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Living with Pain or Living in Pain:  
Narrative Journeys with Low Back Pain.

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PhD

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## **Abstract**

This study used a qualitative method to focus on the perspectives, beliefs and expectations of low back pain sufferers. The research was undertaken within a hospital based pain clinic.

In recent years low back pain research has proliferated, and the epidemiological evidence suggests that back pain is an increasing problem. Much attention has been paid to the impact of low back pain on the population, and to the increasing cost in economic and health terms. Biomedical and psychological evidence abounds to shape acute and chronic management of low back pain, but there is a dearth of information about the viewpoint of those suffering pain. This study attempted to bring the understanding of the back pain sufferer to the fore. Issues of quality of life, functional ability and the impact of back pain on their lifestyle were explored, along with the influence of contextual factors in relation to how back pain sufferers perceived themselves and how others perceived them.

A narrative method was utilized to illuminate the journey with pain. Nine interviews were conducted, and the interpretation and presentation of the narratives generated was influenced by Ricoeur's interpretative theory. Thematic analysis revealed that doctorability, agency, control, separation or acceptance of the pain and the concept of future life were key features within the narratives. The analysis highlighted that for the majority in this study pain arrived uninvited following a traumatic accident or incident,

and back pain became a chronic condition. It was always unwanted and initially it was unexpected as the usual script for pain is one of a transient incapacity followed by recovery. It was precisely this deviation from the norm that resulted in difficulties for the people suffering the pain. Biographical differences did not appear to be identifiable in the themes discerned in the stories, nor in the overall structure.

The narratives showed the complexity of establishing a life with pain, rather than a life in pain. The participants entered previously unknown territory, and consequently adopted diverse strategies to maintain relationships, work and interests from their former life as well as developing new activities and management options. The narratives indicated that some were more successful than others, and constructed a life with pain. Some were less successful, and the people lived within severe limits and led very restricted lives, as such a life in pain. Three central status claims emerged through the narratives: searching for a cure; resignation; and acceptance, and the research built a conceptual model of different ways of living with or in pain with reference to these claims.

In conclusion, it is the individuals understanding of their relationship with pain that shapes that persons life. People differ in their aspirations, backgrounds and experiences, and the individual stories indicated such differences. ‘Struggles discourse’ provided a vehicle by which meaningful identity could be rescued from unfavourable circumstances. This discursive strategy resonated with the idea of identity as a dynamic concept, illustrated by those with chronic pain when they compared their former healthy self with their ill self. It is proposed that being encouraged to relinquish aspects of the self that are

no longer meaningful and incorporate pain related changes to form a new self moves people from separating from and fighting the pain to resigning to the pain, and ultimately it is hoped that acceptance to a life with pain can be achieved.

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## Declaration

I declare that the work contained in this thesis has not been submitted for any other award and that it is all my own work.

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# Chapter 1

## Introduction

### *Background rationale*

My interest in chronic back pain grew as a consequence of working with people who were being investigated and treated for low back pain. I observed a gap between the evidence base employed by health professionals and the understanding and needs of those people suffering from back pain. Professional practice is based on the technical knowledge of the professionals not the experiential knowledge of the patient. Current management strategies are based on the accepted pain paradigm, summed up in the definition of pain proposed by the International Association of the Study of Pain (1994), where pain is an unpleasant sensory and emotional experience associated with actual or potential tissue damage. As Carter (2004) claims this definition is the cornerstone of academic and professional thinking about pain, but she also suggests that this definition fails in a number of ways. Firstly it acknowledges that pain is emotional, but says nothing of the individual emotional experience of pain and fails to convey the way pain shifts and changes the landscape of the person's world. The definition is too generic, and although it is instantly recognizable to professionals it seems to have little resonance for people experiencing pain. Working within this paradigm sets the context, so that people think and believe that pain can be effectively assessed and measured, and ultimately controlled.

In my clinical practice I frequently observed patients being told by the health professionals that they were receiving good news and that surgery or other invasive



procedures were not required for their back pain. The look of bewilderment was not uncommon as people were still facing the same pain and problems but had been told that a cure was not possible. Some patients are left with no clear diagnosis and having failed to respond to treatment are discharged without the prospect for any further treatment and told to 'learn to live with it' (Main & Spanswick 2000). The curative model is relied on by health professionals and patients, and when no longer appropriate because of the chronic nature of the problem patients are moved onto a management approach. The idea of chronicity is not mentioned early within the trajectory so a change to the medical approach is a shock to many, as people still had the same problem - yesterday it was potentially curable, today it is only manageable. People diagnosed with chronic illnesses, such as rheumatoid arthritis and diabetes for example, are told of prognosis and management options from the outset. My clinical experience suggested that this was not the case with low back pain; I saw people in disbelief, frustration, anger and confusion as it became known to them that a cure was not possible. I began to frame research questions: Why do people feel like this? What is it like coping with chronic pain day to day, and does it get better? A brief review of the epidemiology of low back pain provided a useful starting point to frame the experiences of people with low back pain and referenced where treatment and management options stem from.

#### *A brief epidemiological review of low back pain*

In recent years low back pain research has proliferated. Much attention has been paid to the impact of low back pain on the population, and to the increasing cost in economic and health terms. The epidemiological evidence suggests that back pain is an increasing

problem, however there is no evidence that pathology is changing, rather the problem is thought to be due to changed expectations and attitudes (Bandolier 1995). Pain is the most universal physical and emotional stress that human beings experience (Waddell 2004). Most people get some back ache at some time in their lives. Walker (2000) conducted a systematic review of international data and showed that 12 – 33% of people report some back symptoms on the day of interview; 19 – 43% report back pain in the last month; 27 – 65% in the last year; and 59 – 84% at some time in their lives. The British experience is not unusual. Most low back pain is in the form of acute, short term episodes, where 90% of patients recover within four weeks, most without treatment and many without consulting their GP (McKinnon et al 1997).

The South Manchester study looked at patterns of prevalence and incidence of new episodes of back pain over one year (Papageorgiou et al 1996). Initially the population fits into three groups: group 1 includes people who have been free of back pain for the previous twelve months, equals 62%; group 2 is comprised of those who have had intermittent or less disabling back pain during the previous twelve months, equals 32%; group 3 includes those who have had long-standing or serious disabling back pain during the previous twelve months, equals 6%. Papageorgiou et al (1996) found that over the course of the following year about 30% of group 1 would develop a new episode of back pain, though it is not a new episode for some of them. Almost half of group 2 would have further episodes of back pain, and 30% of group 3 would improve and have less severe problems. However they would be replaced by a comparable number from groups 1 and 2 who develop more severe problems during that year. This study challenges the

assumption that severe chronic back pain will continue indefinitely, and shows that people move between groups. However the pool of chronic back pain stays about 6% of the adult population.

As back pain is not a static problem, Croft et al (1998) suggested that the most important epidemiological concept is the pattern of back pain over an individual's life, as back pain is often a recurrent or fluctuating problem. They base this on four observations: that 60 – 80% of people get back pain at some time in their lives; that most acute clinical attacks settle rapidly, but residual symptoms and recurrences are common; 35% of people report back pain lasting 24 hours or more each month and 15-30% have some back pain each day. Croft et al (1998) consider the strongest predictor of a further episode of low back pain is a history of previous episodes.

So far then, back pain can be seen as an increasing problem which will affect most of us at some point in our lives. A reasonable percentage of people will suffer ongoing recurrent back pain, whilst a small number will experience chronic back pain. The peak incidence of back pain is between the ages of 40 to 60, with the age of onset evenly spread from 16 to 40 (Bandolier 1995), reflecting that it is common in people of working age (Palmer et al 2000). There is little difference for men and women (Lamers et al 2005). There is an increased prevalence of back pain with smoking (Bandolier 1995); though this could be a coincidence in view of the complex set of demographic and social factors associated with smoking.

Palmer et al (2000) compared two prevalence surveys at an interval of ten years. The surveys analysed were based on large samples selected in an identical manner with a wide geographical coverage and similar response rates. Over ten years the one year prevalence of back pain rose from 36% to 49%; this trend was consistent across all ages in both men and women, and within social classes and regions. There was also an increase in prevalence of less disabling back pain. Palmer et al (2000) suggest a possible explanation could be that cultural changes have led to a greater awareness of more minor back symptoms and willingness to report them. It is further postulated that this cultural shift may also have rendered back pain more acceptable as a reason for absence attributed to sickness.

It has been mentioned that back pain is common in people of working age and is one of the leading causes of work loss in the UK. The estimated total working days lost in Britain because of low back pain is 52 million; of which 85% of people are off for short periods, and 15% of people are off work for more than one month (Bandolier 1995). The longer an individual is off work the lower the chance of returning to work. CSAG (2000) reviewed the prevalence of chronic pain and found that only 26% of patients classed as having chronic pain were employed, and 91% were limited in household or leisure activities. Lower levels of quality of life were associated with efficiency loss and absenteeism (Lamers et al 2005). Of this group of people identified as having chronic pain 34% had low back pain. The costs of low back pain are estimated to be £4 billion per year in lost production, with an NHS bill of approximately £481million per year.

The impact of low back pain on health services is significant. Elliott et al (1999) conducted a large, prospective cohort study of low back pain patients consulting their GP, and found that patients with chronic pain use health services up to five times more frequently than the rest of the population. Back pain and arthritis were the two most commonly reported causes of chronic pain. In another prospective cohort study it was found that in the UK 25% of back pain patients consult their GP; most stop consulting within three months but 60-80% still have pain or disability one year later (Foster et al 2008). Hadler & Carey (1998) found that seeking care for the first episode of back pain established a dynamic that predisposed to seeking care again. Seeking care was not related to the magnitude of the pain but rather to overwhelming psychosocial factors. Elliott et al (1999) endorsed this view and reported that the response to chronic pain is not solely dependent on pain intensity and disability, but in fact reflects the multi-factorial and subjective experience of chronic pain. Foster et al (2008) continued this theme and concluded that illness perceptions were important determinants of function and outcome. The most predictive illness perceptions were the timeline from acute to chronic pain and the consequences and control patients had over the pain.

Conventional definitions of chronic pain often feature a temporal component, usually length of time since pain onset, with no consideration of pain severity or disability. Such definitions imply that a good outcome of treatment is achieved only by becoming pain free, whereas in the recurrent course of back pain a broader approach to defining pain may be more appropriate, in which improvement to a lower level of pain is a favourable outcome. Dunn et al (2007) conducted a prospective cohort study combining information

about pain history, current status and likely prognosis on a primary care low back pain population. This study has highlighted that it is possible to identify probable chronic pain from initial onset without recourse to time scales.

### *The challenge of low back pain*

Back pain and sciatica have affected man throughout recorded history, however there is no evidence that back pain has changed in severity or frequency (Waddell 2004). What is thought to have changed is how back pain is understood and managed. The participants within this study formed part of the population described in the previous section, and their treatment and management have been based on the recommendation from these surveys and others which influence service design and provision. It is now recognized that present health care and NHS services are unsatisfactory in back pain management and are not solving the problem (RCGP 1999). Routine hospital specialty services and referral patterns are largely inappropriate for patients with simple back pain creating unrealistic expectations of cure and establishing chronicity of problems. There is widespread dissatisfaction with currently available services for people who suffer from back pain, and medical practice appears at times to compound the situation by pursuing policies for management and certification that prolong the problem (CSAG 1994). Back pain can be seen as a problem to both patients and health professionals; patients may feel that they cannot get clear information and advice on cause, management or likely future outcome; health professionals cannot always diagnose any definite disease or offer any medical cure. Back pain represents one of the major challenges in health care today, and getting inside the experience may be the key to understanding the problem.

My clinical experience and particular interest in low back pain had highlighted a gap between the patient and health professional perceptions of living with pain. This research sought to fill this gap, and aimed to reveal the 'journey' from pain onset, generating knowledge of what is important to sufferers of back pain, and indicating where the journey may take them. People with back pain are initially seen in acute settings and then referred to the chronic pain clinic. Biomedical and psychological evidence abounds to shape acute and chronic management of low back pain, but there is a dearth of information about the viewpoint of those suffering pain.

#### *Aims of this study*

This study focused on the patients' perspective and investigated the beliefs and expectations of low back pain sufferers attending a pain clinic; specifically

- ◆ the beliefs the study participants hold on what are the causes of their pain,
- ◆ what their pain means to them,
- ◆ the experience of living with low back pain,
- ◆ what the future might hold.

Issues of quality of life, functional ability and the impact of back pain on their lifestyle were explored, along with the influence of contextual factors in relation to how back pain sufferers perceived themselves and how others perceived them. The research embraced a hermeneutic framework to bring the understanding of the back pain sufferer to the fore. A narrative method was utilized to illuminate the journey with pain, as experienced by

people attending a pain clinic. Stories were told and the interpretation of these stories is presented in this thesis.

Chapter two presents an overview of the literature pertaining to pain, and specifically low back pain. Low back pain has been researched prolifically over the past twenty years and the extensive literature provides a backdrop to the study. Having worked within the field of pain management for a number of years I was already familiar with much of this literature, and this and my personal experience shaped the study. Chapter three provides the details of the research process. This study is interpretive, and uses narrative methodology. The process of sampling, data collection and issues of credibility and rigour are explored within this section.

Chapter four begins with an overview of the theoretical literature upon which a preliminary model is based. The chapter then plots the recurrent features, and provides descriptions and examples as they unfold in the stories. After multiple readings, five themes were identified:

- Doctorability
- Agency
- Control
- The future
- Separation / acceptance



Two strategies employed by the participants are introduced in this section, which outline how the themes are either used to meet pain head on or to give in to the pain.

Chapter five provides a detailed account of the narratives from beginnings to endings, and highlights the importance and influence of the themes throughout the stories. The narratives lead to the concepts of living with pain or living in pain, and the relationship between separating from the pain and accepting it. Chapter six presents a discussion of the importance of accepting the pain, featuring the difficulties and challenges of doing so. Theoretical constructions from the academic literature on grieving, hope and illness narratives are drawn upon to examine a life with pain or in pain.

Chapter seven concludes the thesis and considers the importance of asking people to elaborate their pain journey. A discussion of the implications of these findings for theory and practice development is included. It is hoped that an understanding of the patient journey will help to develop approaches to know and support people to live with pain.

## Chapter 2

### Literature Review

#### *Chapter Overview*

Low back pain has been widely researched and written about, resulting in a great deal of development in the understanding of the pain experience. Any literature search on low back pain will highlight thousands of potential texts, but as the focus of this research is specifically the meaning of low back pain to sufferers and the impact on their lifestyle, the following review is predominantly concerned with literature in this vein. The meaning of low back pain is at the core of the literature review with reference to personal and societal views. Before considering low back pain in depth, a useful starting point is to address the question of what is pain and consider the differences between acute and chronic pain. The back pain literature will then be examined, considering the meanings and consequences for the sufferers. The review will highlight that certain biomedical and psychological views dominate the back pain literature, however alternative views are available, including illness narratives, which offer an abundance of rich literature from which useful parallels can be drawn. Pain and suffering are closely linked concepts, and illness narratives are rich in explanations of suffering and theories of coping. Low back pain research is dominated by biomedical approaches, but together with important insights from such fields as psychology and sociology a full understanding of chronic back pain, in particular peoples experience and conception of their painful life situation, is beginning to be achieved.

## **Pain: A Short History of Ideas**

It can be argued that ideas of pain over the centuries reflect philosophies of science. The history of ideas about pain serves as an example of many of the major debates current in science, social theory, health and illness. Hughes (1990) suggests that different meaning systems entail different models of reality and different propositions about what 'reality' is, and so different ways of establishing what can be accepted as 'real'. The history of pain therefore provides an opportunity to explore both the nature of scientific knowledge and contrasting ideas about pain.

### *Pre-scientific Models*

Pain is ubiquitous to the human experience and has been written about in prose and poetry and depicted in art and music from ancient to modern times (Sofaer 1998). Ancient philosophers thought of pain as an emotion, an imbalance of body fluids or a visitation from an evil spirit (Carr & Mann 2000). The Ancient Egyptians viewed pain as a consequence of influences from the gods or spirits of the dead. The Ancient Indians however saw pain as a frustration of desires but believed that all joy or pain came from the heart, whilst ancient China described pain as an imbalance of Yin-Yang and vital energy. By the 6<sup>th</sup> century BC the brain was considered to be the centre of sensation (Main & Spanswick 2000). Texts from Ancient Greece such as the Iliad and Odyssey placed much emphasis on pain; Homer thought pain was caused by arrows shot by the gods (Rey 1995). Plato believed that pain and pleasure affected the whole body and were from peripheral sensations and the heart and liver, whilst in contrast Aristotle believed

that the brain had no direct function in sensory processes and did not regard pain as a sensation but rather a passion of the soul (Sofaer 1998). Hippocrates considered that pain was a consequence of deficiencies or excesses in the flow of one of the four humours in the body (Main & Spanswick 2000).

Aristotle's theory had considerable influence for hundreds of years. Pain was still considered to be an emotion or sensation experienced in the heart or an effect of evil spirits. The brain was thought to play no part in the experience of pain, even though by the third century BC Galen had distinguished three types of nerve and viewed the brain as the centre of sensibility (Main & Spanswick 2000). Pain continued to be regarded as a sensation or an emotion, until a new theory was developed in the 17<sup>th</sup> century which directly stated a dichotomy between sensory and emotional factors. Descartes explanation of pain represented a significant advance on its predecessors in postulating a mechanism of pain transmission from the periphery of the body to higher centres in the brain (Main & Spanswick 2000). The Cartesian theory assumed a one-to-one relationship between tissue damage and pain experience, set within a dualistic separation of mind and body.

#### *Positivist Models (Clinical-medical)*

Physiological theories became the focus of pain research in the 19<sup>th</sup> and 20<sup>th</sup> centuries, following the traditional biomedical model of disease (Gatchel et al 2007). These early theories can be divided into two perspectives. The specificity theory, based on that developed by Descartes, proposed a pain pathway linking the periphery of the body to the higher centres in the brain, in which pain is considered to be a specific sensation

independent of other sensations (Main & Spanswick 2000). One of the earliest specificity theorists was von Frey, who suggested that specialised nerve endings were involved in the transduction and transmission of painful information (Gatchel et al 2007). The summation theory, proposed by Erb in 1895, suggested that touch was experienced as a painful sensation only when it reached a certain threshold (Main & Spanswick 2000). Similar to the summation theory, and within the second perspective is pattern theory, which suggests that pain is not due to the activation of specific receptors and pathways, but is based on the intensity of the sensation and the processing of the pattern of responses (Gatchel et al 2007). All these theories suggest a simple relationship between tissue damage and pain perception, and as such pain was fixed to the characteristics of the stimulus. Although these theories generated much research and could explain some aspects of pain, the theories could not account for pain in the absence of tissue damage or the variation in pain between individuals.

