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**A LONGITUDINAL INVESTIGATION INTO PATIENTS'
EXPERIENCES OF CHRONIC LOW BACK PAIN (CLBP)
USING INTERPRETATIVE PHENOMENOLOGICAL
ANALYSIS (IPA)**

Sherrill Snelgrove

Submitted to the University of Wales in fulfilment of the requirements for the
degree of Doctor of Philosophy

Swansea University
2010



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THESIS SUMMARY

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Candidate's Forenames: Sherrill Ray

Candidate for the Degree of PhD

Full title of thesis: A longitudinal investigation into patients' experiences of chronic low back pain (CLBP) using Interpretative Phenomenological Analysis (IPA).

Background/aim: Chronic low back pain (CLBP) is a variant of chronic pain and an overarching term for a diverse number of painful and benign conditions of the lower spine. Research has shown that CLBP challenges biomedical explanation and treatments and incurs passive coping strategies. Despite the enduring nature of CLBP there are few longitudinal studies. The aim of this investigation was to gain understandings of any consistencies and changes in the experiences of participants' experiences of living with CLBP.

Design: A qualitative, longitudinal IPA research project that explored participants' pain experiences over two years (2005-2007).

Methods: Semi-structured interviews were conducted with a purposeful sample of ten participants recruited from the waiting list of a chronic pain clinic. Each participant was interviewed prior to attendance and twice after treatment. The data were recorded and transcribed accounts were analysed using IPA.

Results: The participants foreground the physicality of the pain. Further interpretive work showed that whilst participants emphasised the physicality of their condition they experienced embodied, multidimensional experiences characterised by loss. Most participants' continued to manage their pain within a biomedical model of understanding and behavioural focused coping strategies. In comparison, participants who experienced a period of painlessness due to medical interventions demonstrated a reappraisal of their situation and a trend towards adopting a wider, biopsychosocial understanding accompanied by changing coping strategies.

Conclusion:

The accounts revealed the relationship between the participants' painful body and self concept. For some participants, a respite from pain paralleled increasing psychosocial coping strategies and a future orientation that reflected changes in illness beliefs in the absence of a formal psychological intervention. In comparison, remaining participants continued to demonstrate a narrow repertoire of coping and loss orientation. Participants' responses to CLBP resonated with the grieving processes of bereaved individuals. Clinical implications are discussed with recommendations for future research.

Declaration/Statements page

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This work has not previously been accepted in substance for any degree and is not being concurrently submitted in candidature for any degree.

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Sherrill Snelgrove

Submitted to the University of Wales in fulfilment of the requirements for the
degree of Doctor of Philosophy

Swansea University
2010

THESIS SUMMARY

Candidate's Surname / Family Name: Snelgrove

Candidate's Forenames: Sherrill Ray

Candidate for the Degree of PhD

Full title of thesis: A longitudinal investigation into patients' experiences of chronic low back pain (CLBP) using Interpretative Phenomenological Analysis (IPA).

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Declaration/Statements page

DECLARATION

This work has not previously been accepted in substance for any degree and is not being concurrently submitted in candidature for any degree.

Signed (candidate)

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- My children for being patient and “putting up” with my time out to complete this work

CHAPTER 1

INTRODUCTION

1.1 AIM AND METHOD

The aim of this qualitative, longitudinal research was to explore patients' experiences of chronic low back pain (CLBP) by semi-structured interview on three occasions over a period of two years (2005-2007) using Interpretative Phenomenological Analysis (IPA).

1.2 THE NATURE OF CHRONIC LOW BACK PAIN (CLBP)

CLBP is an overarching term for a diverse number of painful and benign conditions related to the lower spine. CLBP is generally considered to be located between the bottom of the rib cage and the buttock creases, although some authors refer to pain in the upper legs within this definition (National Institute for Health and Clinical Excellence [NICE], 2009). There is no single definition of CLBP, with most definitions referring to its duration and frequency of appearance. CLBP is a variant of chronic pain that has been described as, "pain which persists a month beyond the usual course of an acute disease or a reasonable time for an injury to heal, or is associated with a chronic pathological process which causes continuous pain or pain which recurs at intervals for months or years" (Bonica, 1990, p.18). Whilst there is some ambiguity surrounding the notion of "reasonable time" (Verhaak, Kerssens, Dekker, Marjolijn, and Jozien 1998), chronic pain as compared to acute pain is viewed as being of longer duration. The Royal College of Anaesthetists, (2003) similarly, but more specifically, indicate that chronic benign pain may be continuous, cyclical or intermittent with no direct link to a life threatening condition and persists after the point that healing would be expected to be complete (3-6 months).

Von Korff (1994, p.2042S) defines CLBP in terms of its frequency of appearance but with little description of the pain itself: "back pain present on at least half of the days in a 12-month period in a single or multiple episodes". Merskey and

Bogduk (1994, p.xiv) present different definitions of spinal pain in relation to various chronic back pain syndromes but in a similar fashion make relatively limited descriptions of the pain itself. In contrast, The International Association of the Study of Pain, (2010) offers a more comprehensive description of CLBP, referring to its disruptive symptoms that may include stiffness, tenderness, increasingly unalleviated, constant pain accompanied by an impairment of activities of daily living and/or work activities.

Chronic pain such as CLBP is distinguished from acute or nociceptive pain that is regarded as the body's normal response to a noxious stimulant. In comparison, chronic pain is known as neuropathic pain (NeP) that may be initiated by diseases or trauma that produce lesions in the central or peripheral nervous systems (Merskey and Bogduk, 1994). Chronic pain has no particular physiological adaptive function, may become disproportionate to the original injury, may be present despite little or no evidence of tissue damage and is often resistant to treatment. It has been proposed that the original disease or condition that caused the pain may cause a change which, although the condition may no longer exist, has set up continuous noxious stimulation (Grady and Severn, 1997). In light of this, chronic pain may also be viewed as a collection of symptoms and may be treated with little understanding of the underlying cause (McCaffrey, Frock, and Garguilo 2003).

The impact of NeP on patients quality of life has been shown to have negative effects on their physical, emotional and social functioning that supports a biopsychosocial representation of chronic pain (Jenson, Chodroff, and Dworkin 2007). The general understanding of CLBP supports this conceptualisation, with CLBP regarded as a complex phenomenon that is both a sensory and perceptual event and incorporates psychosocial factors as well as sensory stimulation (Turk, 1996). The prolonged duration of CLBP enables increased opportunities for learned behaviours such as maladaptive coping strategies and cognitive and emotional responses such as catastrophising, depression and anxiety that may lead to permanent entry into the sick role (Waddell, 2004; Bury, 1982).

1.3 THE PREVALENCE OF CLBP

Back pain is very common with about 80% of the United Kingdom (U.K) population reporting back pain at some point in their lives (Palmer, Walsh, Bendall, Cooper, and Coogon 2000). A study conducted for the Department of Health (DOH) in the U.K (1996) indicated 40% of adults had complained of back pain in the previous year (Dodd, 1996). Whilst many of these may recover within about six weeks up to 7% will develop chronic low back pain and have considerable discomfort (Nachemson, Waddell, and Norlund 2000).

CLBP is reported by a growing number of people in the UK, Europe and America (Dagenais, Caro, and Haldeman 2008). Estimates of the prevalence of CLBP may vary but all show significantly high rates. Elliot, Smith, Hannaford, Penny, Cairns-Smith, and Chambers (1999) estimated the prevalence of chronic pain in the community in the U.K to be 46.5% with back pain and arthritis being the two most commonly cited causes of chronic pain. A telephone interview study of 4,839 chronic pain sufferers from Europe and the U.K showed an overall prevalence of 32%, with severe pain and 40% of these suffering from osteo-arthritis and 24% diagnosed with depression (Breivik, Collett, Ventafridda, Cohen, and, Gallacher 2006). Overall, the authors indicated that on average, one in five European adults suffer from chronic pain with one third reporting severe pain.

1.4 THE FINANCIAL COSTS OF CLBP

Some individuals with CLBP may be highly dependent on health care services and welfare provision (Welsh Assembly Government, [WAG], 2008). A multitude of studies offer various estimates of the financial cost of CLBP, but most conclude that CLBP places heavy demands on health services and economies. The economic cost of a disease may be defined as, “the sum of all costs associated with that condition which would not otherwise be incurred if that disease did not exist” (Dagenais et al. 2008, p.9). CLBP may incur economic costs to the individual (for example: loss of earnings, treatments, medication), the health service (for example: analgesics and anaesthetics, General practitioner (G.P) consultations, emergency attendances, in patient and out-patient services, radiology, physiotherapy) and to society (for example: productions costs, benefits, stress).

A systematic review of CLBP studies showed that estimates of costs vary because of the heterogeneous methodology used by different researchers. Despite these methodological limitations, there is good evidence that indicates CLBP is costly for society (Dagenais et al. 2008). The costs of CLBP have been estimated as £12.3 billion in the U.K. that is equivalent to 2% of U.K health care expenditure with low back pain accounting for 7% of all consultations in primary care (Dagenais et al. 2008, Maniadakis and Gray, 2000; Royal College of General Practitioners, 1995). The Arthritis Research Campaign, (2002) reported poorly managed pain accounts for significant productivity losses with 208 million days off work that equates to £10 billion a year. An estimated 85% of sufferers have symptoms that do not respond entirely successfully to medical intervention alone (Klabber-Moffat, Richardson, Sheldon, and Maynard 1995) with general practitioners themselves indicating that the management of chronic pain is often inadequate (Stannard and Johnson, 2003).

1.5 THE PERSONAL COST OF CLBP

There is an increasing recognition that whilst there is a preponderance of studies estimating the financial cost of chronic pain (including CLBP) there are a lack of studies that document the personal cost of such conditions (Breivek et al.2006; Elliott et al. 1999). For instance, Breivek et al. (2006) revealed that 30% of their sample of chronic pain sufferers indicated that not being believed was an issue for them and a conservative figure of one in four felt that family, friends and doctors did not understand their position. The study also revealed that activities such as sleeping, household chores, and working, maintaining relationships, attending social activities, lifting and exercising were severely affected by chronic pain. A decreased participation in activities due to chronic pain and CLBP has been documented as leading to physical and psychological deconditioning and possible complications such as obesity, heart disease and diabetes and depression (WAG, 2008; Waddell, 2004).

The economic effects of CLBP for individuals may vary but is the number two reason for long term sickness in the U.K and in manual jobs it's the number one reason (Maniadakis and Gray, 2000). It is therefore hardly surprising that CLBP is related to loss of employment, socioeconomic deprivation and subsequent depression and social isolation (Main, Spanswick and, Watson 2003; British Pain Society, 2003;

Brekke, Hjortdahl, and, Kvein 2002). Overall, there are clear indications that there are significant and wide ranging social, physical and psychological burdens for people with CLBP.

1.6 TREATING CLBP

Traditionally, CLBP has been treated from a biomedical perspective that views illness or disease as a bodily affliction and separate from the psychological and social processes of the person. From this perspective, the main focus is on physical symptoms and medical and physical treatments (Sarafino, 1998). Whilst physical treatments have been found to be useful (Airaksinen, Brox, Cedraschi, Hildebrandt, Klaber-Moffett, and Kovacs et al. 2006), contemporary approaches to treatment increasingly support a view of CLBP as a multidimensional phenomenon best suited to a biopsychosocial model of care. This approach includes physical treatments but also psychological therapies and social aid (Ostelo, van Tulder, Vlaeyen, Linton, Morey, and Assendelft 2005; Turk and Okifuji, 2002; Royal College of General Practitioners, 1995). However, the UK is variably resourced with chronic pain clinics, with just under half being able to offer multidisciplinary pain management programmes (British Pain Society, 2003).

1.7 PSYCHOLOGICAL RESEARCH INTO CLBP

The psychological research into CLBP has been dominated by a positivist approach utilising questionnaire designs. Quantitative studies have identified passive coping, catastrophising, illness perceptions, fear avoidance beliefs, depression and anxiety as predictors of CLBP-related disability and chronicity and poor adjustment to chronic pain (Koleck, Mazaux, Rascle, and Bruchon-Schweitzer 2006; Mercado, Carroll, Cassidy, and Cote 2005; Lamé, Peters, Vlaeyon, Kleef, and Pattijn 2005; Hobro, Weinmann, and Hankins 2004; Grotle, Vollestad, Veirod, and Brox 2004; Risdon, Eccleston, Crombez, and McCracken 2003; McCracken and Eccleston, 2003; Pincus, Burton, Vogel, and Field 2002; McCracken, Spertus, Janeck, Sinclair, and Wetzell 1999; Klapow, Slater, Patterson, Atkinson, Weickgenant, and Grant 1995; Weickgenant, Slater, Patterson, Atkinson, Grant, and Garfin 1993). A main criticism of quantitative research points to narrow conceptualisations of coping (Busch, 2005;

McCracken et al. 1999). In an attempt to redress this, McCracken (1999) proposed an alternative line of research into “acceptance” or “positive adaptation to pain” that has since showed significant statistical association with successful adaptation to chronic pain (Risdon et al. 2003; McCracken, and Eccleston, 2003; McCracken, et al. 1999). However, “acceptance” as a hypothetical construct, is mainly assessed by quantitative analysis and vulnerable to the same charge of being driven by theory and disregarding individual experience as other quantitative research.

The use of standardised questionnaires in quantitative research may be valuable tools for measuring associations between variables and offer valuable explanations for the adaptation or otherwise to chronic pain (Busch, 2005; Smith, 1996). However, illness and suffering are generally understood as complex, multidimensional and contextualised experiences not necessarily captured by quantitative methods. Accordingly, qualitative research methods are being increasingly employed in psychological research to address issues of subjectivity and individuality and extend existing knowledge about patients’ psychological experiences. Qualitative methodologies may be regarded as complimenting rather than replacing existing quantitative psychological research by understanding the meanings of the participants’ experiences, as understood by the participants themselves.

1.8 THE RESEARCH METHODOLOGY:

INTERPRETATIVE PHENOMENOLOGICAL ANALYSIS (IPA)

IPA was considered to be an appropriate methodology for exploring the CLBP experiences of the participants in this research. IPA is an emerging, qualitative methodology in psychology with an emphasis upon discovery and description rather than the more traditional theory testing used in positivist psychology (Reid, Flowers, and, Larkin 2005). The purpose of IPA is to explore the individuals “lived-experience” or the subjective quality of experience relatively unhampered by *a priori* frameworks or assumptions. In order to gain access to individuals’ experiences, the researcher carefully makes inferences from individual accounts, helped by an inductive, reflexive, iterative and idiographic stance (de Visser and Smith, 2006; Smith and Osborn, 2003).

IPA is phenomenological because it makes inquiries into consciousness, mental life or how things seem to an individual. A phenomenological inquiry explores the meaning of a phenomenon for an individual, that is, the message it has for an individual that may include its physical appearance, value, its purpose, the actions and emotions it evokes and the knowledge one has about it (see: Cassell, 2005). IPA is interpretative because there is recognition of the central role of interpretation. Smith (2004) argues for a double hermeneutic, that is, the participants interpret their own experiences for the researcher and the researcher attempts to make sense of or interprets these accounts.

IPA studies have shown CLBP experiences as extending beyond bounded psychological constructs to include meaningful and interrelated psychosocial issues that may override the original complaints of pain. Strong expressions of frustration, anger and helplessness have been found due to perceptions of being disempowered in the health system (Walker, Holloway, and Sofaer 1999). Experiences of loss across all areas of sufferers' lives and disruption to personal relationships have been reported (Sofaer-Bennett, Walker, Moore, Lamberty, and O'Dwyer 2007; Walker, Sofaer, and Holloway 2006). The inability to make sense of the situation, fear for the future, an inability to construct positive self regard combined with concerns about not being believed, an awareness of public scepticism and strong feelings of isolation have also been identified (Osborn and Smith, 1998).

IPA has been compared favourably with other qualitative methodologies in terms of integrating research and practice and is in keeping with a present National Health Service commitment to "the patients agenda" (Reid et al.2005, p. 21).

See Chapter 3 for further explanation about IPA.

1.9 RATIONALE FOR THE RESEARCH PROJECT

The purpose of the research project was to explore the lived experiences of patients with CLBP using IPA. Despite recognition of the subjective nature of chronic pain, there is comparatively little longitudinal, qualitative, psychological research investigating the meaning of pain. Longitudinal studies comprise long term engagement with participants so as to capture the depth and breadth of experiences and any changes in these experiences (Saldaña, 2003).

There is little consensus about the parameters of a longitudinal research project. Saldaña, (2003, p.1) makes ambiguous reference to longitudinal studies as being conducted over “a lonnnnnng time”. However, Saldaña, (2003) also indicates that whilst there are different models of longitudinal studies, a longitudinal study should be at least nine months duration so as to assess any significant changes.

Accordingly, the research design involved the data being collected on three occasions from the same sample of patients over a period of two years. The interviews in this project were conducted approximately 12 months apart, with baseline interviews conducted prior to treatment at a chronic pain clinic and two interviews taking place after treatments. The longitudinal design enabled the identification of any continuity and change in participants’ pain experiences and the determinants and consequences of these over time. To date, there is no known qualitative and longitudinal study using IPA so as to develop understanding of CLBP experiences. In short, the challenges of chronicity have not been fully explored. It was anticipated that a longitudinal study would provide new insights in to the experiences of sufferers and provide service providers with research based evidence to help with making decisions about appropriate psychological care for patients with CLBP.

1.10 STRUCTURE OF THE THESIS

The structure of the thesis was drawn from recognised traditions of report writing and follows the format recommended by Rudestam and Newton, (2001). The thesis is presented in seven chapters. This first chapter has offered a brief aim of the study and a discussion about the meaning of the term CLBP, the prevalence of CLBP and the financial cost of the condition for the U.K economy and the health service. The predominant research paradigms investigating CLBP have been outlined, as has the proposed methodology and rationale for the research.

The second chapter presents a critical review of literature on CLBP and summarises with an overall evaluation and aim of the present research. The third chapter presents the background and rationale for the choice of methodology, a discussion about IPA, its philosophical underpinnings and the procedure of the research. The fourth, fifth and sixth chapters present the findings from each of the three sets of interviews undertaken over the duration of the research project. These

chapters also include a discussion of each theme constructed from the data, an overall discussion, a reflective account and a summary of each chapter. The final chapter presents an overall discussion with reference to previous literature and the contribution of this research to understanding patients' experiences of CLBP. This final chapter also includes a section on clinical applications, discusses the limitations of the study, recommendations for future research, a critical evaluation of the use of IPA and a reflective account of the research undertaken.

1.11 CHAPTER SUMMARY

This chapter has introduced the reader to definitions of chronic pain and CLBP, the financial costs of CLBP for the health services and the personal cost for individuals, contemporary approaches to treatment, existing research and the rationale for the research project. The next chapter presents a review of the literature on CLBP.

CHAPTER 2

LITERATURE REVIEW

2.1 INTRODUCTION

The review of the literature is a fundamental and essential part of the research process as it informs the researcher about contributions others have made to the topic under study. A main purpose of a literature review is to describe and evaluate extant literature on a particular topic so as to distinguish what is known, what is not known and what needs to be known. It also enables the researcher to have an understanding of the main methodologies used and places the research in a historical context, helps limit the scope of an inquiry and informs the design and focus of the proposed work (Hart, 2001).

There is little agreement about the form a literature review might take (Cresswell, 2003). However, the present review includes the discussion of main themes and an evaluation of the quantitative and qualitative methodologies used in the literature. The review presents literature mainly from the psychology literature; however studies from the medical sociology and nursing literature are also included as they were found to include psychological insights and information about the social context of CLBP. The review may therefore be referred to as both “integrative” and “methodological” (Cresswell, 2003; Hart, 2001).

2.1.1 Review strategy

According to Hart, (2001) a literature review informs the overall design and aim of the proposed work and implies that this usually take place prior to the research itself. However, in keeping with much qualitative research, an initial balance has to be kept between gaining background knowledge about the topic area and having few *a priori* assumptions so as to maintain the inductive nature of the research (Murphy, Dingwall, Greatbach, Parker, and Watson 1998). The writing of Cresswell, (2003) similarly informs us that the literature in a qualitative study should be initially used

sparingly so as to preserve the inductive enterprise rather than as a basis for advancing hypothesis as in quantitative studies. In concordance with these views, a decision was taken to keep the focus of the initial review narrow by performing a preliminary literature review that offered a framework for understanding the topic area. This was followed by a strategy of ongoing, broadening searches throughout the writing up of the thesis. This is a traditional way of working with qualitative data, that is, to “work backwards” and conduct the literature review after analyzing the data and maintain the inductive technique (Meloy, 2002).

2.1.2 Structure of the review

The review takes an initial historical stance that provides a perspective upon how the conceptualization of chronic pain and illness has developed over time. This is of particular relevance as models of pain parallel the changing conceptualizations of illness generally that has implications for research and treatment.

The review showed that the psychological literature on CLBP is essentially polarized into quantitative, survey designs and smaller-scale qualitative studies with few studies using a mixed methods design. Studies from the well established quantitative paradigm were reviewed so as to gain a broad understanding of previous work conducted on psychological responses to CLBP. This was followed by a discussion of the models of coping including the problem-solving and emotion-focused model of coping (Lazarus and Folkman, 1984), a review of the quantitative studies of “passive coping” and acceptance in relation to chronic pain (McCracken, 1999). Illness beliefs are discussed with particular reference to The Illness Representations Model (Leventhal, Nerenz, and Steele 1984) and the available literature on illness representations and chronic pain

Further information was gained by reviewing the qualitative literature on CLBP and coping and the social context in which CLBP is played out. Qualitative designs may include a number of different approaches. The review revealed that some authors claimed a phenomenological approach to the study of CLBP. These studies are discussed and evaluated before addressing the IPA studies. Finally, both quantitative and qualitative studies are evaluated.

2.1.3 Box 1: Aim and objectives of the literature review

Aim of the review

The aim of this review is to present and evaluate main models of pain and published research investigating patients' experiences and responses to CLBP.

Objectives

- To provide an overview of models of pain and how conceptualizations of chronic pain have developed over time.
- Present predominant areas of commentary and research pertaining to chronic pain, with a particular focus upon CLBP.
- Describe and evaluate relevant examples of research in this area.
- Critically evaluate the methodologies used to study this topic.
- Develop the rationale for the present research.
- Present an overall evaluation of the literature reviewed.

2.1.4 Review strategy and parameters of the review

A main task for the researcher is to locate and summarize the studies about a topic. A systematic search was conducted and parameters were set in order to gain a coherent picture of the literature on CLBP.

2.1.5 Key terms

The main task was to identify books and articles of relevance and importance to the study of CLBP. The terms "chronic pain" and CLBP were initially used as index terms that yielded a vast amount of pharmaceutical or medically focused research. The requirement was to identify psychological texts and articles on CLBP and therefore there was a need to narrow down the number of records. The search was refined by combining the key terms "chronic pain" and CLBP with the term "review" so as to gain an overview of the topic area and identify the key theorists and debates

(Hart, 2001). The term chronic pain was used as an index term throughout the search as it was often used in papers as an umbrella term for a number of different complaints including CLBP. The terms “coping” AND “psychological responses” AND “CLBP / chronic pain, patients’ experiences” AND “chronic pain/CLBP”, “IPA AND chronic pain/CLBP” also revealed specific psychological studies. “CLBP / chronic pain” was also combined with “cost” AND “prevalence” so as to gain a wider knowledge about the societal impact of CLBP. As the analysis developed, extended and specific searches were undertaken:

Examples of these search terms are:

- Illness beliefs/cognitions and CLBP/chronic pain
- Health professionals and CLBP/chronic pain
- Depression and CLBP/chronic pain
- Anxiety and CLBP/chronic pain
- Social support and CLBP/chronic pain
- Loss and CLBP /chronic pain
- Avoidance behaviours and CLBP /chronic pain

2.1.6 Data bases

The searches were conducted on the following computerized data bases:

Psych INFO (1987-2010) and Psych ARTICLES; British Nursing Index and Archive (1985-2010), Cumulative Index of Nursing and Allied Health Literature (Cinahl) (1985 onwards); PubMed; Wiley Interscience; Cochrane library; GOOGLE Scholar and Applied Social Science Index (ASSIA); RCN data base (Royal College of Nursing); The Interpretative Phenomenological Analysis (IPA) web site www.psyc.bbk.ac.uk/ipa/.

2.1.7 The manual literature search

A manual literature search of current journals was also conducted so to ensure that sources not yet listed in the computerized databases were not overlooked. Reference

lists of the retained articles were scrutinized to find further studies that related to this topic. In addition, a Zetoc Alerts System (British Library data base from 1993 onwards) ensured notification of up to date research findings from a range of sources. The most frequently accessed journals were:

- Annual Review of Psychology
- Pain
- British Journal of Health and Illness
- Spine
- British Journal of Health Psychology
- Qualitative Health Research

Through the process of backward chaining, reading key text books, “grey literature” such as government reports (the department of health library and welsh assembly government sites) and contacting experts on pain other key papers were identified and included.

2.1.8 Parameters of the review

The search was limited to 1995 onwards to ensure currency (apart from reviews of seminal works and those earlier articles and texts commonly cited by more contemporary studies and identified from the literature search), spanned a number of different countries and included only those presented in the English language. The laboratory based studies of cognitive bias of chronic pain patients are not included in this review because they are perceived as not being directly relevant to the aims of the study and also because of the word constraint.

Overall many journal articles and text books and reports were consulted. The search was by no means exhaustive but the extensive searches best ensured a representative sample of research based evidence about CLBP. Each reviewed article, report or text was evaluated with the aid of a critiquing framework that was useful for assessing the quality and significance of the work (Rudestam and Newton, 2001).

2.2 MODELS OF PAIN

The review begins with a discussion about the main models of pain starting with the biomechanical models and historical conceptualisations of pain through to contemporary models that includes biomedical, behavioural and biopsychosocial representations of illness and pain.

2.2.1 The biomechanical models of pain.

According to Gatchel (1999), the 17th century philosopher Descartes was responsible for promoting the conceptualization of pain as a purely sensory activity. A Cartesian notion of pain was underpinned by the “dualistic” perspective of mind and body that was popularized during the Renaissance. It became unscientific in this period to regard the body and the mind as one and the same; rather the body was explained in terms of its own mechanisms and the mind was not required for explanation of physical functions or behaviours. This led to pain being viewed as a “straight through” channel with a stimuli setting off a motion directly transmitted to the brain where a response was activated. This simple, deductive and unsubstantiated theory of pain was a main perspective that influenced the study and management of pain for a very long period in history (Gatchel, 1999).

The Cartesian position was developed further by Von Frey, (1895) cited in Gatchel (1999) who posited The Specificity Theory of Pain and similarly by Goldschneider, (1920) also cited in Gatchel, (1999) who proposed the Pattern Theory of Pain. Von Frey introduced the concept of specific sensors that relayed sensations to particular pain receptors in the brain. Pain was therefore viewed as being relayed to a specific area in the brain by specific peripheral sensors and similar to other body sensory systems. Goldshneider rejected the idea that there was a specific connection between pain receptors and pain sites and proposed an alternative Pattern Theory of Pain. This theory accounted for the transmission of pain via nerve impulse patterns that were encoded at the area of stimulation and produced differences in the quality and strength of the transmission of the pain to the brain. The popularity of these theories dwindled due to a lack of empirical support and explanation for the presence of pain in the absence of organic damage.

A long history of inadequate explanations and definitions of pain led to an increasingly holistic, biopsychosocial approach being considered and psychological and social factors recognized as playing a part in determining patients' responses to pain.

2.2.2 The biomedical model

Despite the increasing recognition of emotions and social factors in patients' responses to pain, the treatment of pain has and continues to be informed by a biomedical model of pain that developed from the earlier Cartesian position (see above). This reductionist, biologically focussed model has been the dominant frame of reference for many health professionals over the past 300 years. Sarafino, (1998) states:

From this perspective, disease or illness is viewed as an affliction of the body and separate from the psychological and social processes of the person. Illness is explained on the basis of aberrant physical signs and symptoms and classified or diagnosed by professionals into different types that are amenable to physical therapy, with an expectation of cure or improvement.
(p.9)

The biomedical model is generally recognised as being successful in the treatment of many diseases. However, the increasing number of patients with chronic illness such as chronic pain and conditions related to lifestyle has exposed the inadequacies of applying a disease model to such conditions (Waddell, 1992). A main focus on pathology and physical aspects of a disease neglects the role of social factors and the individual subjectivity of illness.

CLBP with its accompanying complex characteristics does not lie easily within the assumptions of the biomedical model. CLBP may be related to a previous injury or precipitous condition but it may also have no obvious, organic pathology, no diagnosis and ultimately no cure. The challenge for the health professional is to treat CLBP whilst not being able to fully explain its presence. For the patients the challenge is to understand and manage pain that is not amenable to known remedies and persists despite the avoidance of pain promoting situations and rest. Furthermore, the "medical epistemology of objective knowledge with measurable findings" may be in conflict with the subjective experiences of persons suffering from pain

(Lillrank, 2003 p. 1049). For example, where there is tension between the patients' perceptions of their suffering and medical uncertainty about a diagnosis there may be adverse emotional and social consequences for the patients. They may experience a felt stigma and frustration, anger, rejection and display continued attempts to justify their pain during medical consultations by conforming to expected "illness behaviours" (Lillrank, 2003; Werner and Malterud, 2003; Osborn and Smith, 1998). Similarly, Loeser, (1982) proposes clinicians' assessment of pain should include not only objective and behavioural measures but should be informed by the patients' narrative so to ascertain the extent of suffering (see below for further explanation).

2.2.3 Behavioural models of chronic pain

The shift towards understanding pain as a biopsychosocial phenomenon was generated by the work of Fordyce, Fowler, and DeLateur (1968a) and Fordyce, Rowler, Lehmann, and DeLateur (1968b) who recognized the importance of motivational influences in chronic pain. Behavioural models of pain advance two main explanations for the maintenance of pain and pain behaviours. First, chronic pain behaviours may develop in the acute pain stage and persist as a result of learning that is maintained by secondary gain or positive, external reinforcement contingencies that could include the behaviours of significant others such as families.

Second, pain behaviours may also be maintained by secondary hypertension resulting from negative reinforcement otherwise known as escape / avoidance conditioning. A behaviour closely followed by an aversive event may result in avoidance of that event followed by a frequency in avoidance behaviours such as prolonged inactivity. These behaviours are maintained by a fear of pain causing secondary hypertension such as muscle spasms and catastrophizing (magnification and exaggeration of symptoms).

Fordyce et al. (1968a) proposed that once pain behaviours are maintained by reinforcement they can be regarded as an operant response that is relatively independent of nociception. The treatment at this stage should then focus upon the behaviours and the symptoms. Fordyce et al. (1968a) developed behaviour modification programs for patients and their families based upon conditioning principles that focused upon extinguishing maladaptive pain behaviours. From this perspective the internal beliefs of the patient and the subjectivity of the patients

experience was relatively ignored, with the focus being on the behaviours associated with the pain.

It may be proposed that what is learned may be unlearned. The treatment of chronic pain patients using operant principles has shown improvements in activity and distress levels and a lessening of pain behaviours such as prolonged periods of rest and over dependence on medication (Guzman, Esmail, Karjalainen, Malmivaara, Irvin, & Bombardier 2001; Morley, Eccleston., and Williams 1999). However, the extent to which pain behaviours are maintained by reinforcement alone remains uncertain due to many of the patients in studies already having well established chronic pain behaviours. This makes it difficult to isolate influencing factors (Joliffée and Nicholas, 2004). However, laboratory based studies that base their findings on experimentally induced pain demonstrate support for the role of reinforcement in chronic pain. The weakness of these studies is that the social and emotional context within which clinical pain is experienced is unable to be replicated in such controlled conditions (Joliffée and Nicholas, 2004).

A behaviourist or “black box approach” to chronic pain appears to be one-dimensional and simplistic. A focus on pain behaviours ignores the role of emotions and cognitions in the experience of pain. In defence, behaviourists may argue that they are interested in meanings and do take into account emotions such as fear. However, such a reductionist approach does not fully explain fear avoidance behaviours and cognitive biases such as catastrophizing (see below) (Norton and Asmundson, 2003).

2.2.4 Biopsychosocial (BPS) models of pain

As indicated by Gatchel, (1999) (see above) an increasing dissatisfaction with the reductionist biomechanical model of illness led to a wider, biopsychosocial perspective of illness and pain (Engels, 1977). The term biological refers to the individuals physiological functioning and inherited characteristics, whilst the psychological component of this approach refers to cognitions such as health and illness beliefs or learning and perception, motivations and emotions. Illness is played out in a social context and the social element of this model refers to how interactions with families, friends, health professionals and others in a society or culture impact upon responses to illness and disease (Sarafino, 1998). In addition, social class,

education and other structural, social factors may influence responses. In short, the whole gambit of cognitive and psychological and social influences is included in this wide representation of illness. The model may be understood as a general framework and guide rather than a detailed, testable model, nevertheless it has led to a large amount of literature and research on social-cognitive models of health and illness.

2.2.4a The Gate-Control Theory of Pain (Melzack and Wall 1965, 1982)

The shift away from previous simple, stimulus-response theories of pain such as The Specificity Theory and The Pattern Theory was also accelerated by the explicit recognition of physiological, psychological and social factors in the Gate-Control Theory of Pain (Melzack and Wall, 1965, 1982). The Gate-Control theory postulates that pain is mediated by an integration of sensory, motivational and evaluative elements and should be regarded as both a perceptual and sensory experience.

The key element to this model is a hypothetical chemical gate in the central nervous system that “opens” and “closes” pain pathways. The mechanisms for operating the gate are influenced by afferent nerve impulses leading to the brain and efferent nerve impulses leading from the brain where cognitive processes such as past experiences and psychological responses such as anxiety modulate the reaction of the “gate”. Melzack and Wall propose that the opening or closing of the chemical gate is mediated by a “central control trigger” (located in the dorsal column projection system of the spinal cord). The messages from this are then transferred to the higher cortical areas in the brain where the signals are identified in relation to present and previous experiences. The brain’s interpretation of the pain is thus influenced by internal psychological experiences as well as external factors such as medication and therapies such as distraction and acupuncture.

In relation to chronic pain, the Gate-Control theory explains that particular and ongoing levels of nociceptive pain sensitizes or “winds up” the control trigger on a permanent basis thus producing chronic pain. The Gate-Control theory has contributed towards explaining why a number of psychological factors influence this process. For example, the role of distraction has been found to modify the interpretation of pain and chronic pain is receptive to therapies such as biofeedback that target the mind and the body (Gatchel, 1999).

The Gate-Control theory is being continually challenged, for example, the existence or nature of the “gate” has been disputed as new information about pain mechanisms becomes understood. However, the theory has offered a significant contribution towards closing the mind-body gap and stimulating further theories and research such as the neuro-matrix theory of pain (Melzack, 1999). This theory postulates that the brain possesses a neural network referred to as the body-self neuro-matrix that relates to the chemical gate in the gate-control theory. This matrix integrates multiple sensory and psychological inputs to produce and maintain an output pattern or “neuro-signature” comprising of genetically and sensory determined patterns of nerve impulses that determine the quality of the pain. The theory purports to extend understanding of the brain functioning in pain. Further advances in brain imaging may substantiate the theory.

2.2.4.b Biopsychosocial models of chronic pain and disability

Loeser, (1982) developed a conceptual, integrative biopsychosocial model of pain composed of nociception, pain, suffering and pain behaviours that are recognized as interacting with the environment. The model places pain and suffering in a social context rather than regarding it as a purely nociceptive occurrence. Loeser makes the point that whilst pain behaviours may be assessed by standardized tests, these do not evaluate the internal suffering of the patient and, in the case of chronic pain in particular, the effects on the person’s life. Loeser indicates that a biopsychosocial understanding of the participants suffering is gained by listening to the patient’s narrative as part of any assessment and emphasizes the importance of interpersonal skills in any diagnostic assessment.

Waddell, (1992) built on Loeser’s conceptual model to suggest a clinical model of CLBP and disability. The model was developed in response to the growing recognition of the inadequacies of an acute disease model being applied to chronic pain. Waddell rejected the notion of a straightforward or inevitable relationship between chronic pain and disability and proposed sensory, social, cognitive and behavioural elements that mediate and sustain responses to chronic pain leading to disability. In particular, Waddell focuses upon pathological coping strategies such as catastrophizing and fear avoidance elements.

For example, for some individuals, pain may lead to a fearful response leading to fear avoidance beliefs that leads to avoidance of activities such as work. Relief from pain reinforces further avoidance leading to increasing disability and psychological distress. Waddell suggests the management of CLBP should include developing strategies for overcoming both sensory pain and pain related behaviours that may lead to disability. There is little direct empirical testing of the model, but many studies of patients with chronic pain identify passive coping strategies and fear avoidance beliefs that predict disability (Norton and Asmundson, 2003; Kerns, Rosenberg, and Otis 2002; Sullivan, Thorn, Haythornwaite, Keefe, Martin and, Bradley et al. 2001).

2.2.4.c The three stage model (Gatchel, 1991, 1997)

Gatchel, (1991) conceptualized chronic pain as a stressor and proposed a diathesis-stress model of chronic pain. Gatchel proposes that individuals undergo significant psychological changes as their condition persists and these changes can override the original complaint or nociception. Gatchel suggests a two way pathway existing between physical deconditioning and mental deconditioning, that is, one can affect the other and even the pain perception itself as the individual is caught in a vicious circle of negativity.

The model is composed of three stages that explain the interaction of mental deconditioning (psychological and behavioural problems), physical deconditioning (a disuse model discussed previously) and entry into chronicity:

- Stage one: normal reactions to pain such as anxiety fear and worry.
- Stage two: a prolonged experience of pain that would involve the beginning of involvement of psychological issues such as anger, depression, anxiety-sensitivity, distress, learned helplessness, somatization effects; as these problems persist, the patient may enter stage three.
- Stage three: adjusting to chronic illness by habituating to illness behaviours that encourage entry into the sick role and may act as a reinforcement as responsibilities and obligations are excused as part of this role.

According to Gatchel, the differences in responses between sufferers of chronic low back pain rests partly upon the diathesis the patient brings with them, that is, the pre-existing semi-dormant personality characteristics that influence the ways individuals deal with stress. Gatchel rejects the notion of a “pain prone personality” but indicates that predisposing personality characteristics are activated by the stress of coping with the chronic pain. For example, pre-morbid depressive characteristics may be one factor in contributing to elevated levels of depression of chronic back pain patients; anxiety sensitive individuals may have pre-existing anxiety states that predispose some sufferers to anxiety sensitivity and catastrophizing. The model is intrinsically interesting as it seeks to establish determinants of variations in responses. The model is conceptually appealing but a dearth of longitudinal studies indicates there is little supporting systematic evidence for the relationship between a pre-existing personality characteristic and coping with chronic pain.

Overall, the recent history of illness and pain has revealed a shift from a purely biomedical paradigm towards a biopsychosocial paradigm. This movement reflects the limitations of a medical model for understanding chronic illnesses including chronic pain. The Gate-Control Theory of Pain, The Behavioural Model and the Biopsychosocial models of Waddell, (1984) and Gatchel, (1991) demonstrate attempts to integrate psychological and social factors into the conceptualization of chronic pain.

The following section focuses upon the psychological and behavioural responses to chronic pain and CLBP that have been highlighted by the biopsychosocial models of pain.

2. 3 MALADAPTIVE PSYCHOLOGICAL RESPONSES TO CLBP

Commentators such as Turk and Okifuji, (2002); Waddell, (1992) and Gatchel, (1991) indicate the main maladaptive psychological responses are fear avoidance, depression, anxiety, catastrophizing and passive coping. Cognitions or beliefs about one’s illness, also known as illness perceptions, have also been identified as determinants of patients’ management of chronic conditions, although little work has been conducted with chronic pain patients. The following sections present and evaluate the status of documented psychological responses and illness cognitions in chronic pain and CLBP.

2.3.1 Fear avoidance responses

Fear avoidance is recognized as a learned secondary response in chronic pain with cognitive, behavioural and physiological mechanisms implicit in such behaviour. The recognition of these mechanisms supports a biopsychosocial model of fear avoidance in chronic pain (Norton and Asmundson, 2003). Fear-avoidance models indicate that fearful reactions to the anticipation of pain, the consequences of pain or pain itself induce escape from pain producing activities (Vlaeyen and Linton, 2000; Norton and Asmundson, 2003). A “flight” reaction to perceived noxious or harmful stimuli resulting in fear and avoidance of that stimuli may be regarded as an adaptive and protective response, however such on going behaviours in patients with chronic pain are viewed as a problem that contribute to the development of chronicity and disability (Norton and Asmundson, 2003; Vlaeyen, Kole-Snijders, Boeren, and van Eek, 1995; Asmundson and Taylor, 1996; Waddell, 1992).

From a behavioural perspective, avoidance behaviour becomes a reinforcement agent that reduces fear and pain in the short term but may have severe long term consequences such as wastage of anatomical structures (joints, musculature) that decrease effective movement resulting in a likelihood of functional disability known as “disuse syndrome” (Norton and Asmundson, 2003; Vlaeyen et al. 1995; Linton et al. 1985; Bortz, 1984). Chronicity develops as avoidance behaviours, such as avoidance of social situations or certain pain provoking activities occur in anticipation of pain or social disapproval, allowing few opportunities for fear to be replaced with positive appraisals. Thus, fear avoidance may lead to further disability and possible isolation and depression (Vlaeyen and Linton, 2000).

Grotle et al. (2004) measured the fear-avoidance beliefs of 123 acute low back pain (LBP) patients and 233 chronic pain patients. Beliefs were assessed with the Fear Avoidance Beliefs Questionnaire (Waddell, Newton, Henderson, Somerville, and Main 1993). The findings showed that fear avoidance beliefs influenced the development of disability in both sets of patients, suggesting that fear avoidance beliefs should be assessed at an early stage of LBP.

In contrast, Woby, Roach, Urmston, and Watson (2007) found functional self efficacy had a stronger relationship with disability than pain related fear in a study of 183 CLBP pain patients attending a physiotherapy clinic. Pain related fear was measured by The Tampa Scale for Kinesiophobia, (TSK: Miller et al. 1991).

Woby and colleagues explained these results by suggesting previous studies have not measured both fear-avoidance beliefs and self efficacy and that functional self efficacy could be a mediator between pain-related fear and levels of disability.

The relationship between pain related fear, attention and pain intensity may be similarly undecided (Roelofs, Peters, Patjin, Schouten, and Vlaeyen 2004). The researchers in this study used an experience sampling design by means of an electronic diary with a small sample of 40 CLBP patients. The patients were randomly alerted on a daily basis to answer selected items from the TSK in the form of diary questions presented on a palm top computer. Results indicated independent and significant relationships between pain-related fear and pain intensity but little evidence of pain related fear acting as a moderator between pain attention and pain intensity. In other words the association between attention to pain and pain intensity was uniform for patients with either high or low levels of pain related fear. This result is contrary to many other studies that find significant relationships between attention to pain, pain intensity and pain related fear (Vlaeyen and Linton, 2000) but the results should be viewed cautiously due to the small sample size.

The evidence shows there is uncertainty about the strength of a unique relationship between pain-related fear and disability and the moderating role of pain related fear between attention and pain intensity. However, the existing evidence for a relationship between pain related fear and avoidance behaviours and pain-related fear and pain and disability supports the previously cited proposal that pain related fears should be included in any assessment of chronic pain (Grotle et al. 2004). Overall, there is much evidence suggesting fear, both indirectly and directly is a contributory factor to chronicity and disability (Roelofs et al. 2004; Vlaeyen and Linton, 2000; Waddell, 1996). However, longitudinal and qualitative studies may offer further understanding about the determinants of these fears and their development.

2.3.2 Depression

Waddell, (1994) argues that “Anxiety, increased body awareness and depression are best regarded clinically as forms of distress, a normal reaction to pain and disability” (p. 529). On the other hand, the psychological changes that accompany chronic pain may become as problematic as the original pain and indeed may override the original

nociception (Gatchel, 1991). A review of the psychological literature on chronic pain and psychopathology by Dersh, Polatin, and Gatchel (2002), reported that untreated psychopathology such as depression and excessive anxiety can interfere with treatment and rehabilitation, increase pain intensity and decrease pain thresholds, with magnification of symptoms or catastrophizing. This is supported by a qualitative interview study by Clarke and Iphofen, (2005) who reported how chronic pain patients struggled to cope but attempts were hampered by feelings of depression and embarrassment and grieving for a past active life.

Depression has been widely documented as a concomitant of chronic pain (for example: Magni, Moreschi, Rigati-Luchini, and Merskey 1994; Sternbach, 1974). In contrast, Dersh et al. (2002) conclude that pain and depression may exist separately and the fact that depression and the onset of chronic pain do not always coincide supports this argument. Pincus et al. (2002) argue that the study of depression and chronic pain is beset by problems. Pincus et al. suggest that depression is variously defined and measured; making comparisons between studies difficult. In addition, the overlapping symptoms of depression and chronic pain such as withdrawal from activities may also cause “criterion contamination” and jeopardize the validity of results. However, despite the criticisms, Pincus and colleagues found that a multivariate analysis showed a strong independent function of distress / depressive mood in the development of chronicity that exceeded physical clinical factors measured in the same samples. On the other hand, Pincus et al. urge caution as the evidence was limited. Of eight studies that assessed depression / distress in CLBP patients, only four studies were considered to be a high to satisfactory standard as judged against criteria for assessment that included methodological merit, quality of psychological measurements, and statistical considerations (Pincus et al. 2002 p.110).

A main question also relates to the “chicken and egg” situation between depression and chronic pain, that is, what comes first, the pain or the depression. An evaluation of studies of chronic pain and depression challenged the notion of depression as a preexisting diathesis and showed support for a consequences model. This shows depression is as a result of chronic pain rather than a precursor to chronic pain (Fishbain, Cutler, Rosomoff, and Rosomoff 1997). On the other hand, the jury is still out due to a lack of information about the onset of psychological factors such as depression that would offer insight into any progression from acute to chronic pain.

In summary, the few longitudinal studies, a lack of conceptual clarity and evidence of clinical depression distort the picture of the relationship between depression and CLBP. Studies that investigate previous psychological histories may also develop insights into this topic.

2.3.3 Anxiety

Anxiety as a co-morbid disorder is also well documented in chronic pain patients. Panic disorders and generalized anxiety disorder are the most commonly recorded (Dersh et al. 2002). Whereas depression is mainly associated with chronic pain and disability, anxiety is associated with both acute pain and chronic pain.

Anxiety and fear are often viewed as being similar but are regarded as conceptually distinct. Norton and Asmunden, (2003) describe fear as “An emotional response underpinned by the physiological “fight or flight” mechanisms that motivate escape or avoidance behaviours” (p.18). On the other hand, anxiety is described as a gradual response involving more cognitive processing than fear but similarly integral to avoidant behaviours. However, anxiety and fear may interrelate and form a vicious circle as anxiety leads to fear of fearful episodes with increased arousal levels leading to elevated anxiety and consequential avoidance of the feared event or object (Norton and Asmunden, 2003).

Lang’s, (1968) Three-Response Model of Anxiety cited in Norton and Asmunden, (2003, p.21) has contributed to understandings of social phobias and anxiety disorders. The model proposes anxious and fearful responses as including physiological responses (fight or flight mechanisms), cognitive (beliefs, perceptions and attention processes) and behavioural elements (motivation). These are mutually reinforcing with each varying in intensity according to the individual and context (Norton and Asmunden, 2003). In support, of this model, Sharp, (2001) stipulates that anxiety can also influence beliefs and appraisals of pain and takes a key role in such reactions as panic attacks that involves an increasing spiral of intense reactions.

2.3.4 Anxiety sensitivity

Fearful reactions to pain may be rooted in a hypersensitivity to pain or what is termed “anxiety sensitivity”. Catastrophizing and associated hyper vigilance about

symptoms may overlap with anxiety sensitivity (a tendency to be extremely anxious about one's own anxiety or fear of fear itself), negative affect and subsequent avoidance behaviour. The mechanisms for these psychological constructs are complex, with Asmundson and Norton, (1995) and McCracken and Grost, (1993) reporting that chronic pain patients with higher levels of anxiety sensitivity had greater fear and anticipation of pain and increased avoidance activities as compared with those with lower anxiety sensitivity who reported equal levels of pain. The effects of anxiety sensitivity on behaviour were also investigated by Asmundson and Taylor, (1996). They studied the role of anxiety sensitivity in pain-related fear and escape / avoidance with 259 patients with chronic musculoskeletal pain. They found that anxiety sensitivity exacerbates a fear of pain whatever the level of pain and indirectly promotes pain-related escape/avoidance via its influence on the fear of pain.

Anxiety disorders may be promoted by personality traits such as "anxiety sensitivity". Anxiety disorders may therefore be part of a pre-morbid diathesis exacerbated by the onset of chronic pain (Polatin, Kennedy, Gatchel, Lillo, and Mayer 1993). Whether such states are genetically based is uncertain but the idea of a preexisting anxiety state influencing mental deconditioning is congruent with Gatchel's (1991) model discussed previously.

2.3.5 Catastrophizing

A cognitive approach includes reference to distorted cognitions such as catastrophising. This has been characterized as an automatic, unpleasant, magnification, unrealistic interpretation of feared future events and a negative appraisal of one's ability to cope with pain (McCracken and Eccleston, 2003; Sullivan et al. 2001). The concept is well known but has uncertain theoretical underpinnings (Sullivan et al. 2001). For example, there is ongoing debate about whether catastrophizing is a coping strategy or a cognitive bias inducing a form of psychological distress similar to anxiety or fear (McCracken and Grost, 1993). A popular view is that catastrophizing is not goal directed and therefore cannot be considered as a coping strategy. Supporting evidence also comes from studies that show a lack of correlation with other coping strategies (Sullivan et al. 2001). Despite these views, catastrophizing is often castigated as passive coping and there is strong

supporting evidence for the role of catastrophizing in the onset of pain and as a predictor of chronicity and disability.

Linton, (2000) conducted a prospective study of catastrophizing with back pain sufferers. Baseline measurements of catastrophizing were recorded with a follow up study showing small associations between catastrophizing and the onset of pain and disability. Burton, Tillotson, Main, and Hollis (1995) similarly conducted a prospective study of catastrophizing in back pain sufferers one year after onset. Catastrophizing was assessed by The Coping Strategies Questionnaire, (CSQ: Rosenthal and Keefe, 1983). The CSQ consists of six coping subscales including a catastrophizing scale. Catastrophizing was the single most salient predictor of chronicity.

A follow up study of 571 randomly selected adults from the general population was conducted by Mercado et al. (2005) who investigated passive coping including catastrophizing, as a predictor of disabling neck or low back pain. Passive coping was measured by the well validated Vanderbilt Pain Management Inventory (PMI: Brown and Nicassio, 1987) and was found to be a strong and independent predictor of disabling neck and back pain. Similarly, Wolby et al. (2007) (also mentioned previously in this chapter) measured catastrophizing with the CSQ and found it was significantly and uniquely related to pain intensity although functional self-efficacy was most strongly related to disability. There is growing evidence that self-efficacy or feelings of mastery are an important mediator in coping with pain and development of disability (Lau-Walker, 2006; Turk and Okifuji, 2002).

The methods of measuring catastrophizing and the robustness of the construct itself have been challenged. Hirsh, George, Riley, and Robinson (2007) conducted psychometric testing on the CSQ with 152 patients attending a chronic pain clinic. The results did not support catastrophizing as a unique construct as it related to depression, anxiety and trait anger and contributed minimally to pain. This suggests the CSQ was acting as a multidimensional measure of mood rather than a precise measure of catastrophizing.

Pincus et al. (2001, p.117) report that catastrophizing is theoretically interesting as it has been highlighted both as a risk factor and as an explanatory construct for variations in pain and depression in chronic pain patients. However they indicate that a preponderance of studies has not been able to demonstrate its independent influence on chronic pain. Pincus and colleagues suggest that further

prospective and longitudinal studies should clarify the concept and its relationship to distress and chronicity.

From the research reviewed it appears that the CSQ is used in favor of the Pain Catastrophizing Scale (PCS). This is surprising as the CSQ measures catastrophizing as a sub-scale as compared to the PCS that specifically measures catastrophizing and has reported validity and reliability characteristics (Sullivan et al. 2001). An increased use of the PCS may facilitate further, detailed information about catastrophizing.

2.4 COPING AND CHRONIC PAIN

It is generally recognized that when individuals become ill, they are usually, but not always, motivated to restore equilibrium (Ogden, 2006). These efforts to maintain balance or retain effective functioning and well-being may be referred to as coping.

There is a distinct body of psychological literature that specifically refers to coping styles or strategies and how they relate to adaptation and disability of patients with chronic pain (Richardson and Poole, 2001; Large and Strong, 1997; Jenson, Turner, Romano, and Karoly, 1991).

2.4.1 Defining coping

There is some confusion about the meaning of “coping” that is evidenced by the interchangeable use of the term coping either as referring to a successful outcome or as purposeful and goal directed attempts to manage illness regardless of the outcome. (McCracken and Eccleston, 2003). The conceptual ambiguity in the field is further complicated by constructs such as catastrophizing being viewed as either a coping strategy or a cognitive bias (Sharp, 2001). Despite these difficulties, there are a plethora of psychological studies of coping applied to different areas of health and illness. The following sections describe and evaluate empirical work on coping in relation to chronic pain.

2.4.2 Models of coping

There are many ways of coping with illness discussed in the psychological literature that include avoidant / non avoidant Suls and Fletcher, (1985); approach / avoidant Roth and Cohen, (1986); cognitive / behavioural Rosenstiel and Keefe,(1983); repressive Myers, (2000); emotional (non) expression Solano, Montello, Salvati, et al. (2001) and problem / emotion focused Lazarus and Folkman, (1984). In contrast, Brown and Nicassio (1987) argue that all coping is either passive or active. Active coping is where the person takes control and responsibility for the pain and functions despite it. Passive coping is where the pain is allowed to adversely affect all areas of a person's life and there is little perceived control. Passive coping has been linked to poor adjustment and depression in chronic pain and CLBP and is referred to as catastrophizing, praying/hoping, expression of emotions, wishful thinking, negative thinking/passive adherence and helplessness, reducing activity levels and avoidance (Mercado et al. 2005; Weickgenant et al.1993; Roth and Cohen 1986). Active coping or an emphasis on “approaching”, for example problem-solving and taking direct action rather than avoidance is generally viewed as being better suited to the promotion of health (Roth and Cohen, 1986).

CLBP may be perceived as a stressor as patients encounter increased difficulties and demands from daily living with the pain (Dysvik, Natvik, Eikeland, and Lindstrøm 2005; Pincus et al. 2002; Charmaz, 1983). One model of coping that has received much attention in relation to coping with stress is the problem solving /emotion focused approach of Lazarus and Folkman, (1984). This model initiated a consideration of the dynamic nature of coping strategies and therefore worthy of further consideration in a discussion of chronic pain. Lazarus and Folkman, (1984) recognized that individuals may change their coping strategies over time so as to manage illness demands and constraints of stressful situations. From this perspective, coping is viewed as:

contextual and influenced by appraised characteristics of the person-environment relationship, that is, perceptions of the potential threat as a danger or not; as a process that changes as the situation changes; as multidimensional, including problem and emotion focused functions, approach-avoidance functions and interpersonal and intrapersonal functions. (Lazarus and Folkman, 1984 (as cited in Stroebe et al. 2001, p.565)

Lazarus and Folkman, (1984) referred to problem-solving coping as attempts to reduce stressors or demand by direct planning of activities used to achieve specific achievable goals; whereas emotional focused coping involves attempts to manage emotions by behavioural strategies, for example, sports, excessive drinking and / or cognitive strategies such as distraction by watching a film or denial. People can show both styles of coping when facing illness although there is some evidence to indicate emotion-focused coping is predominantly used in illness and where the problem is not perceived as controllable (Vitaliano, deWolfe, Maiuro, Russo, and Katon 1990; Lazarus and Folkman, 1984).

2.5 STUDIES OF COPING

There are a number of studies that specifically investigate coping from a positivist paradigm.

2.5.1 Problem solving and emotion focused coping

The role of appraisal in coping was evaluated by Dysvik et al. (2005) in a study of 88 CLBP sufferers attending a multi disciplinary clinic. Measures included a depression rating scales, self esteem scale and pain intensity scale. Problem-solving coping, emotion focused coping, avoidance and other forms of passive coping and perceptions of social support were measured with The Ways of Coping Checklist Inventory (WCCL) produced from Lazarus and Folkman's transactional model of stress and coping and a revision of the original scale (WCCL-R) by Vitaliano et al. (1985). Results indicated 53% of the sample related their most significant stressors to family and social life. The research supported two main types of appraisals and coping strategies. Pain appraised as a challenge was predictive of problem-solving coping, whereas pain appraised as a threat was related to higher scores on measures of depression and reduced self-esteem and were predictive of emotion-focused coping. These findings support previous studies that have shown problem-solving coping as being a superior form of coping in chronic pain patients and related to less depression (Endler, Norman, Macrodimitris, and Sophia 2003, Jenson et al. 1991).

A larger study investigated problem-solving coping as a predictor of pain depression and disability in 234 chronic pain patients (51.5% with CLBP) attending a

chronic pain management clinic (Kerns et al. 2002). Problem-solving was assessed with the Problem Solving Inventory (PSI). Overall results showed those patients who showed poor use of problem-solving coping were more likely to experience higher levels of pain, greater functional disability and endorse symptoms of depression. This relationship was buffered by perceptions of pain-relevant social support. The authors recognized that although the significance scores were modest the results were consistent with extant theory and similar studies that demonstrate the efficacy of problem solving coping in chronic pain. They maintain there is a role for problem focused coping strategies to be taught as part of cognitive behavioural therapy for chronic pain patients. The study may offer support for problem solving as adaptive coping but the direction of the relationship between problem-solving coping and pain is not clearly delineated. Those with higher levels of pain may be unable to use problem-solving strategies because of the severity of the pain influencing their ability to “think through” the problem effectively.

2.5.2 Passive coping

Many studies refer to active and passive coping (Brown and Nicassio, 1987). These concepts resonate with problem-solving and emotion focused coping (see above). Passive coping as a risk factor for disabling neck or low back pain was investigated by Mercado et al. (2005). The 571 randomly selected participants from the general public were followed up at 6 and 12 months intervals. Fifty five individuals reported developing disabling and / or neck pain. Coping was measured by the Vanderbilt Pain Management Inventory. The results showed those using moderate to high levels of passive coping strategies were at an over five-fold increased risk of developing disabling pain. This was a longitudinal study therefore offering a more reliable indicator of passive coping as an independent predictor of disability as compared to cross sectional studies. The results support similar findings that indicate passive coping is maladaptive (Dysvik et al. 2005). However, as with other studies there is no explanation as to what determines passive coping strategies. Further qualitative, longitudinal research may shed light on this question.

