical Practice. London, United

Kingdom: The British Pain Society.

Brown, C. A. (2003).Treatments for patients with chronic pain: therapists' beliefs.

International Journal of Therapy and Rehabilitation, *10*(2), 46-52.

Bullington, J., Nordemar, R., Nordemar, K., & Sjöström-Flanaghan, C. (2003). Meaning out of

chaos: A way to understand chronic pain. *Scandinavian Journal of Caring Sciences, 17*(4),

325-331.

Burlingame, G. M., MacKenzie, R. K., & Strauss, B. (2004). Small-group treatment: Evidence

for effectiveness and mechanism of change. In M. J. Lambert (Ed.), *Bergin's and Garfield's*

handbook of psychotherapy and behavioral change (5th ed., pp. 647-696). New York, NY:

John Wiley & Sons.

Burman, E. (1994). *Deconstructing Developmental Psychology.* London and New York:

Routledge.

Burr, V. (2003). *Social constructionism.* East Sussex: Routledge.

Canada. McMaster University. (1999). The effectiveness of cognitive-behavioral

interventions with people with chronic pain. A critical review of the literature. *Review*

Manager, 3.1.1., 1-31.

Caudill, M. A. (2002). *Managing pain before it manages you*. New York, NY: The Guilford

Press.

Chambless, D. L., Sanderson, W. C., Shoham, V., Bennett Johnson, S., Pope, K. S., Crits-Christoph, P., … McCurry, S. (1996). An update on empirically validated therapies. *The Clinical Psychologist, 49*, 5-18.

Chambless, D. L., & Hollon, S. D. (1998). Defining empirically supported therapies. *Journal of Consulting and Clinical Psychology, 66*(1), 7–18.

Charmaz, K. (2006). Grounded Theory. In J.A. Smith (Ed.), *Qualitative Psychology: A practical guide to research methods.* London, United Kingdom: Sage.

Clark, D. A. (1995). Perceived limitations of standard cognitive therapy: A reconsideration of efforts to revise Beck's theory and therapy. *Journal of Cognitive Psychotherapy, 9*(3), 153–172.

Clark, D. M. (1998, September). *Anxiety disorders: Why they persist and how to treat them.* Keynote address. 28th Annual Congress of the European Association of Behavioural and Cognitive Therapies, Cork, Ireland.

Clinical Standards Advisory Group (CSAG) (1994). *Epidemiology review: The epidemiology and cost of back pain*. London, United Kingdom: HMSO

Cole, P. A. (1998). New developments in rehabilitation of neuropathic pain syndromes. *Neurologic Clinics, 16*(4), 937–950.

Coll, R. K., & Chapman, R. (2000). Choices of methodology for cooperative education researchers. *Asia-Pacific Journal of Cooperative Education, 1*, 1-8.

Connor-Smith, J. K., Compas, B. E., Wadsworth, M. E., Thomsen, A. H., & Saltzman, H. (2000). Responses to stress in adolescence: Measurement of coping and involuntary stress responses. *Journal of Consulting and Clinical Psychology, 68,* 976-992.

Copp, L. (1974). The spectrum of suffering. *The American Journal of Nursing, 74*(3), 491-494. doi:10.2307/3469642

Corbin, J., & Strauss, A. (1990). Grounded theory research: procedures, canons and

evaluative criteria. *Qualitative Sociology, 13*(1), 3-21.

Corey, G. (2008). *Theory and practice of group counselling* (8th ed.). Belmont, CA: Thompson

Brooks/Cole.

Cousins, C. (2002). Getting to the "truth": Issues in contemporary qualitative research.

Australian Journal of Adult Learning, 42(2), 192-204.

Crombez, G., Vervaet, L., Lysens, R., Baeyens, F., & Eelen, P. (1998). Avoidance and

confrontation of painful, back-straining movements in chronic back pain patients.

Behavior Modification, 22(1), 62-77.

Crombez, G., Vlaeyen, J. W., Heuts, P. H., & Lysens, R. (1999). *Pain, 80*(1-2), 329-339.

Crossley, M. L. (2000). *Introducing narrative psychology: Self, trauma, and the construction

of meaning*. Buckingham, PA: Open University Press.

Curtin, M., & Fossey, E. M. (2007). Appraising the trustworthiness of qualitative studies:

Guidelines for occupational therapists. *Australian Journal of Occupational Therapy, 54*(2),

88-94. doi:10.1111/j.1440-1630.2007.00661.x

Dahl, J., Wilson, K. G., & Nilsson, A. (2004). Acceptance and Commitment Therapy and the

treatment of persons at risk for long-term disability resulting from stress and pain

symptoms: A preliminary randomized trial. *Behavior Therapy, 35,* 785-801.

Dahl, J. C., Wilson, K. G., Luciano, C., & Hayes, S. C. (2005). *Acceptance and commitment

therapy for chronic pain*. Reno, NV: Context Press.

Dahl, J. C., & Lundgren, T. (2006). *Living beyond your pain: Using acceptance and

commitment therapy to ease chronic pain*. Oakland, CA: New Harbinger Publications.

Davies, H. T. O., Crombie, I. K., Macrae, W. A., & Rogers, K. M. (1992). Pain clinic patients in

northern Britain. *Pain Clinic*, *5,* 129-135.

Davis, C. G., Wortman, C. B., Lehman, D. R., & Silver, R. C. (2000). Searching for meaning in loss: Are clinical assumptions correct? *Death Studies,* 24, 497-540.

DeGood, D. E., & Tait, R. C. (2001). Assessment of pain beliefs and pain coping. In D. C. Turk & R. Melzack (Eds.), *Handbook of pain assessment*. (2nd ed., pp. 320-345). New York, NY: Guilford Press.

Dempsey, P. A., & Dempsey, A. D. (2000). *Using Nursing Research: Process, Critical Evaluation and Utilization*. (5th ed.). Philadelphia, PA: Lippincott Williams and Wilkins.

DeRubeis, R. J., Tang, T.Z., & Beck, A.T. (2001). Cognitive therapy. In K. S. Dobson (Ed.), *Handbook of cognitive behavioral therapies* (2nd ed., pp. 349-392). New York, NY: Guilford Press.

Devor, M., & Tal, M. (2009). What causes low back pain? *Pain, 142*(1-2), 11-12.

Dey, I. (1993). *Qualitative data analysis: A user-friendly guide for social scientists*. London: Routledge Kegan Paul.

Diamond, A.W., & Coniam, S.W. (1997). *The Management of Chronic Pain*. New York, NY: Oxford University Press.

Donalek, J. G. (2005). Demystifying nursing research: The interview in qualitative research. *Urologic Nursing*, *25(2)*, 124-125.

Dunmore, E., Clark, D. M., & Ehlers, A. (1999). Cognitive factors involved in the onset and maintenance of PTSD. *Behaviour Research and Therapy, 37*(9), 809-929.

Dunmore, E., Clark, D.M., & Ehlers, A. (2001). A prospective investigation of the role of cognitive factors in persistent Post Traumatic Stress Disorder (PTSD) after physical and sexual assault. *Behaviour Research and Therapy, 39*(9), 1063-1084.

Eccles, M., & Mason, J. (2001). How to develop cost-conscious guidelines. *Health Technology Assessment , 5*(16), 1-69.

Eccleston, C., Williams, A. C., & Morley, S. (2009). Psychological therapies for the management of chronic pain in adults. *Cochrane Database Systematic Review, 15*(2) CD007407.

Edward, R. R., Smith, M. T., Kudel, I., & Haythornthwaite, J. A. (2006). Pain-related catastrophizing as a risk factor for suicidal ideation in chronic pain. *Pain*, *126*(1-3), 272-279.

Egoscue, P., & Gittines, R. (1998). *Pain free: A revolutionary method for stopping chronic pain.* New York, NY: Bantam Books.

Elliott, R., Fischer, C.T. & Rennie, D.L. (1999). Evolving guidelines for publication of qualitative research studies in psychology and related fields. *British Journal of Clinical Psychology, 38,* 215-229.

Festinger, L. A. (1954). A theory of social comparison processes. *Human Relations, 7*(2), 117-140. doi:10.1177/001872675400700202

Fletcher, L., & Hayes, S. C. (2005). Relational frame theory, acceptance and commitment therapy and a functional analytic definition of mindfulness. *Journal of Rational-Emotive and Cognitive Behavior Therapy, 23*(4), 315-336. doi:10.1007/s10942-005-0017-7

Flor, H., & Turk, D.C. (1998). Chronic back pain and rheumatoid arthritis: Predicting pain and disability from cognitive variables. *Journal of Behavioral Medicine, 11*(3), 251-265. doi:10.1007/BF00844431

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

Fordyce, W. E. (1995). *Back pain in the workplace.* Seattle, WA: IASP Press.

Frank, A. (1993). Low back pain. *BMJ, 306,*901-9*.* doi:10.1136/bmj.306.6882.901

Gardner-Nix, J. (2009). Mindfulness-based stress reduction for chronic pain management. In F. Didonna (Ed). *Clinical Handbook of Mindfulness* (pp. 369-381). New York, NY: Springer.

Gatchel, R. J., & Okifuji, A. (2006). Evidence-based scientific data documenting the

treatment and cost-effectiveness of comprehensive pain programmes for chronic non-

malignant pain. *The Journal of Pain, 7(11), 779-793.*

Gatchel, R. J., Peng, Y. B., Peters, M. L., Fuchs, P. N., & Turk, D. C. (2007). The

biopsychosocial approach to chronic pain: scientific advances and future directions.

Psychological Bulletin, 133(4), 581-624.

Geisser, M. E., Roth, R. S., & Robinson, M. E. (1997). Assessing depression among persons

with chronic pain using the Center for Epidemiological Studies—depression scale and the

beck depression inventory: a comparative analysis. *Clinical Journal of Pain, 13,* 163–70.

Gifford, E. V., Kohlenberg, B. S., Hayes, S. C., Antonuccio, D. O., Piasecki, M. M., Rasmussen-

Hall, M. L., & Palm, K. M. (2004). Acceptance theory-based treatment for smoking

cessation: An initial trial of acceptance and commitment therapy. *Behavior Therapy, 35,*

689–705.

Glaser, B. G., & Strauss, A. L. (1967). *The discovery of grounded theory: Strategies for*

qualitative research. New York, NY: Aldine Transaction.

Glasgow, R. E., McKay, H. G., Piette, J. D., & Reynolds, K. D. (2001). The RE-AIM framework

for evaluating interventions: What can it tell us about approaches to chronic illness

management? *Patient Education and Counseling, 44*(2), 119-127.

Glenn, B., & Burns, J. W. (2003). Pain self-management in the process and outcome of

multidisciplinary treatment of chronic pain: Evaluation of a stage of change model.

Journal of Behavioral Medicine, 26(5), 417-433.

Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*. New Jersey:

Prentice Hall.

Gould, R. A. & Clum, G. A. (1993). A meta-analysis of self-help treatment approaches. *Clinical Psychology Review, 13*(2), 169-186.

Gregg, J. A., Callaghan, G. M., Hayes, S. C., & Glenn-Lawson, J. L. (2007). Improving diabetes self-management through acceptance, mindfulness, and values: A randomized controlled trial. *Journal of Consulting and Clinical Psychology, 75*(2), 336–343.

Guba, E. G. (1978). *Toward a methodology of naturalistic inquiry in educational evaluation*. *CSE Monograph Series in Evaluation, 8.* Los Angeles, CA: UCLA Center for the Study of Evaluation.

Guba, E. G. (1981). Criteria for assessing the trustworthiness of naturalistic inquiries. *Educational Communication and Technology Journal, 29*(2), 75–91. doi:10.1007/BF02766777

Gullacksen A. C. (1998). När smärtan blir en del av livet. Livsomställningvid kronisk sjukdom och funktionshinder. (When pain becomes part of life. Coping with chronic illness and disability). *Helsingborg, Gyllene snittet AB,* (In Swedish, Thesis).

Gureje, O., Von Korff, M., Simon, G.E., & Gater, R. (1998). Persistent pain and well-being. A World Health Organization study in primary care. *The Journal of the American Medical Association, 280*(2), 147-151.

Gutiérrez, O., Luciano, C., Rodríguez, M., & Fink, B. (2004). Comparison between an acceptance-based and a cognitive-control-based protocol for coping with pain. *Behavior Therapy, 35*, 767-783.

Guzmán J., Esmail R., Karjalainen K., Malmivaara, A., Irvin E., & Bombardier C. (2001). Multidisciplinary rehabilitation for chronic low back pain: Systematic review. *BMJ, 322*(7301), 1511-1516.

Hadjistavropoulos, H., & Shymkiw, J. (2007). Predicting readiness to self-manage pain. *The Clinical Journal of Pain, 23*(3), 259–266.

Hadjistavropulous, H. D., & Hadjistavropulous, T. (2000). Health anxiety moderates the effects of distraction versus attention to pain. *Behaviour Research and Therapy*, *38*(5), 425-438.

Hallberg, L. R. M., & Carlsson, S. G. (1998). Psychosocial vulnerability and maintaining forces related to fibromyalgia. *Scandinavian Journal of Caring Science, 12*, 95–103.

Hampson, S. E., Glasgow, R. E., & Zeiss, A. (1994). Personal models of osteoarthritis and their relation to self-management activities and quality of life. *Journal of Behavioral Medicine, 17*(2), 143-158. doi:10.1007/BF01858102

Hardcastle, V. G., (1999). *The Myth of Pain*. Cambridge, MA: MIT Press.

Harldorsen, E.M., Grasdal, A.L., Skoven, J. S., Risa, A. E., Kronholm, K. & Ursin, H. (2002). Is there a right treatment for a particular patient group? Comparison of ordinary treatment, light multidisciplinary treatment, and extensive multidisciplinary treatment for long term sick listed employees with musculoskeletal pain. *Pain, 95*(1-2), 49-63.

Harris, R. (2008). *The Happiness Trap: How to stop struggling and start living.* South Africa: Trumpeter.

Harris, R. (2009). *ACT made simple: An Easy-to-Read Primer on Acceptance and Commitment Therapy.* Oakland, CA: New Harbinger Publications.

Harrison, S. (2002). New Labour, modernisation and the medical labour movement. *Journal of Social Policy*, *31,* 465-485.

Hayes, S. C., Brownstein, A. J., Zettle, R. D., Rosenfarb, I., & Korn, Z. (1986). Rule-governed behaviour and sensitivity to changing consequences of responding. *Journal of the Experimental Analysis of Behaviour, 45,237-256.*

Hayes, S. C., & Wilson, K. G. (1994). *Acceptance and commitment therapy: an experiential approach to behaviour change*. New York, NY: Guilford Press.

Hayes, S. C., Wilson, K. G., Gifford, E. V., Follette, V. M., & Strosahl, K. (1996). Experiential avoidance and behavioral disorders: A functional dimensional approach to diagnosis and treatment. *Journal of Consulting and Clinical Psychology, 64*(6), 1152-1168.

Hayes, S. C., & Batten, S. V. (1999a). Acceptance and Commitment Therapy. *European Psychotherapy*, *1*(1), 2-9.

Hayes, S. C., Bissett, R., Korn, Z., Zettle, R., Rosenfarb, I., Cooper, L., & Grundt, A. (1999b). The impact of acceptance versus control rationales on pain tolerance. *The Psychological Record, 49*(1), 33-47.

Hayes, S.C., Barnes-Holmes, D., & Roche, B. (2001). *Relational Frame Theory. A post-Skinnerian account of human language and cognition.* New York, NY: Kluwer Academic/Plenum Publishers.

Hayes, S. C., Strosahl, K. D., & Wilson, K. G. (2003). *Acceptance and commitment therapy: An experiential approach to behaviour change.* New York, NY: Guilford Press.

Hayes, S. C. (2004). Acceptance and commitment therapy, relational frame theory and the third wave of behavioral and cognitive therapies. *Behavior Therapy, 35*(4), 639-665.

Hayes, S. C., & Smith, S. (2005). *Get out of your mind & into your life: The new acceptance & commitment therapy.* Oakland, CA: New Harbinger Publications.

Hayes, S. C., Luoma, J. B., Bond, F. W., Masuda, A., & Lillis, J. (2006). Acceptance and commitment therapy: Model, processes and outcomes. *Behaviour Research and Therapy, 44*(1), 1-25.

Hayes, S. C., & Strosahl, K. D. (2010). *A practical guide to acceptance and commitment therapy*. New York, NY: Springer Science+Business Media.

Healy, M., & Perry, C. (2000). Comprehensive criteria to judge validity and reliability of qualitative research within the realism paradigm. *Qualitative Market Research – An International Journal, 3*(3), 118-126.

Heffner, M., Eifert, G. H., Parker, B. T., Hernandez, D. H., & Sperry, J. A. (2003). Valued directions: Acceptance and commitment therapy in the treatment of alcohol dependence. *Cognitive and Behavioral Practice, 10*(4), 378–383.

Hellstrom, C. (2001). Temporal dimensions of the self-concept: entrapped and possible selves in chronic pain. *Psychology & Health, 16*(1), 111-124. doi:10.1080/08870440108405493

Herzlich, C. (1973). *Health and illness: a social-psychological analysis.* European Monographs in Social Psychology, (5). London: Academic Press.