Another perspective, relating back to Aristotle, conceptualised pain as a quality of the soul, an emotion rather than a purely sensory event (Gatchel et al 2007). Livingston (1943) supported this perspective, and claimed that pain should be seen as a subjective state arising from activation of aversive networks in the brain. This constituted a dramatic shift in thought suggesting that pain was a factor in motivating behaviour. However both the sensory and affective models were unable to explain much of what was observed experimentally and clinically, and the inadequacy of treatment based on these models led the impetus for a more complex, integrative model.

### *Interpretivist Model*

There has been a great deal of development in the understanding of pain from the earliest theories to the present time, with the culmination of biopsychosocial models of pain management developing in an attempt to integrate physical, psychological and social perspectives. The biopsychosocial model focuses on both disease and illness, with illness being viewed as the complex interaction of biological, psychological and social factors (Gatchel 2005). As Gatchel et al (2007) contend the distinction between illness and disease is analogous to the distinction that can be made between pain and nociception. Nociception is the stimulation of nerves that convey information about potential tissue damage to the brain. Pain, however, is the subjective experience that results from the transmission and modulation of sensory information in tandem with a person's genetic composition, prior learning and pain experiences, psychological status and sociocultural influences. The picture that we now have of the experiences people have when they are in pain and the mechanisms that help to bring those experiences about is very complex (Davis 2000). It involves all aspects of a person's nature from their physiology and biochemistry, to their emotional and motivational make up, to their psychological processes, to their social relationships, and spiritual awareness.

Professional and lay views on pain and how it can be studied have changed over time, and a useful framework for considering such changes is the notion of scientific revolutions. Kuhn (1962) introduced the idea of scientific revolutions, and initiated his own revolution in the understanding of science. He attempted to demonstrate that scientific understanding was itself the outcome of a social process. Kuhn (1962) argued

that science does not progress according to the criteria of falsifying theories because evidence that does not support a theory becomes future research, and in this way theories are not falsified but are the subject of continuous research. Kuhn (1962) calls this 'normal science' employed within a paradigm that characterises the practice of science. A paradigm is a representation of a world view. Science develops according to the culture that scientists inhabit and this determines their practices and choices of theories. Chalmers (1982) summarises Kuhn's ideas as progressing through various stages. The first stage is normal science where scientists work within the ruling paradigm, resulting in a growth of knowledge and understanding within the boundaries of the paradigm. The crisis –revolution stage occurs when the certainty of the paradigm is increasingly questioned and it becomes evident that normal science thinking is inadequate and new explanations are needed. As new or revolutionary thinking occurs there is a move away from the old normal science to a new normal science, creating a paradigm shift. Kuhn (1962) suggests that this process is cyclical, with periods of revolution followed by paradigm exploration.

The current paradigm embodies the complexity of pain, and is completely different to the historical, scientific and religious beliefs of the previous 400 years. Carter (1998) describes how the mind / body duality paradigm of pain was broadly reflective of the scientific, reductionist mode of thinking evident at that time as scientists investigated the mechanistic functioning of the body. Reductionism meant that pain research focused on the desire to find simple solutions to the challenge of pain, which led to explanations of single pain pathways and pain centres. Even when other models of pain were proposed,

the dominance of pain as a physical entity persisted (Carter 1998). Historically the strongest tradition in research is perceived to be positivism, and this type of research has resulted in studies which have contributed to the development of knowledge in the pharmacology, the neuroanatomy, and the biochemistry of pain. The power of the natural sciences lay in the methods of generalisation and abstraction, and in the capacity to view phenomena through particular perspectives, without mythical, cultural, religious and emotional associations (Rustin 2000). An accumulation of a large body of contradictory evidence finally demonstrated that this paradigm was untenable, what Kuhn would term a crisis revolution. New thinking about pain led the way to a period of new normal science, characterised by the development of the gate control theory of pain.

#### *Scientific – Realist Model*

In 1965 Melzack & Wall proposed the gate theory of pain, which has proved to be a turning point to the understanding of pain in two key ways. Firstly pain perception is now accepted as complex neural interactions where impulses generated by tissue damage are modified both by ascending systems activated by stimuli and by descending pain suppressing systems activated by environmental and psychological factors (Melzack & Wall 1965). Secondly pain is recognised as a psycho-physiological phenomenon resulting from the interaction between physiological and psychological events. Melzack & Wall (1965) combined the best features of the specificity theories and pattern theories with the affective emotional view. They recognized that there was a certain degree of specificity for peripheral nerve function, but there was also a degree of pattern recognition central to processing noxious information, and when taken together they formulated that a



comprehensive model must take into consideration the amplifying effects of emotion and the interpretive role of cognitive evaluation (Gatchel et al 2007).

The gate control theory offered a way of integrating concepts of pain behaviour by providing a model of how psychological factors could activate descending pain inhibitory systems and thus modulate pain. The importance of psychological influences on the perception of pain have come to the fore, and subsequently led to research into beliefs about pain and pain related coping strategies. There is little doubt that the gate control theory of pain was a major advancement for pain research and management, however as the field of pain research continues to evolve the adequacy of the gate theory is called into question.

The neuromatrix theory of pain proposes that pain is a multifaceted experience that is produced by a widely distributed brain neural network, called the body-self neuromatrix (Melzack 2001). The body-self neuromatrix integrates cognitive-evaluative, sensory-discriminative, and motivational-affective components. An important component is the recognition that pain is the consequence of the output of the widely distributed neural network rather than a direct response to sensory input following tissue injury (Melzack 2001). The development of this largely hypothetical model is based on patients with spinal cord injuries and phantom limb pain (Gatchel et al 2007). Traditional theories have difficulty in accounting for these situations, but the neuro-self matrix addresses these difficulties as it requires no actual sensory input to produce bodily experiences. Gatchel et al (2007) suggest that the concept of the neuromatrix has potentially important

explanatory implications for brain function and provides a theoretical framework for the biopsychosocial perspective of chronic pain.

The gate control theory proposed by Melzack & Wall (1965) had a significant impact on pain thinking, and a new pain paradigm emerged. This theory provided the fuel for a radical change in thinking about pain, and was acknowledged by practitioners not least by being incorporated into the International Association for the Study of Pain definition (Carter 1998). The current paradigm is very different from what went before as it adopted a more holistic approach to include biological, psychological and social influences to pain. The appreciation of the complexity of pain has legitimated the involvement of researchers from diverse backgrounds such as psychology, biomedicine, nursing and sociology. This interdisciplinarity offers a rich diversity in research paradigms and result in a more comprehensive understanding of pain. The sociology and anthropology of science introduced the idea that scientific knowledge came in many varieties. As a result alternative methodologies, including qualitative and interpretive approaches in the human sciences, were recognised. Research using a constructivist philosophy has led the way to a greater understanding of the meaning and consequences of pain and coping strategies.

Pain is multidimensional; it can equally be seen as something tangible for which evidence can be established, or as something less tangible which exists solely within the individual's experience of it (Carter 1998). Pain is usually perceived as being somewhere between these two extremes. The current consensus definition of pain reflects the reigning pain paradigm, but Carter (1998) reminds us that whilst definitions of pain have

changed over the last several thousand years, pain itself has not changed. For many years pain was seen as something which had to be borne, but over time the impact of pain beyond the obvious physical consequences has become central.

### Operationalising Concepts of Pain

The experience of pain is essentially an individual, internal experience, known only to the person in pain (Davis 2000). Some definitions of pain claim that pain is what the patient says it is (McCaffrey 1968), other definitions incorporate some indication of the link with tissue damage (Sternbach 1968; Mountcastle 1980). The International Association for the Study of Pain (IASP) define pain as ‘an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage’ (p 209 Merskey & Bogduk 1994). This latter definition has almost universally been adopted by those working with and researching pain. However Melzack & Wall (1996) question the relevance of definitions as they find it difficult to accept any definition in its entirety. Pain can mean so many things to so many different people that it is important not to tie down to one particular definition. The IASP definition acknowledges the complexity of the pain experience which is not determined by tissue damage alone, and therefore seems to be congruent with the current understanding of the meaning of pain.

It is worth briefly mentioning the classification of pain, as it has a bearing on the meaning ascribed to the pain by the sufferer, which will be elaborated upon later in the review. There have been several attempts to classify types of pain; Turk & Melzack (1992) describe different ways of achieving this. They have discussed behavioural, cognitive,

empirical, multi-dimensional and clustering methods, and concluded that a system should be used in the clinical setting so that communication and understanding can be evaluated (Turk & Melzack 1992). For the most part a simple clustering system of classification has been used, employing the categories acute, chronic (non-malignant) and cancer. Clear distinctions between types of pain are not always possible, and invariably omissions and overlap can result (McCaffrey & Pasero 1999), for example acute on chronic pain, or recurrent acute pain.

Acute pain is a straightforward concept, suggesting pain of sudden onset with a relatively brief duration that subsides as healing takes place (McCaffrey & Pasero 1999). Acute pain acts has an important biological safety mechanism that warns when something is wrong. It is a classic symptom that prompts people to consult health care professionals, at which time a diagnosis will be made and a cure prescribed (Potter 1998). Acute pain fits well into this medical model, it is a successful approach. In contrast chronic pain is a complex concept, suggesting pain that exceeds the expected duration to recovery or is associated with a pathological diagnosis. Chronic pain serves no useful purpose, as it may no longer be associated with disease, injury or any identifiable cause. Chronic non-malignant pain is persistent and has no endpoint (Carr & Mann 2000). Chronic pain does not fit neatly into the medical model. Applicable to both acute and chronic pain is a general concern to patients of the cause of their pain, the likelihood of it responding to treatment and what they can expect in the future. Wall (1988) suggests that pain functions more as a basic human drive, like hunger, leading to highly predictable responses. Pain

always produces some response in the person suffering the pain but usually also in those around the person.

Different sorts of pain have widely differing psychological impacts and are perceived differently by patients and health care professionals (Main & Spanswick 2000). For example pain associated with disease is not necessarily easier to tolerate but may be more easily understood and managed. Pain differs not only in quality and severity but also in its impact on activities of living, quality of life and work. Acute pain, though very disruptive, is usually time limited and incapacities that result are expected to resolve. Chronic pain by its very nature is ongoing and presents a different array of challenges to the sufferer. People with chronic pain may have often been offered a variety of diagnoses, and this lack of clarity and consistency can be extremely distressing because they may worry that the real cause of their pain has not been established (Main & Spanswick 2000). Main & Spanswick (2000) also suggest that pain of short duration can be coped with reasonably successfully, but chronic pain requires a much wider range of coping skills and strategies.

The public have an expectation of health care to define a cause for a disorder, treat the cause and thus solve the problem. Carr & Mann (2000) suggest that for many people the symptom of pain is not so straightforward, but success in other spheres of health care fuels the demand to cure all ills. In the Western world we have medicalised pain and therefore expect it to fit into the model of finding a cure. Society has high expectations of what health care can deliver, and those in pain are no longer prepared to suffer in silence

(Carr & Mann 2000). However when faced with a pain that challenges the person's and health care professionals ability to relieve it, or in some cases understand it, frustrations arise. Chronic pain does not fit into a curative model and nor is it identified as a chronic illness; the consequences that ensue from this premise are featured in the following sections of the review.

### **Low Back Pain: A History of Medical Ideas**

The previous section reviewed how pain had been defined and modelled over the centuries to the present time. The concept of changing paradigms was used to elaborate how the nature of pain has remained unchanged but that knowledge and understanding of pain have developed. The following section focuses more specifically on low back pain and begins with a review of what low back pain is, followed by an overview of the epidemiology of low back pain. People presenting with low back pain fall into a very circumscribed population which generates expectations of outcomes to both professionals and sufferers. An elaboration of the nature of low back pain and the epidemiological data of this population is useful in framing where the subjects of this study are placed clinically.

#### *Early thoughts on low back pain*

Human beings have had back pain through recorded history; the oldest surviving text about back pain is the Edwin Smith papyrus dating from about 1500<sub>BC</sub> (Waddell 2004). Historically back pain has not been viewed as a disabling condition. By the 17<sup>th</sup> century

medicine was distinguishing between illnesses and introduced the concept of clinical syndromes. At this time Sydenham classified back pain as lumbago with the rheumatic diseases, and treatment was by general measure against rheumatism (Waddell 2004). Two key ideas emerged in the 19<sup>th</sup> century that paved the way for our modern approach to back pain. Firstly that back pain comes from the spine, this was discovered by Brown in 1828; secondly that back pain is due to trauma, up until this time medicine did not consider that back pain could be due to injury. Erichsen described 'railway spine' in 1866 as severe jarring of the spine, thus linking injury to back pain (Waddell 2004). Most people and many health professionals still regard back pain as an injury.

The rationale of rest for back pain started from the 19<sup>th</sup> century in response to the idea that back pain was due to injury. Rest was considered to be essential for healing, movement provoked pain therefore must be damaging and thus should be avoided. There was little scientific evidence for this strategy, however it persisted until very recently. By the 20<sup>th</sup> century, back pain as an injury and a mechanical problem was firmly entrenched with the view that it should be treated by orthopaedic principles (Waddell 2004). Thus the role of surgery for back pain was established, and led to the belief that back pain is a structural problem which can be fixed. It is only in the last twenty years that evidence has become available to support the view that most back pain is not a surgical problem and should be managed with active physiotherapy. Over the last few decades much has been learned about back pain, about pain itself and about how people react and deal with pain, however we still cannot always offer a cure. In many instances the beliefs that people hold are related to advice and management that has subsequently become outdated.

### *Current thoughts on low back pain*

Waddell (2004) defines back pain as a mechanical problem of musculoskeletal origin in which symptoms vary with physical activity and over time, and further highlights that the cause of pain can be any of the spinal structures, and is therefore difficult to know the exact cause. This helps us to understand the lack of efficacy of surgery, especially when coupled with the knowledge that many symptom free people have evidence of degenerative changes on spinal scans. These changes are not always indicative of pain. Most people suffering back pain present with pain in the lumbosacral region, buttocks and thighs. Back pain may be very painful, but severity is not related to diagnosis. It used to be called 'simple backache' to reassure patients that there was nothing sinister nor serious, however it has been re-labelled as non-specific back pain because 'simple' failed to acknowledge the degree of pain and suffering felt by patients. Less than 5% of back pain is due to serious spinal pathology, but 99% of patients with back problems present with pain as the main symptom (Waddell 2004). Pain is a symptom, not a clinical sign of a disease, and cannot be assessed directly and, therefore, will always depend on the patients report.

### *The Epidemiology and Treatment of Low Back Pain*

Epidemiological evidence indicates that back pain is the third most commonly reported symptom after headache and tiredness (CSAG 1994). Back pain is one of the commonest and most rapidly increasing causes of work loss and demand for health care (Waddell 1999), and is the nation's leading cause of disability, rising more quickly over recent



years than any other disability (Labour Force Survey 1998). A third of back pain sufferers' reported that back pain had restricted their activity (Department of Health 1998). A more extensive review of the epidemiology of back pain was presented in the introduction.

Many people cope with back pain themselves and never seek healthcare, but many do not and it is postulated that the decision to seek healthcare is multi-factorial (CSAG 1994). Approximately 5 million adults per year consult their GP with a back pain complaint and 10% go on to consult a complementary practitioner (Palmer et al 2000). Of the estimated 24% of people who consult their GP, approximately 50% will have stopped consulting within one week and 90% will have stopped within one month (Croft et al 1998). The remaining 10% often continue to consult and in many instances go on to develop chronic low back pain (Watson et al 1998). Many of these people will have endured a wide range of investigations, consulted an array of specialists and often express disbelief that their pain will ever be helped. Pain is an everyday experience but the voices of the sufferers are often lost in health care systems (Morris 1991).

Treatment success is more common with acute low back pain, and as the previous section highlighted the majority of low back pain will spontaneously recover within a month of onset, regardless of the type of treatment. Chronic low back pain is quite a different disorder, described by Wheeler (1995) as a complex disorder that must be managed aggressively with a multidisciplinary approach. Recent literature has attributed chronic

back pain to psychosocial factors (McConnell 2002), probably because chronic low back pain does not always respond to treatment directed at the site of symptoms.

Extensive literature exists on pain management techniques and outcome measures (Carragee 2001; Jensen et al 2003; van Tulder 2002). There are over 500 randomised controlled trials published on interventions commonly used in low back pain and a plethora of systematic reviews (van Tulder 2002). Enhancement of a patients level of physical fitness has remained an important goal in the treatment of chronic back pain, as physical disuse is considered to be one of the perpetuating factors for chronicity (Vlaeyen et al 1995; Walsh & Radcliffe 2002). Most treatment methods for back pain aim to reduce pain and are applied with a rationale that the return to normal functioning should lead to pain reduction. Pain control is useful when it can be achieved but can be very problematic to achieve for this patient group. Multi disciplinary pain treatment programs have been advocated since the discovery of the pain gate theory, which include cognitive-behavioural interventions aimed at helping patients improve physical and psychosocial functioning and to cope more effectively with pain (Guzman et al 2001; Morley et al 1999).

A large number of population based epidemiological studies have occurred over the last twenty years, providing information for educational and clinical services. A selection of studies have been reviewed in the introduction, and demonstrate that chronic low back pain is a highly prevalent condition for men and women of working age, with most people suffering back pain between the ages of 20 – 55 (Bandolier 1995). It can have a

substantial impact on work and leisure activities, with associated loss of productivity and financial implications. Low back pain also has an impact on an individual's health and utilisation of healthcare services. Elaboration of the effects of low back pain is the focus of the next section.

### **Living with Low Back Pain**

So far the review has covered the biomedical side of pain knowledge. A historical review of the nature of pain led into a discussion on the definition and classification of pain, followed by an overview of the mechanics and epidemiology of low back pain. Treatment modalities were briefly considered, as the culmination of contemporary knowledge within the currently accepted pain paradigm. The review now turns to the more personal consequences of low back pain, and begins with a section on the effects of back pain and the impact on lifestyle. The following section will then focus on the beliefs and meaning of low back pain.

Chronic pain is a complicated and perplexing condition that can have grave effects on sufferers, family and friends. Epidemiological research, presented previously, highlighted the economic and social burden of pain. This part of the review focuses on the personal effects of pain to the sufferers. People with chronic low back pain have had pain for six months or more and frequently have not been informed of a diagnosis, often because no cause can be found for their continuous pain (Sofaer 1998). Often these people will have seen several doctors, have had many investigations and are at a loss to know why

someone in the health profession cannot tell them what the problem is and take the pain away. A whole host of feelings and consequences then result.