Passive coping was targeted in an intervention study by Spinhoven, ter Kuile, Kole-Snijders, Mansfield, den Ouden, and Vlaeyen (2004) who conducted a follow up study of 148 patients with CLBP attending a multidisciplinary treatment

program. Participants were allocated to one of three groups; operant behavioural treatment plus cognitive coping skills, group discussion or a waiting list control group. Coping was measured with the Pain Coping and Cognition List (PCCL) (Stomp-Vanden Berget et. al. 2001) that included catastrophizing, cognitive coping, and internal and external pain control sub scales. In comparison to the waiting list control group, increased internal control and less catastrophizing mediated the reduction in depression and pain behaviours following treatment as a result of mainly participating in an operant-behavioural programme. However, at a 12 month follow up the decrease in external control was not as significant although improved levels of depression, pain behaviours and activity tolerance were evident. Pain coping was not enhanced although several coping strategies had been targeted (distraction, ignoring pain and using coping self-statements). The authors attributed this to a lack of practice following treatment. They concluded that structured behavioural and cognitive interventions aimed at decreasing what may be termed passive coping, that is, catastrophizing and promoting internal control are important lines of treatment.

2.5.3 Adaptive avoidant coping

In contrast to much of the literature on passive coping, this study presented avoidant passive coping as having an adaptive function. Klapow et al. (1995) categorized the responses of 95 male LCBP patients into clusters on the basis of a discriminate function analysis. Measures included Ways of Coping Checklist (WCCL-R) by Vitaliano et al. (1985) with other measures including an assessment of social support, a life event and difficulties schedule completed by structured interview. Patients were categorized into two groups: those with chronic pain syndrome (CPS) reporting high levels of pain, disability and depression who reported greater life adversity, more reliance on passive/ avoidant coping strategies and less satisfaction with social support networks. The other group was comprised of patients with good pain control (GPC) and low levels of pain, disability and depression and less life adversity, less reliance on passive / avoidant coping, more satisfaction with social support networks.

Interestingly, those with a positive adaptation to pain (PAP) group reported less life adversity, but more reliance on adaptive / avoidance strategies, satisfactory social support networks and high levels of pain with low levels of disability and

depression. The authors suggested that in relation to the PAP group, passive avoidant coping may lead to higher levels of pain but this group of patients were insulated against higher levels of depression and disability because of higher levels of social support. The authors suggest that if the PAP patients were taught active coping strategies this would enable protection against any future threat to disruptions in personal relationships and life adversities. On the other hand avoidant / passive coping may limit disability and depression in a sub set of patients who have high levels of pain but low life adversity and satisfactory social support. Another explanation may be that high levels of pain require passive/ avoidant coping. This study is limited in its power of generalization as it included only male patients.

2.5.4 Maladaptive avoidance coping

Arraras, Wright, Jusue, Tejedor, and Calvo (2002) conducted a cross-sectional, comparative study of coping with fifty one cancer and sixty seven non cancer patients of whom over two thirds reported arthritis and back pain. The investigators used an adapted version of The Ways of Coping Checklist (Folkman and Lazarus, 1985) to measure approach and avoidance coping styles and an adaptation of the Multidimensional Health Locus of Control Scale (Wallston et al. 1978) to measure Locus of Control (LOC) (the attributions people make about how much control they have over what happens during the development of their illness). Avoidant coping was found to be related to perceptions of personal psychological control over pain. There was a strong statistical relationship between avoidance coping, lower internal control and worse mood across the whole sample. The only significant difference between the groups was on internal control with the non cancer group having higher scores on this scale. The use of a cross-sectional design does not allow for explanations about direction of associations; but the authors speculate that in light of previous research findings their results are suggestive of a bidirectional cyclical relationship between the variables with anxiety and depression probably encouraging avoidant coping and an external locus of control and avoidant coping and an external locus of control almost certainly contributing to depression.

2.5.5 Control

Arraras et al. (see above) demonstrated that perceptions of control mediate avoidant coping. In contrast, a study by Wolby et al. (2007) reported the effects of cognitions, including perception of control, on pain intensity and disability measured by the Coping Strategies Questionnaire (CSQ; Rosenstiel and Keefe, 1983). The correlational results indicated that perceptions of control over pain were not related to pain intensity suggesting pain itself was mediated by other cognitive factors including self efficacy and catastrophizing. However, perceptions of control were related to disability although the strongest relationship was between self-efficacy and disability that supports the previously mentioned study by Wolby et al. (2007) and reinforces the notion of self-efficacy as a strong influencing factor on the experience of pain.

In comparison, an earlier study of individuals' locus of control (LOC) showed that ethnic origin and LOC were the best predictors of pain intensity (Bates, Edwards, and Anderson 1993). The study investigated the role of ethnic and cultural beliefs of 372 patients forming six ethnic groups attending an American chronic pain clinic. The study gave strong indications that culturally derived beliefs, expectations and understandings have a role to play in the perception of pain. The authors proposed that a bio-cultural model of chronic pain may be useful to consider in any consideration of chronic pain. Unfortunately the study presents a stereotypical depiction of the different ethnic groups and their responses to pain. It is likely that there are fewer differences between groups than within ethnic groups.

2.6 ILLNESS BELIEFS

The mediating role of beliefs in coping with illness and health has been well documented, (Hagger and Orbell, 2003; Turk and Okifuji, 2002; Sharp, 2001). However, there are comparatively few studies of illness beliefs of patients with chronic pain.

2.6.1 Illness beliefs, coping and catastrophizing

A study by Turner, Jenson, and Romano (2000) investigated illness beliefs, cognitions, coping and catastrophizing of 169 patients at the point of entry to a pain treatment program. The aim of the study was to assess independent associations between pain-related beliefs, coping and catastrophizing and functioning. Coping and catastrophizing were measured with The CSQ Questionnaire (Rosenstiel and Keefe, 1983) and the Chronic Pain Coping inventory (Jenson et al. 1995). Attitudes were measured with The Survey of Pain Attitudes (Jenson et al. 1994). Pain beliefs were measured by The Pain beliefs and Perceptions Inventory (Williams *et al* 1994). Measures of depression and physical disability were also taken using The Centre for Epidemiological Studies-Depression Scale (Radloff, 1977) and The Roland Scale (Roland and Morris, 1983). Findings showed that the coping scores significantly and independently predicted physical disability. Coping strategies such as activity restriction, guarding, resting, and asking for assistance all positively related to physical disability whereas task persistence was inversely related to disability.

Catastrophizing was independently associated with depression only and beliefs were independently associated with both physical disability and depression. The beliefs about the chronicity of the condition and beliefs about the status of illness were significantly associated with physical disability even after controlling for all other predictors such as demographic variables, pain intensity, coping and other belief components. Like Grotle et al. (2004) (mentioned previously) Turner et al. suggested that any pain programme should take into account beliefs, in addition to coping strategies and catastrophizing responses to pain.

2.6.2 Illness representations

A related area is the work on illness beliefs promulgated by Leventhal, Mayer, and Nerenz (1980). Leventhal and colleagues developed the “Illness Representation Model” from qualitative interviews held with patients with a range of chronic illnesses. The original intention was to understand what influenced compliant and non-compliant behaviours of patients. Intrinsic to the model are the beliefs or illness representations people hold about themselves and their illness and their influence upon illness and coping behaviours. These common sense models of understanding

or lay models (CSM) are derived from illness representations. According to Leventhal et al. (1997) understandings of illness or disease are framed around the following illness representations:

- The identity of the illness or diagnosis and the perceived signs and symptoms experienced by the person.
- The perceived cause of the illness and how the person contacted the disease.
- The time line: the perceived temporal element of the condition and whether it is acute, cyclical or chronic.
- The consequences of the illness and effects on the individual's life.
- The curability and controllability of the illness.

2.6.3 Studies of illness representations and chronic pain

Much of the subsequent research into illness representations has been conducted using a positivist approach. A main instrument is The Illness Perception Questionnaire (IPQ) developed by Weinman, Petrie, Moss-Morris, and Horne (1996). In response to criticisms of the psychometric properties of the IPQ, a revised model (IPQ-R) was proposed and tested by Moss-Morris, Weinman, Petrie, Horne, Cameron, and Buick (2002). A re-analysis led to the development of two sub scales entitled control (perceived self-efficacy) and cure (beliefs about cure) and new items developed to assess cyclical time lines beliefs and coherence of illness (the patient's own evaluation of understanding of the illness). Moss-Morris et al. also included an item assessing emotional representations that they argued had previously been overlooked in the IPQ. In addition, an item was added that measured patient's sense of coherence about their illness. These new developments were psychometrically tested with 711 patients from eight different illness groups including both chronic pain patients (41%) and acute pain patients (57%). The data showed good reliability and validity with the authors claiming that the IPQ-R provides further empirical support for the illness representations model and that cognitive dimensions can be measured separately from emotional representations.

Hobro, et al. (2004) used the revised IPQ-R to cluster 130 newly referred chronic pain patients attending a pain relief clinic, into adaptors and non-adaptors

based on measures of beliefs, pain, mood and functioning. The results indicated no significant differences between patients with differing illnesses; therefore the sample was analyzed as one group. The cluster analysis based on the self regulatory model (SRM) revealed two distinct categories; adaptors and non-adaptors that accounted for 75% of participants. Those categorized as non-adaptors articulated more pain descriptions, less energy, poorer physical health functioning and mental health scores. The non-adaptors also viewed medication as more important than adaptors but were also more concerned about its side-effects. The authors propose that the non-adaptors showed more negative affect and this may be a primary determinant of the other factors. The authors suggest a relationship between illness representations such as identity, controllability and consequences and catastrophizing. They suggest the IPQ-R has the potential to enable insight into maladaptive coping that would be a first step towards developing individualized cognitive based treatment packages.

2.6.4 Criticisms of the illness representation model

Hagger and Orbell, (2003) conducted a meta-analysis of 45 studies that had used the common sense model of illness representations with different patient populations. They concluded that there was support for the construct and discriminate validity of the SRM and for the relationship between illness cognitions and coping and illness outcomes in individual tests of these relationships. On the other hand, of the forty six studies that had been reviewed, thirty six were cross sectional in design which limits opportunities for investigations into causality. Hagger and Orbell suggest prospective or longitudinal studies would offer develop understanding about the dynamics of the relationship between coping, illness representations and outcomes and the role of appraisal processes. Hagger and Orbell concluded from their review that there was some support for the construct and discriminate validity of the SRM dimensions.

However Ogden, (2006) maintains “there is a lack of conceptual clarity between some items in questionnaires on illness representations that renders an unclear relationship between illness representations and coping” (p.58). For example, Ogden questions whether the illness representation, “the illness has no serious consequences” should be classed as a cognition or alternatively as a coping strategy.

The SRM was originally developed from qualitative inductive data that facilitated insight into patients own constructions of illness representations. A

subsequent dominant positivist approach to assessing the structure of patient's illness representations may reflect the methodology rather than the patient's representations (Ogden, 2006). In other words, illness representations structures may be an artifact of the positivist methodology rather than a genuine construct. A further criticism points to an assumption of the SRM being that patients form parallel cognitive and emotional representations of the illness threat. However, most of the research has been centered on cognitions rather than emotions (Moss-Morris et al. 2002) and on external support strategies such as social networks and medical help rather than internal perceptions of self efficacy (Lau-Walker, 2006).

2.7 STUDIES OF ACCEPTANCE AND CHRONIC PAIN

There is an expressed disenchantment with studies of coping with chronic pain. A main criticism is that they offer little knowledge about efficacious coping and this has led to an alternative line of positivist enquiry into "acceptance" (McCracken, 1999; McCracken and Eccleston, 2003). Acceptance has been defined as, "A pragmatic way forward, involving disengagement from struggling with pain and instead, engaging in positive adaptive behaviours rather than coping behaviours" (McCracken and Eccleston, 2003, p. 198).

Early studies of acceptance showed significant and positive associations between acceptance and adaptation to chronic pain and lower pain intensity (McCracken et al. 1999; McCracken, 1998). These studies fuelled questions about the conceptual distinctiveness of acceptance and coping. Support for acceptance as being distinct from coping was offered by McCracken and Eccleston, (2003) who measured acceptance and coping in 230 adults attending a pain management clinic. Acceptance was assessed by the validated Chronic Pain Acceptance Questionnaire, (CPAQ). Results showed acceptance as being weakly related to coping and that acceptance as compared to coping was related to less pain, disability, depression and pain-related anxiety, better daily living and work status. The authors report that this study supported other studies that have also demonstrated acceptance as having the potential to make significant contributions to the development of interventions for living with chronic pain.

In comparison, other evidence shows ambivalent support for acceptance as a determinant of both emotional and functional status. Esteve, Ramírez-Maestre, and

López-Martínez (2007) reported acceptance as being a stronger determinant of functional status and functional impairment rather than emotional distress and suggest acceptance has a role in treatments. The authors suggested acceptance and coping as being complimentary approaches to dealing with chronic pain.

The studies of acceptance are vulnerable to the same charge of a lack of longitudinal studies as other psychological surveys. A lack of observations over time may weaken an assertion about the role of acceptance in chronic pain. In recognition of this, McCracken and Eccleston, (2005) conducted a longitudinal study of chronic pain patients using the CPAQ who participated over a period of 3 and 9 months apart. Those who showed greater acceptance at time one reported better emotional, social and physical functioning, less medication consumption and better work status at time two.

There is growing supportive evidence for acceptance, however further longitudinal research is required to clarify the conceptual distinctiveness of acceptance and investigate the role of acceptance as a predictor of adaptation to chronic pain.

The positivist studies into CLBP have offered opportunities for measuring different methods of coping and the role of acceptance. However, the underlying reasons as to “why” people cope with their pain or “accept” their pain in the ways they apparently do, remains relatively unanswered.

The following examples of qualitative studies of coping and chronic pain offer further insight into individuals coping strategies and experiences of living with CLBP. These studies are concerned with gaining personal perspectives of the experience of CLBP within a social context.

2.8 QUALITATIVE STUDIES OF PATIENTS’ EXPERIENCES OF CLBP

In comparison to the quantitative, psychological studies the qualitative literature attends to social context within which CLBP is experienced.

2.8.1 The social context

A biopsychosocial understanding of chronic pain indicates the pain experience is shaped by the pathophysiology of the condition, the psychology of the person and the

social context. The social context within which pain is experienced may determine behavioural reactions to pain and have been identified as potential risk factors in the development of musculoskeletal pain and disability (Blyth, Macfarlane, and Nicholas 2007). Strunin and Boden, (2004) draw on previous work to suggest that investigations into social processes and their influence on the behaviours of chronic patients are well suited to back pain sufferers; where lack of objective legitimization of the pain, role constriction, impoverishment and social isolation serve to marginalize sufferers. The following section presents findings from the psychological, medical sociology and nursing literature that identify the main themes in this area.

2.8.2 Not being believed and issues of validity

The extent to which an individual's experience of illness is accepted by others as a valid form of sickness is partly dependant on society's recognition of that illness as meaningful and conforming to social norms. Talcott Parsons (1951) introduced the concept of the sick role to describe how people achieve acceptance of their suffering and validation of their illness. The concept of the sick role is over fifty years old and yet remains useful in highlighting the social construction of illness. The sick role was described as a deviant role that encompasses obligations to get better as quickly as possible by seeking medical help so as to return to normal functioning and thus continue to contribute to society (Parsons, 1951). In return, there is recognition of suffering and exemption from usual duties. Central to Parson's concept of the sick role is the doctor /patient relationship that is characterized as one of dependency and compliance on the part of the patients. This corresponds with the notion of an obligation to get better by following medical advice. However, CLBP does not "fit" easily into Parson's model as the sick role concept is based upon an acute rather than a chronic model of illness that is characterized as being time-constricted, responsive to treatment and related to physical rather than mental health (Crossley, 1998, as cited in Glenton, (2003, p. 2244). In comparison, CLBP sufferers may have no firm diagnosis, an indeterminate time-line, little or no visible physical symptoms, no cure and medical knowledge may be challenged or deemed as less important (May, Rose, and Johnstone (2000). Sufferers such as CLBP patients who are unable to conform to the expected sick role requirements and gain legitimacy of their condition are

vulnerable to stigma and discrimination, for example, not being believed, malingering, difficulty in obtaining financial benefits and accusations of culpability (Glenton, 2003).

A review of mainly phenomenological studies supports the notion that “not being believed” by health professionals, in particular, is a significant and distressing part of the chronic pain patients experiences (Clarke and Iphofen, 2005). The review was undertaken by a nurse and the implications of patients’ perceptions of not being believed were discussed in relation to developing guide-lines for nursing practice (Clarke and Iphofen, 2005). The authors conclude with recommendations that include confirming patients’ illnesses by appropriate communication and accepting their experiences with little evidence or obvious signs and symptoms. The authors also suggest that, conversely, there is little hard evidence about patients being believed and the implications for the relationship between the health professionals (in this case nurses) and patients and the pain assessment process. Whilst this paper is directed towards nurses there are obvious implications for other health professionals.

An appearance of good health whilst suffering from chronic pain can lead to not being believed. This can result in sufferers having to prove their pain is “real” by adopting overly disabled behaviours. A deep, interview study of ten Scandinavian women with unexplained musculoskeletal pain illustrated efforts the women undertook to legitimize their pain in medical encounters. The strategies included changing behaviour and appearance to conform to biomedical expectations (Wade and Shantall, 2003). The main criticism of this study is the lack of transparency about the analytical procedure. Nevertheless, it pointed to the potency of not being believed and the implications for the relationship between the health professional and the patient. Similar findings were presented by Osborn and Smith, (1998) in an IPA study of nine women with unspecified CLBP who voiced their need to justify their pain to others by adopting expected pain behaviours. Both the above studies indicate “not being believed” is a main issue for patients with CLBP, however both were conducted with female-only samples that leads to outstanding questions about the experience of not being believed for men.

This imbalance was addressed by Glenton, (2003) who also investigated patients concerns about not being believed. The data was drawn from 200 contributors to a Norwegian online discussion group and in-depth interviews that were conducted with nineteen male and female CLBP sufferers. Gender differences

were not discussed but participants' expressed concern about the reality of their pain being questioned and therefore attempted to achieve clinical and social characteristics that would enable them to enter the sick role. The author indicated that such patients become increasingly dependent on the medical practitioner as they search for authenticity in the form of a diagnosis for their condition.

The use of online discussion forums as a means for collecting data is a comparatively new method that invites commentary about the ethics of such practices. For instance, there was no reference to gaining ethical approval in this study. So one can only assume the contributors comments were used without consent.

The medical encounter for CLBP patients is reported as being a particular source of distress and discrimination. May et al. (2000) explored the rhetorical strategies of twelve randomly selected patients attending a back pain rehabilitation clinic in the U.K. The uneasy relationship between the patients and health professionals was illustrated in the patient's accounts that were constructed around three key themes: not being culpable for the onset of the pain, no sensible explanation was forthcoming from the doctors and "smiling through" despite medical skepticism. May et al. suggested the patients were attempting to maintain authenticity based on long experiences of medical doubt and lack of diagnosis for their condition. The participants referred to biomechanical causes for their condition and wanted to achieve a biomedical diagnosis so as to resist being labeled as a "psychological case". The authors recommended approaching patients in terms of facilitating self help and therefore shifting the emphasis away from the uncertain diagnosis to a more positive approach. They also suggested that clinicians should pay attention to the patient's own perceptions of responsibility and potential for recovery and these attributions may be predictive of outcome of treatment and worthy of further investigation.

Similarly, Borkan, Reis, Hermoni, and Biderman (1995) conducted a large qualitative interview study consisting of focus groups, individual interviews and observation with 76 patients. The research showed that many participants described experiences of de-legitimization and suspicion that occurred unknowingly or knowingly at the hands of doctors, friends and families. The participants defensively described their CLBP in purely mechanical or biological terms and this enabled them to maintain their credibility and lack of responsibility for onset of the condition.

Again, in a similar fashion to May et al. (2000), Borkan et al. indicated that practitioners should address patient belief systems when making a clinical assessment.

The social context of pain was explored further by Eccleston, Williams, and Stainton-Rogers (1997) who investigated sixty patients and professionals understandings of the cause of chronic pain by Q-factor analysis. This methodology is qualitative and yet the terminology employed in the study and the procedure undertaken is reminiscent of a statistical factor analysis. The methodology begins by generating a variety of relevant statements, that, as with statistical factor analyses are refined down to a manageable and appropriate amount of statements. Participants sort the statements out in order to offer their viewpoint. A broad range of patients, practitioners and scientists were recruited so as to gain access to a diversity of opinion. The main issues for all the patients were related to apportioning blame by attributing the continuation for their pain to poor medical management thus deflecting responsibility for their condition. They protected their illness identity by strongly opposing any psychological explanation and emphasizing the pain as a “condition” rather than psychogenic in nature. In contrast, the health professionals attributed the chronic pain to the dysfunctional reactions and bad habits of the participants rather than any medical management. This supports the work of Garro, (1994) who proposed that where a cure or satisfactory treatment is not forthcoming, both the participant and the health professional blame each other so as to protect their own integrity. The scientists agreed that the pain had a physical origin and rejected the idea that pain is psychogenic. The alternative practitioners in the sample adopted a physical explanation but indicated the individual has responsibility for their own well being. The study usefully highlights the different beliefs and assumptions about chronic pain that are held by patients and professionals.

Kugelmann, (1999) offered a detailed account of a hermeneutical-phenomenological study of fourteen chronic neck and back pain patients attending a pain management centre. A hermeneutical-phenomenological approach has a primary focus upon speech and the rhetorical positioning of speakers but also seeks to identify and describe the participants “life-worlds”. In short, the approach has similarities to both discourse analysis and IPA. This approach enables the researcher to investigate both the “lens” through which individuals view their worlds but also enables a description and interpretation of the meaning of the experience or

phenomena under study. The data was analyzed at three levels: how the participants depict their pain (in terms of polarities of mind and body); what was said of the pain (inescapability from the pain and limits) and the covert function or genre of the interviews (as vehicles for complaint about the morality of the pain). Kugalmann argues that the genre of the interviews indicate the participants were making a complaint rather than just telling a story and concludes that for these participants pain is firstly and foremost a moral question. As with previously mentioned studies, a task for the participants was to provide evidence for their often invisible complaint in a culture that emphasizes empiricism. Issues of blame and responsibility and identity are apparent throughout the accounts and supports subsequent and previous studies (Glenton, 2003; May et al, 2000; Osborn and Smith, 1998; Bowman, 1993; Charmaz, 1983). Kugelmann argues the interviews are a mode of communication; a stage upon which pain can be presented and become visible. Kugelmann's focus is upon the participants' rhetorical endeavors with little mention of any psychological responses that may be related to these issues.

2.8.3 Social support

The perception of spousal and family support has been reported as being of importance to chronic pain patients (See: Roy, 2004; Roy, 2001). An earlier small scale qualitative study by Strong, Ashton, Chant, and Cramond, (1994) investigated seven patients' experiences of chronic low back pain by focus group discussion. A content analysis revealed the importance of family support and personal relationships. The authors concluded that a consideration of social support networks would be helpful in multidimensional assessments of patients in an occupational therapy setting. Whilst the study did not offer any depth of analysis, that is, single-word coding only, the findings lend weight to the quantitative work of Klapow et al. (1995) where social support was found to be an important mediator of depression in patients viewed as positively adapting to their condition and also those perceived as using predominantly passive coping. Similarly, Mason, (2004) proposed that pain is a relational phenomenon as well as an individual experience and clinical assessments should encompass the family or significant other. Chronic pain has the potential to affect the whole family and working with the family as a team can be a helpful strategy towards enabling a good quality of life for both patients and their families.

Conversely, a study by Miller, Pennington, and Stanley (1999) revealed that family can be both a source of support but also a source of stress. The researchers used a mixed methods design (patient diaries and quality of life measures) as a source of data in a British study of patients with low back pain. The sample comprised of forty four new patients who were undergoing physiotherapy treatment and were recruited from five family doctor clinics. Thematic analysis of the qualitative data offered support for a biopsychosocial understanding of low back pain. The diary data revealed that participants' pain experiences were dependent upon site and severity of lesion, personality and coexistent mental state, prevailing social pressures including family and work. The authors suggested that the use of diaries as qualitative research tools act as an adjunct to treatment as they offer both the patient and health professional insight into coping with the condition.

Similarly, Sofaer-Bennett et al. (2007) in a study of older people with CLBP found tensions between spouses as a result of the impact of chronic pain. In addition, Strunin and Boden, (2004) conducted an ethnographic, interview study of 198 workers with long term back injuries. Findings showed a wide range of limitations on family and social roles. Changes in roles and family relationships caused considerable tensions that according to the authors, should be given as much value as work related impacts, and similarly suggested by Brievek et al. (2006).

Earlier studies show the importance of responses from spouses. Manne and Zaruta, (1998) demonstrated a relationship between spousal attitude and coping with perceived negative responses from spouses related to maladaptive coping. A quantitative study conducted by Goldberg, Kerns, and Rosenberg (1993) reported the findings of a study of 105 married males with chronic pain. The findings were discussed within the context of a buffering hypothesis with spousal support found to ameliorate the relationship between low levels of instrumental activity and depression only. The authors suggest a behavioural model of depression that emphasis the low levels of instrumental activity as a correlate of depression. The data did not indicate any strong support for identification of any one specific spousal response to pain but the authors suggest that patients with low instrumental activity levels were more vulnerable to spousal responses when their opportunities for positive reinforcement from other sources were minimal due to social isolation. The authors indicate that the results were limited in terms of generalization as it is based

upon males only and the authors propose future research should take the quality of the marital relationship into consideration.

The studies reviewed in this section show that patients with chronic pain have to manage their pain at a social level in addition to physical and psychological levels. The reports indicate that not being believed and attempts to authenticate their condition are of main concerns for participants. Social support mainly arises from family and spouses but illness demands may also be a determinant of stress for family members.

The next section presents qualitative research that develops understanding of the ways patients cope with their CLBP.

2.8.4 Coping with CLBP

A study by Large and Strong, (1997) invited nineteen well participants with CLBP to take part in a study exploring the ways people manage their condition. Participants were asked to complete a repertory grid in order to find out how they construed coping. However, the authors acknowledged this as being only partially inductive as the methodology involves the *a priori* construction of the elements and constructs that made up the grid. Results showed that the participants viewed themselves as “copers” and coping well involved learning to accept limitations and adapting to pain, mastery over pain, active stoicism, cheerfulness and acceptance as proposed by McCracken et al. (1999). Coping was viewed as a necessary evil in order to maintain social relations and self esteem but there was an underlying desire to be free of pain. Being a “coper” also meant retaining authenticity as a valid sufferer and not being viewed as a hypochondriac that supports other work conducted with patients with CLBP (Glenton, 2003; May et al. 2000; Eccleston et al. 1997).

Miles, Curran, Pearce, and Allan (2005) conducted a qualitative interview study of 29 chronic pain sufferers attending an outpatient’s pain clinic. The methodology used was Grounded Theory that aims to develop categories of understanding. The researchers identified four coping strategies consisting of acceptance (assimilation referred to as constraints being absorbed and normal life maintained); accommodation (constraints accepted and normal life redefined); resistance (pre-pain identities were pursued despite leading to increased pain) and subversion (where attempts were made to retain pre-pain identities, but activities

altered significantly). The authors likened the coping strategies to processes of adjustment and flexibility in old age and suggested that work on understanding acceptance should consider these adaptive processes that are documented in the aging literature. Identity management was a key finding. Participants protected their identities by avoiding activities where their limitations would be exposed, unfavorable identities emerged and where they “lost face”. The study used theoretical sampling to develop the themes; however, it is not clear what determines the use of either acceptance or resistance by different individuals or whether different modes of coping are used at different times in the course of the condition.

A phenomenological approach focuses the research question upon the “lived experience” of the participant. This methodology allows for the recollection, reflection and analysis of the participants experiences (Van Manen, 1997). Bowman, (1993) claimed to have used a phenomenological approach to study the meaning of CLBP for 15 individuals attending two pain management centers. Two main themes were chosen for discussion from six themes identified in the study: “Altered interactions with others” and “varied psychological reactions”. One assumes these were the most well represented themes as no rationale is offered for the discussion of these two themes above any others. The participants reported that their interactions with others had reportedly changed since the onset of the pain and were often negatively toned. Issues of “not being believed” were a concern and have been previously discussed in this review. Participants told of coping by “fighting back” and “keeping faith” but coping attempts were often hampered by feelings of depression and embarrassment and grieving for a past active life. The author concludes that knowledge of sufferer’s perceptions of their illness and their coping strategies is essential for effective nursing assessment of such patients. Whilst the findings were interesting and relevant to the present study, the author offers very little information about the methodology or any reference to an underlying philosophical framework. Subsequently, the research is hardly distinguishable from any thematic analysis.

The literature on coping is beset by studies that regard coping as a static rather than a dynamic process. A study by Busch, (2005) attempted to redress the balance by investigating the appraisals and coping strategies of twenty-two CLBP sufferers attending a rehabilitation clinic in Sweden. Busch employed a grounded theory design using semi-structured interviews. A three stage dynamic model of

coping was developed incorporating two types of cognitive coping. These are: “disregarding” that is viewed as a form of denial and refusal to change and “regarding” that is a form of direct confrontation with aspects of the chronic pain. Busch claims that most of the participants used disregarding throughout their illness but in three different modes: first, disregarding was used as a defense and regarded as useful, second, a “crisis stage” as participants continued to disregard their worsening condition. This resulted in a magnification of the problem and the appearance of psychological issues such as interpersonal problems and depression. Lastly, the pain was disregarded by the sufferers who deliberately used distraction to aid this strategy.

A weakness of this study is that there are claims to capturing the temporality of coping but the reliance on retrospective data may have invited distorted recollections of the participants’ experiences. A longitudinal or follow up study would minimize memory biases and offer a firmer base for a temporal model of coping. Nevertheless, the qualitative design of the study does capture information about a particular form of denial. Of particular importance is the notion that responses to illness may change outside of any intervention. As the illness progressed participants adapted their coping to their changing circumstances. This supports the notion of sufferers being active rather than passive in the management of their pain and adapting to change with a cognitive form of coping in order to regulate both physiological and emotional symptoms.

2.9 IPA STUDIES

There are a growing number of qualitative studies in health psychology that have explicitly stated they are using IPA to uncover the individual’s perceptions of a phenomenon (see reviews by: Brocki and Weardon, 2006; Reid, Flowers, and Larkin 2005; Smith, 2004).

To date there are six published IPA studies on CLBP. Osborn and Smith, (1998) used IPA with interview data from nine females with non-specific CLBP recruited from one out-patients pain clinic. The age range was wide (25-55 years) and all had experienced CLBP for at least 5 years. The authors used a semi-structured questionnaire as a guide during the interviews with no explanation about its construction (Brocki and Weardon, 2006). The analysis produced four main

themes: searching for an explanation, comparing self with others, not being believed, and withdrawing from others. The authors indicated that the patients were unable to construct positive self regard since having the pain, or able to make sense of their situation, because of a lack of diagnosis and no meaningful explanation. Because the pain was relatively invisible to others, legitimate claims to being ill were made with difficulty. As indicated above, sometimes, the patients felt obliged to appear ill to conform to the expectations of others. The women felt confused, afraid of their future and vulnerable to shame. The participants viewed their own pain as stigmatizing and withdrew from social contact with the consequences of social isolation. The data revealed a picture of individuals striving to authenticate their pain and of coping with feelings of loss. The findings are similar to Glenton's (2003) study where patients with no firm diagnosis were shown to be vulnerable and distressed because of a lack of an illness identity and thus strive to confirm to an illness stereotype. As with the participants in Kugelmann's (1999) study, the pain seems to be first and foremost a moral question.

In a later paper, Osborn and Smith, (2006) proposed that the psychological literature has produced disembodied accounts of the experience of pain (Osborn and Smith, p.217). Subsequently in this paper they reported the relationship between the physical painful body and participants' self-concept. Osborn and Smith claim that their focus on the participants embodied experiences of CLBP provides further understanding of the disruptive effects of pain on even the simplest tasks. The analysis revealed that participants reported a persistent awareness of their damaged bodies as the pain forestalled any spontaneous actions for fear of provoking further pain. In a similar fashion to Kugelmann, (1999), the authors described a fragmentation of self as participants attempted to distance their painful parts from their preferred "real selves". This was interpreted as a protective function that served little rehabilitative purpose. The authors suggested that, "helping the chronic pain sufferer to accept the limitations of their body in pain and accommodate it into a preferred or valued self could prove to be a valuable additional clinical focus for pain management services" (Osborn and Smith, 2006, p. 230). The authors claim to have produced an embodied representation of pain. However, there was no definition of embodiment and little description of the pain itself.

Walker, Holloway, and Sofaer (1999) reported findings from a phenomenological study of twelve males and eight females with CLBP at the point

where the patients sought help from two pain treatment centers in the U.K. The sample encompassed a mix of ages so as to gain insight into a wide range of patient's experiences. Five themes were identified, with Walker and colleagues discussing a central theme entitled "in the system". The associated sub-themes of this theme were waiting, feeling insignificant, getting nowhere and losing faith, skepticism, challenging the medical model, battling for benefits, establishing a legitimate claim and passing the medical test that resulted in frustration, anger and a sense of a lack of direction for the participants. The authors came to the conclusion that those with back pain are encouraged to be passive and powerless and entrapped in medical and legal systems which are supposed to help, but facilitate a negative experience for patients with CLBP. Overall, this study claims to use phenomenology, but contains little discussion of the methodology or the processes that preserves the premises of the approach (Rapport, 2004).

A further paper by Walker, Sofaer, and Holloway (2006) reported from the data originally discussed in Walker et al. (1999). A theme entitled "loss" is discussed with an explicit mention of IPA as the methodology used rather than reference to "inductive interpretations use a phenomenological framework" as in the previous report. This casts a sense of uncertainty upon the main methodology used in the study. However, the authors did detail the openness of the interviews that had encouraged a free flow of dialogue from the participants and conserved the inductive methodology. The theme of loss referred to losses across all areas of the participants lives. The younger participants appeared to be preoccupied with their past with little adaptive resolution. In comparison, the older participants coped with functional losses by referring too CLBP in relation to age related changes. The issues of loss are discussed with reference to theories of grief and stress and the catastrophizing of symptoms. The authors recommended interventions that encouraged patients to accept their losses that resonate with the suggestions of Osborn and Smith, (2006). The authors also report both communalities and differences in the data. The authors wrote of one participants' optimistic approach to the future within a framework of what is termed a "quest narrative" or a continual search for alternative treatments. The lady under discussion attributed her positive attitude to receiving alternative, holistic, non medical treatment. The reasons why some chronic pain patients develop positive perspectives of their illnesses remains relatively unexplored.

Mason, (2004) (also cited above) conducted an IPA study with five men suffering from Ankylosing spondylitis and their partners. The use of semi-structured interviews and focus groups yielded data showing the participants' management strategies were influenced by whether participants had a primary or secondary relationship with pain, if there was a lack of fit between the ideas of sufferers and partners about managing the pain, good support networks, the influence of families ideas about coping, the degree of uncertainty about the future and the condition for both sufferer and spouse. Mason concluded by suggesting that pain is a relational issue that should be treated with a consideration of the relationships between the patient and their family.

Both the phenomenological and IPA studies illustrate that loss across all spheres of their lives, negotiating relationships with family and health professionals, not being believed and experiencing stigma, searching for an explanation and isolation and depression form part of the patients' experiences. Social support, comparing oneself with others worse off and distancing of one's painful body from one's mind are referred to as coping strategies.

2.10 LITERATURE REVIEW EVALUATION

2.10.1 Strengths of the quantitative literature

The positivist approach to the study of CLBP makes use of standardized questionnaires to measure hypothetical constructs and their relationship to disability and chronicity. These large scale studies have demonstrated that depression; catastrophizing; fear avoidance behaviours; passive coping and self efficacy play an important role in the experience of chronic pain. The overall trend is that usually, but not always, these constructs predict chronicity and disability and depression (see Klapow et al. 1995). In comparison, problem solving coping or active coping and acceptance strategies have been found to contribute to better outcomes.

Another mainly quantitative avenue of research into illness representations has indicated that patients' perceptions about their illness are related to their coping strategies. This line of inquiry has been found to offer statistically valid and reliable findings, however just one study has investigated chronic pain and illness representations. This study identified a statistical relationship between illness

representations that included illness identity, controllability, consequences and catastrophizing (Hobro et al. 2004).

2.10.2 Weakness of the quantitative literature

Difficulties arise in the quantitative literature because of the use of different labels for similar concepts of coping and constructs such as depression and catastrophizing being variously defined and measured (Pincus *et al.* 2001). In particular, attention is drawn to the construct catastrophizing and the debate about whether it is a coping strategy or a cognitive bias promoting anxiety and chronicity (Hirsh et al. 2007; Sullivan et al. 2001; Pincus et al. 2001; McCracken and Grost, 1993). These conceptual ambiguities and inconsistencies of use make it difficult to compare data sets and obtain any coherent picture of the independent role of depression and catastrophizing in chronic pain. An added constraint is that whilst there is some evidence to show that catastrophizing is linked to both the onset and the course of pain (Sullivan et al. 2001), most of the studies have recruited long standing participants from pain clinics and therefore have no adequate base line data to trace the origin of the response. The studies that did attempt to do this were not entirely successful as patients were recruited with some experience of CLBP (Linton, 2000, Burton, Tillotson, Main, and, Hollis 1995), therefore caution should be taken when generalizing any findings.

A general criticism of the positivist inquiries relates to the pre-ordained nature of the questionnaires that constrict the participants' descriptions of their experiences within a given framework. This precludes other more meaningful coping strategies and variability of experiences (McCracken and Eccleston, 2003). Acceptance was proposed by McCracken, (1999) as an alternative topic of study with some quantitative studies showing significant and positive associations between acceptance and adaptation to chronic pain, lower pain intensity, disability, depression and pain-related anxiety, better daily living and work status.

The studies of acceptance have broadened the study of chronic pain but hardly address the determinants of behaviour or explore the participants' experiences within a wider social and relational context.

2.10.3 Strengths of the qualitative literature

In contrast to the quantitative literature, the qualitative studies develop understanding about how people cope with pain within their social and personal context. They offer further insight into the psychological and social experiences that underlie patients' responses by gaining access to the participants own perceptions of their pain (Byth et al. 2007).

The qualitative studies show that even small samples of participants may be clustered into those that show acceptance (Miles et al. 2005; Large and Strong, 1997), those who show resistance to adopting the sick role (Miles et al. 2005) and those who deny or disregard pain and those who regard or confront pain (Busch, 2005). Interestingly, the labels of these coping strategies are conceptually similar in some instances to the coping strategies identified in the quantitative literature. For example, the conceptualizations of acceptance identified by Miles et al. (2005) and Large and Strong, (1997) also echo the conceptualization of "acceptance" presented in the quantitative work of Eccleston et al. (1997) thus offering some theoretical support for the conceptual basis of acceptance.

In contrast to the quantitative literature, much of the qualitative research points to the social challenges for CLBP sufferers. For example, not being believed, experiencing skepticism and stigma and negotiating altered relationships between themselves, family, spouses and the health professionals. One of the strongest themes in the literature is "not being believed". The narratives of the patients in the studies subsequently reveal efforts directed towards maintaining authenticity about their condition as a valid illness. In short, there was a moral endeavor evidenced (Kugelmann, 1999). The importance of social support in coping is also apparent but is complex with studies demonstrating that family and spousal support are important moderators of pain and coping but may also be a determinant of stress (Miller, et al.1999).

A small amount of studies claim to use a phenomenological design, although as suggested previously there is often little justification for these claims. Nevertheless, there are strong themes presented that indicate that the participants experiences are predominantly that of endeavoring to cope but beset by loss and

depression and perceptions of being “passed on” in the health services (Bowman, 1993; Walker et al. 1999).

The findings from the IPA studies of CLBP patients indicate that psychosocial issues are of concern that supports many of the findings from the previously mentioned qualitative studies. Social isolation, searching for an identity and diagnosis, coping with the “system” and pain as a moral concept, loss and adaptation, social interactions and negotiating a positive self concept are reported challenges for sufferers. Coping has been reported as including comparison with others, distancing, and framing functional pain related losses within an age related framework or seeking out alternative treatments and support from family and spouses. From this perspective, as with other qualitative research methods, the participants are invited to describe the experience of pain in their own terms without use of predetermined categories; thus enabling a broad insight into their experiences.

The emergence of biopsychosocial models of pain has encouraged researchers to investigate psychological responses and social contexts. However, an emphasis upon the psychosocial experiences of participants has neglected pain as an embodied experience. The study by Osborn and Smith, (2006) addressed pain in this way but offered very little description of the pain itself indicating that the essence of “embodiment” was only partially captured.

2.10.4 Weaknesses of the qualitative literature

The main criticisms of both the phenomenological studies and the IPA studies echo the views expressed in a review of the IPA literature (Brocki and Weardon, 2006). These criticisms are directed towards a general lack of discussion about methodology design, very little description about the development of questionnaire guides and a lack of reflection upon the researchers’ role in any analysis. In addition, a main weakness of both the quantitative and qualitative data is the disembodied presentations of the participants’ pain.

Despite these criticisms, IPA research is viewed as developing existing psychological theory and knowledge that has previously been dominated by a positivist paradigm. The “lived experiences” of the participants in the IPA studies offers an opportunity to understand the situated nature of pain and “why” sufferers respond in the way they do.

2.11 CONCLUSION

Overall, whilst a number of psychological studies have investigated participants' responses to psychological therapies, there are comparatively few longitudinal quantitative and qualitative studies that offer insight into patients' experiences of pain without evaluating a psychological therapy. This is surprising as long illness careers involve changes in both the illness itself and the social context that may contribute to patients continued reappraisals of managing the pain (Busch, 2005). Consequentially, the existing studies depict CLBP as a static phenomenon that hardly accounts for changes in the pain experiences.

Whilst quantitative investigations have offered information about important constructs there is still very little information about why patients adopt certain coping strategies and form particular beliefs about their CLBP and how these are maintained. For example, there was little information in the literature as to why some individuals adopt passive coping strategies and others adapt quite differently to CLBP.

2.12 RECOMMENDATION

It is proposed that an IPA study using a longitudinal design would develop insight into the ways patients attribute meaning to their pain, the determinants of their behaviours and offer further knowledge about the nature of CLBP within changing social contexts.

2.13 CHAPTER SUMMARY

This chapter has presented the main models of chronic pain and qualitative and quantitative studies of CLBP. The quantitative studies have offered valuable insights into the psychological responses to CLBP and predictors of chronicity and disability. The main criticisms of this research were referred to as a lack of longitudinal studies, conceptual fuzziness, a lack of information about the efficacy of coping strategies

and a narrow focus that potentially precludes a consideration of other coping strategies not considered within *a priori* frameworks.

The qualitative research findings develop understanding about the challenges and coping strategies of CLBP with an emphasis upon the meaning of chronic within a social context. The main criticisms of the IPA studies in particular was the lack of transparency about the construction of semi-structured questionnaires, ambiguity about methodological design, a preponderance of disembodied accounts and as with the quantitative studies, a lack of longitudinal studies. However, the small samples that are a feature of IPA are able to offer a detailed analysis of patients' experiences of CLBP.

The next chapter outlines and discusses the methodology and methods used to explore the experiences of patients with long standing CLBP over two years. It is intended that a qualitative, longitudinal research will contribute to understanding the meaning of "chronicity" for patients with CLBP.

CHAPTER 3

METHODOLOGY AND METHODS

3.1 INTRODUCTION

The main aim of this chapter is to offer a detailed account of the methodological considerations pertinent to this research. A reiteration of the aim, objective and rationale will be outlined and justification will be provided for the use of a qualitative, interpretative phenomenological approach (IPA). IPA is described and evaluated along with issues of validity and reliability as these are viewed as particularly challenging in qualitative research because of its indexical and subjective nature (Elliott, Fiascher, and Rennie 1999). A reflective stance is also acknowledged as it forms part of the research process and informs both the researcher and the reader about the role of the researcher as a co-constructor of the final account (Smith, 1996; Elliott et al. 1999). Finally, there is a discussion about the research procedure including the sampling strategy, ethical issues, methods of data collection and the process of data analysis used throughout the programme of research.

3.2 REMINDER OF THE RESEARCH PROJECT AIM, OBJECTIVE AND RATIONALE

3.2.1 Aim

The aim of this research project was to understand the meaning of living with CLBP for participants so as to identify appropriate ways of helping such patients manage their conditions.

3.2.2 Main objective

To extend understanding of the “lived experience” of CLBP by taking a longitudinal IPA approach and describing participants experiences prior to, during and after attending a chronic pain clinic.

3.2.3 The rationale for the use of IPA

As previously discussed, a review of the literature facilitated the rejection of quantitative methods in favour of a qualitative methodology to meet the aim and objective of the research project. The literature review revealed a preponderance of quantitative studies that were viewed as offering valuable insights into the psychological predictors of disability and chronicity and coping strategies of patients with CLBP. However, this approach has been criticised for offering disembodied, narrow and partial pictures of CLBP experiences (Osborn and Smith, 2006; Busch, 2005; McCracken et al. 1999). In summary, the complexity of chronic illness and the boundaries of CLBP were viewed as not being fully explored with the use of a positivist methodology and offered little opportunity for fulfilling the needs of this research.

After further consideration (see below) IPA was chosen as the most appropriate methodology for the project. An IPA analysis was conducted with the qualitative data gained from semi-structured interviews with a sample of 10 participants recruited from a chronic pain clinic prior to invitation to attend the clinic for assessment. Eight of these participants agreed to participate in a further two interviews over a period of two years.

3.3 SELECTING A RESEARCH DESIGN AND METHODOLOGICAL STRATEGY

The processes of selecting the research design and methodological approach were informed by the work of Cresswell, (2003). Cresswell suggests any inquiry should include, “consideration of what knowledge claims are being made by the researcher, what design and strategies of inquiry will inform the procedure, sampling strategy data collection methods and analysis” (Cresswell, 2003, p.5). The following sections identify the positions taken on these issues.

3.4 KNOWLEDGE CLAIMS: A CONSIDERATION OF ONTOLOGICAL AND EPISTEMOLOGICAL POSITIONS

The philosophical underpinnings of research are rooted in debates about the fundamental nature of knowledge or being (ontology) and what constitutes valid knowledge (epistemology). A consideration of these issues is required in order to clarify the choice of a qualitative research design for this research. This section identifies the ontological and epistemological positions taken in this research that led to the chosen methodology.

Qualitative and quantitative research methodologies represent two distinct models of knowledge referred to as idealism and realism. Traditionally, psychology has taken a quantitative and mainly positivist approach to the study of human behaviour that rests on a realist philosophy. Realism is predicated upon the idea that there is an independent reality and the study of this reality is amenable to positivist research methodologies that aim to establish laws and norms that predict human behaviour (Elliott et al. 1999; Giles, 2002). Realism disregards the problems of the relationship between perception and reality by assuming it is possible to have direct access to an objective material world. A fundamental realist approach does not recognise mediating cultural and perceptual effects on scientific observations rendering claims of objectivity inappropriate. "From a realist paradigm, ontology or knowledge is an objective reality existing in the world and valid knowledge may be gained by careful observation and measurement" (Cresswell, 2003, p.7).

Whilst many fields of contemporary psychology are still predominantly concerned with realist ontology, qualitative psychology turns from the search for measurable facts to exploration of subjective realities and the construction of meaning by individuals. Qualitative psychology thus aligns itself with idealist ontology.

Smith, (1984) makes the distinction between fundamentalist idealism or ontological idealism and conceptual idealism. The former holds a view of the world as a series of representations and a creation of the mind with no independent reality (Williams and May, 1996). Smith suggests the latter or conceptual idealism is the contention that reality is mind shaped and it is therefore a less radical form of idealism. From this perspective, realities are constructed as individuals attempt to make sense of their experiences within a social, historical and cultural context (Guba

and Lincoln, 1989; Gergen, 1985; Blumer, 1969; Berger and Luckmann, 1967). Likewise, Hill-Bailey, (1997) argues that, “ontology from an idealist stance is multiple, complex realities relative to social context with methodology involving the search for meaning” (p.18).

If it is accepted in qualitative research that there are multiple versions of reality dependent upon interpretation, then there cannot be absolute certainty about what counts as valid truth or knowledge (epistemology). In response, the sociologist Hammersley, (1992) argues for a third position termed “subtle realism” that recognises an independent external reality but also that different representations of reality exist and all are equally valid. This position resonates with Heidegger’s contextualist, interpretative phenomenology and the “shaping” of reality by social encounters. Heidegger was one of the phenomenologist philosophers viewed as a “minimum hermeneutic realist” (Larkin, Watts, and Clifton 2006). As with Hammersley, a Heideggeran perspective recognises there is recognition of the existence of an objective and independent reality (realism) and yet there is also recognition that the meaning and nature of that reality is dependent on our interpretation of it as social individuals. Heidegger, as a philosopher, was concerned with finding out how things “really are” but claimed it is impossible to gain a “pure” view of reality as we cannot ignore the influences of language, culture, expectations and assumptions that are integral to being “persons-in-context” (Larkin et al. 2006, p.105).

These philosophical positions were considered in relation to understanding the meaning of CLBP for sufferers in this research. It was decided that a fundamentalist realist approach would negate multiple subjective realities and constructed meanings as represented by the participants themselves. A conceptual idealist or constructivist approach seemed compatible with the aim of the study but presented complex questions related to what counts as valid knowledge. Upon further reflection, this research seemed to be straddling both a realist and an idealist position; there was an intention to explore the “real meaning” or true nature of the pain experience for a small number of participants (a realist stance) whilst also recognising that individuals construct their reality through interpretation of their experiences in a social context (conceptual idealism). There was also recognition that the researcher is also part of the social world and a co-constructor of any report and any explanation will be shaped by the researcher’s role in the research process. Thus,

there may be more than one interpretation of the phenomenon under study. This dilemma reflects the inherent difficulties of wholly relating qualitative research with idealism (Hamersley, 1992).

In order to reconcile these issues, there was consideration of Hamersley's "subtle realism" but Heidegger, in particular, seemed to offer a reconciliatory position that supported the intentions for this research. Hamersley offers little guide to conducting research from the perspective of a "subtle realist". In contrast, a Heideggarian perspective recognises that an investigation of subjective meanings is a valid enterprise best accessed through phenomenological study (Larkin et al. 2006). This means appreciation of the subject under study "as it is" by a sensitive and responsive approach and without imposition of personal or theoretical assumptions (idealism) so as to obtain as close a representation of the meaning of the phenomenon under study as is possible. The implications for research being that explicit recognition should be given to the role of the researcher in the research process so as to recognise the forces that shape any explanation (Larkin et al. 2006 p.108).

3.4.1 The ontological and epistemological position taken in this research

From an appraisal of these readings, both a fundamental idealist and realist position was rejected. It was concluded that the ontological stance would be eclectic, that is, the position adopted would be compatible with a realist approach as the intention was to explore the "meaning" or "reality" of a phenomenon for individuals as closely as possible. It was also recognised that realities (s) are constructed through personal experiences and social interactions (conceptualist ontology). Therefore the epistemological approach adopted is that expressed meanings are a valid form of knowledge and may be best represented by an inductive approach that includes sensitive and open-ended questioning and an appreciation of the interpretative nature of the enquiry. It would therefore seem appropriate to adopt a qualitative research design to achieve the aim of the study.

3.5 THE RESEARCH DESIGN: QUALITATIVE RESEARCH

The following section discusses the characteristics of qualitative research. A consideration of the characteristics of qualitative research led to the view that qualitative research design would best meet the aim of the project. Qualitative research is a broad term for a diversity of non-numerical, research methodologies that aim to offer understanding and representation of phenomena but from the individuals' perspectives (Denzin and Lincoln, 1994). Different qualitative methodologies have diverse foci and many accomplish their aims in different ways. For example, phenomenological methodologies are concerned with gaining access to the "lived experience of the participants" by open interviewing, discourse analysis focuses upon the use of language rather than the content of the speech, much ethnographic research uses observation so as to understand others' cultures, grounded theory generates theory from the data and emphasises "theoretical sampling". Despite these divisions all qualitative methodologies contribute to developing and revising understanding, rather than purely verifying earlier conclusions of theories (Elliott et al. 1999; Murphy, et al.1998). These characteristics seemed compatible with the main aim of this study, which was to explore the participants' experiences of CLBP and avoid the imposition of overt or *a priori* frameworks.

The overall aim of qualitative research is to find significance, not in numbers, as with quantitative research, but in the textual accounts of the participants. The themes that emerge from analysis offer identification of the common experiences of the participants. Bryman, (1988) referred to qualitative research as being committed to viewing events, actions, norms and values from the perspective of those being studied. Thus, qualitative research lends itself well to research where a deeper understanding of the phenomenon is required rather than facts as in quantitative research. Questions such as "how", "what", "who" and "why" are appropriate for qualitative research designs and may explore unexamined assumptions (Coyle, 2006; Murphy et al. 1998). These characteristics of qualitative research are compatible with the aim of this research that is to investigate "how" participants' understand CLBP and what meanings are attributed to their pain.

3.5.1 Qualitative longitudinal research (QLR)

Qualitative research challenges the input / output model of quantitative research. A main concern of all qualitative researchers is to understand the meaning of the phenomenon for the participants. However, researchers are aware that meanings can change according to social context and thus qualitative research favours prolonged interaction with participants (Murphy et al. 1998). Longitudinal studies may vary in design but the essential characteristic of longitudinal research is that the same participants are studied over a period of time with change and continuity as a central focus of analytical attention. The main challenges for QLR are recruiting and retaining participants' engagement with the research. Despite these potential difficulties, the temporal sensitivity of QLR can invoke rich and intensive data and adopts an understanding of the self as a dynamic rather than a static entity. A longitudinal design was viewed as appropriate for this research project that intends to explore any changes and consistencies in the participants' experiences over a period of time.

3.5.2 Issues of reliability and validity in qualitative research

Reliability and validity are well known terms in both qualitative and quantitative research. In quantitative research, "reliability refers to the extent to which the same results will be obtained if the research is repeated" (Banister, Burman, Parker, Taylor, and Tindall, (1994, p.10) and validity refers to the degree to which what has been measured corresponds with other independent measures obtained by different research tools. The correlation between a test and other tests of the same variable is a measure of how much that test is picking up and what it claims to be picking up (Banister et al. 1994). In comparison, the aim of qualitative research is specificity rather than generalisation with the recognition that meaning is indexical and may change according to time and social context (Banister et al. 1994; Smith, 1984). These characteristics render a quantitative conceptualisation of validity and reliability as being potentially problematic when applied to the evaluation of qualitative research, including IPA.

There are two different theoretical positions held by researchers about establishing reliability and validity in qualitative research. One view is that if there is

acceptance that there are multiple interpretations of reality (an idealist ontology) then it is unrealistic to accept one interpretation above others and issues of reliability and validity become irrelevant (Smith, 1984). Similarly, Barbour, (2001) argues “that a relativist perspective renders internal validity checks redundant” (p.1117). This position is a logical outcome of a fundamentalist idealist stance but presents a dilemma for psychologists and other qualitative researchers who want to produce knowledge that others can be reasonably confident about (Murphy et al. 1998).

An alternative position is that there should be criteria for evaluating qualitative research but this should recognise the distinctiveness of the qualitative paradigm (Yardley, 2000; Elliott et al.1999; Smith, 1995; Henwood and Pidgeon, 1992; Marshall, 1985). From this perspective it is proposed that qualitative research should be evaluated by a consideration of its credibility and how well the findings address the research question (Elliott et al. 1999). The development of distinctive criteria also includes reference to being reflexive, comprehensive and transparent descriptions of samples and the analytic process, providing examples of data to illustrate analytical procedures and interpretations, credibility checks such as triangulation and a text that resonates with readers (Elliott et al. 1999).

3.5.3 Qualitative research in psychology

According to Giles, (2002) qualitative research began to make a significant appearance in psychology in the 1980s and gained a firmer foothold by the mid nineties (Elliott et al. 1999). Qualitative research methods have also been increasingly used in clinical research and being accepted for publication in science journals (Coyle, 2006; Rennie and Watson, 2002). The move towards the increased popularity of qualitative research methods was also propagated by a report from the British Psychological Society in 1991 that advocated increased teaching of qualitative research methods in institutions of higher education (Stoppard, 2002; Giles, 2002). Contributors such as Coyle, (2006) suggest that qualitative research in psychology foregrounds experience as a valid basis for developing knowledge about what is suitable for care and further research in a particular area. This view is consistent with the intention to develop knowledge about CLBP by exploring patients’ related experiences; so as to offer improved care and psychological interventions for the therapeutic treatment of patients.

3.6 CHOOSING A QUALITATIVE RESEARCH STRATEGY

An appraisal of qualitative approaches led to a consideration of Grounded Theory and IPA as the most appropriate methodologies for the research project. Grounded Theory is a qualitative research methodology developed by Glaser and Strauss, (1967). The methodology enables researchers to derive theories from the data itself rather than testing hypotheses from previous studies, as is the case with many quantitative methods. In a similar fashion to IPA, Grounded Theory is employed by researchers when there is little information about a topic in the research literature or the researcher would like to move away from an established model or theory that has become outdated (Giles, 2002). However, Grounded Theory was rejected on the basis that it is embedded in a predominantly sociological milieu and examines comparatively large data sets in order to build a theory. This is incongruent with the aim of the research that is to closely examine the meaning of CLBP experiences for a small sample of participants, relate the findings to the extant psychological literature and not necessarily develop a theory.

In comparison to Grounded Theory, IPA was viewed as being compatible with the aim of the research. An IPA inquiry is conducted so as to gain understanding of how people make sense of their experiences, that is, how individuals: “Interpret or perceive what is happening to them and the meanings particular people, events, states and objectives have for them” (Smith and Eatough, 2006, p.324). IPA also represents a descriptive and interpretative epistemology that is consonant with the epistemological stance previously outlined, offers guidelines for the research process and has been used in a wide body of health related research (Reid et al. 2005; Smith, 2004). IPA was therefore considered to be a suitable methodology for this study.

3.7 THE RESEARCH STRATEGY: IPA

The main concern of an IPA researcher is to offer a detailed description and interpretation of a participant’s subjective understanding and meaning of personal experiences. The purpose of IPA has been described as, “To explore the participant’s view of the world and to adopt as far as possible an insider’s perspective” (Conrad, 1987) as cited in (Smith, 1996, p.264).