Hildebrandt, J., Pfingsten, M., Saur, P., & Jansen, J. (1997). Prediction of success from a multidisciplinary treatment programme for chronic low back pain. *Spine, 22*(9), 990–1001.

Hitchcock, L.S., Ferrell, B. R., & McCaffery, M. (1994). The experience of chronic non-malignant pain. *Journal of Pain and Symptom Management, 9*(5), 312-318.

Hoffman, B.M., Papas, R.K., Chatkoff, D.K., & Kerns, R.D. (2007). Meta-analysis of psychological interventions for chronic low back pain. *Health Psychology, 26*(1), 1-9.

Hoffman, S. G., & Asmundson, G. J. G. (2008). Acceptance and mindfulness-based therapy: New wave or old hat? *Clinical Psychology Review, 28*(1), 1-16.

International Association for the Study of Pain (1986). Classification of Chronic Pain. Description of pain syndromes and definitions of pain terms. *Pain, Supplement, (S3).*

International Association for the Study of Pain Ad Hoc Committee. (1994). Pain curriculum

for students in occupational therapy or physiotherapy. *IASP Newsletter (3-8).* Seattle,

WA: International Association for the Study of Pain.

Jacobson, N. S., Dobson, K. S., Traux, P.A., Addis, M. E., Koerner, K., & Gollan, J.K., (1996). A

component analysis of cognitive behavioral treatments for depression. *Journal of*

Consulting and Clinical Psychology, 64(2), 295-304.

Jensen, M. P., Turner, J., Romano, J., & Karoly, P. (1991). Coping with chronic pain: A critical

review of the literature. *Pain, 47*(3), 249-283.

Jensen, M. P., Turner, J. A., Romano, J. M., & Lawler, B. K. (1994). Relationship of pain-

specific beliefs to chronic pain adjustment. *Pain, 57*(3), 301-309.

Jensen, M.P. & Karoly, P. (2001). Self-report scales and procedures for assessing pain in

adults. In Turk, D.C. & Melzack, R. (Eds). *Handbook of Pain Assessment*. (2nd ed., pp. 15-

34). London: The Guilford Press

Jensen, M. P., Nielson, W. R., & Kerns, R. D. (2003). Toward the development of a

motivational model of pain self-management. *The Journal of Pain, 4*(9), 477-492.

Jensen, I. B., Bergström, G., Ljungquist, T., & Bodin, L. (2005). A 3-year follow-up of a

multidisciplinary rehabilitation programme for back and neck pain. *Pain, 115*(3), 273-83.

Jerant, A. F., von Friederichs-Fitzwater, M. M.,& Moore, M. (2005). Patients' perceived

barriers to active self-management of chronic conditions. *Patient Education and*

Counseling. 57(3), 300–307.

Johnston, M., Foster, M., Shennan, J., Starkey, N. J., & Johnson, A. (2010). The effectiveness

of an acceptance and commitment therapy self-help intervention for chronic pain.

Clinical Journal of Pain, 26(5), 393–402.

Kabat-Zinn, J. (1990). *Full catastrophe living: Using the wisdom of your body and mind to face stress, pain and illness*. New York, NY: Delta.

Kazdin, A. E., & Mazurick, J. L. (1994). Dropping out of child psychotherapy: Distinguishing early and late drop outs over the course of treatment. *Journal of Consulting and Clinical Psychology, 62*(5), 1069-1074.

Keefe, F. J., & Caldwell, D.S. (1997). Cognitive behavioral control of arthritis pain. *The Medical Clinics of North America, 81*(1), 277-290.

Keefe, F. J., Beaupre, P. M., Gil, K. M., Rumble, M. E., & Aspnes, A. K. (2002). Group therapy for patients with chronic pain. In R. J. Gatchel & D.C. Turk (Eds.), *Psychological approaches to pain management* (2nd ed., pp. 234-255). New York, NY: Guilford Press

Keefe, F. J., Rumble, M. E., Scipio, C. D., Giordino, L. A. & Perri, L. M. (2004). Psychological aspects of persistent pain: current state of the science. *The Journal of Pain*, *5*(4), 195-211.

Keponen, R., & Kielhofner, G. (2006). Occupation and meaning in the lives of women with chronic pain. *Scandinavian Journal of Occupational Therapy, 13*(4), 211-220.

Kleinman, A. (1988). *The illness narratives: suffering, healing and the human condition*. New York, NY: Basic Books.

Kohlenberg, R. J. & Tsai, M. (1995). I speak, therefore I am: A behavioral approach to understanding problems of the self. *The Behavior Therapist, 18,* 113-124.

Kolakowski, L. (1972). *Positivist Philosophy: From Hume to the Vienna Circle*. Harmondsworth, United Kingdom: Penguin.

Krauss, S.E. (2005). Research Paradigms and Meaning Making: A Primer. *The Qualitative Report, 10*(4), 758-770.

Lachapelle, D. L., Lavoie, S., & Boudreau, A. (2008). The meaning and process of pain

   acceptance. Perceptions of women living with arthritis and fibromyalgia. *Pain

   Research and Management, 13*(3), 201-210.

Lazarus, R.A. & Folkman, S. (1984). _Stress, appraisal and coping._ New York, NY: Springer.

Lee, M., & Fielding, N. (1996). Qualitative data analysis: representations of a technology: A

   Comment on Coffey, Holbrook and Atkinson. *Sociological Research Online, 1*(4), 55.

   doi:10.4135/9780857028211

Leventhal, H., Leventhal, E., & Contrada, R. J. (1998). Self-regulation, health and behaviour:

   A perceptual cognitive approach. *Psychology and Health, 13*(4), 717–734.

   doi:10.1080/08870449808407425

Levine, M. & Hayes, S. C. (2009). Is acceptance and commitment therapy superior to

   established treatment comparisons? *Psychotherapy and Psychosomatics, 78*, 380.

Lewis, S.E. (1995). A search for meaning: making sense of depression. *Journal of Mental

   Health, 4*(4), 369-382. doi:10.1080/09638239550037424

Linehan, M. M. (1993). *Cognitive Behavioral Treatment for Borderline Personality Disorder*.

   New York, NY: Guilford Press.

Linton, S. J. (1995). An overview of psychosocial and behavioural factors in neck and

   shoulder pain. *Scandinavian Journal of Rehabilitation Medicine, 32,* 67-77.

Linton, S. J., & Nordin, E. (2006). A 5-year follow-up evaluation of the health and economic

   consequences of an early cognitive behavioural intervention for back pain: A randomized

   controlled trial. *Spine, 31*(8), *853-858.*

Loeser, J. D. (1991). What is chronic pain? *Theoretical Medicine and Bioethics, 12*(3)**,** 213-

   225.

Lohnberg, J. A. (2007). A review of outcome studies on cognitive-behavior therapy for reducing fear-avoidance beliefs among individuals with chronic pain. *Journal of Clinical Psychological Medical Settings, 14*(2), 113-122.

Longmore, R. J., & Worrell, M. (2007). Do we need to challenge thoughts in cognitive behavior therapy? *Clinical Psychology Review, 27*(2), 173-187.

Lorig, K. (1990, April). *Self-efficacy: Its contributions to the four year beneficial outcome of the arthritis self-management course*. Paper presented at the meeting of the Society for Behavioral Medicine, Chicago, IL.

Lundgren, T., Dahl, J., & Hayes, S. C. (2008). Evaluation of mediators of change in the treatment of epilepsy with Acceptance and Commitment Therapy. *Journal of Behaviorial Medicine, 31*(3)*,* 225-235.

Luoma, J. B., Kohlberg, B. S., Hayes, S. C., & Bunting, K. (2008). Reducing self-stigma in substance abuse through acceptance and commitment therapy: model, manual development, and pilot outcomes. *Addiction Research & Theory, 16*(2), 149-165.

Maddux, J. E., & Rogers, R.W. (1983). Protection motivation and self-efficacy: A revised theory of fear appeals and attitude change. *Journal of Experimental Social Psychology, 19,* 469-479.

Main, C. J., & Booker, C. K. (2000). The nature of psychological factors. In C. J. Main & C. Spanswick (Eds.) *Pain Management: An Interdisciplinary Approach* (pp. 19 – 42). London, United Kingdom: Churchill Livingstone.

Main, C. J., Sullivan, M. J. L., & Watson, P. J. (2008). *Pain Management: Practical applications of the biopsychosocial perspective in clinical and occupational settings*. Edinburgh, United Kingdom: Elsevier.

Mao, J. (2009). Translational Pain Research: Achievements and Challenges. *The Journal of Pain, 10*(10), 1001–1011.

Martensson, L., & Dahlin-Ivanoff, S. (2006). Experiences of a primary health care rehabilitation programme. A focus group study of persons with chronic pain. *Disability and Rehabilitation, 28*(16), 985-995.

Maxwell, J.A. (2002). Understanding and validity in qualitative research. In A.M. Huberman & M.B. Miles (Eds.) *The qualitative researcher's companion* (pp.37-64). London, United Kingdom: Sage Publications.

Mayer, T. G., & Gatchel, R. J. (1998). *Functional restoration for spinal disorders: The sports medicine approach*. Philadelphia, PA: Lea & Febiger.

McCaffery, M., & Pasero, C. (1999). *Pain: Clinical Manual* (2nd ed.). St. Louis, MO: Mosby.

McCall, J. (1990). Fostering self-esteem. *Surgical Nurse, 3,* 4-9.

McCracken, L. M. (1998). Learning to live with the pain: Acceptance of pain predicts adjustment in persons with chronic pain. *Pain, 74*(1), 21-27.

McCracken, L.M., & Gross, R.T. (2002). Multi-method assessment of treatment process in chronic low back pain: comparison of reported pain-related anxiety with directly measured physical capacity. *Behaviour Research and Therapy, 40*(5), 585-594.

McCracken, L. M., & Turk, D. C. (2002). Behavioral and cognitive-behavioral treatment for chronic pain. *Spine, 27*(22), 2564-2573.

McCracken, L.M., & Eccleston, C. (2003). Coping or acceptance: what to do about chronic pain? *Pain, 105*(1–2), 197–204.

McCracken, L. M., Carson, J. W., Eccleston, C., & Keefe, F. J. (2004). Acceptance and change in the context of chronic pain. *Pain, 109*(1-2), 4-7.

McCracken, L. M. (2005a). *Contextual cognitive-behavioral therapy for chronic pain*. Seattle, WA: IASP Press.

McCracken, L. M., Vowles, K. E., & Eccleston, C. (2005b). Acceptance-based treatment for persons with complex, long standing chronic pain: A preliminary analysis of treatment outcome in comparison to a waiting phase. *Behaviour Research and Therapy, 43*(10), 1335-1346.

McCracken, L. M. & Velleman, S. (2010). Psychological flexibility in adults with chronic pain: a study of acceptance, mindfulness, and values-based action in primary care. *Pain, 148,* 141-147.

McCracken, L. M., & Gutierrez-Martinez, O. (2011). Processes of change in psychological flexibility in an interdisciplinary group-based treatment for chronic pain based on acceptance and commitment therapy. *Behaviour Research and Therapy, 49*(4), 267-274.

McLean, S. A., & Clauw, D. J. (2005). Biomedical models of fibromyalgia. *Disability and Rehabilitation, 27*(12), 659-665. doi:10.1080/09638280400009048

McLeod, J. (2001). *Qualitative research in counselling and psychotherapy.* London, United Kingdom: Sage.

Meehan, T., Vermeer, C., & Windsor, C. (2000). Patient's perceptions of seclusion: A qualitative investigation. *Journal of Advanced Nursing, 31*(2), 370-377.

Melzack, R., & Wall, P. D. (1965). Pain mechanisms: a new theory. *Science, 150,* 971-979.

Melzack, R., & Wall, P. D. (1996). *The challenge of pain: A modern medical classic*. London, United Kingdom: Penguin Books.

Mercer, J. (2007). The challenges of insider research in educational institutions: Wielding a double-edged sword and resolving delicate dilemmas. *Oxford Review of Education, 33*(1), 1 - 17.

Merskey, H., & Bogduk, N. (1994). *Classification of chronic pain. Descriptions of Chronic Pain Syndromes and Definitions of Pain Terms*. Seattle, WA: International Association for the Study of Pain.

Mikulincer, M., & Segal, J. (1990). A multidimensional analysis of the experience of loneliness. *Journal of Social and Personal Relationships, 7,* 209-230.

Mondloch, M. V., Cole, D. C., & Frank, J. W. (2001). Does how you do depend on how you think you'll do? A systematic review of the evidence for a relation between patients' recovery expectations and health outcomes. *Canadian Medical Association Journal*, *165*(2), 174-179.

Morley, S., Eccleston, C., & Williams, A. (1999). Systematic review and meta-analysis of randomized controlled trials of cognitive behaviour therapy for chronic pain in adults, excluding headache. *Pain, 80*(1-2), 1-13.

Morley, S. (2004). Process and change in cognitive behaviour therapy for chronic pain. *Pain, 109*(3), 205-206.

Morley, S., Davies, C., & Barton, S. (2005). Possible selves in chronic pain: Self-pain enmeshment, adjustment and acceptance. *Pain*, *115*(1-2), 84-94.

Morley, S., Eccleston, C. & Williams, A. (2009). Systematic review and meta-analysis of randomised controlled trials of cognitive-behavioural therapy and behaviour therapy for chronic pain in adults, excluding headache. *Pain, 80,* 1-13.

Moseley, L. (2003). Unraveling the barriers to reconceptualization of the problem in chronic pain: the actual and perceived ability of patients and health professionals to understand the neurophysiology. *The Journal of Pain, 4*(4), 184-189.

Mountford, V., Corstorphine, E., Tomlinson, S., & Waller, G. (2007). Development of a measure to assess invalidating childhood environments in the eating disorders. *Eating Behaviours, 8(*1), 48-58.

National Institute for Health and Clinical Excellence. (2009). *Clinical Guideline 88 – Low Back Pain: Early management of persistent non-specific low back pain.* London, United Kingdom: NHS.

Nicholas, M. K., Wilson, P. H., & Goyen, J. (1992). Comparison of cognitive-behavioral group treatment and an alternative non-psychological treatment for chronic low back pain. *Pain, 48*(3), 339-347.

Nicholas, M. K., Molloy, A., Beeston, L., & Tonkin, L. (2000). *Manage Your Pain: Practical and positive ways of adapting to chronic pain.* London, United Kingdom: Souvenir Press.

Nicholas, M. K., & Asghari, A. (2006). Investigating acceptance in adjustment to chronic pain: Is acceptance broader than we thought? *Pain, 124*(3), 269-279.

Nicolson, P. (1995). Qualitative research, psychology and mental health: Analysing subjectivity. *Journal of Mental Health, 4*(4), 337-346.

Nimon, G., Murray, D., Sandow, M., & Goodfellow, J. (1998). Natural history of anterior knee pain: a 14- to 20-year follow-up of non-operative management. *Journal of Paediatric Orthopaedic, (18)*, 118-122.

Notcutt, W. (2008, June). *Nice 'n nasty, interestin' and mundane-Fairness in the Clinic.* Paper presented at The British Pain Society - Special Interest Group for Philosophy and Ethics: Suffering and Science, Launde Abbey, United Kingdom.

Notcutt, W., & Gibbs, G. (2010). Inadequate pain management: myth, stigma and professional fear. *Postgraduate Medical Journal, 86*(1018), 453–8. doi:10.1136/pgmj.2008.077677

O'Leary, A. (1990). Stress, emotion and human function experience. *Psychological Bulletin, 108*(3), 363-382.

Opler, M. E. (1945). Themes as dynamic forces in culture. *American Journal of Sociology, 51*(3), 198–206.

Orsillo, S. M., Roemer, L., & Barlow, D. H. (2003). Integrating acceptance and mindfulness into existing cognitive-behavioral treatment for GAD: A case study. *Cognitive and Behavioral Practice, 10*(3), 222-230.

Ost, L. G. (2008). Efficacy of the third wave of behavioral therapies: A systematic review and meta-analysis. B*ehaviour Research & Therapy, 46(*3), 296-321.

Ostelo, R. W. J. G., van Tulder, M. W., Vlaeyen, J. W. S., Linton, S. J., Morley, S. & Assendelft, W. J. J. (2008). *Behavioural treatment for chronic low-back pain (review).* [Wiley Online Library]. doi:10.1002/14651858.CD002014

Paley, G., & Lawton, D. (2001). Evidence-based practice: accounting for the importance of the therapeutic relationship in the UK National Health Service therapy provision. *Counsel Psychotherapy Research, 1*(1), 12-7

Parsons, S., Harding, G., Breen, A., Foster, N., Pincus, T., Vogel, S., & Underwood, M. (2007). The influence of patients' and primary care practitioners' beliefs and expectations about chronic musculoskeletal pain on the process of care: A systematic review of qualitative studies. *The Clinical Journal of Pain, 23*(1), 91-98.

Pasero, C. (2004). Pathophysiology of neuropathic pain. *Pain Management Nursing, 5*(Supplement), 3-8.

Patton, M. Q. (1990). Qualitative evaluation and research methods. (2nd ed.). Newbury Park, CA: Sage.

Paulson, G., Everall, R. & Stuart, J. (2001). Client perceptions of hindering experiences in

counselling. *CPR, 1*(1), 53-61.