### *Physiological and behavioural effects*

Living with chronic pain can alter life patterns resulting in negative physical, psychological and social effects (Breen 2002; Laursen et al 2005). The physical effects of living with chronic pain include alterations in eating, resting, sleeping, and can result in the need for reduced activity and frequent periods of rest. Alterations in mobility can result in the loss of the ability to perform activities of daily living, and eventually disability, which in turn can result in work loss. Bowman (1991) employed a phenomenological design to look at the experience of living with chronic low back pain, and found that daily activities were altered relative to work or pleasure; people came to realize that pain had to be endured. The effects of chronic pain fall within three primary dimensions: physical, behavioural and psychological.

Chronic pain behaviours can be categorized into expressive behaviours, movement behaviours, and functional behaviours (Breen 2002). Expressive behaviours include such things as moaning and the use of pain words. Movement behaviours are used to communicate and relieve chronic pain and include grimacing, massaging, and protective movements. Functional behaviours are used to cope with or relieve pain and include the use of socially defined sick behaviours such as decreased mobility, inactivity and bed rest.

### *Anxiety, depression and anger*

Chronic pain threatens the patient's integrity and may engender anxiety, depression and increased feelings of helplessness (O'Farrell et al 1993). Most studies of emotional difficulties in this population report on depression and anxiety, however clinical observation indicates that anger is at least as prominent an emotion as sadness and fear in the experience of chronic pain. Wade et al (1990) assessed depression, anxiety, anger, frustration and fear on visual analog scales, and discovered that when pain was at its minimum it was significantly predicted by anger and anxiety, and when pain was at its maximum it was best predicted by anxiety. Frustration was a significant predictor of all levels of pain.

Anxiety is a feature of chronic pain. There may be high levels of uncertainty about the future in relation to the course of the pain (Diamond & Coniam 1991), or uncertainty in relation to the impact of the condition on an individual's lifestyle, or the effectiveness of treatment (Roy 1992). These uncertainties may flare up at different times and generate anxiety. There is a marked correlation between pain and anxiety, with the anxiety of pain being generated by the unknown. Anxiety may become worse as the pain persists and short term expectations of relief fail (Wall 1999).

The relationship between pain and depression is complex and has been the subject of much debate (Banks & Kerns 1996). People suffering chronic pain frequently seem to be depressed and there are undoubtedly similarities between people who are depressed and those with chronic pain; however it is important to distinguish between dysphoric mood

and depression. Furthermore debates occur around the issue of whether depression or pain is the primary problem. Research has demonstrated that although a history of depression increases the risk for the development of chronic pain, pain has a stronger influence as a precursor of depression (Magni et al 1994). Research shows that depression is a common correlate of chronic pain, and that this population experiences more depression than individuals without pain (Fishbain et al 1997).

Although chronic pain can lead to depression it does not affect all people with chronic pain, and seems to occur more often at times of particular stress (Turk et al 1995). Turk et al (1995) also suggest that women and older people have a greater tendency to depressive symptoms. When measured on tests such as the Beck Depression Inventory (Beck et al 1988) the scores of people with chronic pain tend to be at the low end of the scale indicating a depressive mood but not clinical depression. Nevertheless some people in chronic pain do become severely depressed (Davis 2000). Thus the person in pain may report depressive symptoms, dysphoric mood, irritability, loss of energy, fatigue, loss of appetite, poor concentration, and of being socially undesirable.

Anger is commonly observed amongst people with pain and is described by Fernandez & Turk (1995) as one of the significant elements of pain along with fear and sadness. Schwartz et al (1991) acknowledge the high frequency with which chronic pain sufferers' exhibit anger and hostility. Kinder et al (1986) suggest a greater role of anger in male chronic pain sufferers, whilst for women anxiety was more prominent. People may be angry with many aspects of their situation, ranging from mild annoyance to rage. The

precipitating factor in chronic pain is often an injury arising from an accident in which someone may be held answerable; thus anger may be directed to the self or another. Gatchel et al (2002) concluded that people who attribute pain to a specific trauma event have increased levels of pain severity, emotional distress and life interference, relative to people who reported an insidious onset. If the damage is seen as the result of something intentional or preventable then the anger can be intensified (Fernandez & Turk 1995). The role of anger in chronic pain has not been investigated in great depth, nonetheless anger appears to be a salient feature of the chronic pain experience.

### *Sense of loss*

People experiencing back pain may be particularly vulnerable to the effects of loss; serious health problems can engulf people in losses of many types (Gordon & Benishek 1996). Loss may infiltrate virtually all domains of life, including physical functioning and autonomy, social relationships, financial stability, employment and family roles and self-esteem (Gatchel et al 2002). Such changes may diminish the person's overall sense of security and well-being, hope for the future and ability to cope. Loss is a significant factor for adults younger than sixty five as they feel they can never return to their pre-illness state of health (Siddell 1997). Patients with chronic pain will have sustained a significant primary loss of good health and normal physical functioning, plus secondary losses determined by the psychosocial contexts of the illness. Secondary loss is a long-term, rippling effect that can reach far beyond the initial event and intensify the trauma.

Several studies have explored persistent pain from a client's perspective and identified a number of recurring themes. Osborn and Smith (1998) studied the personal experience of chronic lower back pain via an interpretative phenomenological analysis. They describe four themes: searching for an explanation; comparing this self with other selves; not being believed; and withdrawing from others. The participants in this study shared an inability to explain the persistent presence of their pain despite using comparisons to try and help them make sense of their situation. They were unable to establish the legitimacy of the pain and hence in certain situations felt obliged to appear ill to conform to the expectations of others. The participants treated their own pain as stigma and withdrew from social contact because of confusion, fear for their future and vulnerability. Similarly, Carson & Mitchell (1998) in a series of researcher-participant discussions identified three themes associated with living with persistent pain. The themes duplicate those described by Osborn & Smith (1998), but add the idea of forbearance because of persistent anguish, and extend the theme of withdrawal coexisting with comforting engagements.

A 'typical story of back pain' is elaborated by Walker et al (1999). Narrative accounts of the participants lived experience of back pain were analysed using a phenomenological approach, which identified the following themes: the pain takes over; sense of loss; in the system; they don't understand; and coming to terms. Participants described how their lives were irrevocably changed as a result of back pain, leading to a profound sense of loss. People found themselves trapped within the health care system, the benefits system and the legal system, which made them feel misunderstood and stigmatized. These



experiences made it difficult to come to terms with their current situation and most could see no future for themselves. This research illustrates how those with back pain are rendered passive and powerless, entrapped by systems which were designed to help and protect. Fear, loss of self and withdrawal again feature in this research, but in contrast to the previous studies the main focus is on the relationship between those with pain and society. Kugelman (1999) examined the 'lived body of pain' from a hermeneutical perspective. He suggested that pain is the private property of an individual who must prove that pain exists in an objective manner. The analysis centered upon the torment of having to inhabit the intolerable, upon how pain unmakes the life-world of the sufferer, and how the place of pain is at the boundary of human dwelling, expressed as a non-place, a prison or homelessness.

#### *Impact on sense of self*

Pain can involve the total being of a person (Sofaer 1998), and a number of studies focus on the impact of pain on the self. Intractable pain possesses the self insofar as it leaves no aspect of life untouched (Kugelman 1999). Wilde (2003) corroborated this sentiment, and stated that some people who suffer chronic, unrelenting pain feel taken over by intense physical sensation and are totally immersed in it. Borkan et al (1995) in contrast highlight the shared torment of pain suggesting that in extreme cases back pain has the power to become the central organizing principle of the family, with everyone having a role in taking care of the sufferer. Thomas (2000) described how peoples' ordinarily silent bodies were noisy reminders of changed physical conditions. People did not experience pain as a mental representation localized to a certain part of the body, but

rather as a total change in their way of being in the world – an estrangement from their bodies. Leder (1984) described this situation as a paradox of pain, whereby pain was focused upon and became the centre of attention whilst at the same time people had to look outside for the relief of pain.

Understanding what it means to the patient to live with chronic pain and how this influences the functioning self in social and clinical contexts was the topic explored by Hellstrom (2001). The temporal aspects of chronic pain and peoples conceptions of their selves were considered from an interpretive, phenomenological perspective. People described a variety of selves. Past selves were usually competent and active; entrapped selves were locked into the present; and projected selves as defined by others. Ultimately people could not think of other situations than their own painful one. People felt that they were in a hopeless situation with an uncertain future, which was compounded by the perceived attitudes of hopelessness from health care workers. Doctor shopping and living up to expected, projected identities of ‘the typical pain patient’ were the result.

Increasingly pain is being defined and recognized as a subjective experience (IASP 1992) leaving room for a greater focus on phenomenological and other individual oriented approaches. Feelings of hopelessness, depression, anxiety, comparing previous selves to current selves and withdrawing from social contact have all emerged as constant themes. Pain is frequently described as overwhelming and disrupts the taken-for-granted, usually pain free world of the sufferer. Many of the effects of chronic pain described above relate to the quality of life of people in pain.

## **Social Meaning of Low Back Pain**

We have seen that pain is a common problem and a fundamental aspect of the human condition. Paulson et al (2002) suggest that pain can be perceived as an intersection of body, mind and culture, and is therefore open to a variety of meanings and interpretations, both positive and negative. Melzack (1973) described pain as a highly personal experience depending on cultural learning, the meaning of the situation and other factors unique to each individual.

### *Cultural influences*

Cultural background will influence the experience and expression of pain. People respond quite differently to painful stimuli, some may become extremely vocal and distressed, others appear unconcerned irrespective of the severity of the stimulus (Carr & Mann 2000). A society may value and encourage stoicism, or expect pain to be accompanied by a vigorous verbal and behavioural response. It is important to note here that the author is aware that such claims are open to the idea of cultural essentialism. People from different cultures can experience and express pain in different ways, however there does not seem to be any evidence that people from different cultures have a different sensory experience of pain (Davis 2000). In many cultures there are two languages relating to health and illness: the medical language and lay language (Helman 1994). The languages reflect different understandings of disease and illness, but usually the lay language reflects more cultural values.

Although pain is neurological information at one level, the pain experience is a cultural phenomenon. The uniqueness of the individual's experience is undeniable, but it is informed by cultural aspects of situation, behaviour and belief (Smith 1998). Various studies have demonstrated the connection between culture and pain behaviour (Zola 1966; Zborowski 1969; Kleinman 1988). Culture is implicated from the pain to diagnosis to care. In broad terms cultural factors determine what is abnormal, and help shape these emotional and physical changes into a pattern which is recognizable to both the sufferer and those around them (Smith 1998). There are generally accepted, socially constructed expectations of the role of the sick person. This was described by Parsons (1951) and these expectations reflect the values and beliefs of the particular society. Even decisions about what is an acceptable illness, the course of that illness and the behaviour expected of someone suffering from that illness are socially constructed.

### *Social influences*

Social factors can influence the pain experience itself, not only the type or bearability of the pain, but the way in which it is expressed. Ways of behaving when in pain are communicated to people from childhood when parents provide examples of expected behaviour, or encourage or punish particular behaviours (Davis 2000). The expression of pain or pain related behaviour is important in a social setting. There are social and familial norms to be met, which are communicated in a variety of ways through school, media, friends, colleagues (Davis 2000). The person in pain will have been receiving this information throughout their life, and coupled with influences from the past and the

present, including health professionals, will determine the meaning and interpretation of their pain. In the words of Wall (1999) ‘there is continuous development in the child and adult; experience teaches skills; society adds its methods of help and its prohibitions; expectation becomes tuned’. Skevington (1995) suggests people have ‘a structured system of beliefs that is widely shared with others and is constantly changing’. Our picture of ourselves and the way we would expect to behave is very much related to the way we expect others to behave.

### *Beliefs about pain*

A significant body of research focuses on associations between measures of pain beliefs and measures of functioning among people with low back pain (Affleck et al 1987; Jensen et al 1991). Sufferers of low back pain hold various beliefs about their pain, based on prior learning and social influences. Pain beliefs are peoples own ideas about their pain and what it means to them. DeGood &Tait (2001) described four main elements to people’s beliefs: beliefs about the cause and meaning of the illness; beliefs about its likely duration and outcome; consequences; and finally cure or control. Beliefs provide a framework from which to make sense of the illness and how to deal with it, including decisions about health care. Beliefs have also been shown to play an important role in the persistence of pain and how people adapt to it (Pincus & Morley 2002).

Beliefs can be defined as stable thoughts people have regarding their pain problem (Spinhoven et al 2004). Two important types of belief can be discriminated: attributions and expectancies. Attributions concern interpretations of the pain in terms of relevance

and potential danger, whereas expectancies are thoughts with respect to the anticipated consequences and include thoughts about one's ability to control pain and the effectiveness of these coping efforts (Spinhoven et al 2004). The following evidence suggests that attributions such as catastrophising and expectancies such as perceived control over pain mediate some of the relationships between pain and adjustment. Both attributions and expectancies can have direct and indirect effects on adjustment.

Pain is a physical and emotional stress, and the impact depends not only on the intensity and duration of the pain, but also on how people feel able to deal with it (Waddell 2004). Von Korff & Moore (2001) found that people with back pain have a number of fears. Most people were anxious to understand the cause of their pain, but were equally concerned about damage that may already have occurred and the risk of any future damage. Fear of what may happen was even more important than present pain. Tarasuk & Eakin (1994) interviewed people claiming compensation for back injuries, and found that many workers felt their back problems were permanent. This belief arose from their experience of persisting pain and the view that their backs were permanently vulnerable to re-injury. Symonds et al (1995) looked at the future course and inevitability of back pain. They found that people with a previous history of back pain were more likely to believe their backs would give continuing problems, and were more negative about their ability to control the pain and to take personal responsibility. The greater the number of recurrences of pain and the more time taken off work the more negative the beliefs. People who believed that low back pain is a lifetime problem sought more health care, took more bed rest and used more medication (Szpalski et al 1995).

The degree to which a person believes that they are disabled by their pain is a powerful factor in the extent of their functional impairment. People's beliefs about the cause of their pain and the anticipated effects of treatment will also influence whether they take up a particular treatment and the likely outcome of that treatment (Walsh & Radcliffe 2002; Seers & Friedli 1996). People with chronic pain are likely to be very sceptical toward an approach that is incompatible with their beliefs about pain. Seers and Friedli (1996) concluded that the most important thing for people was that the pain was acknowledged as real by others and not thought just to be in their head. Foster et al (2008) conducted a prospective cohort study of people presenting to GP practices with low back pain and found that sufferers held a wide range of illness perceptions about their back problem and as a group these perceptions remained stable over time. Those with a good clinical outcome perceived less serious consequences, reported fewer emotional responses such as fear and anger, experienced fewer symptoms and had stronger perceptions about the controllability of their problem. People's perceptions recorded shortly after consultation were important determinants of their future clinical outcome. Medical advice to keep active and self manage may not make sense to an individual with low perceptions of personal control who believes that back pain is a serious long term problem.

### *Fear of pain*

There is increasing evidence that fear of pain and fear of hurt and harm is a fundamental mechanism in low back pain and disability (Vlaeyen & Linton 2000). In the first instance most people's reaction to back pain is instinctive and automatic in that they try to avoid

what seemed to be the cause of the pain. However fear may then lead to continued attempts to avoid that situation, and fear can become associated not only with recurrent injury but also with pain itself. People with back pain may believe that physical activity or work could increase their pain or injure their back, and these beliefs are closely allied to their conviction that they should not or cannot do these activities (Waddell 2004). Waddell (2004) suggested that low back disability depends more on fear avoidance than on pain itself, where fear avoidance beliefs seem to relate more to the uncertainty of diagnosis than to the severity of the problem. Such fears have been found to act at an early stage and contribute to the development not just the maintenance of chronic pain, and in fact can predict outcome in the short and longer term (Klenerman et al 1995).

There are links between beliefs, coping strategies and pain behaviour. Recently there has been a large amount of interest and research in this field (Main & Spanswick 2000; Large & Strong 1997; Carroll et al 2002; Woby et al 2004). The common themes that emerge suggest that beliefs about pain and coping strategies can influence the perception of pain and its impact. People differ in the coping strategies they use, some of which are more effective than others. Dysfunctional beliefs and negative coping strategies can aggravate illness behaviour and are thought to act as obstacles to recovery and rehabilitation. Rose (1995) suggests that people are trapped in a vicious circle of trying to cope with pain and getting help. When this repeatedly failed, people felt more overwhelmed and isolated.

Pain catastrophising has been defined as an exaggerated negative orientation toward pain stimuli and experience (Sullivan et al 1995). Sullivan et al (2001) went on to claim that



catastrophising is an interpersonal coping strategy used to maximize proximity or to solicit assistance or empathic responses from others. High catastrophising patients tend to receive more support from caregivers (Keefe et al 2003). People with high catastrophising cognitions have a lower quality of life than people who were less catastrophising, and in fact catastrophising is the most prominent predictor of social functioning, mental health, vitality and general health (Lame et al 2005; Crombez et al 1999).

Lack of knowledge regarding the nature of their pain may be particularly common among individuals with chronic back pain given that we have seen in a previous section that many of these people have no identifiable cause for their pain. Geisser & Roth (1998) studied a sample of musculoskeletal patients referred to a pain rehabilitation clinic. The participants were asked to complete a series of questionnaires and group differences were examined. Participants who were unsure or disagreed with their diagnosis tended to report a greater belief in pain being a signal of harm, and described themselves as more disabled which resulted in them using maladaptive coping strategies. Participants unsure of their diagnosis had the lowest levels of perceived control over the pain. A regression analysis indicated that lack of knowledge, a belief that pain is a signal of harm and catastrophising all significantly predicted increased disability.

Dean et al (2005) studied patient and physiotherapist perceptions of exercise adherence using interpretive phenomenological analysis. Society views time as a commodity, which in turn inflicts pressure on people to prioritize whether they can afford to spend time on

managing their pain rather than looking for a quick fix. They concluded that the current biomedical context of low back pain prevents it from being regarded as a normal part of the human existence and drives people to look for a cure.

### *Lay versus professional view of illness*

It is not uncommon for people to understand illness in ways that differ from the medical view (Nordby 2004). During the last few decades there has been much debate on the nature of the basic concepts of disease, illness and sickness. Hoffman (2002) observes that they have been standardized within a framework, such that disease is the bodily problem as conceived by the medical profession, illness is the problem as conceived by the person, and sickness is the problem as conceived by society. The term illness can be used in a variety of ways, but the meaning of illness is largely shaped by mass media, and common sense understandings derived from personal experience or from consultation with friends and family (Lupton 1995). Nordby (2004) summarises the lay conceptions associated with illness which include the belief that illness is always an acute episode rather than a chronic condition; to have an illness is to have a substantial weakness; to have an illness is to be in a state that interferes with normal activities; abnormal symptoms constitute illness only if they are difficult to diagnose; socially deviant behaviour is a symptom of illness; and that illness is not part of oneself. Extensive research has shown that the ways people conceive of illness differ along dimensions such as gender, education, ethnicity and social class, and the only conclusion that can be drawn is that people use the term illness in different ways.