In order to obtain this aim, IPA studies are characterised by small samples that may range from a single case study to five to ten participants with a minority of IPA studies having larger samples such as forty five (Reid et al. 2005). Smith and Eatough, (2006) argue there is no right sample size but is dependent upon a number of factors such as the degree of commitment to the ideographic level of analysis, pragmatic restrictions, the richness of the individual cases and how one wants to compare or contrast cases. Essentially, a small sample means that the researcher has the time and opportunity to conduct a comprehensive, detailed analysis of each account rather than ending up with a larger, superficial qualitative analysis (Smith and Eatough, 2006; Smith, 2003).

IPA takes on board elements of descriptive phenomenology and interpretative phenomenology. The IPA researcher attempts to get as close to the participants view as possible by maintaining an inductive approach that is facilitated by sensitive, open ended interviewing. Therefore the aim is to allow the phenomenon to “show itself as itself” in a Heideggarian sense (see below). On the other hand it also takes the view that it is impossible to gain direct access to participants lived experiences and the resulting analysis is always an interpretation by the researcher of the participants’ interpretation of their own experiences. From this perspective, the final interpretation is therefore regarded as a co-construction between the participant and the researchers who both try to translate the participants’ experiences and is therefore a double heuristic rather than a first order account (Larkin et al. 2006; Smith, 2004).

Whilst the researcher’s own conceptions are recognised as being essential for gaining access to the meaning of the phenomenon for the participant these attempts are also recognised as being a potential source of tension (Smith, 1996). A main task for the IPA researcher is therefore to keep the analysis free from any potential, unnecessary and distorting preconceptions. In keeping with this, the researcher may draw on the work of Husserl and maintain the “phenomenological attitude” (Willig, 2008). This means that in order to achieve a close representation of the participants’ experiences and appreciate the quality of it, the researcher may attempt to “bracket out” or withhold his or her own preconceptions, assumptions and judgements. IPA researchers recognise the impossibility of entirely “bracketing out” past knowledge and there is no formal attempt at bracketing out or setting aside one’s own personal prejudices. However, this can be facilitated during the interview itself by focusing on participants’ accounts as they are and not thinking about what is already known. In

other words, the researcher has to experience the moment rather than looking forward or backwards at other experiences (Willig, 2008). The researchers may also work with their conceptions by testing any presuppositions against any evolving meaning and going back and forth between these suppositions and the data that is known as the “hermeneutic circle” (Willig, 2008). In addition, the researcher may maintain an inductive approach and limit exposure to pre-readings so as to ensure the analysis is firmly grounded in the data rather than structured by *a priori* frameworks.

The ideographic (particular) and qualitative stance of IPA is very different from the mainly nomothetic (universal) and quantitative approach that is also used to study the psychological responses of patients with CLBP. Whereas nomothetic inquiries are concerned with producing facts informed by pre-existing theories, an IPA study is concerned with the meaning of a phenomenon for individuals and the description and interpretation of these experiences. It has been proposed that an ideographic approach is a valid part of psychology and a logical avenue towards establishing universal laws (Harré, 1997). Furthermore, Smith, (1994) argues that IPA is a suitable methodology for health psychologists as health psychology, like IPA, draws heavily on the cognition paradigm that is premised on the assumption that, “people think about their bodies and what they say about their bodies is in some way related to their thoughts” (Smith, 1994, p. 264). This claim rests on the argument that the concern of IPA with meaning and “mentation” and “sense making” is similar to cognitive and social psychology and may therefore be described as cognitive psychology (Smith, 1994). This view is contested by the argument that a focus on cognition is not entirely compatible with IPA that is concerned with capturing the subjective experiences of participants and, “involves non-propositional thoughts that maybe unmediated and unfocused” (Willig, 2008 p. 68). However, Smith, (2004) aligns IPA with Bruner’s meaning-making rather than the more traditional information-processing view of cognitive psychology.

In short, despite the ongoing debate surrounding the use of the word “cognition”, cognition remains a significant element of an IPA inquiry that attempts to understand, “the participants ‘hot cognitions’ or primary and current issues or dilemmas and ‘cool cognitions’ or the participants longer term reflections” (Smith and Eatough, 2006, p. 327).

Furthermore, IPA takes a midway position between the social cognition approach and Discourse Analysis that focuses upon deconstructing the use of

language rather than the content of language. In a similar fashion, an IPA researcher may focus upon an empathetic approach by its concern with trying to get an insider's viewpoint (emic stance) but also questions what is said and searches for nuances in the data that may reveal a more covert agenda. This is referred to as an "etic" approach and means a richer, more insightful analysis may be made (Larkin *et al.* 2006; Reid *et al.* 2005; Smith, 2003). Smith, (1994) argues that whilst IPA theorists take account of the ways participants talk about their experiences they also acknowledge the presence of contrived talk in research.

3.7.1 Reliability and validity in IPA

As indicated in the previous section on reliability and validity, commentators such as Elliott *et al.* (1999) advocate the use of distinct criteria for evaluating qualitative research. Smith, (1996) also proposes evaluative criteria for IPA research and recognise the issue of multiple interpretations: "The aim of validity checks on qualitative data is to ensure that the particular account presented is a sound one warrantable from the data, not to prescribe the singular true account of the material" (p. 69). This position is congruent with the ontological and epistemological position that was taken throughout this research. It addresses previous expressions of concern about the evaluation of qualitative findings by suggesting that there should be explicit recognition of the relativity of any interpretation but steps should also be taken to establish the legitimacy of the account. Osborn and Smith, (1998) specifically suggest triangulation and independent validation checks of the analysis, the use of criteria such as internal coherence, whether the argument in a study is consistent with the data and also the presentation of sufficient data so as to allow other readers to examine the interpretations.

3.7.2 Theoretical underpinnings of IPA

The philosophy of any research methodology does not explicitly contribute to research practice. However an exposition of the underpinning philosophies and schools of thought of a methodology offers insight into the development of the main tenants of a methodology. IPA has a strong theoretical connection to descriptive

phenomenology, hermeneutic phenomenology and symbolic interactionism (Smith, 1996). This section presents these philosophies:

3.7.2a Descriptive Phenomenology

The founder of the phenomenological movement has been regarded as Husserl (1917/1981) who described phenomenology as: “The science of objective phenomena of every kind or the science of consciousness” (p.3). Central to Husserl’s work was his quest to understand fundamental meanings or genuine perceptions of the world in order to understand how we as subjects gain knowledge of objects that make up our world (Todres, 2004; Maggs-Rapport, 2001). The objects that Husserl alludes to may be real entities or immanent objects such as fantasies, dreams, thoughts, in short, anything that presents itself to consciousness (Maggs-Rapport, 2001). Husserl was not interested in the objects themselves and their properties rather he was interested in what makes it what it is, in other words his inquiries centred on seeking out raw cognitions. Husserl’s aim was to establish a rigorous description of a phenomenon so as to gain understanding of its essence and the perceptual processes that are undertaken to achieve this purpose. Husserl contended that our view of the world is always intentional and we impose meaning on an object so as to allow us to sustain recognition of objects in the world. Husserl refers to the “life world” or our “lived experiences” as a starting point for an inquiry. The endeavour is to “find” the natural world or pure experience of the person before theoretical sciences and everyday experience distort them or they undergo a process of transcendence (Chadderton, 2004).

Husserl went on to describe a process of phenomenological reduction (epoche) to obtain knowledge of the essence of an experience. This involved bracketing out or suspending preconceptions or transcendences of everyday experiences, by eidetic reduction or exploring the phenomenon in its various forms and finally reaching the pure untainted essence of the phenomena.

There are many criticisms of Husserl’s philosophy, not least from Heidegger (1927/1996) who challenged the notion of absolute meanings (see below) and Larkin et al. (2006) who argues that: “the aim of the IPA researcher may be to reveal a phenomenon ‘as itself’ but we will always fall short of this as the researcher is also part of the world and we can never fully escape the preconceptions our world brings

with us” (p.108). The main proponents of translating phenomenological philosophy into empirical research methods are Todres, (2001) and Giorgi and Giorgi, (2003) who propose that insights from phenomenology may be modified to accommodate empirical research. The biggest contribution of Husserl has been to establish the distinctiveness of and direction of phenomenological orientated research by his particular method that includes questioning the nature and construction of phenomena within “life worlds” (Todres, 2001).

3.7.2b Interpretative Phenomenology

Interpretative phenomenology is another branch of phenomenology that has influenced the direction of IPA. Interpretative phenomenology or hermeneutics research is concerned with: “Saying, explaining and translating the meaning of phenomena” (Palmer, 1969 as cited in, Chadderton, 2004, p.56). Heidegger, (1889 - 1976) is purported as being a main influence on the development of interpretative philosophy, post Cartesian philosophy and existentialism of the 20th century (Maggs -Rapport, 2001). In a similar vein to Husserl, Heidegger rejected the view that people as conscious beings, can be studied through positivist methods or empirical investigations, as in the natural sciences. However, in contrast to the descriptive phenomenology of Husserl, Heidegger focused upon human consciousness in terms of interpretation rather than description. Heidegger (1927/1996) explained that hermeneutic phenomenology is the discovery of the significance of perceptions that individuals themselves have shaped by “being-in the-world”.

A fundamental part of Heidegger’s philosophy relates to “dasein” or being-in -the world. This approach posits “us” as having an inseparable relationship with our world and the objects within it. Heidegger therefore contested Husserl’s apparent dualistic consideration of the subject-object relationship. From this understanding of “being in the world” Heidegger challenged Husserl’s idea that absolute understandings or meanings may be reached through phenomenological reduction (Chatterton, 2004). Heidegger claimed it is not possible to find an absolute and definitive perception of a phenomenon as we are always part of the world. We cannot attempt to find untainted cognitions or perceptions as we already exist in the world “*a priori*” to conscious knowing and our experiences of our world shape our perceptions.

Heidegger suggests our subjective worlds are not hidden inside but are communicated, located and observable in our relatedness to some meaningful context. For Heidegger the role of language and speech is where “unconcealedness” of “being” takes place. Heidegger also indicates consciousness is always intentional and directed towards an object. On the other hand, Heidegger suggests that we are so immersed in our everyday experiences and “being in the world” that many of our every day behaviours are conducted without thought until a change occurs and it becomes an emergent reality. An example would be our breathing, an involuntary action that does not have to be consciously directed, it is only when we have a chest infection or similar that we become conscious of our actions. Heidegger indicated we do not know the world through “pure ego and consciousness” but rather by being in the world and engaging in activities that may be *a priori* to conscious knowing (Maggs-Rapport, 2001). Another example here would be the infant who acts within the world prior to gaining consciousness of being in the world.

Heidegger’s philosophy has implications for phenomenological researchers including IPA researchers who try to uncover the ways people give meaning to their experiences and actions. In order for researchers to uncover a subject matter in its own terms and offer opportunity for it to show itself there must be an appropriate research methodology. A successful research study based upon Heideggerian phenomenology takes a sensitive and responsive approach so as to enable the subject matter to reveal itself in its own terms. Researchers are also “persons-in-context” and as such are situated in the world we are observing and it is therefore unlikely that we fully escape preconceptions that we bring with us and therefore to be wholly inductive is an impossible task (Larkin et al. 2006, p. 107). The role of reflection in research therefore becomes important as it facilitates awareness of the researcher’s role in a study.

3.7.2c Symbolic Interactionism (SI)

A main tenet of IPA is the recognition that individuals construct meanings within a social context. This underlying premise echoes an ontological understanding of individuals portrayed in Symbolic Interactionism (SI) (Smith, 2003). SI is a major sociological perspective arising from the work of Mead, (1934), with the term originating from Blumer, (1969). SI researchers are interested in how people

construct meanings during social interactions, how they present and construct a self identity and how they define situations.

Blumer, (1969) summarised the perspective as: “People act towards things based on meaning those things have for them; these meanings are derived from social interaction and modified through interpretation” (p.11).The approach contrasts with behaviourist explanations of human behaviour that do not allow for interpretation between stimulus and response behaviours. The main concern of SI research is to gain understanding of human behaviour from a social constructionist approach. The focus is upon how reality is constructed by individuals interacting with others, and the meaning they attribute to an action or situation.

Mead (1934) took a pragmatic approach that highlighted the social processes involved in the formation of a self identity. Central to the approach is that the construction of self identity is acquired through interaction with others in a particular culture via knowledge of shared symbols and meanings. Language is an obvious shared symbolic system that facilitates this process. Metaphors used by integrationists such as “the looking glass self” illustrate the importance of a self identity developed in part by others reactions to ourselves and how we see ourselves through the eyes of others. Mead refers to this as the “me” part of a dialectical “self”. The other half of self being the “I”. The “I” part of self is the relatively autonomous part that develops from interaction with others. SI highlights a mid ground between the debates of free will versus determinism by suggesting that people are both “constructed” and constructors of their self identity (Ashworth, 2003).

This section has referred to the purported theorists that have informed the development of IPA. Both Husserl and Heidegger may be regarded as realists (Larkin et al. 2006) as they both seek to obtain “the truth” or “reality”, however, it is the work of Heidegger in particular that resonates with the interpretative nature of an IPA inquiry and is compatible with the expressed ontological position. In addition, Symbolic Interactionism supports the use of expressed meanings as a valid form of data in IPA.

The following section offers a critique of IPA.

3.7.3 Critique of IPA

IPA is an emerging methodology in psychology (Smith, 2004) but resonates with phenomenological methodologies that are well established in Medical Sociology and Nursing research.

Further-more some elements of IPA are indistinguishable from other qualitative methodologies, including Grounded Theory, where semi-structured interviews are also used and both start the analytical process by coding descriptive categories and immersing oneself in the data from the data collection stage to the analytical stage. With both IPA and Grounded Theory methods, the analysis moves from open descriptive coding to abstract core categories and themes with the aim being either to identify one overarching theme or several significant themes. On the other hand, IPA differs from Grounded Theory as Grounded Theory examines multiple cases in order to attempt to build a theory covering all the cases. In comparison, an IPA usually means an analysis of one case before moving onto the next and may be used to identify general themes but also particular life experiences (Smith, 1999).

Whilst there are similarities with existing qualitative methodologies, IPA represents a unique configuration with the three terms that make up the term IPA (Smith, 2004). IPA has been subsequently viewed as an interpretive phenomenological methodology committed to examining mental processes and well-suited for psychological inquiry. A main claim is that IPA is relatively unique in its ideographic approach as it enables the researcher to focus upon generic themes of a sample but also particular participant's experiences (Smith and Eatough, 2006).

IPA is a qualitative research methodology and as such is susceptible to the same criticisms about subjectivity and bias as other qualitative research methodologies (see above). Reviews by Reid et al. (2005) and Brocki and Weardon, (2006) concluded that there is evidence of good research practice but increased visibility and documentation of the research process is required in many published IPA studies. Brocki and Weardon, (2006) recommend detailed accounting of the development of interview guides, clarification of the role of the researcher in the interviews and theoretical reflexivity by the researcher so as to improve the rigour of IPA studies. They also recommend the increased use of researcher triangulation or independent audits to establish the validity of themes derived from the transcripts. In

a similar vein, the analytical process of developing themes has been described as lacking clarity with little distinction made between themes being derived from inductive abstraction or intuition (Osborne, 1994).

IPA studies are also challenged on the grounds of little attention being paid to the sequencing that might take place in individuals accounting and the processes by which participants change or amend their viewpoints during the course of an interview. A consideration of this could lead to further information and understanding of the phenomenon under study (Collins and Nicolson, 2002).

Despite the criticisms directed towards IPA it offers psychological researchers an alternative, inductive method by which to develop further understanding and knowledge of psychological phenomena previously studied by a positivist approach.

The following section describes the research procedure conducted in this IPA research project.

3.8 PROCEDURE

The aim of this section is to offer an account of the procedure including the sampling strategy and selection strategies, the sample characteristics, the setting, ethical concerns and the analytical procedure.

3.8.1 Sampling strategy

The sampling strategy in this study was purposeful sampling. Purposeful sampling comprises deliberate sampling of participants with particular characteristics rather than selecting at random as in probability sampling. Purposeful sampling was viewed as being appropriate for this study where the aim was to report in detail about participants' experiences of CLBP (Smith and Osborn, 2003). This method allows the researcher to select participants on the basis of which participants will be the most productive in terms of useful data. In order to achieve this aim, participants were selected because of their experiential knowledge and for whom the research question was significant. Denzin and Lincoln, (1994) suggest, "Many qualitative researchers employ purposeful and not random sampling methods. They seek out groups, settings and individuals ... where the processes being studied are most likely

to occur” (p.202). The participants were therefore closely defined according to the criteria outlined below.

Purposeful sampling is congruent with IPA and its focus upon the “particular” rather than the “general.” IPA researchers may make “theoretical generalisations” and make links with existing literature that will contribute to developing the “bigger picture” but do not claim that their findings are representative of all such individuals (Smith and Osborn, 2003).

As suggested previously in this chapter, Smith and Osborn, (2003) propose that there is no “right” sample size. However, the samples in IPA studies are usually small so as to obtain a detailed and nuanced analysis. Likewise, the main interest in this research project was to obtain as detailed a picture of the participants’ experiences as possible by studying a relatively small sample, but of a size that is not unusual for IPA and would enable an in-depth and detailed analysis to be conducted along with the identification of any similarities and differences (Smith, 2004; Smith and Osborn, 2003; Smith, 1999).

The inclusion of participants into the study was guided by the following criteria:

Inclusion criteria:

- An assessment of unrelieved CLBP by the referring medical practitioner.
- CLBP being the primary concern
- Aged 18 years and over.
- Fluent in English and able to understand the purpose and procedure of the research

Exclusion criteria:

- A psychiatric or neurological condition requiring hospitalization in the past five years
- A malignant cause for pain

A primary inclusion criterion was that only English speaking participants were included. There were several reasons for this criterion. Importantly, the researcher’s

primary language was English and it was thought that the use of any translation service could pose a threat to capturing the participants' perspective and therefore compromise any understanding of the meaning of the experiences. In addition, recruiting an interpreter and the associated financial implications for transcribing and travel expenses was deemed outside the scope of this project.

The research criteria also included only those over eighteen years of age. This was due to the possibility of further complex ethical requirements threatening the time scale of the project but also because the intention was to capture the experiences of a relatively homogenous sample of participants (in this case adults) with long standing experiences of CLBP.

As suggested above, the sample was closely defined and for this reason, those with malignant or recent neurological conditions were also excluded. Those with known psychiatric conditions also fell into these exclusion criteria as it was perceived that such interviewing may require particular skills outside the researcher's expertise.

3.8.2 Sample characteristics

The sample was identified from a waiting list held in a chronic pain clinic where patients had long standing experiences of unrelieved CLBP. The patients had been referred to the clinic by hospital consultants for assessment and possible treatment of CLBP. A pragmatic decision was made to access all twenty sufferers of CLBP identified from the list and who met the inclusion and exclusion criteria. This decision was made in anticipation of a high attrition rate due to symptoms associated with chronic illness.

3.8.3 The chronic pain clinic

The aim was to interview participants with long histories of CLBP who could offer rich descriptions of their pain based on their experiences. This intention led to liaising with staff at a chronic pain clinic in order to contact such patients. The participants were accessed from the chronic pain clinic situated in a general hospital. This site was chosen because the clinic offered a "specialist assessment service" for

people with long standing experiences of chronic pain. For many patients this clinic was viewed as a “last port of call”. The clinic is run by three consultant anaesthetists and one specialist pain nurse. Patients are only assessed in the clinic after being referred from other specialists within the hospital and who do not have any underlying malignant pathology. The waiting list time is in the region of 12-24 months with patients complaining of back pain comprising 60-70% of the referrals. Treatment is mainly medical intervention with some onward referral for surgery and some nurse led interventions comprising acupuncture and transcutaneous nerve stimulation (TENS). There is no psychologist attached to the clinic. The clinic focuses upon the assessment and management of patients with chronic pain but the absence of interdisciplinary assessment and management distinguishes this from a multi professional centre or clinic (Welsh Assembly Government, 2008).

3.8.4 Negotiating access to the participants

There had been no previous contact with the chronic pain clinic prior to the research project. The researcher was not known to the staff or patients and initially approached the Specialist Nurse and Lead Consultant so as to gain permission to have access to the patients in the clinic. The clinicians were concerned about the reasons for the research, the aims of the research and why access to patients from this particular clinic was requested. They were also concerned about issues of confidentiality and the potential for misleading patients into believing participation in the research would lead to favoured positions on the waiting list. As suggested by Bogdan and Biklen, (1992) a short proposal was submitted to the clinicians that answered their concerns. Subsequently, verbal agreement to the research was given by the clinicians subject to ethical approval from National Health Service Local Research Ethics Committee (LREC).

3.8.5 Ethical considerations

Prior to any data collection and after permission was obtained for access to patients, the project was presented to LREC, The Hospital Research and Development department (R & D) and The Caldecott Guardian, that is, the hospital research

advisor (approved 07/07/04). As vulnerable patients were being interviewed an application was submitted and approved by the Criminal Records Bureau (CRB).

Any discussion around ethical issues and research involves consideration of ethical principles and theories. The main tenants of contemporary ethical requirements for research originated from The Nuremburg Code devised in response to The Nuremburg Trials of World War 11. As a consequence of the trials it was recognised that the protection of participants in research should be paramount and regulated by government and professional bodies. Within the framework of the ethical theories of deontology and utilitarianism, Beauchamp and Childress, (2001) identify four ethical principles widely recognised in the medical ethics literature. These are: respect for autonomy, non-maleficence (doing no harm), beneficence (doing well) and justice. The ethical code of The British Psychological Society (BPS, 2009) reflects these principles and acts as an ethical regulator in psychological research. The main ethical principles proposed by the BPS may be summarised as a regard for informed consent, confidentiality, subjects rights and welfare, voluntary participation and withdrawal, issues of deception. These principles guided the research conduct throughout this project. The LREC identified patient protection, confidentiality and anonymity along with informed consent as key ethical issues pertinent to this research (Ethics approval 21/12/04,REC reference:04/WSE02/90).

3.8.6 Patient protection

The protection of vulnerable individuals such as children, mentally ill and as in this case, clinic populations, is particularly important as they are more likely to be unable to withdraw from the research setting for various reasons and may be vulnerable to distress (Giles, 2004). As Oppenheim, (1992) points out, an interview is an event where an individual's perceptions, beliefs, feelings and experiences are elicited and this may lead to distressing and painful memories being brought up. This latter issue was a concern for both the researcher and members of the ethics committee who queried how the researcher would respond to any distress displayed by the participants. Three of the participants did become visibly upset during the interviews as they related their experiences. The interview was immediately halted and the participants were asked whether the interview should continue and they all wished to do so after a short period of time.

3.8.7 Confidentiality and anonymity

A significant ethical issue in research is protecting confidentiality or privacy of the participants (Giles 2004; Creswell, 2003). The more individual data that is produced the more likelihood that privacy will be threatened. In order to preserve confidentiality in this research and protect the patients from any unwanted contact by the researcher, potential participants were initially contacted by the lead medical clinician and specialist nurse from The Chronic Pain clinic. This was in accordance with the requirements of the Data Protection Act (1998) that stipulates, “information obtained about a participant during an investigation is confidential unless agreed in advance”. Clinic staff wrote to patients informing them of the research and requesting their permission to communicate their details to the researcher who would then approach them directly. The researcher then contacted those who were willing to participate by telephone so as to offer further explanation about the purpose of the research, to confirm arrangements and answer any questions about the research. All the participants were assured of confidentiality and anonymity and the voluntary nature of participation.

The ethical issues concerned with confidentiality and anonymity should be considered throughout any research project (Creswell, 2003). In accordance with this, the participant’s identity was protected throughout the research by replacing actual names with pseudonyms in the transcripts and in the final report. Names were also replaced in the accounts with a symbol such as an “x”. All the tapes were placed in a locked filing cabinet in a secure office and the typewritten transcripts stored on a computer file with personal access only. It was agreed the tapes would be destroyed after the completion of the research so as to ensure that the data did not become misplaced, stolen or used for other purposes.

3.8.8 Informed consent

An ethical principle in research pertains to the issue of participants misunderstanding the purpose of the research and their role within it (Giles, 2004). Both the researcher and The LREC held concerns that the participants would take the view that a refusal to participate would affect their place on the waiting list. There was also an awareness that participants may feel they would be unable to voluntarily withdraw

from the study if they wished. The response was to offer detailed information at the outset of the study that would offset any misunderstanding about the research (Giles, 2004). All the participants were required to read an information sheet that emphasised participation in the research would not affect their place on the waiting list and they could withdraw from the research at any time. Participants were also asked to sign a consent form indicating they had understood the information and agreed to participate voluntarily in the study. All the participants agreed to their interviews being tape recorded and were aware that these would be kept in a safe place and eventually destroyed. GPs were informed about their patients' participation (See Appendices section for letters of communication with patients and GPs).

3.8.9 Interview setting

The venues for interviews were at the discretion of the participants. One interview took place in a quiet room in the hospital; all the other interviews took place in the participants' homes. All the interviews were tape-recorded with the participants' knowledge and consent.

3.8.10 Data Collection

Semi-structured interviews were used in this research and are a popular form of data collection in IPA studies, although diary entries and possibly focus groups have been mooted as acceptable forms of data collection (Smith, 2004). Interviews are especially useful for examining sensitive issues and the privacy afforded by a well-set up interview will often encourage the participant to open up and talk.

The amount of interviews in the research project was guided by the work of Saldaña, (2003) who recommended at least two reference points in order to confidently analyse any change and consistencies. Data were thus collected from three semi-structured interviews with each participant that were conducted prior to, during and after treatment or a consultation at the chronic pain clinic over a period of two years. The aim of the first interview was to establish baseline data so as to aid understanding of any change, with two subsequent interviews conducted to gather detailed understandings of participants' experiences.

Each interview was guided by a semi-structured interview (see below) that allowed the participants to move freely in their descriptions of their experiences whilst maintaining the focus of the inquiry. This meant the participants were offered the opportunity to describe their experiences and thoughts in their own words rather than imposing themes and categories by the interviewer. The emphasis was upon maintaining a “phenomenological attitude,” that is, focusing upon the participants’ accounting so as to note the quality and texture of their experiences (Willig, 2008). Each first interview lasted from about 60 to 90 minutes; subsequent interviews were shorter due to far less time spent on detailing backgrounds and so on. A primary task was to put the interviewees at ease so they felt they were able to express themselves honestly without fear of censure. The interview style was conversational with probes and prompts used to explore interesting themes or some element of the interview guide. Throughout the research, there were attempts by the interviewer to maintain a neutral but supportive stance so as to facilitate insight into the participants “lived experiences” relatively unhampered by the interviewer.

3.8.11 Semi - Structured Interview schedule

A semi-structured interview schedule was constructed as a guide for all the interviews. A guide is useful in interviews as it enables the researcher to explore specific areas of interest whilst also allowing a degree of latitude for participants’ responses. In comparison to a structured questionnaire the participant shares the direction or even leads the direction of the interview that may offer unanticipated and valuable information. The less desirable side to this method has been recognised as the interviewer having less control over both content and time and yields complex data harder to analyse (Smith and Osborn, 2003). Despite these purported drawbacks, the use of a semi-structured interview guide seemed to be a method that would enable the production of “rich” and informative data in a relatively unstructured fashion.

The semi-structured interview schedule was constructed from an initial reading of psychological literature on chronic pain and discussions with individuals suffering with chronic pain who were not included in the research (see Box 2). The initial guide was composed of questions about personal biography including age, occupation, marital and family status and relevant illness history followed by a broad

“lead-in” question, “Please can you tell me about your experience of pain?” and when required, followed by several open-ended prompts in relation to the effects of their CLBP on their personal, work and social experiences, any observed changes to their personalities’ and mood since the onset of the CLBP, the ways they managed the pain and sources of control, threat and support. The interviews ended with an open-ended question enquiring whether there were any unexplored issues they would like to discuss.

The second and third interviews differed slightly and were usually of a shorter duration as the biographical details had already been discussed. They began with an amended “lead-in” question “Can you tell me how you have been since I last spoke to you?” Prompts were sometimes used to follow up topics mentioned in previous interviews. As mentioned previously, the guide was used throughout the research project. Overall, there was little amendment in subsequent interviews, apart from the slightly changed lead-in question and occasional use of prompts. This often led to the guide acting as an *aide memoire* as participants increasingly led the interview agenda and introduced new topics.

Box 2: The Semi-Structured interview schedule.

Semi-Structured Interview Schedule

Introduction

Thank you for giving up your time to talk to me today.

My name is Sherrill Snelgrove. I am a pain researcher and am investigating people's experiences of chronic low back pain. I am particularly interested in attempting to understand people's views and beliefs about their condition and their ongoing pain. In order to obtain an insight into your experiences of living with a painful condition, I would like to listen to your experiences.

Background: Please can you tell me a little about yourself. For example, your occupation, partner/married, children, age, duration of pain, treatments, brief medical history.

Pain experiences

Lead in Question: 'Please can you tell me about your experience of living with chronic low back pain?'

Prompts

- Has the pain affected your:
Social life. Please give an example.
Work. Please give an example.
Personal life. Please give an example.
- What is most difficult about living with pain?
- What makes the pain worse? What is particularly threatening for you?
- Could you tell me about how you manage the pain at present? What makes it better? Please give an example.
- How do you feel in yourself? Your mood? Please give an example
- Do other illnesses affect your back condition
- Who gives you most support?
- Are there aspects of the pain that you have control over?
- What helps you to gain control?
- Do you think living with the chronic pain has changed you?

Are there any issues that we haven't mentioned that you feel are important for you and would like to discuss further today?

I will now summarise what you have said and please let me know if I have misunderstood anything.

Thank you, you have been very helpful.

3.8.12 Pilot study

Subsequent to ethics approval, two individuals with CLBP not included in the main research project were interviewed. (One was accessed from the pain clinic and one other was a volunteer who did not attend the pain clinic) These prior interviews were conducted so as to ensure that the semi-structured interview schedule was understandable and meaningful to individuals with similar complaints as the intended participants. This also enabled a rehearsal of the researcher's interviewing and transcribing skills. The recordings were listened to several times so as to refine the interview process. No amendments were made to the schedule.

3.8.13 Transcribing process

The interviews were transcribed as soon as possible after the interview, usually within a couple of days of the interview taking place. This enabled an examination of the role of the researcher with a view to any possible refining of the interviewer's approach for subsequent interviews. For example, any comments that could reveal the researchers values and areas of interests. The interview tapes were transcribed and assisted by the note-taking made during the interviews. These aided the deciphering of words that were often difficult to distinguish due to the strong local welsh accents of some of the participants. Notes were also made about voice tone, pauses and non verbal communication during the interviews. These were valuable cues to understanding the emotional status of the participants (Silverman, 2000). The written text was punctuated as closely as possible to the verbal account so as to adequately represent the verbal report, but there is acknowledgement that this process is also interpretative and selective and not an objective record of the interview.

3.8.14 Presentation of the data

The data is presented in the form of representative quotes taken from participants' transcriptions. The themes constructed from the data are supported by these quotes that are selected on the basis of their relevance to the theme and are representative of

the participants' experiences. This is an editorial function of the researcher that was independently judged by the PhD supervisor (see section on reliability and validity).

The convention for the presentation of the quotes is as follows: each quote is accompanied by an identifier composed of a coded name and the transcript page number and line numbers. Indistinguishable responses in the quotes are identified in parenthesis with the identifying recording number. Paralanguage and emotional responses are also identified within parenthesis. Pauses are identified by short, broken lines.

3.8.15 Analysis of Data

3.8.15a *Maintaining an inductive approach*

The aim of the analysis was to gain access to participants' personal perception of their pain experiences rather than imposing *a priori* frameworks on the data by the researcher. Strenuous attempts were made to ground interpretations in the data and to put aside or "bracket out" any beliefs or misconceptions that may distort the participants accounting (see above for a full discussion). However, it was recognised that to be completely inductive and to be completely free from bias is almost certainly impossible (Larkin et al. 2006). On the other hand, there are opportunities to identify preconceptions and reflexively evaluate judgements and so on with a degree of self-awareness throughout any research (Beck, 1993). This issue was discussed previously in the chapter with reference to a reflective diary that was maintained throughout the research and where any emerging methodological issues were documented that facilitated a reflexive approach. During the interviews the researcher focused upon the participants' accounts without reference to what was already known. This was facilitated by an initial, limited reading of previous psychological literature that only began as themes emerged and theory building began. Whilst analytical notes were made throughout the research and even during the interviews, the main bulk of the theorising was developed in the latter stages of the analysis where the interpretation was discussed in relation to previous work so as to gain new understandings of the phenomenon under study (Smith, 2004).

3.8.15b *Levels of analysis*

Both an empathetic and heuristic approach to the analysis was taken that included a focus upon describing the pain experience for the participants but also a more critical approach that focused upon nuances in the data, particularly what was not said and the discourse used by the participants to “position” themselves rhetorically during the interview. In order to achieve this level of analysis it was particularly important to read the whole of the script several times at least in order to keep close to the data and understand the rhetoric in the accounts. These different levels of analysis are not viewed as being separate rather the “positioning” of the participants is viewed as a connection to the meaning of the experience of pain for these individuals (de Visser and Smith, 2006; Smith, 2004).

3.8.15c *Analytical notes*

A preliminary analysis was undertaken during and immediately after interviews. These analytical notes were made on the basis of immediate impressions rather than any systematic analyses. However, they proved to be useful when relating the findings to existing empirical work at a later stage of the research process. Some theorising was also undertaken as the analytic procedure proceeded and, again, these notes fed into the final analysis.

3.8.15d *Analytical steps*

The analytical procedure was guided by the work of Smith and Osborn, (2003). An ideographic and iterative stance was adopted with a detailed examination, analysis and rereading of each transcript prior to moving onto the next script. Each transcript was treated independently that helped to maintain an inductive approach. A table of super-ordinate themes was produced for each participant before moving onto the next transcript. The themes for each individual were then compared across the data set that allowed for different concepts or meanings to be identified as either a new manifestation of an existing theme or a new theme and integrated into master or super-ordinate themes that represented the sample as a whole (Willig, 2008). This process was repeated for each of the three sets of interviews with super ordinate

themes from each study being compared with those previously elicited from the data. This enabled the identification of continued themes and also any new themes.

The sample was relatively homogenous as the participants shared the experiences of long standing and unrelieved CLBP. Thus, the view was that it was appropriate to obtain a generalized understanding of CLBP by developing super-ordinate themes that were purported to represent the participants' experiences. However, the particular experience of individuals was noted and is characteristic of the ideographic commitment of IPA (Smith and Eatough, 2006).

A detailed account of the analytical steps is presented:

- (1) First, a free-text analysis was conducted with each transcript read in its entirety several times (Smith and Osborn, 2003). This was done so as to gain a holistic understanding of the account before moving onto a line-by-line analysis. This is concordant with a phenomenological perspective and enables a fuller and overall appreciation of the concerns of the participant (Georgi and Georgi, 2003). This stage was accompanied by initial observational and analytical notes, questions, and descriptions and so on.
- (2) These initial notes or "open annotations" (Willig, 2008) were subsequently summarised and written in the right hand side column alongside the relevant piece of text. Some of the annotations were summaries about what was said and others were brief descriptions or attempts at analysis.
- (3) A third step included making further comments in the left hand margin that corresponded to the previous comments but were more concise encapsulations about the meaning of what was said by the participant. Smith and Osborn, (2003) suggest the analysis at this stage may refer to psychological terminology and be increasingly abstract but should remain close to the data. However, it was noted that on occasions there was use of "in vivo" terms and an adoption of the term or word used by the participant themselves (Creswell, 2003). This implied that the observations were remaining faithful to what was being said by the participant.

(4) As a fourth step, for each participant a provisional list of themes was constructed from the comments in the left hand margin. These clusters were grouped together on the basis of similarity and were readjusted several times. This procedure involved a close inspection of the themes with some themes that were not well represented being removed, others over-lapped with similar themes and these were merged and become one theme. Care was taken to continually check the themes with the data, to ensure that every theme captured the participants' experiences. This was found to be the most difficult stage of the analysis and was rather an intuitive process and likewise it was noted that Smith and Osborn, (2003) had referred to, "the "magnetic like" quality of some themes that draws others to them" (p. 71).

The researcher was also aware that by clustering the themes the sequencing of the themes was being overridden and the participants' own prioritizing of important themes would be sidelined. Smith and Osborn, (2003) note that whereas in the previous stage the themes had been in sequential order, in this stage there is now a "clustering" of similar themes that distorts the sequencing but is the start of the development of super ordinate themes. This concern was dealt with by making notes about the sequencing of the participants concerns.

(5) Step five involved "feeling the way" a little, although by repeatedly returning to the data there was reassurance that the analysis was remaining close to the participants accounts. A table of super-ordinate themes was constructed for each individual from the themes or clusters. Labels were attached to these super ordinate themes that reflected the nature of the themes. An iterative approach was continued with the super-ordinate themes and sub-themes checked against the data for representation. The outcome for this stage was a set of super ordinate themes with related sub-themes outlined for each participant. These super-ordinate themes were compared across the data set and those themes that represented the participants' accounts were presented and discussed. The data supporting the themes were presented and identified in the text by using an identifier that includes the participants' pseudonym, transcript page and line numbers (Smith and Osborn, 2003).

(6) This was a longitudinal study with each set of interviews treated as independent accounts and super-ordinate and sub-themes identified for each of the times that the participants were interviewed. These super-ordinate themes were then cross referenced across the whole of the data set, that is, across each of the three sets of interviews. This was undertaken so as to gain an understanding of any changes in the participants' perspectives of their pain, mood, coping strategies and so on and enabled an understanding of communalities and variations in the data set. It was noted that some themes continued to be represented throughout the length of the study but also new themes became apparent in subsequent interviews.

3.8.15e Validity procedures in this research

In this research, the suggestions of Osborn and Smith, (1998) were adopted and efforts were made to produce a coherent account qualified with sufficient evidence in the form of a wide range of quotes from the participants' transcripts. Other steps undertaken to demonstrate credibility were:

- a detailed methods section for transparency and reliability
- reflexivity
- Triangulation procedures that included validity check of the themes with the PhD supervisor

A discussion of these procedures is presented below.

3.8.15f Transparency and Reliability

The reliability of a qualitative study as with quantitative research is enhanced by transparency of the research process (Yardley, 2000). This may be achieved by the methods section containing enough detail to be checked and reproduced and include an audit trail or full documentation of the research process in the form of research diaries or similar (Giles, 2002; Silverman, 2000).

There was no formal record of the research process in the present research project. However, there is a detailed account of the research process in the procedures section that was partly informed by methodological notes maintained

during the collection and analysis of data (Richardson, 1994, as cited in Silverman, 2000, p.95). In addition, relevant documentation such as transcripts and tapes were made available that not only enables other researchers to “track” the analytic process and establish reliability but also acts as a validity check for the representative value of the quotes (Giles, 2002). Checking and rechecking theory or analysis for “fit” against the data is also one way of checking validity as is taking note of examples that don’t fit or “negative case analysis” as described in grounded theory studies but also used in IPA and in the present research (Smith, 2004 ; Silverman, 2000).

3.8.15g Reflexivity

Reflexivity in relation to research refers to the researcher’s responsiveness to their role in mediating the shape and output of the research. The work of Woolgar, (1988) informs us that qualitative research such as IPA sits in the middle of a continuum of reflexivity that ranges from constitutive reflexivity (a post positivist position where there is no distinction made between the researcher and the researched) and benign reflexivity that echoes a positivist stance (a distinctiveness between the researcher and the researched). The former position identifies the researcher as an intimate part of the constructed reality and reflexivity as integral to the management of the research analysis. In comparison, the latter end of the continuum intimates a loose connection or no connection between the researcher and the researched and where a degree of reflection may only be present so as to clarify the objectivity of the analysis.

In the case of an IPA study, the researcher recognises their similarity with the people that are being researched, that is, they are people researching other people, but at the same time claim to adhere to a scientific ideal of objectivity. The role of the IPA researcher, in this instance, is to adhere to the phenomenological attitude (see above) and manage any tension between the recognition of oneself as a constituent of any representation and at the same time also maintaining some distance so as to produce a presentation of the participants experiences that offers faithful understandings of the phenomenon under study but is rather more than a regurgitated and indistinguishable image. However this requires rather more than merely reflection or, “thinking about what he or she is doing” and indicates that the

researcher should carefully monitor their responses and critically acclaim their methods throughout the research (Woolgar, 1988, p. 22).

In order to achieve a closely aligned but distinct representation, proactive self-management is required with explicit reference made to the researchers' theoretical position and any presuppositions, prejudices and interests that may bias the research (Rennie, 2000; Murphy et al. 1998; Elliott et al. 1999). There are various means by which any potential researcher influences are recognised. Self conscious reflection documented in research diaries, memos and notes taken prior to, during and post data collection may help with assessing the impact of any researcher influences on the research outcomes and is recognition of the contribution of the researcher to the knowledge created. Peer debriefing, that may include reflective discussions with a PhD supervisor or someone not involved in the data collection is another method by which the researcher can manage the research process (Murphy et al. 1998).

Methodological aids such as the previously mentioned bracketing or the act of disengaging from other sources of information about the topic under study may be applied whilst undertaking the research. This enables the researcher to gain open perspectives of the experiences being related to the researcher by the participants (Giorgi and Giorgi, 2003). However, any notion of being purely objective is disregarded in qualitative research as being naïve with values, expectation and any possible biases acknowledged as part of the research process. As stated above, explicit reference to these may be acknowledged by a reflective approach that states what and who shaped the research (Smith, 2004; Cresswell, 2003; Bannister et al. 1994).

In this research, the researcher was not known to the participants and had little initial in-depth knowledge or any recognised, strongly expressed views or pre-conceptions of CLBP. However, a reflective diary was maintained throughout so as to document the views and role of the researcher in the analysis. Thoughts, perspectives and views were recorded prior to, during and immediately after an interview took place. For example, excerpts from this diary show worries about being able to bracket information received from a previous participant so as not to influence or "colour" the interview with a subsequent participant. There was a recognition early on in the study that it was difficult and even impossible to be purely inductive as the study progressed. However, this did not hinder attempts as suggested

by Larkin et al. (2006) who similarly proposes that it is inevitable that we fall short of this target (Larkin et al. 2006).

In the present research, a reflexive approach was also facilitated by reflective sessions with the PhD supervisor who, on certain occasions, debriefed the researcher by listening and offering verbal feed-back when the researchers own feelings such as empathy and sympathy became a significant and acknowledged response to some interviews. The supervisor also viewed the transcript closely for any undue biases creeping into the analysis (Cresswell, 2003).

3.8.15h Triangulation

Triangulation refers to the use of a variety of perspectives on the research topic so as to verify findings (Giles, 2004). The main types of triangulation include researcher triangulation, method triangulation, data triangulation and respondent validation.

Researcher triangulation is where the analysis is checked by independent analyses or an additional auditor conducting a verification step. The auditor may be another researcher experienced in the field or an expert in that area. This may also involve a collaborative effort where different members of a team participate in the analysis, although group dynamics such as group census may lead to bias (Rennie, 2000).

In comparison, method triangulation involves a mixed-methods approach to investigating one phenomenon. This approach is well used in the social sciences and elsewhere, however, this approach may not always lead to a fuller picture due to the use of uncomplimentary theoretical frameworks and subsequent under-analysed data (Silverman, 2000).

Data triangulation is achieved through interviewing different participants or conducting interviews in different settings and comparing the findings. A main flaw with this method is that this may just lead to many different versions mounting up and distort any clarity of the findings (Rennie, 2000).

Respondent validation is where the researcher returns to the participants to check whether the analysis resonates with them. This latter form of triangulation may be problematic as an exercise in validation. The participants may have a different agenda to the interviewer, not be as critical and be reluctant to raise contentious issues and cause conflict (Bloor, 1997). This option was rejected for this research as

there were concerns that presenting participants with transcripts of their account may be emotionally upsetting for them as it has the potential to reinforce any feelings of vulnerability towards sensitive issues.

In this research it was decided to adopt researcher triangulation, with the PhD supervisor conducting an independent reading of the interviews and analysis. The PhD supervisor was an experienced researcher and an expert on the psychology of pain and, “acted as a check on the emergent analytic accounts” (Osborn and Smith, 1998 p. 68).

This section has focused upon a discussion about the issues of reliability and validity pertinent to the research and the means by which these issues are addressed and methodological rigour established.

3.9 CHAPTER SUMMARY

Despite an acknowledgement of the weaknesses of IPA, it has been proposed as a suitable methodology for this research project. The rationale for its use and the characteristics of IPA as an interpretative and descriptive methodology has been described and evaluated. The underpinnings of the methodology have been suggested as being descriptive phenomenology, interpretative phenomenology and Symbolic Interactionism. The subtle realism of Heidegger’s interpretative phenomenology in particular, has particular significance for this research and is consonant with the stated aim and ontology of this project, that is, to offer an accurate account of participants’ experiences as far as is possible but with explicit recognition of the interpretative nature of the enquiry.

The research process is presented in a detailed, systematic and coherent fashion with rationale given for the procedural strategies (Osborn and Smith, 2006). The small purposeful sample has been viewed as essential for a detailed analysis of the data and is consonant with previous IPA studies (Reid et al. 2005).

The next chapter presents the findings from data collected prior to the participants attending the chronic pain clinic for assessment.

CHAPTER 4

BASELINE UNDERSTANDINGS: PARTICIPANTS' ACCOUNTS PRIOR TO ATTENDING THE CHRONIC PAIN CLINIC

4.1 INTRODUCTION

This chapter presents findings from initial interviews with 10 participants with CLBP recruited from the waiting list of a chronic pain clinic. The themes identified from the transcripts of the participants are presented and supported with relevant quotes. The presentation of sufficient quotes to support the themes is important as it offers validating evidence for the interpretation of the data (Smith and Osborn, 1996). Each theme is accompanied by a detailed discussion with reference to the extant literature. These detailed discussions are followed by the presentation of an overall discussion. The chapter continues with a reflective account followed by a chapter summary.

4.1.1 Aim

The aim of the first interviews was to establish an initial understanding of the participants' pain experiences prior to attending the chronic pain clinic. The analysis of this data will offer a baseline for comparison with the data from the subsequent interviews that took place one and two years later.

4.2 METHODS

4.2.1 Procedure

A full discussion of the methods has been presented in Chapter 3. As discussed previously, the sampling strategy was purposeful sampling that allowed the researcher to select participants on the basis of their experiential knowledge (Smith and Osborn, 2003). In order to achieve this, participants were selected from the waiting list of a chronic pain clinic in 2005. None had previously attended the chronic pain clinic at the time of the first interview and were referred to the clinic by

hospital consultants for assessment and possible treatment for unrelieved CLBP. The interviewer contacted each participant by phone and a mutually agreed location, date and time was agreed upon. All the participants were interviewed in their homes apart from one participant who chose to be interviewed in a quiet hospital side room.

4.2.2 Participants

Of the 20 patients contacted by letter, 12 agreed to take part in the study. Subsequently two participants withdrew from the study citing ill health as a reason for non participation. The final sample consisted of 10 Caucasian adults, including seven women and three men. Participants' ages ranged from 39 years to 76 years with a mean age of 59.2 years that supports statistical estimations of age as a risk factor for back pain. The prevalence of chronic back pain has been documented as increasing with age with around one in three men and one in four women aged 65 and over suffering back pain for a whole year compared with approximately one in 12 men and women aged between 25 and 44 (Office for National Statistics, 1998). All participants reported long standing experiences of pain of at least four years that was unrelieved by previous surgery and / or medical treatment. None had previously attended the chronic pain clinic at the time of the first interview. In the communication sent to the pain clinic by the referring physicians there were references to underlying conditions that were possibly related to the chronic pain. However the cause of the ongoing and seemingly untreatable pain was not determined by these physicians who had sent them to the clinic for further assessment and treatment. The characteristics of the participants who took part are detailed below (table 1).

Table 1: Demographic and Medical Characteristics of Participants

Participants N = 10	Ethnic background	Age	Marital status	Work status	Previous work	*No of years chronic pain	**Known medical history
Paul	Caucasian Welsh	59 yrs	married	Retired/ill health	Warehouse manager	5 years	Small lumbar disc protrusion
Don	Caucasian Welsh	58 yrs	married	Retired/ill health	Miner	5 years	Cervical Spondylosis/ disc protrusion/ lower back pain/ laminectomy
Will	Caucasian Welsh	76 yrs	married	Retired/ill health	Carpenter	At least 4 years	Degenerative changes in spine
Sara	Caucasian Welsh	39 yrs	married	Housewife/ finished work ill health	Social work assistant	8 years	Arthritic changes
Eirlys	Caucasian Welsh	63 yrs	married	Retired / ill health	Nursing assistant/cleaner	At least 4. years	Degenerative Changes in spine & neck
Cara	Caucasian Welsh	54 yrs	married	Retired / ill health	Administrator	5 years	Arthritis/spinal surgery
Doris	Caucasian Welsh	58 yrs	married	Retired / ill health	Market researcher	12 years	Degenerative changes in spine/ decompression surgery
Sian	Caucasian Welsh	57 yrs	divorced	Retired / ill health	Driver	At least 4 years	Disc degeneration and small prolapsed disc
Mona	Caucasian Welsh	66 yrs	married	Housewife	Machinist	23 years	Degenerative changes in spine
Paula	Caucasian Welsh	62 yrs	married	Retired / ill health	Secretary	At least 10 years	Arthritis

* As reported by participants

** Information taken from the participants and communication sent to the chronic pain clinic from the hospital consultant referring the patients to the clinic

4.2.3 Data collection

The interviews began with introductions, the documentation of biographical details and background to the participants CLBP. The researcher reiterated the aims of the research project, participants' rights, issues of confidentiality, anonymity and the interview process. The interviews were guided by the interview schedule (see Chapter 3, Box 2). Interviews began with an open-ended question "can you tell me about your experience of living with chronic low back pain?" Prompts were available if required and were directed towards gaining information about the effects of CLBP on participants' personal, work and social lives, the main difficulties and threats of CLBP, managing the pain, support, control and any perceived changes in personality. The interviews were recorded with the participants consent. Handwritten notes were also maintained as an *aide-mémoire* for the final analysis.

4.2.4 Analysis

A full description of IPA and discussion of the analytical procedure was presented in Chapter 3. Some immediate and tentative analysis began during the interviews with the interviewer listening to the participants accounting but also recording immediate thoughts and ideas as the interview proceeded. These were often found to be useful when analysing the final account, however they could be adopted and discarded according to their observed fit with the data. In keeping with an IPA analysis an iterative approach was adopted with the researcher returning frequently to the data to ensure that the thematic analysis represented the participants' accounts (Osborn and Smith, 1998).

Super-ordinate themes were constructed from the data of each participant and comparisons made across the entire data set. A final number of super-ordinate themes were established that were considered to represent the participants reported experiences. The analysis included a descriptive "emic" approach and an "etic" approach that included a more critical appraisal and a close examination of the ways the participants talked about their experiences that included their use of language and metaphors and expressions used (Willig, 2008).

4.2.5 Validity checks

As suggested in Chapter 3 the validity checks included an independent examination of the transcripts and themes by the PhD supervisor. After a lengthy discussion, the interviewer and PhD supervisor agreed upon the themes but the titles of the conceptual labels merited further debate. Finally, after much revision of the themes, the titles were agreed upon and considered by both parties to be good representations of the themes.

4.3 PRESENTATION OF DATA

The following super-ordinate themes and associated sub-ordinate themes represent the participants' reports about their personal pain experiences. The sub-ordinate themes are viewed as distinct elements of the super-ordinate themes. The main themes and their corresponding sub-ordinate themes are presented in table 2.

Table 2: Super-ordinate themes and sub-ordinate themes

Super-ordinate themes	Maintaining integrity	Not being believed	The essential nature of the pain	Loss of social roles	Managing the pain	Relationships with significant others/ social support	Relationships with health professionals and organisation of services
Sub-themes	The onset of the pain: altruistic acts and biomechanical damage	Lack of visibility	Constant pain	Loss of a previous active life	The dialectical relationship with the medication	Support of family and friends	Search for a coherent explanation
	Reluctance to enter the sick role and establishing moral worth		Unpredictable and unbearable pain	Loss of family roles	The side effects of the medication	Lack of understanding	Loss of faith in health professionals
			Loss of mobility Good days, bad days, very bad days.	Loss of social life	Inefficacy of the medication		Scepticism and lack of understanding
			The intrusive nature of CLBP		Physical focused coping Strategies: Adopting bodily postures Adjunct remedies Fear avoidance behaviours		A low priority
			The painful body and self - concept The painful body and fragmentation of self		Cognitive focused coping Strategies: Comparisons with others Pragmatism Distraction		
			Emotional responses				

4.4 THEMES

4.4.1 Maintaining integrity

The participants were primarily concerned to establish the authenticity of their condition by foregrounding the physical cause of their chronic pain. In addition, the participants emphasised their reluctance to enter the sick role, a previous, valued working life and a moral worth that is viewed as an impression management strategy in an attempt to demonstrate personal integrity.

4.4.1a *The onset of the pain: altruistic acts and biomechanical damage*

A distinctive feature of the participants' accounts was the detailed stories about the onset of the pain. The accounts were characterised by reference to acts of altruism, often work related activities that entailed "going beyond the call of duty" but unfortunately resulting in the onset of the participant's chronic pain. These "stories" emphasised a physical cause, an initial reluctance to enter the sick role and a previous active and worthy life of the participant. The participants are viewed as rhetorically "positioning" themselves as moral, physically ill participants. Positioning has been described by Harré and Langenhove, (1999) as a metaphorical concept relating to the presentation of ones personal identity and moral attributes in discursive practices. The following quotes offer examples of the participants' perceptions of the onset of the pain.

The onset of the CLBP was mainly attributed to participating in a physical and often altruistic act resulting in biomechanical damage.

'I think what was the main thing that did it was I had a friend who has MS and I was helping her out of her wheelchair and I think I probably did some damage there' (Doris: 2. 23-25).

Another participant attributed the onset of her pain to an instance when she went to the aid of a colleague and fell awkwardly to the floor:

'Obviously the client was struggling because he wanted to sit and didn't want to help us at all. So he was struggling and shouting and what ever. Well, anyway I don't know how it happened but this carer nearly had him to his feet



and somehow he lost his hold on him. The next thing I obviously fell back to the floor with him and at the time I felt crunch, my neck and fell in a heap on the floor. So I thought oh well it will stop hurting sometime in the day. So anyway [078], going from Cardiff to Barry I couldn't move it was excruciating' (Sara: 2.14-20).

Mona had received a diagnosis of arthritis but attributed her worsening condition to "overdoing it" whilst caring for her mother:

'My mother used to love to go out. She used to go by car everywhere 'cause she couldn't walk. She used to go by car everywhere 'cause she couldn't talk. You know, we used to take her, we used to go on holidays in the winter and if we went on a day trip I'd take her in a wheel chair and my mother was a big woman and she was heavy but I couldn't show anybody that it was killing me to do it and I think maybe I shouldn't have been so foolish because I think I over done it and now its piling on me. I think it's got a lot to do with it. I'm not blaming my mother I wouldn't blame my mother for nothing' (Mona: 11.10-17).

Will describes how his pain began after participating in an unusually risky work related task that resulted in injuries to his back and leg:

'I was a carpenter in the factory I was like a maintenance man doing a bit of everything more or less. And I was [ahem] and they sent me up to do this job, there was water coming in through the chutes and in the factory and [420] and I went up there and I see all the water on the floor and I had to squeeze in behind some boxes and all that. And where the water had gone on the floor it was a whatsername floor [ahem] that chipboard stuff and I put it in there and it was porous and had all broke up because water had got in it. Down through I went down onto a machine below and I was hanging on a hook like that on a machine in work. So that it stemmed from that really' (Will: 2.25-33).

4.4.1b *Reluctance to enter the sick role and establishing moral worth*

One participant attributed the onset of the pain to a significant work related episode that marked the beginning of her "pain career". This participant presented herself as a committed worker caring for dying people who viewed a bad back as part of the job. The following extract shows how she reluctantly sought help:

'You know people die, so we cared for them so they needed a lot of attention nursing wise and so yes, I always had back problems I'd come home and I would say "Oh gosh my back is dreadful" But I just put it down to the work I was doing at that time. You know because most people say 'oh my back ...' *laughter*. [Ahem] and it wasn't until, [ahem], I actually had this fall in work

one afternoon and just at the end of the shift and the staff nurse I was working with she did say to me 'oh gosh, do you want to go and see the doctor?' I said 'no it's the end of my shift I'll go home'. And, so I went to the doctor because the following day I could hardly move.' (Eirlys: 4. 10-18).

Paul also emphasised his reluctance to enter the sick role and receive sick benefit. This participant was keen to establish that any decision to stop work was made by his employers rather than himself:

'I had to retire from my post of Purchasing Officer nineteen years ago. This I found hard to come to terms with. Having to leave my job after 20 years service made me feel inadequate because I had never received sick benefit before' (Paul: 4. 14-18).

The participants prefaced themselves as previously active and hardworking despite their increasing pain. One participant recalled a previous life where she had been a hard working individual who had experienced little illness:

'I was lucky when I was hospitalised twice then I actually went in to have ops as well. I was working for a very good company and unfortunately made redundant from there but I mean I had, I was paid full pay all the time I was on the sick, I mean that was probably the first time I had been on the sick for I don't know how long' (Cara: 11. 23-26).

Another participant described arduous efforts to receive treatment and maintain her job. In a similar fashion to Paul, Mona describes how the decision to terminate her employment was made by her employers rather than herself and presents a picture of a life of hard work, resistance to sickness and entry to the sick role:

'Well, I've been a machinist all my life but for the last 11 years I was supervising [022] So then I developed arthritis all of this side into my head. I had to have glasses because it affected my right eye and I was having treatment three times a week then in the old hospital I was going out 8.30 in the morning and sometimes I wasn't home till 5 in the evening. I'd catch three buses there and three buses back so that went on then until I went back to work. Well then, I was so bad then with this arthritis in my neck [028] I had to come back down the hospital they put me in a collar and I had to come back and forth for that and because they couldn't tell me in work they [029] when I could start they finished me after 20 years! I never had a penny. And it have all stemmed from that really' (Mona: 1. 24-33).

4.4.1c Theme summary

The participants' accounts demonstrated their concerns about establishing the legitimacy of their condition and their own moral worth by emphasising the physical onset, their past active lives and resistance to the sick role. These attempts are viewed as impression management strategies.

4.4.2 Not being believed

The moral endeavours of the participants are better understood as a response to the participants' long standing experiences of "not being believed" that is a main theme running throughout the accounts.

The participants referred to the scepticism of health professionals. Don perceived accusations of malingering by a doctor who hadn't been able to find any evidence of pathology from examining the x-rays of Don's spine (a later Magnetic Resonance Imaging [MRI] scan did find some abnormality). Any psychological evaluations by health professionals were fiercely opposed:

'And he said we can't do anything more for your pain Mr X because I think it's in your head' (Don: 6. 15-17).