Peolsson, M., Hydén, L. C., & Sätterlund Larsson, U. (2000). Living with chronic pain: A

dynamic learning process. *Scandinavian Journal of Occupational Therapy, 7*(3), 114-125.

doi:10.1080/110381200300006069

Pepper, S. C. (1942). *World Hypotheses: A study in evidence.* Berkley, CA: University

California Press.

Pincus, T., & Williams, A. (1999). Models and measurements of depression in chronic pain.

Journal of Psychosomatic Research, 47, 211-219.

Pincus, T., & Morley, S. (2001). Cognitive-processing bias in chronic pain: A review and

integration. *Psychological Bulletin, 127*(5), 599–617.

Pincus, T., Burton, A. K., Vogel, S., & Field, A. P. (2002). A systematic review of psychological

factors as predictors of chronicity/disability in prospective cohorts of low back pain.

Spine, 27(5), E109 –E120.

Pincus, T., & Morley, S. (2002). Cognitive appraisal. In S. J. Linton (Ed.), *New avenues for the*

prevention of chronic musculoskeletal pain and disability. Pain research and clinical

management (12). Amsterdam, Holland: Elsevier.

Platt, F. W. (1981). Research in medical interviewing. *Annals of Internal Medcine, 94*(3), 405-

7.

Pope, C., & Mays N. (1995). Reaching the parts other methods cannot reach: An

introduction to qualitative methods in health and health services research. *BMJ,*

311(6995), 42–5.

Powers, M.B., Sive Vörding, M. B. Z. V., & Emmelkamp, P. M. G. (2009). Acceptance and

Commitment Therapy: A meta-analytic review. *Psychotherapy and Psychosomatics, 78,*

73-80. doi: 10.1159/000190790

Prochaska, J. O., & DiClemente, C. C. (1992). Stages of change in modification of problem

behaviors. *Progress in Behavioural Modification, 28*, 183-218.

Ray, M., & Hester, J. (2009). A patient's journey with persistent pain. *BMJ, 339*(b2786).

doi:10.1136/bmj.b2786

Rehnsfeldt, A., & Eriksson, K. (2004). The progression of suffering implies alleviated

suffering. *Scandinavian Journal of Caring Science, 18*(3), 264-272. doi:10.1111/j.1471-

6712.2004.00281.x

Renn, C. L., & Dorsey, S. G. (2005). The physiology of processing of pain: A review. *AACN*

Clinical Issues: Advanced Practice in Acute and Critical Care, 16(3), 277-290.

Rice, P. L., & Ezzy, D. (2000). *Qualitative research methods, a health focus.* Melbourne:

Oxford University Press.

Richardson, J. C., Ong, B. N., & Sim, J. (2006). Remaking the future: Contemplating a life with

chronic widespread pain. *Chronic Illness, 2*(3), 209-218.

Richardson, P. (2003). Evidence-based practice and the psychodynamic psychotherapies. In

S. McPherson, P. Richardson & P. Leroux (Eds.), *Clinical Effectiveness in Psychotherapy*

and Mental Health (pp. 49-67). London, United Kingdom: Karnac.

Risdon, A., Eccleston, C., Crombez, G., & McCracken, L. M. (2003). How can we learn to live

with pain? A Q-methodological analysis of the diverse understandings of acceptance of

chronic pain. *Social Science & Medicine, 56*(2), 375-386.

Ritterband, L. M., Cox, D. J., Gordon, T. L., Borowitz, S. M., Kovatchev, B. P., Walker, L. S., &

Sutphen, J. L. (2006). Examining the added value of audio, graphics, and interactivity in an

internet intervention for pediatric encopresis. *Child Health Care, 35*(1), 47-59. doi:10.1207/s15326888chc3501_5

Robinson, D., & Henry, S. (1978). *Self Help and Health.* London, United Kingdom: Martin Robertson.

Robinson, M. E., & Riley, J. L. (1999). The role of emotion. In R. J. Gatchel & D. C. Turk (Eds.), *Psychosocial factors in pain: Critical perspectives (pp.* 74-88). New York, NY: Guilford Press.

Robinson, P., Wicksell, R. K., & Olsson, G. L. (2004). ACT with chronic pain patients. In S. C. Hayes & K. Strosahl (Eds.), *A practical guide to acceptance and commitment therapy* (pp. 315-345). New York, NY: Springer Science + Business Media.

Robson, C. (2002). *Real World Research: A Resource for Social Scientists and Practitioner-Researcher* (2nd ed.). Oxford, United Kingdom: Blackwell Publishing.

Rosenstock, I.M., Strecher, V.J. & Becker, M.H. (1988). Social learning and the health belief model. *Health Education Quarterly, 15*(2), 175-183.

Rosenzweig, S., Greeson, J. M., Reibel, D. K., Green, J. S., Jasser, S. A., & Beasley, E. (2010). Mindfulness-based stress reduction for chronic pain conditions: Variation in treatment outcomes and role of home meditation practice. *Journal of Psychosomatic Research, 68*(2010), 29-36.

Rothwell, R. (1998). Philosophical paradigms and qualitative research. In J. Higgs (Ed.), *Writing qualitative research* (pp. 21-28). Sydney: Hampden Press.

Rotter, J. B. (1954). Social learning and clinical psychology. Englewood Cliffs, NJ: Prentice Hall.

Roy, R. (1992). *The social context of the chronic pain sufferer*. Toronto, Canada: University of Toronto Press.

Ryan, G. W., & Bernard, H.R. (2000). Data management and analysis methods. In N. K.

Denkin & Y. S. Lincoln (Eds.), *Handbook of Qualitative Research* (2nd ed., pp. 769-802).

Thousand Oaks, CA: Sage.

Safran, J. D., & Muran, J. C. (2000). *Negotiating the therapeutic alliance: A relational*

treatment guide. New York, NY: Guilford Press.

Salter, M.J. (1992). What are the differences in body image between patients with a

conventional stoma compared to those who have had a conventional stoma followed by

a continent pouch? *Journal of Advanced Nursing, 17*(7), 841-848.

Sandelowski, M., & Barroso, J. (2003). Classifying the findings in qualitative research.

Qualitative Health Research, 13(7), 905-923.

Sanders, S.H. (2000). Integrating practice guidelines for chronic pain: From the Tower of

Babel to the Rosetta Stone. *American Pain Society APS Bulletin, 10*(6).

Schneider, J. W. & Conrad, P. (1980). In the closet with illness: epilepsy, stigma potential and

information control. *Social Problems, 28*(1), 32-44.

Schwarzer, R. & Fuchs, R. (1995). Self-efficacy and health behaviours. In M. Conner, and P.

Norman (Eds.), *Predicting Health Behaviour* (pp. 163-196). Buckingham, PA: Open

University Press.

Seers, K., & Friedli, K. (1996). The patients' experiences of their chronic non-malignant pain.

Journal of Advanced Nursing, 24, 1160-1168.

Segal, Z. V., Williams, J. M. G., & Teasdale, J. D. (2001). *Mindfulness-based cognitive therapy*

for depression: a new approach to preventing relapse. New York, NY: Guilford.

Segal, Z. V., Williams, J. M. G. & Teasdale, J. D., (2004). Mindfulness-based cognitive therapy:

Theoretical rationale and empirical status. In S. C. Hayes, V. M. Follette, & M. M. Linehan

(Eds.), *Mindfulness and acceptance: Expanding the Cognitive-Behavioral Tradition* (pp. 45-65). New York, NY: Guilford Press.

Sephton, S. E., Salmon, P., Weissbecker, I., Ulmer, C., Floyd, A., Hoover, K. & Studts, J. L. (2007). Mindfulness meditation alleviates depressive symptoms in women in fibromyalgia: Results of a randomized clinical trial. *Arthritis & Rheumatism, 57*(1), 77-85.

Shipley, M., & Newman, S. P. (1993). Psychological aspects of rheumatic diseases. In S. Newman and M. Shipley (Eds.), *Bailliere's Clinical Rheumatology: International Practice and Research.* London, United Kingdom: Bailliere Tindall.

Siddall, P. J., & Cousins, M. J. (2004). Persistent pain as a disease entity: implications for clinical management. *Anaesthesia Analgesia Journal, 99,* 510-520.

Smith, J. A., Lumley, M. A. & Longo, D. J. (1999). The relationship of cognitive and emotional coping to adjustment to chronic myofascial pain. *Psychosomatic Medicine, 61*(1), 103.

Smith, J. A., Jarman, M., & Osborn, M. (2000). Doing Interpretative phenomenological analysis. In M. M. A. K. Chamberlain (Ed.), *Qualitative Health Psychology: Theories and Methods*. London, United Kingdom: Sage.

Smith, J. A. & Osborn, M. (2003). Interpretative phenomenological analysis. In J. A. Smith, (Ed.), *Qualitative psychology: A practical guide to methods* (pp. 51-80). London, United Kingdom: Sage.

Smith, J. A. (2004). *Qualitative psychology: A practical guide to research methods.* London, United Kingdom: Sage.

Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretative Phenomenological Analysis: Theory, Method and Research*. London, United Kingdom: Sage.

Spinhoven, P., Ter Kuile, M., Kole-Snijders, A. M., Hutten Mansfield, M., Den Ouden, D. J., & Vlaeyen, J. W. (2004). Catastrophizing and internal pain control as mediators of outcome

in the multidisciplinary treatment of chronic low back pain. *European Journal of Pain*, *8*(3), 211-219. doi: 10.1016/j.ejpain.2003.08.003

Sprangers, M. A. G., de Regt, E. B., Andries, F., van Agt, H. M. E., Bijl, R. V., de Boer, J. B., … de Haes, H. C. J. M. (2000). Which chronic conditions are associated with better or poorer quality of life? *Journal of Clinical Epidemiology, 53*(9), 895-907.

Stanos, S., & Houle, T. T. (2006). Multidisciplinary and interdisciplinary management of chronic pain. *Physical Medicine and Rehabilitation Clinics of North America*, *17*(2), 435-50, vii.

Starks, H., & Brown Trinidad, S. (2007). Choose Your Method: A Comparison of Phenomenology, Discourse Analysis, and Grounded Theory. *Qualitative Health Research, 17*(10), 1372-1380. doi:10.1177/1049732307307031

Strauss, A., & Corbin, J. M. (1990). *Basics of qualitative research: Grounded theory procedures and techniques (2nd ed*.). Thousand Oaks, CA: Sage Publications.

Strong, J., & Unruh, A. M. (2002). Psychologically based pain management strategies. In J. Strong, A. M. Unruh, A. Wright & D. G. Baxter (Eds.), *Pain: A textbook for therapists* (pp. 169-187). London, United Kingdom: Churchill Livingstone.

Sullivan, M.J.L., Rodgers, W.M., Wilson, P.M., Bell, G.J., Murray, T.C. & Fraser, S.N. (2002). An experimental investigation of the relation between catastrophizing and activity intolerance. *Pain, 100,* 47-53.

Tang, N. K. Y., & Crane, C. (2006). Suicidality in chronic pain: A review of the prevalence, risk factors and psychological links. *Psychological Medicine, 36*(5), 575–586. doi:10.1017/S0033291705006859

Tang, N. K. Y., Salkovskis, P. M., & Hanna, M. (2007). Mental Defeat in Chronic Pain: Initial exploration of the concept. *The Clinical Journal of Pain, 23*(3), 222-232.

The British Pain Society. (1997). *Desirable criteria for pain management programmes*.

London, United Kingdom: British Pain Society.

The British Pain Society. (2007). *Recommended guidelines for pain management*

programmes for adults. London, United Kingdom: British Pain Society.

Tota-Faucette, M. E., Gil, K. M., Williams, D. A., Keefe, F. J., & Goli, V. (1993). Predictors of

response to pain management treatment. The role of family environment and changes in

cognitive processes. *The Clinical Journal of Pain, 9*(2), 115–123.

Turk, D.C., Meichenbaum, D., & Genest, M. (1983). *Pain and Behavioral Medicine: A*

Cognitive-Behavioral Perspective. New York, NY: Guilford.

Turk, D.C. (1990a). Customizing treatment for chronic pain patients: Who, what, why? *The*

Clinical Journal of Pain, 6(4), 255–270.

Turk, D. C., & Rudy, T. E. (1990b). Neglected factors in chronic pain treatment outcome

studies-referral patterns, failure to enter treatment and attrition. *Pain, 43*(1), 7-25.

Turk, D. C., & Flor, H. (1999). Chronic pain: A biobehavioral perspective. In R. J. Gatchel & D.

C. Turk (Eds.), *Psychosocial factors in pain: Clinical perspectives* (pp. 18-34). New York,

NY: Guilford Press.

Turk, D. C., & Okifuji, A. (2002). Psychological factors in chronic pain: Evolution and

revolution. *Journal of Consulting and Clinical Psychology, 70*(3), 678-90.

Turner, J. A., Holtzman, S., & Mancl, L. (2007). Mediators, moderators and predictors of

therapeutic change in cognitive-behavioral therapy for chronic pain. *Pain, 127*(3), 276-

286.

van Tulder, M. W., Koes, B. W., & Bouter, L. M. (1995). A cost-of-illness study of back pain in

the Netherlands. *Pain, 62,* 233-40.

Veehof, M. M., Oskam, M. J., Schreurs, K. M. G., & Bohlmeijer, E. T. (2011). Acceptance-based interventions for the treatment of chronic pain: A systematic review and meta-analysis. *Pain, 152*(3), 533–542.

Viane, I., Crombez, G., Eccleston, C., Devulder, J., & De Corte, W. (2004). Acceptance of the unpleasant reality of chronic pain: effects upon attention to pain and engagement with daily activities. *Pain, 112*(3), 282-288.

Vlaeyen, J. W. S., & Linton, S. J. (2000). Fear-avoidance and its consequences in chronic muscluoskeletal pain: A state of the art. *Pain, 85*(3), 317-332.

Vlaeyen, J. W. S., & Morley, S. (2005). Cognitive-behavioral treatments for chronic pain: What works for whom? *Clinical Journal of Pain, 21*(1), 1-8.

Vo, P., Marx, S., & Penles, L. (2008). Unmet needs among patients experiencing acute and chronic pain: Results from a survey of 606 pain patients and 491 physicians. *The Journal of Pain, 9*(4), suppl. 2.

Vowles, K. E., McCracken, L. M., & Eccleston, C. (2007). Processes of change in treatment for chronic pain: the contributions of pain, acceptance, and catastrophizing. *European Journal of Pain, 11*(7), 779-787.

Vowles, K. E., & McCracken, L. M. (2008). Acceptance and values-based action in chronic pain: A study of treatment effectiveness and process. *Journal of Consulting and Clinical Psychology, 76*(3), 397-407.

Vowles, K. E., Wetherell, J. L., & Sorrell, J. T. (2009). Targeting acceptance, mindfulness and values-based action in chronic pain: findings of two preliminary trials of an outpatient group-based intervention. *Cognitive and Behavioral Practice 16*(1), 49-58.

Vowles, K. E., & McCracken, L. M. (2010). Comparing the role of psychological flexibility and traditional pain management coping strategies in chronic pain treatment outcomes. *Behaviour Research & Therapy, 48*(2), 141-146.

Walker, J., Holloway, I., & Sofaer, B. (1999). In the system: The lived experience of chronic back pain from the perspectives of those seeking help from pain clinics. *Pain, 80*, 621-628.

Wall, P. (1999). *Pain: the science of suffering*. London, United Kingdom: Weidenfeld & Nicolson.

Wallston, K. A. (1993). Psychological control and its impact in the management of rheumatological disorders. *Clinical Rheumatology, 7*(2), 281-295.

Walser, R. D., & Pistorello, J. (2010). ACT in group therapy. In S. C. Hayes & D. K. Strosahl (Eds.), *A practical guide to acceptance and commitment therapy* (pp. 347-372)*.* New York, NY: Springer Science + Business Media.

Walsh, D. A., & Radcliffe, J. C. (2002). Pain beliefs and perceived physical disability of patients with chronic low back pain. *Pain, 97*(1-2), 23-31.

Walsh, D.A. (2009). Are treatments for pain over-rated? *Pain News, Summer, 28*.

Watkins, E. A., Wollan, P.C., Melton, L. J., & Yawn, B. P. (2008). A population in pain: Report from the Olmsted County health study. *Pain Medicine, 9*(2), 166-174.

Webb, C. (1992). The use of the first person in academic writing: objectivity, language and gate keeping. *Journal of Advanced*, 17, 747-752.

Wetherell, J. L., Afari, N., Rutledge, T., Sorrell, J. T., Stoddard, J. A., Petkus, A. J., … Atkinson, J.H. (2011). A randomized, controlled trial of acceptance and commitment therapy and cognitive-behavioral therapy for chronic pain. *Pain, 152*(9), 2098–2107.

Whittington, A., & Burns, J. (2005). The dilemmas of residential care staff working with challenging behaviour of people with learning disabilities. *Journal of Clinical Psychology*, 44(1), 59-76.

Wicksell, R. K., Olsson, G. L., Bond, F. W., & Melin, L. (2008). Avoidance and cognitive fusion-central components in pain related disability? *European Journal of Pain*, *12*(4), 491-500.