Lay people view health as a far wider concept than the biomedical model (Shickler 2005). Shickler (2005) believes that people want to participate, be involved and have their experiences of health and illness listened to, and in fact this process of participation may itself be important in health and wellbeing outcomes. Having an optimistic attitude to life is a prime factor in maintaining wellbeing, such that enhancing self esteem and boosting confidence can provide the tools for people to gain their own autonomy and control. People with chronic illness need time to reinvent their life histories and retell their stories in order to adapt to a different way of life without losing a sense of coherence.

So far it has been shown that the mechanisms by which people cope with low back pain are determined by factors not related to physical pathology or pain severity. In particular peoples beliefs are influenced by past pain experience, culture, social and economic factors. It may also be the case that beliefs are reinforced or challenged by their doctor. Fullen et al (2008) conducted a systematic review and concluded that doctors' beliefs could contribute to the development of chronic spinal disability through over or under treating, failing to use effective pain control or reactivation strategies, and reinforcing people's unhelpful illness perceptions by advising increased spinal vigilance and restricting normal activities. Differences in beliefs among specialties may in part contribute to the frustration many people with low back pain express after visiting health care professionals. In a survey of GPs and patients with low back pain, McIntosh & Shaw (2003) found that patients were dissatisfied with the information they received from their GP, especially regarding diagnosis and treatment. Patients tended to access information from a variety of other sources, and the information was often contradictory and

conflicted with research evidence. Potentially this could have an effect on patient's expectations.

*Biomedical expectations and private experiences*

Recent literature highlights disjunctures between professional and sufferers accounts of back pain, and draws attention to the complex interrelationship between the biomedical paradigms need to diagnose and the private experience of pain (May et al 1999). Professional paradigms are seemingly maintained without acknowledgement that patient's experiences could be at variance. Ong and Hooper (2003) conducted a research project to determine how lay and professional perceptions of low back pain relate to the use of health care and to subsequent outcome. The patient focus group narratives presented personal histories, beliefs and experiences of low back pain. The research highlighted the discrepancy between the personal experience of pain and the medical assessment. Participants felt that they were not listened to as individuals, which affected the recognition of their pain and legitimization of it through appropriate treatment. The medical referral system only allows for a specifically defined route to appropriate help, and lacks responsiveness and individuality. Dissonance existed between professional and lay perspectives.

One explanation for this could be that the training of doctors has tended to inculcate a biomedical worldview in an attempt to create a professional rationality that eschews feelings, emotions and sentimentality (Nettleton et al 2008). Medical attention is therefore not focused on the patient but on the disease. James & Hockey (2007) comment

that the dominance of the medical paradigm often means that practitioners views are likely to be at odds with the more subjective and variable responses to illness of their patients. Rich (1997) argues that the medical model accepted the implicit assumption of Cartesian metaphysics that cleaved the person into two distinct dimensions of mind and body, and medicine exists in the physical dimension because it is an objective science. This approach is manifested in society's acceptance of the medical or curative model and construes people as passive recipients of care. Bendelow (2006) agrees with the conceptualization of pain as a medicalised problem which has resulted in the dominance of the neurophysiological aspects of pain, and disregard for the psychosocial consequences. The dominance of medical ideology, which Sakalys (2000) believes dominates and objectifies the patient, in tandem with the Parsonian sick role as a means of social authority, results in the displacement of any subjective experience. The medical perspective is indispensable and reassuring to the patient but can be overwhelming (Sakalys 2003). Patients express satisfaction with technical care but their subjective needs are often unmet. Patients have a medical disease but feel illness, which is an experience.

### *The importance of legitimacy*

There are assumptions, expectations and prescriptions about medicine that prevail in society. One such view is that doctors have a humanitarian and ethical responsibility to manage and relieve pain, a view endorsed by the medical profession: 'By any reasonable code freedom from pain should be a basic human right limited only by our knowledge to achieve it' (Royal college of Surgeons and Anaesthetists 1990). Thus the medical and lay perspective concur on this point, however paradoxes occur when pain relief and diagnosis

do not occur. For example some doctors can accept that diagnosis may not occur long before a person may accept it; equally some doctors will suggest the person is at fault if a diagnosis cannot be reached (Seers & Friedli 1996). The theme of legitimacy is enshrined in everyday language which contains numerous terms for patients who inappropriately seek medical care, such as hypochondriac and malingerer (Heritage 2006). People are labelled as malingerers who exaggerate pain intensity to gain compensation or relief from obligations, whilst some people are labelled as hypochondriacs if the pain is perceived as unreal. The onus is then on the sufferer to confirm the existence of pain with evidence other than just their word. There is little evidence in support of malingering or exaggeration of pain (Skevington 1995).

In a study taking data from an online discussion forum and in-depth interviews, Glenton (2003) describes the fear expressed by back pain sufferers that their pain is being questioned. Glenton (2003) suggests that feelings of delegitimation can be understood as a result of failing to achieve a sick role. A lack of proof that back pain sufferers are sick, including medical diagnosis, appropriate health care treatment and visible disabilities, can lead to accusations, felt and enacted, of malingering, hypochondria and mental illness. This in turn can lead to problems in achieving visible signs of the sick role, such as benefits or medication. The sick role still appears to reflect the expectations of health professionals, the public and the patient. Doctors' inability to offer chronic back pain sufferers a clear diagnosis, explanation, and cure appears not to liberate the patient from the sick role but prolongs their dependence on the doctor.

We have seen that people with chronic low back pain, with symptoms incongruent with physical findings, could well be engaged in less effective coping styles, catastrophising, feeling less in control and displaying compromised physical functioning. Reesor & Craig (1988) looked at such people and concluded that these people were often erroneously labelled as malingering simply because no obvious pathological cause for their pain was established. An initial injury that results in ongoing pain way beyond the time at which acute pain would have been expected to subside is very real but more likely to be associated with feelings of distress, poor coping strategies and loss of self esteem (Carr & Mann 2000).

The literature on pain highlights the particular dilemmas surrounding legitimizing symptoms and the limitations of the medical model. The absence of identifiable signs of physical damage can make doctors reliant on people's accounts. Making pain visible through discourse depends on the ability of the person to communicate and the doctor to decode language into disease categories. Having their pain recognized and made legitimate is a major issue for sufferers, as well as their need to understand the cause of the pain. Bendelow (2006) described a hierarchy of pain, where some forms of pain are more socially acceptable than others. For example pain with a pathological, usually a physical cause appears to have more respectability, validity and authenticity. Doctors and patients make sense of and speak about bodily problems and illness experiences in different ways; Friedson (1970) characterizes this disjunction as the 'professional and lay construction of illness', whilst Mishler (1990) refers to it as 'the voice of medicine and the voice of the lifeworld'.

Lillrank (2003) asked the question ‘What does the route from initial symptoms to diagnosis look like?’ and people were asked to write their story. The common story appeared to be biomedical and featured bodily causes of pain, followed by narratives on coping and control. Lillrank (2003) described two outcomes in the narratives. One outcome is a medical diagnosis resulting in satisfaction and relief despite the possibility of a chronic condition. The other outcome is a moral dilemma experienced as a lived certainty and a medical uncertainty for the person. This research suggested that there is only one satisfactory outcome which is dependent on diagnosis, and this extends our understanding of how diagnosis is necessary to achieve a satisfactory outcome.

### *Causality and diagnosis*

The search for causality is well documented in the literature (Osborn & Smith 1998). Not knowing the pain’s aetiology is associated with an increased use of medical services in an attempt to have pain validated (Wells et al 2003). Wells et al (2003) examined the impact that diagnosis has on information processing, and hypothesized that diagnosed patients would have an enhanced sense of control and legitimisation regarding their physical condition. The results suggest an association between receipt of a diagnosis and better psychological outcomes. Wells et al (2003) suggested that a label may provide a name for the patient’s experiences through which they can more easily communicate, give their pain a sense of tangibility, validity, or control, or provide justification for suffering thus protecting from guilt, shame and self blame. Dissatisfaction with health care professionals may develop as multiple encounters fail to be effective (Carr & Mann



2000). Without proper explanation for their continuing pain, patients become increasingly inactive as they associate undiagnosed pain with further damage, and frequently increase their medication use. Patients withdraw from activities and social interactions, focusing more and more on their pain

We have seen that pain has emotional, existential and physical aspects (Bendelow 2006). Personal beliefs and value systems affect how pain is evaluated and interpreted, and thus shape the expression of pain. Defining pain and understanding pain is a social and cultural process as well as medical or scientific. Chronic pain challenges the biomedical model since it obscures the division between mind and body, objective and subjective, real and unreal, physical and psychosocial.

Chronic low back pain has significant physical, psychological and social impacts. The meanings and beliefs people hold concerning low back pain have been researched in recent years mainly from a phenomenological perspective. The issues range from anxiety, helplessness, a sense of loss, to feelings of estrangement and imprisonment. Quality of life in chronic pain is more associated with beliefs about pain than with pain intensity. Searching for an explanation and not being believed are regularly discussed in the literature and linked with the discrepancy between the lay perspective and the medical perspective. The effects of pain, and the beliefs and meanings attributed to pain have been explored, but what is there to know about living with pain? The next section draws on the literature surrounding normalization and illness narratives to shed light on this area.

## **Narratives of Normalisation**

For many people managing a chronic condition it is a story of normalization. The dominant view of society for people living with a chronic condition is one of deviance and difficulty. Living with pain implies a life full of limitations on a day to day basis, in fact a different kind of life from one led during good health. In this context Robinson (1993) asked the question how do families construct and live an alternate story. The results indicated that initially life was problem saturated with little life beyond the condition, but that gradually a new story emerges as the problem is reframed to minimise its significance (Robinson 1993). A certain level of pain was re-constructed as normal and accepted whereby people could focus on abilities rather than deficits.

Paulson et al (2002) identified a number of themes in a phenomenological study looking at living with fibromyalgia type pain. They described living with a reluctant body, living day by day, not being the same as before, not being understood, living as normally as possible, searching for alleviation, and having to nurture hope. They characterised chronic illness as crashing into a person's life and separating the person in the present from the person in the past (Corbin & Strauss 1983). As in the previous research Paulson et al (2002) concluded that an early focus on loss and burden shifts to a more positive image of normality, but that this struggle for a tolerable existence takes a long time.

### *The concept of transition*

The term transition is often used rather than normalisation which incorporates the idea of an evolving construct and change. Transition is the result of and results in change in lives, health, relationships and environment (Meleis et al 2000). It has been defined as a process, a perspective and a framework, and awareness is a defining characteristic of transition (Chick & Meleis 1986; Meleis et al 2000). For transition to occur the person must be ready to change, and seeks out information and support in readiness to proactively modify activities. Bridges (1991) described how transitions follow a time-span, and commence from first signs of anticipation and perception through a period of instability, confusion and distress to an eventual calming with a new period of stability.

Transition is a complex process of intense personal development, characterised by the idea of moving on. Kralik et al (2005) established an email discussion group for people with chronic illness, and used the responses and narratives as data. The collective response to illness was a strong desire to move on. Moving on involved knowing ones response to illness; developing inner conviction; refraining from making comparisons with a former self; prioritising what is important; sharing stories with others; awareness of shifting self identity; and being in tune with the process of learning. Understanding the confines of illness was perceived to be liberating, as the reconstructed self could accommodate the reality of living with chronic illness in a way that preserves a sense of dignity and value.

In contrast Paterson (2001) undertook a metasynthesis of qualitative research about the experiences of adults with chronic illness. It challenges the assumptions of previous models of a single linear trajectory, and suggests a shifting process. The shifting perspectives model suggests that living with chronic illness is an ongoing, continually shifting process, in which people experience a complex dialectic between themselves and their 'world'. People with chronic illness live in the dual kingdoms of the well and the sick, where either wellness or illness takes precedence. When illness is in the foreground, people focus on sickness, suffering, loss and burden and seem to be absorbed in their illness experience. However it serves a useful purpose too in that it helps people to come to terms with the illness. When wellness is in the foreground people attempt to create consonance between self-identity and the identity shaped by the disease. Any threat to control that exceeds a person's threshold of tolerance will cause a shift from wellness to illness. To bounce back to wellness a person must recognise a shift to illness has occurred and implement changes to resolve or accommodate to the situation. A paradox of this shifting perspectives model is that living in wellness in the foreground perspective, requires the management of the disease to be foremost even though the illness is distant. Illness requires attention in order not to have to pay attention to it.

Similarly Delmar et al (2005) outline the concept of achieving harmony with oneself whilst living with a chronic illness. They describe a pendular movement between hope, doubt and hopelessness, and suggest that during this process a person experiences a rupture of meaning and after a time may find a new way of living, and with it a new meaning to life. It is not the seriousness of the disease which determines how the person

is feeling, but how they relate to themselves, to the disease and to life. Chesla (2005) suggests that living hopefully in the presence of chronic illness is probably not something that can be achieved as a permanent or even a stable state, rather tension between hope and despair, suffering and possibility is experienced as an oscillation between the varying positions. Time orientation is a key factor, as hope is typically thought of in the future, but for persons with a chronic illness the future holds the greatest risk, it holds uncertainty and threat. For Chesla (2005) the significance of this lies in the small, quiet moments of suffering which comprise living with chronic illness. Suffering does not usually come in big doses or dramatic form, most suffering comes in day to day living with and working out the small tensions that the illness creates

### **Illness Narratives**

The sociological literature on chronic illness offers a framework for understanding the experience of pain by focusing on the lived experience, including narratives of suffering. Chronic low back pain is frequently viewed as a chronic illness, and it would seem appropriate to consider some of the literature on illness narratives in order to elaborate a patient-centered knowledge of illness, from which parallels can be drawn regarding low back pain. Bendelow & Williams (1996) suggest we need to offer a conceptual and methodological examination of pain which will move away from a reductionist emphasis on pain and sensation to one that embraces the social aspects, and one way to achieve this is via narratives and subjective accounts of illness. By taking account of the social

contexts of illness, social and personal aspects have been opened up. Cassel (1991) argues that we should incorporate the concept of suffering, because in some pain experiences the experience is more holistic and thus justifies the term suffering rather than pain. Illness narratives can elaborate the concept of suffering.

Much sociological literature on chronic illness focuses on the person rather than the symptom, such as pain (Charmaz 1983; Bury 1982; Williams 1984). Chronic illness has always been a feature of human existence, but as a research topic it is a relatively new phenomenon and affects people in a myriad of ways. Definitions can be formulated around several dimensions, such as time, lifestyle and symptom management (Siddell 1997) but people face crucial adjustments at three key phases: when the illness is first diagnosed; when the disease flares up; and when the situation must be coped with outside the presence of medicine (Pollin 1984).

### *Disruption of self*

The notion of self and identity are key features of illness narratives, and in fact are key to this study and as such are discussed in greater detail within the results and discussion sections. Bury (1982) framed chronic illness as a biographical disruption, a concept informed by Giddens (1979) notion of a critical situation. He interviewed people recently diagnosed with rheumatoid arthritis, who described a major disruptive experience, and highlighted the complex and multi-faceted ways in which the experience of chronic illness leads to a fundamental rethinking of a person's biography and self-concept. Charmaz (1983) generated the concept of 'loss of self', where former self images

crumble away without a simultaneous development of equally valued new ones. She researched the experiences of people with a variety of chronic diseases, intentionally confining the analysis to extreme cases. Loss of self was a multi-faceted experience for people who because of their illness often led restricted lives, experienced social isolation, were discredited by self and others, and experienced humiliation of being a burden on others. Loss of self extends our understanding of the concept of loss, which has been outlined as an important feature of chronic pain in a previous section of the review.

Kameny & Bearison (1999) using illness narratives investigated constructions of self in a paediatric oncology setting. Cancer threatens the integrity of the physical, social and psychological self. In this research narratives were seen as a means of understanding experiences. A key issue was the struggle to gain mastery over illness, with the perceived impact of the illness having a greater influence on coping than the reality of the situation. Kameny & Bearison (1999) found that coping with chronic illness involves control in three domains – biomedical, social, and personal. The personal domain refers to the thoughts and feelings of the narrator; the biomedical domain is the story of the narrator as a medical patient and refers to diagnosis, treatment and symptoms; the social domain is the narrator's assessment of family, friends and healthcare staff. A sense of agency was expressed in a variety of ways throughout the narratives, for example the pronoun 'I' was more common in the personal domain, whereas self-as-object was expressed in the biomedical domain, and a sense of losing or gaining control was found in the social domain.

Timing and the existence of co-morbidities plays a role in the framing of illness as disruptive or anticipated. Carricaburu & Pierret (1995) interviewed asymptomatic HIV positive men infected through gay sex or medical treatment of haemophilia. Those infected through gay sex experienced HIV as biographically disruptive but haemophiliacs perceived HIV as a form of biographical reinforcement because they were already organising their lives around an illness trajectory. Sanders et al (2002) and Pound et al (1998) discuss biographically anticipated events. Sanders et al (2002) found arthritis in old age to be a normal and inevitable aspect of later life. Pound et al (1998) researched stroke in an elderly population, and found that despite having a considerable impact on peoples lives it was not perceived as extraordinary, but was classed as a normal crisis because many had already suffered other morbidities prior to the stroke and thus led restricted lives.

Where Bury (1982) and Charmaz (1983) consider disruption and loss, Williams (1984) took a more positive turn and developed the concept of narrative reconstruction, to describe the strategies people employ to create a sense of coherence, stability and order in the aftermath of a biographically disruptive event of illness. He interviewed people with rheumatoid arthritis of longstanding duration to explore the longer term aspects of chronic disease on self-concepts, in particular why people chose to select certain models to explain the onset of their disease when other explanatory models were equally plausible. Williams (1984) viewed narrative as actively constituting social reality. Narrative reconstruction is the reconstitution and repair of ruptures between the body, self



and world by linking and interpreting different aspects of biography in order to realign present and past and self and society.

These papers underline the importance of looking at timing, setting and individual biographies in order to understand the complex and variable ways in which people experience and live with illness (Lawton 2003). The age and stage of the life-course at which the person becomes unwell is important, as a disease may be experienced as more or less disruptive depending upon the point at which the disease first manifests. It is equally important to look at the individual's whole biography. Bury's (1982) assumption that illness always enters lives hitherto untouched by illness or struggle is challenged by subsequent research (Sanders et al 2002; Pound et al 1998; Carricaburu & Pierret 1995). Williams (2000) extended his original concept of narrative reconstruction and suggested that self identities are fashioned in a reflexive and contingent process involving a constant cycle of biographical appraisal and re-appraisal. Biographical uncertainty may be an inherent feature of people's lives and does not simply come to the fore in the event of illness.