The participants recognised that many people, even doctors, found it difficult to understand the experience of CLBP:

'[Ahem], you go to the doctor and even they seem to, you know, shrug you off. Oh, you've got a bad back, here's a packet of tablets go home and you'll be alright in a few weeks' (Eirlys: 14. 20-22).

'I was subjected to disrespect and humiliation by Mr X in front of his staff and patients. He told me that bed rest was a thing of the past and my bed could have been needed by a more urgent case. He referred to my weight saying it was excessive. I was 15st 2lbs at that time. When I explained that I found exercise difficult, his answer was people in Belson did not exercise and the weight fell off them' (Paul: 6. 21-27).

The participants were aware of a public discourse of scepticism about CLBP. In response to the interviewer's query about receiving sympathy from others, one participant remarked she was aware of other people's adverse reactions and

understands these responses because prior to her own CLBP she been similarly suspicious about people complaining about a bad back:

‘No, not really, I mean my family yes, because they know what I’ve been through. And they know what I go through and but [ah] probably because I’ve done it myself. You know people say oh “I’ve had a bad back and all”, before, I used to be a bit sceptical I don’t know, [laughs] but not any more, no, I mean I wouldn’t wish this on anybody’ (Cara: 5. 4-7).

‘If you’ve got a bad arm or a big cut they say that’s terrible you know. You can show them a big operation scar and they’ll say that’s awful but you say you’ve got a bad back and [ahem], of course, there have been so many jokes cracked over the years haven’t there? “Oh, I’ve got a bad back, I’m on the sick”. You know’ (Eirlys: 14. 16-19).

The following participant suggests that sympathy from others helps her but suggests that she has had to convince people about her pain:

‘I can’t think of anything that would help in any way. I think that people who believe that you got it and are sympathetic that helps when you’ve got someone that’s sympathetic at least you’re not fighting that as well and trying to get people to believe you, not that you want people to feel sorry for you or anything its just that some people understand that there’s certain things you can’t do that’s all’ (Doris: 7. 1-5).

4.4.2a *Lack of visibility*

Not being believed has been attributed to a lack of visibility and understanding of conditions such as chronic pain that render patients vulnerable to accusations of malingering (Clarke and Iphon, 2005). The participants referred to feelings of not being believed and understood and experiencing a “felt stigma” that facilitated feelings of isolation. The participants held the view that the invisible nature of CLBP contributed to others lack of understanding about the pain.

‘Nobody fully understands, there is nothing physical to see, people don’t understand. They ignore me’ (Sara: 11. 25 -27).

A lack of sympathy from others can be an emotionally upsetting dimension of the pain experience:

‘Yes it is, but people [ahem] because people see you and like, if you cut you’re hand they say its awful isn’t it, but when they can’t see your back [yeah] they don’t say that’ [*interviewee upset*] (Eirlys: 6.152 - 154).

Doris similarly acknowledged that the invisible nature of CLBP renders it difficult for people to understand the suffering it inflicts on her:

‘People find chronic pain difficult to understand as it is ...I suppose they are right to a degree but probably most people wouldn’t believe you that much. I just think that most people don’t understand what its like to be in constant pain. To be permanently in pain, it’s not easy for people to imagine it, is it really? And because I can walk and don’t look any different [ahem]’ (Doris: 4.23-26).

4.4.2b Theme summary

The accounts show that previous experiences of not being believed are a main source of concern for the participants and probably a main determinant of their desire to authenticate their condition to the listener. The participants reported that it is difficult for people to understand their suffering due to a lack of visible damage and have experienced scepticism from both health professionals and the public.

4.4.3 The essential nature of the pain

The participants emphasised the physical pain rather than any psychological response to the pain. The pain was characteristically reported as physically exhausting and debilitating, constant, unpredictable and intrusive with the participants experiencing very bad days where they had great difficulty in managing their pain. Emotional responses tended to be referred to later on in the accounts.

4.4.3a Constant pain

The pain was typically referred to as constant by the participants. Typically, Eirlys described the pain as constant, affecting her mobility and experienced in many parts of her body. She tried to articulate the severity of the pain but resorted to gestures to indicate its severity:

‘It’s there all the time. All the time you’re never, never free of it, it’s in my hips it’s in my groins [ahem] it’s down my leg it affects my feet and now its affected

my feet very badly and when I get out of bed in the morning or during the nights [ahem] I have to [162] because I can't balance myself you know and my feet will cramp up you know my feet are like that' [*makes a picture with hands*] [aaaaaahem] (Eirlys:5.17-22).

'I'm in pain constantly, every day of the week no matter how you position yourself - most people go to bed and just lie there and I can't do that. Nothing seems to work. I've tried plates and I've tried.... Can't put pressure on my back. I've tried different things; I've tried wheat pads that are no good' (Sara: 11. 8-11).

'It's there all the time but it can be aggravated by the sitting so that it's not much [065] it's more like nagging pain that's just there constantly, difficult to explain really but it's just there permanently there all the time' (Doris:3. 21-23)

'It's there all the time but it can be aggravated by the sitting so that it's not much, its more like nagging pain that's just there constantly, difficult to explain really but it's just there permanently there all the time' (Don: 1. 16 -17).

4.4.3b *Unpredictable and unbearable pain*

The following quotes represent many of the participants' perceptions of the pain as unbearable and unpredictable:

'Excruciating is one, and like I said other times I might be walking casually down my daughters and then suddenly something just [ah] and it knocks you, it knocks your breath away' (Don: 9. 25-27).

This participant reinforces the notion of CLBP as unpredictable:

'Nothing It's just there, its like every joint in my body seems to be seizing up my ankles and then its just like pain all over really but the pain in my back ... really triggers me off makes me tired can't do things you'd like to do' (Sian: 1.21-33)

When asked to describe the pain, participants sometimes found it difficult to articulate the experience. The following quote describes the severity, unpredictability and hopelessness of the pain experience:

'But as I say it's awkward to explain as I said you could go one day and it's so bad that you virtually crawl over the doctors and then you get a "what do expect me to do for you" sort of thing' (Don: 9. 1-3).

Some participants made use of analogous comparisons in order to translate the painful experiences to the listener. Paul described the pain in terms of extreme pressure and heat:

‘The pain in my back is constant. It feels as if someone is pushing an iron bar into me. When sitting, pain generates across causing not only pain but gets hot. It also generates down the right leg’ (Paul: 2. 18-20).

Eirlys likens the pain to toothache, that is, constant and unrelieved. However, in comparison to toothache the CLBP cannot be removed:

‘I’d love to wake up in the morning and have no pain but its there all the time you know. So, it’s not like toothache where you can have your tooth taken out you know’ (Eirlys: 7.17-19).

4.4.3c *Loss of mobility*

Participants were unable to undertake tasks without conscious effort and there was little spontaneous activity. The pain adversely affected the participants’ daily living by hindering their ability to carry out the most routine activities previously taken for granted. Despite the pain, the participants talked about continuing to struggle with daily activities and mobility:

‘In my groins, here, you know terrible pain in my groins. And I think, I will walk, I’ll walk over to the bus-stop you know and get on the bus but [ahem] oh, the pain in my back after, is terrible you know and trying to get on that bus then is dreadful’ (Mona: 5.20-25).

‘I do used to like my garden and I can’t do the gardening anymore I love jigsaws but my daughter have bought me the big folder I can put it on the table by there and then I’ve got to kneel and then within say 10, 15 minutes you’re in that position and then it will take me another twenty minutes then to get up from that position’ (Don: 9. 15-19).

For Sian, the pain is a determinant of her housebound existence:

‘I can’t get out, it would be nice to think you could go out but you can’t go out for the day, you can’t get out because the pain is that bad’ (Sian: 3. 9-10)

Will described how the pain affected his walking:

‘Well sometime it’s just there like a... how can I (*wife mumbles something*) it’s not a strong pain but its there like toothache, you know what toothache is like,

it aches all the time well that's what my back is. Right. And if I walk a bit it aches, more after that you know. So I can't walk like I used too, I can take the dog around the block by here and that's about it like' (Will: 3.21-25).

Doris explains that her activities are severely limited by the pain:

'Basically I spend a lot of time lying down I was in bed when you came. I can potter around the house doing little jobs but anything too strenuous would be too painful. I can just manage to I have lots of help. My Mum comes over and helps me to do things like this so I have lots of help' (Doris: 3.11-14).

4.4.3d *Good days, bad days, very bad days*

The participants' described the pain in terms of good days when the pain was constant but just about bearable, bad days when the pain was just about manageable and then very bad days when the pain was uncontrollable by drugs or most other means.

Don described good days and bad days when the pain interfered with his personal relationships and he felt severely depressed:

'Well, it's how can you say, as I said, I have a quarrel with my wife or she told my daughter and we've had words, I have had days as I stated earlier on you could say there's the bottle of tablets and you don't want to continue like this sort of thing like. But then there are people worse off than me sort of thing but you have your good days and you have your bad days and the bad days are bad' (Don: 8. 2-7).

Will spoke of relatively good days when the pain was constantly there in the background but was bearable:

'And the pain, as I said, it's there all the time. Some days I forget about it and if it's really bad I take tablets' (Will: 8-9. 34-2).

Sara commented that even on good days there was pain in her back:

'Even if I have a good day there's still a dull ache that comes from the pain in my back' (Sara: 10. 2-3).

In comparison, on bad days the medication had little effect:

'I like reading but on a good day – I'll read a couple of lines. On bad days I'll bring everything around me. After a bad night I can't settle, but the only way I find if after you've taken the pain killers and the pain is still there is to actually slide off the chair and kneel facing the chair, taking all the weight on my knees' (Sara: 10. 16-19).

'I have bad days, I can have a week when I'm in chronic pain and can't seem to get rid of it at all and no matter how my pain killers I take its just there, you can't do anything' (Eirlys: 8. 20-22).

Similarly Sian indicates that on bad days her activities are severely limited by the pain and the medication is ineffectual:

'Nothing it's just there, it's either a good day or a bad day. If think I'll go for a little walk to-day if I walk too far [yeh] then I know I've done too much and the following day is a bad day. When it's really bad I can't knit or anything' (Sian: 3. 19-21)

On bad days, sleep is the only option for Doris:

'Oh, I just try and sleep and I find that I'll sleep and sleep and sleep a couple of days sometimes just going to sleep and waking up going to sleep and waking up' (*voice quiet here*) (Doris:5.8-10).

The very bad days were debilitating, and again, there was a sense of the pain gradually threatening to overwhelm them and even on some days doing just that.

The effect of the pain on the participants' mood was apparent when they referred to very bad days:

'The pain is always there but some days it's really bad you don't want to get out of bed' (Don: 4. 15-16).

'If it is a really bad day you do get a little bit perplexed with yourself' (Sian: 7. 3).

'Just not listening to anyone or anything and taking the painkillers and putting boiling hot water on my back. I can't carry on like this, I don't have a life, I don't go out, I don't do nothing I clean cook I can't do anything, I'm tripping, I'm falling and things are slipping out of my hands you know they are really black days' (Sara: 8. 26-30).

4.4.3e *The intrusive nature of CLBP*

Lack of sleep is a well reported effect of CLBP (Naughton, Ashworth, Skevington, 2007). All the participants reported pain intruding into their sleep, with a lack of sleep leaving them tired and diminishing their ability to cope with any daily tasks:

‘To put it, it would be nice to go to bed one night to have four or five hours sleep without waking, it would be nice to get up one morning and just say, oh, no pain’ (Don: 3. 27-30).

Fatigue was often experienced and attributed to lack of sleep:

‘I’m so exhausted, because I’ve had no sleep you know. If I had three hours at the most in the night I’m lucky’ (Mona: 3. 29-30).

Sleep was difficult to attain and often resulted in a cycle of pain composed of adjustment, sleep, pain and so on throughout the night. For example:

‘Oh yes if you move then the pain just shoots and you’re awake, then well you think I’ll try and get comfortable again and that’s how it is its like a vicious circle, three hours, wake up for half an hour get comfy and get back and then. I can go up to bed about 11 o’clock and I wake and think what the hell is this; that’s the worse part is not sleeping’ (Sian: 7. 8-12).

‘I keep waking up in the night and having to put cushions between my legs. I can’t lie on the left all night. Aching all the time. Your spine can’t bear the weight of lying on the side. I’m in pain constantly, every day of the week no matter how you position yourself - most people go to bed and just lie there and I can’t do that’ (Sara: 11. 6-9).

4.4.3f *The painful body and self concept*

The data showed how participants’ appraised their body image in a negative light that adversely affected their self worth. For example, Eirlys, Mona and Cara referred to the impact of the pain on their self concept. The painful body had become sharply apparent with their bodies “letting them down.” Eirlys viewed her body as heavy and unresponsive and affected her mobility. Eirlys indicated that she looked older and felt that she was a burden to her husband:

'It makes me feel so tired so heavy I think back pain, [ahem], like toothache, [ahem], you can have pain in other parts of your body, I think your back makes you feel so heavy and tired because it controls so many other parts of your body doesn't it you know' (Eirlys: 6. 32-34, 7. 1-2).

'I wouldn't say so much depressions it just makes you [ahem], feel old, to begin with, it makes you feel older than you are. Makes you feel old, yes, because, [ahem], the way you walk, I know I walk differently than if I could just walk along like you would walk along I feel as if I am hampering my husband because if we do go on holidays, you know, he'll say, come on we'll walk down the front here and I think, oh, I can't you know' (Eirlys: 9. 27-33).

Mona was included in social occasions but felt a burden to others as she was so slow:

'Well something I've got to do isn't it. But it's so uncomfortable, I mean I go out I like to go shopping and things like that, go with my sister and we go on a trip you know I go on holiday with my sister and my friend but, I want to go, they say come on lets go on. But then I think, oh, I feel such a burden so I'll say to my sister well you go on you walk on and I'll toddle behind you and I can't use a walking stick cause I'll topple over' (Mona: 5. 20-25).

Cara talked about her frustration. The pain has changed her but she tries to be positive:

'[Ahem] well I get very down which I suppose is natural really and I get frustrated because I can't do what I want to do anymore. I do find that very frustrating because I've been an active sort of person you know I was. I done every thing for myself as I said painting and decorating you name it I've done it. [Ahem] you know and gardening and I just can't do it the type of things I used to do. [Ahem] it does get me down and all and my...it has changed me and there you are but I try and be positive but it's difficult on times and I can't get away with it' (Cara: 7.27 - 33).

4.4.3g *The painful body and fragmentation of self*

There was a perception of the pain as a growing threat, gradually "taking over" the participants bodies. The participants' accounts indicated a fragmentation or separation of self by cognitive distancing themselves from the painful bodily parts by externalising and objectifying the pain. This is illustrated in their references to the pain as "it" and "the pain" affecting "me". Sara referred to it (the pain) spreading to "my" knee. Sara was constantly aware of pain; it accompanied her continually and

prohibited her from conducting daily household chores. She emphasised her struggles to maintain normality; but the pain had the better of her:

‘I’m so used to not being without the pain now. I wouldn’t know what it was like to actually have a day without any. Even when the painkillers take away that dragging pain away you got, its spreading to the joints in my knee..., my knees click and clack and my fingers do that [*demonstrates a movement*], I’m clumsy, I can’t do my daily tasks...I can’t physically do it’ (Sara: 6. 19-25).

Similarly, Molly depicts the pain as a threat and as separate to her sense of self:

‘The pain is so severe its like as if there’s... I don’t know have you seen that film alien? You know when that thing came out that’s how my leg feels as if there’s something in here and it wants to come out. I’m watching for it to burst open that’s how bad the pain is’ (Mona: 2. 20-23).

The pain was not only depicted as distinct from the participants sense of self, but as mentioned previously, could appear with little warning with the participants unable to account for its appearance:

‘And as I say some days I can’t sit down on the toilet because some days the pain is in the cheeks of your bum sort of thing and well it’s awful strange to explain it’ (Don: 11.17-19).

Similarly:

‘I think it was because I was walking in such a weird way, it, I think that’s the only way I can describe it. It just came on me suddenly no reason at all, like a dull ache and then it burns’ (Sian: 3. 15-17).

4.4.3h *Emotional responses*

A salient feature of the interviews was the sequencing of the reporting of the participants’ experiences of pain. First and foremost, the participants emphasised the physical pain followed by reference to their emotional responses. It was not until later on in the interview or when asked about their emotional well-being that many of the participants referred to at least a lowering of mood or depression. The following quotes represent the emotional responses of the participants:

'There is never one day that you can say you take a tablet or you put this gel on and you can say that's nice, it's constantly there like and like I said some days you just think you've had enough' (Don: 2. 5-8).

'Oh, yes I do get down. And then I go upstairs and I'm lying there and just [hmm]. Oh God, is that what I'm going to be like for the next couple of years' (Mona: 11. 20-21).

'Oh aye, aye, I'm down in the dumps most of the time as (wife) knows. If it wasn't for the missus I'd be blooming terrible I think' (Will: 8.16-17).

'It's been all the way through really. With the pain being there I find that with the tablets they give me they just seem to just give me [175] occasionally, I get a little bit black days but other times I can usually manage to pull myself out (*laughs*). Yes some days, if it is a really bad day you do get a little bit perplexed with yourself' (Doris: 6.13-15).

The most commonly cited emotional responses were depression or a lowered mood. However, some of the participants referred to strong feelings of anger. Anger has been noted as a well known affective response to chronic pain (Fernandez and Turk, 1995). Two of the men in particular were voracious in their anger about their experiences. For example:

'I know I sound bitter but I did not ask for this curse upon my body, this living hell' (Paul: 7.13-14).

One participant talked about directing his anger outwards at his wife:

'I quarrel with my wife, nothing to do with her. It's just my own what's its name, how can you say is [ahem] I personally put it down to the pain. Just don't want to be bothered and the slightest thing or, can, trigger an argument off, quite simple' (Don: 13. 30-31, 14. 1-2).

Much anger is also directed towards the perceived disorganisation of the health services (this theme is developed later).

'I got numerous letters and as I say through temper I just rip them up. I've had numerous letters saying my name has been submitted to the list I'm on the waiting list. I had one letter back saying that I could be in the X one' (Don: 17. 26-30).

Anger may also be directed inwards. Paul related how he becomes angry with himself for not being able to control the pain:

‘One example of emotional upset was when my grandson was taken ill and admitted to hospital, I felt the need to visit him. I was so intent on the visit, but the pain in my back became so bad that I could not even get into the car. I became very upset, agitated and angry with myself over this’ (Paul: 5.8-11).

4.4.3i Theme summary

The overall representation is that the pain was primarily a physical dysfunction and intruded into every part of the participants lives. The participants’ were constantly aware of the pain that adversely affected their mobility and also their appearance that in turn, contributed to a lowered self esteem. There were references to the “painful body” that suggested a distancing of self from the pain as the pain became an increasing threat to their self worth and functioning. The main emotional experiences were feelings of depression, anxiety, distress and anger. From the viewpoint of the researcher, Paul and Don expressed the most anger, complained of very severe pain and limitations in function and relied heavily on spousal support.

4.4.4 Loss of social roles

We define ourselves in terms of the roles we occupy (Roy, 2001). For all of the participants, social roles were “spoiled” in light of growing immobility. The participants emphasised the difference between “then” and “now.” These descriptions served as an index of the degree of impairment caused by the pain.

4.4.4a Loss of a previous active life

The participants referred to previously active and independent lives:

‘And I used to be so active but it’s too painful, I used to be so fit [*sad voice*] and to think I’m in this state now, I mean I looked after my mother (dead for 8 years now) and I used to push her around in a wheel chair’ (Mona: 4. 12-15).

'I've been an active sort of person you know I was I done every thing for myself as I said painting and decorating you name it I've done it. [Ahem] you know and gardening and I just can't do it the type of things I used to do' (Cara: 7. 29-31).

'I'm clumsy, I can't do my daily tasks, clean around, my house is slowly, you know, I cant do anything and it drives me crazy, because you know I used to be so house proud' (Sara: 6. 22-25).

'[Ahem] how can I say, you get cross with yourself because there's things you can't do. You know like just getting down to the oven and cupboards and silly little thing' (Sian: 2.27-29).

Don talked nostalgically about his past life:

'I do used to like my garden and I can't do the gardening anymore' (Don: 9.15).

4.4.4b Loss of family roles

A significant consequence of the pain was loss of independence and valued family roles:

'On some days you could say enough's enough. And I rely on my wife quite a lot because sometimes I can't even get down to put my shoes on, she assists me sometimes with my socks' (Don: 1, 14-16).

'I have become the dependant instead of being the depended upon and this has affected me deeply' (Paul: 4.13-14).

'And I can't do my work. I do all the cooking. I love cooking but as far as the cleaning, I put the cleaner over last night, I wash and iron but I'm so slow' (Mona: 3. 26-28).

The pain interfered with Paula's activities with her granddaughter:

'Then we have a sixteen year old granddaughter we used to go shopping a lot when she came and all that you knew but of course you can't do that now she wants you to go all round, Next and River Island and all those she wants you to around all those places so what we do is tell her to go and look see what she likes and then she comes back and tells us what she likes then we go and get it then' (Paula: 6.28-32).

4.4.4c Loss of social life

The loss of a social life and social outings were commented upon by all the participants. Sara did not attempt to go out and depended entirely on her family for necessities such as food:

‘[Ahem], I don’t go out at all now. My daughter and husband go shopping to the large out of town supermarkets’ (Sara: 10. 24 -25).

Will indicated that his life was severely curtailed by the disabling effects of the pain:

‘So I can’t walk like I used too, I can take the dog around the block by here and that’s about it like’ (Will: 4. 20-21).

Don spoke of a previous active social life:

‘Ah, social life? I used to have quite an active social life but I go out now once a week. As regards before it used to be about four times a week’ (Don. 13. 27-29).

Paul referred to his love of the theatre but the experience of pain in the public domain now prohibited this activity.

‘The pain has affected my social life immensely. I loved going to the theatre. My wife took me once to see a play in the X, but I had to go outside the theatre periodically to stretch my legs because the seating aggravated my lumber region’ (Paul. 3. 23-25).

4.4.4d Theme summary

Loss is chronicled as a significant element of the pain experience. Loss of function, previously valued roles, a social life and feelings of being a burden served to isolate the participants further in their pain experiences.

4.4.5 Managing the pain

Medication was the main method of managing the pain for most of the participants. The participants’ relationship with the medication and their attempts to relieve the pain constitute a main theme.

However, the medication was often inadequate and caused severe side-effects that were viewed as troublesome as the pain itself. The participants also used a

preponderance of personally derived and mainly physical strategies in an attempt to relieve their pain.

4.4.5a The dialectical relationship with the medication

All the participants apart from one (the side-effects were too severe to continue taking any medication) were taking prescribed pain killers. The medication was viewed as a necessity, with the participants suggesting they could not do without the medication, and yet on the other hand, disliking this dependency and also the severe side-effects of the medication. In short, the medication was viewed as a necessary evil.

‘So anyway it’s just there all the time without the pain killers that’s when I have really, really bad days’ (Sara: 8. 22-23).

‘I can’t cope with the pain when it’s bad without medication. It would be lovely not to have to take it’ (Don: 2.2.3).

Cara indicated that whilst she was not happy about taking the medication it was essential for reducing the level of the pain:

‘[Ahem] permanently I’m on 50mgs of Amitriptyline at night and I tried getting down lower than that because I [998] horrible but I can’t do it because I as I say they did try and cut them out but [ahem] you get alright when you are on the move but as soon as you sit or lie it’s back’ (Cara: 2. 24-27).

The participants spoke of the medication as being part of their lives. For some of the participants taking medication was an established daily routine and the following quote indicated dependency on the medication. Don described how taking the medication was his first task of the day and a significant part of his life:

‘Because I get up in the morning and the first thing I do is go straight to the Tablets’ (Don: 3. 30-31).

Sara reports that she self administers medication when there is no prescribed medication available:

‘When I haven’t got the prescribed pain killers only strong ones that I can buy from the pharmacy and I’m taking them all day, every day when I haven’t got a prescribed medication’ (Sara: 8.18-20).

The participants spoke of the amount of medication required to ease the pain and this served as an index of the level of the pain. One participant spoke of looking at her tablets objectively and realised they reflected the severity of her condition:

‘I look at my tablets sometimes and I think I’m ill – that’s how bad it is’ (Mona: 2.18-21).

4.4.5b The side effects of the medication

The participants reported the tension between the need to take the medication and suffering the side effects. One participant, who was prescribed morphine, remarked:

‘The problem is I’m on so much medication and of course I’m on morphine for the pain which means you get used to it and getting the dose increased. I try not to but of course you know if it doesn’t work you take anything to try and stop the pain. [Ahem], but that causes problems itself then that causes other problems so a vicious circle’ (Doris: 2. 18-21).

This participant describes the side-effects from taking strong medication for the pain:

‘I saw three different doctors in a matter of four days and in the end I was taking 100 mgs of co-codamol and ... three times a day and the Voltarol PR at night and Amitriptyline I take by mouth and really you just end up doped. Right up to the eyeballs [Laughter]. But then you just got to and it plays havoc with your stomach Oh terrible. I do try and eat healthily you know, veg, because I know my back will play up if I get constipated and all these tablets bung you up terrible and cause different sort of problems’ (Cara: 3. 18-25).

‘Essential medication for back pain has produced stomach problems, for which I had to have an endoscope and when my back, and my stomach are both causing distress at the same time, I have to lie down with a diet of milky products’ (Paul: 5.27-29).

4.4.5c Inefficacy of the medication

The participants depend on medication but indicate this is only partially effective:

‘The only trouble is when I do have a bad flare up like this is its difficult to control the pain because I’ve triedpro... and doesn’t work and co...what is it called...something, it didn’t work and I’ve tried paracetamol and all those I tend to have in the cupboard anyway and nothing, no nothing works. No’ (Cara: 3.14-17).

‘After taking medication and finding no relief, this makes me angry, as the only solution is back to bed rest’ (the old routine) (Paul: 5.18-19).

‘I take a pain killer called Gabypentoin for the trapped nerve and then I take Cocodimol for then the back but [ahem] they do work in a sense but then they don’t I know it might sound strange but I also have a gel which is Traxam which you put on the back and all that to relieve the pain when some days it becomes really unbearable’ (Don: 1. 34-36, 2. 1-3).

4.4.5d Physical focused coping strategies

The participants spoke of mainly physical, self directed management strategies as an adjunct to the medication.

4.4.5e Adopting bodily postures

The participants had learned to manoeuvre their bodies into more comfortable positions:

‘After a bad night I can’t settle, but the only way I find if after you’ve taken the pain killers and the pain is still there is to actually slide off the chair and kneel facing the chair, taking all the weight on my knees’ (Sara: 10. 17-19).

On very bad days the pain was uncontrollable and for many of the participants lying down and being quiet was the only way to deal with the pain.

‘Some days it’s worse than others. I’ve got to go upstairs, I’ve got to go one at a time up the stairs one at a time and I’ve got to go upstairs and lie on the bed I know I’m worse when I’m in bed but I’ve got too’ (Mona: 9. 22-24).

Don spoke of bad days when he was only able to cope by “cutting himself off from the world” and taking the maximum amount of medication:

‘The pain is always there but some days it’s really bad you don’t want to get out of bed, you don’t want anyone to bother with you, hold a conversation, you switch yourself off and like I said on days I take the maximum doses of the tablets prescribed’ (Don: 4. 15-19).

4.4.5f Adjunct remedies

For Sara, extreme measures of pain control had resulted in permanently scarred skin and ongoing problems that compounded the original problem:

'I had taken the physio's advice and put heat on my back, it started off a towel around a hot water bottle, the water was gradually going from tepid to warm, the towel was gradually coming off then the water was in the end boiling. In the end I was boiling the kettle' (Sara: 6. 25-28).

Paula also referred to coping on really bad days by curling up and using heat and topical creams:

'Well, if I'm really bad I'll curl up on the settee by there with a hot water bottle and a blanket or ... and I try and sleep it off. Rub my back with cream although it doesn't help really, it helps the arthritis but not the disc-pain you know' (Paula: 7. 13-17).

4.4.5g Fear avoidance behaviours

The unpredictability of the pain and adverse impact upon social life has been documented by Sofaer-Bennett et al. (2007) and is echoed in the present study. The unpredictable nature of the pain and associated and often embarrassing symptoms often had considerable impact resulting in avoiding public areas and a limited or non-existent social life:

'[Ahem] see it does it affect you, we don't want to socialise because it's like if you sat down at a table and you want to get up you know you either make some noises and some grunts and when you go to walk then you're walking this way and that way and so you feel you don't want to go as people are looking you know' (Eirlys: 5. 13-17).

'I can remember going with my husband he had to go to the solicitors once and I went with him. My pain was so bad I said look I've just got to lay on the floor, in the solicitor's office' (Doris: 7. 25-27).

'I am a good swimmer. My oldest son took me once, but the children jumping in made me a bit panicky in case they bumped me, therefore I haven't been since' (Paul: 3. 27-29).

'Well what I can't do ...I can't go anywhere on my own as I was falling down so much I hit my head I was falling quite a lot. I fell into a shop window in Porthcawl as I was walking along' (Paula: 2. 21-23).

For one participant, a normal social life was not possible, but she compensated for this by making her home the centre of social activities:

‘You can’t really have one (*referring to a social life*). We have friends and they come to visit us quite a bit and I’ve got my chair or if I’m in bed they’ll come and sit up there you know on a bad day’ (Doris: 5. 19-20).

The participants felt they were spoiling others enjoyment or holding them back:

‘ I like to go shopping and things like that, go with my sister and we go on a trip you know I go on holiday with my sister and my friend but, I want to go, they say come on lets go on. But then I think, oh, I feel such a burden so I’ll say to my sister well you go on you walk on and I’ll toddle behind you’ (Mona: 5. 20-25).

‘I don’t feel as if I’m holding him (*referring to her husband*) back ... too much. Mind you, he is still very active even being 12 years older than me so I do feel I am really’ (Doris: 10. 2-3).

‘I go on holiday, as it affects my holiday, as regards not so much myself as my wife because I am limited in what I can do and where I can walk’ (Don: 13. 25-27).

4.4.5h Cognitive focused coping strategies

In the first instance many of the participants referred to physical coping strategies, but they also spoke of cognitive focused strategies in an attempt to relieve any lowered mood.

4.4.5i Comparison with others

The participants spoke of cognitive coping strategies that included a downwards comparison with others. For example, the following quote illustrated that one participant found a bad back particularly difficult to live with, partly because people found it hard to believe that she was suffering when there was little outward sign of disability. In response, she “pulled herself up” by comparing herself to a friend with a similar, but worse problem:

‘And because I can walk and don’t look any different, laughs, [ahem] so it’s not easy but on the other hand I suppose I there are an awful lot of people who are worse. I have a friend who’s paralysed and she’s in a wheel chair. She had a

similar operation to mine and it went wrong. She had the disc operation' (Doris: 4 26-29).

Paul described how he compared himself to his father:

'When you are in constant pain, other people's suffering don't come into your equation and it is not always easy to think that there are so many worse off than one self, but obviously there are and when I see such pitiful sights, it does have a humbling effect. My father was blind and I thank God I have sight' (Paul: 5.22-25).

In contrast, for those who made upwards comparisons this led to further reflections of what could have been and led to a lowered mood as the participants realised they couldn't do things that comparable others could do.

'Yes. I do get depressed, yes. [Ahem] but because what I feel is that I can see people going on holidays and things like that you know and like we used to go abroad but we haven't been abroad for a few years cause not only is it a fact of going and being afraid of being ill when you are there but [ahem] its [ahem] also say we went to Tenerife, its four hours on the plane and you get all stiff and all that also' (Paula: 4. 21-25).

4.4.5j Pragmatism

Some of the participants spoke of just having to live with the pain. Cara suffers from the medical side-effects but has learned to live with them:

'I know my back will play up if I get constipated and all these tablets bung you up terrible and cause different sort of problems. [Laughter]. You know so [ahem] I know I am not too bad at the moment but I'm not on [073] at the moment I've stopped taking those. But you learn to live with it' (Cara: 3.23-26).

Paula and her husband are pragmatic about their situation:

'But, as I said we try to plod on quietly. The thing is we really haven't got a lot of help, you know, we do have this young lady in to help us clean and all that you know, and our family is away so we just have to carry on best we can' (Paula: 5. 1-4)

Sian expressed less anger and resentment about her pain than some of the other participants such as Don and Paul who were particularly voracious and spoke angrily and bitterly about the pain (see previous theme on the emotional responses to the pain).

‘[Ahem], I just accept it and get on with it. You know’ (Sian: 5.8).

Don oscillated between anger and pragmatism. In the following quote Don vividly showed a resigned pragmatism in response to a situation over which there is little control. Don needed to be alone to manage the severe pain:

‘Well, on the bad days I have said to my wife and her said, look at the state on you again. And I go on my knees and crawl up the wall by there along the pipes, she tried to help me and I said “Leave me alone” and I’ve just got to get on with it sort of thing. There’s no way that somebody can help you when you’re on your bad days. The unfortunate part is there is nobody at all can help you’ (Don: 15. 4-9).

4.4.5k *Distraction*

Participants spoke of trying to distract themselves by alternative activities such as outings, reading, listening to music or working.

Paula and her husband took outings every so often:

‘I do read, we do try and go out even if it is only to the... we try and go out about every other day’ (Paula: 5. 12-13).

Cara describes how living around her pain by keeping busy has become an established way of living:

‘Doing something, just keeping busy, as long as it doesn’t involve bending and it’s hard to describe you knows, it’s a way of life now. And you just struggle on’ (Cara: 4. 15-17).

Mona describes how on bad days she lies down and distracts herself with music:

‘Some days its worse than others. I’ve got to go upstairs, I’ve got to go one at a time up the stairs one at a time and I’ve got to go upstairs and lie on the bed I

know I'm worse when I'm in bed but I've got too, I say lying on the bed I'm propped up with four or five pillow behind me and I got a blanket on and I have a bit of music' (Mona: 9. 20-25).

'Well, I try to let it go over my head you know which I suppose you've got to do you know. Otherwise you just sit in a chair and. This is why I tried to do a little job. Because when I'm over there I talk to the girls in the office and have a little gossip with the cleaner in the other office and yes it does distract you. Probably, if I was... being in work distracts you from the pain' (Eirlys: 7. 23-27).

4.4.5l Theme summary

The participants' had a dialectical relationship with the medication. On one hand it was viewed as a necessity but on the other hand it was also disliked because of its side-effects and viewed as only partly effective. The medication was augmented with self-management strategies that included physical adaptations and cognitive strategies such as comparing themselves with others worse off, pragmatism, distraction and isolation to help relieve their pain.

The next theme illustrates the participants' views about social support.

4.4.6 Relationships with significant others / social support

Chronic pain is experienced within a social context. Mason, (2005) writes about chronic pain being a relational issue that affects the family and other relationships. Whilst the participants spoke of the importance of supportive spouses, families and friends, some also spoke of changed relationships and feelings of isolation and not being understood despite this support.

4.4.6.a Support of family and friends

Perceived support from the participants' family and friends countered some of the psychological and social impact of the pain.

'When I have a severe flare-up (during which I have actually passed out) I take to my bed and "weather the storm" with my family's help. I am glad I have

relatives and do not live alone to face the “Xs” [*reference to an unsympathetic medical encounter*] of an uncaring society’ (Paul: 7. 8-11).

Relatives could reinforce family membership and offer reassurances of worth. Will spoke of being needed as a grandfather and at the centre of family life despite being physically impaired by the pain and co-pathologies:

‘O aye they are pretty good. The first thing he’ll do now when he comes home from Swansea tomorrow or today, he’ll phone and say I’m coming up for dinner tomorrow and Sunday and he’ll have his Sunday dinner here’ (Will: 11. 1-3).

Friends could also offset feelings of isolation:

‘No, no I’m quite happy in my own company along as I got a bit of knitting, a good book to read I’m fine, that’s I, unless my friends call in now and again. I’ve got one or two popping in you know, so I’m not on my own all day that would drive me up the wall’ (Sian: 5. 29-32).

Generally, spouses were a main source of support for many of the participants. The participants spoke of instrumental and emotional support from spouses.

‘I couldn’t really stand cooking I couldn’t stand the length of time so I don’t do an awful lot really just eating, watching TV, and reading. My husband does it all’ (Doris: 7. 19-20).

‘My wife gives me the most support by helping me in all aspects. She helps me with my dressing needs, especially my shoes and socks and on occasions, I have had to wake her to help me out of bed for toilet purposes’ (Paul: 4. 32-34).

Will indicated that it is his wife that offered him emotional support:

‘Oh aye, aye, I’m down in the dumps most of the time as (wife) knows. If it wasn’t for the missus I’d be blooming terrible I think. Fortunately she’s been great like and my brother and my son and all that have been alright’ (Will: 8. 16-18).

4.4.6b Lack of understanding

Conversely, the concerns of friends and family could also highlight their lack of understanding about the chronicity of the condition. In the case below, Don suggested that despite being concerned about him, his wife and his family and friends do not seem to understand “the nature of the beast”.

‘As regards to...well I have got family who’s very concerned about me and I have brother in-laws and different things who always ask constantly how you are [ahem] but in a sense you do get fed up because I know they are kind hearted asking but you know you have got it every day and you’re fed up of saying well I’m in the same pain with.. They think you’re a bit of a whiner now like because you’re telling them the same thing and sometimes as with my wife and she asking what’s the matter with you this morning or then you want to shut off as if to say well you know exactly what’s wrong, but of course they are only concerned about your health. But it can at times get on your nerves sort of thing. ...’ (Don: 5. 11-21).

Some of the participants did not always find their families supportive. Sara expressed her psychological and social isolation despite having a partner and family members in close proximity. Sara spoke of a lack of understanding from her family. She attributed this to the invisibility of her CLBP and the duration of the pain. In response to the perceived lack of understanding from her family, she had developed a defensive independence.

‘My family have heard it all before. They’ve given up the ghost. They are concerned about the amount of painkillers. I don’t need [anybody], I play on people’s nerves. X [husband] doesn’t ask me any more. I’m full of moans and groans. You haven’t seen anybody for... groans – I grizzle at the first person I see. Nobody fully understands, there is nothing physical to see, people don’t understand. They ignore me. I understand their point of view, I’d do the same, there’s only so much grizzling and moaning, you can’t expect people to listen all the time, fetching and carrying all the time’ (Sara: 11. 15-28).

Mona spoke of the scepticism of her husband:

‘You know you imagine you got this and that and sometimes my husband said to me you’re taking all those tablets there’s no need’ (Mona: 7.2-4)

Some participants spoke of increased arguments between themselves and their spouses. The increased dependency and changes in roles could have an adverse effect on relationships. The following participant described how his wife had become a carer:

‘I well, as I say, I can’t what’s its name my family enough because well, without my wife I wouldn’t be ... “cause how can you say I’m not, I’m not safe enough to be left in the kitchen, the, because these pains just triggers off and I drop things and as I said she, [X], makes most of my meals [ah] as I said she had to assist me in the shower sometimes because I can’t get down to wash my

feet and lower limbs sort of thing, pull my socks on, help me change my underpants sometimes and its embarrassing even though its my wife, its embarrassing on times. My wife gives me the most support by helping me in all aspects. She helps me with my dressing needs, especially my shoes and socks and on occasions, I have had to wake her to help me out of bed for toilet purposes' (Don: 17. 7-15).

Don continued:

'So it have actually affected the social life and on times I quarrel with my wife nothing to do with her, it's just my own what's its name is, how can you say is [ahem], I personally put it down to the pain. Just don't want to be bothered and the slightest thing or, can trigger an argument off, quite simple' (Don: 13. 29-31, 14. 1-2).

'Friends are tolerant and sympathetic, but they of course can leave, but family have had to endure the mood swings, the lack of humour and I worry more about trivial matters. This has left a mark on relationships with my wife and my sons, although they are very supportive, I don't always show appreciation' (Paul: 4. 18-21).

One participant suggested the pain was so bad that her husband had to do household chores and this placed extra demand on her husband:

'I'm really bad like this past week this last bout that I had my husband was walking the floor with me as well because I was in so much pain and sort of I've got to do something I've got to sort this out you know but [ahem] the day to day things I mean I wait for him to come home to empty the dishwasher because I find that difficult' (Cara: 7. 11-14).

However, it was apparent that the older couples in the sample were mutually supportive and viewed the participant's condition as a joint experience. The following participants refer to the notion of both partners experiencing the consequences of the pain:

'Our family is away so we just have to carry on best we can' (Paula: 3.14).

'Oh [yeah], [yeah], stopped us going out because I had this op and it's curbed our lives really haven't it. We looked forward to going abroad, we started going abroad about 5 years ago with a friend of ours. We used to enjoy going abroad it was lovely, go to Spain or something like that. And [ahem], the last three years we haven't been nowhere' (Will: 5. 30-34).

4.4.6c Theme summary

The participants' spouses, friends and family were a great source of support. However, the change from being independent to dependent, caused at least some frustration and disruption to relationships. For some participants, there were feelings of isolation despite being surrounded by family members. The older couples in the sample perceived the pain as a shared experience with both sharing the associated losses. Whilst family and friends offered a valuable source of support, the participants' accounts also revealed isolated pain experiences and a lack of understanding about chronic pain.

4.4.7 Relationships with health professionals

4.4.7a Search for a coherent explanation

The participants required a coherent understanding of their continuing and unrelieved CLBP. The explanations offered by the health professionals were often confusing, Eirlys commented:

'They tell you different things you know' (Eirlys: 11.5).

'My doctor referred me to the neurologist in Cardiff, well as soon as I had a scan they found the collapsed discs but according to the doctor it was all in my head' (Don: 6.17-20).

'I am considering having a [027], it hasn't really been explained to me what it's all about' (Doris: 2. 15-16).

In response, participants began to offer their own opinions or draw up "lay versions" as no convincing medical explanation was offered:

'It was two of my discs had crumbled and they gone up in side the spinal cord. But, I do wonder if two had crumbled at the time and because I got such severe damage to my spine from working in the pit and the accidents have I got reoccurrence of what had happened in the first place? Have another disc collapsed? When I asked him that in the beginning could this reoccurrence or could another disc, very unlikely he said what have happened to you Mr X is

one in a million. But if it could happen once my own belief it could happen again. But [Mr Y] said it would be very, very rare for a disc to collapse and go up inside your spinal column' (Don: 12. 26-32, 13. 1-3).

Similarly,

'[Ahem] they just said that there were several discs that had bulged and, but the bones in the spine was rather knotted and [ah] overgrown [ahem] but really, it's really scar tissue that's causing the problem now I think from the operation. You get, you know, obviously because there's the risks of having another operation. I could be crippled so totally, so that's the problem with that, they don't like to do many of these operations. I am considering having a [027], it hasn't really been explained to me what it's all about' (Doris: 2. 10-15).

'So I asked my own doctor how we know if I've got a clot in here. Because it feels to me there's something in there that wants to come out. That's the feeling I've got and it's with me all the time it's with me morning and night' (Mona: 3. 5-8).

4.4.7b Loss of faith in health professionals

There was disenchantment with the doctors' knowledge of CLBP:

'They discharged me in the X and they said there was nothing wrong with me and yet I go to see a neurologist in X, gives me a scan, two scans, one finds a trapped nerve and one was diagnosed as two tumours. And yet there's a doctor telling me there's nothing wrong with me!' (Don: 6. 27- 32).

Paul went on to describe his growing loss of faith in the health professionals. Paul touched upon the subjectivity of pain and how his perceived severity was treated with scepticism. Paul had lost faith in the changing advice offered:

'I hated Health Professionals telling me "Perhaps you have a low pain threshold". How could they measure the severity of pain I'm feeling? Bed rest was the treatment in the early years, but after trying physiotherapy etc it seems "there is nothing can be done" but to take medication and live with the problem' (Paul: 2. 27-30).

Likewise, Eirlys commented upon physiotherapy treatment and questioned the therapist's skills:

'I wonder if it did me more harm cause since I think [ahem] I got more pain so you know so I really don't know cause she used to put me on a table and she use to drop my legs you know [ahem] she used to try and describe to me what she was doing but I didn't know what she was doing but I think my pain is worse but then my back is deteriorating so I can't say' (Eirlys: 5.31-34, 6. 1-2).

Sara wanted to see a specialist in chronic low back pain as she didn't have a formal diagnosis from her GP:

'I told the GP "I said look, you know, I need to see somebody about my back". I don't know why the pains gone from my original neck and shoulder area why it's spread down I don't know. I don't particularly care – I need to see a specialist' (Sara: 6. 149-152).

Despite the growing loss of faith in medical treatments, the participants did not consider alternative forms of treatment apart from Eirlys:

'I've even been to a healer myself within the... a girl I work with was into going to a spiritualist church, you know? So I went along just to have a session of healing at the end. [Mm], I got to be honest, I sat there and it was so, so relaxing that I really, really relaxed you know. But I don't think it done my pain any good after, but it certainly did whilst I was there' (Eirlys: 12. 21 -25).

Whilst there was an expressed loss of faith in medical treatments and health professionals, the participants retained a firm belief in the power of medical technology (for example, MRI as a means of offering a definitive diagnosis).

'No, sorry, perhaps I jumped the gun, before I'd had any operation at all I was under [Dr X] in The X Hospital. And he said we can't do anything more for your pain Mr X because I think its in your head, but I hadn't had a scan or nothing then but then my [Dr X] referred me to the neurologist in Cardiff well as soon as I had a scan they found the collapsed discs and. but according to the doctor ...it was all in my head!' (Don: 6. 14-20).

'That's the feeling I've got and it's with me all the time it's with me morning and night. The only time I get relief is when I use the deep freeze gel or spray because it freezes the pain of a kind. I get it off my doctor because I'm supposed to take that but [ahem] I'm hoping you know that perhaps I can have another scan to see because in two years you don't know what have....what's been going on' (Paula:4. 20-26).

'But I suppose it's difficult for even Doctors cause there's nothing you can see. [Ahem], even the X- ray doesn't always show up and you have to have a scan and the damage is there' (Eirlys: 14.23-24).

Sian was eager to establish a formal diagnosis but had had little explanation for her pain from her GP. She requested a specialist to send her for a scan so as to offer her further explanation:

So I made an appointment for an MRI scan which I had. They said they would send the report back to Mr X and he would be in contact (Sian: 2. 5 -7).

4.4.7c Scepticism and lack of understanding

Two main areas of concern for the participants were first, the perceived scepticism of the health professionals, and second, the lack of understanding by some practitioners.

‘I was subjected to disrespect and humiliation by Mr X in front of his staff and patients. He told me that bed rest was a thing of the past and my bed could have been needed by a more urgent case’ (Paul: 6. 21-24).

Some doctors were reported as underestimating the severity of the pain:

‘He will not give them one day before the month is up so I’ve had it. I keep telling him can’t you up the dose more and he is not willing to do it. So anyway it’s just there all the time without the pain killers that’s when I have really, really bad days’ (Sara: 8. 20 - 23).

Eirlys described how General Practitioners (GPs) only offered medication. Eirlys suspected that they didn’t understand her condition and she wanted a fuller consultation. Eirlys wanted to talk about her condition to her GP and was frustrated that the GP didn’t want to discuss alternative treatments with her. Eirlys was losing faith in the medical model:

‘They don’t seem to understand, you know particularly GP practitioners, I suppose they haven’t got a lot of time anyway have they? So you feel go in and they say we’ll up your pain killer and that’s it’ (Eirlys: 11.28-30).

Similarly Mona related that some doctors took a narrow medical stance, prescribing only medication. But, she wanted understanding and confirmation of her pain as a multi-dimensional experience. In contrast, Mona referred to another doctor in positive terms as he understood her experiences:

‘Well, it’s only Dr X, I’ve been to my own doctor and to get me tablets and you just take them what else can you do? [Ah] like I said I’ve only seen Dr X once and I thought he was marvellous. But I said to him its nice to talk to a doctor that understands what you’re going though because some doctors I’ve seen down here, I’ve seen so many I don’t know them. You lie on the bed and they’re lifting your leg and you’re in so much pain that you can’t..... And [oh] it’s alright to discharge you, arthritis, well that’s not the end of a problem to me either I think well I might as well sit in my corner’ (Mona: 9. 8-15).

Understanding of the patients experience seemed to be an important feature of a successful consultation. Those doctors that were considered to be able to demonstrate understanding were viewed in a favourable light:

‘I’ve got a very nice GP she’s lovely she’s very sympathetic and she knows what I’m going through you know [ahem] to be honest though every GP I’ve seen has been very good and Dr X is another one and he is the one who actually referred me to the pain clinic when I went to see him’ (Cara: 7. 2-5).

Mona indicated that some doctors did not listen to her and showed little understanding about the effects of the CLBP, whereas one doctor was understanding and positively valued:

‘Dr X is marvellous he would listen and he understood how I felt. Whereas other doctors, oh it’s arthritis you know but you can’t put everything down to arthritis this is a different pain’ (Mona: 4. 1- 3).

4.4.7d *A low priority*

The participants expressed dissatisfaction with the organisation of their care and were aware of being “passed on” and being considered as a low priority in the health care system.

Three of the participants spoke of a lack of communication between themselves and the health authorities. Lost medical notes added to their frustrations and feelings of being let down and they expected little from the chronic pain clinic.

‘I have no expectations from the pains clinic. Judging by the past twenty years of “being passed from consultant to another” I feel they have given up on me. The reason I state this is because I saw X on the twenty second, 2003 who was passing me on to the Pain Clinic. I do not know if I am on the Pain Clinic List. Perhaps there has been another “breakdown in communication”. I feel despondent’ (Paul: 2. 32 - 34, 3. 1-2).

‘Well, as I said when we get an appointment to go down there they didn’t do nothing they didn’t have my notes or whatever it was and they didn’t know who sent you that was about 7 weeks ago’ (Will:8.14-16).

Several participants spoke of considering having private treatment as they became despondent about waiting for appointments. For example:

‘That is getting worse all the time, like I said I do feel narked sometimes and when I went first went which was about four and a half years ago now if I could have paid, because I initially paid privately to see Mr X, he said to me I can do that operation next week for you. And my doctor was [Dr] at the time she said to me, I said, could you find out how much it would cost me and it was about £15,000 . But I feel if I could have had that operation then, it would have probably prevented all the damage that I’ve got now, so sometimes I feel really narked that... everyone is in the same , I’m going back now to how long you wait for your operation’ (Eirlys:14.25- 33).

Will spoke of waiting yet again for another hospital appointment:

‘He said we’ll make a further appointment to see you, when I get all the notes together all the [404] and now we haven’t heard nothing yet, nothing at all (*tone falls flat*)’ (Will:3.1-4).

4.4.7e Theme summary

The participants’ experiences of the health services were dominated by feelings of not being understood, a low priority and being passed on. The participants were in a continual state of waiting for appointments and treatments. Some had little expectation that the chronic pain clinic would be of any help to them.

4.5 DISCUSSION OF THEMES

The first two themes “maintaining integrity” and, “not being believed” are discussed together. These themes contribute to understanding the participants’ salient concerns about establishing the validity of their pain. Apart from these first two themes, all the themes are discussed separately so as to gain a deeper understanding of each, prior to an overall discussion of the pain experiences.

4.5.1 Maintaining integrity / not being believed

A main finding was that participants strongly attributed the onset of their pain to a physical and altruistic act, made frequent references to a past valued life and emphasised their resistance to “the sick role”. These justifications were viewed as part of an “impression management strategy” and a moral endeavour that supports previous research with chronic pain patients (Kugelmann, 1999). As explained in chapter 2, Parsons (1951) proposed the sick role concept that postulates illness is accepted as a valid form of sickness when society or those surrounding the sufferer view it as complying to social norms. The sick role concept is predicated upon physical illness and postulates that sufferers have a personal responsibility to seek help and authorisation of their illness from legitimate sources such as medical practitioners. A noted challenge for sufferers of CLBP is that owing to the invisibility of the condition and a frequent lack of diagnosis they are vulnerable to accusations of malingering and therefore violating the norms of the sick role (Glenton, 2003; Eccleston, Williams, and Stainton-Rogers 1997; Chew and May 1999; Borkan et al. 1995). All the participants in the study had had long patient careers that exposed them to the vulnerability of felt stigma and accusations of culpability. The participants reported that family, friends and even health professionals showed scepticism and lack of understanding about their condition. Chronic pain patients have been found to have to work hard to convince others of their legitimate occupancy of the sick role (Wade and Shantall, 2003). Like-wise, the participants endeavoured to validate their moral worth and occupation of the sick role by referring to the biomechanical nature of their pain and authorisation of their condition by significant others.

There are both rewards and losses associated with claims to the sick role. For the participants in this study, emphasising a valid occupation of the sick role provided legitimacy for associated illness behaviours such as lying down, exemption from work and household duties. Such avoidance behaviours may be described as secondary gains associated with illness and may be sub-consciously sought and unwittingly reinforced by significant others (Freud, 1911/1933). On the other hand, there are also secondary losses that often accompany secondary gains, and many patients seek gains in spite of these secondary losses (Fishbain, 1994). As in this

case, secondary losses are expressed as dependency on medication and family and health professionals, a growing distance from one's former self, difficult communications with health professionals and feelings of dissonance about a sick role dominated by medication that has limited effect. Despite these "losses" the participants were eager to establish they were legitimate occupants of the sick role.

The data support the findings of Glenton, (2003); Kugelmann, (1999) and Chew and May, (1999) who write of patients with CLBP as "striving for the sick role" in order to gain validation of their illness and legitimacy for illness behaviours that have potentially character spoiling effects; such as giving up work or excessive rest. As such, the accounts may be viewed as a rational response evoked to protect identities as moral individuals with a valid right to the sick role (Eccleston et al.1997).

4.5.2 The essential nature of the pain

The participants emphasised the physicality of the pain experiences. An understanding of "physicality" is drawn from the data with participants referring to the level and extent of the sensory aspects of pain and reporting experiences dominated by an acute awareness of painful body parts. These data continued to depict a biomechanical view of CLBP that was emphasised in the stories about the onset of the pain and further illustrated in the participants references to their lack of mobility and restricted function. This understanding is reinforced by the brutality of the painful experience that focused the attention of the sufferers onto their physical suffering and physical coping strategies, rather than a consideration of any psychological issues.

The pain was described as a constant, intrusive presence with the participants experiences mapped out by reference to good days, when the participants could participate in some activities, bad days when the pain was present but manageable, and very bad days which had to be weathered or endured in very different ways. Participants spoke of desperation on very bad days when time stood still and all efforts focused upon the sensory aspects of pain. At this time, no-one could help and coping strategies included curling up, being left alone, over medicating and in one case applying extreme heat which resulted in further injury and pain. These findings echo the work of Charmaz (1983) who documented the good days and bad days of

chronically ill patients. The good days were viewed as offering hope and the bad days narrowed horizons making participation in valued pursuits difficult. However, these data indicate an extra dimension that is, very bad days that are described as being so severe that all activities cease. The participants in this study also reported the unpredictability surrounding the onset of bad days and because of this they were living in a constant state of vigilance and “lived around their pain” so as to minimise any recurrence of the “very bad days”.

The participants reported a constant awareness of painful body parts with participants suggesting little perfunctory movement. The painful body parts were a continual reminder of the debilitating effect of the chronic pain and its growing influence upon daily activities that were previously conducted with little contemplation. These findings support the distinction made between a “bodily disappearance” in the absence of pain, where little thought is given to performing most activities and its “dys-appearance” in the presence of pain when our bodies are at the forefront of our consciousness and become a vehicle of discomfort (Williams, 2000). The painful body became the focus of the participants’ attention as they monitored the progress of their pain by attending to bodily signs.

This heightened awareness was also apparent when the participants voiced concern about their bodies “letting them down” with the appearance and heaviness of their bodies making them look and feel old. These findings parallel the literature on physicality and ageing. McKee, (1998) wrote about a concept of “body drop” with reference to older people and falls and the body letting them down. For some of the participants, CLBP accelerated the aging process with daily living and social activities becoming increasingly difficult to undertake with a lack of spontaneity and slowness when undertaking tasks.

The data showed that a growing consciousness of the painful bodily parts was accompanied by a dualistic concept of self that resonates with a Cartesian mind-body split. Such a subject-object distinction (self as subject and body as object) supports the reports of the participants who distanced themselves from the pain and acted as detached observers of their own bodies. An explanation of this is forthcoming from Osborn and Smith, (2006). Osborn and Smith drew on the work of Vranken, (1989) to explain that such data represent participants’ efforts to protect their integrity by psychologically distancing themselves from the painful parts. From this perspective, pain is viewed as a “psychophysical dualism” (Vranken, 1989, p. 442). An

understanding of the participants' reports in this way indicates that for these participants' the accounts negated any suggestion of "acceptance" or engagement with the pain as conceptualised by ((McCracken, 1999). Rather, the participants are continually engaged in a psychological and physical battle against their "pain".

Generally, any reference to negative emotional experiences were sequenced later on in the accounts or inadvertently referred to when describing very painful experiences. This lack of immediate recognition by the participants may be interpreted as a result of a focus on the sensory elements of the pain. However, this may also be part of the moral endeavour, whereby an initial concern of the participants is to establish the validity of their conditions as physical illness so as to establish authenticity for entry into the sick role (Kugelman, 1999).

As suggested previously, when participants had a great deal of relatively uncontrollable pain they referred to very bad days. It is when describing very bad days that the participants also referred to periods of feeling very low and having "had enough". A lowered mood is not necessarily pathological and feelings of depression may be an expected response to repeated, severe and often uncontrollable episodes of pain. However, some of the participants had experienced these feelings for extended periods of time that had adversely affected their relationships, motivation and self esteem. For these participants, a cycle of unrelieved feelings of anxiety and depression and increasing social isolation may contribute to the development of clinical depression and further disability.

Depression and anxiety have both been implicated as precursors of disability (Waddell, 1992; Gatchel, 1991), with CLBP patients reporting higher rates of depression and anxiety as compared to the general population (Dersh et al, 2002). The notion of whether self reported "depression" in chronic illness is negative affective distress or clinical depression has been critically acclaimed by Pincus and Morley, (2001). From a review of empirical studies, Pincus and Morley concluded that patients with chronic pain do have elevated rates of depression but have a limited shared set of characteristics with patients with clinical depression from mental health settings (Pincus and Morley, 2001). However, they also argue that the methods used to measure rates of depression may obscure accurate estimations of those patients with chronic pain who also have depressive symptoms very similar to those in mental health institutions.

A diagnosis of depression is not in the remit of this study. However, some of the participants reported symptoms that are characteristic of a standard nomenclatures of depression (loss of self worth, loss of confidence, frequent low moods and expressing suicidal thoughts, isolation) as portrayed in the American Psychiatric Association, (1994), Diagnostic and Statistical Manual of Mental Disorders (4th ed.). Two of the participants were already being treated with Amitriptyline that has both analgesic and antidepressant properties (Saarto and Wiffen, 2007). However, one may conjecture that whilst the medication may offset severe depression, the long exposure to pain had continued to promote negative affective distress, even in those prescribed amitriptyline and for other participants not prescribed any anti-depressant, possible clinical depression.