Williams, A. C. de C., Richardson, P.H., Nicholas, M.K., Pither, C.E., Harding, V.R., Ridout, K.L., Chamberlain, J.H. (1996). Inpatient vs. outpatient pain management: results of a randomised controlled trial. *Pain, 66,* 13-22.

Willig, C. (2001). Discursive Psychology. In C. Willig (Ed.), *Introducing qualitative research in psychology: adventures in theory and method*. Buckingham, PA: Open University Press.

Woolf, C. J. (2007). Central sensitization: Implications for the diagnosis and treatment of pain. *Pain 152*(Suppl. 3), S2–S15.

Yardley, L. (2008). Demonstrating validity in qualitative psychology. In J. A. Smith (Ed.), *Qualitative Psychology: A practical guide to research matters* (2nd ed.). London, United Kingdom: Sage.

Zettle, R. D., & Hayes, S. C. (1986). Dysfunctional control by client verbal behaviour: The context of reason-giving. *The Analysis of Verbal Behaviour, 4,* 30-38.

APPENDICES

APPENDIX 1: Session Plans for Luton & Dunstable ACT programme for Chronic Pain

Session	Topics Covered
Assessment	• Outcome measures completed including Chronic Pain Acceptance Questionnaire (CPAQ, McCracken et al., 2005b). • Structured Assessment
Week One	• Introduction to Programme (Facilitators, group rules, content, confidentiality) • What is the difference between acute and chronic pain? • What affects the way we experience pain? • Exploration of different treatment approaches tried and tested-The struggle with pain • Introduction to an alternative way of coping with pain-acceptance • Introduction to mindfulness meditation • Past participants talk to group • Home based learning pack provided-pain and willingness diary
Week Two	• Experiential avoidance discussed-why language leads to suffering • Context of willingness introduced • Metaphors and experiential exercises provided such as Chinese handcuffs task, quicksand metaphor • Body scan meditation
Week Three	• The trouble with thoughts-consequences of trying to control the pain • Cognitive Defusion-Part 1 • The mind train metaphor • Review-home based learning-pain and willingness diary • Stretch and breath mindfulness meditation
Week Four	• Cognitive Defusion-part 2 • Pacing encouraged • Review of defusion techniques • Gentle stretch and exercise • Mindfulness meditation
Week Five	• Stress and pain management • Managing pain and sleep problems • Goal setting • Values and valued life directions • Building patterns of effective action • Mindful Yoga

Week Six	• If I am not my thoughts-then who am I? • Increasing self-awareness • On-going cognitive defusion-what alternatives • Mindfulness meditation-sitting 20mins • Review of goals set
Week Seven	• Reviewing conventional treatments for chronic pain • Medication considerations • Application of ACT-committed action • Mindfulness sensate focus exercise
Week Eight	• Reviewing the choice to live a vital life-ACT strategies • Presentation of goals • Employment options • Dealing with flare ups • Programme feedback and evaluation • Outcome measures completed
Follow Up	• Outcome measures completed • Group feedback and progress session

N.B: Course material in relation to Acceptance and Commitment Therapy is adapted from the following text books:

Hayes, S. C., & Smith, S. (2005). *Get out of your Mind and Into Your Life. The New Acceptance and Commitment Therapy*. Oakland, CA: New Harbinger

Dahl, J.C., & Lundgren, T.L., (2006). *Living beyond your pain: Using Acceptance and Commitment Therapy.* Oakland, CA: New Harbinger.

Materials provided by and shared by Lance McCracken and colleagues from the Royal National Hospital for Rheumatic Diseases NHS Foundation Trust pain management programme in Bath.

APPENDIX 2: Interview Schedule for Semi-Structured Interviews

1. **What made you want to take part in the programme?**
   i. How did you understand your pain before you took part in the programme?
   ii. I understand from your medical records the history of your problems BUT how do you see your condition <u>now</u>?

2. **What have you <u>learnt</u> from attending the acceptance and commitment therapy pain management programme?**
   i. Can you tell me what the programme wanted to achieve? (yes/no)
   ii. Give me an example of something that you have taken away with you as a result of attending the programme

3. **When you started the programme what were your hopes/expectations?**
   i. Give me an example of a goal you set yourself
   ii. Have you achieved the goals you set yourself? (yes/no)

4. **To what extent do you fight the pain as opposed to accepting it now?**
   i. What have you found useful about the acceptance and commitment therapy approach to pain management?

5. **What (if anything) did you find more challenging whilst attending the programme?**
   i. Were there any disappointments with the programme?

6. **Did the group setting work for you or not? (yes/no)**
   i. If yes, what in particular did you gain from being in a group setting?
   ii. If no, what was it about being in a group that didn't work for you?

7. **Would you recommend this programme to a friend in a similar situation to yourself?**

8. **Can you suggest any ways of improving the programme?**

APPENDIX 3: Letter from NHS Health Research Authority

NHS

Health Research Authority

NRES Committee East of England - Hertfordshire

Victoria House
Capital Park
Fulbourn
Cambridge
CB21 5XB

Telephone: 01223 597750
Facsimile: 01223 597645

13 January 2012

Mrs Melissa Harrison
Trainee Clinical Psychologist
Cambridge and Peterborough Trust
University of Hertfordshire
College Lane
Hatfield
Hertfordshire
AL10 9AB

Dear Mrs Harrison

Study title: **Acceptance and commitment therapy for chronic pain in an outpatient setting**

REC reference: 11/EE/0497

Thank you for your letter of 12 December 2011, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Vice-Chair.

The Vice Chair had one comment for you to consider, this is as follows 'the newly created reply slip (which is essentially a <u>statement</u> from the potential participant) would be better without the words - "Thank you for your interest in this study" - as this does not fit with the purpose of the document - as a statement *from* a potential participant. I recommend removing them'.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

A Research Ethics Committee established by the Health Research Authority

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Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Covering Letter - from Melissa Harrison		07 November 2011
Evidence of insurance or indemnity - Zurich Municipal		02 August 2011
Interview Schedules/Topic Guides - Appendix A	2	November 2011
Investigator CV - Melissa Harrison (Student and CI)		
Investigator CV - Joerg Schulz (Academic Supervisor 1)		
Investigator CV - Dr Gregory Damien Wood (Academic Supervisor 2)		
Letter from Sponsor - Professor John Senior, University of Hertfordshire		07 November 2011
Other: Letter from Sunderland REC following Proportionate Review 16/09/2011		16 September 2011
Other: Letter from Sunderland REC following full review 26//09/2011 - Unfavourable Opinion		06 October 2011
Other: Appendix D Reply Slip for Participants	1	December 2011
Participant Consent Form: Appeindix C	3	December 2011
Participant Information Sheet: Appeindix B	3	December 2011
Protocol		
Protocol	2	November 2011
REC application - IRAS application Parts A&B 93595/265133/1/538		10 November 2011
Referees or other scientific critique report - Letter from Dr Nick Wood (Research Tutor) and Summary Feedback Sheet for MRP Proposal - Melissa Harrison		14 November 2011
Response to Request for Further Information - Email from Melissa Harrison		12 December 2011

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

<u>Reporting requirements</u>

The attached document *"After ethical review – guidance for researchers"* gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

<u>Feedback</u>

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

11/EE/0497	Please quote this number on all correspondence

With the Committee's best wishes for the success of this project

Yours sincerely

Dr Steve Eckersall
Chair

Email: april.saunders@eoe.nhs.uk

Enclosures: "After ethical review – guidance for researchers"

Copy to:

Professor John Senior (Sponsor Contact)
Pro-Vice Chancellor (Research)
University of Hertfordshire
College Lane
Hatfield, Herts
AL10 9AB

Diana Hardy (NHS R&D Contact)
Luton and Dunstable Hospital NHS Trust
Lewsey Road
Luton
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APPENDIX 4: Letter from Luton and Dunstable Hospital

Luton and Dunstable Hospital
NHS Foundation Trust

NHS

Lewsey Road
Luton
LU4 0DZ

Department of Research and Development
Director: Dr. Christopher M. Travill

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Our ref: CMT/js/LDH0422

27th January, 2012   / Sent 1/2/12

Mrs Melissa Harrison
Trainee Clinical Psychologist
University of Hertfordshire
College Lane
Hatfield
Hertfordshire
AL10 9AB

Dear Mrs Harrison,
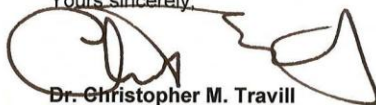
**Re: Acceptance and Commitment Therapy for Chronic Pain in an outpatient setting.
         Protocol version 2**

Thank you for submitting your research application in respect of the above. I am pleased to inform you that this study has been approved by the Research & Development Department to be carried out at the Luton & Dunstable Hospital.

I would like to take this opportunity of informing you that should any amendments be made to the study, e.g. protocol, consent form, participant information sheet, etc. it is your responsibility to inform not only the Research Ethics Committee but also the Research & Development Department of these changes. I would also like to inform you that, as part of the monitoring process, at the end of your study we require documented evidence that the findings from your research are published and made available to those participating in the study. This can take the form of an individual letter, or you could provide an article to be published in our Research & Development Newsletter, which is sent to each participant.

I should be grateful to receive a follow up on the progress of the study in six months and attach a form for this purpose. Thereafter, please update me on progress at six monthly intervals.

Yours sincerely,

Dr. Christopher M. Travill
Director of Research & Development

c.c. Professor John Senior, University of Hertfordshire, College Lane, Hatfield, Hertfordshire AL10 9AB
      Mr Joerg Schulz, University of Hertfordshire, College Lane, Hatfield, Hertfordshire AL10 9AB
      Dr. Greg Wood, Psychology Department, SEPT Disability Resource Centre, Poynters House,
      Poynters Road, Dunstable LU5 4TP
      Mrs. Louise Young, General Manager of Division of Diagnostics, Therapeutics and Outpatients, LDHFT

Enc:

Chairman Mr Spencer Colvin, Chief Executive Pauline Philip
The Luton and Dunstable Hospital is an Associate Teaching Hospital of the University of London

APPENDIX 5: Participant Information Sheet

Created: Jan 2012   Version: 4   Reference Number: 11/EE/0497

<u>**PARTICIPANT INFORMATION SHEET**</u>

Hello,

My name is Melissa Harrison and I am a third year trainee clinical psychologist at the University of Hertfordshire. As part of my training I have to do a research project. This study is being undertaken for educational purposes, as part of my Doctorate in Clinical Psychology. I am writing to you because I am interested in understanding more about *chronic pain management* and I hope that you might be willing to take part in my research project which is called:

Acceptance and Commitment Therapy (ACT) for Chronic Pain

Recent research has identified the benefits of ACT for chronic pain sufferers however there is less research focusing on how people with chronic pain find the experience of attending an ACT pain management programme. This project aims to emphasise the understanding of people who have attended such a programme and allow chronic pain sufferer's to voice their experience. It is hoped that this project will also increase professionals understanding of the experience of attending an ACT programme for chronic pain.

What would participation involve?

You would be asked to take part in a recorded interview that will take place in a confidential setting at the Luton & Dunstable Hospital or the Disability Resource Centre in Luton. The interview will be confidential, it should take approximately 1 ½ hours and it will involve me, the researcher, asking you about your experiences of having attending an ACT programme for chronic pain. Some of the experiences that we may talk about could be upsetting due to the nature of chronic pain however you are encouraged to only participate if you feel able to share these experiences.

Do I have to take part?

You do not have to take part in this study if do not wish to do so and your routine care will not be affected in any way. If you decide to take part in this study, you can change your mind at any time without having to give any reason. Again your routine care will remain unaffected.

What will happen if I take part?

You will be asked to sign an informed consent form that will state that you have a right to withdraw from the project at any time. The researchers contact details will be on the form. Your care from the Luton & Dunstable pain management clinic will remain the same whether or not you choose to participate. When the interview is complete you will have the opportunity to discuss your experience of the interview with the researcher.

Your car parking costs (if applicable) will be reimbursed in cash on the day of the interview

The researcher will then look at the interview transcripts and will try to find any themes in what you talked about.

Foreword:

This study has been reviewed by the Hertfordshire Research Ethics Committee. The Research Ethics Committee is an independent body whose role is to ensure that research is conducted in a safe and ethical manner. The research design has also been formally peer reviewed by the University of Hertfordshire's Doctoral Programme in Clinical Psychology.

1. **Confidentiality**
   - Your participation is confidential. However the team who are supporting you may be aware that you will take part in this project. The team will have access to your personal details but they will not have access to the interview transcripts.
   - Your audio recording and your personal details will be stored securely, in a separate location from the transcript, so as to further ensure confidentiality.

- Anonymised transcripts only will be viewed by the research supervisors (Dr Greg Wood, Joerg Schulz and Dr Saskia Keville), and by those responsible for examining the researcher.
- The only circumstance under which confidentiality would be broken is if you disclose information that leads the researcher to have serious concerns about your safety, or that of others. In this instance then I will contact your care co-ordinator in order to discuss these concerns.

2. The interview process

- The interview will last for approximately 1 ½ hours.
- The interview will be audio recorded.
- The interviewer will address particular questions; however, the aim is to hear about your individual experience. What the interviewer is interested in includes:
    - i. What have you learnt from attending the programme?
    - ii. What did you find difficult during the programme?
    - iii. How will you continue to use what you have learnt?
    - iv. Suggestions for improvements to the programme?

3. During the interview

- You are not required to answer all questions however it would be preferred that you are able to offer your thoughts in relation to the questions asked.
- Further to this, if at any time, for any reason, you wish to take a break or terminate the interview, it is your right to do so.
- If you become upset at any stage during or after the interview, a member of the pain clinic staff team will be available to talk to you.

4. Following the interview

- After the recording has stopped you will be invited to talk about your experience of being interviewed and how it has left you feeling.
- There will also be the opportunity to ask questions. In the event that the researcher is unable to answer you, she will contact you with an answer following the interview.
- The researcher will then look over the transcript from the interview and will try to establish themes that make sense of what was talked about. If you consent, the researcher will then contact you and arrange a meeting to discuss these themes with you, to see if you feel they accurately reflect your experience.

- The researcher will reimburse you for the costs of parking at the hospital on the day of the interview in cash
- You will be given a token book at the end of the interview to thank you for participating in the study. The book is titled "The Happiness Trap" by Russ Harris and is a recommended book by the Pain Management Team.

5. What will happen to the results of this research study?

a. The results of the interviews will be reported in a thesis for the purpose of gaining a qualification in Clinical Psychology.

b. The thesis will be held in the University of Hertfordshire Learning Resource Centre and will be accessible to interested parties.

c. It is planned that the results of the study will use direct quotes from your interview. However, your personal details will be kept anonymous in the write up of the project.

d. Further to this, a summary of the main research findings may be published as an article.

6. How long will my personal information be kept?

a. Your personal information and recordings will be kept for up to five years after the research is submitted for examination (until approximately June 2016). The information will be stored securely according to the University of Hertfordshire's 'Good practice in research' guidelines.

7. What if there is a problem?

a. If you have concerns about any aspect of the research process then please speak to the researcher. Alternatively, you can contact the Primary Research Supervisor, Joerg Schulz, on 01707 285284, if you wish to make a formal complaint.

b. Alternatively, you may wish to complain to the Independent Complaints Advocacy Service (ICAS). ICAS specifically for individuals wishing to pursue a claim against the NHS (http://www.dh.gov.uk)

   i. The contact details for the areas covered by this study are as follows:
   - ICAS Bedfordshire & Hertfordshire Tel: 0845 456 1082

8. Do you have any questions?

Thank you for taking time to read this information. If you are still happy to take part in the research please look over and sign the enclosed opt in form and return it to me in the enclosed stamped addressed envelope asap. (given 2 week notice date)

My contact details are:

07790024469

m.harrison3@herts.ac.uk

Many thanks,

Melissa.

APPENDIX 6: Reply Slip for Participants

Created: Dec 2011   Version: 1 Ref Number: 11 /EE/0497

Reply Slip for participants

Project Title: Acceptance and Commitment Therapy for Chronic

Name of researcher: Melissa Harrison, Trainee Clinical Psychologist

I am interested in participating in the above study and agree to be contacted by Melissa Harrison to discuss the study further. My contact details are as follows:

Name……………………………………………………………

Date of Birth……………………………………………………......

Telephone Number: …………………………………………….

Address……………………………...

Preferred method of contact:

APPENDIX 7: Informed Consent Form

Created: Jan 2012   Version: 4 Reference Number:11/EE/0497

INFORMED CONSENT FORM

Project Title: Acceptance and Commitment Therapy for Chronic Pain

Name of researcher: Melissa Harrison, Trainee Clinical Psychologist

To be completed by participant (Please initial each box):

1. I confirm that I have read and understand the information sheet dated………………. (Version: 4) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
2. I understand that I am free to decline entry into the study and I am able to leave the study at any time without giving a reason, and without my care being affected in any way.	
3. I consent to the tape recording of the interview.	
4. I give permission for the use of audio recording of the interview and for the use of anonymised verbatim quotations.	
5. I understand that a professional transcription service may be used to transcribe the interview; however my recording will be anonymised. Furthermore, the service will have signed a confidentiality agreement.[7]	
6. I understand that relevant sections of my medical notes and data collected during the study may be looked at by individuals from regulatory authorities or from the NHS Trust where it is relevant to my taking part in this research. I give permission to these individuals to have access to my records.	