Historical and socio-political contexts may be salient to the ways in which illness and disability are experienced. Ville et al (1994) explored self-perceptions of people with physical impairments by comparing the experiences of three distinctive groups – people with paraplegia, people with severe complications of poliomyelitis and a group without any physical impairment. The socio-political context proved to be key to the understanding of group differences because of conformity to the prevailing social norms.

Ville et al (1994) suggest that locating the illness experience in 'collective' contexts that extend beyond the life and biography of the individual is very important.

### **In Summary**

In ancient times pain was thought to be an emotion and the effect of evil spirits. Gradually over time physiological theories became the mainstay of pain knowledge, and specificity and pattern theories dominated the human understanding of pain until fairly recently. Following a revolution in thinking, the gate control theory of pain took precedence and resulted in our current biopsychosocial approach to pain understanding. It can be argued that the affective component of pain has come full circle from ancient to modern times, and in fact the development of the neuromatrix theory resulted because of the importance of affective and discriminatory factors.

Pain has been defined and classified in many ways, but not without problem as no single definition can incorporate all the elements entirely. Acute and chronic are familiar labels to describe and account for pain and its responses, however, the current medical management of pain challenges the sufferers and health professionals' ability to relieve chronic pain. Frustrations inevitably arise, not least because the effects of chronic pain are easily evidenced in epidemiological studies but the meanings and beliefs that surround chronic back pain are not so easily packaged and dealt with. There appears to be

a disparity between what patients believe and want, and what professionals perceive to be the solution.

The literature on transition and illness narratives provides a useful viewpoint on managing a chronic condition such as low back pain. Transition is a complex process of intense personal development, and illness narratives frame this development and help to elaborate patient centred knowledge of illness and the move towards acceptance of a chronic condition. Framing life with low back pain as a journey, a transition, proved to be a useful device and could not be considered without sociological and cultural reference.

There has been much development in the understanding of the pain experience in recent years. The experiences people have when they are in pain and the mechanisms that generate those experiences are very complex. It involves all aspects of human nature from physiology and biochemistry to a person's emotional and motivational make up, through to social, cultural and spiritual relationships. When a person experiences pain their whole being can be involved. Pain presents many challenges to the sufferer and cannot be considered as an isolated entity. There is much research evidence involving a wide range of academic disciplines and professions, with each specialism having a different perspective of the same condition. Research has increased our knowledge of pain greatly, but I feel that to understand pain more fully we need to consider the context in greater detail and take note of where people are in their journey with pain, in an attempt to get inside the experience. Pain is one facet of the sensory world in which we live, and as such cannot be considered as an isolated entity but must be understood in the

context of its existence. People who experience pain have a unique set of life experiences that go hand in hand with the pain. These events and experiences, past and present, need to be explored in the context of the pain. This research seeks to explore just that, and aims to reveal the 'journey' from pain onset, generating knowledge of what is important to people, and indicating where the journey may take them.

## Chapter 3

### Methodology

#### *Chapter Overview*

This chapter outlines the philosophical underpinning of this study, and proceeds through the decision making behind and the processes of sampling, data collection, and analysis incorporating ethical issues and issues of rigour. It was noted in a previous section that back pain can be seen as a problem to both patients and health professionals, and in fact back pain represents one of the major challenges in health care today. Biomedical and psychological evidence abounds to shape acute and chronic management of low back pain, but there is a dearth of information about the viewpoint of those suffering pain.

Low back pain has been researched across all health care disciplines, utilizing both quantitative and qualitative approaches. As previously mentioned, in my clinical practice I frequently observed patients being left with no clear diagnosis and being moved onto a management approach; where the curative model had been initially relied upon it was no longer appropriate because of the chronic nature of the problem. I began to frame research questions: Why do people feel like this? What is it like coping with chronic pain day to day, and does it get better? I felt that these questions fell within the domain of qualitative inquiry, specifically the interpretivist arena as these questions are asking about the experiences and meanings ascribed by back pain sufferers. Much has been written on back pain but the voices of the sufferers are often overshadowed by the professional discourse. This study sought an approach that elicited the accounts of those with low back

pain and the meanings that are within those experiences, and focused on the patients' perspective. The following account provides the rationale for the methodological choices made and the format of the study.

### Philosophical Framework

#### *An Interpretivist Epistemology*

The study takes an interpretivist approach, as it is based on others accounts of their realities and the author's interpretations of them<sup>1</sup>. From within the humanistic persuasion it has been argued that hermeneutic principles need to be used in order to produce systematic studies of society. Hermeneutic refers to the theory and practice of interpretation through engagement with the subject as a condition for understanding social life (Outhwaite 1991). Hermeneutics is a diverse discipline which can be traced back to Ancient Greece, although it was not until the 17<sup>th</sup> century that the discipline of general hermeneutics came into being. However hermeneutics is now considered to be a theory concerned with interpretation gained through bridging the understanding of researcher and researched. In this tradition the understanding and interpretation of the

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<sup>1</sup> The interpretivist approach stemmed from the constructivist paradigm and emerged as a reaction to the positivist quest for objectivity. As natural science deals with matter which is not conscious, researchers of the social sciences argue that its methods cannot deal with social life and should, therefore, be discarded from this arena (May 2001). To speak of cause and effect is not applicable to researching social life for people, unlike molecules, contemplate, interpret, and act within their environments. The methods of the social sciences are therefore fundamentally different from the natural sciences. People are constantly engaged in the process of interpretation and it is this we should seek to understand (May 1997). Social theory should, therefore, take account of people's everyday understandings. Constructionism adheres to a relativist position that assumes multiple, apprehendable and equally valid realities (Schwandt 1994). Reality is constructed in the mind of the individual rather than it being an externally singular entity (Hansen 2004), and the constructionist position espouses a hermeneutic approach. A distinguishing characteristic of constructionism is the centrality of the interaction between the researcher and the researched.

social world are necessary conditions for understanding research. Humans engage in hermeneutic processes of interpretation that involve making meaning out of life experience. Thus, hermeneutics is recognised as a philosophy that supports an approach to health research which focuses on meaning and understanding in context (Charalambous et al 2008). The sense of belonging to a society and the techniques used for understanding are not impediments to research.

Social life is diverse and complicated by not being amenable to understanding through the use of a single paradigm, and as such a number of theoretical perspectives have been used to explain the meaning of low back pain (Turk 1997; Vrancken 1989; Seers & Friedli 1996). This research aimed to reveal the 'journey' that some patients take from the onset of their low back pain through to their current destination, generating knowledge of what is important to patients, and indicating where the journey took them. This study focused on the patients' perspective and investigated the beliefs and expectations of low back pain sufferers attending a pain clinic. As observed frequently in sociological text facts do not speak for themselves, theory is needed to interpret the findings (Bulmer 1986). The interpretivist tradition stresses the involvement of the researcher in trying to unravel the meaningful worlds of the social group that are the topic of interest (Layder 1994).

Interpretivist epistemology sees social realities as inseparable from researchers because researchers construct the world they research (Sparkes 1992). Annells (1996) suggests that ontology and epistemology merge in interpretivism, because the 'knower' is

inseparable from whatever can be known within the construction of a particular reality. This study was based on others accounts of their realities concerning back pain and the authors personal interpretation of those. Interpretivist epistemologies see knowledge as created through the interaction of the researcher and the researched. Given this assumption interpretivists focus on the interests and purposes of all those involved with the research process. It must be acknowledged, therefore, that only perspectives of research participants lives can be gleaned, with the aim of discovering why people do what they do and to uncover possibly hidden knowledge. The attempt is to try to explain and understand other realities.

### Narrative

#### *Why narrative?*

Clinical experience shows that patients tell stories of their pain problem, and frequently lead the clinician on a journey through the history of their low back pain (Greenhalgh & Hurwitz 1998). The researcher had observed that people readily tell stories of actual life events and it was felt that a process whereby back pain sufferers were able to tell stories of their everyday occurrences would be most appropriate.

Narrative has been used in the health field to understand clinical practice and the experiences of health professionals (Dingwall 1977), to explore patient physician interaction (Baruch 1981), and to elaborate the patient experience of illness and suffering (Hyden 1997; Mishler 1995). Narratives have gained importance in the study of chronic



illness as a means of understanding the attempts of patients to deal with their life situations and the problems of identity that illness brings with it (Werner et al 2004). Narrative offers the opportunity to understand what is perceived as normal or ordinary, as well as extraordinary or abnormal (Eggly 2002). Narrative is an activity undertaken by people as a way of organizing and interpreting their world, and thus allows exploration of health and illness from the perspective of the story teller. Narrative can, therefore, value the words spoken by people who historically have been seen as marginal (Chamberlayne et al 2000).

Narrative data, with their emphasis on people's experiences, are fundamentally well suited for locating the meanings people place on the events, processes and structures of their lives in relation to pain (Miles & Huberman 1994). Actions always occur in specific situations within a social and historical context, which influences how they are interpreted. Words, especially organized into incidents or stories, have a concrete, vivid, meaningful flavour that often proves very convincing to the reader (Miles & Huberman 1994). The aim of the study was to uncover the patients perspective of their low back pain by focusing on their narrated experiences. Elliott (2005) lists some of the common themes that run through narrative research which further influenced the choice of narrative: an interest in people's experiences and an appreciation of the temporal nature of that experience; an interest in process and change over time; and an interest in the representations of the self. Stories have many purposes and storytelling offers a way to make sense of what has happened, and all of these issues are apposite to the current project.

This form of analysis complements the research area and the wider interpretive approach, as it is the experience, the meanings, beliefs and perceptions of back pain that are to be investigated. Woike (2008) suggests that narrative analysis is a particularly good choice for researchers interested in complex, subjective experiences as well as intentions and attempts to find meaning in personal experiences. Narrative research is often lengthy, for example narrative interviews are opportunities for people to tell long, in-depth stories about their thoughts, emotions and lives in ways they may not have done before. Narrative analysis allows an exploration of life's experiences in all its varieties, intricacies and untidiness (Smith & Sparkes 2009).

#### *Definition and meaning*

Narrative can be defined in many ways. Bruner (1986) employs a broad definition of the term used to describe a variety of ways people perform the telling of events, whilst Fisher (1984) is a little more specific and describes narrative as a series of symbolic interactions, words and / or deeds that have a sequence and meaning for those who live, create or interpret them. Thus narratives can be described as discourses that organize a sequence of events into a whole so that the significance of each event can be understood through its relation to the whole (Elliott 2005). This presents three key features of narratives: they are chronological, meaningful and social in that they are created for a particular audience. These key features are apparent within the narratives generated in this study; all the narratives are chronological, they are certainly meaningful as evidenced by the level of emotion expressed, and were the product of a non-clinical interview and hence created for a particular audience. A different time, a different location and a different interviewer

would have resulted in a different narrative. Despite a similar format each interview was different, with individual experiences shaping the narratives and how they were created.

McKevitt (2000) suggests that there are certain core features of illness narratives: they have a story-like form; they retell events, episodes and experiences in an ordered way; and are concerned with meanings of illness and suffering for the narrator. Thus they transform an individual experience into a collective one. Stories help constitute meaning and lived experiences and undertake the communication of them, but are more than a personal production (Smith & Sparkes 2009). Narratives are shaped by the social world, and thus are social activities. They are shaped by the audience and the cultural repertoire to which the story teller has access. The narrator will have a template of previously learned narratives. The power of the narrative comes from the connotative language and the use of imagery, literary and performative devices used to persuade the listener to a particular point of view (Mattingly 1998). Thus, stories have two sides, one personal and one social. Narrative methods are of particular value in that they accord significance to both sides, such that people can be thought about as individuals with capacity to shape the socio-cultural world they live in, and equally as socio-culturally shaped by the world they inhabit (Smith & Sparkes 2009).

One of the earliest definitions of narrative can be traced back to Aristotle, who states that a narrative is a story with a beginning, a middle and an end (Elliott 2005). Temporality is accepted as a key feature of narrative, and although temporal ordering of events is common to most definitions of narrative, narratives are not only chronicles of events as

they configure or plot both chronological and non-chronological events and experiences into meaningful wholes (Sakalys 2003). Temporal succession alone is not a story, it needs to be linked with the notion of plot. Stories rely on the presumption that time has a unilinear direction moving from past to present to future, and the plot within a narrative relates events to each other by linking a prior event to a subsequent event (Polkinghorne 1995). It is the importance of the chronology of events that distinguishes it from a description. Temporality is fundamental to establishing the meaning of events because of the way that narratives impose beginnings, middles, and ends on what are continuous streams of happenings. Related to the idea of plot is the notion of narrative closure, because it is the ending that determines the meaning of the actions and events within the narrative (Ricoeur 1984). The narratives in this study did feature a beginning, middle and an end with a definite shift from past to present to future. The ending determining the meaning of the events was an obvious element within these stories.

Labov & Waletzky (1997) described fully formed narratives as having six separate elements: the abstract is the summary of the subject; the orientation, that is time, place, and situation; the complicating action is what actually happened; the evaluation is the meaning and significance of the action; the resolution being what finally happened; and lastly the coda which returns the story to the present. All six elements do not have to be included in a narrative, but at the least should include a complicating action, a temporal element and an evaluation. All elements featured to a greater or lesser extent within the narratives, which are fully explored within the analysis and discussion sections.

*Truthfulness & narrative, the problem of versions*

As narratives purport to be accounts of things that actually happened, an obvious difficulty arises in terms of truthfulness which can be considered in relation to the realist / constructionist debate surrounding this issue. Is data a one-to-one correspondence to reality or is a version simply one explanation of what happened? All narration is interpretive, discursive reconstruction, a version, and as such is an attempt to impose an order and a shape onto a life which is essentially unknowable. Narrative approaches have acquired this problematic epistemological status as personal accounts of past events are difficult to verify. Atkinson & Silverman (1997) suggested a number of criticisms of narrative, for example that sociologists should be story analysts not story tellers, and narratives can have a preoccupation with revelation leading to hyper-authentic, misleading, sentimental and exaggerated constructions. However, it can be argued that the real issue is not about an 'objective' account of events but a record of how those events were interpreted and experienced by the people and the symbolic importance accorded to these matters. A narrative is a kind of summing up, it is only by looking back that the real meaning of initial actions can be understood (Mattingly 1998). Narratives should not be treated as social facts, but require theory, categorization and analysis. Narratives have two important characteristics: they tell a story; and the story is co-constructed by both participants. Clark & Mishler (1992) caution against reifying participants stories because a person's story is a specific narrative reconstruction of illness constituted within a specific social interaction at a particular time and place. What is included in the story and the way in which it is expressed is contingent on that interaction, as the story emerges in the context of requests, acknowledgements,

expansions and elaborations. It, therefore, represents the joint effort of researcher and researched.

## Sampling

### *The Sample*

The research population has been identified as low back pain sufferers attending a pain clinic. A sample was drawn from people that attended the pain clinic based at a hospital within the North East of England. Miles and Huberman (1994) suggest two stages to sampling in qualitative research. Firstly it is necessary to set a boundary, which is to define aspects of cases that can be studied within the time limits which connect directly to the aims. There was a finite amount of time for the study and it would have been impossible to interview every member of the research population. The boundary has been defined as low back pain sufferers currently attending the clinic. Information on size of the population, the prevalence of low back pain and ultimately the number able to participate was drawn from the clinic. Secondly, a frame was created to help uncover and confirm the constructs of the study. Sampling involved decisions not only about which people to interview, but also about settings, events and social processes.

### *Purposive Sampling*

This study used the concept of a sampling matrix developed by Reed, Proctor & Murray (1996). It provided a systematic way of identifying theoretically useful cases, allowing informed and coherent choices, and, thus, allowed the process of research to be clear and

public in order to be understood and evaluated. The sampling matrix addressed questions of how the sample was selected and why, but also provided information of who was not selected. A matrix was developed which identified the key variables elicited from the literature and conceptual framework; gender, age, marital status, occupation, pain problem, length of time in pain, surgery, and health care professional referral (see appendix 3). Each cell of the sampling frame is essentially unique; each cell has a few properties it shares with many others, some properties it shares with some others, and some properties it shares with no others. The choice of cases was made on conceptual grounds.

A purposive sample was taken; a strategy frequently used in qualitative research, designed to extend knowledge by deliberately sampling those areas known to be rich in the type of data required for the study (Reed, Proctor, & Murray 1996; Denzin & Lincoln 1994). Qualitative samples tend to be purposive, partly because the initial definition of the study group is more limited and partly, as Kuzel (1992) suggests, social processes have a logic and a coherence that random sampling could reduce to uninterpretable sawdust. Purposive sampling allows the researcher to choose a case because it illustrates some feature or process of interest. However, this does not provide a simple approval to any case we happen to choose, rather purposive sampling demands that we think critically about the parameters of the population we are interested in and choose our sample carefully on this basis (Silverman 2000).

All patients actively attending the pain clinic were included in the research population, not all patients on the clinic database. The author developed the matrix previously described, and manually went through patient records to add the required information to the matrix. The initial two patients were selected for two reasons: firstly they were within the matrix, and secondly they were due to attend the clinic within a few weeks. Following their clinic visit, the author discussed the research with them, and provided information leaflets. The people agreed to be interviewed and a mutually agreeable time was selected. Consent and ethical issues were discussed prior to interview. The other participants were selected in a similar fashion: they were chosen on conceptual grounds which continued to develop from the previous interviews, as well as convenience for accessing the clinic.

Table 3.1 shows the sample drawn from the matrix. Nine people have been interviewed and were picked to represent gender, age and retirement / occupational status. The sample was not pre-specified, but evolved as fieldwork occurred. The initial choice of participants lead to further selection of similar and different cases from the matrix, in an attempt to achieve conceptually driven, sequential sampling (Miles & Huberman 1994). The strength of qualitative research design is that it allows for far greater, theoretically informed flexibility. Theoretical or purposive sampling is a set of procedures where the researcher manipulates their analysis, theory and sampling activities interactively during the research process (Mason 1996). This flexibility is appropriate to this study because as new factors emerged, as outlined in the conceptual framework, the sample needed to increase to say more about them. Sampling like this, both within and across case expands general constructs and their relationships, and has an iterative or rolling quality, working



Table 3.1 The sampling matrix

Name	Age	Gender	Occupation	LBP +/- Radiating pain	Time since onset	Surgery Y / N	No. of contacts	Health Care Prof. Complementary/ alternative	Time since Pain referral	Gap between Onset & referral
Annie	66	F	Housewife	LBP	16 years	Y	7	C & A	2 years	14 years
Robert	36	M	Sick Benefit	LBP, bilateral leg pain	15 years	Y	5	C	2 years	13 years
Laura	40	F	Admin Officer	LBP, left leg pain	9 years	N	7	C	3 years	6 years
Fred	57	M	Retired Care Assistant	Degenerative sacro-iliac joint	6 years	N	4	C	2 years	4 years
Jane	38	F	Civil Servant	LBP, leg pain	21 years	Y	5	C	1 year	20 years
Susan	37	F	Unemployed	LBP	18 years	N	6	C & A	1 year	17 years
Jack	35	M	Factory Worker	LBP	3 years	N	5	C	1 year	2 years
Linda	37	F	Admin Officer	LBP	14 years	N	5	C & A	3 years	11 years
Clare	40	F	Unemployed	LBP	6 years	Y	5	C	1 year	5 years

in progressive waves. At each step along the evidential trail sampling decisions were made to clarify the main patterns, see contrasts, identify exceptions and uncover instances where the pattern did not hold. The analytic conclusions depend on the sampling choices made.