Anger was another emotion experienced by the participants. Anger is a common response to chronic pain but is not so well addressed in the literature (Hirsh et al. 2007; Sator-Katzenschlager, Scheisser, Kozek-Langenecker, Benetka, Langer, and Kress 2003). Anger and frustration were strongly expressed by two of the males in the sample. These participants were particularly voracious about their inability to gain coherent understanding about their pain from health professionals. They were also frustrated and consequently angry, because of perceiving the pain as the cause of disrupting activities and not being able to control this effect. Anger was subsequently vented onto their families and sometimes themselves, possibly serving to cause lowered self esteem and isolation in their experiences.

Anger is a known consequence of frustration due to goal attainments being perceived to be blocked by pain (Berkowitz and Harmon-Jones, 2004). Whilst there is little information about the role of anger in the maintenance of chronic pain, anger has been found to be associated with catastrophising, a response strongly associated with amplifying negative pain perceptions and a predictor of depression and chronicity in pain populations (Hersh et al. 2007; Berkowitz and Harmon-Jones 2004). Further studies show that frustration and anger are implicated in mental deconditioning or passivity that is observed in patients with chronic pain experiences. These emotions may override the original pain itself and contribute to maladaptive illness behaviours (Pincus and Morley 2001; Gatchel 1991).

4.5.3 Loss of social roles

Loss is a central feature of the participants' experiences. One participant remarked "everything I value is being taken away from me". The loss of social roles across many areas of their lives was reported by the participants. Charmaz, (1983) refers to the "diminished self" resulting from chronic illness and wrote about how a restricted life caused by chronic illness and disability or long term treatment can cause a diminishment in self esteem and self identity as a restricted life gradually eliminates opportunities for positive self regard. Participants described the loss of ability to conduct previously easily executed tasks such as emptying a dishwasher or changing their socks independently, and these descriptions serve as an index of the growing gulf between an active former life and inactive present life. Comments such as "this isn't the real me" and "I used to be so active" suggests a distinct sense of loss as the participants compare present selves with past selves and social norms (Walker et al. 2006).

The loss of a work role and disruption of conjugal roles supports previous studies (Walker et al. 2006; Roy, 2004; Osborn and Smith, 1998). A strong theme running through these accounts was the difficulty of accepting the change from being a previously independent worker or a breadwinner to being a dependent family member. The data indicate the participants adopt "diminished roles" in response to the inability to carry out previous full family roles.

Married participants were concerned about the demands placed on their spouses and changes in their relationships, as partners became carers and participants "the cared for". Role theory suggests that we all have expectations of each others behaviours that are consistent with social norms. In particular, the loss of the role of breadwinner for some male participants led to a loss of an important role identity associated with male social norms and expectations associated with that role. This led to some participants "lashing out" at their spouses and was the cause of marital tensions. The husband / wife relationship had become the dependent/ carer relationship and this change has been documented as causing marital discord (Roy, 2001).

Interestingly, most of the participants in the study spoke of close relationships with spouses, despite some disharmony. On one hand the chronic pain provoked changes that in turn caused some friction in relationships, but on the other

hand many of the participants and their spouses remained closely bonded. (A later section contains a detailed discussion about social support, including relationships with spouses).

4.5.3a Loss of social life

A loss of social life was of significant concern for the participants and reflects previous findings (Sofaer-Bennett et al. 2007; Walker et al. 2007; Charmaz, 1983). Many of the participants commented upon the disabling effects of the pain and spoke of how they were unable to participate in favoured past activities because of physical disablement and fear of further pain. However, fear of social disapproval or attention was also a barrier to participating in social outings. Nearly all the participants reported avoiding social situations because of fear of embarrassment or injury. Two of the participants spoke of fear that had exacerbated to such an extent that they hardly participated in social outings. Previous adverse social experiences had acted as a conditioning stimulus sufficiently significant enough to perpetuate continual reinforcing avoidance behaviours but leading to subsequent feelings of isolation. Existing literature indicates that fear avoidance behaviours may lead to further disability and depression (Vlaeyon and Linton, 2000; Gatchel, 1991). For these participants, such was the fear of public places, that feelings of safety gained from not venturing into public places, acted as a reinforcer for avoidance of public places and overrode those feelings of isolation or a lack of a social life. Again, a formal diagnosis of agoraphobia is not possible here but the symptoms of some of the participants are reminiscent of agoraphobia that has also been commonly diagnosed in chronic pain patients (Gatchel, 2001).

As with Kathy Charmaz's participants, the focus of the participants' lives had become their medical regimens, appointments with medical practitioners and coping with the pain on a daily basis and these had replaced the more valued activities of a previous life.

4.5.4 Managing the pain

Coping may be referred to as, "the processes, strategies or styles of managing a situation" (Stroebe, Hansson, Stroebe, and Schut 2001, p.9). These terms are often

used interchangeably in the literature but for the purpose of this study the participants' efforts to regulate or manage their pain are referred to as coping strategies. Coping strategies may refer to cognitive focused strategies or more physical, behaviourally focused coping strategies (see Grossi, Soares and Lundberg, 2000). In this research, the participants' engaged in both physical focused and cognitive focused acts of coping.

As previously discussed all the participants in this study struggled to maintain mobility with most living around their pain as compared to "living with their pain" with activities organised around the pain so as to avoid pain (Borkan et al. 1995). The participants in this study described three distinct ways of coping with CLBP. First and foremost, taking the medication was a central part of the participants' lives. For most, the first task of the day was to take their medication and this may be considered as a daily ritual. The relationship between the participants and the medication was an intimate and complex one. There was ambivalence expressed about taking medication. On the one hand it was viewed as essential for keeping the pain under a certain amount of control and on the other hand the participants vehemently disliked taking so much medication as they were aware of the deleterious side-effects, for example, dizziness, drowsiness and constipation. A fear of the side-effects of medication in chronic illness is well known and has been reported by Horne and Weinman, (1999). However, for most of the participants, the side effects that were incurred through taking so much medication were often outweighed and reinforced by the gains of having the edge of the pain relieved.

The treatment of CLBP by medication alone was insufficient and exposes the weakness of the biomedical model (Waddell, 1992). The present data revealed that whilst the efficacy of the medication was often questioned, few alternatives were considered or offered. For example, acupuncture was offered and sometimes worked but was for a limited period. As with the CLBP participants in Osborn and Smith's (1998) study, there was a tension between the reality of coping with the chronic pain and the application of a primarily biomedical model to relieve the pain. This failure of the prescribed medication to fully relieve the pain when the pain was viewed as a biomechanical failure contributed to the participants' lack of a coherent understanding about their condition and the growing disenchantment with medical treatment.

For all the participants, the amount of medication taken was an index of the severity of the pain. Most denied being addicted to the medication but some felt that the doctors underestimated the amount of medication they required and reported receiving subtle or explicit accusations of drug dependency by their doctors which served to discredit their claims of severe pain. The work of Glenton, (2003) indicates that medication usage may be a form of legitimisation of a condition and supports legitimate claims for entering the sick role, but this may be seen as problematic by others when there is no significant improvement and used over a long period of time. Glenton further suggests that the use of regular and prolonged medical treatment as validation for entering the sick role is complicated when applied to chronic pain as long term medication usage could be viewed as a sign of weakness and drug addiction rather than a means for recovery.

4.5.4a Self directed management strategies

The use of a qualitative methodology has enabled identification of personally devised behavioural coping strategies that may not be captured in large scale quantitative studies that focus mainly on cognitive coping strategies (McCracken and Eccleston, 2003). The participants described a “trial and error” experience of learning to live with the pain. The manipulation of the body played a pivotal role in managing the pain. The participants attempted to minimise any pain by devising creative physical strategies including sitting or kneeling in particular positions or avoiding particular activities and also adopting extended periods of rest. These behavioural “coping strategies” may be perceived as “passive coping” (see Chapter 2) but were important palliative measures tailored to the immediacy of the situation. Daily household chores and social lives were tailored to reduce the experience of the pain. The avoidance strategies referred to by some participants (for example, avoiding public places) may have incurred an initial positive reinforcement, that is, less pain, but also culminated in secondary losses, such as loss of social life and social isolation contributing to further physical deconditioning (see Chapter 2) and chronicity. Such behavioural avoidance was initially noted by Fordyce, (1968a; 1968b) and latterly Gatchel, (1991) who recognized the importance of motivational influences in the development of disability.

There was little initial reference to cognitive coping strategies. However, participants later reported using deliberate strategies such as distraction, for example, by listening to music, reading and also comparisons with others. For the participants in this study comparing themselves with others worse off served as a “leveller” and enabled them to situate their own concerns within a less fearful framework. However, this strategy did not help them in relieving their own distress in the immediacy of their pain experience or anxiety about a future that could include increasing disability. Downward comparisons have been found to be problematic and have an uncertain function for individuals with chronic illness (Osborn and Smith, 1998). Negative emotional responses were also regulated by “thinking about ones children” or a form of resigned acceptance or pragmatism “I just get on with it” and are consistent with findings in similar samples (Walker et al. 2006; Osborn and Smith, 1998).

4.5.5 Relationships with significant others: social support

Patients may be offered, or seek support from different sources during illness. (Roy, 2001, p. 96) proposes support may be informal (for example: family and friends); semi formal (for example: church support, voluntary organizations) and formal (for example: hospital services, compensation boards and unemployment authorities). There are also different types of social support recognised such as esteem support, whereby other people increase ones own self esteem; informational support, whereby other people are available for advice; social companionship, which involves support through activities and instrumental support, which involves physical help (Wills, 1985).

Loss in this study is offset to a certain extent by esteem support from informal support networks, for example, being perceived as needed by the family despite illness, also instrumental support received from family and friends who help with household chores and so on. There is also some social companionship offered by family and friends and informational support from more formal sources such as sympathetic GPs and other health professionals. Despite these recognised support networks, statements such as “no-one understands” and “only the person suffering know what it feels like” echo feelings of isolation in the experience of pain.

The data support the stress buffering hypothesis of Cohen and Wills, (1985), where social support is proposed as a buffer against stressful occurrences such as illness, with social support influencing the appraisal of the stressor or degree of threat (pain and associated issues) and ability to cope with the perceived stressor. For most of the sample, perceived support from families attenuated the somatic effects of the pain and associated secondary losses such as loss of social life and disability and negative toned emotions such as “feeling down in the dumps” and pessimism. The perceived support of family has been associated with lower levels of depression in a range of patients as reported in a literature review by (Roy, 2001). Earlier findings from Goldberg, Kerns, and Rosenberg (1993) also reported the buffering effects of social support from significant others in a sample of chronic pain patients, with social support flattening the relationship between low levels of social activity and depression.

Conversely, it has been observed that participants who have high levels of social support may feel less depressed but demonstrate high levels of pain behaviours, for example, being excused from responsibilities because of reinforcing agents such as sympathy from family and others (Kerns, Rosenberg, & Otis. 2002; Roy, (2001); Kerns and Payne, 1996; Fordye, 1976). These findings are from quantitative studies but compliment the data from this study that shows that despite optimal conditions for adaptive coping, that is, perceived support from family and friends, the participants in this study reported a life dominated by avoidance behaviours and passive pain behaviours. For example, Paul reported high levels of pain and avoidance behaviours and was the central focus of his family with both him and his family living around the pain. All activities were tailored to meet the requirements of this ill family member that had the consequences of a limited social life for both the participant and his wife.

The participants reported both instrumental and emotional support from their spouses. In particular, the encouraging reactions from spouses to expressions of pain or lowered mood were highly valued by the participants. For instance, the older couples in the sample reported the experience of pain as a shared experience that is described as “weness” by Mason, (2004). These participants spoke of the pain in terms of how it affected them as a couple. The relationship was often one of mutual support rather than friction as described by a previous study of older couples with CLBP (Sofaer-Bennett et al. 2007).

Not all the participants spoke in positive terms about spousal support. One of the participants commented upon her partner offering instrumental help but little emotional support, resulting in a reported defensive attitude that served to isolate her further from her family. Another participant spoke of her husband's scepticism and also reported little support from her husband. However, similar to the former participant she took on a contrived independence, speaking frequently about her pride in her ability to "go it alone" but also spoke of an intensely isolated experience. Maladaptive coping has been shown to be related to perceived negative attitudes and responses from spouses (Manne and Zaruta, 1998).

4.5.6 Relationship with the health professionals

The participants' relationship with the medical practitioners was fraught with tension with many references to the felt scepticism and indifference of the medical practitioners. There were several participants citing instances where they had been shown little sympathy and understanding by the doctors. In response, the participants talked of losing faith in both the treatment and the medical practitioners, with some viewing the medical practitioners as incompetent and uncaring that echoes the findings of Garro, (1994) and Priel, Rabinowitz, and Pels (1991). Garro, (1994) explains that both the medical practitioner and the patient have a vested interest in protecting their professional and personal identities and deflecting blame for the lack of success in finding a cause. The medical practitioner and the patient both seek a cause or a treatment for the pain, "hunting the cause," and as time goes on, and a cure or satisfactory treatment is not forthcoming, both parties attempt to rationalise this on their own terms. Several participants spoke of their medical practitioner's inability to legitimise their condition. Rather than recognising any failure of the medical model the doctors were reported as accusing participants of imagining their illness or being culpable for their own condition due to mismanaged lifestyle (Eccleston et al. 1997).

A "Good Back-Consultation" has been described as including a demonstration of understanding, discussing psychosocial issues, receiving reassurance and discussing what can be done (Laerum, Indahl, and Skouen 2006). Most of the participants described consultations that hardly fit this model. For example, one participant succinctly referred to the inadequacy of a consultation. She

reported that the doctor pronounced a diagnosis and then terminated the clinical interview without any further discussion. This data shows that whilst the participants have predominantly biomedical understandings of their conditions and required medical treatment from the practitioners, they also required understanding and recognition of the wider impact of the pain on their lives. For example, for some of the sample, those doctors who had listened to such concerns and showed understanding were spoken of in favourable terms.

The participants were aware of the doctors growing disinterest and felt they were viewed as a burden and “passed on in the system” (Walker et al. 1999). Surprisingly, whilst the participants indicated a growing disenchantment and confusion with the advice of medical practitioners and other health care professionals, they retained faith in medical technology. Eccleston et al. (1997) point out that an enduring faith in the medical model should not be surprising, given the power and prestige of this approach to illness.

4.6 OVERALL DISCUSSION

The intention of this study was to explore the participants’ perceptions of their pain prior to attending a medically staffed pain clinic. The IPA methodology captured the participants’ main concerns and descriptions of their “lived experiences” that is consistent with a descriptive phenomenological and contextualised approach (Larkin et al. 2006). The data showed that the participants’ core concerns were centred upon managing their physical pain and the difficulties associated with mobility and daily living. The painful body was at the forefront of their daily consciousness. The participants reported constant, unpredictable, disabling, intrusive and unbearable physical pain. The pain was depicted as a biomechanical dysfunction with its management being predominately undertaken by the use of medication and physically focused coping strategies. In short, the “painful body” was the prominent part of the participants experiences and counters previous studies that present CLBP as “disembodied experiences” (Osborn and Smith, 2006).

Whilst the participants strongly prefaced the physical pain as a primarily biomechanical dysfunction with little initial and spontaneous reference to any emotional responses or social influences, a close inspection of the data also revealed a significant interplay between the physical pain and distress in relation to not being

believed, loss of function and social roles, altered relationships, altered appearances and mobility, inadequate explanations, lack of understanding and experiencing disorganised care by the health services. In short, the findings supports previous work that shows the meaning of CLBP is about managing multidimensional experiences of pain (Osborn and Smith, 1998) and endorses an embodied experience of CLBP referred to as “the physical and mental experiences of existing with pain” (Cregan, 2006, p.3).

Larkin et al. (2002, p. 113) writes that: “whilst there is an uncertain distinction between description and interpretation, an IPA inquiry aims to make both descriptive and analytical claims by further interpretative work that may include a more critical approach”. Further analysis revealed that whilst the participants’ accounts illustrated multidimensional experiences their accounts turned on a biomedical model of understanding (see Chapter 3 for a full explanation of the biomedical model). The biomedical understandings are illustrated by an emphasis upon the physical cause of the pain and biomechanical consequences, the painful body, behavioural self management strategies and an enduring faith in medical technology despite the articulated disappointment with the health professionals. Waddell, (1994, p. 221) indicates: “How people think and feel about back pain is central to what they do about it and how it affects them.”

Biomedical understandings of illness are thought to be underlined by pain beliefs that are defined as, “the cognitions or thoughts patients have about what the pain is and what it means for them” (Daykin and Richardson, 2004, p. 783). Patients’ pain beliefs are understood as arising from various sources such as the individuals own interpretation of their symptoms, illness experience and perceived self-efficacy in coping with the condition. But also, as developing from past medical encounters, communicating with others about the condition and also the information available within a culture (Leventhal et al. 1984). For the participants in this study, with long histories of chronic pain, it is proposed that the illness experiences dominated by the constant physical symptoms and the mainly pharmaceutical and medical treatments offered acted as an impetus for biomedical conceptualisations of pain and self management of the pain within a predominantly biomedical model. However, it has been suggested that a mainly biomedical approach to CLBP is ineffective and inappropriate. The suggestion is that it leads to a narrow approach to managing pain that may be partially successful (the patients had some relief from

pain due to medical interventions) but is a reflection of a simplistic model of biomechanical dysfunction that does not allow for beliefs, feelings and social context that all may have an impact on the experience of pain and disability (Waddell, 1994, p. 267).

The participants seemed “stuck” in their experiences with references made to a discrepancy between a previous valued ideal self, “I was always so active” and a present lesser valued impaired “self” accompanied by little evidence of the participants engaging with the pain (as suggested earlier) or re-establishing any valued behavioural activity. The theory of self-discrepancy (Higgins, 1987) indicates that negative evaluations of oneself in relation to what one ought to be doing, that is, the “ought self” or an “ideal self” is apparent in individuals with depression. As mentioned earlier, the design of the study did not allow for any formal clinical evaluation of depression but some of the participants did refer to subjective evaluations of depression in relation to their feelings of loss.

A similar study of patients with CLBP by Osborn and Smith, (2006) explored the nature of the relationship between the painful body and the self with reference to The Enmeshment Model (Pincus and Morley, 2001). The Enmeshment Model is proposed as an extension of the Theory of Self Discrepancy (Higgins, 1987). A main claim of the enmeshment model is that it represents the extent to which the sufferer’s life is in a state of discrepancy rather than purely suggesting it is by referring to the degree and focus of enmeshment or interrelationship between proposed pain, illness and self schemas [referred to as an individual’s knowledge about an illness] (Pincus and Morley, 2001, p.15). The Enmeshment Model asserts that when elements from illness and pain schemas are frequently activated at the same time as elements from ones self-schema, the content of the three schemas can become incorporated into one another, or enmeshed. Thus, the individuals view of himself or herself is disrupted. The degree to which the self is negatively evaluated and enmeshes with an inappropriate illness schema may prevent the re-establishment of behavioural activity and be an indicator of distress or depression (Pincus and Morley, 2003, p.19). Depression, or affective distress, is offered as the primary mediating factor of the extent of the enmeshment, however, whether depression is the cause or consequence remains unknown.

The present data show conceptual support for enmeshment of the self, pain and illness schemas that compose the Enmeshment model. All participants referred to the

sensory-intensity of the pain that fits with the pain schema, all had an awareness of being chronically ill with little control over the pain, that is consistent with an illness schema, all referred to a strong sense of discrepancy between previous positively evaluated selves and present negatively evaluated selves that is indicated in Pincus and Morley's references to the self-schema. As mentioned previously some of the participants in this study did appear to have experienced symptoms of clinical depression, whilst others reported chronic distress and lowered mood that may lead to depression. The participants made few positive personal appraisals about their present lives and it is suggested that the participants' pain and self-schemas appear to be enmeshed and "trapping" negative aspects of the self that reiterates Osborn and Smith's (2006) analysis.

Whilst it is proposed that there was evidence of enmeshment in the data it had also been noted that there was a dualism of self apparent in the accounts that was viewed as protecting the individual's integrity. This may be considered as an unconscious defence mechanism used in response to internal threats (Freud, 1911/1933) and supports the findings of Osborn and Smith, (2006). However, whilst Osborn and Smith offered little explanation for the contradictory presence of both enmeshment and distancing of self from the pain, an explanation may be proposed that suggests whilst the participants demonstrate "enmeshment" they continued to attempt to resist the damaging effects of the pain to their valued self-concept by distancing themselves from the pain.

Furthermore, Osborn and Smith, (2006) observe that any such contradiction in self could represent an obstacle to therapeutic rehabilitation and suggest that an acceptance of pain that has been found to be useful in effective pain management (Osborn and Smith, 2006). They indicated that for such individuals, encouraging an "integrated" or coherent sense of self as part of an acceptance therapy may be useful. However, a contrasting view may be that for some patients, acceptance therapy (see Chapter 2.) would be unsuitable with some benefiting from continuing to "distance" themselves and developing a "fighting strategy" rather than "acceptance" and engagement with pain.

The Enmeshment Model has been proposed as a useful contribution towards understanding the participants' experiences in this study. However the model is applied cautiously as it was developed as an explanation for variances found in response bias studies of patients with chronic pain and has little supporting empirical

evidence. Whilst the present data appear to show conceptual support for the model it does not fully represent the psychological processes and social influences apparent in the data. For instance, the present data show that the biomedical illness beliefs of the participants are an important influence on the participants' conceptualization and management of their pain. However, there is little explicit reference to illness beliefs in The Enmeshment Model that may sustain any illness behaviours. In addition, in this study, many of the participants' reported loss across all spheres of their lives that are not adequately captured by The Enmeshment Model.

Overall, the accounts show how the participants constantly struggle with the management of their CLBP. The participants concern is upon managing their constant and sometimes overwhelming pain with physically focused treatments and strategies. Despite the inefficacy of the medication there is little consideration of any alternative treatments. Yet, their accounts show their suffering is determined not only by the physical pain but also its psychological and social consequences, for example, fear and fear avoidance behaviours that perpetrate social isolation, immobility and possible further pain.

The participants strive to be pragmatic and just about "cope" with the help of family and friends but their "actual or present selves" are almost always portrayed in a negative light as compared with their portrayal of their "past selves" and their "ought selves" that causes despondency and depression in some cases (Higgins, 1987). The participants actual selves are complex with participants having to negotiate many new fears and uncertainties, including issues surrounding the cause of the pain itself and establishing its validity and their own moral worth alongside their increasing pain and immobility that suggests they are managing multiple selves (see: Hilgard, 1986).

A main claim of the analysis is that the participants' pain experiences are underpinned by biomedical pain beliefs that "enmesh" the participants in a narrow and only partially effective way of managing with CLBP.

4.7 REFLEXIVITY

The integral role of a reflexive stance in IPA has been previously discussed in Chapter 4 with reference to the work of Smith, (1996) and Elliott et al. (1999). In

keeping with this, reflective discussions took place with the PhD supervisor and a reflective diary was maintained throughout the research project where analytical field notes and reflective accounts of the interviews were maintained. The following section focuses upon my reflections concerning emotional responses, managing the interview process, research relationships and ethical dilemmas. Because of the subjective and introspective nature of reflection all reflective accounts are written in the first person.

4.7.1 Emotional responses of the researcher

These first interviews began with some anxiety that led me to question the effects of my own emotional experiences upon the analysis or what is termed in positivist psychology “experimenter effects”. There is not much information in the IPA literature about emotions experienced by the researcher and the possible effects of these emotional experiences upon the integrity of the analysis. A phenomenological research project requires researchers to take “the phenomenological attitude” that includes putting ones own judgements, assumptions and expectations aside so as to stay close to the reported experiences (Willig, 2008). However, it is readily admitted that bracketing or distancing oneself from these prior expectations may be difficult to undertake in any research project (Osborn, 1994). Conversely whilst bracketing is advocated, empathic-intuitive understanding and even personal warmth are regarded as contributing to a successful interview (Reid et al. 2005; Osborn, 1994). Thus boundaries between the interviewer and interviewee in IPA research are not clearly set out.

This tension has been debated by Kleinman and Copp (1993) who advocate that researchers recognise the importance of admitting their emotions as it can inform the interpretation of the data and is a necessary part of the reflexive process. Qualitative health researchers, in particular, may be exposed to potentially distressing information and situations not experienced by the more “distant” quantitative researcher. A reflective approach may encourage the researcher to “unpack” any emotional distress or uncomfortable feelings and expose how these feelings influence the analysis.

This issue is illustrated by my diary entries after the first interviews that showed the prolonged contact with participants had meant I was beginning to engage

with them as individuals that sometimes left me feeling helpless and uncomfortable. I note from an excerpt in my reflective diary that I was empathized with one participant who was of a similar age and had expressed very difficult circumstances. I left the interview with strong feelings of gloom that paralleled the participant's articulated hopelessness:

'I left the house feeling very miserable and felt helpless as I couldn't do anything for her. I thought of buying her a bunch of flowers but I was just glad to be heading home as fast as I could. I returned over the mountains and I was very nervous as the mist had fallen and visibility was limited. I arrived home tired and tense and smelling of smoke. I went for a walk and tried to shake off my feelings of gloom. I had a shower to get rid of the smoke lingering in my clothes and on my skin' (Reflection upon interview 1 with Sara: 1, 1. 16-21).

This led to my reflecting upon the complexities of the boundaries between me as an IPA researcher and me as a caring individual and whether my strong empathic feelings would affect the analysis of the accounts of this participant. Empathic-intuitive understanding and even personal warmth are regarded as contributing to a successful interview (Reid et al. 2005; Osborn, 1994). However my experience reflected the tension between this unavoidable subjectivity and avoiding any superimposition of these feelings upon the interviews and the final analysis. The recognition of this issue promoted questions about how to respond to my uncomfortable feelings in readiness for the next interview. My responsiveness to these issues was shaped by my understanding that an empathetic understanding was in keeping with the tenets of IPA research and could help develop the analysis. I subsequently undertook discussions about these issues with my PhD supervisor as suggested by Elliott et al. (1999) and Smith and Osborn, (1996). These sessions resembled a quasi "debriefing", with my supervisor who reassured me that my empathetic feelings reflected my "closeness" to the data and that by reflective discussion and recording of the interview process I would be able to analyse the data without showcasing or biasing particular experiences of the participants that resonated with my own empathetic feelings rather than representing the participants experiences.

I also felt it was important that I maintained an outwardly calm and interested presentation during the interviews, despite any dissonant feelings, so as to

facilitate detailed and frank accounting by the participants. Subsequently, I considered the work of Hochschild, (1983) who proposed the concept “emotional labour” that involves managing ones emotions so they are consistent with the “display rules” or the presentation requirements of a situation. For example, health professionals are required to display positive emotions towards patients regardless of whether this is discrepant with their internal feelings. This concept seemed relevant to my concerns about displaying emotions during research interviews and was consistent with my implicit knowledge of display rules during research interviewing. Whilst I may have felt empathetic I recognized that it would not be appropriate to publicly display emotions during the interviews as this may unduly influence the responses of the participants. This issue was also discussed with my supervisor who advised me about considering my non verbal behaviors such as facial expressions and verbal styles such as speaking rate, loudness and so on during the interviews as these may unintentionally reveal my emotions.

I continued to reflect upon these matters throughout the research project and found that I responded to my concerns by an increasingly relaxed approach whilst simultaneously focusing upon the participants that enabled me to put aside or bracket any strong and immediate emotional responses so as to maintain as inductive and unbiased approach as possible.

4.7.2 Managing the interview process: use of the semi-structured guide

The semi-structured guide proved to be useful as a data collection tool as the initial open question allowed the participants to talk liberally whilst the pre-constructed probes acted as an *aide-memoire* and enabled me to keep track of issues that I wanted to explore. I also encouraged the participants to talk freely with non-verbal signs such as head nods and also verbal affirmations. This worked well for most of the interview but occasionally the participants would deviate into unrelated matters such as inquiries into my background or debates about the costs of holidays and so on. I had to balance this type of discussion against the desire for more relevant insights. I found I was able to lead them back to the main thread of the discussion with the use of the probes (see semi-structured guide above). As the interviews progressed I became increasingly confident and began to facilitate the interviews more effectively.

On the other hand, this type of open interview can be wearing for the interviewer as I had to focus on the discussion, pay attention to the guide and the direction of the conversation whilst also checking the tape-recorder was working and taking field notes about any immediate impressions (Denscombe, 2003). This meant I had to fluctuate from one task to the other. Willig, (2008) writes about the importance of focusing upon the participants talk during IPA research. Therefore, after a couple of interviews I decided that I would relinquish more expansive note-taking during the interview in favour of focusing on the present interaction and not being too anxious about the course of the discussion.

4.7.3 Managing the interview process: dealing with silences

Generally, the participants appeared very keen to have the opportunity to talk about the impact of CLBP on their lives. The reason for this was not always clear to me and I did speculate about their intentions. However, in light of the participants' reports of isolation, I thought that it was probably an opportunity for them to be able to discuss their experiences freely with someone other than their family or a health professional treating them. There may also been an element of altruism as one remarked:

'Well I put my name down for this (interview) because hopefully through my own experience and other people's experience you can develop some sort of reading into it and possibly in years to come you would understand more why, possibly not a cure to it, but you can understand why some people are like this...' (Don: 19-20, 31-4).

However, whilst the talk generally flowed, there were also some prolonged silences and times where I felt I "jumped in" far too quickly with a prompt when I should have left it to the participant to initiate the continuation of the interview. By doing so, I considered that I may have missed valuable accounts of their pain experiences by intervening so rapidly. One participant in particular was rather slow in answering and I felt I had to fill the silences with questions. On the other hand, I realised that whilst she didn't offer as much information as others, what she did say often had a distinct clarity about it and enabled me to understand her position just as much as more expressive participants.

The silences were awkward but as the interviews progressed I found that if I waited, participants would often continue with little encouragement. My view was that these silences may have been due to the participants finding difficulty in articulating their experiences. I conjectured that maybe this was partly why they felt isolated in their pain experiences as they were not able to explain their position adequately.

4.7.4 Managing the interview process: research relationships and ethical dilemmas

An unforeseen occurrence highlighted issues of managing research relationships and practising ethically. Unexpectedly, two of the participants' spouses were present during the interview. This was either a source of tension or conversely, contributed to understanding the participants' pain experiences.

On these occasions participants' spouses started to participate in the interview. This posed a dilemma about whether to include their contributions as data. On the one hand, the presence of the spouse could inform the analysis, but I also conjectured there may be ethical implications for including their accounts as the spouses were not included in the research design presented to the ethics committee. I was also worried that they would answer for their wives and by doing so I would be subject to their interpretations rather than the participants' accounts.

I deliberated about how to manage the situation. I decided that I would acknowledge the spouses' responses in the interviews as their presence often added insight into the participants' experiences of pain as a shared experience or "weeness" (Mason, 2004). It therefore seemed entirely reasonable that they would be accompanied by their spouses. However, their voices were not audible on the tap-recorder and I did not transcribe their comments. Their main function seemed to be to jog participants' memories.

During another interview the husband of the participant hovered over us during the interview. I tried to ignore him but he was rather intrusive by his physical presence rather than any conversation. The husband put some earphones on and started to listen to some music, but he was also listening to the interview as he interjected a couple of times. For example, when the participant said she could become irritable and nasty with the pain he turned and nodded in agreement. The

participant also seemed to find his presence disturbing and when he finally left the room became far more relaxed.

On balance, participants' spouses could illuminate data but also cause undue constraints during interviews. I subsequently couldn't find any written guidelines about what course of action to take under such circumstances and so decided that prior to the next interview I would remind them of the purpose of the research that is, that my main priority was to interview the participant.

4.8 CHAPTER SUMMARY

An IPA analysis revealed seven super-ordinate themes that represented the meaning of the pain for the participants and offers an initial understanding by which to compare subsequent accounts. These themes represent the participants embodied and multidimensional pain experiences. The interviews began with participants relating detailed stories about the onset of the pain that reflected attempts to authenticate their condition and construct a case for valid entry into the sick role. These moral endeavours were viewed as being a consequence of long experiences of not being believed.

The participants' prioritised the physicality of the pain and conceptualised the pain as a biomechanical dysfunction with little initial reference to the role of emotions. However, a close examination of the data revealed embodied and multi-dimensional experiences. The painful body and associated loss of function and mobility were seen to have a negative effect upon the participants' self-concept and mood with strong expressions of loss in relation to past lives, activities and impaired social roles. There was little reference to the participants engaging with the pain or any positive self appraisal and these findings were discussed with cautious reference to The Model of Enmeshment (Pincus and Morley, 2001).

The pain was managed by a heavy reliance on medication, behaviourally focused coping strategies and support from family, friends and some health professionals. Marital relationships were a cause for concern for some, but "shared pain" could draw couples closer together. The participants' experiences of the health services and health professionals were often unsatisfactory with a lack of information available about the cause of the pain that led to incoherent understandings about the

pain. Subsequently, some of the participants held little faith in the any future treatment offered by the chronic pain clinic.

A reflective account demonstrated the main methodological challenges were dealing with ones own emotions and the tension that occurred between experiencing empathy and offering a representative analysis, managing the interview process that included managing ones self-presentation, the discussion itself and simultaneously using the semi-structured guide and making notes, dealing with silences and confronting ethical dilemmas related to contributions by participants' spouses.

The next chapter presents the findings from the second set of interviews held with the participants after being invited to attend the chronic pain clinic.

CHAPTER 5

AFTER ATTENDING THE CHRONIC PAIN CLINIC: THE PHENOMENOLOGY OF CLBP

5.1 INTRODUCTION

This chapter presents super-ordinate and sub-ordinate themes drawn from the second set of interviews with eight participants who participated previously. Initial interviews revealed that embodied and multidimensional pain experiences were underlined by a biomedical belief system and that these beliefs had implications for the way participants managed their illness and their relationships with others.

A second interview with each participant allowed for further exploration of the participants pain experiences, comparisons with the previous interviews and insights into how the participants continue to conceptualise and manage CLBP.

As in Chapter 4 the presentation of themes is accompanied by a short summary. A discussion of the themes is followed by an overall discussion that compares the present responses to the participants' previous accounts and discusses these findings in relation to the extant literature. A reflective account is followed by a conclusion summarising the findings.

5.1.1 Aim

The aim of conducting a second set of interviews was to develop an understanding of participants' experiences of CLBP and explore any changes and consistencies in the participants' experiences one year after the first set of interviews and subsequent to attendance at the chronic pain clinic.

5.2 METHODS

5.2.1 Procedure

The interviewer remained in contact with the participants and was updated about their attendance at the pain clinic. The second interviews were held after participants had attended the clinic and were all held in the participants homes. The interviews took over a period of four months in 2006 and 2007, between 11 and 15 months after the first set of interviews.

5.2.2 Participants and treatments

Eight participants participated in second interviews with two of the previous participants being unavailable for personal reasons (see table 3). Five participants had received treatment. Doris reported a significant, ongoing decrease in pain due to an intrathecal pump implantation. This is a surgically implanted device placed in the abdomen that offers pain relief by delivering morphine via a catheter near the spinal cord. Cara and Don underwent epidural steroid injections that deliver medication very near or directly to the source of the pain. Many patients have short term pain relief from this intervention. Cara reported a pain free period and Don indicated the treatment had had no effect on his pain. Eirlys attended for acupuncture that had some effect and Sian had her medication adjusted with no significant improvement.

Paul was referred to a multidisciplinary pain clinic, Will attended the clinic but did not receive treatment because of lost medical notes and Sara could not receive treatment because of co-pathologies.

Table 3: Demographic and Medical Characteristics of Participants

Participant N = 8	Age	Marital status	Work status	No of years of chronic pain	Known Medical History	Treatment at chronic pain clinic	Participants perceptions of their pain
Paul	59 yrs	married	Retired/ill health	5 years	Small lumber disc protrusion	Referred to a multi disciplinary pain clinic	No change
Don	58 yrs	married	Retired/ill health	5 years	Cervical Spondylosis/ disc protrusion/ lower back pain/ laminectomy	Epidural steroid injection	Getting worse
Will	76 yrs	married	Retired/ill health	At least 4 years	Degenerative changes in spine	No treatment	Getting worse
Sara	39 yrs	married	Housewife/ finished work ill health	8 years	Arthritic changes	No treatment	Getting worse
Eirlys	63 yrs	married	Retired / ill health	At least 4 years	Degenerative Changes in spine &neck	Acupuncture	Getting worse
Cara	54 yrs	married	Retired / ill health	5 years	Arthritis/spinal surgery	Epidural steroid injection	Getting worse
Doris	58 yrs	married	Retired / ill health	12 years	Degenerative changes in spine/ decompression surgery	Referred and received Intrathecal pump injection	Improved
Sian	57yrs	divorced	Retired / ill health	At least 2 years	Disc degeneration and small prolapse	Medication adjustment	No change

5.2.3 Data collection

All the interviews took place in the participant's homes at a time convenient to them. The same semi-structured interview schedule continued to be used as a guide to ensure experiences could be compared across interviews. However, the initial format took a different turn, with each interview starting with a slightly different open-ended "lead-in" question, "How have you been since I last spoke to you?"

Unlike positivist research that uses fixed interview schedules, a longitudinal qualitative approach allows for flexibility in questioning thus accommodating the emergence of changing experiences (Saldaña, 2003). In keeping with this, note was taken of the previous methodological reflection that cautioned against a prescriptive style and participants were increasingly encouraged to move freely in their descriptions of their experiences. This led to a focus upon descriptions of their recent treatments and experiences within the health services rather than detailed accounts of the nature of the pain. In addition, the period of painlessness reported by some participants raised interesting questions with the development of a new question that probed the pain free experiences: "Please describe your experiences when you didn't have any pain?"

Each individual interview was shorter in duration than previously as biographical details and the participants back-ground history had been recorded previously. The duration of each interview was 40 to 60 minutes, with one interview lasting 30 minutes. All interviews were tape-recorded and transcribed as previously described. One tape recording (Will) was unintelligible and unsuitable for transcription. Notes had been taken during the interview and after a discussion with the PhD supervisor the decision was made to incorporate Will's views in the presentation of themes.

5.2.4 Analysis

A similar analytical procedure took place as in study one with the coded themes for each participant in this study compared across the data set and then compared with the previously elicited themes from the first interviews. This allowed for the identification of themes and a decision made as to whether they were a manifestation

of a previous theme or were new themes (Willig, 2008). An iterative and cyclical approach was maintained to ensure the researcher stayed close to the participants' meanings and their experiences were adequately represented in the final account. All the main themes constructed from the first interviews were represented in the second study, although as suggested, some included new manifestations and salience. The analysis continued to consist of both a thematic analysis and also a focus upon the "rhetorical positioning" of the participants, their verbal expressions and the ways the participants talked about their pain. As suggested in the methods chapter, the rhetorical positioning of the participants is regarded as connected to the implicit meaning of the experience of pain (de Visser and Smith, 2006; Smith, 2004).

5.2.5 Validity checks

The transcripts were examined independently by the PhD supervisor and a discussion ensued about the structure and content of the themes. The researcher and the PhD supervisor undertook a lengthy discussion about the conceptual nature of the themes and finally agreed upon the researchers' original thematic structure and metaphorical analysis and so no amendments were undertaken.

One recorded interview had been of poor quality and the researcher deliberated about whether or not to use the notes taken during the interview as data. It was acknowledged that a reliance on notes taken during the interview may be selective and partial and that significant information may be lost (Breakwell, 2006). This was balanced against not including the views of a participant who had kindly given his time and was keen to be heard. The notes were adequate and themes could be identified and so where appropriate, use was made of the notes as data.

5.3 PRESENTATION OF DATA

The following super-ordinate themes and sub-ordinate themes were constructed from the data and are summarised in table 4.

Table 4. Super-ordinate themes and sub-ordinate themes.

Super-ordinate themes	Maintaining integrity	The essential nature of the pain	Painlessness: a window of opportunity	Loss of social roles	Managing the pain	Losing faith in the medical services and health professionals
Sub-themes	Bravery and fortitude	Getting worse	Uncertainty	Loss of mobility and function	The dialectical relationship with the medication	Lost in the system
	Through no fault of mine: being let down by the health services	No change	The future	Loss of social life: then and now	The side-effects of the medication	The waiting game
	Through no fault of mine; being let down by my body	Improved levels of pain	A new role	Loss of independence	Learning to live with the pain	Losing faith in the Health Professionals
		Good days, bad days, very bad days			Behavioural Coping strategies: Adopting bodily postures Adjunct remedies Pacing Fear avoidance behaviours	
		The intrusive nature of CLBP			Cognitive coping strategies: Pragmatism Being positive Distraction	
		The painful body and fragmentation of self				
		Emotional responses				

5.4 THEMES

5.4.1 Maintaining integrity

The participants are viewed as continuing to rhetorically position themselves as moral, physically ill participants. Positioning has been previously described with reference to the work of Harré and Langenhove, (1999) who proposed that positioning is a metaphorical concept relating to the presentation of one's personal identity and moral attributes in discursive practices (see Chapter 4). The participants emphasised their integrity of self in different ways that demonstrated a continued moral endeavour. Those who had received treatments in the pain clinic emphasised their bravery and fortitude whilst undergoing arduous and painful treatments in the clinic. Those who had not received treatment or had had unsuccessful treatment spoke of strenuous attempts to gain treatment but were let down by the inefficacy of the health professionals and disorganisation of the health services. One participant, unable to attend the clinic because of fear and self inflicted injury similarly deflected blame and emphasised her non-attendance was through no fault of hers.

5.4.1a *Bravery and fortitude*

Cara and Doris described the painful treatments they had received:

'Steroid injections. And the explanation I was given was that it's got to be painful because without finding where the worst pain is you know in order for them to get the injection in the right place it has to be painful to work It's dreadful and I'm absolutely dreading going dreading it. I'm even toying with the idea of not having it to be honest with you. But you know it's very painful very painful' (Cara: 3. 2-6).

'But they said it's exactly in the right place and I'm so pleased because when I had the trial it wasn't in the right place and my nerves and it was causing me terrible pain in the legs' (Doris: 2. 5-7).

'I feel happier in one way because [ahem] as I said I'm leading a slightly more normal life. I mean still get back pain but it's not the same its not so crippling back pain. Back pain, I mean it's so uncomfortable, but nothing like the pain before (Doris: 2. 32-34).

5.4.1b *Through no fault of mine: being let down by the health services*

Three of the participants had attended the chronic pain clinic but had not received treatment because of misinformation about appointment times and lost medical notes (two eventually did have further appointments, with one receiving an epidural steroid injection and the other a referral to a multidisciplinary clinic). These participants emphasised that whilst they were compliant and kept their side of the “bargain” their attempts were thwarted by the inefficacy of the health service. They positioned themselves as compliant patients but “let down” by the disorganisation of the health services. For example, Will had been challenged about missing an appointment but indicated he was a compliant patient.

‘He always turned up for an appointment and if he couldn’t, his wife would inform them and make another appointment. He always believes in searching for a cure’ (Will: drawn from researcher’s notes due to a spoilt tape).

Paul’s medical records had not been present and he couldn’t proceed with the consultation:

‘Lost in the system [Laughs] ‘It’s [ahem], that statement has been made to me many times, it’s got lost in the system’ (Paul: 1.17-18)

The lost medical records contributed to feelings of being a low priority in the health care system and also contributed to a lack of control over their condition by having to play the ‘waiting game’.

‘As I said the first time I went there [ahem] I kept the appointment and couldn’t do anything, just went in and sat down and he said we’re very sorry but we can’t do anything for you because we have no record (Don:1. 4-6).

I believe that when certain patients, and I think I’m one of them, they just say we can’t do no more for you so you don’t become a priority do you know what I mean? That’s my own personal belief’ (Paul: 2. 12-16).

5.4.1c *Through no fault of mine: being let down by my body*

One participant presented herself as a compliant patient but through no fault of her own had other problems that prohibited her attendance and treatment. Sara related how she was keen to receive treatment but couldn't due to causes outside her control:

'But of course my back is breaking down anyway so I know that, he couldn't stress that enough, that there was no possible way they could do it' (Sara: 1. 31-33).

'Well when I went down and saw the doctor he said because I burnt the bottom of my back that was imperative that the skin on the burnt area where they injected hadn't broken down. If it did break down they could do the injections but there is a higher chance of heavy bleeding. So they couldn't do it' (Sara: 1.4-7).

Sara continued: 'I have to have a dreadful phobia of needles anyway. Which I should have explained to the doctor in the first place but I was down there on my own and I was just so relieved that they were going to do something that I thought to myself that I would have to tell them when I got there. I didn't like to seem ungrateful' (Sara: 1. 21-25).

5.4.1d *Theme summary*

This theme represents the participants' continued attempts to establish their integrity of self. The participants emphasised their compliance with medical direction despite painful and arduous treatments, experiences of disorganised health care, failed treatments and co-pathologies.

5.4.2 The essential nature of the pain

The participants continued to refer to the pain experiences in terms of its physicality. Physicality was defined in Chapter 4 as a mainly sensory experience with nearly all the participants, including most of those who had received treatment, reporting little change or worsening levels of pain. Only Doris reported less pain for a prolonged period of time due to an effective intrathecal pump implantation.

5.4.2a *Getting worse*

Will and Don referred to increasing pain levels. Don noticed that he had increased his intake of medication that acted as an index of the growing levels of pain.

‘[Ah], the pain is I believe definitely increasing, I would say yes. When the pain comes, well, I seem to be taking more painkillers than I was before’ (Don: 7. 27-28).

Eirlys described increasing sources of pain that she suspected originated from her back problems. There is little understanding about the aetiology of the pain:

‘Oh, I don’t know I can’t lay on my side because my hip is so bad, and I’ve been to the doctor and, I know you don’t want to know all this these are all medical problems, but from my two knees down, how can I say they are very, very painful and all burning inside from my knees down. I don’t know whether it’s something to do with my back perhaps my nerves are trapped’ (Eirlys: 1. 34. 2. 1-3).

Cara had received an epidural steroid treatment and experienced a short pain free spell. However, subsequently, she had experienced worse levels of pain:

‘[Ahem] I was really disappointed when it came back [quiet voice] and that it didn’t last 6 weeks I was sure it was going to last longer than that. It was excruciating when it came back, absolutely awful’ (Cara: 2. 31-34).

5.4.2b *No change*

Sian and Paul indicated there was no change and Sian took a pragmatic approach:

‘It’s been no better. And I can’t say exactly no worse whether it is or not I just grin and bear it. You know’ (Sian: 2. 4-5).

‘I still have the same problem with my spine as I did in the beginning and it’s a continual gripping feeling and Mr X was very surprised’ (Paul: 6. 6-7).

Sara despondently remarked:

‘No, my life is the same you know. All that changes are the seasons and the days’ (Sara: 3. 13-14).

5.4.2c Improved levels of pain

Doris was the only participant who reported ongoing, improved levels of pain due to an Intrathecal Pump Insertion. Doris suggested a 'trade off' between the pump distorting her appearance and gaining increased pain relief:

'It's quite a big lump. That side of it isn't so good but the pain relief it gives, is very good. I was on 200 mgs of morphine a day orally and now I don't have to take any orally at all' (Doris: 1. 27-29).

5.4.2d Good day, bad days and very bad days

The pain continued to be described as being constant and characterised in terms of good days, bad days and very bad days.

Don reported his pain as getting worse but still referred to the pain as fluctuating in intensity:

'The good days are bad and the bad days are awful. I know I'm repeating myself, it would be nice one-day and take a tablet and say I feel great now' (Don: 6. 20-21).

Cara referred to the constant but fluctuating nature of the pain:

'Yes I get my good and bad days [*sounds weary*]. Because I always have a reminder constantly you know' (Cara 4. 24-25).

For Sian there were only bad days. Sian took a pragmatic approach:

'You know one day you think 'Oh I feel fine to-day, I'll do this'. But then the next day or a couple of hours later you're suffering. There is no good or bad they're nearly all bad. There you go' (Sian: 5. 1-3).

5.4.2e The intrusive nature of CLBP

The pain affected the participants at all times of the day and night. Lack of uninterrupted sleep continued to be a problem.

Sara commented about the lack of sleep:

'I'm up till about 6 in the morning and then I'm absolutely exhausted and then you know you do manage to catch up one or two hours of sleep' (Sara: 3.17-18).

Similarly, Eirlys had received acupuncture and had experienced a pain free period. It had now returned and she continued to experience constant pain:

'Yes, yes, yes, you're never free of pain. I would love to just for a few hours, even a few hours, especially at night of having no pain' (Eirlys: 5. 14-15).

Cara reported sciatic pain that was increasingly troublesome during the night:

'I don't really notice the leg pain [ahem] in the day because when I keep moving it tends... I tend not to feel it but when I get in bed at night I still have to have my pillows under my knees I can't lie flat I can't lay on my side either I can't lie on my sides at all if very conscious of it because I very, very rarely but the times that I do [ahem] woken up with it but when I go to bed at night, just relax that's nice you know and then you get this.... in the leg' (Cara: 1. 14-19).

5.4.2f *The painful body and fragmentation of self*

The participants continued to refer to a constant and acute awareness of their painful body parts. This had been referred to in Chapter 4 as the body making a dys-appearance when in the presence of pain (Osborn and Smith, 2006; Williams, 2000). The participants were acutely aware of their bodies and feelings of heaviness were a common complaint:

'You do feel so, so heavy. And from my waist down you feel as if you're dragging yourself you know? Another thing it alters your composure, the way you walk, the way you stand' (Eirlys: 9. 28-30).

I drag my foot because they are heavy (Eirlys: 10.7-8).

'I mean you feel wonderful when you're in the water its boiling and I seem to be able to do a lot more, you know. But the minute you get out of that water and get back to reality and gravity your body feels so heavy and you are back to where you started'(Cara: 8. 16-18).

The dys-appearance of the body is particularly apparent in Sara's account with Sara tracking the progress of the pain as it spread throughout her body. She spoke of feelings of discomfort and heaviness with the pain being represented as an external agent with an uncontrollable momentum. Sara continued to refer to her relatively pain free body parts with the use of a personal pronoun. For example, "my knee" and externalised the

encroaching pain, by reference to “it” (the pain). This was interpreted as a rhetorical distancing of the painful parts from her unaffected self. This had been previously suggested (see Chapter 4) as indicative of the participants’ efforts to protect their valued selves from the potentially depreciating effects of pain:

‘No it is gradually getting worse as I said it’s, I said, its spreading to my knee its just not the pain it’s the weird sensations, your legs become heavy and you got, you’re knee grinding and clicking and just you’re feel like your legs are three times the weight you know its seems to be spreading you know the pain.’(Sara: 4: 5-8).

Sian made a similar distinction between the pain and her “self”. For example:

‘I want it to go away. Do you think it will? [Laughs]
I hope it doesn’t get any worse put it that way’ (Sian: 6. 2).

In contrast, Eirlys indicated a degree of control that was reflected in her reference to pain. The example below suggests Eirlys was aware that complete pain control was not possible and “my pain” was now part of her (use of possessive pronoun), but she could contain the pain with medication.

‘When you’ve got a lot of pain all below the waist, you got a job to tell where it is coming from. You don’t know, whether my hip is aggravating my back or my back is aggregating my hip you know. I got pain in both knees, I don’t really know. But other than that you know I keep my pain I don’t say I keep it at bay but I cope with it with a lot of tablets’ (Eirlys:2. 11 -16).

5.4.2g *Emotional responses*

The participants were increasingly ready to talk about their emotional responses to pain. The loss of function and mobility caused feelings of frustration and anger. Sara talked about the pain ageing her and experiencing feelings of frustration due to a lack of mobility and spontaneity:

‘As I said, I do tend to get a bit upset and do cry you know and it, it’s the frustration as well as the pain because it...more and more and I am going out less and less, its stopping me from going to sitting down, to perhaps, going to the toilet. You know and it slows you down, you feel ancient you know with the pain and its so debilitating. You know I’m in agony and then I get frustrated and angry with myself’ (Sara: 3.15-20).

Don referred to the hopelessness of the situation and his feelings accompanying severe pain:

‘Mad I think. Especially when it’s really bad when you take two pain killers then you, you know, you bite your tongue with it. Then you’re in that situation and nobody can help you sort of thing’ (Don: 4. 17-19).

He continued:

‘Well I know I bite people’s heads off. I can’t [ahem], I might put it down to the pain personally. I haven’t got no patience sort of thing’ (Don: 5. 18-19).

Eirlys talked of the undeserved experience of chronic pain:

‘And I think I’ve had eight operations for different things and then I’ve got all this, and I think oh God, it’s not fair so you do emotionally get upset. You know, why you should have all this. So yes it does emotionally upset you’ (Eirlys: 7. 9-11).

Doris states that despite the improved pain relief she continues to need antidepressants to cope on a daily basis:

‘Yes. I’m much better. Am still on the Prozac though still taking that. I came off it at one point or tried to and I found I couldn’t cope so ... (Doris: 2.31-32).

5.4.2h *Theme summary*

The nature of the pain continued to be reported as intrusive with experiences dominated by an acute awareness of painful body parts. As at time one, the participants reported their bodies letting them down and prematurely ageing them. For some participants a dualism of self continued to be apparent in the data as they spoke of the pain as a threat and as uncontrollable and external to themselves. Participants increasingly and spontaneously referred to their emotional experiences. They talked about feelings of frustration and anger in relation a loss of function and mobility (see Chapter 4 for a full discussion).

5.4.3 *Painlessness: a window of opportunity*

Eirlys, Cara and Doris had received treatment that had resulted in periods of painlessness. All three had received different treatments; acupuncture, an epidural steroid injection and an intrathecal pump implantation respectively. These pain free periods had opened up

possibilities that may be described as a “window of opportunity” enabling them to conduct basic daily activities unaided. For example:

Doris refers to the efficacy of the intrathecal pump implant:

‘It helps a lot with the back pain I can sit still quite a bit more than I used too’ (Doris: 1.19).

‘But to do the simplest things like that you know it was great, the realisation that it wasn’t there [laughs]’ (Cara: 2. 31-32).

Eirlys recalls having acupuncture that helped her with daily living:

‘I did find it helped me and yes and [ahem] at the time I had three or four I cant remember now, it was only a few weeks ago And I had them in quite a close succession two one week two the next week and she said you are seeing the doctor next week this is my post op appointment, she said get back in touch with me when they’ve seen you but [ahem] I haven’t, but I’m going to as I would like to have some more acupuncture (Eirlys: 24-29).

5.4.3a *Uncertainty*

There were mixed feelings experienced during the pain free period. Cara talked of feelings of uncertainty about boundaries of activity. Whilst she had a feeling of freedom from the pain this was combined with worry the pain may return. Cara also talked about a perceived gap in her life and how she had missed the pain.

‘I don’t know what I’m going to do in that pain free period I [ahem], I was very, very nervous of doing anything out of the ordinary in case it all came back and I was very tentative and [ahem] about doing anything [ahem] it took a while to sink in do you know what I mean? [ahem] I’ve been , had pain for so long you know, that being without it I don’t know you almost missed if that makes sense. Probably don’t, I know’ (Cara: 2. 17-21)

Cara was advised to participate in exercises but no advice had been offered:

‘When I was talking to the doctor he said their idea would be that they would improve the strength of my back and be able to do exercises while I was pain free hoping it would build up the strength in my back’ (Cara: 3. 15-17).

Interviewer: Did you manage to exercise?

Cara: 'No Because I didn't know what to do' (Cara: 3.20).

Doris was cautiously optimistic:

'It's early days. Yes, I'm still a bit wary because as I say I'm its early days from the operation itself so I'm finding lifting and that sort of thing to much for me yet. But ...' (Doris: 3. 24-25).

5.4.3b *The future*

Despite the difficulties associated with the periods of painlessness, these participants talked about the possibility of working again or an improved social life. There was a perception of a meaningful future.

'It's been a long learning process I am toying with the idea of going back to work but I really don't what I would be capable of doing' (Cara: 3. 33-34).

Eirlys had received acupuncture that had relieved her pain for a while and revised her hope for the future. Whilst Eirlys had faith in acupuncture and had also explored alternative ways of relieving pain, she also retained faith in proposed operations that would enable her to lead a more active life:

'But I'm hoping when I have had my operations [ahem] I could go and do something voluntary you know. Mediation or working in a charity shop or something you know because I've always worked in caring and there are lots of things you can do. If it's only going along and talking to people you know' (Eirlys: 3. 14-18).

'But I'm not ruling anything out in the future you know? (Eirlys: 3. 31).

Doris referred to the implications of being without pain and fulfilling social obligations with far less discomfort:

'Well it will mean that I will be able to go out for a meal, and sit in a chair without having to lie on the floor' (Doris: 2. 9-10).

'I can't say I can go back to the youthful era before I had the pain. But it is certainly better than it was [ahem], giving me a more positive outlook' (Doris: 3.18-19).

Doris looked forward to a renewed and happier social life:

'Oh, and I should be able to go to the cinema. I haven't been yet as I'm still recovering from the op [ahem] I've been out for a meal which was lovely' (Doris: 2. 3-4).

'I feel happier in one way because [ahem] as I said I'm leading a slightly more normal life' (Doris: 2. 26-28).

5.4.3c *A new role*

Cara had developed a new social role. During the previous interviews, Cara had focused upon loss of a past "useful life". However, at time two Cara had now taken on a new role as a mentor to her daughter who also had CLBP, using her own experiential knowledge to support her daughter:

'She is seeing occupational therapists and she is really upset by it all but [ahem], she's found it a big help because of my situation. Although, it may not be similar problems because mine is definitely a disc problem [ahem] Hers may not be, because of ...she's been through hell in the last few months and it's a sort of a roller coaster because you're up and down so much and she's exactly the same, I'm trying to tell her to pace herself, she's like me she is...that's why I've been over Monday and Tuesday to try and help her out you know get things right and I know she's suffering'(Cara:6. 7 -14).

The responses above may be compared with those who yearned for a pain free existence but had not experienced any respite:

Sian referred to the hopelessness of her condition, the inefficacy of the medication and her unrelieved pain:

'They don't touch it. They just give me all these funny reactions but the pain doesn't go away. I can't cope with this much longer' (Sian: 2. 33-34).

'But then you know there is only so much you can cope with when you haven't got... [ahem] you haven't any pain relief you know but as I said [ahem] my GP is sympathetic to anything but he's tends to be to want to get you off medication rather than recognising the fact that you're in constant pain'(Sara:2.34, 3. 1-4).

Sara viewed her future bleakly:

She continued: 'You know and on really bad days you think you yourself if this is what it like now what I'm I going to be like in say 10 years. If I'm still alive like what kind of state am I going to be in you know as I said it does affect you mentally as well as physically.'(Sara: 5. 2-5).