---

[7] Participants were verbally informed that the transcription service would receive a copy of the recorded interview to transcribe, and that the final transcripts would be anonymised.

7. I agree to be contacted for my comments on the findings of the study.	
8. I agree that anonymised quotes from my interview may be used in any publications.	
9. I agree to take part in the above study.	
10. I have received £3 in cash to cover the costs of my car parking today	

Name of Participant: ……………………………. **Signature:** ……………........................

Date:

Name of the Researcher taking the consent   …………………………… **Signature:** ………………….

Date:

Thank you for your help with this study

APPENDIX 8: Transcription Confidentiality Agreement

Transcription Agreement

Doctorate in Clinical Psychology

University of Hertfordshire

Transcription confidentiality/ non-disclosure agreement

This non-disclosure agreement is in reference to the following parties:

Melissa Harrison **('the discloser')**

And

Executive Typing **('the recipient')**

The recipient agrees to not divulge any information to a third party with regards to the transcription of audio recordings, as recorded by the discloser. The information shared will therefore remain confidential.

The recipient also agrees to destroy the transcripts as soon as they have been provided to the discloser.

The recipient agrees to return and or destroy any copies of the recordings they were able to access provided by the discloser.

Signed: Margaret Clow

Name: Margaret Clow

Date: 5th March 2012

APPENDIX 9: Example of Interview Transcript

1　I　　Okay so ▮▮▮▮, the first question that I have for you is,
2　when did you attend the group?

3　R　　It was last May.

4　I　　May 2011. And that was for eight weeks.

5　R　　Yeah.

6　I　　Did you manage to go to all of them?

7　R　　No I didn't.

8　I　　No? How many did you make?

9　R　　I believe it was either five or six.

10　I　　Okay.

11　R　　But I received all the paperwork for every session. They
12　sent them to me.

13　I　　And what do you feel you have learned from attending the
14　Acceptance and Commitment Therapy programme?

15　R　　It helped me to link with my pain, em...whereas before, I
16　would say that my pain took up most of my day, em... I was able to
17　realise that I could still have a life, but also still have the pain.
18　Em...and it was made clear right from the very beginning that they
19　couldn't take the pain away. That was made very clear, that they
20　weren't there to take the pain away.

"Life despite pain"

(Hope)

21　I　　How did that feel hearing that in the beginning?

22　R　　Em...at first a bit deflating, because when you're in pain, all
23　you want to know is how to get out of it. But I think what made the
24　difference was that they actually accepted the fact that you was in
25　pain...(coughs), because people can't see pain and because they
26　can't see the pain you're in, if you look healthy then there's nothing
27　wrong with you, and outwardly – other than using my mobility aids
28　– I don't look ill, but I have an awful lot going on inside that people
29　don't see and more than just the pain side of it as well. I have many
30　other conditions which I have to deal with on a daily basis, and so,
31　just being accepted and someone saying, "Yes. We know you're in
32　pain. We understand you're in pain. We can't cure your pain, but
33　we might be able to help you live with it." That made a big
34　difference – just being accepted.

- Avoidance
- Release

Feeling misunderstood

Validation of unexplained symptoms

"Invisible nature of pain"

Being believed = being accepted

35　I　　Just being accepted. Okay.

36　R　　Yeah...and also seeing the other people in the group, you
37　know, that were also in pain, that probably had been feeling as I
38　had, em...probably feeling very alone, em...and even though you're
39　not alone – you've got family and you have friends – em...pain can
40　be a very lonely place to be. And, you know, just seeing the other

Isolation of experience

the
Group
Experience

Negative
Experience
→ judgement

Work
issues –
Expectations

Difficulty
not working

shame

Doubt
Apprehension

Feeling
Supported
Understood

Invisible
pain = judged

Expectations
of others

→ Judgement) (negative)

Downward
Spiral – loss of
job – – –

Feeling Dis-
Empowered
Vs.
Empowered
(control),

Expectation
of program

41 people made me realise that no I wasn't alone, there were people
42 out there that were suffering like I was, em...who all looked just as
43 healthy as I did, em...and maybe they were being judged like I was.
44 Do you know what I mean? And that I think, is the worst thing
45 about being in pain, is being judged.   ⊗

46 I   Did you find that before you started the group, the people
47 that you had met did tend to judge you then?

48 R   I did, on an outwardly basis, because as I say you can't see
49 pain, and...

50 I   What do you mean? Can you tell me more about that?

51 R   I think it's, "Oh you look fine. Why aren't you working?" Do
52 you know what I mean? You know. Em...there's no visible reason
53 for you not to be in work. Em...and that is, I mean they may well not
54 be doing that, but it is an instinct I think, that you feel when, you
55 know, you're talking to strangers oh, "How are you?" you know,
56 "Are you working?" you know. People that I haven't seen for a long
57 time. I mean, when I left work, through illness. So, some of my old
58 workmates that I see now, "Are you working yet?"

59 And I still say, "No."

60 "Ooh!" you know, " Been a long time."

61 Well since I left, I've got progressively worse, you know. Em...things
62 certainly didn't...I was ill when I left work, but not as ill as I am now.
63 So things became even more difficult after leaving work through
64 illness.

65 I   How do you see things are now, compared to when you
66 started the group?

67 R   I see it a lot better.

68 I   Okay. In what way?

69 R   I don't feel...if people ask me, you know, just generally, if I
70 meet people out and about. And they say, "Hello. How are you?"
71 you know, "Are you working?" and things like that.

72 And I say, "No." I don't feel ashamed to say, "No" because I know I
73 have a reason that I can't work. Em...and doctors have told me, you
74 know, that there are reasons why I can't work. Em...and why should
75 I feel ashamed of something that is beyond my control, now? And
76 that, I did get out of the group.

77 I   Can you tell me, in your own words, what you felt that the
78 programme wanted you to achieve.

79 R   I wasn't sure, to be honest. Em...I was really sceptical.
80 Em...but I, as I said when I visited the group, em...to do my little talk
81 of being one of the

171

Desperation ↓ *try anything*   82 pre-patients on the course, <u>I was very sceptical of the course</u>, but   *Searching for 'Cure'*
                                                 83 having been in pain for so long, deprived of sleep because of pain, I
                                                 84 think you get to a pitch where you'd do anything to get out of pain.
                                                 85 You'd try absolutely anything. I mean, if someone had said to me,
                                                 86 "Go and stand on your head in the corner." It might take me four
                                                 87 days to get on my head, but I would have tried, because you get to a
                                                 88 pitch where medication can do so much, but you've got to be able
                                                 89 to have a life as well, and I was very very sleepy because of my
                                                 90 medication. Em...but the medication was getting me through, so it
                                                 91 was a case of either being very sleepy or in real lots of pain, and you
                                                 92 know, at that time it was the medication that I was taking and   *Apprehension with MMMC?*
Doubt   93 em...but no, I was sceptical and I didn't really know,to be honest,
                                                 94 how the course was going to help. Em...and it...don't think it really
                                                 95 became clear until I started em...when I started in the
                                                 96 em...Mindfulness Programmes and the relaxation techniques.
                                                 97 And...some of them, even though they were quite long, forty
                                                 98 minutes some of them lasted, but just for that forty minutes when
                                                 99 you were doing that mindfulness exercise or listening to one of the   *Techniques to distract from Pain*
Distraction   100 c.ds that had been provided, em...I always felt that, for that forty
                                                101 minutes, or for however long it was, I wasn't actually concentrating   *– "mindful Awareness"*
                                                102 on the pain, I was concentrating on something else. And so for that
                                                103 amount of time, I actually didn't notice the pain. And so, I can't   *Whole program*
                                                104 explain, it's really difficult to explain, 'cos my mum actually asked
                                                105 me why did it work, and I honestly don't...I don't have an answer. I
                                                106 just think that each piece fitted together. Em...

                                                107 I   ...okay

metaphors {   108 R   em...little sayings. Being the chess board or the monsters
                                                109 on the bus and things like that. Be a passenger on the bus, and
                                                110 things like that. And...dirty pain and clean pain. And...I still use
                                                111 being the chess board, or...

                                                112 I   **Tell me a bit about being the chess board. What does that**
                                                113 **mean?**

                                                114 R   Basically, you will not either side, you are the base, and so   *"Not in battle with pain"*
                                                115 you don't get into conflict with your pain.

                                                116 I   **Okay.**

Fighting Pain /   117 R   <u>You don't fight it. You live with it. You deal with that</u>   *'living for moment"*
Connecting   118 <u>moment.</u> Em...but instead of trying to battle with it, em...you just
with it   119 live it. It's like when we did the raisin exercise - which was very
                                                120 perculiar – em...

                                                121 I   **The raisin exercise?**

                                                122 R   You feel it, then you smell it, then you look at it, then you   { *"mindfulness Exercise"*
                                                123 put it to your ear to listen to it. Em...you then put it into your mouth
                                                124 but you don't actually chew it, just feel it, and then you start to
                                                125 chew it, but you don't swallow it, and so you're living that
                                                126 experience. And I tend to use that quite a bit, em...with washing up,
                                                127 em...obviously I'm not using the raisin but I'm using washing-up

128 liquid, so I tend to try and feel...close my eyes and feel each bit that I
129 pick up, and try and decipher what it is. Em...and you feel the
130 difference in textures and things like that. So there are...it does
131 work, by living that experience.

Applying strategies to Activities of Daily Living

132 I   **Yeah.**

133 R   It does, and it also helps...it helps me to complete the task
134 that I want to do i.e the washing-up, whereas before I would start
135 but then have to sit down because I was in too much pain to carry
136 on. I mean, now I would be able to wash-up a whole bowl of
137 washing-up. Em...I might then have to sit down before I did the
138 drying-up, em..but again, I tend not to dry-up a lot because you
139 can't really have your eyes closed when you're drying-up `cos you
140 might drop things but... Em...I do try to use different strategies
141 when drying-up, i.e being the chess board, em...or the passenger on
142 the bus, and trying to keep the pain behind me while within the
143 driving seat. So...there are those...they do work, those strategies do
144 tend to work.

Mindful Exercise — difusion from pain → Focus on task.

145 I   **How did you understand your pain before you took part in**
146 **the programme?**

x understanding

147 R   I don't think I did. I don't think I actually understood it at all.
148 Em...because I have a lot of different pain. Em...from different
149 conditions. Em...so I don't think I really understood...I mean, when I
150 went to see the pain doctor, I was really quite off the scale with
151 pain, and she said, "You're at a pitch now where we have to...your
152 pain management has gone so high, we're gonna have to bring you
153 back, so in years to come we've got somewhere to go." And that's
154 when she said, "I want you to do a Pain Management Programme.
155 I'm gonna try you on that." I mean I'd had other therapies before.
156 I'd had accupuncture, em...for different parts of body pain – which
157 again, that did help – but it's only a short term solution to the
158 problem. Em...but I don't think I did understand the pain, to be
159 honest.

Previous S/T solutions to long-term problem

Lack of insight Previously –

160 I   **How do you see your condition now, that you've been on**
161 **the programme? How do you make sense of the pain?**

162 R   Basically, I look at it as a day to day thing now. Em...If I get
163 up in the morning and I want to go out, I'll go out. Em...depending, I
164 suppose as well, on how badly a night I have had. But, I would say, I
165 live each day as it comes. And I look at it as, if I do today – or I can't
166 do today what I did yesterday – then that's fine, because I did it
167 yesterday and I'll probably be able to do it tomorrow. So I don't
168 again, become ashamed of not being able to do things and
169 embarrassed that I couldn't do it, or worry that it wasn't done.
170 Em...I mean my husband is very good, and does an awful lot for me,
171 em...but I do try to do small things in the house, like the washing-up
172 and the drying-up. And I do do some ironing – not a lot – but I do
173 try. Em...but we've got ways around that now. I sit down to iron, I
174 have a perching stool, I only do so many items, then I stop, and then

SELF ACCEPTANCE

Shame Embarass-ment.

Accepting Limitations ↓ Decrease Shame ↓ Less Worry.

Self Acceptance

Cognitive Refusion

Adjusting Expectations Of Self - Kinder To Self more Accepting of Limitations "

175 I'll start again. Em...it could take me three hours to do the amount
176 of shirts that I've set to do, but...or items of clothing that I've set to
177 do...but, I don't worry about that now whereas before I used to
178 think, em...it was wrong that I couldn't do it and that I should be
179 able to do this. I did used to beat myself up quite a bit em...and I
180 suppose again that's the dirty pain, "Why aren't you able to do this.
181 You should be able to do this, you know, so you are always
182 bickering with yourself. Em...but no, I just take each day as it comes,
183 and I live each day as...not my last, but as I want to. And I don't beat
184 myself up if what I did yesterday I can't do today.

185 I   It's really nice to hear that. When you started the
186 programme, what were your hopes and expectations? So perhaps
187 maybe you can give me an example of the goal that you set
188 yourself when you started the programme.

Goals.

189 R   The goal I set originally, was to be able to walk from my
190 home to my doctor's surgery with my walking stick, em...without my
191 walker. But I realised quite early on that goal was going to be a bit
192 too much for me. So I adjusted it slightly and got a second walking
193 stick. And so instead of thinking that as a failure, I just did it that I
194 had to just adjust it slightly, but I still made it with the two sticks,
195 rather than the one. And so instead of looking at it as a failure, I just
196 thought when I had to adjust it slightly, I just needed two supports
197 rather than one.   Em...and that was the goal that I set, but
198 unfortunately I didn't get there on the one stick – but I made it on
199 the two, so...

Adjusting Expectations "Kinder to self" ? compassion—

200 I   You still made it there.

201 R   Yeah.

202 I   Which is great! Have you set yourself any other goals since
203 completing the programme?

204 R   Em...I did a couple of goals where I wanted to be able to
205 walk to the shops again with my sticks, em...without my walker –
206 which I have achieved. Em...it takes a time, em...because I can't go
207 too fast. Em...and my husband's always there with me, em...because
208 obviously he's scared of me falling, or whatever. Em...but I've not
209 made what I call many massive goals, I mean my biggest goal would
210 be to go to Australia, but I don't know whether I could do the flight
211 because of... you know. That would be the ultimate goal.

Future Goal Setting

Meeting goals –

Setting further goals.

212 I   Is that the dream holiday destination?

213 R   Well we've got friends out there, and they keep saying to
214 come out, come out, but it is very difficult...

215 I   It's a long flight.

216 R   And it's a long flight.

217 I   Yeah. Can you see yourself, perhaps making a shorter
218 journey, in the meantime?

219 R   I have made a shortish journey, with my pain. This is before
220 I went on the Pain Management Programme. We did a flight twice
221 to Florida, em...which is quite a gruelling flight when you're in pain.

222 I   It's for how many hours?

Difficult Experience pre program

223 R   Em...it was eight and a half. Em...first one was nine, but that
224 was... I think the plane we was on. But the second time, it was eight
225 and a half. That was Virgin, but, em...that was quite em...quite a
226 feat to get there.   Em...but again that was before the Pain
227 Management Programme and I was in an awful lot of pain when I
228 got off the plane. And you know, it was quite a ...but the way round
229 the Australian thing would be to fly to Singapore, I think, and then
230 go from Singapore through and have a stop-over. That way, break-
231 up the journey. There are ways round it.

Previous Experience before program –

232 I   And how hopeful do you feel about it?

233 R   (Sighs) We are hopeful, but it all depends on if we win the
234 lottery, I suppose. (Laughs)

235 I   (Laughs) Okay. To what extent do you - I suppose you've
236 kind of answered this in a way – but to what extent do you fight
237 the pain as suppose to accepting it now? Or aren't you accepting
238 it?

"Good Days" + "Bad Days"

239 R   No. I accept it now. I don't fight it. I mean there might be
240 the odd day where you do slip back into your old ways, em...and I'm
241 not saying that doesn't happen. I think sometimes if you're feeling
242 really low, em...if you've had a few really bad days, and you're
243 feeling low, you can sometimes slip back into the oh, "Why me?"
244 But then it's not long before it kicks back in and you say, "No. I'm
245 not going to do this again." And you get back into accepting the
246 em...I think that's the key to it, the acceptance of it.

Emotional Reality of living with Pain (Low mood)

247 I   The acceptance of the pain...is the key.

key = Acceptance ?!

Emotional Impact Accept What have = key

248 R   Is the key. Is the key. Without the acceptance, I don't think
249 you can...I don't think you would ever...the course would ever work
250 for you. I don't think if you don't accept what life's thrown at you,
251 em...and that you've got to deal with that, I don't think the Pain
252 Management Course can work, because it deals with acceptance.

"need to accept the things you have"

253 I   Yeah.

254 R   Rather than fighting.

Acceptance vs. Fighting

255 I   What - if anything - did you find more challenging whilst
256 attending the programme?

257 R   I found the exercising quite challenging because of mobility
258 issues. Em...I also...some of the em...not Mind Form, the relaxation

175

259   ones, I found could be quite long – as I've said before. And
260   sometimes you could fall asleep. But...I don't think...