The number of people needed to interview was not answerable statistically; the issue had to be dealt with conceptually. Choices of informants, episodes and interactions were being driven by a conceptual question, not by a concern for 'representativeness'. To get to the central construct and map out a journey of living with low back pain, it was important to see different instances of it, at different moments, in different places, with different people. The prime concern was with the conditions under which the construct or theory operated, not with the generalization of the findings to other settings. In this study a small, relatively homogeneous sample of individuals living in a specific geographic area have been interviewed, which immediately raises questions about the generalizability of the findings. Multiple case sampling provides confidence that the emerging theory is generic, by looking at a range of similar and contrasting cases we can understand a single case finding, which may be possible to ground by specifying how and where and if possible why (Miles & Huberman 1994). Thus, the generalizability of this evidence depends upon the demonstration of how widely the inter-subjective meanings are shared (Elliott 2005). Mason (1996) suggests that research should produce explanations that have a wider resonance if not generalizability. However this is not to say that findings cannot be generalised at all, and Williams (2000) suggests that moderatum generalisations are possible. If we believe that everyone is different then it

can be argued that it is never actually possible to represent the background population. This research does not set out to represent a population but attempts to build a theory which may be cautiously generalizable to others.

### Ethical Issues

People with chronic pain are potentially vulnerable and it is particularly important, as in any research that involves the participation of people, to consider the potential impact of the research on those involved. To date there has been little discussion of specific ethical issues that arise through the use of narrative in research. The use of narrative does give participants more opportunity to become more active within the research process, and to come into direct contact with the researcher. To this end the issues of privacy, confidentiality and anonymity need to be addressed. The BSA (2002) acknowledges that social research intrudes into the lives of those studied and that whilst some participants may find the experience a positive and welcome one, others may find it disturbing. As Elliott (2005) highlights this can be a particular issue in research that encourages people to construct and share narratives about their lives and experiences in the context of a research interview. Avoiding harm is a basic ethical principle, but topics may be discussed that cause a person to focus on unpleasant situations. The interviewer should be experienced to manage the interaction and minimise any negative effects of the research process. As a novice interviewer the researcher in this study drew upon her experience of working within a pain speciality and engaging with people who at times displayed a range of emotions, including anger, sadness and fear.

### *Privacy, anonymity & confidentiality*

Privacy is the control over others' access to the information and the preservation of boundaries against giving away protected information. At the beginning of each interview the participants were assured that only the researcher had access to the recordings and transcripts, and that they would be securely stored within the researcher's office. Confidentiality is an agreement with the participant about what will be done with their data. Confidentiality and the right to privacy are two crucial issues in studies where questions are raised regarding thoughts, beliefs and experiences. Privacy and confidentiality must be safeguarded because of the effects they have on consent and credibility of research findings.

Narrative raises a particular issue concerning privacy and anonymity. The commitment to present data holistically in a narrative study meant that specific stories and experiences were likely to be identifiable by people that knew the participants. Despite using pseudonyms there would be chance of recognition, and this needed to be made clear at the beginning of the interview. As Mishler (1986) argues people may be happy to be identified within the research, and it is more honest to discuss this possibility than to promise levels of anonymity that are difficult to ensure in practice.

Traditionally the research participant is seen as a source of data, which implies that the ethical principles guiding this approach focus on obtaining consent to give away their data and being treated respectfully in doing so (Elliott 2005). However personal

narratives deal with the meaning of a person's life and therefore touch on issues of identity. People have a great deal of investment in the stories they provide in a research interview, and do not simply relinquish information but jointly construct it with the researcher. The recognition that narrative is bound up with individual identities raises important questions about the analysis and the impact of the analysis on the participant. If the production of narratives is seen as a central process by which people comprehend their own lives and establish a sense of self then a researcher's deconstruction and interpretation of the narrative may be damaging. The representation of others is important to mention here, as the private and personal worlds of the participants are brought into the public domain. Issues of disclosure and what the narratives represent need to be considered. The stories are constructed and not representative of an absolute reality, though this may be the first time that has been made explicit to a participant and as such may have concerns as to how they will be represented and the accuracy of portrayal (Harrison & Stina Lyon 1993). It was important, therefore, for the researcher to explain what the research was about in appropriate detail, and agree with the participant at the outset how the research would be presented, and how they would feature in the research product.

The researcher was unknown to the participants prior to interview. The participants were contacted by telephone or were visited after a clinic appointment by the researcher, who introduced the research. After the preliminary discussion and if agreeable an interview was arranged. The researcher established the nature of the research and outlined her research role to the participants. As highlighted the researcher is an experienced member

of the pain management team and felt able to deal with clinical issues if they arose. The participants were aware that the interview was a research meeting not a clinical meeting, and the research was conducted within a hospital environment, specifically in a research wing, away from the usual clinic setting familiar to the participants. The role of the researcher needs to be explicit at any given time, and hence the positions of nurse and researcher were declared to the participants, who at times would acknowledge the researchers knowledge base as a clinician. Occasionally requests for clarification about medical matters and treatments were sought. At such times the researcher would acknowledge the question and if appropriate answer directly.

Explicit confidentiality agreements about where the raw data and analyses would be stored and who would have access to them were verbally agreed at the beginning of the interview. Furthermore, written information was provided to this effect on the information and consent forms. It was important that the people being studied had full information about the study and that their consent was freely given. Informed consent was sought at the outset, participation in the study was voluntary, and the participants were assured of confidentiality and privacy. Participants were also made aware that they had the right to refuse participation in the study and could withdraw at any time. The participant was given an estimation of how long the interview would take, and asked for consent to tape-record and transcribe the interview.

Anonymity refers to the lack of identifiers in the research product. The unique and personal nature of the data may make it relatively easy for participants to be recognised.

Attempts to minimize this risk include paraphrasing, and the inclusion of analyses without actual reference to the event. The participant was given a pseudonym so that the researcher is the only one to match true identity with tapes and notes. Anonymity cannot be guaranteed and this was made explicit at the outset.

The research was undertaken within an NHS Trust in the North East of England. Approval was granted from the Trust. Written agreement was sought from the consultants within the pain clinic to access the database and select patients attending the clinic. LREC approval was granted for the design of the study.

### Data Generation

As it was the intention of this study to discover the beliefs and experiences of a group of low back pain sufferers and employ a narrative analysis, in-depth interviews were chosen as the method of data collection. Interview can be used as a mechanism for understanding how individuals make sense of their world and act within it (May 1997), and many authors have described the richness and detail of data gathered at in-depth interviews (Polit & Hungler 1993; May 1997). In terms of methodology, the qualitative interview has been the research tool used to learn about the thoughts, experiences and feelings of the participant. The meanings that individuals attribute to events and relationships can be understood on their own terms providing a greater understanding of the subject's point of view. Flexibility and discovery of meaning characterize this method, as interviews can yield rich data into people's experiences, opinions, attitudes and feelings, which are

important considerations when examining beliefs and expectations of low back pain sufferers.

### *Narrative Interviews*

The unstructured, or depth, interview is often described as a form of conversation (Burgess 1982), and one of the attractions to the researcher was that this method married well with the development of narratives. It was decided that a standard set of questions would be too narrow and would restrict the researcher's perspective. The unstructured interview, however, is a theoretical construct in that it may appear to be without a structure but the interviewer has had to establish a framework within which the interviews can be conducted. In this sense the unstructured interview is planned but remains flexible resulting in a guided, interactive conversation (May 1997; Polit & Hungler 1993; Glesne & Peshkin 1992). Developing narratives requires that the interview process is refocused. There has been a growing awareness of the role of the interviewer in helping to construct and not just to collect biographical information from interviewees (Hollway & Jefferson 2000; Holstein & Gubrium 1995). The interview is not just a means of collecting data but is itself a site for the production of data, as Barbour (2001) suggests qualitative data is always generated.

Traditionally, the interviewer is in control of the process, selecting the questions to ask, probing areas of interest. To a certain extent this remains true within a narrative approach, but the questions are much more open ended and the narrative is constructed by both interviewer and interviewee (Mishler 1986). Less questioning occurs by the



interviewer, it is much more like a conversation with a shared sense of control. The interviewee becomes a 'teller' or 'narrator' in a conversation and takes the listener, the interviewer, into a past time (Riessman 1993; Gaydos 2005). A personal narrative is not a simple chronology nor is it a linear process, people start with their stories in many different places. When following the story, the listener is pulled in and interprets it in the light of their own experiences, as such the narrator and listener co-create meaning. The interviewee is encouraged to tell their story and directs the flow. There is, however, still a degree of direction by the interviewer in initiating the dialogue and probing to clarify meaning. The aim of the interview should be to stimulate the interviewee's interpretive capacities and the interviewer should activate narrative production (Mishler 1999; Holstein & Gubrium 1995).

Nine people were interviewed, drawn from a sampling matrix discussed within another section. Each interview lasted between one to two hours and yielded a large amount of data. The appropriate length for a research interview is open to debate, but ninety minutes has been proposed as an optimum length (Hermanowicz 2002). The interviews conducted within this study range from forty-five minutes to two hours. What is more important is the idea of listening to, and not suppressing, stories, and negotiating with the interviewee an optimum time. The aims of the study and the conceptual framework directed the actual interviewing technique and generation of the narratives, which is discussed below.

### *Conceptual Framework*

Identifying the main elements in the data according to some theoretical scheme was an early stage of analysis (Silverman 2000). A conceptual framework was developed at the outset, based on the literature review, which suggested matters to be investigated and the direction of the conversation in the interviews. It became apparent after the first two interviews that the conceptual framework (appendix 1) was slightly at odds with the stories being told, and as such the conceptual framework changed en route. At the outset it was anticipated that health care professionals would play a central role in the development of understanding that patients had of their low back pain. It was speculated that different professional groups would impart information differently and this may lead to a lack of clear understanding for the patient. However, as the initial data was collected this did not seem to be a key consideration to the participants. Subsequently the framework was revised (appendix 2). Miles & Huberman (1994) suggest that as qualitative researchers collect data they revise their frameworks, make them more precise, replace empirically feeble concepts with more meaningful ones, and re-construe relationships. Conceptual frameworks are simply the current version of the researcher's map of the territory being investigated and as the knowledge of the terrain improves, the map becomes correspondingly more differentiated and integrated (Miles & Huberman 1994). The resultant set of analytic categories is highlighted in the interpretation sections as recurrent features (Mishler 1990).

### *Interview Guide*

The original questions that sparked an interest in this research formed the basis for the aims, and together with the proposed conceptual framework formed an informal guide from which the interviewer asked questions. This guide is highlighted in appendix 5. The questions were broad, particularly the opening question, and as the interview progressed and a form of conversation developed the guide became more of a reference rather than an actual script. The interviews remained flexible and relatively unstructured. Issues raised by the participants were adopted into the questions and conversations of subsequent interviews, but the latter interviews did contain elements absent or unprobed in the initial interviews. There was also an element of developing experience by the interviewer which coloured the data collection; as the interviewer's experience increased so did her ability to probe and unpick key issues as broached by the interviewee. The iterative approach to data collection, study design and framework development is depicted in appendix 7. The inherent flexibility of qualitative studies gives further confidence that a level of understanding of the key issues emerged (Miles & Huberman 1994).

At the outset of an interview the researcher asked the interviewee to tell them about their pain. This allowed the interviewee to choose where to start their story, and as addressed in the previous section implies something of the importance and significance of events to the narrator. However it is important to be aware that some people might find it difficult to respond to such a broad question. It is generally agreed that questions in interviews should be framed in everyday language rather than sociological language (Chase 1995).

Narratives are most likely to be elicited if simple questions that clearly relate to life experiences are asked. The interviewee was encouraged to continue their account to completion, after which questions and comments were broached by the interviewer in a conversational style. If the interviewer wants to encourage the production of narratives they must also be a good listener, and should avoid interrupting a story which may cut off a whole area of information. Glassner and Loughlin (1987) call this approach a 'methodology for listening', and are, thus, concerned with 'seeing the world from the perspective of our subjects' and suggest interview responses are treated as both culturally defined narratives and possibly factually correct accounts. The notion of 'facticity' will be addressed below. In this study all participants responded to a broad opening question and provided detailed narratives, but at times during the interview short answers were given without any elaboration despite questioning.

### *Recording & Transcription*

The interviews were tape-recorded and transcribed. Tape recording was important to allow the interaction between the researcher and the interviewee to be the focus. Full attention could be given to the interviewee rather than needing to take notes. It would be impractical to remember the stories and responses, and make notes after the interview given the length of the interview. Hermanowicz (2002) advises that it is now considered good practice to record all interviews, since data could be lost. Immediately after each interview the process of transcription began.

Transcription should be recognised as more than a task because decisions about transcription need to be addressed as part of the analytic process (Wengraf 2001). A transcription is always a compromise because it cannot capture all of the meaning and nuances communicated during the interview. Transcriptions often erase the context along with some crucial non-verbal data and are inescapably selective (Miles & Huberman 1994). The more detail provided in the transcript, the more clues for interpretation. The aim when transcribing in-depth interviews is to preserve some of the additional meaning conveyed by the use of intonation, pauses, and body language (Elliott 2005). Transcripts can be done at different levels of detail, from the 'ers', pauses, word emphases, mispronunciations, and incomplete sentences, where facial expressions, explanatory gestures, and tone of voice can be included, to a smooth apparently straightforward summary of the main ideas presented by the speaker. A clean transcript focuses on the content of what was said, and makes it easier to read, though provides no information as to the manner in which it was communicated (Elliott 2005). The researcher adopted the former style, and field notes taken during the interview allowed annotation of the transcript to include facial expressions, gestures and tone of voice. Some editing did occur in the form of punctuation.

Interviews and medical consultations are examples of situations where particular types of stories are required, and institutional settings can restrict narratives. Medical consultations are usually time limited and focus on history taking, which invariably means closed questions in a directed format. The research interview, in contrast, guides the participant through a process of self exploration, where individuals are encouraged to

seek self knowledge and share this with the researcher (McCabe & Holmes 2009). It is hoped that by allowing the voice of participants to be heard in their own words, by being open to questions and information gathering from participants, by adjusting the research agenda to reflect the ideas and concerns that are important to participants and by recognizing the socio-political context the traditional approach is left behind and a move toward a reciprocal relationship emerges.

### *Truthfulness & respondent validation*

Interviews are a tried and tested method for eliciting respondents' perceptions. However people rarely attach a single meaning to their experiences, rather there may be multiple meanings of a situation or of an activity represented by what people say to the researcher, to spouses and to others (Gubrium 1997). Holstein and Gubrium (1995) raise the important methodological issue about whether interview responses are to be treated as giving direct access to 'experience' or as actively constructed narratives. Stories do not provide a transparent account through which we learn the 'truth' (Hollway & Jefferson 2000). The assembly of narratives in interviews is always a two-way process. Therefore, the interviewers' questions must not be treated as gateways to the authentic account but as part of a process through which a narrative is collectively assembled. By abandoning the attempt to treat respondents' accounts as potentially 'true' pictures of 'reality' we highlight the methods through which interviewers and interviewees in concert generate plausible accounts of the world.

The concept of measuring truthfulness sits uneasily with in-depth interviewing, where the researcher is aiming to elaborate a detailed description of experiences and meanings (Elliott 2005). Two opposing claims have been raised to address the issue of truthfulness and narrative interviewing. The first claim advocates the use of narrative interviews because they empower the respondent to set the agenda and prevent fragmentation of the experiences, implying that narrative interviews produce data that are more accurate, truthful or trustworthy than structured interviews (Mishler 1986). The second claim stresses that narratives are never simply reports of experiences, rather they make sense of and therefore inevitably distort those experiences (Ferber 2000; Atkinson & Silverman 1997). However, it is not necessary to assume that the person will provide an objective, truthful account, but that it is preferable to obtain a story that reflects the interpretations and values of the individual. It would seem to be more pertinent to ask whether narratives are produced specifically for the research or whether those told in interview are related to those told in spontaneous conversation. Cox (2003) suggests that the fact that the interview is not the only interaction in which people expect to give an account of their life means that it is difficult to draw a distinction between the interview and real life. This would lead to greater confidence in the veracity of interviews. However it does need to be pointed out that stories told in interviews may not be naturally occurring stories in everyday conversation, as it is usual to recount anecdotes but rare to provide an extended account of life experiences. This does lend weight to the argument that the meanings and understandings people attach to their experiences are not necessarily preformed, and that telling stories is a jointly constructed, meaning making activity.

Respondent validation, or member checking, is the practice of asking participants to confirm or dispute the researcher's interpretations (Williams 2000). The crucial issue is how far the researcher's understanding of what was going on in a social setting corresponds with that of the participants (Bryman 1988). When undertaken it is hoped that this will enhance the transparency of the research process and lend weight to the findings described. This study did not employ this practice, as participants were not invited to comment on the interpretation, beyond clarification and summing up during the interview. Concerns regarding what could be validated were based on the fact that even if participants were able to corroborate the data, they could at best agree with the researchers interpretations of their interpretations. Based on their experiences of using respondent validation, Emerson & Pollner (1988) and Bloor (1997) point to several difficulties with its use, and highlight the need to be sensitive to its limits if seeking reassurance about one's ability to comprehend the social world of others.

The interview process requires an evaluation of the researcher's role. The characteristics of the interviewer will influence the interviewee and hence the type of data collected (May 1997). Issues of reflexivity are subject to further exploration below. The relationship between the interviewer and the interviewee plays a crucial role in data obtained. Researchers have their own understandings, their own convictions, their own conceptual orientations; they too are members of a particular culture at a specific historical moment (Miles & Huberman 1994). The researcher needs to study their characteristics and the potential influence on the research. This is of practical concern as well as epistemological and theoretical concern. In this study I felt that it was necessary



to preserve the presence, concerns and experience of myself as the researcher, so that subjectivity would be a visible part of the project and thus available for examination by the reader (Miller & Glassner 1998). A biography is included within the thesis, as well as an overview of the rationale for the study. My background knowledge of pain management and health care practices could lead to the possibility that details, complexities and subtleties within the interviews and data could be seen and deciphered that would elude a less knowledgeable observer. Which questions to ask, and which incidents to attend to closely were relative to my theoretical interests and review (Miles & Huberman 1994).