Nothing seemed to work for Don:

'Well as I said I [ahem] you take them it assists but doesn't help. I know that sounds a bit daft I mean in an hour or so you are well it's like as if you've never taken it'(Don: 3. 1-2).

Don was fearful of his future:

'I believe 15-18 months before I go for that scan I could well be on support crutches or even a bloody wheel chair. Well, I've always said to my wife and family no one will ever push me down the road in a wheel chair' (Don: 6. 14-18).

5.4.3d *Theme Summary*

The participants who had received treatment and had experienced less pain reported improved physical and emotional experiences. Conversely, Cara and Doris also touched upon some of the issues raised by experiencing painlessness or beneficial treatments. Cara also commented about a lack of helpful advice from the health professionals as to how she should proceed with exercise and so on. The absence of the pain (albeit temporary for two of them) appeared to have the effect of enabling them to reappraise their situation. The optimistic responses of those who had received treatment were contrasted with the rather pessimistic responses of those who hadn't experienced painlessness.

5.4.4 Loss of social roles

The participants continued to talk about their loss of mobility and function, loss of a social life and independence as a significant burden.

5.4.4a *Loss of mobility and function*

Participants continued to complain of the pain interfering with their ability to carry out daily tasks and their dependency on their families. Sian and Sara referred to their impaired housewife roles:

Sian attempts to complete household tasks but finds it impossible and is partly dependant on her daughter. Sian knows her limits:

‘I can’t move furniture around my daughter has to come around for that. Anything that’s strenuous I can’t do. Ordinary vacuuming quietly, I do. I try to keep myself mobile. But the corners I can’t do’ (Sian: 2. 12-14).

Sara expresses worries about being unable to fulfil her role as a mother and as a partner. There is concern expressed about letting her family down but admits there is nothing she can do about the situation:

‘I know there’s things my daughter would like for me to be there to see her and I can’t and I get frustrated with myself and feel I’m letting her down, she’s putting a brave face on it, she’s a good girl but at the same time you can just see in her face you know that the disappointment then with my partner you know I really know he’s more like a carer than a married partner you know it’s not fair but there’s not a lot I can do. Housework is impossible’ (Sara: 5.31-34, 6. 1-4).

Sara referred to the tensions caused by her condition and her relationship with her partner. Her partner had articulated a felt impatience:

‘I finding I’m going out less and less and you know it frustrates my partner because he’s got people in the street saying, I haven’t seen you, where’s S you know and all this. He wonders what they think. He says I haven’t buried you out the garden but as I say I can’t go out as I can’t walk’ (Sara: 2.20-24).

Eirlys spoke about her increasing immobility that affects the most mundane activities:

‘No, no it’s a small thing obviously. The bus stops outside here but I find the step is so high you know I have difficulty getting up the step it’s because of the hip. Before the hip and the knees it’s the kind of thing I could do my back didn’t affect that type of thing but now [ahem] I have much more difficulty doing things when I just had a bad back’ (Eirlys: 5. 22-26).

5.4.4.b Loss of social life: then and now

The participants continued to talk of their past active lives and compared this with their present lives.

‘Yes. It has affected my work. It’s affected my whole lifestyle. We don’t go out anywhere no longer. Very ,very, little, my husband does a little job, he delivers parcels and if I can manage it I go out with him in the day just to get out of the house actually’(Eirlys: 3. 20-23).

‘Well as I said I used to be quite an active sports man. I, when I gave it up I started to follow them and even now they was at the final in X the other day and I thought I couldn’t go in there just to stand there to watch the match as I would be constantly moving agitated and ... so I got to the stage where I don’t even feel like going to watch the rugby match like’ (Don: 3. 29-33).

Sian missed being able to shop:

‘You know as I say perhaps because I’m old school you grin and bear it. The only thing I do miss is going out shopping you can’t walk and walk you know’ (Sian: 4. 20-21).

Cara and Eirlys talked about how they missed taking holidays:

‘Oh Yes. Oh yes and planning holiday breaks in the summer months and everything, it does get you more so because I can’t do what I want to do you know’ (Cara: 3. 33-34).

‘But it does affect your life I mean going on holidays again, you know, we used to love going on holidays I used to love walking you know I’d walk to town and back. I mean I was working as a carer for twenty years with the social services? I never took the bus to work’ (Eirlys: 6. 15-18).

Sara suggested that she was feeling increasingly depressed because she had no social life and remained isolated:

‘Well as said it’s depressing really. You try not to think about it really you try not to think about it because either. The more you mull over it in your mind that you don’t go out and how it affects your social life, you know, you know I just turned forty in march and I feel one hundred and forty’(Sara: 4. 33-34, 5. 1-2).

There was a persuasive sense of loss as participants described the discrepancy between present and past selves in terms of decreasing mobility and function.

5.4.4.c *Loss of independence*

All the participants disliked their loss of independence and dependency on others.

Sian relied on her daughter to help her and she compared her present dependency with her previous independent self. Losing her independence was one of the worst aspects of the CLBP:

‘Yes [*indicating it is the worse part of CLBP*]. Yes I’ve always been so independent to rely on someone is not nice’ (Sian: 2.17).

Similarly, Don talked about his increasing disability and dependence on his wife. He had become the dependant one rather than the one depended upon:

‘My wife still does quite a lot for me’ (Don: 4. 1).

‘My wife rubs Transtec in my back on a more frequent basis that it used to be, but as I said I try and get up and walk about as much as I can sort of thing’(Don: 3. 5-7).

‘On time it makes you feel, oh, I don’t know how to put it, [ahem] It makes you feel embarrassed sometimes when you have to ask your wife to put your socks on or your underwear on’ (Don: 4. 3-5).

Paul suggested that he had become the dependant one and his wife had become his carer. He recognised that she was overburdened with her responsibilities and resented the fact that he could do little to help her:

‘So to-day she had our shopping, her mothers shopping and her brothers shopping so she’s done that by 11 this morning. Sometimes I try and help her but my youngest helped this morning, to get things out of the car. And she’s nearly 61’ (Paul: 7. 5-8).

Sian spoke about struggling to participate in family activities. She managed to maintain her role as matriarch and hosted Sunday lunch. However, she recognised this role was impaired as she now had to be helped by her daughter.

'She's good as gold and comes a couple of times a week and mostly at week-ends she cooks the dinner and I clean up. That's fair isn't it? [*Laughs*]' (Sian: 2. 21-23).

Sara thought her family held the view that she was becoming increasingly dependent on them:

'Yes. Probably perhaps from somebody else's perspectives like my partner or my daughter they may say I'm relying on them more. [*Ahem*], but I personally feel it's just the same' (Sara: 6. 18-20).

A main concern for Sara continued to be the erosion of her role as mother and her changing relationship with her partner. She didn't know how to change her situation:

'Oh, I know there's things my daughter would like for me to be there to see her and I can't and I get frustrated with myself and feel I'm letting her down, she's putting a brave face on it, she's a good girl but at the same time you can just see in her face you know that the disappointment. Then, with my partner you know I, really more and more he's more like a carer than a married partner you know its not fair but there's not a lot I can do'(Sara: 5. 21-26).

Sara felt powerless to do anything to help stop the process.

'You know everything I take for granted is being slowly taken away from me you know it's just horrible know, it's just horrible you don't know what do to with yourself '(Sara: 2. 26 - 27).

A different perspective was offered by Doris who recognised that her "hardy" personality had enabled her to 'come through' and fight the pain:

'I suppose so I was always a bit of a fighter obstacles to I would try and find answers. It does help if you if you have that kind of personality where you can try and cope with things' (Doris 4. 24 -27).

5.4.4.d Theme Summary

All the participants had experienced some change in their social lives and family roles. Some of the participants' accounts centred upon these impaired roles. Two of those who had received treatment had developed new roles within the family or were able to consider a fuller social life.

5.4.5 Managing the pain

All the participants continued to depend on medication as a main method of pain control despite its perceived inefficacy and adverse side-effects. However, participants also referred to physical and cognitive coping strategies that they had learned to adopt to augment the medication.

5.4.5a The dialectical relationship with the medication

The medication was perceived as a necessity but continued to be disliked:

‘Because they don’t actually work, they assist but they don’t work I’m sitting by here now and its very, very uncomfortable’ (Don: 2.13-14).

Eirlys indicated that she is always in pain despite the medication:

‘Yes, yes, yes, you’re never free of pain’ (Eirlys: 5.12 -14).

‘I would like to throw all my tablets away obviously, like everybody would like to do you know’ (Eirlys.9 1-2)

Sian had positive evaluations of the doctor in the pain clinic but has little faith in the efficacy of the medication:

‘Fine he’s very nice and very helpful you know and he and he wants to make me take the medication but nothing works’ (Sian: 1. 18-20).

5.4.5b The side-effects of the medication

Sian described the side effects as so severe that she had stopped taking most medication:

‘The back of my legs have gone. Dr X tells me its it’s trapped nerves in the bottom of my spine causing the problems, but I took the medication he gave me but I had so many reactions that I come off it all so I came off it a week tomorrow’(Sian: 1. 3-6)

Similarly, Don and Paul commented:

‘Dr X tells me its it’s trapped nerves in the bottom of my spine causing the problems, but, [Ahem], I took the medication he gave me but I had so many reactions...it’s been no better. And I can’t say exactly no worse whether it is I just grin and bear it. You know’ (Don: 2.13-14).

'I take a laxative quite often because that does affect me. So many people with back pain who have got that problem if they are using [ahem] pain killers regularly or if you haven't been to the toilet for three days that's something that really affects your back'(Paul:3. 1-4).

5.4.5c Learning to live with the pain

Most of the participants talked about having to learn to live with the pain.

'Yes. I can, I know most of my limits now; what I can and can't do' (Sian: 2.8).

'Oh yes. Yes you have too. It's been a long learning process I am toying with the idea of going back to work but I really don't what I would be capable of doing (Eirlys: 4. 33 -34).

'As I said well I think you learn to cope with pain you learn to live with it' (Paul: 4. 26).

5.4.5d Behavioural focused coping strategies

Behavioural focused coping strategies continued to be frequently mentioned ways of managing the pain.

5.4.5e Adopting bodily postures

Cara referred to the constant nature of the pain and how it interfered with daily activities. She had learned to adopt certain positions to aid her functioning:

'[Ahem], its, its there all the time but I think its more so if I bend If I stay vertical then I'm alright you know but the moment I veer off, anything which involves bending down, like the dishwasher that's a killer. I know I've got very little strength in my back and if I do bend down I just need help and I just hold onto something and getting up as well I need to hold on [ahem] so, its all well and good to say bend your knees, bend your knees'(Cara: 9. 3-8).

5.4.5f Adjunct remedies

Paul had learned that warm showers help with his pain, he doesn't understand why heat helped:

'The social services are beginning to help me, with the power shower over my bath so I can get at it and then obviously at the time it broke I bought an ordinary one so I said I cannot be without this. This morning I stretched forward like that and letting the water onto my side and I stretched out like that and I, I'm not saying the pain had gone but it helped something I don't know what it is'(Paul: 4. 28-33).

Don continued to use a topical ointment as an adjunct to his medication and attempted to take exercise:

'I said I sit down and the pain gets worse and I'm down on the floor and I sit and watch the television down there on the floor rather than on the pouf sort of thing and then I lie down in bed until 8.30. My wife rubs Transtec in my back on a more frequent basis than it used to be, but as I said I try and get up and walk about as much as I can sort of thing' Don: 3. 13-16).

5.4.5g Pacing

Cara suggested that she had learned to pace herself:

'You know which is, that is very true you have to pace yourself. But people tend, I used to think at one stage that I was having a good day, I would do what I could do in that one day but you suffer you know it would be worse so you know so you have to pace yourself and do things quietly not rush to do things because yes you are having a good day Just do what you can and then without pushing yourself too far. You know have a break, sit down, have a cup of tea you know, that kind of thing (Cara: 3-9).

5.4.5h Fear avoidance behaviours

The participants' social lives were curtailed by their continued avoidance of public places. Sara, Paul and Don in particular, continued to avoid the challenge of public spaces that led to social isolation and in turn reinforced a fear of public spaces.

Sara spoke of her fears about public spaces and attributed these to her prolonged periods of isolation. She considered that her psychological state may be at the root of her problems rather than her physical status:

‘I don’t like open spaces I don’t like [ahem], being in a situation where I am talking to people, you know, as long as it’s in the confines of my own home its fine. But, you know being in a big hospital with people and them because I think it’s got something to do psychologically because I don’t go out. I can’t stand busy areas’ (Sara: 7. 34, 8.1-4).

As in the first interviews Paul talked about his family encouraging him to “live around the pain” and he did this by self imposed limitations and avoiding public places:

‘But if I got to go somewhere I get all tight about it and then I don’t know why and I think its because I think negatively, what if ... what if... there’s something wrong with my back when I’m down there’(Paul: 7. 23-25).

Paul continued: ‘I went to X, right, and they bought me a mobile phone and I still got it it’s one of those old ones. And I had a tingle in my spine and I had to get away from the people and used the phone and said to the wife come and fetch me. I, it’s like a panic attack and once people start milling and I am afraid they will bump into me and that started to get me more panicky and once I got away from people I said come and fetch me I’m getting worse. She said ‘What’s the matter?’ I said I was by Woolworths in nit and I get panicky and I don’t know why’ (Paul: 7.27-33).

Don similarly talked about his feelings of vulnerability whilst out shopping. Even this everyday activity posed a threat to his well-being:

‘If I do go occasionally shopping with the wife, I can’t bear crowds and stuff like that. Most of the time somebody accidentally bumps into you and they jars you and [OH]!’(Don: 6. 26-30).

Don continued by referring to how he managed to take a little exercise in places where there was limited opportunity for contact with others. For example, Don helped his daughter by exercising the dog. This helped him to retain a sense of worth (being useful) and also maintain a routine:

‘Well it’s not so much as taking him out as regards to I take him down to the common site and I take him off the lead and he just runs around and then I just call him and he comes back. And I put him back on the lead then and its only say 50 yards up the road to my daughter’s house and its back home’(Don: 7. 21-24).

5.4.5i Cognitive focused coping strategies

The participants' also referred to more cognitive focused coping strategies such as pragmatism, being positive and distraction.

5.4.5j Pragmatism

Don employed a form of pragmatism. He suggested that the doctors could only do so much and he had to help himself:

'I don't know about other people but I find that if like myself you're in pain 24/7 you think you're be able to acclimatise to it, its like as if you know you've got the pain and you can't do nothing about it, the doctors can't help no more than they are helping you sort of thing so you've just got to try and get on with it' (Don: 4. 8-12).

5.4.5k Being positive

The participants who had experienced painlessness were more inclined to report being positive.

Cara and Doris talk about being positive and determined:

'The way I was looking at it when I read up about it don't dwell on the negative aspects of it look positively very difficult to be positive when you are in so much pain and you cant do the simplest of tasks (*voice sounds strained*) do you know?' (Cara 3. 29-31).

'Well it could be, I think a lot of it is will power? I honestly think if you are determined to conquer something and not make it a higher disability, I mean it is a disability, but determined to overcome some of it then it does help instead of giving in' [*Laughs*](Doris: 4. 18-24).

5.4.5l Distraction

In contrast to some of the participants, Eirlys participated in activities despite the pain. Eirlys had accepted that pain was part of her life but recognised that she would have to distract herself and participate in activities despite her fears and the pain:

‘Well as I said my pain has got a lot worse in the last year because of my other complaints, [ahem], I think I have accepted it more now’. Although I get emotionally upset when I talk to someone about it. I think you learn to live with things you know. Yes. I have tried to do other things like I have tried, no, I haven’t not tried ‘(Eirlys: 8. 23-26).

‘Well [ahem], yes, I tried lately this deep breathing you know, and trying to focus my mind on other things other than my pain you know. [Ahem], and I think that helps a little bit yes. I went to calligraphy classes which are quite close and it was in the morning and I used to enjoy that, I thought I would, if I can, taking up Indian head massage. But again, that’s if I can do the movements, you know. Yes, so I try to take my mind off myself’ (Eirlys: 4. 27-31).

5.4.5m Theme Summary

The participants continued to manage their pain with medication despite the adverse side effects. All the participants talked about learning to live around the pain by use of predominantly physical orientated coping strategies used as an adjunct to medication, adapting their physical postures, pacing and avoidance behaviours. Cognitive strategies were mentioned rather less but distracting hobbies, pragmatism and being positive were referred to by the participants. One of the participants attempted to adopt new hobbies and activities despite the pain.

5.4.6 Losing faith in the medical services and the health professionals

The relationship of the participants with the health professionals was a significant theme that had also been present in the previous interviews. The theme took on increased significance at time two by those participants who had not received treatment at the pain clinic or had little or no pain relief. Those participants who had received no treatment because of information being lost by the health services or experienced ineffective treatments or long delays for treatments and investigations, were particularly voracious in their condemnations about the “system”.

5.4.6a *Lost in the system*

Several of the participants (including Will) related stories about how their appointments at the pain clinic could not take place because of lost medical records (this had been mentioned previously). The participants also reported long waiting times for appointments. They had learned from previous experiences to have low expectations of health service delivery. Paul and Don expressed a sense of anonymity; they felt “lost in the system.” Paul had been referred to a multidisciplinary pain clinic but had been waiting for an appointment:

‘Well I feel as I said I will go somewhere that will help me with my pain. I will be willing to go, and yet I get letters sent me and if I rang them up now they would say there’s a waiting list or whatever, and well that’s that. I don’t know but I haven’t heard nothing from X and if I, I, went to see Dr X or what ever his name is, he , that’s as embarrassing because I didn’t hear from him. ‘I can see now you’ve been lost in the system’, and I think, now I am 6ft 1 inches; I am a bit big to get lost in the system’ (Paul: 4.15-21).

Don pointed to a lack of communication and feelings of anonymity:

‘You get to the stage that my stage is in that we’re just a number on a box and no knowledge about what number you are like. So you get to the stage where you lose faith in everyone’ (Don: 5. 33, 6. 1-2).

5.4.6b *The waiting game*

As previously, waiting was of particular significance for the participants. The participants talked of waiting for an appointment to attend the pain clinic and then not being able to be seen by the doctor because of the disorganisation of the service.

Don indicated that he had waited a long time for an appointment and then no-one had “bothered” to get his medical records that reinforced his feelings of being regarded as a low priority by the health professionals:

‘I’ve waited twenty seven months for the first appointment. So I know there’s a hell of a lot of people that’s being looked into sort of thing, but to me it’s the system is immobile. As it is it’s a long time a frustrating time to be seen then (Don: 2. 1-3).

‘Then my case of twenty seven months and the first appointment, how can I say it was an appointment that was a waste of time for the hospital and for myself as regards somebody made the appointment for me and no one bothered to get my files. And you can see from the situations I have why the NHS is in the mess it is’ (Don: 24-28).

Paul referred to the felt impatience and indifference of the medical practitioner. Paul himself articulates a parallel indifference with the health services:

‘Well, when I went to the chronic pain clinic and saw Mr X and I just had a quick, I seen you, there is nothing I can do about you. I don’t like you taking diazepam. That’s it in a nutshell. [Ahem] but there’s a place for back pain management and I will get in touch with them and I thought well I’ll go if it will help me. They haven’t been in touch and I don’t see why I should get in touch with X and see what is happening as they said they would get in touch with me’ (Paul: 1. 7-10).

Eirlys continue to wait and hope for another appointment:

‘Still hoping. I haven’t seen anyone since then. What happened; my name was put on the list and I went to see him privately initially and I went on the list to have my back operation as he said I needed a back operation and it was just then ahem it was just decompression of two of my discs at the bottom of my spine. But as the years went on [ahem] while I waited for my operation it worsened’ (Eirlys: 4. 18-24).

5.4.6c Losing faith in the health professionals

Some of the participants continued to express a loss of faith in the health professionals and medical treatments. Paul expresses his disappointment with the health professionals. Paul has a biomechanical view of his CLBP and found it difficult to understand why there was no cure:

‘And all that time those people have seen me I feel like if it was a car with something wrong with it they would have found out how to fix it you know’ (Paul: 4. 6-7).

Don, in a flat tone, seemed to express little surprise at the inefficacy of the epidural steroid injections:

‘... the second time I went they made an appointment for me to go to theatre to have the injections in the spine. And, well, I had two injections and didn’t do ‘nothing at all’ (Don: 1. 6-8).

Interviewer: 'Nothing at all'?

No. By the time I left the hospital I was in the same condition as I was when I walked in' (Don: 1. 10-11). '

Sian appreciated the doctor's help but there was an air of despondency as she spoke of the doctor continually offering her medication that had no effect:

'Fine he's very nice and very helpful you know and he, and he, wants to make me take the medication but nothing works. I don't know where we're going after we've tried them all' (Sian: 1. 18-20).

Eirlys suggested that the doctor at the pain clinic inferred she was addicted to the prescribed medication:

'I was quite annoyed with the pain clinic when I went to see a Mr X he annoyed me because he said, more or less he said I was addicted to my tablets'(Eirlys: 9. 3-4).

Paul related that he had felt very depressed when he had to give up work twenty years ago because of his back problem. Lately he had been told there was no cure and on the face of it had accepted his condition as a chronic one:

'I thought I had peace of mind when I saw Mr X the neuro surgeon in the X and he said 'I would not operate on this protrusion' as he called it as [*phone ringing*] because I think it would be too risky. Since he told me that, I have accepted that there is perhaps no cure for me' (Paul: 1. 34, 2.3).

However, he remained doubtful about this opinion as he had lost faith in the doctors.

'And yet as I said I'm meeting eminent people like Mr X who said he doesn't think it's a trapped nerve through. And a lot of people who I don't think can deal with backs. Anyway there's no specialist, that is, it's a slight protrusion so we can't do it, the neuro people can't do it, so go home and live with it like. That's it in a nutshell' (Paul: 4. 7-11).

Don suggested he had also lost faith in the doctor's opinion:

'And as I said when Mr X put in the injections and he believed he might have put them in the wrong place and I thought how you can put them in the wrong place? That's my own personal opinion and I'm not educated to the standard of medication to know if they are [*unable to hear this part of the statement*]' (Don: 6. 4-6).

Don vacillated between criticising the medical staff and suggesting they were doing as much as they can:

‘I don’t know about other people but I find that if like myself you’re in pain you think you’re be able to acclimatise to it. Its like as if you know you’ve got the pain and you can’t do nothing about it, the doctors can’t help no more than they are helping you sort of thing so you’ve just got to try and get on with it. As I said the worst part is getting up every morning in pain and going to bed every night in pain so your quality of life isn’t there sort of thing’(Don: 4. 9-13).

Whilst the participants voiced criticism they did not seek alternative treatments. During the previous interview, Eirllys was the only participant to suggest she had searched for alternative treatments. During these interviews she asserted her wish to have acupuncture rather than medication:

‘I had some acupuncture done at the pain clinic and the first time I went to see them he put me on Gabapentin I can’t remember yes I think they were. But they completely knocked me off and my speech was slurred and I thought I didn’t want that so I went back and I asked, “Could I have acupuncture?” and yes’(Eirllys:1: 17-20).

5.4.6d Theme Summary

The disorganisation of their care was a focus of the participants’ accounts. The participants spoke of this at some length at the beginning of the interviews in relation to being let down by the health services, but it continued as a theme throughout the interviews. The continual waiting, feelings about being of a low priority and the perceived disorganisation of the service continued to generate a loss of faith in the health care system. The males in particular, reported inadequate care. The participants were also losing faith in the health professionals as treatments failed and no definitive diagnosis was offered.

5.5 DISCUSSION OF THEMES

The following discussion focuses upon the super-ordinate themes elicited from the data. The themes “maintaining integrity”, “the essence of the pain”, “painlessness”, “managing

the pain”, “loss of social roles “losing faith in the health services” and “losing faith in the health professionals” are discussed and followed by an overall discussion that relates the present findings to the previous study.

5.5.1 Maintaining integrity

This theme has been discussed in depth in Chapter 4 but continued as a prominent theme during the present interviews. The main claim in the previous interviews had been that the participants’ detailed accounting about the onset of their pain represented an impression management strategy. The participants had been concerned with establishing authenticity of their conditions in order to provide justification for entry into the sick role.

During the present interviews, the participants’ impression management strategies were expressed in different ways but were viewed as continued attempts to establish legitimacy of their occupancy of the sick role and protect their integrity. The participants rhetorically positioned themselves as brave patients undergoing painful treatments or as compliant patients who were thwarted in their attempts to gain help for their pain. They were “doing the best they could” to obtain treatment that corresponds with Parson’s conceptualisation of the sick role, that is, the obligation of the ill person to get better is by complying with medical advice (Parsons, 1951). However, this was challenging for the participants as CLBP does not fit well into Parson’s model because of the inability of chronic pain sufferers to make a full recovery. The characteristics of CLBP also render sufferers further difficulties as it is often invisible to others and sufferers are vulnerable to charges of malingering (see the previous chapter for a full discussion). Therefore, a main task for the participants was to establish a valid diagnosis and maintain integrity. The participants’ accounts continued to be viewed as a vehicle for establishing integrity of self against a background of felt stigma (Kugelmann, 1999).

5.5.2 The essential nature of the pain

The participants continued to foreground the physicality of the pain experiences and revealed a constant awareness of their painful bodies. The participants’ indicated that the pain had either stayed the same or become worse with just one participant reporting continued and improved pain levels due to an intrathecal pump insertion. Despite these differences in pain levels, the pain continued to be referred to in terms of its constancy

with the participants reporting good days when the pain was in the background, bad days when the pain was just about tolerable, but also an increasing amount of almost intolerable very bad days that was previously discussed in Chapter 4 and remained a key feature of the pain experience for the participants. Participants were never free of pain or stiffness and feelings of heaviness that affected their daily living and promoted negative self perceptions with participants continuing to reveal the ageing effects of the pain (see Chapter 4). In addition, the debilitating effects of the constant pain were exacerbated by the intrusion of the pain into sleep time that in turn contributing to feelings of exhaustion (Sofaer-Bennett et al. 2007).

The participants' accounts continued to reveal their attempts to maintain some control with some participants strongly depicting the pain as an external threat and distinct from themselves, suggesting a division or fragmentation of self (see Chapter 4). This was previously referred to as a protective mechanism (see Chapter 4), and may be compared with others who were viewed as increasingly accepting and engaging with their pain (Osborn and Smith, 2006; McCracken et al. 1999). Osborn and Smith, (2006) suggest that further longitudinal studies may shed light on the developmental nature of this fragmentation of self. However, an alternative view might be that the participants' references to pain in this way may be a reflection of established patterns of speech about self rather than a subconscious protective device.

From the present data, it may be conjectured that cognitive distancing continued for some participants who continued to make reference to the pain in this way. This might indicate that these participants continued to have little acceptance or engagement with the pain (McCracken, 1999). In comparison, the accounts of others, for example, Eirlys, indicated engagement with the pain rather than fighting it and possibly linked to a period of painlessness (see below).

The participants' emotional experiences reflected the frustration, anger and helplessness they felt in relation to their pain and its effects on their self-esteem. Participants attempted to retain control by "distancing" themselves from pain, but it was also evident that these attempts may have been only partially successful as participants' revealed frustration, anger, depression and distress in response to the pain and associated lack of mobility and functioning. In other words, the daily demands of managing the pain and its sequelae combined to cause both emotional and physical suffering that represented an embodied experience of pain. Furthermore, Cassell, (2005) informs us that suffering involves emotional experiences that are also experienced physically. The

embodiment of suffering is similarly reflected in the present data. For example, Sara suggested that the effects of CLBP takes its toll physically and mentally and overall, “wears her down” (Sara: 3.15-20). Also, Doris indicated that despite improved pain levels she continued to take an anti depressant to deal with an impaired lifestyle that supports the idea that suffering is not rooted purely in physical sensory pain experiences but is also determined by the psychological responses and social issues it evokes.

5.5.3 Painlessness: a window of opportunity

A period of painlessness or a continued absence of pain had offered Cara, Doris and Eirlys “psychological space” from attending to the somatic aspects of the pain. Despite the resurgence of significant pain for both Cara and Eirlys, and to a lesser degree, Doris, the data resonated with increased cognitive control as participants spoke about hopes for the future with one speaking optimistically about returning to work, another about taking up new hobbies and all spoke of becoming less dependent on their spouses and increasing social activities (these issues are discussed further in the overall discussion below).

The chronic illness trajectory is often irregular with no linear progress (Paterson, 2001). As with other sufferers of chronic illness the experiences of CLBP patients may fluctuate and change according to personal and social context that may include treatment changes. Paterson, (2001) proposes ‘The Shifting Perspectives Model of Chronic Illness’ to represent the chronically ill person’s responses to their condition over time. The model was synthesised from a meta-analysis of two hundred and ninety two qualitative research studies concluding in a description of two main perspectives termed “illness in the foreground” and “wellness in the foreground” with either becoming the focus of attention at any given time in the patient’s experience:

A continually shifting process containing both illness and wellness perspectives. As people’s personal and social context changes, the people’s perspectives shift in the degree to which illness is either in the foreground or background of their world. (Patterson, 2001, p. 23)

Drawing on the work of Paterson, those participants who had received treatment and experienced painlessness are viewed as experiencing wellness in the foreground. The pain free periods had allowed a change of perspective with a focus upon restoration rather than pain and loss.

There is a paucity of information about pain remission in chronic pain patients. Sator-Katzensclager et al. (2003) reported cognitive, affective and behavioural effects of medical treatment with 477 chronic pain patients (122 with back pain) attending a university outpatients clinic over a period of a year. Results showed less avoidant behaviours and increased cognitive control (self taught skills of relaxation, imagination and self instruction) after treatment that is similar to participants in this study; however psychological well-being and mood (liveliness, happiness and activity) measured by The Profile of Mood States scale "POMS" (McNair et al. 1971) did not improve despite an improvement in pain intensity. The authors explained these latter results as a consequence of the participants' knowledge of the unchanging and persisting nature of their condition undermining psychological well-being. In comparison to the study conducted by Sator-Katzensclager et al. the present study has shown that a pain free period did improve the self reported mood of participants.

However, for two of the participants in the present study, painlessness was double edged, as their painlessness was accompanied by a concern about managing unknown boundaries. There was little guidance as to what they could do and couldn't do whilst pain free. Participants were in a state of liminality (an ambiguous betwixt and between state) as they were still physically impaired but responding (in a limited fashion) to treatment.

Sontag, (1978) wrote:

We are all citizens of the dual kingdoms of the well and the sick: although we all prefer to use only the good passport, sooner or later each of us is obliged at least for a spell to identify ourselves as citizens of that other place. (p. 203)

These participants were simultaneously in both kingdoms and the challenge was to extend ones stay in the kingdom of the well but there was a lack of guidelines about how they could achieve this.

As suggested in Chapter 4, one study reported advice about appropriate exercise and self help supported by reassurances are an important feature of a good consultation (Laerum et al. 2006). These issues would seem of particular importance when patients are experiencing remissions or temporary reprieve from chronic pain as in the present study.

5.5.4 Loss of social roles

Loss was a central part of the participants' pain experiences and supports the work of Charmaz, (1983) and more recently that of Kindermans, Goossens, Roelofs, Huijnen, Verbunt & Morley et al. (2009) who documented the adverse affects of a loss of social roles on individuals' self-concept in chronic illness. The present interviews showed a continued loss of mobility, function, social life and increasing dependence that created challenges at both physical and emotional levels for participants.

Participants held significant concerns about their increasing dependence that was highlighted by their references to difficulties in performing even the most essential of daily tasks. The salience of these concerns was illustrated by Cara who had experienced a pain free period and expressed her relief at being able to "do the simplest things" (Cara: 2.30). In most cases, participants' spouses or even family members had become carers who helped with essential, intimate tasks that caused feelings of embarrassment and guilt for the participants. The participants' dependence on others meant that the participants were often unable to fulfil their role obligations and this caused further suffering. These obligations may have been implicit in their relationships in the past but were only now realized when the participants could no longer do it and echoes Charmaz, (1983) who wrote of irretrievable loss as undermining our understanding of ourselves.

Accounts were marked by distress in relation to a sense of loss of identity with frequent references to a previous, valued active self. As one participant remarked "this isn't the real me" (Sara: 7. 30-31). Their present lives compared unfavourably with selectively remembered past images as they were now unable to claim, for example, a "sportsman' identity" or a "hard working" identity. An accompanying loss of social life that was maintained by fear of public areas meant there was little opportunity for developing valued activities by which to maintain a positive self-esteem. Previous authors have noted that a sense of loss may arise from comparing ones present self with ones previous self and social norms (Risdon et al. 2003, Osborn and Smith, 1998). However, as discussed above, these data also illustrate the adoption of new valued roles may moderate the effects of lost or impaired roles.

5.5.5 Managing the pain

The prescribed medication was the main method of dealing with the pain. For participants this meant the edge was taken off the pain but the side-effects were almost as intolerable as the pain itself with symptoms such as constipation reported as aggravating the CLBP. A reduction of side-effects such as constipation and sleepiness has been shown to be a significant, desired end-point of medication for patients with chronic pain (Casarett et al. 2001). However, the heavy reliance on medication ensured the continuation of adverse side-effects for these participants.

Most participants talked about having to learn to live around the pain that is commensurate with previous findings (Walker et al. 2007). This involved adopting personally derived coping strategies by trial and error that had an immediate, possibly short term effect on the pain and associated muscular tension but did not facilitate any decrease in medication. Participants referred to various strategies but emphasised behavioural focused strategies such as pacing, adjusting one's body, the use of heat and adjunct topical treatments.

Self-management strategies sometimes resulted in contributing to further physical and mental deconditioning. Participants' continued to avoid activities that incurred pain or stress and caused fear and anxiety (see Chapter 4). Paul and Eirlys described "panic attacks" when in public places, Sara related how she could not communicate with others outside her home, other participants described being anxious about social outings because of the threat of publicly noticeable and embarrassing symptoms or having to seek help from strangers. Fear-Avoidance models such as Lang's Three-Response Model of Fear (1968) continue to contribute to understandings of social phobias and similar disorders. The Three-Response Model in particular relates well to the experiences of these participants. The model represents fearful responses as including physiological (fight or flight mechanisms), cognitive (beliefs, perceptions and attention processes) and behavioural elements (motivation) that are mutually reinforcing, with each varying in intensity according to the individual and context (see: Norton and Asmunden, 2003).

The three-response model of fear may be applied to the case of Paul who described feelings of anxiety prior to outings, based upon fear of the development of back pain symptoms whilst in public places. This anxiety predisposed him to a hyper vigilance about his symptoms. Paul described how on one occasion he 'felt his spine tingling' whilst on his own in a busy shopping area. He interpreted this tingling as a sign of further

potential embarrassing symptoms and this elevated his anxiety leading to fear and panic. He attempted to distance himself from the crowds and this led to a development of “fight or flight symptoms” that compounded the panic response. This type of episode then acted as a reinforcer for future avoidance behaviours.

Overall, participants struggled to manage the pain through a combination of medication, adjunct applications, pragmatism, pacing, adopting postures and avoidance behaviours.

5.5.6 Losing faith in the health services and the health professionals

There was continuing criticism of the health professionals and the health care system. Criticisms were voiced mainly by participants who also reported unsatisfactory experiences in the pain clinic and referred to being let down and being “lost in the system”. Three participants had attended for an interview at the chronic pain clinic but were unable to have a clinical interview because of lost medical notes. These participants were keen to emphasise their compliance but their experiences reinforced their previous perceptions of being a low priority. These findings support Sator-Katzenschlager et al. (2003) who also found that participants perceived themselves as compliant but similarly expressed anger and frustration due to the disorganisation of care. Similarly, CLBP patients have been described as “entrapped in systems that are designed to help, but render individuals powerless, helpless and angry” (Walker et al. 1999 p. 621). The similarity between the responses of the participants in this study and those in Walker’s study supports the notion of a negative attitude held by patients with CLBP towards the organisation of their care that is reinforced by frequent unsatisfactory experiences.

The participants also continued to lose faith in the health professionals’ knowledge about chronic pain and treatments that echoes findings from Walker et al. (1999), Osborn and Smith, 1998; Seers and Friedli, 1996). Apart from two participants, who reported a measure of success with steroid injections, acupuncture and a surgical intervention, participants in this study all spoke of repeated failed medical and surgical interventions. For some participants whilst there was a loss of faith in medical treatments there were no alternatives considered and the medical model remained the predominant frame of reference (This latter issue is discussed below).

5.6 OVERALL DISCUSSION

The second interviews took place subsequent to the participants being invited to attend a chronic pain clinic. The data revealed the continuation of most of the super-ordinate themes from study one. These themes were composed of either the same sub-ordinate themes as previously or included new manifestations. However, the theme “relationships with significant others/social support” was not strongly supported in study two due to participants focusing upon other aspects of their experiences. Whilst the theme was not adequately represented it is important to note that mention of social support was peppered throughout the accounts that indicate spouses, families and friends continued to be an important source of support. In addition, a new super-ordinate theme labelled “Painlessness: a window of opportunity” was elicited that demonstrated the emerging differences within the sample.

Five participants indicated their pain was worsening, one had improved pain levels and two reported no change. However, whilst there were some changes in pain levels there was little change in the conceptualisation and management of the CLBP. In comparison, there were changes in the conceptualisation and management of pain for those participants’ who experienced painlessness.

The following sections present the continuities and changes in the participants’ experiences and the emerging differences between participants. The first section describes the shared continuities experienced by the participants.

5.6.1 Continuities

A close inspection of the rhetorical construction of the accounts revealed the participants’ attempts to portray their legitimate occupancy of the sick role that was referred to as a moral endeavour (Kugelmann, 1999). These had been discussed under the themes maintaining integrity and not being believed. These themes illustrated participants’ attempts to establish their authenticity as CLBP sufferers against a backcloth of scepticism and not being believed. The participants implicitly referred to their moral worth, the biomechanical nature of the pain and its physical cause.

Maintaining integrity continued in the second interviews but was expressed in a different way. Participants emphasised their attempts to get better by being compliant with medical direction, attending the pain clinic and enduring extremely painful

treatments. However, despite these efforts they indicated that they were no better and were let down by the organisation (lost notes and so on), and the treatment (little effect). The participants' attempts to get better are consistent with societal expectations of sick people but the chronic nature of their back pain meant they could never fully meet the criteria of the sick role and ultimately recover (Parsons, 1951). Thus, as suggested in Chapter 4, the participants perceived they were vulnerable to accusations of malingering because of the ongoing and often undiagnosed nature of their pain and so continued to fore-ground themselves as compliant, legitimate but reluctant occupants of the sick role. The compulsion of patients with chronic pain to authenticate their pain has been previously documented. A study of female patients with CLBP reported participants' attempts to conform to the expectations of others so as to "prove their pain existed" (Osborn and Smith, 1998). Patients with confirmed diagnosis of Multiple Sclerosis have also been shown to seek validation and affirmation of their pain experiences (Douglas, Windsor and Wollin, 2008). These findings indicate a perception of not being believed is not an exclusively CLBP phenomenon and that the very nature of chronic of pain contributes towards patients being misunderstood by health professionals and public alike. The continued presence of this theme illustrates not being believed and issues of authenticity are well-established and ongoing concerns for the participants in this research project who are well versed in adhering to what may be termed "defensive scripts" or moral endeavours (Kugelman, 1999).

Despite having received treatments or medication changes (see table 3), all the participants continued to complain of pain, with some suggesting it was worse, for others there was no change and just one participant experienced prolonged, improved levels of pain due to a surgical intervention (Some of the participants had experienced a short remission in pain but for most of these the pain ultimately returned). Whilst there were variations between pain intensity and coping, all participants continued to describe CLBP in terms of its physicality and as constant, intrusive and debilitating. Essentially, the nature of their CLBP remained unchanged since the pre-clinic interviews. In keeping with this, Sara succinctly likened the unchanging nature of CLBP to the regular rhythms of the seasons: "All that changes are the seasons and the days" (Sara: 3. 13-14).

The participants' painful body was at the foreground of their consciousness, with pain and feelings of heaviness and slowness ageing them (McKee, 1998). Participants continued to talk of trying to distance themselves from their pain by conjuring up metaphorical images of battling against pain that was depicted as an external entity that

had to be resisted. However, the battle was not always won as there was evident distress when referring to bad days and extreme pain.

In the previous interviews, depression or a lowered mood, anxiety and anger had been reported predominantly when participants discussed their particularly painful experiences or “very bad days”. During these second interviews, participants continued to report lowered moods with anger and frustration experienced as a function of the severe pain and also in relation to their negative experiences in the health service as they continued to perceive they were being passed on or were a low priority and (for most) there was no perceivable improvement in their situation. The unsuccessful treatments in the pain clinic strongly reinforced an increasing awareness that theirs was a “chronic, irreparable condition”.

In comparison to study one, emotional responses were increasingly acknowledged as part of the pain experiences. As mentioned in the thematic discussion, this may be partly because the participants felt they had established the physicality of the condition previously and were ready to acknowledge their emotional responses.

Perceptions of unfairness also contributed to feelings of distress as the participants indicated a moral justification in relation to their suffering. A certain level of pain was just about tolerable but on bad days the ongoing pain promoted questions relating to their continued suffering. The intimation was that CLBP was an undeserved punishment and these references illustrate perceptions of moral indignity and inequity that may also reflect the participants’ ongoing search for an explanation.

There was also growing frustration and hopelessness in response to an increasingly perceived loss of function and mobility. A growing dependency on families because of loss of function and increasing disability was a main threat and fear of participants. Whilst chronic pain is not always consonant with disability, previous studies have shown that chronic pain is a source of disability and a main fear of sufferers is loss of functioning (Osborn and Smith, 1998). A study investigating the important end points of medication for forty patients with chronic pain found that patients who identified less pain as an important end point also believed pain was causing more interference in their lives (Casarett, Karlawish, Sanker, Hirschman, and Asch 2001). These findings support the participants’ experiences that showed a focus on minimising pain as they believed the pain was increasingly interfering in their lives. However, the extent of any interference and chronicity in these CLBP experiences may partly be a function of perception as some

participants were found to have changed their appraisal of their situation and their coping strategies with some perceived success on their mood and functioning (See below).

Participants were particularly distressed when talking about loss of their previous lives, functioning, mobility and a growing dependence on their families. Loss had been a main theme in the previous study and continued with many participants referring to a perception of increasing dependence. An irretrievable sense of loss of physical or mental functioning undermines an understanding of ourselves and promotes a lack of control over our self image (Charmaz, 1989). For some participants there remained huge discrepancies between past, present and future selves with increasing losses and dependency promoting a loss of control over their lives. Despite the participants' rhetoric depicting a dichotomy between physical pain and their emotions, distress was an integral part of the pain experiences, with the accounts continuing to lend support to the notion of pain as an embodied experience and as affecting the whole of their being (Cregan, 2006).

Medication continued to be a main method of managing the pain. Participants referred to medication as essential but continued to talk about its inefficacy and increasingly worrying side effects. Despite these concerns, most of the participants had a continued dependency on medication that demonstrates the power of the medical model (see Chapter 4) and the didactical nature of the relationship with the medication, that is, on one hand the medication continued to be a necessity, and on the other, disliked because of its side-effects.

The participants continued to alleviate their pain with adjuvant coping strategies such as pacing that was learned by trial and error. Such coping strategies could temper the pain in the short term but often meant that the participants lived around their pain by avoiding activities and adopting a restricted life-style (Borkan et al. 1995). Pain and fear of the pain organised the participants lives, with the social lives of some participants restricted not only by physical immobility but by fear of embarrassment and experiencing difficulties in public spaces (previously mentioned in this chapter).

The participants' experiences in the health services continued to be a strong theme. During study one the focus of participants' accounts had been on their relationships with health professionals rather than the organisation of their care. Participants had spoken of having a loss of faith in the health professionals due to repeated failed treatments but also due to receiving incoherent explanations, scepticism and little understanding. This theme was voraciously embellished in study two by those participants who referred to their disappointment with the treatments at the pain clinic.

Despite a previously professed lack of hope for any cure or effective treatment, the participants were disappointed with the failed treatments at the pain clinic. These disappointments were probably determined by any hope resting on an enduring biomechanical understanding of their CLBP. Participants subsequently found it difficult to understand why the concomitant medical treatments were ineffective for their CLBP. As Paul reported, “And all that time those people have seen me I feel like if it was a car with something wrong with it they would have found out how to fix it you know” (Paul: 4. 6-7).

Conversely, the accounts also showed that whilst participants were often dissatisfied with their treatment they also referred to doctors as “doing as much as they can” and “he’s very nice, but what more can he do” that continued to reflect their dependence on the medical model and an appreciation of the difficulties of treating the CLBP, but also implied continued, unaddressed fears and anxieties about the future and a suspicion that nothing more could be done. In short, the participants’ fears were unaddressed and they continued to have little coherent understanding of the CLBP.

It is hardly surprising that the strongest criticism about the organisation of their care came from participants who reported lost notes, unsuccessful treatments and disorganised appointments. All the participants had previously reported feelings of being perceived as a burden for the health services and of being a low priority. In comparison to the previous interviews there was an increased focus by these participants on their unsatisfactory experiences in the health service combined with very little control over their knowledge and management of the condition. This is consistent with previous reports of patients’ dependency on the medical model and dissatisfaction with the health services that facilitates feelings of disempowerment (Walker et al. 1999).

5.6.2 Main changes and emerging differences between participants’ pain experiences

Whilst there were commonalities in the participants’ experiences there were also differences emerging between the coping strategies and appraisals of three participants (Doris, Cara and Eirlys) who had experienced painlessness and the remaining participants who experienced continual pain. Doris, Cara and Eirlys had experienced pain relief from a physical treatment that was conjectured as offering these participants a window of

opportunity or time to reappraise their situation and focus on their own needs rather than the pain. Apart from psychological treatment evaluation studies there have been very few studies that have analysed the natural development of adaptive behaviours or the effects of pain remission in chronically ill patients (see: Busch, 2005; Sator-Katzensclager et al. 2003).

In comparison to the participants who had not experienced painlessness, there was a noticeable shift towards substituting past valued activities and roles with valued activities, new roles and planning the future. Loss remained a central part of these participants' experiences but these changes are indicative of a lessening of the "gap" between a present self and ought self (Higgins, 1987) (See Chapter 4). A growing recognition that activities may be conducted and valued social roles continued, despite pain and disability is also consistent with acceptance and engagement (Esteve et al. 2007; McCracken and Eccleston, 2003). Such an increased use of a wider range of coping strategies also illustrates support for models that explain coping as a dynamic process (Lazarus and Folkman, 1984).

These changes are also viewed as being consistent with a move away from a dependence on medical interventions and a medical model of understanding to a wider psychosocial understanding and increased personal control. The data show these participants' pain beliefs and coping strategies were changing without the aid of a psychological intervention but parallel a period of painlessness and a realisation that medicine or medical interventions were not wholly adequate for treating CLBP.

These findings contrasted with those of the other participants who had not experienced painlessness and continued to rely on medication; had not developed any new activities or new roles, and focused on the present and past rather than the future. These participants maintained a predominantly biomedical view of their condition. They all continued to depend on medical help, despite a perceived inefficacy of treatments (Walker et al. 1998). Despite losing faith in the medical model, these participants remained entrenched within a medical model of understanding of their condition with a focus on the past and the present rather than any meaningful future.

All the participants participated in activities and attempted to distract themselves but for the participants not experiencing painlessness, in particular, their activities were bounded by fear of being exposed to known difficult public situations or pain. There were few new activities. However, it is important to recognise that these participants had had

no opportunity of painlessness that would enable them to consider anything other than the regulation of the somatic effects of the pain.

For these participants there was very little acceptance of pain (McCracken and Eccleston, 2003) (see above for a definition of acceptance). For example, Sara, Don and Paul talked about learning to live with the pain and accepted their chronicity but there was little attempt to live with the pain, seek alternative ways of managing the pain or engage in more positively valued activities or develop new roles. These participants may be viewed as continuing to have comprehensive enmeshment between their self, pain and illness schemas (Pincus and Morley, 2001). In Chapter 4 it was proposed that was a high degree of enmeshment between the pain schema of the participants and the self schema and this continued for these participants.

The data has revealed changes in some participants' experiences and emerging differences in the participants' management of pain. Clustering of patients with chronic pain has been developed mainly in the quantitative literature. Hobro et al. (2004) identified non adaptors as reporting less energy, poorer physical functioning and mental health, greater emotional distress and lower personal control beliefs and more emotionally threatening views of their condition than adaptors. There are similarities between the characteristics of the participants in the above study and participants in the present study. However, the present study has shown that whilst there are emerging differences in the data set there is also much communality between participants that challenges a distinct and discrete categorisation of these participants.

5.7 REFLEXIVITY

A main purpose of reflection in qualitative research is to inform the researcher about the impact of their approach upon the participants and analysis of the data. Reflecting upon the research process may thus inform the design of the research project. Previous reflections in study one had not contributed to any significant reshaping of the research design although there was a consideration of the interview style and unexpected methodological and ethical issues.

In response to these reflections, I learned to use less intervention and prompting that led to the semi-structured guide being increasingly used as an *aide memoire* rather than as a prescriptive agenda. I became increasingly tolerant of silences and delayed any prompts as I realised the participants required time to articulate complex pain

experiences. The participants appeared to be very keen to express a range of concerns but focused upon their experiences in the health services. This is hardly surprising as I was interviewing them after their recent, clinical experiences. In comparison to the previous interviews the present interviews were far more relaxed as participants' had knowledge about the interview process and I was able to manage my own emotions by intently focusing upon the participants responses.

In study two, I noted that issues reported during study one continued to be discussed, but novel aspects or more graphic details were now included. This demonstrated the worth of interviewing more than once so as to gain a richer, nuanced picture of participants experiences. For example, participants continued to refer to their "depression" but offered further understanding of the meaning of being depressed. However, I increasingly conjectured whether participants were "clinically depressed" or the term was being used to express lowered moods. I did feel rather frustrated that a clinical assessment or administering a depression rating scale was not in the remit of the research. Similarly, there was still an emphasis upon maintaining integrity but this revealed itself in a slightly different way.

Only one participant was accompanied by her husband on this occasion and as indicated in study one I had decided upon a strategy for this scenario. I had decided to make it clear that I was interested in the participant's account rather than their partner's version of events. I found it useful to reiterate the aim of the study to the participants prior to these interviews and in this case, purposefully directed my questioning to the participant who gave her account with little interference from her husband. However, the spouse was able to jog the participant's memory on occasion and gave reassuring support when there was recall of a distressing incident. I ultimately decided that the participant's husband was not intrusive and his presence facilitated an informative account. The main challenge for me as an interviewer during study two is detailed below.

5.7.1 Emotional responses of the participants

As with all psychological studies response bias and demands should be considered. Researcher effects such as the characteristics of the interviewer are known to influence the respondent's responses. The age of the interviewer, social class, appearance, accent, gender, age and similarity with the participant may all be confounding influences (Breakwell, 2006). Participants showed increasingly, spontaneous emotional responses

and I thought my gender may have influenced their responses. Research conducted by Bloor, Fincham, & Sampson (2007) points to the gendered expectations of participants who expect female researchers to be sympathetic, interested and concerned confidantes. It was also likely that familiarity with just one researcher rather than many different interviewers facilitated a rapport and feelings of relaxation that allowed some emotional “leakage”.

I had been partly prepared for some emotional display as discussing pain experiences are likely to evoke distress and had been discussed at the ethics committee where concerns had been expressed about managing distressed participants. It had been agreed that if an interviewee was upset then I would offer to terminate the interview and offer advice and support from an available counsellor.

Researchers have a responsibility to ensure no harm has been caused by research and should end interviews with a discussion about the participants experience as an interviewee. This could be a type of debriefing where any intervention or referral for further help could be implemented or discussed (Breakwell and Rose, 2006). My response was to acknowledge the participants distress and I turned the recorder to “pause” while I waited for the participants to compose themselves. I also offered to terminate the interview and proposed further support if required. However, all the participants wished to continue as the majority of them suggested their participation would help people with similar conditions. I did feel awkward and as previously mentioned in study one, I thought it best that I didn’t display any strong emotions myself but at the same time I experienced empathy towards the participants. My conduct may be described as applying “feeling rules” in the management of emotions (Hochschild, 1983). Hochschild proposed these as social norms relating to feelings and display that help to sustain an outward appearance and are consistent with cultural guidelines. The participants themselves were apologetic about their emotional displays and probably felt a little embarrassed as they had traversed social norms but I was able to reassure them that I could understand the reasons for their release of emotions.

I thought my actions reflected the British Psychological Society ethical code (BPS, 2009) and showed that I intended to do no harm, that is, I did not conduct maleficence but respected the autonomy of the participants. On the other hand, an entry in my reflective diary revealed that I felt rather intrusive at times and wondered what use these interviews were to the participants apart from helping other people to understand

CLBP. I presumed they enable people to release their pent up feelings and there was a possible, immediate therapeutic function.

5.8 CHAPTER SUMMARY

An IPA analysis revealed seven super-ordinate themes that represent the meaning of the pain for participants and offer understanding of the participants' experiences subsequent to attendance at the chronic pain clinic. These themes illustrated embodied and multidimensional pain experiences with a continued emphasis upon the physical pain and associated physical limitations. Most participants continued to have a predominantly biomedical understanding of their pain and little acceptance and continued to be regarded as "enmeshed" in their pain experiences with a focus upon the pain and a past life.

Since the previous interviews nearly all participants reported either continued or unchanging levels of pain or worsening pain. Only one participant had ongoing relief due to an intrathecal implant. Most were disappointed with the outcomes of their visits to the pain clinic and the inefficacy of medical treatments in light of their understandings of CLBP as a biomechanical phenomenon. Unsuccessful treatment outcomes confirmed participants' views that medical treatments were ineffective and the realisation that the pain may not be able to be fully apprehended. The failed treatments also contributed towards increasing anxiety and despondency about the future. Paradoxically, whilst the participants held sceptical views about medical treatments; most of them continued to hope for a cure or effective treatment.

Despite the clinic attendances participants continued to experience anxiety and frustration because of little coherent understanding about their pain. Their lack of understanding was also fuelled by the dissonance between their biomechanical conceptualisations of CLBP and failed medical treatments. Whilst there was some recognition that the health professionals were doing their best there continued to be unanswered questions about the cause of the pain and their future.

The unchanging nature of their situation highlighted the meaning of chronicity for the participants as being one of endurance. The themes revealed ongoing and increasing concerns about unrelieved pain, a growing dependency on families, relationships with spouses and feelings of isolation that were exacerbated by perceptions of not being believed and establishing credibility as sick persons. The daily demands of dealing with the pain combined with a lack of sleep and its intrusion into every aspect of their lives

exhausted them and their families. The pain and its management were at the epicentre of the participants lives. Despite expressing scepticism about medication and a dislike and worry about its side-effects, the management of the pain continued to be mostly by medication. However medication was accompanied by learned and mainly behavioural focused coping strategies.

The main difference to study one was that some participants had experienced painlessness due to physical treatments but this pain-free period was marred by a lack of information and support in relation to activities. However, the pain remission and realisation that medical treatment could only do so much was a turning point for these participants and facilitated a reappraisal of their management of CLBP. This was evidenced in their coping strategies that illustrated a move towards a biopsychosocial understanding and a degree of acceptance or engagement with the pain. Whilst the pain returned for two of these participants their changing coping strategies enabled them to deal more effectively with their pain, helped to improve their self-esteem and future outlook.

A reflective account revealed that managing the interview process and responding to any emotional responses of the participants were the main methodological challenges during study two.

The next chapter explores participants' experiences of pain after a further period of one year during which the participants continued to have access to the chronic pain clinic. A third set of interviews will enable exploration of continuities and changes and any enduring effects of painlessness on participants' psychological well-being.

CHAPTER 6

ONE YEAR AFTER INITIAL ATTENDANCE AT THE CHRONIC PAIN CLINIC: THE PHENOMENOLOGY OF CLBP

6.1 INTRODUCTION

This chapter presents findings from a third set of interviews. The interviews took place one year after participants' first attendances at the pain clinic. The previous two interviews had shown that participants shared common, multidimensional and embodied experiences but there were also differences emerging in the sample. The study two data revealed that some participants continued to have a predominantly biomedical understanding of their CLBP whilst others were moving towards a biopsychosocial perspective of their condition. These variations had been most apparent in the participants' self management strategies. A set of further interviews enabled comparison over time and developed insight into participants' pain experiences.

Super-ordinate and sub-ordinate themes are presented followed by a detailed discussion of each with reference to relevant literature. An overall discussion relates the present themes to the previously presented themes, followed by a reflective account and a conclusion summarising the main findings.

6.1.1 Aim

The aim of interviewing participants a third time was to explore any further changes and continuities in experiences since the previous interviews and subsequent to their attendance at the chronic pain clinic.

6.2 METHODS

6.2.1 Procedure

The interviews were conducted approximately twelve months after the previous interviews and took place over a period of one month in 2007 in the participants' homes. The researcher contacted the participants by phone to arrange a mutually suitable date and time for a further interview.

6.2.2 Participants and treatments

Eight participants participated at time three (see table 5). Two of the original sample declined to be interviewed for personal reasons. All the remaining participants apart from Sara had attended the chronic pain clinic (Sara had attended her local GP surgery). Since the previous interview Sara had been referred to a psychiatrist by her G.P. and had been prescribed Fentanyl patches that had improved her pain levels. Fentanyl is a strong, opioid analgesic recommended for patients with stable, chronic pain (NICE, 2008). Will had subsequently received acupuncture and an epidural steroid injection with little effect. Don had previously reported an epidural steroid injection with no effect but no further treatment. Sian had been recently prescribed Amitriptyline that she viewed as helping to lighten her mood and promote sleep. However, drowsiness is a well known side effect of this medication and had not been tolerated by others in the sample (British National Formulary, 2009). Eirlys and Paula both reported acupuncture as being effective for a short period of time. Paula also claimed Transcutaneous Electrical Nerve Stimulator (TENS machine) as being helpful for a short period of time. Paul had previously been referred for counselling sessions. Cara had received another epidural steroid injection with no effect.