261   I   Is there anything that you were disappointed with?

Mindfulness Exercise

262   R   No. I can't say I was disappointed, I just, sometimes I think,
263   you know, when you go in and you do a lot of the em...they do a lot
264   of em...sort of Mindfulness exercises. They then do...you may do
265   one at the beginning and then you'll do another one further in, and
266   then one right before you leave, so sometimes you could do three,
267   em...in one lesson em...or session. I think sometimes a lot of people
268   you see, "Oh..not again." But I didn't...I don't think...I think you
269   have to accept that this is part of it. I mean, as I said, I did find the
270   exercise quite demanding, em...but there were ways round that, you
271   know. Em...because I can't lie on the floor – because of issues of
272   mobility and things like that – I do some exercises laying on the bed.
273   Em...and also I can hold onto the sink and do exercises, you know,
274   just running on the spot or lifting my legs, or, you know, just
275   stretching or something at the sink. Em...so there are ways round it.
276   But I think a lot of people probably found the exercising
277   quite...because obviously if you're in pain, exercise can be quite an

In congruence – if hurts don't want to use it !

278   issue, because if you try to do something and it makes you sore,
279   then you really don't want to do it, em...but you do still try. I mean
280   there was a man in the course that really did suffer when we did the
281   exercises in the actual classroom. He really, he'd physical problems,
282   you know, you could see it really on his face – the amount of pain
283   that he was in. But he would still try and so...no I don't think there
284   was anything I could say.

285   I   Did you find that the group setting worked for you, or not?

286   R   Em...yes and no

287   I   What did you gain in particular?

288   R   Em...I mean there was...I met ████ em...one of the lot
289   that came...I mean we haven't got each other's phone number or
290   anything, but she was really about the only one that ever spoke to
291   me really, in the classroom. Em...there were quite a few that got
292   together. I wasn't actually at the very first session, so it might have
293   been...that might have been the problem because I wasn't there at
294   the very first session. Em... but I found when we went back for the
295   em...when we went back in November, I think it was, for the follow-
296   up, ████ and I were the only two that turned up. And we were
297   there – just the two of us – and it seemed really quite a good group,
298   you know, just the two of us. It wasn't like one-to-one tuition but it
299   was more central, around what our perceptions of the course and

Positive Experience of group –

300   everything and that seemed quite well. But no, I think group
301   settings do work as I say, because it makes you feel that everyone
302   else is suffering the same as you, so you have that as well. It just
303   depends if you can fit into that group setting.

304   I   Did you find that the number of people was an issue?

Struggle with Repetition of Strategies !

Alternative Strategies – Mobility Issues Fatigue .

– Avoidance –

meeting Others in Similar Situation .

Support –

305　R　　No I don't think that it was the amount of people, em...I just
306　think that maybe had I been at the first session, I might've bonded
307　more with the people on the course. I mean I'm not saying they
308　never spoke to me the whole time I was there, but I know other
309　people who got phone numbers from the first session and things like
310　that, em...so. And it was a mixed group as well, there was men and
311　women in the group.

if attended
1st session —
felt closer!.

312　I　　**How did you feel about that?**

313　R　　And that was fine, you know, I think it gave you perspective
314　from both sides, you know, because obviously men do suffer as well
315　as women – it's not just all one-sided. Whereas I noted when I went
316　back to the...to do my talk with the other programme, they were all
317　ladies. Em...so whether or not that's just how it had worked out, I
318　don't know, it's just, it just seemed quite strange seeing all ladies
319　sitting there.

Being able to
See both sides –

Variation in
groups

320　I　　**Would you recommend this programme to a friend in a**
321　**similar situation to yourself?**

322　R　　Yes I would. Yeah...I would. I've spoken to my mum and
323　said, you know, about it. I do have a friend who is very sceptical and
324　she was umming and arring but, I actually have a friend that did the
325　course in Bath, and in a four week actual in-patient course at Bath,
326　and when he came back he was totally acceptant of what his life was
327　like. Em...I mean the man is very sick, I'm not disputing...I mean
328　apart from his pain, he is now a very sick man. Em...but when I did
329　my weekly course, I used to say to him about it and he said, "Can
330　you explain why it works?" And I said, "No I don't know how it
331　works, but it does work." And he said, "Yes it does." And even now,
332　I will use some of the Mindfulness exercises, em...if I'm having a
333　really bad day I will still use some of the tapes to get me through
334　that blip. Em...and they are useful. Some of them are really useful.
335　There were some that were made shorter, because we had said
336　about them being quite long. There was only one that I could never
337　do, and that was, I think it was a relaxation one, and it's fine until I
338　had to walk on the beach, where I have this phobia of sand. So as
339　soon as they hit the beach, that was it, I couldn't listen to it any
340　more, I had to stop because I knew the sand was gonna get wet and
341　once...that's it, I just...can't be doing with wet sand or anything. It's
342　just a thing from my childhood, so I couldn't listen to that one, but I
343　do have a relaxation one that my husband actually had when he
344　went to therapy. Em...and it's about a garden, and that's really good
345　so I use that one instead. It's only about ten minutes, but, that's
346　really quite good.

Comparing
Experience
with others.

Use of
Strategies –

Struggle with
tapes

347　I　　**The visual techniques.**

348　R　　The visual techniques.

349　R　　I don't think all the group were completely em...into the
350　group. I don't believe they all...some of them didn't believe it was

Gender –

Expectation
of
Program –

Practice
Post –
group –

Disruption
during
group.

177

Lack of
belief /
Commitment
from others -

351 going to work, right from the very beginning. And even though they
352 were there, they were just...there. I got the feeling from some of
353 them that it wasn't helping them, but they were gonna do it
354 anyway. Em...but for me, myself, I have to say it was...it worked for
355 me.

356 I   Finally, can you suggest any ways of improving the
357 programme?

Practical
Aids -

358 R   Em...I'm trying to think...em...I mean they do show you
359 mobility aids that are out there, em...but not a lot. I know they can't
360 have a complete array, but I think if they could have some more on
361 show, and maybe get it across to people that em...don't be ashamed
362 to use things. They're out there for your help, they're out there to
363 make things easier for you. That's why when I went back and did
364 my talk to the new group, I specifically said about my two-handled
365 mug. Yes it might look strange an adult holding a two-handled mug,
366 but I'd rather hold with two hands than get burnt. Em...and my
367 cutlery, yes I've got thick-handled cutlery, but at least I can cut my
368 own food. And if that's taken away from you, at an age where you
369 think, "My God! This shouldn't be happening to me." I mean I was
370 in my late twenties, early thirties when I started having real
371 problems with dexterity and things like that, and not being able to

Independence

372 cut my food. I would rather starve...I would just say I wasn't hungry.
373 And my husband used to say to me, "Are you hungry?" "No I'm not
374 hungry." And in the end, one day he came in and my dinner was
375 completely cut into pieces, and I just sat there, crying. And he said,

Confidence

376 "You either eat, or you're gonna be ill." And he said, "If it means
377 cutting it, then so be it." And so I think even just showing them
378 things like that - just cutlery, practical things – might just get them
379 to understand that yes there are things there that...yes, all right, you
380 have to buy them, but it's a one-off expense to make your life that
381 little bit easier. And I don't see the problem, you know. So maybe
382 just a little bit more of what's out there, you know. I mean even if
383 they had em...I don't know, some brochures with the bits and pieces
384 in, or maybe, I don't know, borrow some from a Disability Centre
385 just to show them what's there. I mean I know the hospital used to
386 have a lot there but they don't hold that much now. But I think...cos
387 I asked about a few things, privately, and they were absolutely
388 brilliant with me. They were really good. They told me where to
389 look, you know, where to go for it and so the information's there. I
390 mean she did say to me they were hoping people go to them
391 afterwards and say, you know, is there anything specific, because
392 some people don't like opening up in big crowds. But I think if
393 they're shown things outright, em...people can say, "Oh well, that
394 might help me. You know, that would just make my life that little bit
395 easier." And I mean, I have so many different things in the home
396 that have been supplied by Social Services, and Occupational
397 Therapy that really do make my life a lot easier.

Increasing
Awareness of
practical
aids -
= ↑ confidence

Increasing
Awareness of
use of
practical
Aids -

398 I   Do you think that helps you think in terms of accepting
399 your condition as well?

400 R   Yeah, yeah.   Because if they weren't there, I probably
401 wouldn't be able to do the things that I do now. Em...you know, just
402 taking tea from one room to the other, to me is a major operation
403 because I have to use a stick, so I can only carry one cup at a time.
404 Whereas with my little trolley that they've supplied me, I can put
405 three cups on there if I've made three cups of tea. I mean I don't
406 use a kettle. I have a press button boiler so that it's easy for me to
407 make tea. I only have a pint carton of milk, where my husband
408 refills it, so it's easier to hold out of the fridge. So everything has
409 been made to help. You know, even the toaster is a push-button. I
410 don't even have to press the lever, it's a push-button, to push it
411 down. So everything...there are things out there, and that's why I
412 say alright, I know maybe there's that expense at the beginning, but
413 I did have kettle tippers but I wasn't able to put the lid on the kettle
414 properly, so I had boiling water going everywhere. And so, even
415 though the kettle tipper was there to help me, I was still burning
416 myself because I wasn't getting the lid on properly. So whereas with
417 the push-button I have now, it's just a case of pressing the button
418 and a hot cup of tea is there in four, five seconds. So just people
419 knowing what's out there, I think is a lot as well.

420 I   **Thank you so much! Is there anything else that you want**
421 **to add?**

422 R   Not that I can think of, I mean, just to say that em...I was
423 sceptical of the course at the very beginning, but I would just say to
424 anybody, stick with it and do everything that you're asked to do and
425 hopefully you'll see the results at the end of it.

426 I   Thank you.

427 R   Thank you very much

APPENDIX 10: Thematic Network Analysis-Stage 1

Table 1: From Codes to Basic themes

Codes	Identification of BASIC THEMES	Underlying Notions (Concepts)
• Being believed/accepted • Validity of unexplained symptoms • Invisible nature of pain • Need to prove pain • Lack of understanding from those not in pain • Need for clarity of programme • Was this going to "fix" the pain • Need for certainty • Fighting a losing battle? • Suicidal thoughts and hopeless feelings • How can I accept its going to always be there? • Wanting to avoid pain • This isn't a quick fix • Doubtful emotions • How much more can I take? • Long term nature of problem • Programme is the last resort! • Habit • Drugs don't work	1. Being accepted is being understood 2. Invisible symptoms lead to misunderstanding of problem 3. Seeing is believing 4. Reassured leads to sense of security and belonging 5. Receiving validation 6. Feeling Misunderstood 7. Being Invisible 8. Difficulty in accepting something you want to be rid of 9. Searching for a solution 10. Scepticism 11. When all else has failed 12. The Last Resort 13. Desperation	➢ Feelings prior to attending the ACT programme for chronic pain ➢ Motivation to attend the programme

• A different outlook on problem • "opening eyes"-realisation of what hasn't worked in past • Try anything to help • I'm not alone • An alternative approach • "Blinkered" vs. "open eyes" • Not succumbing to the pain • Commitment to do something about problems • Motivation to make adjustments • Inner strength • Patience • Self-belief •	14. Accepting what you can do and not what you cant 15. Compassion towards self leads to hope 16. Living for the present 17. Wanting to take control over life 18. Wanting to live a better life 19. 2 paths to pain-acceptance vs. surrender 20. Willingness to try	➤ What participants have learnt from attending the ACT programme for chronic pain
• Tiredness • Waiting room • Being present • Mindfulness • Relaxation • Frustration • Good days vs. bad days • Contradictions • Disempowered by others e.g. employers	21. not living-existing 22. Cycles of emotions 23. Always a before and after but not a during 24. Giving up the fight 25. Lack of understanding from *others* not in pain 26. Fighting pain 27. Employment Issues	➤ Challenges whilst attending the ACT programme for chronic pain
• Compassion • Focus on what I *can* do not what I *can't*	28. Learning to Live with "it" in a better way 29. Pain hasn't changed *relationship* with pain has 30. Compassion towards self leads to hope	➤ Things participants had learnt during the ACT programme for chronic pain

• Re-thinking values/goals • Not being controlled • Present living • Self-Focus • Choice to live • Ownership • You are not your pain • Responsibility • Metaphors • Applicability	31. Back in the driving seat 32. Being in the present 33. I am not my pain 34. Can use acceptance in other areas of life 35. You can either *live with pain* or *LIVE (with pain)* 36. Adjusting Expectations	
• Timing Issues • Is it too late? • Waiting • Personal issues • Habit • Mobility Issues • Exercise • Mindfulness • Fight • Society • Struggle with word-"acceptance"	37. Programme should have come earlier on in the beginning of the journey 38. Difficulty changing old habit 39. Cant just stop and accept 40. Societal attitudes 41. Struggle to focus on present-its painful 42. Language	➢ Challenges faced during the ACT programme for chronic pain
• Support • Shared experience • Increased confidence • Mirroring-seeing what others do and how they manage • Humour • "family" • Trust • Social network	43. Normalising experience of pain 44. Mutual Support 45. Understanding 46. Increasing Confidence	➢ Positive Experience of the group setting
• Judgement	47. De-personalisation	➢ Negative experience of the group setting

• Fraud • Interruptions • Group too big • Self judgement/comparison • Challenge seeing others in pain	48. Seeing others in pain 49. Need for smaller working groups 50. Intimidation	

APPENDIX 11: Thematic Network Analysis-Stage 2

Table 2: From Basic to Organising to Global Themes

Themes as BASIC THEMES	ORGANISING THEMES	GLOBAL THEMES
1. Being accepted is being understood 2. Invisible symptoms lead to misunderstanding of problem 3. Seeing is believing 4. Reassured leads to sense of security and belonging 5. Receiving Validation 6. Feeling Misunderstood 7. Being Invisible	Hope	Pre-group Expectations
8. Difficulty in accepting something you want to be rid of 9. Searching for a solution 10. Scepticism 11. When all else has failed 12. The Last Resort 13. Desperation	Hopelessness	
14. Accepting what you can do and not what you cant 15. Compassion towards self leads to hope 16. Living for the present 17. Wanting to take control over life 18. Wanting to live a better life 19. 2 paths to pain-acceptance vs.	Benefits of acceptance	Outlook on problems

surrender 20. Willingness to try		
21. not living-existing 22. Cycles of emotions 23. Always a before and after but not a during 24. Giving up the fight 25. Lack of understanding from *others* not in pain	Barriers to acceptance	
26. Employment Issues 27. Fighting pain	Barriers to acceptance	
28. Learning to Live with "it" in a better way 29. Pain hasn't changed *relationship* with pain has 30. Compassion towards self leads to hope 31. Back in the driving seat 32. Being in the present 33. Pain doesn't define you 34. Can use acceptance in other areas of life 35. You can either *live with pain* or *LIVE (with pain)* 36. Adjusting Expectations	Benefits of acceptance	Outlook on problems
37. Programme should have come earlier on in the beginning of the journey 38. Difficulty changing old habit 39. Can't just stop and accept	Barriers to acceptance	

40. Societal attitudes 41. Struggle to focus on present-its painful 42. Language		
43. Normalising experience of pain 44. Mutual Support 45. Understanding 46. Increasing Confidence	Positive experience	Experience of the group setting
47. De-personalisation 48. Seeing others in pain 49. Need for smaller working groups 50. Intimidation	Negative experience	

Acceptance and Commitment Therapy for Chronic Pain

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ABSTRACT

Background

In recent years *Acceptance and Commitment Therapy* (ACT) has gained increasing status as a promising approach to treating chronic pain physical functioning and psychological well-being. The basic premise of ACT as applied to chronic pain is that while pain hurts, it is the struggle with pain that causes suffering. This approach aims to restore effective and adaptive functioning for an individual within a context of continuing pain so that the individual can live a more vital and meaningful life.

There is a growing empirical support for the effectiveness of ACT however research has relied on self-reported quantitative outcomes, focused on addressing changes in pain intensity and the physical and psychological impact of chronic pain. There appears to be a gap in the literature on the exploration of the experience of attending an ACT programme for chronic pain from the patient's perspective.

Aims

The study sought to explore the experience of attending an ACT based programme for chronic pain within an outpatient NHS hospital setting. Furthermore the study sought to explore the modulating factors influencing clients learning and understanding of the construct of acceptance from the perspective of the participants. Additionally, the experience of attending a group based ACT intervention was explored.

Methodology

A qualitative methodology was chosen for the project. The study used a purposive sample of twelve participants, who had all attended the Luton & Dunstable Hospital ACT 8 week outpatient programme for chronic pain. The participants were interviewed through the use of a semi structured interviews, and the transcripts were transcribed and then analysed using Thematic Analysis. Identified themes were further organised using the tool of Thematic Network Analysis.

Results

Three global themes emerged from the analysis of the data. The first global theme encompassed the participant's pre-programme expectations and this theme highlighted the participant's feelings of hope and hopelessness prior to attending the programme. The second global theme demonstrated the ongoing process of living with chronic pain and highlighted the benefits and barriers to adopting and ACT based approach to chronic pain. Finally the third global theme addressed the experience of a group based intervention and included the positive and negative aspects of this experience for the participants.

Clinical Implications & Conclusion

Based on the results of this study a number of clinical implications were highlighted in relation to future development of ACT based programmes for chronic pain. These included

suggestions in relation to engaging participants in such programmes. Notably, timing issues, validation of physical symptoms, and consideration of the potential barriers to acceptance and understanding of the benefits of adopting and ACT group based pain management approach were discussed.