### Narrative Analysis

People appear at all times to be telling stories about past, present and future. Plummer (1997) argues that to exist in society is to tell stories; there is an unavoidable social expectation that we can and will give accounts of ourselves and the world around us, and he goes on to suggest that the social world exhibits the same qualities of flow, development and creativity as we would experience in a conversation. Clinical experience, as previously mentioned, suggested that people suffering from low back pain like to tell their stories.

Abductive reasoning strategy, of which narrative analysis is an example, is based upon the hermeneutic / interpretivist tradition. In this instance *abduction* is the process of producing social scientific accounts of social life by drawing on the concepts and

meanings used by social actors, and the activities in which they engage (Blaikie 1993). Interpretivism uses meanings and interpretations, motives and intention which people use in their day to day lives and which direct their actions. In abductive reasoning strategy the research begins with the researcher describing the participant's everyday activities and meanings. Something is only significant to researchers if the researched tells them that it is part of their social reality. However the use of abductive reasoning strategies would be sterile if confined to merely reporting peoples' accounts. To counter this, once categorical distinctions emerge and interpretive frameworks are imposed the researcher has moved beyond the essence of the people's description to a theoretically dependent description of social reality.

Narrative analysis takes the story itself as its object of investigation (Riessman 1993). Analysis in this study is concerned with the telling of the experience, not simply the content. Narrative analysis can reveal the underlying meanings of a story, and in this research allowed the researcher to understand how the story teller interpreted their experience of back pain through an examination of the text as well as the content. Traditional approaches to qualitative analysis often fracture texts to aid interpretation and generalization but this would eliminate the sequential and structural features that characterize narrative accounts (Mishler 1986).

Coffey & Atkinson (1996) describe analysis as a pervasive activity throughout the life of a research project. In this study analysis was not simply one of the later stages of research and did not come after data gathering. The researcher followed this recommendation,

such that transcription immediately followed the interviews and the data was analyzed as the study progressed with the research questions in mind, in order to test out methods, findings and concepts. As the researcher cycled back and forth between thinking about the existing data and generating new data, analysis proceeded whereby bits of discrete information came together (Miles & Huberman 1994). The analysis and the activity of data collection formed an interactive, cyclical process and contributed to the whole process becoming a continuous, iterative enterprise (see appendix 7).

Qualitative research, like this study informed by an interest in narrative, is about more than just allowing the voices of the participants to be heard. The words used have been edited and filtered through a theoretical framework (Elliott 2005), and the analysis places the narratives within a social context. Narrative is not merely repetition of a story, but it is a newly re-formulated description, and as such is able to cast new light on that which has previously been experienced (Frid et al 2000). Narrative analysis places the individual in the foreground, and seeks to understand the choices people make and the constraints and assumptions as well as the decisions which structure their lives (Chamberlayne et al 2000). The data has challenged the researcher to understand the individual's current attitudes and behaviours and how they may have been influenced by time and place (Hagemaster 1992). The data focused on naturally occurring, ordinary events in natural settings, and provided a story of what 'real life is like' for people with low back pain. The data is grounded as the influences of the local context are not stripped away but are taken into account, and have been particularly important in reframing the initial concepts.

There is no common definition, method, technique or mode of analysis when applying a narrative approach (Denzin 1994); the author has selected Ricoeur's (1991) approach to interpretation due to his focus on the construction of stories as a primary form of mental representation and communication, and not just on the importance and impact of stories (Skjorshammer 2002). Ricoeur (1991) claimed that a story is constructed by mimesis and emplotment. Mimesis refers to cognitive imitations of events and incidents in actual life, whilst emplotment is a dynamic linking process whereby a succession of events, incidents and heterogeneous elements are transformed into a unified story. A story imitates life by configuring the succession of actions and events into a plot, in other words a meaningful, coherent picture, and for this to occur there needs to be internal coherence within the plot, otherwise known as concordance. Concordance is made up of events having a beginning, a midpoint, and an end, and ultimately leads to the story having wholeness. Ricoeur (1991) argued that there are three levels of mimesis. Level one is composed of incidents, events and experiences in 'real life', filtered through language and culture. Level two is where a narrative structure is imposed through the story telling process and results in a story that makes sense. Level three occurs in responses by the listener which either corrects or confirms the story.

### *Interpretive Theory*

This study aimed to understand the experiences of people living with back pain, and so the research had to enable people to express their experiences. The participants were invited to tell their stories and as they did they could reflect on the events they were

recalling, thus new meanings could be established as they discussed their experiences. The telling of these experiences and the joint construction of narratives between the researcher and the participants was then followed by the process of interpretation. A review of Ricoeur's work helped clarify some issues in relation to interpretation, explanation and authorial intent.

### *Appropriation and distanciation*

The interpretive framework used in this study needed to allow a shift from a description of low back pain to an interpretation of living with low back pain, creating a means to capture multiple interpretations of the experiences of chronic pain. Ricoeur elaborated upon the relation between explanation and understanding (Charalambous et al 2008). Ricoeur (1981) viewed hermeneutics as a theory of interpreting text as a whole, which did not involve understanding the intentions of the author but involved an understanding of the meaning of the text itself. Ricoeur (1981) asserted that interpretation allows actualization of the meanings of a text and this occurs through *appropriation*, which is the perception of new meaning. To understand the narrative (the text) is to follow its movement from manifest description of what the text says to what it talks about, here the text discloses possible ways of being in the world that can be appropriated (Wiklund et al 2002). To interpret is to appropriate the intention of the text, by seeing things in a different way (Ricoeur 1995).

Distanciation was another concept discussed by Ricoeur (1995). Distanciation is the presupposition that we can distance ourselves from our pre-understanding in order to

perceive new meaning. This is not to claim objectivity, rather it entails a reflective ability to be aware of one's horizon and partially detach from it (Sandage et al 2008). Appropriation and distanciation culminate in understanding (Ricoeur 1995). Thus according to Ricoeur (1995) we cannot understand anything new until we understand it in a way that changes our perspective, and that is only possible if we are willing to distance ourselves from our pre-understanding. Distanciation attempts to remove the authorial intent and the idea that the meaning of a text resides only with its author, which allows researchers to move beyond the notion that only one understanding is meaningful or correct (Geanellos 2000). Thus the interpreter is able to approach the text with an open mind and thereby appropriate its sense through the use of the explanations the text provides the reader with (Charalambous et al 2008). Ricoeur (1995) was working from the premise that situations of speaking and writing are different and that written texts are already somewhat distant from the author's mind. The purpose is to present the text within its historical context so that understanding emerges from the present in light of the past.

#### *Ricoeur's three phases of analysis*

Ricoeur's hermeneutics suggested a theory of interpretation, the goal of which is to achieve a new and deeper understanding of being in the world (Dreyer & Pedersen 2009), in this case of being in chronic pain. Ricoeur suggested a theory rather than a method, formulated around explanation and understanding, which proceeds through three phases of analysis from the whole to parts of the text. The following theory / method informed the analysis. A naïve reading is the first interpretation of the text as a whole and provides

the direction for further analyses (Sorlie et al 2003). The first naïve interpretation has the characteristics of a qualified guess and gives a hint of the researchers pre-understanding (Wiklund et al 2002). This guess is related to the meaning of the text and provides the first understanding of the relationship between the whole and the parts of the text. A structural analysis is then undertaken which examines parts of the text, and is intended to validate or refute the initial understanding obtained in the naïve reading. Here the text is de-contextualised and it is possible to understand the meaning of the text by studying the structure. Emplotment is the way by which a sequence of events is fashioned into a story (White 1973). According to Polkinghorne (1996) the plot includes specification of the problem with orienting actions and events; organisation of actions and events into a narrative with a beginning, a middle and an end; and clarification of the point of the story and thereby the meaning of actions and events. The structural analysis is conducted firstly as a search for narrative structures as outlined by Polkinghorne (1996), and then as a search for deeper structures to underpin a new understanding. The final phase is a critical in-depth interpretation based on the researchers pre-understanding and conceptual framework, the naïve reading and the structural analysis. Ricoeur (1984) argued that a text has always more than one meaning, and, therefore, there is more than one probable interpretation.

Thus according to Ricoeur and his ideas of appropriation and distanciation, interpretation arises through a dialectic movement between the whole and the parts of a text, and enables a shift from what the text says to what it talks about. This process moves from pre-understanding to explanation to understanding as interpretation develops. Ricoeur

(1981) argued against a dualism between understanding and explaining, and instead suggested that they are continuations of each other and in fact prerequisites for being able to achieve productive interpretations. However, there must be critical distance as well as belonging for methodical appraisal of the sense of the text, as well as for the event of understanding. Ricoeur's theory provides a way of looking at the meaning of a text in a way that makes appropriation of new meaning possible.

Ricoeur focused on textual interpretation, taking into account language, reflection and dialectical movements between explanation and understanding (Dreyer & Pedersen 2009). By following this method it was hoped that the researcher would be able to achieve a comprehensive understanding. The interpretation was performed in the three phases previously outlined. Following transcription of the interviews the texts were read in order to acquire a sense of the text as a whole – naïve reading. These first repeated readings were done with a conscious effort towards distanciation, and resulted in an initial impression of what the researcher understood the texts to be about. The structural analysis followed providing an interpretation of what the text says and an interpretation of what the text speaks about. In this research what the text says refers to the identification of recurrent features and the use of quotations. The quotations were interpreted and structured in order to say something meaningful about suffering chronic low back pain. What the text speaks about has been framed as the narratives, and again quotations are used to illuminate the journey with back pain from the beginnings, through the middles to the ends of the stories. Finally the critical interpretation was undertaken, and is presented with relevant literature to argue one interpretation. The naïve reading,



the structural analysis and the researchers pre-understanding were taken into account, and this interpretation led to the formulation of an initial understanding of living with pain or living in pain. By conducting the interpretation process in several steps there is the possibility of presenting different levels of interpretation.

### Rigour

Rigour is central to the debates surrounding the quality of qualitative approaches (Rolfe 2006). Rigour is closely linked to concerns of validity and the accuracy of what is being measured, and in terms of qualitative study this may include the accuracy of information and the interpretation of the data. The control of researcher bias has been emphasized as a way to ensure rigour, and to this end reflexivity can be seen as a useful tool for informing the whole research process.

Reflexivity can be thought of as a focused reflection on the researcher's ability to be unbiased, whilst also recognizing and considering the effect of any existing biases on the research (McCabe & Holmes 2009). In this way reflexivity indicates an awareness of the identity of the researcher within the research process. Reflexivity is the process of analyzing how various elements affect and transform the research (Roberts et al 2006), particularly how the researcher affects the research process and the participants, and how the participants affect the researcher. Some researchers employ reflexivity as a means of controlling the effects of researcher bias, for example by bracketing<sup>4</sup>. Others use it as a

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<sup>4</sup> Bracketing is a process where researchers attempt to recognise and set aside their personal beliefs at the beginning of their study, but remain aware of them throughout the entire research project (Speziale & Carpenter 2007).

tool for gaining new depth in research, as a mechanism for informing the researcher and the research process. However, as Allen (2004) argues unless the actual use of reflexivity becomes more explicit it will remain a device for according studies the appearance of academic rigour rather than enhancing the understanding of the research process and strengthen the quality of studies. The researcher did not attempt to eliminate or control social influences but sought to identify the role and impact of these forces on the research process, including the researcher's theoretical stance and the socio-historical location (Allen 2004).

A qualitative study can be evaluated accurately only if its procedures are sufficiently explicit so that readers can assess their appropriateness and the research standards that the researcher has assumed are appropriate to the study (Kirk and Miller 1986). Verification entails checking for the most common biases that can steal into the process. Huberman and Miles (1998) discuss a checklist to consider when assessing bias: data overload, missing information, over-weighting findings; the salience of first impressions or dramatic incidents; selectivity and overconfidence in the data; co-occurrences taken as correlations; and finally unreliability of information from some sources. However, Barbour (2001) cautions researchers to use checklists wisely, as rigour can only be strengthened in research if the evaluation criteria are embedded in the design and analysis. Critical qualitative research requires the researcher to have a solid theoretical framework to guide the strategies of data collection and data analysis (McCabe & Holmes 2009). The previous sections discussing data collection and analysis gave an overview of the considerations made regarding truthfulness and generalizability. As

Higgs (2001) advises it is important to embed the research in methodological understanding and identify criteria for assessing research from the outset.

A number of processes can help to strengthen the claim to quality assurance; adopting a systematic approach to sampling, checking interpretation with research participants, checking the interpretation of the interview material, and including quotations in the report. There is never one 'objectively' valid interpretation of a social situation. All that is possible is culturally and historically situated accounts leading to a number of interpretations (Blaikie 1993). Truthfulness of answers derives not from their correspondence to meanings but from their ability to convey situated experiential realities in terms that are locally comprehensible (Holstein and Gubrium 1995).

A reflexive approach was adopted, which Koch and Harrington (1998) suggest results in a form of sign-posting allowing readers to see not just 'what is going on' but also to see the influence of the researcher on 'what is going on' during the research. The final research product includes the literature, the data generated, the analysis and discussion as well as the professional and personal positioning of the researcher within a social and political context. This will allow the reader to decide whether the text is believable or plausible. Whilst acknowledging that all research accounts will be partial and shaped by the biography of the author, the researcher has attempted to make this account as informative as possible, providing insights into the means and circumstances of its production.

In this study, the researcher and the researched developed a shared understanding of life with back pain. The researcher had knowledge of pain theory and experience of working with people suffering low back pain, and the participants had experience of living in pain. Together both contributed to the narratives created and any resultant understanding. Some philosophers take the position that objectivity should be maintained by ignoring previous experience or by bracketing pre-understandings (Husserl 1931; Merleau-Ponty 1968), however, Gadamer (1975) would argue that the knowledge and experiences of the researcher do not impede the ability to understand, rather that to interpret requires the use of ones own preconceptions. Thus the researcher declared her work background and previous understanding of back pain, a description of which is included in a later section. Ricoeur's interpretation theory has contributed to the process of interpreting peoples narratives of their life with low back pain, and has helped to achieve a deeper understanding of the journeys and worlds of those who participated in this study. The following sections describe the analysis and interpretations derived from the data, and are presented as a naïve interpretation, a structural analysis featuring the recurrent features (what the text says) and narratives (what the text talks about) and a critical interpretation where the concept of living with pain or living in pain is introduced.

## Chapter 4

### Recurrent Features of the Stories

#### First Stage of Analysis: Naïve Reading (Ricoeur 1981)

##### *Chapter Overview*

Earlier it was noted that Ricoeur (1981) described three levels of mimesis, which roughly accord with the stages of narrative analysis: naïve reading, structural analysis and critical interpretation. This chapter outlines the naïve reading of the data which is the first interpretation of the text as a whole, and provides the direction for further analyses. The following chapter features the structural analysis, where the text is decontextualised and the meaning of the text is explored by studying the structure and sequences. Chapter six is an elaboration of the final phase, the critical interpretation, and is based on the pre-understanding, the conceptual framework, the naïve reading and the structural analysis.

Narrative analysis allows the researcher to keep the text whole rather than fragment it. Formal coding (in the sense of grounded theory (Strauss & Corbin 1990)) is not being used in this study, but through continued readings of the source material it was possible to capture the essence of an account – what is constant in a person's life across its manifold variations (Miles & Huberman 1994). Quotes from the participants' stories are included in the report. The importance of including representative examples as part of an audit trail is addressed in the section on rigour. The people in this study use very vivid and sometimes quite strong, emotive language to express their story, and are typical of people talking and telling about pain. The quotations selected are true to the words used

by the participants, but any discussion thereafter uses softer language to consider the claims made.

Initially it was thought that differences in the narratives would be produced by differently positioned individuals in terms of life experience, illness experience, and gender. The following paragraph summarises the biographical differences of the sample. The sample was made up of six women and three men, aged between thirty-five and sixty-six. Two women and one man had young children; one woman and one man had older children; one man and three women had no children. Two women and one man were unemployed because of their low back pain, one man and one woman had retired early due to pain, and two women had changed jobs as a consequence of their pain. They had all received a diagnosis of chronic low back pain, with four of them also suffering radiating leg pain. The length of time that had elapsed since onset of the pain ranged from three years to twenty-one years. Four of them had had surgery for their pain problem. All had seen a number of health care professionals, the least being four separate practitioners, the greatest being seven. Three women saw both conventional and alternative practitioners, the others including all the men saw only conventional practitioners. All the participants had been referred to the pain clinic between one and three years prior to interview, and the gap between pain onset and referral to the clinic ranged from 4 years to twenty years. However, no major or gross differences were identifiable in the themes and features discerned in the stories, nor in the overall narrative structure. Subtle differences and tendencies were noticeable and are alluded to in the following sections.

After the initial readings of the stories and as preliminary analysis progressed, common recurrent features became evident. These recurrent features are artificially abstracted from the narratives for the purposes of illustration, because in reality they are interconnected dimensions of living with low back pain. During the preliminary readings of the data, story elements emerged that were common to all the narratives. These story elements are referred to as recurrent features within this study and are presented in table 4.2. When the transcripts of each narrative were laid out, the features were apparent to a lesser or greater extent in each narrative, however they did not always occur in the same part of the story, in the same order nor were they used to the same effect. The recurrent features, or themes, are discussed in some detail in this section, which is then followed by a section where the narratives are discussed in detail with reference to these themes.

Table 4.2 Recurrent features and their dimensions

<b>Recurrent Feature</b>	<b>Dimensions</b>
Doctorability	
Agency	External = escaping control Internal = exerting control
Control / dominance	Pain / self Good days / bad days Fighting
Future	Looking for a cure Resignation Looking forward
Separation /Acceptance	

## Doctorability – the quest to establish medical legitimacy

### *Doctorability & legitimacy*

Doctorability refers to the idea that a patient must satisfy the health care professional, usually a doctor in the first instance, that they have a problem requiring investigation and intervention. Heritage (2006) proposed the term ‘doctorability’, and suggests that when visiting a GP a patient must assert the existence of a problem which they lack the knowledge, skill or expertise to manage on their own. The patient must project the problem as one which is properly handled by medical expertise and intervention. Legitimacy is important to patients, specifically that the visit to seek medical care should be properly motivated by an appropriate medical problem (Heritage 2006; Horton-Salway 2002; Seers & Friedli 1996). The experience needs to be described and labelled by expert language, in order to provide sufferers, families and employers with a benchmark against which the experience may be evaluated (Kelly & Field 1996). This concern helps to explain the peculiar conflict we sometimes experience when we go to the doctor – we want to be told that we are well, but we also would like to have had good reasons for believing that we were not.