Table 5: Demographic and Medical Characteristics of Participants

Participants N = 8	Age	Marital status	Work status	No of years chronic pain	Known Medical History	Treatment at pain clinic	Participants perception of their pain
Paul	59 yrs	married	Retired/ill health	5 years	Small lumber disc protrusion	Referred to a Pain Management Centre	No change from study two
Don	58 yrs	married	Retired/ill health	5 years	Cervical Spondylosis/ disc protrusion/ lower back pain/ laminectomy	Epidural steroid injections	Pain continues to be worse for longer periods
Will	76 yrs	married	Retired/ill health	At least 4 years	Degenerative changes in spine due to arthritis	Acupuncture Epidural Steroid Injections	Pain continues to be worsening and spreading to other areas
Sara	39 yrs	married	Housewife/ finished work ill health	8 years	Arthritic changes	Referral to a psychiatrist, change in medication to Fentanyl	The pain improved due to new medication that also helped improve her mood.
Eirlys	63 yrs	married	Retired / ill health	At least 4 years	Degenerative Changes in spine & neck	Acupuncture	Pain continues to be getting worse
Cara	54 yrs	married	Retired / ill health	11 years	Arthritis/spinal surgery	Epidural steroid injections/ hydrotherapy	No change from study two
Paula	65 yrs	married	Retired	At least 4 years	Arthritis	Hydrotherapy Tens Acupuncture	No change from study two and spreading to other areas
Sian	57 yrs	divorced	Retired / ill health	2 years	Disc degeneration and small prolapsed disc	Change in medication to amitriptyline	No change from study two but mood improved due to recently prescribed medication

6.2.3 Data collection

As previously, the data continued to be collected by semi-structured interview with use of an interview guide (see Chapter 3). The biographical details and background to the participants' pain had been recorded during the first interviews, thus the interviews were generally shorter in duration and ranged from 30 minutes to 70 minutes in length. The interviews began as in study two with an open-ended lead-in question "How have you been since the last interviews?" As in the previous two interviews, the guide did not dictate the course of the interview; rather it was used as a reference for prompts when required. The interviews continued to be exploratory with the participants increasingly and spontaneously leading the discussion topics with little encouragement.

A main objective of the research project was to capture any change in participants' perceptions and management of CLBP. In study two some unexpected changes had been noted for participants who had experienced painlessness / less pain. This promoted further inquiry into the continuity or otherwise of these experiences. The following questions and prompts were used: "When I spoke to you previously you spoke of a period of painlessness /less pain. How have you been since?" "Have you experienced further episodes of pain relief?" "Please describe your experiences".

6.2.4 Analysis

The analytical procedure described previously (Chapter 3) continued to be repeated during this study. An iterative and cyclical approach was maintained to continue to ensure the participants' experiences were accurately represented in the final account. The thematic analysis continued to be accompanied by a critical or etic approach whereby the interpretation of the data focused upon implicit rather than explicit meanings that were viewed as offering further insight into the meaning of CLBP for these participants (Smith, 2004; de Visser and Smith, 2006).

The sets of themes elicited during the present study were compared with the previously coded themes in study two and commonalities and differences noted. The majority of the themes from study two continued to represent the participants' experiences. However, whilst these themes were conceptually similar to their previous

counterparts some also took on new manifestations. In addition, a new theme was constructed from the accounts entitled “Treatment, personality and mood”.

6.2.5 Validity checks

The validity checks were conducted as previously. In short, the PhD supervisor read the transcripts and made an independent judgement about the formulation of the themes. The researcher and the PhD supervisor proceeded to discuss their formulations and there was some debate about new manifestations of established themes, that is, whether they were conceptually similar or merited being constructed as new themes. After further independent scrutiny and discussion about the data, there was consensus about the outstanding issues and final themes.

6.3 PRESENTATION OF DATA

The following super-ordinate themes and sub-ordinate themes represent the participants’ main concerns and are summarised in Table 6.

Table 6: Super-ordinate themes and sub-ordinate themes

Super-ordinate themes	Maintaining integrity	Essential nature of the pain	Effects of a period of painlessness	Loss of social roles	Managing the pain	Losing faith in the health professionals / organisation of services
Sub-ordinate themes	Enduring the pain and its consequences	Getting worse	Treatment, personality and mood	Loss of social life: then and now	The relationship with medication	Losing faith in the health professionals
	Enduring the treatment	No change		Loss of family roles	Medication and its side-effects	Searching for an explanation
	Enduring delays	Painlessness		A new role	Learning to live with the pain	Perceptions of support from health professionals
		Loss of spontaneity and mobility			Behavioural focused coping strategies: avoidance behaviours Adopting bodily postures exercise Pacing	Losing faith in the organisation of services: A waiting game
		Fragmentation of self			Cognitive focused coping strategies: distraction	
		Emotional responses				
		Improved emotional experiences				

6.4 THEMES

6.4.1 Maintaining integrity

Participants emphasised how they continued to endure the pain, the treatment and delays in receiving treatment. The participants were keen to emphasise that their experiences continued to be arduous and they continued to seek help.

6.4.1a *Enduring the pain and its consequences*

The following quotes show that the participants endure the pain and associated depression and immobility. Will commented upon a catalogue of related illnesses and pain that he endured pragmatically:

‘All in all the last 2 to 3 years I have had everything. It is terrible. Say I feel really down I do, but I have to carry on’ (Will: 2. 24).

Sian indicated that she endures having to conduct tasks even when she is experiencing very bad days:

‘There are days when you try to do things but you are in so much pain you do not want to do it but you do’ (Sian: 6. 28-29).

In a similar fashion, Cara suggests she feels miserable because of the consequences of the pain as it restricts her mobility. Cara does her best to carry on:

‘When you are in pain you are miserable really. Most mornings I get difficulty in getting out of bed. I have not gone back to work I carry on as best I can’ (Cara: 2. 33-34).

6.4.1b *Enduring the treatment*

Cara reported enduring painful treatment at the pain clinic. In comparison to previous injections, a second round of epidural steroid injections had not been successful. Because of the pain associated with the treatment she was reluctant to have further injections. She would rather endure the pain:

‘When I came home, it is so painful to have it done, when I checked the plasters they were really low down on my bum and I felt as if it was not in the right place it was too low. I have not been back since and they have not contacted me either’ (Cara: 1. 31-34).

Paul indicated he travelled a long distance to the pain clinic to have ineffective treatment:

‘They put about forty needles in my back. When I got home I could not feel it but when I changed my vest there were all red dots down my back. I thought it did give me bit of relief but it did not last long. Every time you went to the pain clinic in X you know its hell of a way to go’ (Paul: 4. 21-27).

Sara had been prescribed new medication from her G.P. She reported side-effects that were tolerated in exchange for improved pain levels:

‘I just know when I get up in the morning; I feel it and know it is going to be one of those days when you are going to feel sick even with a glass of water. If you are sick in the morning you are going to be sick all day’ (Sara; 7. 30-32).

6.4.1c *Enduring delays*

The following quotes illustrate the participants’ experiencing long periods of waiting for treatments that often had little or no effect. Don, Cara and Paul reported long periods of waiting that often culminated in unsuccessful treatments at the pain clinic. Don’s remarks indicate he expected failure and he has little optimism about the future.

In contrast, Cara had been optimistic, had waited patiently for treatments but was rewarded with only a brief period of painlessness. The quotes illustrate a long term dependency on the health services characterised by waiting. The participants wait for appointments, wait for treatments to work and then wait again for the next appointment:

‘The first time I went there he did not have any notes, so they had to cancel that appointment and then the second time they made a new appointment and then on the third time they admitted me onto the ward to give me the injections into the spine. It did not work. They worked for about 5 minutes but I think that was just the anaesthetic they put in the back before applying the injections. Nothing at all. I have an appointment now to see the doctor who did it last time. Monday, which will be the second in five years (Don: 1.11-17).

'I waited so long to see the pain team I was really hopeful for much better pain relief, but the injections that I had gave total pain relief for 6 weeks which was brilliant but then it came back which I was really disappointed about '(Cara: 1.1-5).

Paul related how he had to endure a long wait between appointments:

'I had a letter from X that was dated the 7th September 2005. I then had a letter on the 14th June 2006' (Paul: 1. 17.20-21).

6.4.1d *Theme summary*

The participants were keen to emphasise their experiences of enduring the pain and the painful treatments. The pain experiences were accompanied by long waits for what usually was an unsuccessful painful treatment and caused further distress.

6.4.2 Essential nature of the pain

Participants' reported the pain as either becoming worse or staying the same. Just one participant experienced improved levels of pain due to changed medication. The pain remained intrusive and challenging for the participants across all spheres of their lives.

6.4.2a *Getting worse*

There were no positive long term effects reported from treatments at the pain clinic. Eirlys had received acupuncture that had initially helped her, but the course of treatment had been for a limited period (see below) and at the third interview she considered her condition to be worse. The intrusiveness of the pain remained a problem with disturbed sleep a main concern. For Eirlys, the night was the worst part of the pain experience. She longed to be like other "normal people" and have a good nights sleep. Her disturbed sleep was viewed as an index of the severity of the pain.

'By having acupuncture I can cope with doing the physiotherapy. But I am gradually going back to square one now; I think I had the last one about September. I mean the pain has gradually got worse once I stopped going but I am getting back to square one before I went up there. The worst part is the night. It is dreadful. You are unable to go into bed and lie down like normal

people and go to sleep. Sometimes it is 3 o'clock and not sleeping. You just take some more painkillers and go to bed for an hour and because I have a bladder problem, my bladder then disturbs me' (Eirllys: 2. 15-22).

Don described his pain as becoming worse and less controllable. He continued to refer to good and bad days but was experiencing increasingly severe symptoms on the bad days.

'The pain is getting more severe. I get up in the morning in pain and I go to bed in pain. The good days are bad and the bad days are awful, but when I say awful I have more severe pain over longer periods. I am uncomfortable even sitting as I am now, but then there are days I do not know what to do with myself and they are getting more frequent'(Don: 2. 32-34, 3. 1-2).

As a result of hydrotherapy and acupuncture the pain in Paula's leg had improved but her back pain was worsening and accompanied by unpredictable symptoms:

'That is a different pain because I could be just walking anywhere and all of a sudden I am in absolute agony, sweating with the pain and it is pressing down on my coccyx and makes me want to open my bowels and to pass water. So it is really, really painful' (Paula: 2. 2-5).

Will's condition was deteriorating:

'It has gone to my shoulders now and what they say is on the x-ray when they got the report back that they are deteriorating' (Will: 2. 11-12).

'I cannot lift my arm about that height. If I lift it any higher against the joint there is a terrible pain in both shoulders' (Will: 2. 3-4).

6.4.2b *No change*

Cara, Sian and Paul reported no change in the levels of their pain:

'The same, I get up in the morning, most mornings I sit on the edge of the bed I struggle in the morning, terrible' (Cara: 3. 15-16).

Paul reported that his pain continued to be unpredictable, intermittent and invasive. There was a perception that the pain had led to his immobility and ultimately promoting agoraphobic behaviours:

'I would not say worse. Since I have had this I have had flare ups, not only am I hurting right by there, my legs are also hurting especially my left one. I will be

honest with you, because I do not go far I think I have agoraphobia' (Paul: 3. 14 -16).

Sian's pain was no worse but the doctors in the pain clinic prescribed Amitriptyline. that improved her mood and well-being:

'I saw Mr X in May and he put me on Amitriptyline. It has helped me no end; the pain has not gone, but it makes me feel better as well' (Sian: 1. 12-13).

6.4.2c *Painlessness*

Sara was the only participants who reported improved pain levels. This was due to new medication. She had become tolerant of the side-effects:

'It just takes the pain away. With the Fentanyl patches the only thing I did not like is that they make you feel sick and you are nauseous, but that is just on rare occasion now' (Sara: 7. 28-30).

6.4.2d *Loss of spontaneity and mobility*

A loss of spontaneity and mobility continued to be a significant issue. Don reported that even the simple act of standing up was a considered movement and he had learned to manipulate his body:

'I try and distract myself, I pull the jigsaw out and I will try to do some of that and I go down on my hands and knees and I bend over and because I am in that position I am all right. But then if I have to sit up, like if I have to go to the toilet, it is wham, big time and perhaps I have no feeling at all in my back and I have to go to the wall and crawl up the wall to get up'(Don:12. 23-30).

Paula found the most basic, instrumental activities difficult:

'Some days my husband has to help me put my clothes on, because I have pain in my arms and I cannot move my arms' (Paula: 6. 17-18).

Will spoke of his lack of mobility and difficulty in maintaining his balance:

'My brother took me shopping for the family and I came out and I tripped over the pavement when I was unloading the goods' (Will: 2. 14 -15).

Even sitting was unbearable. The participants' spoke of long, painful excursions that deterred them from taking holidays:

Sian and David referred to the discomfort of extended sedentary periods:

'One day you feel fine the next day you feel bad. You should have seen me yesterday. I went to London to see a show, it was my birthday present. But yesterday I was really bad. In London everything is so fast, you try and keep up. We were sitting too long in the coach going up and the theatre. Sitting is unbearable. Yesterday I slept all day' (Sian: 2. 7-11).

'I only went to Gran Canarias and I cannot remember how many tablets I took to get there' (Don: 6. 2-3).

6.4.2e *Fragmentation of self*

The participants' continued to refer to the pain as a growing, external threat, gradually "taking over" their bodies. Some of the participants continued to display a cognitive distancing and a fragmentation of self, as they made reference to the pain as "it" and the pain affecting "me".

Paula referred to her pain as an external and uncontrollable agent that she observed spreading to different parts of her body:

'Not only is it at the bottom of my back now it goes right up the side of my back and to my left arm and left side and of course it affects my neck and shoulder as well' (Paula: 1. 17-19).

Will indicated that his pain was spreading and no one seemed to be able to help him. He referred to the amount of medication that was required to manage the pain and this worried him:

'Nobody seems to be able to do anything about it now it has gone too far. I have this arthritis and that is probably the cause of my shoulders and all that. All I do is take the tablets; I take loads of tablets' (Will.5. 20-22).

Don talked about his painful body orchestrating his actions:

'Because as I said to him through the day now it is not too bad I can cope with it but by 6 o'clock I am in no man's land. I know whatever I have done, walked or helped my wife in the house, and in fairness I do not do that much because of the discomfort I am in. But whatever I have done or if I have walked

down to my daughter's it is like the time of day it says your body has had enough and the pain increases'(Don: 5. 10-15).

6.4.2f Emotional responses

The participants continued to express their pain experiences primarily in terms of the physicality of the conditions and associated immobility, but as in the previous interviews, they were increasingly willing to talk about their emotional responses to their pain and the consequences of these emotional responses. The participants referred to depression, anger and anxiety:

Paula initially presented a brave face:

'I do not get really depressed and cry and things like that. I do not do any of that, but I do not feel like going out some days, cannot be bothered' (Paula: 4. 18-19).

However, a little later on in the interview she admitted she did feel depressed at times:

'I must admit I do get fed up and depressed a bit, but I do not sit and cry and mope and things like that' (Paula: 4. 22-23).

Don reported how on bad days he became angry and this anger was projected towards his wife:

'The very bad days are getting worse' (Don: 3. 4).

'On occasions when the pain is worse you do snap and bite at people. I can be very sharp my wife will tell you that' (Don: 7. 23-25).

He also commented:

'Me and my wife have quarrels, like, something happened yesterday, something about 10 years time, And I said, the way I am I said I do not want to be here in 10 years time'(Don: 3. 15-17).

Interviewer: 'How did she respond to that?'

'As you can imagine there was a big bust up and she referred to me talking stupid as I have got to think not only of her I have grandchildren and children, what about them'(Don: 3. 21-22).

Cara spoke of the continual pain and her concomitant misery:

‘When you are in pain you are miserable really. Most mornings I get difficulty in getting out of bed. I have not gone back to work’ (Cara: 2. 33-34).

Will spoke of having to carry on despite his feelings:

‘Say I feel really down I do, but I have to carry on’ (Will: 2. 28).

6.4.2g Improved emotional experiences

In contrast to the other participants, Sara had been prescribed new medication by her new G.P that had been controlling the pain far better than previously. Sara also showed a more positive outlook for her future than in the previous interviews and hoped to regain her previous life:

‘Yes, the medication I am on is helping in that respect. I am hoping that when I see the psychiatrist and go back to the Pain Clinic I can get further along with my life, try and get it back to what it was’(Sara:5. 23-25).

Sara increasingly acknowledged that her feelings of depression and anxiety rather than the pain interfered with her lifestyle, but she continued to be reluctant to participate in social activities or even leave the house. However, she acknowledged that it was her depression rather than the pain that had been contributing to agoraphobic behaviours:

‘Occasionally a close friend will come and visit me but I still cannot get over getting back into going out. That could possibly be more to do with my nerves and my depression I suppose, now that the pain is being controlled at least for now. I do not like it, I still cannot face that’ (Sara: 4. 24-27).

Similarly, Sian had recently been prescribed amitriptyline and referred to improvements in her feelings of well-being. Sian had previously underplayed any depression. She now revealed her depression:

‘... It makes a big difference. It helps with the depression because the pain gets you down and I have been a lot better and I am sleeping better’ (Sian: 2. 1-3).

6.4.2h Theme summary

The participants' pain experiences continued to be dominated by the physical pain. The pain was depicted as a threat to mobility and functioning. However, there were an increasing number of spontaneous references to emotions such as depression, anger and anxiety.

Only Sara reported significantly less pain that was accompanied by an improvement in her mood and general well-being. Sara had also become increasingly aware of the role of depression and anxiety in her agoraphobic behaviours.

6.4.3 The effects of a period of painlessness

Two of the original three participants who had previously reported a period of painlessness continued to reflect upon how the treatments had had a positive effect on their mood (Doris was unavailable due to personal reasons).

6.4.3a Treatment, personality and mood

Eirlys referred to how a second but incomplete set of acupuncture treatments at the chronic pain clinic had improved her pain temporarily and lifted her mood. The perceived discrepancy between her past and present self that she had previously expressed as contributing to depression was diminished for a short while as acupuncture had helped with her mobility and sense of well-being. There was also a realisation that her previous self was still accessible:

‘Yes emotionally. I think why it gives you a lift is because it takes the edge off your pain, you are able to do things that you could not do before. Therefore that is what gives you the lift. You think I can still do these things, if I did not have a bad hip and bad knee and all this pain I could do all these things and therefore you feel better’ (Eirlys: 3.11-15).

Eirlys spoke of acupuncture helping her with her emotional state. She attributed her present emotional state to the pain:

‘When I went up there initially I used to get very emotional because of the pain and she did give me some acupuncture which was for emotions anyway. She was excellent really. I found her very good’ (Eirlys: 2. 1-3).

Cara had previously received an epidural injection that had improved her daily functioning. She continued to reflect upon how a lack of pain had highlighted the severe effects of the pain on her daily life and her personality:

‘Elated. Strange really I was doing little things, after the first couple of days, when you were in pain from the procedure, you could get out of bed with no pain, I could walk, I could bend, I could put on my socks without struggling, you know little things like that. It was brilliant it really was, I felt on top of the world. It changes your whole personality’ (Cara: 2.10-14).

Sara had recently been experiencing frighteningly, depressing thoughts that had motivated her to change her doctor who had prescribed new medication and had referred her to a psychiatrist for assessment:

‘I started to have really frightening sort of feelings. I have just battled on and then when I went to the new General Practitioner surgery and explained a bit about it he said that I really needed to be referred back’ (Sara: 3.34-35, 4.1-2).

This new medication had enabled her to have far less pain and on occasions no pain. She was able to regain some mobility and recognised a return of some elements of her “old self”. She recognised that she would not entirely return to her previous self, but the discrepancy between her old self and present self was now perceived as being less. One of her previously reported concerns was her increasing dependency on her family. She was hoping that she would be less dependent on her family in the future:

‘There are days, as long as I am in the security of my home, I can be quite up, and like I said, I could not manage household tasks before, and now on a good day I can go out and peg the washing out on the line or fetching things in or wash a couple of dishes. I cannot go back to the way I used to clean and tidy and everything and iron. I am hoping it will improve and I will not have to rely on other people so much to do household tasks’ (Sara: 6.10-15).

However, Sara was reluctant to be wholly dependant on medication and recognised that alternative therapies may prove useful for her:

‘I do not really want to go back on the antidepressants if I can help it. If there is some sort of discussion group or something like that where you are talking to people who are in the same circumstances. I am hoping they are going to offer me something like that instead of just giving me medication’ (Sara: 4.11-15).

6.4.3b *Theme summary*

The participants who had previously received treatment and had had a temporary respite from the pain had been reassured that their “previous, fundamental self” was still available and attributed any changes in their personalities to the pain. For Sara, a recent change in medication had facilitated improved pain levels and had contributed towards improving her sense of well-being and a wider consideration of managing her CLBP.

6.4.4 **Loss of social roles**

As in the previous interviews, there was a sense of loss as participants reported missing valued activities.

6.4.4a *Loss of social life: then and now*

‘I cannot do what I should do. I used to play bowls, I used to be good at that and played for Wales and all but I have been unable to play for 3 years’(Will:3.11-12).

Eirlys previously enjoyed shopping trips that was an activity she had enjoyed in the past:

‘Not being able to do things and go places. My husband says lets go shopping. I would like to go to Ikea but I just cannot do it now. Hopefully after I have had my hip done things will be better’ (Eirlys: 2.26-28).

Don compared his previous working life with his present life that he considered to be rather aimless:

‘I have always worked 6 to 7 days a week and that goes with the job like a lot of other people, but over the first couple of years you are just reading books, scratching your head, my daughter bought a load of jigsaws and things for me’ (Don: 9. 4-7).

6.4.4b *Loss of family roles*

Paul talked about how the pain had affected his roles as a husband and family member. He felt embarrassed about his inability to help his wife:

‘It affects every part of your life and it affects all the family. It affects your sex life it affects every part of your life. I tell you what gets to me most is when I see my wife carrying the black bags out and I cannot do it, I go upstairs out of the way’(Paul:3. 21-23).

Similarly Don referred to an increasing dependence on his wife for assistance with essential personal tasks. He had become the dependant one:

‘I feel a burden on my wife sometimes when she has to do those things for me’ (Don: 13. 4-5).

As reported during the first interviews, the pain was an unpredictable experience that deterred the participants from participating in shared activities with their spouses. Eirlys indicated that the pain had undermined her self-confidence and mood:

‘We went into Marks & Spencer about three weeks ago, he had gone over there and I reached over to look at a T-shirt and my hip went and I thought I was going to pass out and I will have to scream. The pain was dreadful, where is he, I could not hold onto anything I should have had my stick with me. If I had had my stick I could have moved, but I could not move because I had nothing to hold onto. I said to him come on let’s go back home. Then I came back home. So I do not go out. It does get you down’ (Eirlys: 5.9-15).

Sian suggested her role as a housewife was impaired considerably by the pain and associated immobility. The importance of this is demonstrated by her comparison between good days and bad days:

‘It is nice to think that you can stand and clean something or do a bit of ironing because other times you cannot. I cannot sit and iron. When you have achieved that it is lovely’ (Sian: 3. 15-17).

6.4.4c *A new social role*

Whilst Cara reported impaired family roles and continued pain (she had previously experienced a period of painless), she had also developed a new, valued family role. Her daughter was complaining of similar symptoms and Cara acted as her mentor:

‘Because my daughter is suffering the same problem, she is still in the early days and it is having a bad effect on her mentally because she does not know how she is going to be from one day to the next. When she is having a good day she tends to do too much. I have been there, done it and bought the T-shirt. So I am trying to tell her, just because you are having a good day does not mean that you can clean from top to bottom or whatever’ (Cara: 7. 18-23).

Cara and her daughter were mutually supportive:

‘We compare notes. One thing that she said and it is so true, about her husband, he asks, ‘are you all right?’ She doesn’t tell him anything much, what is the point. Then they tend not to ask you, they assume because you are doing something you are OK and that does bear down on you, it is hard. It is as if they do not care she says. I know exactly how she feels, that is why she rings me and comes over’ (Cara: 4. 3-7).

Cara also retained some hope for the future. Whilst Cara recognised that full-time work was not possible for her, she was still hopeful that she could return to work:

‘As to the future, I do not know. Our lives are going to change dramatically with her coming here what the future holds for me I do not know. Possibly I might go back to work, but I would not go back full time. I just could not do it’ (Cara: 7. 31-33).

6.4.4d *Theme summary*

There was a recall of loss of a past life that was contrasted favourably with the participants’ present lives. The disabling consequences of the pain adversely affected the participants’ abilities to continue with valued activities and fulfil their family role. In comparison, Cara had adopted a new, valued role and looked to the future in a more positive fashion.

6.4.5 Managing the pain

Medication remained the main way of managing the pain despite its perceived inefficacy and adverse side-effects. However, medication took the edge off the pain.

6.4.5a *The relationship with medication*

‘I am seeing Dr X next week and he will probably he will take me off it, I do not know how I am going to cope without a pain killer’ (Sian: 1. 6-8)

‘When I am really in pain the only thing that works is diazepam’ (Paul: 2. 30).

‘That’s all I do is take loads and loads of tablets. I do not like taking them; I try and avoid taking them. I have got rid of a few’ (Will: 5. 21-22. 26).

‘They have changed my painkillers to see if one would help more than the other but whatever one they seem to prescribe it is the same thing. Perhaps I am expecting too much from the medication, I do not know’ (Don: 11. 1-3).

‘Like I said it’s there all the time it never goes away. You can take the edge off it when you take your tablets. Then the space between the tablets gets less and less because your system gets used to them (Eirlys: 7. 10-11).

Paula reported extreme pain accompanied by feelings of helplessness. The medication helped but was often slow to have effect and the relief was partial.

‘I do not know what to do with myself to be truthful. If I take two paracetamol, say if I get in the car to come home from wherever I am it can take me miles before the pain goes when with Co-proxamol it would take effect much quicker’ (Paula: 6-11).

6.4.5b *Medication and its side effects*

Most of the participants were prepared to endure the side-effects of their medication to gain some benefit:

Cara had stopped taking most of her pain killers due to their adverse side effects. She subsequently took amitriptyline that also made her drowsy in the day but facilitated a good night’s sleep:

‘Amytriptyline is not very nice it makes you feel groggy but I have got used to them and it helps me sleep’ (Cara: 5. 29-30).

Eirlys endured the side effects so as to gain some pain relief:

‘You tend to have terrible bad stomachs and problems because of the tablets I am taking. But that is not too bad’ (Eirlys: 6. 1-2).

Will spoke of the side-effects that were causing him as much trouble as other painful symptoms:

‘This rash is terrible; it is itching all the time. I have tablets and cream to rub in every night all over. It does not seem to be working. I have to see him now middle of April about this rash’ (Will: 2. 28-30).

6.4.5c *Learning to live with the pain*

Participants had learned to adopt personal coping strategies as an adjunct to medication. These predominantly mentioned behavioural focused strategies were avoidance behaviours, adjusting ones position, exercise and pacing oneself. As previously the participants talked about learning to live with their pain.

‘The only thing I can actually say to you, you learn to live with the pain’ (Don: 7. 19).

6.4.5.d *Behavioural focused coping strategies*

Most had learned to lower their expectations about their abilities and participated only in activities that caused the least pain. For the most part, these were deliberate attempts, learned through a process of trial and error, for example, “learning one’s limits”. This theme was mentioned previously, but had been foreground again during this set of interviews.

6.4.5.e *avoidance behaviours*

Cara talked about avoiding activities that caused pain:

'Not to do gardening, which I love. You learn to live with what you can and cannot do. I know what will cause me problems, so you do not do it. Hoovering, shopping and pushing a trolley are not on' (Cara: 3.25 - 27).

Eirlys talked about avoiding previously enjoyed activities:

'I could go (bingo) but I do not want to go because I have to keep moving my knee and find a different position to put myself in. If you put in the same position for too long you cannot move' (Eirlys: 10.2- 4).

Paul talked about not being able to go to the theatre:

'I used to like to go to the theatre and see plays. The last time I went I sat there for ten minutes but I could not get comfortable and I spent most of the time outside. I cannot have a social life' (Paul: 8. 21-23).

6.4.5.f Adopting bodily postures

A lack of spontaneity and mobility had been discussed in the previous chapter with reference to the painful body emerging into daily consciousnesses. There continued to be reference to the body as a vehicle of pain but it was also used to relieve pain.

Don described how he had learned to adjust his position so as to participate in a distracting activity:

'My daughter bought a load of jigsaws and things for me, there is a jigsaw under the settee by there, but I have to do it on the floor because I cannot sit down and do them anymore' (Don: 9. 6-8).

Sara referred to the difficulty of performing the most mundane activities and learned to adjust her seating position to alleviate the pain:

'Getting in and out of bed is still very difficult and there is no way I can throw the duvet over and tidy it up you know. To try and do that it pulls on my back. I am all right if I have not been sitting down for hours but if I have sat down like in the night and watch television to try and get up from the seat then it is difficult. I use cushions' (Sara: 7. 2-7).

6.4.5.g Exercise

Paula explained how exercise helped both with stiffness and her mood. Her husband encouraged her:

'My husband says come on you have got to get out, you have got to get exercise because you get stiff. I mean some days we only go down X and walk through and come back home, but it is just getting out. Then you do not get so depressed' (Paula: 4.19-22).

Paul explained what he meant by "practising his leg". He described a ritual of simple exercise that was often unobtainable and demonstrates the effects of the pain on his mobility. He sounds despairing as he indicates that he couldn't complete even a short walk:

'I make myself go. The first thing I do is put my coat on and practice my leg, that is what I call it, I walk up and down the street three times and then when I get to the end I go and cannot make it back, I cannot make it back' (Paul: 7. 25-27).

6.4.5h Pacing

Pacing oneself was mentioned by nearly all the participants as enabling them to participate in daily tasks and avoid painful consequences. Pacing meant recognising one's limits and pausing in tasks and assessing ones ability prior to proceeding. Sian related how she paced herself, but if she did too much she "paid for it" the next day.

'I do a bit and then sit down. I have been doing a little bit more, but if I go mad, the next day I am not good for nothing'. I do feel better on Amitriptyline' (Sian: 2. 24-25).

Cara indicated that housework was difficult to do but she too had learned to pace herself:

'All aspects of housework have an effect on me, but you have to take your time' (Cara: 6.21).

Eirlys could manage on holiday as long a she had a rest:

'As long as we go and just have a little walk down the front and a sit down and have a coffee and a little walk again and then a coffee I can cope'.(Eirlys:10. 5-6).

6.4.5i *Cognitive focused coping strategies*

There was also mention of more cognitive focused coping strategies. Two of the participants who had experienced a pain free period spoke of distraction.

6.4.5j *Distraction*

Distraction is illustrated in the following quote. Eirlys was unable to garden anymore but she realised the importance of developing other distracting activities:

‘I suppose it is. I write a little column for the local paper; only X News and I do that on the internet and email it to them. That is something I sit down and do. Anything that you are involved with takes your mind off your pain. If you sit down and think about your pain, obviously it is worse I will admit’ (Eirlys: 4. 20 -23).

Cara had also had to stop her much loved gardening, however she talked about her role as a grandmother that was valued and distracted her from her own problems:

‘Yes. Trying to get something to occupy your mind helps’ (Cara: 6.20).

Cara explained how her granddaughter distracted her:

‘The baby has been a help, she is wonderful to me she lifts your mood. It is wonderful to see her and she is such a sweet little thing, she really is I adore her’ (Cara: 3. 31-33).

However, Will was able to pass the time in various ways but was severely limited in what he could do. There was a sense of Will having to fill time:

‘Do a bit of gardening, walk up the mountain and watch television. That’s all it is really I sit here and watch the people go by’ (Will:4. 14-15).

Eirlys similarly spoke of her perceived aimlessness:

‘All my time is spare really. I do sit here and make some cards which take my mind off things’ (Eirlys: 4.14-16).

6.4.5k *Theme summary*

The participants continued to depend on medication accompanied by a combination of personally devised physical and cognitive strategies. The participants spoke of learning to live with the pain by accepting one's limitations, using different method of distraction, adjusting ones physical position and pacing one's activities.

6.4.6 Losing faith in the health professionals/organisation of services

Participants' relationship with the health professionals was a strong theme with participants losing faith in medical treatments and the organisation of their care.

6.4.6a *Losing faith in the health professionals*

Some participants continued to lost faith in their doctor's ability to deal with CLBP. The range of treatments offered by General Practitioners (GPs) in particular was often limited to medication and injections. For example, Eirlys and Sara both reported dissatisfaction with the General Practitioner's knowledge and understanding about the treatment of pain:

'Other than that, I am on the same medication. I do not bother to go to the doctor because I do not find they are very helpful when it comes to pain' (Eirlys: 1.25- 26).

Sara had changed her G.P because they did not show understanding and they were not legitimising her problems. She had to insist on being referred back to the pain clinic:

'Also they would just keep on trying to tell me "get on with it" like, you are on medication and you should be better than what you are. When I explained that I wasn't and I wanted to be referred back to the Pain Clinic and I also felt that I needed to be referred back to the psychiatric doctor, but they just had this vacant look and they were not really looking at you, there was no eye contact when you went to see the doctor' (Sara: 2.28-33).

Cara suggested that even in the pain clinic the doctors were mainly interested in medical interventions:

'The General Practitioner is unable to help, they do not know a lot about it that is why I was referred to the Pain Clinic. They are most interested really in giving you the injections' (Cara: 4. 29-31).

She also spoke of her disappointment with the lack of medication offered at the pain clinic, but she inferred that perhaps she was expecting too much as she had tried everything:

'I know they say they are the pain specialists, but I was not offered any pain control medication. I have tried everything anyway, Diclofenac was very good but I cannot take that orally so I have to have Diclofenac suppositories which are brilliant after the operations I have had. I do not take anything other than Amitriptyline' (Cara: 5. 12-16).

Don suggested he had not expected treatment at the pain clinic to work and it did not work. This expectation was based upon previous experiences, was a recurring pattern for him and reinforced his lack of faith in medical treatments:

'After the first time of going to theatre when they put the injections in and they did not work, they said they would review in so and so time. I am just assuming now this is just a follow up. To me, I do not know about others, but to me it is not good at all' (Don: 1. 21-24).

Conversely, whilst Don had lost faith in the medical model he was reluctant to consider any alternative therapy:

'I am not as qualified as some of these people, but I believe they talk garbage sometimes. Because if in the instance they believe that it is all in the mind why is another doctor prescribing you medication and if some doctor says it is mind over matter sort of thing then there is a possibility in my eyes that I can see an hypnotist and do it that way, but that is not the case, because if that is the case then the NHS would not have the pain clinic with regard to having injections and patches they would have you see a hypnotist. In that sense where these certain doctors and professors whatever they want to call themselves says it is mind over matter I say no' (Don: 11.17-25).

Paul indicated he was wary of medical treatments. He recalled being offered medication indiscriminately and this had resulted in him experiencing adverse side effects. Paul would rather be in pain than in a drug induced state of inertia:

'I remember once I was in hospital and I was given Hydrochloride and I was in space. I said what did you give me, and I said who told you to. I did not know

anything; I said you should not have given me a tablet I have never tried before. To be in that state all the time would I was in space I would not like to live my life like that' (Paul: 5. 27-31).

In a similar fashion to Don, whilst Paul espoused a loss of faith in doctors, he was reluctant to completely reject their views; Paul fleetingly considered holistic treatments such as acupuncture:

'The woman across the road was asking about acupuncture. I said a lot of doctors pooh, pooh it' (Paul: 4.19-20).

Paul also continued to view his condition within the framework of a biomedical model. Paul rejected other non medical therapies. He had been referred by the pain clinic doctor to a pain centre that offered therapeutic discussion sessions:

'Like I told you on the phone, I think it is held in the village of X. If it is a village hall where you go and have a cup of tea and talk about pain, what is the point? I can hardly sit here and talk to you' (Paul: 2.3-6).

6.4.6b *Searching for an explanation*

The participants lacked a coherent understanding of their pain. Don described a lack of consensus between the doctors about his diagnosis and a lack of a clear explanation. Two doctors had given Don different opinions and he questioned the doctors' integrity:

'The reason I say that is because either the one doctor just looked at the scan or he did not look at the scan and I cannot say that because there is no way of proving it but how I can I say to one doctor you have seen them and yet he had not and yet they are both reading the same scan' (Don: 4. 29-32).

After many years of being assessed Paul was still unclear about the cause of his ongoing pain. Paul searched for an explanation. There was a moral justification present as Paul spoke of his undeserved pain:

The thing is I have not eaten anything. Because some people suggest that it is what you eat' (Paul: 4. 6-7).

Cara would like some explanation about the injections she had received:

'General contact would be nice, someone you can ask about things. With regard to the last injection a) they do not know how these injections worked b) if I wanted further injections. They do not know what has been happening and what effect they have had on me' (Cara: 6. 30-34).

6.4.6c Perceptions of support from health professionals

The relationship with the health professionals was complex. When treatment had had some success or when doctors were in agreement with the participants, they were looked upon favourably and were an important source of support.

In comparison to her previous doctors, Sara's new doctors affirmed her complaints. Sara referred to her new doctors in a positive light as they supported her requests for medication:

'He asked if I had enough Dihydrocodeine to try and combat it over the weekend' (Sara: 2. 12-13).

'The old doctors, when I went to explain to my doctor that I had not gone back for the treatment in the Pain Clinic, I asked the doctor if he could refer me back and he just looked at me and did not give me an answer (Sara : 2. 26-28).

Sian viewed her G.Ps' as supportive as they managed her most recently diagnosed medical condition:

'Marvellous with me, fair play. I cannot fault anybody. Since I have developed this lupus, my blood pressure has gone sky high, so I am back and forth to the doctor, but they have been brilliant with me'(Sian:4.25-27).

Another participant valued advice offered by the physiotherapist at the pain clinic:

'Then I said to her if you were me would you have this operation, obviously it is a big operation of the back they were going to put a rod in and so on. Put it this way she said, 'if I was pain free I would not have it' (Eirlys: 6.7- 9).

Eirlys had a good relationship with the physiotherapist who she thought understood her CLBP:

'The acupuncture and she was lovely which makes a bit difference, if it is someone you bond it makes a big difference, doesn't it' (Eirlys: 4. 2-3).

Paul had received a clear message from the surgeon:

When I met that surgeon the way he spoke to me and the way he explained to me I knew from that time on I would be like this for the rest of my life. I had faith in that fellow' (Paul: 6. 33-35).

In comparison, Paul also experienced scepticism:

'When I saw X in X he asked why I had stopped going for physiotherapy. He looked at me in disgrace. He went down and had a private discussion with her. I could see he thought I was telling lies and he wrote something down' (Paul: 5. 12-15).

The lives of the participants continued to be dominated by waiting for hospital appointments, for further appointments at the pain clinic or other illness related appointments.

6.4.6d *Losing faith in the organisation of services: A waiting game*

The participants were in an almost permanent state of indeterminacy and may be regarded as patients "in-waiting".

Will was used to the delays and open-endedness of the arrangements:

'I was supposed to see him in February but it was cancelled, so God knows when I will see him now' (Will: 1. 8-9).

Sara waited for a psychiatric referral and Eirlys continued to wait for a hip operation. Eirlys as with the other participants told of waiting for scan results that would inform further treatments:

'Which could have taken place but they had not had the MRI scan result for my back which I had done 2 weeks previously. So Mr X would not do my hip in case he did more damage to my spine' (Eirlys: 1. 8-11).

Don was waiting for a possible operation:

' I was expecting to see this Mr X yesterday and he was just going to suggest another path for me to go down, but in saying that he looked at my chart and said you have a scan and went to read it and came back saying there are abnormalities on it. Then he suggested an operation without diagnosing me, he

cannot diagnose me until he opens me up again to see what these abnormalities are' (Don: 5. 2-7).

There were perceptions of being passed on in the health services.

'I have lost a bit of faith in Mr X now as if he said to me he is another customer let him go away and shunt him off sort of thing, that is what I feel he has done, because he passed me on to someone else' (Don: 4.35, 5.1-2).

Paul commented that he had lost faith in the health service; he had been referred from the pain clinic to a pain management centre for assessment. He expressed his lack of hope in the usefulness of any further assessment and was not going to attend:

'They would leave it open for us to ring for an appointment, but I have not bothered. The thing is I have been like this for so many years and they have arranged for an assessment on me. I think I have had enough assessments' (Paul: 2.1-3).

6.4.6e *Theme summary*

The relationship with the health professionals and the participants' experiences with the health services continued to be a central theme. There was interminable waiting and expressed loss of faith in the health professionals' knowledge about CLBP as any adequate and lasting pain relief was not forthcoming. The participants were continually searching for an explanation for the unrelieved pain and could not make sense of their situation. Whilst there was a loss of faith in the health professionals there was also a coexisting hope that future possible operations and diagnostic tools such as scans would help them.

When the doctors and the participants were in agreement the doctors were viewed in a positive light and perceived as an important source of support for the participants.

6.5 DISCUSSION OF THEMES

The following discussion focuses upon the super-ordinate themes elicited from the data. The themes: maintaining integrity, the essence of the pain, managing the pain, loss of social roles, relationships with the health professionals and organisation of

services are discussed followed by an overall discussion that relates the present findings to the previous study.

6.5.1 Maintaining integrity

The participants' immediate responses focused upon how they endured the ongoing pain, arduous treatments and being compliant even when faced with ineffective treatments and disorganised medical care. The participants rhetoric was concerned with "heroically doing the best they could" in light of the often worsening pain and the continued lack of a coherent explanation for the pain. Whilst the participants' accounting may be interpreted as having an overt function, that is, they were reporting their experiences as patients in the health care system there was also a covert function, that is, they were rhetorically positioning themselves as patients who were making strenuous attempts to get better that is consistent with the social norms proposed within the sick role (Parsons, 1951). However, as suggested in chapters one and two, CLBP does not fit into the sick role easily; in many cases CLBP is invisible, indeterminate and incurable that lends sufferers vulnerable to accusations of malingering (see Chapter4). The participants' accounts showed they experienced scepticism, a lack of understanding and legitimisation by health professionals that undermined their claims to the sick role. Thus the participants' emphasis upon enduring the different treatments and services may be viewed as a continued moral endeavour to legitimize their sick role and maintain integrity of self (Kugelman, 1999). The data support the work of Charmaz, (1983) who proposed that, "those with chronic illness are vulnerable to being discredited in a number of situations but especially when the person is unacknowledged as a bona fide sick person by significant others such as health professionals" (p.184).

Overall, the participants were investing in "heroic" accounts by stressing their endurance and fortitude. This discourse enabled the participants to present a moral account of themselves against a background of felt stigma and showed that the meaning of the CLBP for them included having to maintain a moral identity and manage interactions with others.

6.5.2 Essential nature of the pain

The participants' accounts indicated that the level of pain had become worse for some, for others it had remained the same and had improved for one participant. However, none of the participants spoke of the pain being eliminated entirely. The participants continued to report the pain in terms of its physicality and in relation to a growing lack of mobility, dependency and the associated challenges to every day living. The pain and associated symptoms such as stiffness and interrupted sleep meant that even the most basic tasks and activities were carried out with difficulty. The pain was intrusive and referred to in terms of good days, bad days and very bad days and for some participants the very bad days were reported as increasing in frequency and intensity.

It is likely that the pain was maintained in a number of ways. From a biological perspective it is likely that the participants were experiencing neuropathic pain caused by nerve damage that is irreversible and may have caused permanent damage (Welsh Assembly Government, 2008). The participants' accounts also supported a behavioural perspective, that is, it was also likely the pain was maintained by external reinforcement contingencies that in turn propagated secondary muscle hypertension. As discussed below the participants "lived around their pain" and avoided pain provoking or embarrassing situations. Their reduction in pain and social discomfort therefore acted as a reinforcement that was useful in the short term but may have incurred both mental and physical deconditioning in the long term (Norton and Armundson, 2003; Vlaeyen et al. 1995; Linton, 1985; Bortz, 1984). From a cognitive perspective, it is proposed that fear avoidance beliefs, that is, a belief that certain activities promote pain and should be avoided also underlined participants' behaviours. This promoted a preoccupation with the physical pain and a sense of helplessness that has been shown to be predictive of increasing disability (Waddell, 1992).

A metaphorical analysis of the data showed that the pain continued to be depicted in terms of an external threat. The data illustrated the participant's attempts to distance their valued selves from the pain. This had previously been referred to as a dualism of self or a mind-body split and viewed as a sub-conscious, protective device (See: Chapters. 4 & 5 and Osborn and Smith, 2006). It is proposed that these depictions of pain continued to reflect the relationship between the participant and

their CLBP as one of a psychological battle rather than any acceptance or engagement with the pain as described by ((McCracken and Vowles, 2006; McCracken and Eccleston, 2003; McCracken, 1998, McCracken et al. 1999). (Acceptance is formulated as individuals carrying out activities despite the pain, accepting that trying to control the pain does not work and engaging in positive adaptive behaviours rather than struggling with the pain). The pain was the main protagonist in all the participants' lives and the participants struggled to maintain control. There was a growing sense of helplessness as the pain was observed as spreading in an uncontrollable fashion to different body parts with the participants attempting to avoid confrontation of the pain by living around their pain.

The internal representation of the pain as an external object and distinct from a valued sense of self was also noted in an analysis of the narratives of patients with non-specific CLBP (Osborn and Smith, 2006) and was conjectured to be unhelpful in any successful adaptation to CLBP (for a full discussion in relation to the participants in this project see Chapter 4). A recent phenomenological and metaphorical analysis of patients' experiences of Lupus similarly concluded that the patients' relationship with their illness, that is, the internal representation of the illness as an object influenced their affective state and patterns of coping (Schattner Shahar and, Mahmould 2008). In comparison, whilst the present data show that the participants particular relationship with the pain was a coping strategy in itself, their accounts also illustrated that their coping patterns varied according to the sufferer's relations with their CLBP. As suggested above, those participants who predominantly expressed their relationship with their pain in terms of an external threat were also those who showed little acceptance and engagement with the pain. Whereas, those who tended not to depict their pain so strongly in this fashion were viewed as moving towards engagement and acceptance of their pain (see below for further discussion about these emerging differences).

Participants prefaced the physical symptoms and consequences of their CLBP but also spoke of negative toned emotional responses and interpersonal disruption that supports previous findings (Sofaer-Bennett et al. 2007; Walker, Sofaer, and Holloway 2006). Emotional responses were expressed as depression, feeling down, misery, anger and anxiety about the future. For example, Don spoke about how he projected his anger onto his wife and Paul expressed his frustration and guilt about not being able to help his wife with the most basic household chores. These low

feelings came to the fore when the participants discussed bad days or very painful and disturbing episodes but they could also be a background presence and only mentioned upon further consideration by the participants.

However, in comparison to the other participants, Sara experienced improved pain levels and demonstrated a growing recognition of the influence of her lowered mood on her life style. She recognised that it was her mood status rather than the pain that was having such an adverse effect on her life. As with the participants who had experienced painlessness previously the improved pain experience had enabled the focus of her concern to shift from the medication and physical symptoms to her psychological status. Sara showed a move towards a biopsychosocial understanding of her CLBP and referred to her wish to attend a “talking based therapy” group as she recognised that many of her problems were linked to her psychological responses rather than the pain itself.

6.5.3 The effects of a period of painlessness

The participants who had experienced painlessness in study two referred to personality changes since the onset of the pain. This indicates support for the view that chronic pain is a determinant of personality changes rather than personality dispositions predisposing maladaptive responses to chronic pain (Gatchel, 1991). Whilst the inefficacy of the medical treatments has been an enduring theme, paradoxically, the subsequent pain relief attributed to the physical treatments had enabled the participants to get in touch with their former selves and recognise the changes in their personalities and functioning since the onset of the pain. For Cara, Eirlys and Sara in particular, the idea of a core personality or former self being retained but masked by the pain offered them relief and facilitated a ‘hope-full self’ rather a “feared-for self” (Morley, Davies, and Barton 2005). In comparison to many of the other participants, there were expressions of hope such as “becoming in some way normal again” or participating in some part-time work. For Sara and Cara, this was accompanied by developing their self-management strategies, accompanied by an increasing awareness of the influence of their mood on the pain and a loss of faith in many of the medical treatments (see below for further discussion). The realisation that medicine can only do so much has been described as a turning point in self-management and part of a process of working through loss and associated grief

towards acceptance of one's chronicity and finding a new normality (Shariff, Carter, Dow, Piloey, Salinas, and Ridge 2009). In comparison, the remaining participants had also lost faith in medication but they had not developed alternative ways of managing the pain.

6.5.4 Loss of social roles

Reports of loss were centred on loss of a previous, active life and a loss of family roles. The participants made sharp contrasts between their previous, valued, busy working lives and their presently perceived aimless lives. Self-esteem and self-efficacy may be adversely affected by CLBP and these reported losses illumine the wider challenges of CLBP and undermines a narrow medicalized view of suffering (WAG, 2008; Gordon and Benishek, 1996; Charmaz, 1983).

Bereavement following a death may be a very different experience to having to deal with the losses incurred by CLBP. However, coping with the loss of family roles and loss of a previous active, independent self promoted emotional responses similar to those seen in bereavement. In addition, the data showed that many of the participants had not developed any valued activities or social roles to substitute for the loss of those valued activities that was reminiscent of a sustained grief response (Stroebe and Schut, 1999). There was distress from loss in every area of their lives in addition to anticipated grief for a future that now had to be re-drawn. The data highlighted the gap between the participants' perceptions of their "present self" their previous selves and ought selves that endorses the work of Higgins, (1987) but also the notion of the participants grappling with multiple selves.

In contrast, Cara had developed a new valued role by becoming a mentor to her daughter that offered a distraction and a new valued family role that is viewed as an adaptive way of coping with loss (Charmaz, 1983).

6.5.5 Managing the pain

All participants' reported medication as the main method of relieving pain. In addition, a predominance of physically focused self-management strategies were used such as adopting pain relieving body postures and pacing and avoidance behaviours that meant generally living around the pain ((Borkan et al. 1995).

Distraction was also mentioned but the adoption of mainly physical strategies is consonant with a biomedical approach to CLBP where there is little consideration of cognitive influences. The rationale for making the distinction between physical and cognitive focused strategies has been made previously in Chapter 3 with the default implication being that physical strategies involve little cognition. However, most behaviour involves some thought and in this study the participants did speak of tailoring their medication (that may be considered as a physical-coping strategy) to suit their own needs that demonstrated some consideration rather than autonomous and unthinking actions. For example, the medication could be over administered on bad days but stopped as the side-effects worsened and became more troublesome than the pain itself. However, the prescribed medication continued to be the main method of attempting to control the pain but with various reports of success and with many of the participants suggesting it had very little effect on their pain.

In contrast, some medication had worked well. Amitriptyline was newly described for Sian who found that it helped her mood. In support of this, a review of the use of Amitriptyline as both an antidepressant and as a treatment for neuropathic pain showed at least one third of patients who take this or similar antidepressants have moderate pain relief or better (Saarto and Wiffen, 2007). Sara had been prescribed Fentanyl patches that had alleviated some of the pain. These medications were at least partly successful and these findings may be contrasted with commentary referring to the weakness of the medical model with prescribed medication alone being reported as having limited efficacy for chronic pain (Waddell, 1992).

Interestingly, all the participants continued to refer to controlling the pain by using one's body or adjusting one's body to minimise any pain that was accompanied by lowering one's expectations of what one could and could not do (Charmaz, 1983). The physical limitations imposed by the pain meant that even basic postures such as sitting or getting up from a seating position required deliberate bodily strategies to be enforced. Ultimately, this often meant an increased dependency on others and avoiding valued activities that in turn continued to reinforce a lowered self esteem and contributed to feelings of passing time.

Pacing was also mentioned in relation to managing activity levels and flattening out the over/under cycle of activity referred to by some participants. The participants had learned when they were about to reach their limits and planned their

activities accordingly. It is possible that this strategy may have the effect of winding down the wind up control trigger described in relation to chronic pain in The Gate-Control theory of pain (Melzack and Wall, 1965, 1982) by avoiding turning on the system so frequently and allowing it to have a chance to reset.

In addition to the more physically orientated coping strategies, the participants' spoke of learning to live with pain that also involved trial and error learning. Most of them used some sort of distractive coping method to deal with the pain. For some participants such as Cara, this meant adopting new hobbies or social roles that offered new distractions and positive affirmation. However, for others such as Will, this often meant adopting activities that were perceived to be a poor substitute for a previous active life and were viewed as "passing time". Distraction was the main cognitive-focused coping strategy mentioned and as suggested in Chapter 3 is thought to modify the interpretation of chronic pain by occupying the mind (Gatchel, 1999).

6.5.6 Losing faith in the health professionals / organisation of services

The most salient issues arising from the participants' interactions with the health professionals in the hospital, the pain clinic and in the GP surgeries were gaining a coherent understanding, waiting for treatments and making decisions about the future. The participants reported a significant loss of faith in the doctor's knowledge of chronic pain and interventions that supports the findings of Walker et al. (1999). The lack of a coherent and consistent explanation about their situation and a frequently expressed lack of recognition of their concerns served to frustrate and in some cases anger the participants with associated feelings of being let down and being of a low priority that were not relieved by their experience of the pain clinic.

Conversely, whilst the participants' faith in the efficacy of the health professionals was diminishing they were also reported as being a source of support at certain times. In particular, Sian reported how her doctor hadn't fully understood her CLBP but, in comparison, had been marvellous when treating co-morbidity with an identifiable cause and treatment. The doctor presumably found a straightforward medical condition easier to treat than the more complex CLBP. The management of recognisable physical symptoms and an identifiable diagnosis may cause less

dilemma and tension for both the physician and the patient when medical professionals work with conditions that sit easily in the medical model.

6.6 OVERALL DISCUSSION

The third interviews took place one year after the second interviews. The participants' experiences were illustrated by super-ordinate themes that continued from study two and illustrate the relatively unchanging experiences of the participants. However, a new theme was also constructed that highlighted the participants' appraisal of a period of painlessness previously reported in study two.

Since the previous interviews, three participants reported worsening pain, one participant reported improved pain levels and mood and another reported improved mood. Despite the continuing and worsening pain for several participants, two continued to adopt coping strategies previously used in studies one and two. However, whilst one of these participants had previously adopted a wider psychosocial perspective in study two, in study three she began to adopt a predominantly biomedical approach previously noted in study one (see below).

The following sections present the continuities and changes in the participants' experiences and the continued, emerging differences in pain experiences within the sample.

6.6.1 Continuities

The participants' accounts continued to reveal shared, multi-dimensional and embodied experiences that were found in the previous two interviews. An empathic and heuristic approach continued that included a focus upon what was said and how it was said, or the participants' rhetorical positioning (Smith, 2004; de Visser and Smith, 2006). From an analysis of the participants "talk" the accounts continued to reveal a moral endeavour against a background of felt scepticism (Kugelmann, 1999). The participants continued to endeavour to establish their claims to the sick role by emphasising their arduous attempts to get better that involved endurance and fortitude in light of ongoing and sometimes worsening CLBP, painful treatments and

the disorganised organisation of their care. These experiences of the organisation of participants' care continued to be a strong theme running through the accounts. In particular, participants indicated they made every effort to be compliant with the requests of the National Health Service (NHS) but were often let down by a disorganized service. The participants' lives remained closely entwined with the health services as they waited for appointments that often led to referrals and further waiting that in turn led to a strong sense of being passed on, and as mentioned in chapter 5, a sense of disempowerment (Walker et al. 1999).

The participants' relationship with the health professionals also continued to be complex with participants talking about a loss of faith in the health professionals as they experienced painful treatments with little successful outcome and a perceived lack of understanding, explanation and scepticism. However, this was accompanied by positive comments when being treated for more straightforward medical conditions that had a definable cause, when treatment for their CLBP had some success or when they were given a clear explanation that was consonant with their own view. Some participants also retained hope in medical or surgical treatments and rejected a consideration of any alternative therapies despite their dissatisfaction. In short, the data continued to show the dominance of the medical model that reflects the power of medical knowledge in our society (Lupton, 1998).

There was some variance in the participants' reported pain levels in comparison to the previous interviews. However, all the participants continued to preface the physicality of the pain and its effects on their mobility and functioning. The pain remained constant and intrusive, with some of the participants reporting an increasing number of bad days with worsening and uncontrollable symptoms that were often unrelieved by medication.

As in study two there was an increasing readiness to talk about emotional experiences; however the references to emotions were similarly offered as an afterthought that may be viewed as a reflection of a continued predominant focus on the painful body and participants' biomechanical beliefs. Their negative-toned emotions often traced their pain experiences, that is, on the good days when they found the pain tolerable, their emotions were manageable and on the bad days when the pain was intolerable, their emotions came to the fore of their consciousness and there was recognition of their emotional state.

The participants expressed depression, guilt, anxiety, anger and “feeling down” in relation to a loss of social roles, increasing dependency and loss of mobility. Loss was discussed in chapters 4 and 5 with reference to the work of Charmaz, (1983) who referred to the “diminished self” resulting in a lowered self-esteem and the theory of self-discrepancy (Higgins, 1987) which proposes a perceived gap between the perceived self and an “ought self” or an “ideal self” and is a determinant of depression in chronic illness. Losses remained a salient feature of the participants’ experiences and were accompanied by strong emotional responses likened to grieving responses (Walker et al. 2007; Walker et al. 2006; Sofaer-Bennett et al. 2007; Roy, 2004; Osborn and Smith, 1998; Charmaz, 1983; Stroebe and Schut, 1999). The present study also indicates that participants struggled to maintain management of multiple selves including loss of a past self and also the fear of loss of a future self or grieving for what has gone and what could have been. As mentioned earlier, the design of the study did not allow for any formal clinical evaluation of depression but some of the participants did refer to subjective evaluations of depression in relation to their feelings of loss.

A fragmentation of self or a mind / body dualism also continued to be present in the form of the pain being narrated as an external threat with metaphorical references to it as a lurking and often uncontrollable presence. This was interpreted in the previous study as a psychological defence against the growing intrusion of the pain on their valued selves and as illustrating little acceptance or engagement of their situation (Osborn and Smith, 2006). The findings from the present study concur with the previous interviews and those of Osborn and Smith, (2006) and Schattner et al. (2009) who further informs us that an internal representation of illnesses influences coping patterns. The present data develops this work by illustrating that the differing and underlying pain beliefs of participants underlie their relationship with their illness (in this case CLBP) and is also a determinant of their relationship with the pain and differences in coping (discussed in detail below). Similarly, the present data shows emerging differences in the data (see below) with participants who evidenced a significant rhetoric about their pain as an external threatening object continued to use a narrow range of coping strategies, whereas those who did not demonstrate such strong rhetoric about their pain showed consideration of a wider repertoire of coping.

Overall, the participants continued to manage their pain with medication. As in the previous interviews there was a dialectical relationship evident with a dislike of dependency, perceived inefficacy and adverse side effects balanced against the medication taking the edge off the pain. Only two participants spoke of medication having a significant and positive effect on their pain and mood (see below for a full discussion). The efficacy of these treatments highlights the notion of a physical treatment facilitating improvements in well-being in the absence of any cognitive based therapy.