Introduction

Pain is a common complaint in primary care, with chronic pain reported in twenty percent of visits to general practitioners (McCaffery et al., 2003). It is estimated that one in three adults suffer from chronic pain, rising to half of those of the older age population (Cousins et al. 2004). Chronic pain is frequently associated with decreased health-related quality of life and high levels of psychological distress such as depression and anxiety (Bair et al., 2003).

Most traditional medical treatments for chronic pain aim at reducing or managing pain sensations. The use of analgesics, surgeries and procedures to control pain have been reported to be of limited benefit (Cousins et al., 2004) and despite conventional healthcare utilization it has been for that nearly half of patients with chronic pain report that their pain is *not* under control (Rosenzweig, 2010). In recent years several meta-analyses evaluating the established pain treatments used today (Morley et al., 1999, Gossens et al., 2000) have shown that these medical treatments, which may be effective in acute pain, are not effective with chronic pain and may in fact, be causing further problems. These limitations of traditional western medicine reflect the complex physiology of the condition, as well as the profound contribution of psychosocial factors to the perpetuation of pain and suffering (Keefe, 2004).

Hoffman et al. (2007) carried out a meta-analysis of psychological interventions for chronic pain. They provided support for psychological interventions in reducing self reported pain, pain-related interference, depression and disability. The study also demonstrated that multi-disciplinary programs that include psychological interventions were superior to other active treatment programs at improving work-related outcomes at both short and long term follow up.

The cognitive behavioural perspective introduced in 1983 emphasizes the role of attributions, efficacy expectations and problem solving. Cognitive Behavioural therapy (CBT) soon became the standard treatment for chronic pain patients, contending with the psychological distress and disabilities. CBT, incorporating both cognitive restructuring and operant and respondent learning reinforces techniques to alter behaviour and therefore helps individuals to manage their pain conditions. CBT for chronic pain represents a wide variety of interventions including education, relaxation, skills training and goal setting (Turk et al., 1983). Despite sound evidence that CBT-based treatments are effective, a systematic review carried out by Morely et al (2009) reported only moderate effect sizes for patients with chronic pain.

In recent years there has been a growing interest in alternative *"third wave approaches"* to manage clinical health problems. Mind-body medicine is receiving increasing recognition as one alternative. Mind-Body medicine is defined by a range of therapies intended to enhance the minds capacity to improve bodily function and symptoms. Within this umbrella term, *Acceptance and Commitment Therapy* has gained increasing status as a promising approach to treating chronic pain physical functioning and psychological well-being (Hayes 2004).

Acceptance and Commitment therapy (ACT) (Hayes, Strosahl & Wilson 1999) is an acceptance based approach that can be applied to many problems and disorders including

chronic pain. The basic premise of ACT as applied to chronic pain is that while pain hurts, it is the struggle with pain that causes suffering. This approach aims at the restoration of effective and adaptive functioning within a context of continuing pain (Hayes & Wilson, 2003). The clinical goal of ACT includes the general loosening of verbally based influences on behaviour, the strengthening of present-focused awareness, and increasing flexibility in responding to aversive experiences, so that this responding is more congruent with vital and meaningful living (Hayes & Wilson 2003). The primary goal of ACT according to Hayes et al (2006) has recently been more broadly defined as *"psychological flexibility"*, in essence treatment aims to enable pain sufferers to flexibly respond to pain, distress and related experiences in a particular way, such that needless and ineffective struggling with these experiences decreases with frequency, options for living well with them are maximized, and, ultimately, that one's behaviour is in accord with one's goals and values.

A growing number of studies appear to support the effectiveness of ACT in a diverse range of clinical populations including chronic pain. A series of early treatment outcome studies found that ACT program participants, with various self-reported chronic pain conditions demonstrated significant changes in pain intensity, medical symptoms, psychological symptoms, coping ability and inhibition of daily activity by pain, most of which were superior to standard medical care alone (Dahl et al 2004, McCracken et al 2005, Vowles et al.2007). Furthermore following a ACT model has been found to facilitate significant improvements in the mental as well as the physical aspects of chronic pain (Sephton et al. 2007).

McCracken and Eccleston (2005) reported that pain intensity and functioning were unrelated, however individuals reporting greater acceptance of their pain were better in terms of emotional, social and physical functioning when assessed four months after first evaluation. It has been argued that their work is questioning the cognitive-behavioural beliefs, which follow the assumption that if attention and awareness of pain are lessened, the physical and emotional effects of pain will reduce. Acceptance correlated with better functional and emotional outcomes than reduction in awareness and vigilance to pain. Therefore studies indicate that integrating acceptance strategies might enhance interventions aimed at increasing activities and restoring a high level of functioning in the presence of chronic pain

These findings question the drive of pain management programmes to focus on controlling pain and distress in order to increase quality of life and to facilitate physical and social activities (McCracken et al. 2004). Although CBT has proven to be an important contribution in chronic pain management, there is much that is unclear with regards to the process of change (Morley 2004).

In a meta analysis carried out by Vehof et al (2011) looking at acceptance based interventions for chronic pain, it was highlighted that acceptance based therapies so far have small to medium effects on physical and mental health in chronic pain patients that are comparable to CBT. They noted that a promising new direction is therapies that integrate ACT with behavioural therapy (Vowles et al 2009), however to the authors knowledge very few studies have been conducted with chronic pain patients to date.

Many authors question the ability of traditional psychological self report measures to capture changes ascribed to acceptance and this may contribute to some ambiguity in reported findings. Capsi et al (2005) have argued that all future studies of ACT must fully integrate quantitative and qualitative data. The exclusive use of self-report inventories may expose trials to significant response bias (Kabat-Zinn 2005). Furthermore no studies have explored qualitatively, the experience of attending mindfulness based chronic pain management programmes to the author's knowledge to date.

An outpatient Pain Management Program has been running at the Luton & Dunstable Hospital since August 1999, based on recommendations by the BPS. The program was originally delivered as a Cognitive Behavioural PMP intervention and was managed and delivered by a Multi disciplinary team of healthcare professionals with experience in pain management rehabilitation, comprising of; Consultant Clinical Psychologist, Consultant Anaesthetist, Clinical Nurse Specialist, Occupational Therapist and Physiotherapist.

Over the past three years the program has been adapted and the approach has incorporated the ACT model of change to help individuals with CP (Hayes et al., 2010). Within this framework, learning to live as best as possible with pain is the overarching desirable treatment outcome. Ownership of pain and personal choice to live a valued life despite pain are key strategies utilized within the program (Dahl & Lundgren). Clients are encouraged to learn new ways to relate to pain and are taught to modify their routines and improve their functioning. The emphasis is to increase client's sense of self efficacy and control and reduce the feelings of helplessness and hopelessness as is often the experience of a person suffering with CP (Caudill, 2002).

The goal of treatment is not necessarily to improve the pain, but rather to increase psychological flexibility and enhance adjustment to pain, and reduce the negative impact of the suffering that arises from behavioural avoidance of pain. This is in contrast to "functional restoration" programs which tend to focus on physical conditioning and management of symptoms (Stanos et al, 2006).

Outcome research shows that the majority of clients undertaking ACT programs for CP make significant improvements, however an understanding of why and how this treatment approach works relies on generalisations and assumptions derived from other interventions and standardised self report questionnaires. Research into client's experience of therapy has been gaining increasing importance over the last two decades (McLeod, 2001). Information from client's accounts of their experience is vital to our understanding and yet is overlooked in research (Paulson, Everall & Stuart, 2001).

The aim of this study is to qualitatively evaluate the Luton & Dunstable Hospital ACT program for CP. This will generate an understanding of the experience of attending an ACT program for CP within an outpatient NHS setting. The study aims to also provide an insight into how this program can influence treatment outcomes and further service development.

The evaluation will aim to identify the modulating factors which can influence the clients learning and understanding of the construct of acceptance from the perspective of the participants. Furthermore, the experience of the group based intervention will be explored.

Method

Given the aim of this study was to evaluate an established ACT programme for CP, a qualitative research approach was particularly suited to this study to help discover the reason for the success or failure of the intervention, and to help identify barriers and facilitators to change (Starks & Brown 2007).

The Luton and Dunstable Hospital ACT programme for chronic pain is continually evaluated, both from quantitative analysis of outcome data and from service user feedback. It was decided that a qualitative design and analysis would therefore add to this data and was fitting to the initial idea of the exploration of the subjective experience of the clients attending the ACT programme.

Qualitative data for this study was collected through use of semi-structured interviews with each participant, ideal for exploration of issues that may be too complex to investigate through quantitative measures (Burman, 1994).

An interview schedule was drafted by the researcher and then reviewed by the clinical team. The final schedule aimed to elicit an understanding of the motivation for attending the ACT programme, the learning outcomes, any aspects considered particularly helpful or unhelpful and the impact of a group based intervention.

Ethical approval for this study was granted by the Hertfordshire Research Ethics Committee and Luton & Dunstable Hospital Research Ethics Department. The research is in accordance with the British Psychological Society's Code of Conduct, Ethical Principles and Guidelines for conducting research using human participants (The BPS, 2004) and the Good Practice Guidelines for the conduct of psychological research within the NHS (The BPS, 2004).

Participants were selected using a purposive sampling method (Patton, 1990). The researcher initially selected a sample of twenty potential participants from a pool of approximately 47 participants who had already completed the ACT programme for CP. Participant selection was collaboratively identified with the consultant clinical psychologist co-ordinating the programme. The 20 potential participants were all sent an information sheet about the study and an opt-reply slip to return to the researcher if they were interested in being contacted to participate in the study. Out of a potential 20 participants, 13 participants returned the opt-in forms, expressing an interest in participating in the research. Of the 13 participants, 12 were finally recruited and were invited to be interviewed about their experiences of attending the ACT programme for CP. One potential participant declined participation after the interview had been arranged as she explained she had later decided it was not possible for her to attend.

The written information sheet provided clearly stated that participation was voluntary and the decision to participate would not affect the health care provided via the service.

All participants were given time to talk about the risks and benefits of taking part in the study and the researcher reinforced that they had the right to withdraw from the study at any time. Participants were made aware that any data collected would be kept confidential, no demographic information would be taken off site, audio-recordings would be password

protected and subsequent transcriptions would have any potentially identifying information removed. They were also made aware that the researcher knew only their names and contact details and had no access to their records and no knowledge of their histories. Participants were informed any transcription services used would sign confidentiality agreements. Participants were also made aware that research supervisors would have access to anonymised transcripts in order to help with analysis. The limits of confidentiality were also discussed in person prior to receiving informed written consent.

The participants were reminded verbally and written that they were free to withdraw and stop the interview at any time. Furthermore the researcher ensured that a member of staff from the MDT involved in the ACT programme would be available for participants to meet with following the interview, if required. Support from staff at the interview site was therefore negotiated prior to the interviews being carried out.

Interviews were conducted in the same outpatient department the participants attended for assessment to attend the ACT programme for CP. This helped to reduce any unnecessary anxiety for participants of travelling to an unfamiliar location. Participants were asked to allow for up to 90 minutes for the interviews.

The interviews were conducted using a semi-structured schedule. This was used flexibly in order to ensure an informal, conversational atmosphere that would facilitate detailed descriptions of participant's experiences of attending the ACT programme and allow exploration of areas of interest. The interview schedule was reviewed after each interview and refined where necessary. Interviews lasted between 35 and 60 minutes and were recorded using a digital voice recorder. At the end of the interview the participants were given a book, *The Happiness Trap,* by Russ Harris, as a token of thanks for participating in the research. This is a recommended text as per the ACT programme for CP.

Following each interview, a reflective diary was used to record reflections on the interview and any issues around content and process, aimed at increasing reflexivity.Each interview was audio-taped and notes made. A transcriber was used due to time limitations but accuracy was verified by the researcher listening to tapes whilst examining transcripts and checking notes to avoid loss of context.

Thematic analysis was the method chosen for analysis the qualitative data in this study. Thematic analysis is a method for identifying, analysing and reporting patterns (themes) within data (Braun & Clarke, 2006).

The data analysis for this study initially followed the first three stages of a systematic procedure of Thematic Analysis; a method for identifying, analysing and reporting patterns (themes) within data, outlined by Braun and Clarke, (2006). In addition, the thematic analysis was aided by *thematic networks,* an analytic tool used to organize a thematic analysis of qualitative data (Attride-Sterling, 2001). Four stages of analysis were carried out in the analysis of the data from the semi-structured interviews.

The first stage of analysis consisted of reading and re-reading the twelve interview transcripts. Both manifest and latent levels of data were coded on a paragraph by paragraph basis. An inductive coding method was used, therefore the themes arising from the data

were strongly linked to the raw data, and were not heavily influenced by existing theories or research. Inductive coding was considered more suitable for the analysis of the data in this study in order to better explore the experience of participants, as this is an under-esearched area.

The second stage of the thematic analysis consisted of writing the initial codes from each paragraph in the transcripts. Codes refer to the "most basic segment, or element, of the raw data or information that can be assessed in a meaningful way regarding the phenomenon" (Boyatzis, 1998). At this stage, it became apparent that some of the codes had a degree of overlap and merged to form overarching themes. These were typed with examples alongside them and potential themes were identified. The third stage involved sorting the codes into potential themes and collating all the relevant coded data extracts within the identified themes. Visual representations were used to allow the researcher to start to analyse the codes and consider how the codes may combine to form an overarching theme.

Thematic maps were drawn out in order to negotiate the relationships between codes, which were then reconsidered and revised in order to create a more cohesive understanding of the emerging theme. Different levels of themes were identified at this stage, and this allowed for the creation of sub themes and overarching themes. Data that did not appear to fit with the emerging themes were put under the bracket of miscellaneous themes at this stage.

During this stage, the process of thematic networks was followed in order to structure and review the themes generated from the data. This approach also provided an illustrative tool in the interpretation of the text (Atteride-Sterling, 2001). Thematic networks systematized the extraction of lowest order premises evident in the text-*Basic themes.* Categories of basic themes grouped together summarised more abstract principles and these were noted as *organizing themes.* Finally super-ordinate themes encapsulating the principle metaphors in the text as a whole were recorded as *Global Themes.*

Results

Table 1 highlights the three super-ordinate three *Global Themes,* six *Organising Themes* and 45 *Basic Themes* which emerged from the data in this study.

Table 1: The three global themes, six organising themes and 24 basic themes which were found to be representative of the data

Global Themes	Organizing Theme	Basic Themes
	Hope	• The Last Resort • Receiving Validation

Pre-program Expectations	Hopelessness	- When all else has failed - Scepticism - Feeling Misunderstood - Being invisible - Desperation
Living with Pain	**Benefits of Acceptance**	- I am not my pain - Adjusting Expectations - Being in the present - Giving up the fight - Willingness to try
	Barriers to Acceptance	- Fighting pain - Cycles of emotions - Societal Attitudes - Employment Issues - Struggles to focus on present - Language
Experience of Group Setting	**Positive experience of Group**	- Understanding - Mutual support - Increasing confidence
	Negative experience of Group	- De-personalisation - Seeing others in pain - Intimidation

Pre-Programme expectations-*Hope vs. Hopelessness*

The results highlighted that the sample were divided in their expectations prior to attending the programme, and the organising themes of *hope* and *hopelessness* distinguished these differing experiences.

Overall some participants expressed that their sense of hopelessness was attributed to by previous failed attempts to alleviate their pain. Some participants noted that they had seen several doctors, had numerous investigations and were at a loss to know *why* they pain could not be taken away. As a result this had left many of the participants feeling anxious, sceptical and apprehensive about the ACT intervention itself.

"The reality is that nobody can wave a magic wand and take your pain away.. so you think well how is anything going to make a difference?"…"I was very sceptical you know as to whether it would work, But I was open minded you know and gave it a go"	Jamie (39 yrs old)

Some of the participants spoke about the search for validation and belief about their symptoms prior to attending the program. It appeared that for these participants being

accepted and "believed" by health care professionals such as the facilitators of the ACT programme for CP, meant that they felt that their pain was acknowledged and that this was a positive experience for them. This also provided a more hopeful outlook on their problems and their pain.

"just being accepted and someone saying, "Yes. We know you are in pain. We understand you are in pain. We can't cure your pain, but we might be able to help you live with it". That made a big difference-just being accepted"	Linda (45 yrs old)

Living with Pain - Benefits of Acceptance vs. Barriers to Acceptance

The results highlighted that participants in this study oscillated between adopting the strategies that were provided through the programme, to struggling with particular aspects of the programme in ongoing process. The organising themes of *benefits of acceptance* and *barriers to acceptance* encapsulated the experience of living with pain since attending the ACT programme for chronic pain

Some of the participants in this study described a number of strategies that were beneficial to them which they learnt as a result of attending the programme, including; adjusting their expectations about what they can and can't do, being in the present (mindfulness), giving up the fight with pain and being willing to try to engage in a valued life despite their pain.

"I've learnt to accept what you can do and not what you cant" I try and be positive and if I cant do something one day then I say well there's another day and just limit myself to what I can do" I'm not afraid to say no"	Tracy (60 yrs old)

The results of this study suggest that for some individuals, psychological flexibility and ultimately acceptance of their CP was easier to comprehend and practice than others. A key finding of the study was that some of the participants felt that the timing of the ACT programme was too late in their journey with their pain and this could have been seen as a further barrier to acceptance.