The medication was augmented with self-management strategies that served to inhibit the pain for short periods of time but conversely could be maladaptive and contribute towards further mental and physical de-conditioning. The participants' use of predominantly physically-focused coping strategies highlights their continued biomechanical beliefs about their pain with little thought given to the effects of their own beliefs and attitudes towards the pain acting as mediators of their pain. The participants' bodies continue to be visible both as a vehicle of pain but also as a moderator of pain as participants used their bodies to minimize any discomfort. In comparison to previous psychological studies, this study highlights the salience of the body in the pain experience. Similarly pacing served to help the participant avoid flare-ups. Avoidance behaviours also continued to be an established form of coping and as suggested in previous chapters, behavioural avoidance strategies may reinforce further avoidance leading to increasing disability and psychological distress (Norton and Asmundson, 2003; Kerns et al. 2002; Sullivan et al. 2001). Correspondingly, Waddell (1994) suggests the management of CLBP should include developing strategies for overcoming both sensory pain and pain related behaviours that may lead to disability.

6.6.2 Main changes and emerging differences between participants

There continued to be changes and emerging differences in the participants' experiences of CLBP that was initially documented in the second interviews. The participants who had had little opportunity for painlessness and a subsequent reappraisal of their situation continued to predominantly depict the pain as an external, threatening entity that represented a continuing psychological and physical struggle with the pain rather than any acceptance and engagement with the pain. The

perceptions of their ability to take control over the management of their pain remained essentially unchanged and whilst there was a loss of faith in their treatments there was little evidence of any paradigm shift or transition from a biomedical model to a biopsychosocial understanding of their pain. In some cases there was even a refusal to consider any counselling or alternative treatments. There was little consideration of how their psychological responses and their social situations may have mediated their pain experiences and they continued to have a focus on their losses rather than gaining any new distractions or social roles. These participants continued to experience a lowered mood and made few positive personal appraisals about their present lives. It is therefore proposed that these participants' pain and self schemas appear to remain comprehensively enmeshed and "trapping" negative aspects of the self that reiterates the previous data from studies one and two and corresponds with Osborn and Smith's (2006) analysis and the notion of being comprehensively enmeshed (Pincus and Morley, 2001).

These experiences may be compared with those who had experienced painlessness and were considered to be moving towards a biopsychosocial model of understanding of their pain. During the present interviews, those who had experienced periods of painlessness continued to reflect upon the effects of pain on their personalities. The period of painlessness had enabled them to touch base with their previous selves that was referred to as the "real me" and reassured them that their "core" selves and capabilities were intact. This enabled them to consider the possibility that their present selves were an artefact of the pain rather than a permanent change in personality. This was perceived as reassuring as the participants were able to deny a permanent loss of self and a view that if the pain wasn't there they would continue to be their "old selves". This contrasts with research that has indicated acknowledgement of a loss of self is an adaptive turning point in accepting ones condition (Shariff et al. 2009). In comparison, these participants felt encouraged to have access to their 'old selves' alongside a growing acceptance of their pain.

The main turning point occurred during the period of painlessness when there was a realisation that treatments alone could not offer permanent relief and has been conjectured as leading to an increased consideration of psychological responses and social actions influencing their pain experiences. As suggested in the thematic discussion, an awareness of the limitations of medication can be a turning point in self-management and highlights a growing acceptance of one's chronicity that is

accompanied by an increased use of a range of mind-body strategies (Shariff et al. 2009).

The case of Sara is worth mentioning as Sara had been previously regarded in studies one and two as comprehensively enmeshed in her pain with a focus upon the sensory-intensity of her pain, little control over the pain despite a dependency on medication and a strong sense of discrepancy between a previous positively evaluated self and a present negatively evaluated self (Pincus and Morley, 2001). During study three, Sara's reference to improved pain levels due to medication is proposed as enabling her to experience a window of opportunity or psychological space to reassess her position and focus upon her future. This was originally suggested in study two in relation to Eirlys, Cara and Doris and was accompanied by a similar shift towards a biopsychosocial understanding of pain that involved a consideration of alternative coping strategies and a vision of the future rather than a focus on the past. The turning point for Sara had been the pressure of increasing symptoms and perceived inefficacy of her medication that led to her changing her doctor and medication with subsequent painlessness and an opportunity to reassess her own coping strategies.

However, the case of Eirlys highlights the danger of viewing these participants changed experiences as a unidirectional trend or transition from a biomedical understanding towards a biopsychosocial understanding and acceptance. During study two, Eirlys had demonstrated increased self-directed management of her pain, looked to the future in a positive light and appeared less dependant on a medical model. However during the third interview, Eirlys reported worse pain and she appeared less "up-beat" about her ability to distract herself. The worsening pain had rekindled hope in the efficacy of the medical model and she pinned her hopes for relief of her pain on future operations. Whilst Eirlys continued to engage in distracting activities and considered possible future employment, she also spoke of anticipated and worsening losses with less enthusiasm about the future that showed a focus upon loss.

The Dual Process Model of Coping with Bereavement (DPM) (Stroebe and Schut, 1999) may offer further explanation about the participants' fluctuating experiences. The DPM was developed to explain responses to bereavement but has the potential to be applied to other types of bereavement or loss (Stroebe and Schut, 1999). A central tenet of the model is the dynamic process of oscillation between

loss-orientated and restoration-orientated coping in bereaved individuals. Loss-orientation refers to the bereaved individual concentrating on the stress of loss including the emotional attachment to the deceased person whilst restoration-orientation refers to a focus upon the process of dealing with secondary losses associated with bereavement such as social isolation and changing social roles. The dynamic element of this model suggests that individuals fluctuate from one to the other at different times in the bereavement experience. "Sometimes individuals will focus upon distracting themselves from their grief and take 'time off' or have to engage with additional stressors such as work or household activities; at other times they may be confronted by their loss" (Stroebe and Schut, 1999, p.215). The authors draw on previous evidence to claim that constant preoccupation with bereavement is detrimental to well-being and claim that oscillation is a regulatory process necessary for a positive outcome as it regulates the effects of bereavement. Drawing on this model, the data shows that many of the participants remained preoccupied with their losses or "stuck" in a state of loss-orientation and enmeshment whilst others were increasingly engaging in restoration activities and acceptance.

6.7 REFLEXIVITY

The duration of this longitudinal research project has required continual reflection as unanticipated ethical and process issues unfolded. In study two the main challenge had been dealing with participants' emotions. A third set of interviews highlighted the difficulties of retaining a relatively inductive and unbiased stance. The challenge was to manage the tension between an increasing knowledge of CLBP and familiarity with the participants whilst attempting to comply with IPA principles and gain empathic and yet relatively unbiased accounts of participants' experiences.

6.7.1 Effects of prior knowledge

As previously indicated in Chapter 3 my initial knowledge about CLBP was deliberately limited to my preliminary readings so as to avoid the imposition of *a priori* frameworks and understandings on the final account. However, as the project progressed, it was inevitable that I would read around the topic further so as to inform my analysis. This led to *a priori* frameworks and understandings from previous interviews threatening to intrude on subsequent analyses. I noted that as the

project progressed there was a tendency to read around topics that were relevant to the participants' accounts in one study and implicitly applying them to their accounts in the next study that threatened to jeopardise the integrity of the latter accounts. I found that I had to make a substantial effort to retain as inductive an approach as possible by distancing myself from any previous information and reading and rereading the data prior to comparing it with the extant literature so that I wasn't "squeezing" the data into previously used theoretical frameworks.

In order to maintain this inductive approach I maintained the same analytical procedure throughout and analysed each transcript independently prior to making a comparison with the remainder of the dataset. This helped me to remain relatively inductive and to identify new themes or manifestations of old themes without the imposition of the previous analysis. I obviously had implicit knowledge of the earlier themes but by continuing to take an iterative and reflective approach I was able to remain close to the data and construct representative themes that were also independently validated by the PhD supervisor.

6.7.2 The interview process

A second and related challenge was continuing to interview the participants in an unbiased fashion as possible. I have previously discussed the tensions inherent in dealing with both my own emotions and those of the participants. However, it was inevitable that I would gain further personal knowledge of the participants' as the project developed and along with this, develop my own views about the participants that may influence the analysis.

I noted from my research notes that my initial view of patients with CLBP was relatively uninformed. However, I gradually learned that the wider view of such patients was often one of scepticism that reflected the participants concerns about malingering and not being believed. One participant had even commented that she had previously held a negative view of people with CLBP until she herself had the condition. The public view of CLBP intrigued me and I considered whether I too was making unacknowledged negative assumptions about the participants. After all, I was part of wider society and I may also have absorbed some of the biased views about patients with CLBP. If I had, I reflected upon whether this had had an adverse effect on my analysis by either encouraging a biased account or conversely, sharpening my

analysis. A key methodological question was therefore related to whether I had developed strong, prejudicial views as I gathered the data and if so, were these views masking or manipulating my understandings of participants experiences of CLBP. In my defence, I thought I was able to empathise with the participants but also offer a reasonable representation of their experiences. For example, this quote is from my reflective diary:

This council estate makes me feel rather restless and disturbs me but I don't know why really. There are obviously some very poor people on the estate and there seem to be a lot of young people and young mums wheeling their babies around. I suppose this place reinforces stereotypes. This participant lives in a small neat little housing association house. She is divorced and seems much older than her years. SH was very welcoming and again I was surprised and humbled by these people who welcome me even though they do not really know why I am there. It must seem strange just talking freely about your condition and life. I always feel a little intrusive (Reflection upon interview three with Sian: 6.7.151-158).

From this quote it is apparent that I had made observations of the participants' social context and also acknowledged my views about the environment. However, these comments represented empathetic feelings rather than strong valued judgements. A reflective approach enabled me to come to the conclusion that I did not have any strong views about the participants and was able to offer an analysis that was a close representation of the participants' experiences. I was able to focus on the participants' accounting and whilst I experienced no strong feelings I thought that any empathy facilitated further insight into their understandings of their pain experiences (Willig, 2008).

These types of methodological issues are viewed as "part of the job" in traditional, ethnographic research where researchers in long term, naturalistic inquiry engage with those being studied so as to capture social meanings without imposing external meanings upon them (Brewer, 2000). However, there is very little written about these issues in the IPA literature.

6.8 CHAPTER SUMMARY

A third set of interviews continued to reveal themes that represented the participants' multidimensional and embodied experiences of CLBP. All the participants, bar one, had attended the pain clinic with some having repeated treatments with no long term

gain. All the participants continued to experience pain as either worsening, unchanged, or in the case of one participant, slightly improved due to new medication prescribed by her General Practitioner (G.P.). Acupuncture and Transcutaneous Electrical Nerve Stimulator (TENS) treatments appeared to offer short term relief for some participants. During these third interviews the participants emphasised how they were enduring their ongoing situation. The participants continued to fore-ground their integrity and referred to their compliance to medical instructions whilst also enduring pain, treatments and delays in the organisation of their care that reinforced previously reported feelings of being a low priority. Participants continued to report their pain in physical terms and losses in every sphere of their lives. A loss of function and associated loss or impairment of social roles, loss of positive relationships with significant others such as spouses and maintaining integrity of self remained main concerns.

Participants reiterated previous reports of learning to live with the pain and they did so in similar and also different ways, with their management of the pain theorised as reflecting different pain beliefs. The understandings of those who had not experienced painlessness remained comprehensively enmeshed within the medical model and they resisted any alternative therapies, whilst at the same time being highly critical of medical treatments. These participants showed little engagement or acceptance retaining a mainly passive approach to their pain that rendered them increasingly helpless and angry.

In contrast, those who had experienced painlessness and had reappraised their coping strategies, were continuing to learn to live with their pain by increasingly taking into account the influence of their social actions and psychological responses on their pain experiences. This had been previously referred to as increased cognitive control and a move towards a biopsychosocial understanding. The period of painlessness had also facilitated recognition of a valued "previous self" that participants perceived as being hidden by the pain that reassured them that their old selves were still accessible and personality changes determined by the onset of CLBP. This challenges the notion of personality dispositions predisposing pain (Gatchel, 1991).

However, a unidirectional trend towards a biopsychosocial understanding was discussed cautiously as one participant expressed a renewed hope in the medical model as her pain increased and her mood worsened. These changes were likened to

bereavement processes or loss-orientated and restoration-orientated behaviours conceptualised in the DPM (Stroebe and Schut, 1999).

A reflective account presented the main challenges related to maintaining an inductive approach in a longitudinal research project.

The next chapter presents a discussion of the overall findings from all three sets of interviews, limitations of the project, implications for health professionals and future research, an evaluation of the use of IPA in this project and a conclusion.

CHAPTER 7

OVERALL DISCUSSION AND CONCLUSION: THE PHENOMENOLOGY OF CLBP

7.1 INTRODUCTION

The aim of this research project was to use IPA to explore the CLBP experiences of a sample of ten patients over a period of two years. A main concern was to understand the meaning of CLBP relatively unhampered by *a priori* frameworks or theories. In comparison to many previous studies of patients with CLBP a longitudinal design has offered the opportunity to explore continuities and changes in the participants' pain experiences. Each of the participants participated in a semi-structured interview prior to attendance at a chronic pain clinic and twice after attending the clinic. This final chapter includes a summary of the main findings and a consideration of these findings in light of previous research. This is followed by a discussion about the contribution of this research to developing further understanding of CLBP, psychological treatment of CLBP and recommendations for future research. Finally, the limitations of the study are discussed and the use of IPA is evaluated.

7.2 SUMMARY OF KEY FINDINGS

This research project has offered insight into the meaning of living with CLBP as understood by participants (see Box 3). The accounts revealed an emphasis upon the centrality of the "painful body" in the participants' experiences. Participants reported constant, intrusive pain accompanied by an acute awareness of their painful body parts that alerted them to the progress of their pain. Paradoxically, whilst the pain was referred to as a constant, intrusive presence it was also mentally represented as an external threatening entity separate from a sense of self. The accounts revealed a "cognitive distancing" from the pain that was interpreted as an important protective psychological mechanism by which the participants were able to maintain a sense of a fundamentally sound and healthy self.

The accounts illustrated embodied and multidimensional experiences. Whilst the pain experience was foreground in terms of its physicality there was a significant interplay between the physical pain and distress and relation to the participants' loss of function, loss of social roles and subsequent loss of self-esteem.

The participants' depiction of CLBP as a mainly physical experience was concomitant with the participants understanding of their chronic pain as a purely biomechanical dysfunction and their predominantly biomedical approach to managing the pain. The power of the medical model was evidenced throughout with the participants emphasising the biomechanical nature of the CLBP so as to establish legitimate entry into the sick role and offset accusations of malingering in light of the invisible and often indeterminate nature of CLBP. Despite persistent criticisms directed towards the inefficacy of the medical treatments the participants' management of the pain was primarily by medication. The negative pain experiences were also tempered by spousal support and support from family, friends and health professionals. However, participants often experienced unsatisfactory relationships with health professionals especially when little understanding was shown, there was little explanation, and there was a perception of not being believed and of being a low priority.

Participants' experienced varying levels of pain through out the research project with some individuals experiencing worsening pain but with little change in management strategies. In comparison, three participants reported periods of painlessness facilitated by different medical treatments and began to reappraise their own role in the management of their pain. These participants developed alternative management strategies indicating a wider biopsychosocial understanding of CLBP and less reliance on medication as the only method of relieving the pain. However, the period of painlessness was complicated by a lack of advice about exercise and support from health professionals. In comparison, the participants who had not experienced periods of painlessness continued to manage their pain within a predominantly biomedical framework despite a loss of faith in medical treatments.

Overall, the data revealed that whilst the participants endorsed an embodied multidimensional experience of pain their accounts turned on a biomedical model of understanding represented by an emphasis upon the biomechanical nature of the pain, the painful body and behavioural self-management strategies. A period of painlessness for some participants facilitated a change in these pain beliefs and their management of the pain that showed a move towards a biopsychosocial understanding of CLBP.

BOX 3: Summary of key findings

- The participants' accounts illustrated "The painful self" - with an emphasis upon the painful body
- CLBP internally represented as an external object
- Pain expressed as a dichotomy consisting of physical pain and emotional experiences that reflects a bio medical conceptualisation of CLBP
- A close inspection of the data offers evidence of embodied, multidimensional and enmeshed experiences
- Emotional responses include anxiety, anger, depression and guilt
- The participants endeavour to maintain personal integrity in light of not being believed
- Medication as the main method of managing the pain accompanied by a predominance of behavioural focused coping strategies
- Pain beliefs determined the participants coping strategies
- Support sought from spouses, families, friends and health professionals
- Complex and often unsatisfactory relationships with health professionals
- Participants sought understanding about CLBP
- Dissatisfaction with the organisation of care including feelings of being a low priority
- Painlessness related to the participants reappraisal of the management of their CLBP. A turning point as participants realised the inefficacy of medical treatment could be supplemented by their own attitudes, behaviours and social actions.
- Painlessness viewed as related to an increasingly biopsychosocial understanding of CLBP
- Patterns of coping reminiscent of grief responses

The next section presents a discussion of the findings in relation to the extant literature.

7.3 A DISCUSSION OF THE KEY FINDINGS:

7.3.1 Continuities: physicality of pain and embodied experiences

This IPA research project revealed broad and detailed accounts that illustrate the participants' lived experiences and how they make sense of these experiences (Smith and Eatough, 2006). The participants expressed their daily concerns about managing CLBP that have been termed hot cognitions, but also their longer term concerns for the future and reminiscing about the past that is consistent with the notion of cool cognitions (Smith and Eatough, 2006). However, it may be argued that all the participants' responses reflect salient concerns or hot cognitions. The recollection of past, valued activities, impaired roles and a consideration of an uncertain future were viewed as distressing as the more immediate demands with daily living and reflects the participants' struggles with managing the temporal elements of CLBP.

The research project revealed consistent super-ordinate themes that illustrated the enduring meaning of CLBP for the participants. Whilst there were some changes in the levels of pain experienced and sub-ordinate themes showed subtle variations, many of the participants' pain experiences were continued, shared experiences. The concept of consistency in participants' accounts may be viewed as either revealing nothing out of the ordinary or may be a significant part of the participants' everyday world or lived experience (Saldaña, 2003). The significance of these continuities in this research was apparent as they highlighted the ongoing and generally unchanging nature of the CLBP that characterised participants' experiences and could facilitate a lowered mood or even self-expressed depression. Thus the meaning of CLBP for these participants was endurance as they struggled to manage a never-ending daily treadmill of pain.

A main finding throughout the research was that the participants emphasised the corporeal nature of the pain with the pain reported primarily as a phenomenon experienced of and through the physical body. This finding contrasts with previous psychological studies that have been criticised for presenting disembodied representations of chronic pain (See: Osborn and Smith, 2006). However, this is countered to some extent by the acknowledgement that quantitative studies have demonstrated statistical relationships between levels of pain, mood and self-esteem (see: Dersh et al. 2002). On the other hand, little attention has been paid to the qualitative nature of the relationship between painful bodily experiences and the individuals' self-concept (Osborn and Smith, 2006). In

comparison, in this project the accounts of the participants clearly illustrated the embodied nature of their CLBP experiences that supports biopsychosocial understandings of CLBP.

The participants' levels of pain were variously reported over the period of investigation with some participants reporting a trend of worsening and often intolerable levels of pain, others reporting no change and several reporting a period of painlessness. However, the constant, intrusive and debilitating nature of the pain was relatively unchanged throughout the period of the research. In normal circumstances, individuals take their bodies for granted, but because of the pain's unpredictable progress and threat to daily living the participants were living in a constant state of vigilance and constantly monitoring its progress. As suggested previously, this awareness of their painful bodies supports the distinction made between a bodily disappearance in the absence of pain, where little thought is given to performing most activities and its reappearance in the presence of pain when our painful bodies are at the forefront of our consciousness and become a vehicle of discomfort (Williams, 2000).

The heightened awareness of their bodies was also apparent when the participants voiced concerns about their bodies "letting them down" with the appearance and heaviness of their bodies making them feel and look old. All of the participants referred to the ageing effects of the pain. The CLBP accelerated the ageing process with daily living and social activities becoming increasingly difficult to undertake and accompanied by a lack of spontaneity and slowness when undertaking tasks. These findings were previously suggested as paralleling the literature on physicality and ageing. For instance, McKee, (1998) wrote about a concept of body drop with reference to older people and falls and the body letting them down.

The participants spoke of their bodies letting them down in public places and a fear of losing their balance, falling and experiencing further pain and embarrassment that contributed to the avoidance of public places. Previous quantitative studies have acknowledged the importance of motivational influences in the development of chronicity and have described the processes involved in fear avoidance behaviours (Grotle et al. 2004; Vlaeyen and Linton, 2000; Waddell et al. 1993; Gatchel, 1991; Fordyce, 1976). The present research lends further understanding about the meaning of avoidance behaviours for patients with CLBP and supports biopsychosocial models that indicate physiological, cognitive and social mechanisms are implicated in fear avoidance behaviours (Norton and Asmundson, 2003). For instance, the participants' avoidance behaviours were often viewed as a consequence of a single distressing occurrence, for example, a shopping trip that ended in a

frightening fall or having been pushed in a swimming pool. The participants suggested they were reluctant to risk any further distressing episodes and had learned to try and avoid public places. For some, this had generalised into ongoing agoraphobic behaviours with little social activity and social isolation reported. The participants continued fear and avoidance of public places thus became a central part of their lived experience with the consequences that many of them reported feelings of depression and loss as they organised their activities around their pain, their social lives become eroded and they were unable to fulfil their role expectations (Borkan et al. 1995). Studies have shown that whilst behavioural avoidance strategies offer an initial positive reinforcement that is, less pain or embarrassment, secondary losses such as loss of a social life and social isolation have been documented as having the potential to contribute towards further physical and mental deconditioning or a disuse syndrome (Norton and Armundson, 2003; Vlaeyen et al. 1995; Linton, 1985; Bortz, 1984). The data also resonate with the concept of the “diminished self” that refers to a lowered self esteem as a restricted life gradually eliminates opportunities for positive self regard (Charmaz, 1983). The findings would lend support to previous suggestions that fear avoidance beliefs should be assessed at an early stage of CLBP so appropriate interventions may be applied and further deconditioning halted (Grotle et al. 2004).

The participants described their experiences in terms of good, bad and very bad days. These descriptions were present throughout the research project with some complaining of an increasing amount of very bad days when the pain was unbearable and uncontrollable. On these days the pain interfered with their daily activities to the extent that even undertaking routine tasks was extremely difficult or even impossible to complete. The participants’ predominant feeling at this time was isolation as they realised no-one could understand their suffering. The descriptions of very bad days adds an extra dimension to the good and bad days previously described by chronically ill patients (Charmaz, 1983) with the very bad days described as morally unjustified.

The pain was more than a threat to physical functioning; it was also a threat to a fundamental sense of a coherent and valued self (Eccleston and Crombez, 1999). A close inspection of the accounts showed a dichotomous representation as the participants struggled to maintain control by rhetorically distancing themselves from the pain. Such “distancing” of the painful self from one’s valued self was described in the project as being reminiscent of a Cartesian dualism or a mind-body split and as representing the participants’ attempts to protect their personal integrity (Vracken, 1989). This explanation was supported further by drawing on the work of (Freud, 1911/1933) who had referred earlier to unconscious defence

mechanisms used in response to perceptions of threat. The subject-object relationship of the participants to their pain is also proposed as influencing their self-management strategies. Those participants who continued to refer to the pain as a threatening external object also demonstrated little engagement with the pain and a narrow range of behavioural-focused coping (Osborn and Smith, 2006) (for a full discussion see Chapter 4). In contrast, other participants who did not show such a strong relationship with their pain were viewed as moving towards engagement and acceptance of their pain and developed alternative coping strategies (see below for further discussion about these emerging differences). A similar metaphorical analysis conducted by Schattner et al. (2008) also revealed that internal representations of illness reflects affective states and influences patterns of coping. This partially supports the present research that showed the participants “externalisation of pain” was an unconscious defence mechanism in itself.

Furthermore, Osborn and Smith, (2006) proposed that it may be useful to encourage an integrated sense of self by facilitating engagement with the pain as part of acceptance therapy. In support of this, several studies have demonstrated that engaging with the pain is significantly associated with successful adjustment (McCracken, 1999; McCracken and Eccleston, 2003; Risdon et al. 2003). However, this may be challenging for patients used to “battling with CLBP” who have long standing biomedical beliefs about CLBP and who may be resistant to participating in counselling sessions.

The participants’ dichotomous representations of their pain were further underlined by any reference to their emotional responses sequenced later in the interviews or when there were references to bad days, a loss of social roles, anxiety about the future and the organisation of their care. However, it was also possible that once the participants had established the biomechanical nature of their pain they felt easier talking about emotions. The participants talked about ongoing and unrelieved anxiety, anger and even depression; all of which have been documented in the pain literature as normal reactions to pain but as having the potential to override the original complaints of pain and contribute to disability (Waddell, 2004; Gatchel, 1991). As suggested in Chapter 4 the design of the study did not allow for any clinical diagnosis of depression but all the participants referred to subjective evaluations of depression that concurs with evaluations showing CLBP patients have higher rates of depression as compared to the general population (Dersh et al. 2002).

In contrast to quantitative assessments of depression, an IPA analysis has developed understanding of the meaning of depression for sufferers rather than purely evaluating levels of depression. Participants viewed their lowered moods and self diagnosed depression as a

direct consequence of the pain and loss of function. Depression was often expressed as “feeling low” as participants perceived they were letting their partners down by not fulfilling expected roles. They spoke of being depressed because of the tedium of limited functionality and observing life rather than participating in life, “I sit here and watch the people go by” (Will: Interview 3. 4.15). Depression was cited as they referred to previous active lives and compared this to their present, impaired lives. The very bad days were frightening, isolating and highlighted worries about a painful and perhaps disabled future. In short, the constant demands of CLBP wore them down and promoted low moods.

Anger was mainly reported by the males in the sample and it is worth mentioning that this could be a gendered response and may merit further investigation. These participants vehemently reported frustrating experiences related to the disorganisation of their care, the pain interrupting valued activities and social obligations and a lack of a coherent understanding of the pain. As observed in Chapter 4, anger is a known consequence of frustration due to goal attainments being perceived to be blocked by pain (Berkowitz and Harmon-Jones, 2004). Whilst there is little information about the role of anger in the maintenance of chronic pain, anger has been found to be associated with catastrophising, a response strongly associated with amplifying negative pain perceptions and a predictor of depression and chronicity in pain populations (Hersh et al. 2007, Berkowitz and Harmon-Jones, 2004). Further studies show that frustration and anger are implicated in mental deconditioning or passivity that is observed in patients with chronic pain experiences. These emotions may override the original pain itself and contribute to maladaptive illness behaviours (Pincus and Morley, 2001; Gatchel, 1991). In this project, those participants who expressed the most anger and frustration also appeared to be comprehensively enmeshed in their pain (see below).

Loss was implicated in the participants’ experiences throughout the research project. All the participants made references to a loss of function, social roles and a valued previous life or what they “ought” to be doing with little mention of any meaningful future. This changed for some participants (see below) but there was a general sense of loss and depression evident throughout the research project. Loss is mainly documented in the qualitative literature with medical sociology researchers such as Charmaz, (1983) depicting chronic illness as an experience of loss above anything else. Previous phenomenological, psychological studies have also found CLBP patients experience loss across all areas of their lives with their personal relationships disrupted and an inability to construct positive self-regard (Sofaer-Bennett et al. 2007; Walker et al. 1999; Osborn and Smith, 1998). Some of

the participants in the present research reported similar losses alongside subjective evaluations of depression, with little uptake of any valued behavioural activity or social roles so as to re-establish a sense of worth. This was referred to in Chapter 6 as being reminiscent of a loss orientation reported in bereavement with a constant preoccupation upon losses acknowledged as detrimental to well-being (Stroebe and Schut, 1999). The theory of self-discrepancy (Higgins, 1987) also informs us that negative evaluations of oneself in relation to a perception of what one ought to be doing or an ought self is apparent in individuals with depression.

The participants managed their CLBP with help from spouses, family and friends. This support was essential and was referred to throughout most of the research project. There was reference to both instrumental and emotional support with the help of spouses being particularly valued. The older couples in the sample spoke of sharing the pain and gaining closeness described as “we ness” (Mason, 2005) that contrasts with the friction described by older couples in a previous study (Sofaer-Bennett et al. 2007). However, whilst most of the participants depended significantly on their spouses they also spoke of disrupted marital relationships, feelings of guilt and “letting their partners down” that has been reported previously (Walker et al. 2006; Roy 2004; Osborn and Smith, 1998).

Overall, the findings from the project showed that perceived support from the participants’ families moderated the every day struggles of living with CLBP and endorses previous findings that shows family support is an important buffer against stress as it influences the patients’ appraisal of the threat and ability to cope (Roy, 2001; Cohen and Wills, 1985). On the other hand, when families and spouses failed to acknowledge the ongoing emotional isolation of the CLBP experiences then this served to isolate some of the participants even further.

The participants also sought support from the health professionals. Busch (2005) explains that the long term nature of CLBP, the iatrogenic effects of medication, comorbidities, the continual waiting for an appointment or treatment and the search for an explanation all serve to ensure a continued and enduring interaction with health professionals. It is therefore hardly surprising that the relationship with the health professionals was a main theme throughout the research project.

The support from the health professionals was often considered as being unsatisfactory, especially when little understanding was shown, there was little explanation, and there was a perception of not being believed and of being a low priority. These findings have been suggested as contravening a Good Back-Consultation that has been described as

including a demonstration of understanding, discussing psychosocial issues, receiving reassurance and discussing what can be done (Laerum et al. 2006). Strong expressions of frustration, anger and helplessness were revealed in response to perceptions of being a low priority, being 'passed on' and a life dominated by waiting for appointments that were often cancelled or unsatisfactory. Similar findings have described chronic pain patients as being disempowered rather than empowered in the health care system (Walker et al.1999). The participants in this project had all experienced CLBP for a significant amount of time and had experienced repeated treatments with little or no effect. There was little hope expressed for any successful outcome from the pain clinic and for most of the participants this was justified as there was little improvement in their condition after being treated at the clinic.

Overall, the accounts illustrate a paradoxical relationship between the pain and participants. It was suggested that whilst there was a fragmentation or dualism of self apparent in the accounts, that is, participants spoke of the pain as separate from themselves and an external threat; there was also evidence of "enmeshed pain experiences" (Pincus and Morley, 2001). In the Theory of Enmeshment, Pincus and Morley, (2001) developed the work of Higgins, (1987) to offer insight into the extent of any discrepancy between the present self and an ideal self in patients with chronic pain (see Chapter 4 for a full explanation of this model). In short, the model describes the extent to which the patients self schema is enmeshed or engaged with their illness and pain schemas. The degree of this enmeshment influences the patients' self concept. Depression is implicated and offered as the primary mediating factor of the extent of the enmeshment, however, whether depression is a determinant or the consequence is unknown.

The present data resonates with the conceptual elements of the enmeshment model, that is, the participants' experiences were embodied ones with a significant disruption to a sense of self and an awareness of the chronicity of their condition Furthermore and as mentioned previously, some participants in this study did appear to have experienced symptoms of clinical depression, whilst others reported chronic distress and lowered mood that may lead to depression. Participants made few positive personal appraisals about their present lives and it is suggested that the participants' pain and self schemas schema's appear to be enmeshed and trapping negative aspects of the self that reiterates Osborn and Smith's (2006) analysis. However, Osborn and Smith offered little explanation for the contradictory presence of both enmeshment and a dualism of self that is also present in these accounts. One explanation may be that whilst the participants are enmeshed in their pain experiences they

continued to attempt to resist the damaging effects of the pain to their self-concept by distancing themselves from the pain.

Overall, the participants' accounts showed embodied and multidimensional experiences that are marked by loss and are similar to the reported experiences of bereaved individuals (Stroebe and Schut, 1999). The Enmeshment Model offers insights into the participants' experiences and preoccupation with a past and ought self. However, there is little reference in the model to any illness beliefs that may sustain any "enmeshment" or "distancing" and the experience of loss that is such an evident part of the participants CLBP experiences.

7.3.1a *Biomedical beliefs*

The data revealed that whilst the participants endorsed embodied and multidimensional experiences, their accounts turned on a biomedical model of understanding. The participants' biomedical beliefs were represented by the dualism evident in their accounts with an emphasis upon the biomechanical nature of the pain, the physicality of the pain and a predominance of behavioural and biomedical focused coping strategies.

The biomechanical nature of CLBP was continually emphasised by participants who felt they had to continually justify their CLBP as a physical "real" pain. These endeavours echo previous work that views such rhetorical responses as a moral endeavour and a rational response to not being believed (Osborn and Smith, 1996; Kuglmann, 1999; Eccleston et al. 1997; Borkan et al. 1995). Participants described experiences marked by distress and anger in encounters with health care professionals where scepticism was evident and their moral integrity was doubted. Not being believed is therefore associated with the participants' emotional well being in addition to personal integrity and illustrates that Cartesian dualistic thinking remains influential in both patients and health care professionals' conceptions of pain.

It has been conjectured that the participants' long illness experiences dominated by the constant physical symptoms and access to predominantly medical treatments had reinforced the participants' biomedical beliefs about the pain, despite the perceived inefficacy of the medical treatments. Leventhal et al. (1980) similarly proposed that patient's representations of their illness arise from information based on bodily experiences, the social environment and past experiences and have been shown to influence compliance to treatment (Leventhal et al. 1980). There is little information about the relationship between the

biomedical beliefs of patients and how they manage or cope with CLBP. However, an increasing number of quantitative studies have provided support for the effects of patients' beliefs on pain outcomes. Catastrophising beliefs have been statistically related to pain intensity (Woby et al. 2007), the onset of pain and disability (Linton et al. 2000), chronicity (Burton et al. 1995) and as a predictor of disabling neck and back pain (Mercado et al. 2005). In addition, fear avoidance beliefs have been shown to influence the development of disability (Waddell et al. 1993), isolation and depression (Vlaeyen and Linton 2000). Related work on illness perceptions has also shown that perceptions about the chronicity of the condition, personal control and consequences of chronic pain rather than the underlying beliefs about the cause have been found to predict the clinical outcome of low back pain patients (Foster, Bishop, Thomas, Main, Horne, Weinman, et al. 2008).

Two previous studies that investigated patients' pain beliefs support the present findings. As with the participants in the present research, Borkan et al. (1995) found that many of their subjects described the causes of their low back pain in purely biological or mechanical terms that was similarly accompanied by strong expressions of disappointment with the inefficacy of medical treatments. Similarly, Walsh and Radcliffe, (2002) used The Pain Beliefs Questionnaire (PBQ: Edwards, 1992) to investigate the relationship between pain beliefs and the perceived physical disability of eighty four patients with low back pain. The results showed that those patients with unhelpful organic (biomechanical) beliefs about the origins and consequences of their pain reported higher levels of physical disability. These studies support Waddell, (1992) who proposes that a narrow biomedical approach to managing pain may be only partially successful (the participants in this project had some relief from pain due to medical interventions) but is a reflection of a simplistic model of biomechanical dysfunction that does not allow for beliefs, feelings and social context that all may have an impact on the experience of chronic pain.

Whilst there were continuities and shared experiences illustrated in the accounts there were also changes evident and differences emerging between participants. These are discussed below.

7.3.2 Changing experiences

The second and third set of interviews showed differences between the pain experiences of those who had experienced painlessness and those who continued to experience continued, unremitting CLBP. Those who had experienced unrelieved pain throughout the duration of the project continued to manage their pain within a predominantly biomedical framework despite the perceived inefficacy of the medication. These participants were regarded as being psychologically inflexible and remaining comprehensively enmeshed in their pain, with little engagement or acceptance and a loss-orientated focus (Pincus and Morley, 2001; Stroebe and Schut, 1999). It is worth mentioning that reinforcement processes probably play an important role in these participants' behaviours. The continued narrowness of their coping strategies and lack of attention to the influence of their own beliefs on their pain experiences was probably maintained in part by family members who reinforced pain behaviours such as extended periods of rest that contributing to the maintenance of their enmeshment (Fordyce, 1976; Fishbain, 1994).

In comparison, other participants had experienced painlessness or a temporary period of pain relief and there were different pain experiences emerging from these participants' data. These participants' accounts indicated a pain remission was accompanied by changing pain beliefs and coping strategies. Previous commentary has referred to participants' illness beliefs as enduring cognitive styles but may be receptive to change due to cognitive behavioural therapies (Turner et al. 2000; Edwards, Pearce, Turner-Stokes, and Jones, 1992). In contrast, the data from the present study indicates that the participants' beliefs could change in the absence of any cognition-based therapy.

The data indicate these participants had moved from a predominantly biomedical understanding towards a biopsychosocial understanding of their pain. These participants were developing an increased awareness of the psychological and social determinants of their pain experiences that was reflected in their remodelled pain management strategies and resonated with restoration-orientated coping in bereaved individuals (Stroebe and Schut, 1999). Their coping strategies changed from a focus on controlling the pain by medication and behavioural strategies with little consideration of psychosocial factors to increasingly engaging in activities and new social roles despite their pain. It was suggested that these participants were showing increased cognitive control and signs of engaging with and accepting their pain (McCracken and Eccleston, 2003).

Because of the lengthy duration of CLBP it is likely that changes will occur and perspectives shift according to social and personal context (Busch, 2005; Paterson, 2001). However, commentators such as Busch and Paterson offer little specific explanation for the determinants of any changes. In contrast, an explanation for the present findings is that the constant and intrusive nature of CLBP had previously militated against any consideration of restorative activities or any alternative ways of dealing with the pain. The period of painlessness had enabled these participants to re-establish a connection with their 'previous selves' and focus their attention upon increased self management and restoration rather than their losses.

On the other hand, there is little evidence of a neat, uniform fit of all the data into this analysis. Saldaña reminds us that the complex and messiness of human life doesn't always lend itself to orderly, consistent development (Saldaña, 2003 p. 119). Likewise, there was an exception to the proposed uni-directional development from biomedical to biopsychosocial frames of reference for all of the participants who had experienced painlessness. For example, one of the participants alternated between a dependence on biomedical treatments and alternative therapies and distraction. When alternative therapies and distraction did not contain her pain she refocused her hopes on surgical treatments and biomedical approaches with a renewed focus on her losses that resonate with the dynamic process of oscillation between loss-orientated and restoration-orientated coping seen in bereaved individuals (Stroebe and Schut, 1999).

7.4 CONCLUSION

This IPA study has offered insight into the meaning of CLBP for the participants over a period of two years. The data challenges previous psychological work that offers disembodied depictions of CLBP. The participants' accounts illustrate an embodied pain experience that has returned "physical pain" into understandings of CLBP. Whilst the data showed continued embodied and multidimensional experiences, that is, dealing primarily with the sensation of pain alongside experiencing felt stigma and isolation and more psychological aspects such as depression and loss, participants experiences were underlined by biomedical conceptualisations of CLBP that contributed towards narrow coping strategies and an enmeshment of self with the pain.

In comparison to previous studies, the longitudinal design showed that pain experiences are often unchanging but are also "dynamic" and marked by gradual, subtle

changes such as worsening pain, but also more significant changes in the conceptualisation of pain or illness beliefs and subsequent personal coping strategies according to opportunities for reappraisal for some participants.

There is little information in the literature about the determinants of changing pain beliefs unless associated with psychological interventions. The narrative work of Carr et al. (2005) informs us that the experience of persistent pain may vary with the intensity of pain. In this project it has been proposed that a period of painlessness was a turning point and offered some of the participants' opportunity to reassess their appraisal of CLBP and their pain management strategies.

The participants in this study have all experienced CLBP for a significant amount of time and have had repeated treatments with little effect. The participants reported that their complaints of CLBP challenged the health professionals and they were sometimes subject to scepticism, feelings of rejection and being passed on. Patients with an uncertain diagnosis, long clinical histories and who generally make greater use of the health services have been termed "heart sink" patients, with health professionals often having no clear intentions with regard to treating them and little hope of any improvement in their conditions (Daykin and Richardson, 2004; Butler and Evans, 1999; O'Dowd, 1988). The participants in this research project expressed a parallel loss of hope and helplessness. However, as shown, some of these participants did report changes in their perceptions and management of their illness that demonstrates even "heart sink" patients can change their management of their situation.

7.5 IMPLICATIONS FOR PRACTICE

7.5.1 Psychological Therapies

The conclusions of the research project have a number of implications for psychological therapy. If there is an understanding that the participants have a predominantly biomedical understanding and these beliefs limit their management of the pain to partially effective "medical only" treatments then a focus on therapies that change illness beliefs and subsequent "coping" might be worthwhile. The aim of Cognitive Behavioural Therapy (CBT) is to modify the patient's responses and reduce disability and distress (Vlaeyen, Kole-Snijders, Boeren, and van Eek, 1995). Cognitive Behavioural therapies (CBT) have been extensively evaluated in the psychological treatment of chronic pain with mixed conclusions. Recent studies show that CBT may be more effective in treating some responses than others. Morley

et al. (2008) conducted a large follow up study over ten years investigating the effectiveness of CBT for 600 chronic pain patients. The findings showed significant clinical changes in pain, emotional distress and self-efficacy with a lesser effect on behavioural activity. In contrast, a systematic review of fifty-two randomised controlled studies (RCT's) was conducted by Eccleston, Williams, and Morley, (2009) who reported CBT as reducing depression and anxiety but had a lesser effect on improving disability and pain.

An alternative may be a consideration of Acceptance Therapy and Mindfulness Therapy for these patients. If one supports the notion of many of the participants having a high level of enmeshment between self, illness and pain schemas that involves strong feelings of self discrepancy, they may respond to therapies that focus on capabilities and engagement with the pain, for example, acceptance therapy (ACT) (Hayes and Smith, 2005). The therapy differs from CBT in that instead of helping people to control or change their innermost thoughts and private events, ACT focuses on enabling patients to control what they can control more directly, that is physical reactions and so on and engage with or accept their pain. An acceptance of pain includes noticing but not reacting to pain. There is growing evidence from treatment outcomes studies that acceptance therapy improves functioning in people with chronic pain (McCracken and Vowles, 2006).

The role of mindfulness therapy in psychological treatments has also been proposed for patients who become fixed in habitual and restrictive ways of thinking about their pain (McCracken, Gauntlett-Gilbert, and Vowles 2007). Mindfulness is similar to acceptance but takes a broader approach and includes noticing and not reacting to pain, emotions, urges, thoughts and other feelings in the body rather than purely pain. There is a lack of systematic investigation into the efficacy of mindfulness therapy. However McCracken et al. (2007) investigated mindfulness with one hundred and five chronic pain patients and found that greater mindfulness was associated with better functioning and improved mood. Morone, Greco, and Weiner (2008) demonstrated that mindfulness meditation led to improvement in pain acceptance and physical function in older adults with CLBP.

For those who have less enmeshment and are likely to participate in activities in the presence of pain then they are likely to respond well to therapy such as distraction (Turk and Jenson 1993) and focused problem-solving so as to further develop an internal locus of control (Roelofs et al. 2004). The participants deeply embedded beliefs about illness may be resistant to cognitive change so a focus on 'behaviours only' may be advised. If the focus is on behaviours then the adoption of operant conditioning principles including the use of rewards and reinforcing attention away from maladaptive pain behaviours may be useful

(Fordyce, 1976) and / or graded physical treatments (Verbunt, Seelen, Vlaeyen, van de Heijden, Heuts, and Pons et al. 2003). Loss across all areas of life is a main theme and is partly offset by social support but participants may require help to work through loss and any difficult emotions by applying the principles of Stroebe in psychotherapy (Stroebe et al. 2001).

7.5.2 Communication between patients and health professionals

The participants' accounts articulated their struggles to maintain their integrity and self-esteem as patients. There were ongoing concerns about not being believed, a lack of understanding, explanation and legitimization of their pain that has salient implications for clinical encounters. It would seem important that health professionals acknowledge and validate the patients' pain experiences by developing their listening and interview skills. Fordham and Dunn, (1994) suggest techniques of engagement and active listening so as to "come alongside" the patients and to develop trust and rapport with the patient. This may be achieved by use of simple non verbal and verbal communications that demonstrate an awareness of the patients concerns and confirm they are believed. The data also implied that in order to understand the meaning of the pain for the patients with CLBP there has to be patience, understanding and empathy. The importance of health professionals demonstrating these qualities in back consultations has been discussed previously with reference to the work of Laerum et al. (2006).

Furthermore, it may also be worthwhile to incorporate time in a consultation for education and explanation so as to minimise patients' feelings of uncertainty and distress. The participants in this study held predominantly biomedical views about CLBP and their accounts suggest that many of the health professionals also held these views. Therefore, education for both patients and health care professionals about the multidimensional, biopsychosocial nature of CLBP may be a useful and cost effective resource especially if it is delivered to the patients at the onset of symptoms and the health professionals in both primary (community) and secondary (hospitals) health care.

Another concern of the participants was the expressed perception of being a low priority that was promoted by the disorganisation of their care. Lost notes, perceptions of being "passed on" with little explanation all contributed to their loss of confidence not only in the health professionals but in the organisation itself. The continued development of the formation of dedicated multi-professional chronic pain clinics could answer many of these complaints. These clinics would increase the possibility of improved liaison between health

professionals that would go a long way towards improving the services for CLBP and also contribute towards empowering disempowered patients who at present do not know where to turn to for help.

7.6 RECOMMENDATIONS FOR FUTURE RESEARCH

The findings that emerged from this study have important implications for further research in this area.

- The constant and intrusive nature of the pain and its sequelae had an impact upon the participants and the participants' families' lives. There is a deficit in the literature about the experiences of CLBP patients' spouses, families and carers. Further IPA studies investigating the meaning of CLBP for spouses and families may offer valuable information about the effects of CLBP on family life that will contribute towards understanding the needs of patients and their families.
- Loss was at the centre of the participants experiences. Any future research could be aimed towards developing understanding about the relationship between loss and depression in chronic illness.
- The participants' relationship with the health professionals has been shown to be a significant part of their pain experiences. Any future research could be usefully applied to the question of how the illness beliefs of patients with CLBP compare with health professionals beliefs about CLBP and how different understandings influence the relationship. A multi-methods approach that combines an IPA of patients and health professionals with an ethnographic observational study of the interaction in clinical interviews would offer further insight into the relationship between health professionals and CLBP patients.
- The data show that a period of painlessness paralleled some participants' reassessment of their situation and a move towards a biopsychosocial understanding of their pain. The mechanisms of these changes are complex and merits further exploration in patients who have periods of remission from their pain or illness.
- The study showed that there was a lack of support and information for those experiencing remission from their pain. Any future research should explore and compare the remission

experiences of patients with different chronic conditions so as to inform the needs of patients at this time.

- Some of the participants referred to changes in their personality since the onset of the pain. There is a lack of research into personality as a determinant of coping with CLBP. Research in this area would help to develop knowledge about the role of personality in the pain experience and also what, if any, elements of the patients' personality is vulnerable to change.
- There have been many proposed changes in recent years in the care of patients with chronic pain in the community (Welsh Assembly Government, 2008). Further research may focus upon a comparison and evaluation of the provision of services for patients with CLBP and others with comparable chronic conditions.

7.7 THE STUDY LIMITATIONS

7.7.1 A snap shot view

A lack of longitudinal studies is a main criticism in the psychological literature. Further research is often recommended in order to develop understanding about the onset and maintenance of pain behaviours and beliefs. Subsequently, both the quantitative and qualitative studies of CLBP offer little insight into 'chronicity' and the dynamic nature of chronic pain. There are a number of studies that measure patients' responses to psychological interventions but hardly any that document the unfolding of experiences over a period of time. In comparison the present project enabled comparisons of the participants' experiences over a period of two years. However, the participants in this research project had experienced CLBP from approximately four to twenty three years and it may be argued that two years may be viewed as a relatively short period of time in their long chronic illness careers. A follow up study of a longer duration would enable further knowledge to be gained about the influences of chronicity and treatments on patients coping styles and the patterning of beliefs and mood.

7.7.2 Sample size and generalization of findings

The sample consisted of ten CLBP sufferers. This is a small sample in comparison to quantitative studies but supports the ideographic commitment of IPA (Smith and Eatough,

2008). A purposeful and small sample size has had the advantage of enabling a detailed analysis of the data with attention given to both communalities and variations in the data set not usually acknowledged by large scale surveys apart from recognition of statistical outliers. However, the purposeful, sampling design and relatively small sample indicates that any generalisation of the findings should be made with caution. For example, the sample was restricted to those over the age of 18 years and therefore does not explore the experiences of adolescents or younger people with CLBP. Younger patients' experiences may be different to those of the older participants in this sample.

In addition, the accounts showed that many of the participants held subjective evaluations of depression. The small sample militated against assessing levels of depression with recognised instruments and making generalisable claims and comparisons with larger samples.

The IPA project has developed insight into the subjective experiences of the participants. It is not claimed that the findings from this research project represents all patients' experiences but may offer valuable insight into similar experiences and develop existing knowledge for health professionals working in this field.

7.7.3 A longitudinal design: maintaining an inductive approach

IPA is a qualitative methodology that claims to offer a relatively inductive approach to the analysis of the findings so as to uncover the subjective meanings of individual's experiences. A longitudinal project has enabled an exploration of the participants' pain experiences over a period of two years and highlighted the dynamic nature of chronic pain. However, maintaining an inductive approach throughout the study has been challenging (see below). The accruing knowledge of the participants' pain gained from each interview coupled with an increasing knowledge about CLBP threatened to colour an unbiased analysis of the data at each subsequent interview. The use of a reflective diary enabled a reflexive approach that acted as a personal check of any unintended influences upon the researcher's interpretation of the data. In addition, (as discussed below) an independent validation check by the PhD supervisor was undertaken to ensure the themes represented the data throughout the study.

7.7.4 Interpretation of the data

One of the tensions inherent in qualitative research such as IPA is that the analysis rests on interpretation and subjectivity that suggests any final account produced by the researcher cannot be presented as “the one single true account” or a “fact” as in quantitative research. In chapter 3 it was suggested that qualitative researchers accept the notion of multiple realities (idealist ontology) but from this perspective any validity procedures are made redundant. This has the potential to devalue the authenticity of phenomenological research as any readers; critics and so on want to have reassurance that the final account is a legitimate interpretation of the participant’s experiences.

In keeping with an idealist ontology there is no claim that the analysis of this data is the one true single account. On the other hand, validity checks were implemented that were advocated by Smith and Osborn, (1996) who advised the use of distinct criteria for evaluating IPA research. An independent check of the data by the PhD supervisor who is also an experienced pain specialist added weight to the authenticity of the final interpretation (Smith and Osborn, 1996).

7.8 USING IPA IN THIS RESEARCH PROJECT

7.8.1 Multilevel analysis

A multilevel analysis was undertaken that included trying to get an insiders viewpoint (emic stance) but also a more critical or etic stance by questioning what was said and searching for nuances in the data that may reveal a more covert agenda (Smith and Osborn, 2003). For example, the theme ‘maintaining integrity’ was constructed from a close examination of not only what was said but also the discourse used by the participants to “rhetorically position” themselves during the interviews (Harré and Van Langenhove, 1991). It may be argued that this is a departure from IPA. However, the inductive and interpretative enterprise is maintained, only with a focus upon both what the participants said and also “what they did with their talk” (Silverman, 1985). From this perspective accounts are viewed as linguistic devices, but also viewed as being connected to the underlying meaning of the pain for the participants that is consistent with cognitive psychology rather than being a purely discursive analysis (Murphy, 1999; Smith, 2004; de Visser and Smith, 2006).

7.8.2 Fragmentation of data

The initial analysis of the data involved a line by line analysis that “pulled the accounts apart” or fragmented the accounts. At this stage the connections between the themes are hardly made but this research closely followed the guidelines of Smith and Osborn, (2003) and the construction of emerging clusters interrelated to make up generic super-ordinate themes. This procedure and the overall discussion brought the data back together to form an integrated and coherent whole.

7.8.3 Sequencing of responses

IPA has also been criticised for a lack of consideration of the sequencing of the participants accounting (Collins and Nicholson, 2002). The current study also referred to the importance of documenting the sequencing of responses that was achieved by a reiterative approach that included a close examination of the data. This had led to noting the later references to emotional responses that was interpreted as reflecting the participants’ more immediate and main concerns with the physical symptoms.

7.8.4 Being reflexive

A reflexive approach is an acknowledged part of phenomenological research and has been advocated for use in IPA studies (Smith and Osborn, 1996). A recognised dilemma in qualitative research is the tension between the researcher’s attempts to produce a faithful representation of the participants’ experiences and the role of the researcher in the construction of the final account. Thus, a main aim of maintaining a reflexive approach during IPA studies is to manage this and respond to methodological issues (Smith, 2004). Reflexivity is therefore a qualitative researcher’s tool that may be activated by reflective practice.

A number of methodological issues were reflected upon during the course of the project. One of the main issues throughout this project was a lack of guidelines about how to manage any preconceptions and unintended biases. Husserl (1917/1981) proposed the notion of bracketing or distancing oneself from one’s beliefs and disbeliefs in relation to the phenomenon under study. Descriptive phenomenologist researchers generally regard bracketing as one method by which the researcher is able to free one-self from restricting understandings and gain access to the essence of the phenomenon. Whilst Husserl describes the mental manipulations

required to access the “essence” of the phenomenon under study, IPA commentators have questioned whether being purely inductive is attainable and there is no formal attempt at bracketing (Larkin et al. 2006).

In this research project it was recognised that to approach the research with a “*tabula rasa*” would be impossible due to the researcher having some knowledge about chronic pain from previous health services work and readings about chronic illness. Thus, attempts were made to remain as inductive as possible by purposefully conducting an initial, limited literature search so as to remain relatively unaware of overriding theoretical frameworks. However as discussed in Chapter 6 it was inevitable that further reading and accruing knowledge about the participants’ would interfere with this aim. In response to this, determined efforts were made to bracket any prejudgements and information as far as possible by adopting several strategies. For instance, intently focusing on the participants accounting and not being distracted by presuppositions or ones own feelings, asking open-ended questions so as to facilitate undirected responses, maintaining a reflective diary and conducting reflective discussions and credibility checks with the PhD supervisor (Willig, 2008; Smith, 2004). It is, however, unlikely that the final account is a mirror image of the participants’ experiences or that this account is the only interpretation available. The main claim is that a reflective, iterative and inductive approach facilitated an authentic representation of the participants’ experiences.

Finally, in contrast to previous studies of CLBP a qualitative, longitudinal IPA research project has facilitated a broad, nuanced and detailed account of these participants’ experiences. The research project has highlighted the salience of the “painful body” and developed understanding of CLBP as an embodied experience with CLBP endured and managed on a daily, often repetitive basis. Yet, while participants’ pain experiences and coping strategies were often unchanging they could also change according to a modification of illness beliefs that corresponded with a pain-free episode that afforded participants an opportunity to reappraise their management of their pain.

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APPENDICES

Appendix 1: copy of invitation letter from clinic to patients

[Headed note-paper]

Contact details of chronic pain clinicians

Date

CHRONIC PAIN SERVICES

Dear,

RE: Participation in a research study investigating patients' experiences of living with chronic lower back pain

We are writing to ask you whether you would be interested in taking part in a research study that will involve you taking part in three interviews with a researcher, prior to, and whilst and after receiving treatment at the chronic pain clinic (see attached). The research is being undertaken by a researcher from the University of Wales Swansea who intends to explore the experiences of patients with chronic lower back pain. The interviews will be held at a place and time that is suitable to you and your responses will be confidential to you and the researcher, who will not identify you by name in any publication of the results.

The study is not part of treatment and will not affect your position on the waiting list.

This is a valuable study that will enable health professionals to develop present understanding as to how people cope with chronic lower back pain.

If you are interested in participating in the study, please complete the accompanying form and return it to the chronic pain clinic in the SAE as soon as possible. We will then inform the researcher, Ms Sherrill Snelgrove, of your intention to participate in the study who will contact you.

Yours Sincerely,

Chronic pain clinic Clinicians names/signatures

Appendix 2: copy of patients response form

RE: Participation in a research study investigating patients' experiences of living with chronic lower back pain

I am willing for my name and contact details to be given to Ms Sherrill Snelgrove so that she can contact me to arrange a time and place to discuss participating in a research study about chronic pain. I understand this is a research study and the information gained by the researcher will remain confidential and anonymity maintained in any future publications.

Name: -----

Address: -----

Telephone: -----

E mail: -----

Signature -----

Appendix 3: copy of consent form

[headed note-paper]

Contact number of researcher and clinicians

CONSENT FORM

An interview study investigating patient's experience of living with chronic low back pain

Following an invitation by staff of the chronic pain clinic to participate in this research on Chronic low back pain I allowed my contact details to be made available to Ms Sherrill Snelgrove. I have since contacted Ms Sherrill Snelgrove and read the information sheet about the research and I agree to take part in the interviews as part of the research into chronic pain.

I understand that my participation is voluntary and that I am free to withdraw from the study at any time.

I understand that the interviews will be tape-recorded and that the information gained from the interviews will be kept in a safe and secure location. Confidentiality will be maintained throughout the study and that information used in the study will not be attributed to named individuals.

Signed..... Dated:

Appendix 4: copy of information letter to patients

[headed notepaper]

Contact details of researcher and clinicians

Re: An interview study investigating patient's experience of living with chronic lower back pain

Dear,

I are writing to ask you whether you would be interested in taking part in an interview study exploring the experiences of people with long term low back pain.

The study involves your participation in three tape-recorded interviews with myself (I am an experienced nurse studying for a higher degree), prior to and after receiving treatment at the chronic pain clinic. The interviews will be about 30 – 90 minutes long and can be terminated upon your request. They will be held at a place and time that is suitable for you. Whilst your G.P will be informed about our participation, all responses will be confidential; you will not be identifiable by name in any publication of the results. You may withdraw from the study at any time.

The study is not part of treatment and will not affect your position on the waiting list.

This is a valuable study that will enable health professionals to develop understanding as to how people cope with chronic low back pain.

If you decide to take part, please complete the reply slip in the envelope provided and we will arrange a mutually convenient time to meet. If you wish to talk to me further about the interviews I can be contacted on the above number and at the above address. Sister Helen Williams from The Chronic Pain clinic is also be willing to explain any issues that you might like to raise regarding your participation in the study.

Yours Sincerely,

Sherrill Snelgrove (Lead researcher)

Appendix 5: copy of courtesy letter to patients General Practitioner (G.P.).

[Headed note-paper]

Contact numbers

Dear

RE: A Longitudinal investigation of patients' experiences of living with chronic low back pain

I am writing to inform you that your patient..... has agreed to participate in a longitudinal interview study exploring the experiences of chronic low back pain. The study is a PhD research project that has been approved by the local ethics committee and Caldicott Guardian and is supported by the key clinicians in the Chronic Pain Clinic. The study will include three interviews conducted by myself, whilst is receiving treatment in the pain clinic.

Yours Sincerely,

Sherrill Snelgrove

(Lead researcher)

Appendix 6: papers published from PhD work

Snelgrove, S & Liossi, C. (2009) An Interpretative Phenomenological Analysis (IPA) of living with benign chronic low back pain. *British Journal of Health Psychology*. 14, 735 - 749.