"I don't expect it to work it the blink of an eye because I've been in this situation for so long and habits are hard to break"… its too late to accept, I needed this earlier then I wouldn't have been spent all my	Dave (51 yrs od)

energy trying to get rid of my pain"	

Some of the participants in this study identified that societal and employment issues further contributed to the barrier to acceptance of CP. Some of the participants noted that they felt that often others judged them, and they described the experience of stigmatisation, which often fuelled a fear to return to work, and an apprehension of whether they would be accepted in society and within the workplace because of their CP.

"I'm continuing to try to prove to the system and still not being heard. I actually have said to my employers you are listening, but you are not hearing what I'm saying because you are not accepting that I have told you I have a disability, I have limitations that prevent me from doing this and no matter what you do they are not listening"	Sharon (40 yrs old)

Experience of Group Setting - *Positive vs. Negative*

For the majority of the participants in this study the experience of attending a group based intervention was seen as positive. Participants noted that the mutual support and understanding they felt from fellow group members also experiencing CP or similar situations to themselves, fostered a sense of positivity, and self efficacy in their belief in themselves and their acceptance of their problems.

"I realised I was not alone, and that was very very important…actually being in a group where other people, okay they don't have the same pain as me, but they are in pain nonetheless. Any they are experiencing the same frustration that I am, um, most of them have been through the same, um process I have…trying to find a solution of some sort"	Annalie (42 yrs old)

Notably, getting the "group mix right" was seen as difficult for some of the participants who attended the programme in this study. The results highlighted that some of the group members who dominated or were disruptive in the group had a negative impact on the experience of the group setting.

"It is intimidating at first because I feel if I could have verbally participated a bit more, I would have got a little bit more out of it, but I don't feel confident enough to a group that is so big"	Siobhan (48 yrs old)

Furthermore some of the participants explained that they struggled with making comparisons with other group members pain experiences and this was a challenge in the group based setting.

"I saw some people that were in much more pain than I am and makes me feel a bit like a fraud, you know, what am I doing here? Is it really something for me? Maybe I'm taking the place of someone else?"	Tracy (60 yrs old)

Discussion

The findings of this study have several important implications. According to Glasgow (2001), identifying the barriers to "accepting" a particular model or intervention is helpful in the development and implementation of successful future self management programmes for patients with chronic illness. Furthermore it is acknowledged that understanding CP sufferers from their own perspective may have important clinical implications (Walker et al., 1999). Self management practices are believed to promote physical and emotional health, therefore health care providers should be aware of what interferes with or helps patients to engage in these activities or interventions. The barriers and facilitators identified in this study may apply, not only to the management of CP, but also to the care of patients with many other chronic conditions.

These issues raised from this study highlight concerns about the current evidence based practice (Barker, 2009). By offering ACT based programmes as a last resort option to patients with CP can lead patients to feel frustrated and let down by the medical route, therefore finding this approach as "second best" (Barker, 2009). by offering ACT programmes at an earlier stage in the process, this may result in fewer cure seeking appointments, savings through lower drug costs and patients may spend less time and money on alternative therapies. The option of an earlier ACT intervention may not be right for everyone; however it may work better than the current "end of the road" referral system?

It is noteworthy that when an intervention might improve quality of life, emotions inevitable come into play (Ray, 2009). As identified within this study, hope and hopelessness appear to be prisms through which people with pain may see possible outcomes, and these same emotions may cloud their listening making it harder to receive the messages from an intervention when they eventually reach that stage in their journey with pain.

More extensive research could consider other factors such considerations of the length of the programme to achieve beneficial and enduring outcomes. Further investigation of the composition of the group members and questions such as whether the programme should be homogenous in age?

A possible suggestion as a result of the findings of this study is that clients are offered an orientation session prior to attending the ACT programme for chronic pain. This could serve to provide clients a space to begin to foster an atmosphere of *creative hopelessness* (Hayes et al., 1999), ie addressing what treatments haven't worked and why? This could provide an

opportunity for clients to review their own as well as others previous experiences with a view to empowering the clients to generate a more hopeful outlook in adopting the ACT approach.

The arising notion that group members might experience *cognitive fusion* when comparing themselves to with other members experiences in the group, provides another possibility of addressing this more explicitly within the sessions themselves. Perhaps identifying the impact that this may have on a individuals suffering may also provide further consideration of the impact that chronic pain has on the systems around the individual with chronic pain. The integration of a family/friend session during the programme help people to address these issues further and more openly within the group and systemically with those around the group.

Overall, the results from this study suggest that the group based approach was conducive to self-management if the group mix was supportive of all the group members, social networks were gained and positive group dynamics were achieved.

The use of qualitative semi-structured interviews in this study enabled the researcher to gain a better understanding of individuals personal perspectives on their pain, acceptance and group based ACT intervention. As noted by Hallber & Carlsson (2000), this methodology is particularly valuable tracing developmental changes and in capturing the complexity of adaptation to CP. However, capturing this developmental process relied on the retrospective account of their experience of pain acceptance, which may have been influenced by their present acceptance and current pain experiences.

Rothwell (1998) noted that science does not occur without a specific context, and that qualitative approaches are "bringing into light of something that is taking account of its context". Qualitative research which considers the subjective experience of those living with CP has increasingly been identified as providing empirical evidence across a number of personal dimensions. These dimensions include peoples beliefs about pain, its impact on their lives and their experiences of attending CP management programmes (Keponen & Kiehlhofner, 2006; Parsons et al., 2007). However, few studies have examined the impact of CP beyond 12 months post CP intervention (Jensen et al., 2005). There is little research addressing how people live with CP on an ongoing basis and this is a consideration for future evaluative research within the area of acceptance and CP.

One methodology issue commonly cited when qualitative research is used is its limited generalisability across groups. As qualitative research aims for a deeper understanding of a phenomenon, being able to generalise the finds to others was not the aim here. However, Curtin & Fossey (2007) have asserted that transferability should apply to qualitative research if "detailed descriptions of the participants experiences are provided to enable the reader to make comparisons with other individuals and groups". It can be argued that through providing accounts of the salient features of the participant's experiences *pre, post*

and *during* the Luton and Dunstable Hospital ACT programme for CP in this study, comparisons to other ACT based interventions for CP can be made in future research.

Accordingly thematic analysis provided the best methodological fit with the research questions aiming to provide a qualitative exploration of the experience of attending a specific ACT programme for CP, rather than an exploration of the lived experience of adopting an ACT approach to chronic pain. The findings from this study however could be used to generate further research within this area and has highlighted factors which may be further understood in relation to a longitudinal study of chronic pain and acceptance.

To build upon the findings from this study it would be necessary to conduct a longitudinal study design to provide additional information about the nature of the transition of the individual's journey with acceptance as they move from the ACT programme onwards and the significance of factors such as relationships with health professionals, age, social support.

Brown (2004) argues that knowing *what* treatment components people with CP believe to be important, is of little value without knowing, *why.* This study has served to provide a preliminary profile of a sample of CP patient's beliefs in relation to one ACT group based programme for CP. Future research could consider the underlying processes of change with a view to further the development of the provision of acceptance based interventions for CP.

Finally future research could also explore further the focus of the presence of therapist support within ACT based interventions. Therapist support has previously been seen to be beneficial in self-help interventions (Watkins et al., 2008), however it would be of clinical interest to consider the role of the therapist in the ACT based programmes and furthermore to investigate the comparisons with manual-based self lead ACT interventions for CP. This exploration could provide a valuable addition to the findings raised within this study.

Conclusion

This study has made an important contribution in qualitatively exploring the experience of attending the Luton &Dunstable Hospital ACT programme for chronic pain (CP). To the authors knowledge, this is the first study to conduct semi-structured interviews with participants who have attended an ACT programme for CP, and the results have identified some interesting findings in relation to the expectations that individuals have prior to attending the programme. Furthermore the role of acceptance whilst living with CP has been addressed and the experience of a group based delivery of the ACT intervention has been discussed.

These findings provide some insight into the processes which may underlie the ability for an individual with CP to accept their difficulties and embark on the journey of living a valued life despite their pain. However acceptance of pain and related problems appears to be a stumbling block for many. Furthermore CP appears to remain a poorly understood by society and many health care professionals.

The results from this study support the growing body of evidence that Acceptance and commitment therapy shows promising results in the treatment of chronic pain treatment (Hayes et al., 2004)**.** This research has provided an opportunity for people with chronic pain, to share their expectations, understanding and experience of attending the Luton & Dunstable Hospital ACT programme for pain. This insight can set a foundation for further research to elaborate on the themes highlighted and any possibly connections between these themes and longer term outcomes. Additionally the role that facilitators of such programmes play in this process could be explored further.

It is hoped that sharing their experiences of this specific ACT programme for CP, the participants have in turn helped others who find themselves in similar circumstances and those who are in a position to provide such interventions for individuals in the future.

REFERENCES

Attride-Stirling, J. (2001). Thematic networks: An analytic tool for qualitative research. *Qualitative Research, 1*(3), 385-405.

Bair, M. J., Robinson, R. L., Katon, W., & Kroenke, K. (2003). Depression and pain comorbidity: A literature review. *Archives of Internal Medicine, 163*(20), 2433-2445.

Barker, K. (2009). Explaining the successes and failures of a chronic pain management course. *European Journal of Pain, 13,* 263–264.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology, 3*(2), 77-101.

Brown, C. A. (2004).Treatments for patients with chronic pain: therapists' beliefs. *International Journal of Therapy and Rehabilitation*, *10*(2), 46-52.

Burman, E. (1994). *Deconstructing Developmental Psychology.* London and New York: Routledge.

Caudill, M. A. (2002). *Managing pain before it manages you*. New York, NY: The Guilford Press.

Cousins M.J., Brennan F., Carr D.B. (2004). Pain relief: a universal human right. Pain 112, 1-4.

Curtin, M., & Fossey, E. M. (2007). Appraising the trustworthiness of qualitative studies: Guidelines for occupational therapists. *Australian Journal of Occupational Therapy, 54*(2), 88-94. doi:10.1111/j.1440-1630.2007.00661.x

Dahl, J., Wilson, K. G., & Nilsson, A. (2004). Acceptance and Commitment Therapy and the treatment of persons at risk for long-term disability resulting from stress and pain symptoms: A preliminary randomized trial. *Behavior Therapy, 35,* 785-801.

Glasgow, R. E., McKay, H. G., Piette, J. D., & Reynolds, K. D. (2001). The RE-AIM framework for evaluating interventions: What can it tell us about approaches to chronic illness management? *Patient Education and Counseling, 44*(2), 119-127.

Hallberg, L. R. M., & Carlsson, S. G. (2000). Psychosocial vulnerability and maintaining forces related to fibromyalgia. *Scandinavian Journal of Caring Science, 12*, 95–103.

Hayes, S. C., Strosahl, K. D., & Wilson, K. G. (2003). *Acceptance and commitment therapy: An experiential approach to behaviour change.* New York, NY: Guilford Press.

Hayes, S. C. (2004). Acceptance and commitment therapy, relational frame theory and the third wave of behavioral and cognitive therapies. *Behavior Therapy, 35*(4), 639-665.

Hayes, S. C., Luoma, J. B., Bond, F. W., Masuda, A., & Lillis, J. (2006). Acceptance and commitment therapy: Model, processes and outcomes. *Behaviour Research and Therapy, 44*(1), 1-25.

Hayes, S. C., & Strosahl, K. D. (2010). *A practical guide to acceptance and commitment therapy*. New York, NY: Springer Science+Business Media.

Hoffman, S. G., & Asmundson, G. J. G. (2008). Acceptance and mindfulness-based therapy: New wave or old hat? *Clinical Psychology Review, 28*(1), 1-16.

Jensen, I. B., Bergström, G., Ljungquist, T., & Bodin, L. (2005). A 3-year follow-up of a multidisciplinary rehabilitation programme for back and neck pain. *Pain, 115*(3), 273-83.

Kabat-Zinn J. An outpatient programme in behavioural medicine for chronic pain patients based on the practice of mindfulness meditation: theoretical considerations and preliminary results. General Hospital Psychiatry 1982; 4:33-42.

Keefe, F. J., Rumble, M. E., Scipio, C. D., Giordino, L. A. & Perri, L. M. (2004). Psychological aspects of persistent pain: current state of the science. *The Journal of Pain*, *5*(4), 195-211.

Keponen, R., & Kielhofner, G. (2006). Occupation and meaning in the lives of women with

chronic pain. *Scandinavian Journal of Occupational Therapy, 13*(4), 211-220.

McCaffery, M., & Pasero, C. (1999). *Pain: Clinical Manual* (2nd ed.). St. Louis, MO: Mosby.

McCracken, L. M., Vowles, K. E., & Eccleston, C. (2005b). Acceptance-based treatment for

persons with complex, long standing chronic pain: A preliminary analysis of treatment

outcome in comparison to a waiting phase. *Behaviour Research and Therapy, 43*(10),

1335-1346.

McCracken, L. M. (2005a). *Contextual cognitive-behavioral therapy for chronic pain*. Seattle,

WA: IASP Press.

McLeod, J. (2001). *Qualitative research in counselling and psychotherapy.* London, United

Kingdom: Sage.

Morley, S., Eccleston, C. & Williams, A. (2009). Systematic review and meta-analysis of

randomised controlled trials of cognitive-behavioural therapy and behaviour therapy for

chronic pain in adults, excluding headache. *Pain, 80,* 1-13.

Morley, S. (2004). Process and change in cognitive behaviour therapy for chronic pain. *Pain,

109*(3), 205-206.

Morley, S., Eccleston, C., & Williams, A. (1999). Systematic review and meta-analysis of

randomized controlled trials of cognitive behaviour therapy for chronic pain in adults,

excluding headache. *Pain, 80*(1-2), 1-13.

Parsons, S., Harding, G., Breen, A., Foster, N., Pincus, T., Vogel, S., & Underwood, M. (2007).

The influence of patients' and primary care practitioners' beliefs and expectations about

chronic musculoskeletal pain on the process of care: A systematic review of qualitative

studies. *The Clinical Journal of Pain, 23*(1), 91-98.

Patton, M. Q. (1990). Qualitative evaluation and research methods. (2nd ed.). Newbury Park, CA: Sage.

Paulson, G., Everall, R. & Stuart, J. (2001). Client perceptions of hindering experiences in counselling. *CPR, 1*(1), 53-61.

Ray, M., & Hester, J. (2009). A patient's journey with persistent pain. *BMJ, 339*(b2786). doi:10.1136/bmj.b2786

Rosenzweig, S., Greeson, J. M., Reibel, D. K., Green, J. S., Jasser, S. A., & Beasley, E. (2010). Mindfulness-based stress reduction for chronic pain conditions: Variation in treatment outcomes and role of home meditation practice. *Journal of Psychosomatic Research, 68*(2010), 29-36.

Rothwell, R. (1998). Philosophical paradigms and qualitative research. In J. Higgs (Ed.), *Writing qualitative research* (pp. 21-28). Sydney: Hampden Press.

Sephton, S. E., Salmon, P., Weissbecker, I., Ulmer, C., Floyd, A., Hoover, K. & Studts, J. L. (2007). Mindfulness meditation alleviates depressive symptoms in women in fibromyalgia: Results of a randomized clinical trial. *Arthritis & Rheumatism, 57*(1), 77-85.

Stanos, S., & Houle, T. T. (2006). Multidisciplinary and interdisciplinary management of chronic pain. *Physical Medicine and Rehabilitation Clinics of North America*, *17*(2), 435-50, vii.

Starks, H., & Brown Trinidad, S. (2007). Choose Your Method: A Comparison of Phenomenology, Discourse Analysis, and Grounded Theory. *Qualitative Health Research, 17*(10), 1372-1380. doi:10.1177/1049732307307031

Turk, D.C., Meichenbaum, D., & Genest, M. (1983). *Pain and Behavioral Medicine: A Cognitive-Behavioral Perspective.* New York, NY: Guilford.

Veehof, M. M., Oskam, M. J., Schreurs, K. M. G., & Bohlmeijer, E. T. (2011). Acceptance-based interventions for the treatment of chronic pain: A systematic review and meta-analysis. *Pain, 152*(3), 533–542.

Vowles, K. E., Wetherell, J. L., & Sorrell, J. T. (2009). Targeting acceptance, mindfulness and values-based action in chronic pain: findings of two preliminary trials of an outpatient group-based intervention. *Cognitive and Behavioral Practice 16*(1), 49-58.

Vowles, K. E., McCracken, L. M., & Eccleston, C. (2007). Processes of change in treatment for chronic pain: the contributions of pain, acceptance, and catastrophizing. *European Journal of Pain, 11*(7), 779-787.

Walker, J., Holloway, I., & Sofaer, B. (1999). In the system: The lived experience of chronic back pain from the perspectives of those seeking help from pain clinics. *Pain, 80*, 621-628.

Watkins, E. A., Wollan, P.C., Melton, L. J., & Yawn, B. P. (2008). A population in pain: Report from the Olmsted County health study. *Pain Medicine, 9*(2), 166-174.