At societal level legitimacy is enshrined in everyday language which contains numerous terms for people who inappropriately seek medical care, for example hypochondriac, malingerer and crock, and is present in contemporary popular culture (Heritage 2006). It is highly probable that socially competent people have a tacit knowledge of the rules of the game; from childhood we are schooled in the rules of engagement with health



professionals (Carter 2004). For patients a doctorable problem is one that is ‘worthy of medical attention, worthy of evaluation as a potentially significant medical condition, and worthy of advice and where necessary medical treatment’ (Heritage & Robinson 2006). The need to make the problem ‘doctorable’ relies on the assumption that doctors can roll up their sleeves and find the answer, and as such patients believe in the medical model (Rhodes et al 1999; Illich 1976).

The data suggests that all the participants use the notion of doctorability to some extent; they all provide a ‘convincing’ argument as to why they sought medical care and how they passed through a gateway into the medical domain. Linda gives an example of doctorability.

(8) 12-17

it was the lifting and twisting which did something I believe to my right hand side ligament wise, and then I was sort of in a lot of pain with that for about a week or so and then the left hand side began to react badly to it I think, muscle spasm and all of that kind of thing and then subsequently I think it was about a month or two I started getting sciatic pain and erm a lot of discomfort in my back wise and it just got aggravated from there really but that was initially what happened to it.

Linda uses a combination of lay terms and technical terms within this extract. Initially the injury is described as occurring after lifting and twisting, both of which are known as potential agents of low back pain, and this establishes the notion of a reason or cause of the low back pain. Linda then introduces the idea of what she perceives to be the resulting problem in technical language, a ligament problem, which she then elaborates upon and subsequently proposes muscle spasm and sciatic pain. The timescale detailed in

this extract highlights that medical help was sought only after a period of time had elapsed and in fact the pain had progressed and got worse. The initial wait prior to seeking medical help and the description of potential cause provide examples of the need to establish convincing arguments to access health care and suggests the impression of cognitive reasonableness, the underlying rationale behind the judgment. This maps Linda's reasoning and judgements and ultimately the presentation of a dilemma requiring resolution (Witenberg 2007). All participants highlighted the need to establish a doctorable problem; similar to Linda, Annie related:

(1) 18-25

I got woken up and tried to get out of bed one morning, but couldn't with pain along the back you know, this was through the night, nobody about, you know, with this horrible pain, so I got my feet down onto the floor and when I stood up the left side from the hip down to the big toe was all pins and needles, all down from there to the toe, so this went on for a week and I thought this is no good I've got to go along and see the doctor, so I went along to see my doctor and she lifted my legs and tested me to see, and she said that that was alright lifting up my leg, she said it wasn't hurting with that, and so she thought it was a trapped nerve.

This extract highlights the importance of the onset and severity of the pain to this participant, the pain woke Annie up and is described as 'horrible'. Again Annie attempts to manage this pain for a week before finally deciding that medical help is required. The fact that this lady lives alone, and the severity of the pain, are used to justify why health care is sought. The examination by the GP confirms Annie's belief that this was a genuine problem by conferring a diagnosis. This extract is much less technical than the first extract but they both highlight the importance of providing a convincing argument. Jane in contrast focused on technical details and achieves a surgical resolution.

(5) 18-23

I started to go downhill probably about 6 years ago, erm and the bad sessions were getting longer and the good sessions were getting shorter and that was when I was getting a lot of pain into my legs and the pain in my back itself was actually a lot worse, a lot more intense and I couldn't get the relief from it that I'd been able to get previously, erm and then I had a fusion, L3-4 fusion

Jane feels that the pain is worsening and describes bad sessions which occur more frequently and for longer. Relief from the pain was proving more difficult to get. Here Jane is establishing that the pain needed to be dealt with surgically because she had previously been able to manage the pain but now it was at such a level the pain was unmanageable. This suggests that Jane had done all she could and then asked for help. Having surgery justifies this approach and attributes cause to a physical reason. Susan, however, did not have surgery but equally justifies her pain with physical findings.

(6) 21-25

I had some x-rays and it was just horrendous what I saw, there were two curves in my spine, erm my pelvis twists this way, erm I've got an extra vertebra at the base of my spine, and it was just quite a shock to see all that and it was like well actually yes there are mechanical reasons why I'm in such pain, erm and it sort of affects my sciatic nerve on my right hand side

This extract describes a diagnosis received from a chiropractor not a GP. Susan obviously has confidence in this diagnosis which she feels confirms the genuine nature of her back pain by establishing physical reasons for the pain. The tone of the extract suggests that Susan is relieved to find mechanical reasons for her pain, though uses superlative speech to account for the findings. This could be to ensure we understand the degree of pain from which she is suffering and that this is a genuine problem.

### *Diagnosis & authenticity*

The importance of diagnosis and authenticity of their pain would seem to be key features here, the participants needed to establish a genuine, physical reason for the pain and attribute cause. Most respondents were driven by difficulties in performing their daily activities to seek the cause of their pain (McPhillips-Tangum et al 1998). For people with chronic back pain these issues are intensified by the fact that the problem may be invisible both externally and internally. Pain that cannot be seen or confirmed by objective signs threatens a crisis of meaning (Kleinman 1988). Thus while in other conditions a positive test may be feared, for back pain patients a positive result confirms a real problem. Tests have the power to legitimise pain and can contribute to a sense of alignment with medicine, or alternatively can alienate patients with inconclusive or negative results (Rhodes et al 1999). Most imaging tests fail to provide a meaningful diagnosis for chronic back pain.

Each participant lists the investigations and health care professionals they engage with in chronological order, and encounter a series of steps that they must go through. Interestingly most retain their own views on the causes of their pain, which seldom reflect the views of the clinicians. Two extracts are taken from Robert's story to highlight this point.

(2) 39-41,

When I seen Dr G he reckons it was just a weak back, but I still say like from being a child and getting my leg twisted and that, and I have got one leg slightly longer than the other, you know.

and later,

(2) 148-149,

....and you're thinking why I've had 3 operations and you're telling me there's nothing wrong, why I know there's something wrong

Here Robert disagrees with the expert view that it was just a weak back. He has had a number of investigations and surgeries for low back pain, but firmly believes that it all stems from his childhood problem. This opinion has been dismissed by the medical expert but holds firm with Robert. This could be because having a congenital musculoskeletal problem is a much more obvious cause of pain and something solid to base a management plan on rather than something speculative. Further on in the interview Robert explains how the surgeons continue to suggest that there is nothing wrong with his back now. He finds this unbelievable and states that he knows there is something wrong; the implication being that after three operations there has to be something wrong because there is no resolution of his pain. It would seem that the original problem that resulted in surgery was considered genuine, but this change in medical opinion now causes Robert to question the ongoing legitimacy of his back pain if it is not supported by a medical diagnosis. An often cited reason for the lack of understanding between the patient and the doctor is the disparity between the explanatory models of illness held, such that the patient speaks the 'lifeworld' and the doctor speaks 'medicine' (Lupton 1995; Mishler 1997; Bendelow 2006). Medicine constructs the subjectivity of a patient's experience and thus shapes diagnosis. Laura also has a firm view on the causes of her problems.

(3) 135-138

I just don't think there's anything that can be done at the moment. Erm I think adhesions have caused a big problem with the pain, but adhesions are funny things, you'll know, trying to get a doctor and pinning him down to admit that adhesions are probably what's causing the problem is impossible

Laura believes that adhesions are contributing to the pain now. Her original surgery did not relieve the pain; she describes the pain as different to the presenting complaint and this is what leads her to believe that adhesions are causing the problem. Laura firmly expresses her view on adhesions despite not being able to get her doctors to commit to this view. By describing adhesions as 'funny things' she is allowing the doctors some leeway in not firmly committing to her view. It could be that the expectation of pain relief after the surgery now leads her to suspect that a new problem has occurred. As in the previous example if the original cause of back pain has been removed then another problem must have occurred for the pain to still be considered as genuine. It would seem that participants buy into the medical view on cause very decidedly, or they do not. There appears not to be a grey area.

#### *The importance of diagnosis*

Perplexity and frustration are partly remedied by an official medical diagnosis. Hilbert (1984) suggests that people in pain search for a diagnosis, and are motivated to do so because they hope that diagnosis will bring treatment and cure and locate them with others sharing the condition. Diagnosis is related to the legitimation of sickness and can be associated with narrative reconstruction (Williams 1984). Diagnoses for chronic pain sufferers are often long in coming if indeed they come at all. Hilbert (1984) goes on to say that medical evidence suggesting that there was nothing wrong forces people to

consider whether they were experiencing reality correctly. Medical science is the ultimate criterion that something is truly wrong.

The data suggest that the presentation of a complaint determined to be ‘non-doctorable’ can deprive the patient of authoritative medical support for their claim to enter the sick role, limiting financial and other benefits (Heritage 2006; Glenton 2003). ‘Chronic disease leads clearly to a different and perhaps more complicated way of being sick – it requires a different, longer lasting performance’ (Frankenberg 1986). The degree to which a person’s experience of illness is accepted is tied to the degree in which this illness experience is transformed into sickness, that is the degree in which it becomes socially meaningful (Frankenberg 1986). Thus people who experience bodily suffering but who fail to gain acceptance for this suffering by the medical profession find themselves with illness but without sickness. The sick role<sup>5</sup> (Parsons 1951) is limited in describing the realities of low back pain, but it still appears to describe the expectations of doctors, families and back pain sufferers (Glenton 2003). The sick role concept has come to be seen as inappropriate for chronic illness because, it is argued, it is based on an acute medical model of sickness (Crossley 1998). In this acute model the doctor-patient relationship is central, but for long term illnesses such as back pain, where doctors have little biomedical insight to offer, the doctor-patient relationship is seen as far less important. In this approach the authority of professional technical knowledge and

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<sup>3</sup> The sick role concept was first developed by Parsons (1951). To achieve the sick role is to achieve recognition of ones suffering and is also a social license to be exempt from particular duties for a given period of time. The exemption requires legitimation by a medical doctor because of their ability to identify objective biological or pathological signs of disease. The sick individual is not expected to get well by an act of decision alone but is exempted from responsibility for their condition and must be looked after. In return they are expected to display a visible attempt to get well, including a desire to co-operate with those seen as appropriate and competent.

competence assumed in Parsons model is challenged and the persons own ability to master their situation is emphasised (Crossley 1998).

If diagnosis or adequate management is not achieved then the data suggests people continue in their quest for this. Lack of diagnosis can lead to chronicity of pain, and ultimately result in people being given vague labels of non-specific back pain or back pain syndrome (Wells, Pincus & McWilliams 2003). Heavy use of medical services in an attempt to find medical answers to legitimise and validate pain follows. Lack of diagnosis may be related to a lack of perceived control and increased helplessness (Banks & Kearns 1996). Wells, Pincus & McWilliams (2003) found that a label provided a name for patient's experiences and allowed them to communicate more easily, give their pain a sense of tangibility, validity, and provide justification for suffering thus protecting them from guilt, shame and self blame. However current guidelines do not advocate the use of labels or diagnosis among chronic pain patients. Many of the participants had seen numerous health care professionals during their time with pain ranging from traditional to non-traditional practitioners, for example neurosurgeons, orthopaedic surgeons, physiotherapists, psychologists, pain specialists, acupuncture, chiropractors, reiki, magnet therapy and flotation therapy.

It could be that the pervasiveness and acceptance of the medical model by all the participants explains why biographical differences do not seem to feature within this theme. People seem to fully understand and engage in their role position in relation to medical practitioners, for example as previously mentioned the sick role (Parsons 1951)



still seems to describe the expectations of doctors and pain sufferers. It may be that role position and the need to provide a convincing argument are enough to transcend any possible differences in personal biography.

### Agency – who's making decisions?

Agency has been defined as the belief that one can initiate and sustain movement along imagined pathways to goals (Snyder et al 1991). Agency taps the individual's perceived capacity for initiating and maintaining the actions necessary to reach a goal, whilst a pathway, is the perceived ability to generate routes to one's goals. Snyder et al (1991) describes successful agency as goal-directed determination. Agentic thinking is reflected in such self-talk as “I can do this”, “I'm not going to be stopped” (Snyder et al 1998), and is particularly important when the initial routes are blocked as in chronic illness, and the necessary motivation must be channelled to alternate pathways (Irving, Snyder, & Crowson, 1998; Snyder, 1994). It is possible to consider that people exhibit high or low agency in all areas of their life, and this is no less true when managing low back pain.

Thus, in this discussion agency describes the mode of acting or action needed in order to achieve an outcome, and is framed as passive (low agency) and active (high agency). The terms active and passive mirror a frequently used dichotomy in relation to coping with pain, where active coping refers to strategies used to control pain or to function despite pain, and passive coping is related to withdrawing and surrendering control over the pain (van Damme et al 2008). These concepts can be related to the notion of locus of control,

which is a theory much discussed within the pain literature. Locus of control is a term used to refer to the extent to which people believe that they can control events that affect them; an internal locus means the person believes that they can control their life, whilst an external locus means that some other person must control their life and decisions (Bates & Rankin-Hill 1994). Internality and externality represent two ends of a continuum (Rotter 1975). An internal locus of control promotes the likelihood of minimising, tolerating and reducing pain (Bendelow & Williams 1996).

(2) 9-12

when I was born one of my legs was twisted inwards, so they twisted it back and I was going there til I was 14, you know, and I was thinking it might be something do with that, so I asked to go to the (hospital) and they done x-rays and says no problem at all with it.

Robert has asked to go to a specific hospital to a specific team whom he knew as a child. He is unsure whether this is a new problem or a problem related to his childhood condition, but asks to go back to the hospital he was treated at. Here Robert has taken control in initiating medical help and has clear wishes which he manages to convey by taking charge of his situation, which highlights an active strategy. In contrast, Jack adopts a passive stance.

(7) 142-147

he turns round and he goes 'I don't know why you're coming, because there isn't anything we can do for you', I says 'I know that but I've just got to keep my employer happy, I've got to do what them tell me to do, cos otherwise I'm like trying to be awkward and don't care about my injury', I says 'It's good of them to pay for us to come, so if you tell them that you cannot do anything then that's your prerogative but I've got to do it til then'

This extract was a reconstruction of a dialogue between Jack and a physiotherapist he had been referred to, and highlighted a passive response whereby Jack declined control. He either was not able or did not feel able to exert control in this situation despite agreeing with the physiotherapist that this therapy was not helping. By engaging in the therapy Jack can be seen to be participating in his own care and seen to be taking it seriously; he was also complying with the sick role. If, as in this instance, the therapy did not help it was not his fault, and directed us to view the problem as severe.

Agency can be seen as having both passive and active processes. Most participants actively chose to engage with health care in pursuing an initial visit to their GP.

(8) 26-27

Initially I saw physios, erm I paid for a private physio first of all, I then went to the GP and got referred to an NHS physio

Linda had previously described the onset of her pain problem as occurring at work whilst working with physically disabled children. She actively pursued help by referring herself for physiotherapy, and then sought medical help when the situation was not resolving. This highlighted an active approach in taking her health seriously. Musculoskeletal pain is often dealt with by physiotherapy and by trying this first suggested a tacit knowledge of health care systems. Only when this proved unsuccessful did Linda seek medical help. Similarly Fred highlighted initial contact with medicine.

(4) 12-14

I was on night shift and in such pain I went back to the doctors and you're definitely off work now

Fred had sustained an injury at work, visited his GP but chose not to take time off. This extract highlighted that despite his best efforts the pain was so extreme that he had to go back to the doctors who signed him off work at that point. Fred initially adopted a very active approach and took management of his pain into his own hands, but when this did not succeed accepted the medical view that time off was required.

### *Passivity & the medical journey*

Participants seem to externalize their pain and its management as the pain becomes a longstanding problem, and the active element seems to change and a passive approach is adopted. However three participants were brought to an emergency department at the onset of their pain, and were passively engaged from the start. Whether active or passive initially, people described a series of steps that they went through on their medical journey whether they wanted to or not.

(3) 320-327

My GP's been fantastic, erm, very understanding, erm, I've seen a psychologist and she was marvellous, she was just really helpful and gave me loads of confidence. my gynaecologist, lovely fella, and I think, I just think that he just didn't know what else to do at the end (sigh), and then he referred me to a bowel doctor, who, I don't know, he was the one who suggested I was depressed, I don't know

Laura listed some of the doctors that she had encountered during her time with low back pain. She highlighted how nice they were, and generally how helpful they were, but seemed to question how effective they or their treatment strategies were. Laura was describing a sequence of steps she went through with no real gain in pain management.

She seemed to go from speciality to speciality without questioning the rationale, but adopted a very passive approach despite continually wondering what the point of it was. Clare, in contrast, did not question the rationale but simply described health care encounters.

(9) 27-33

I started having physio on my neck and then I moved on to having acupuncture for a couple of years and I must admit the acupuncture was quite good but very short relief, very short relief, so really once I started it was after I had my neck operation and my back still wasn't getting any better, the doctor then says 'Right we'll send you for another x-ray on your back', and that come back and they said everything is fine (laugh) and I says 'Oh right then'

Clare listed the practitioners seen during this phase of the pain journey. We can see the time-frame is more than two years but this was played down by Clare; it seemed that the focus of this extract was to highlight the continuing nature of the pain and the inability to reduce it rather than the length of suffering. Clare was adopting a passive approach.

Adopting a passive or an active approach to pain management does not seem to be related to age, occupation or length of time since pain onset. It appears that all the participants adopt both active and passive positions during their journey depending on the situation rather than always acting actively or passively. However, three of the women who engaged in alternative therapies could be described as showing active agency in pursuing not only conventional therapies but those deemed more alternative or less mainstream. Age was not important here, nor occupation, and therefore it is not possible to suggest

more than a tendency to active approaches by women, as not all the women engaged in this.

*Agency, legitimacy & causation*

Managing agency is another concept that appeared in the data and followed from the idea of passivity and control. Describing a morally credible activity, for example work, just prior to the onset of pain will help establish causation and therefore legitimacy of the back pain. People vary in the extent to which they feel obligated to legitimate a medical concern (Heritage 2006). Some conditions scarcely require elaborate justification, for example accidental injuries, whilst those with a more insidious onset frequently manifest a concern with the legitimisation of the condition.

(8) 7-12

I worked with deaf children who some had additional handicaps, and physical or mental or additional to being deaf, and the incident that actually created my back problem was a child we had he'd broken his leg while doing whatever he was doing in school one day and he'd had his plaster cast off and the nurses at the hospital had said don't let him put any weight on it for 24 hours, so myself and a colleague were lifting him into the bath and it was the lifting and twisting

Linda described a challenging environment and highlighted a very specific incident that she knew caused her back pain problem. The incident involved a young boy who had broken his leg and suffered from other handicaps, but these were not detailed specifically. The actual mechanism of injury was depicted as lifting and twisting whilst putting the child into the bath. The impression was given that Linda could not be blamed for this injury because of the nature of the boys needs and that others had instructed a certain

course of action. The injury resulted whilst she was undertaking her expected duties. This was a feature of Jack's story too.

(7) 7-11

so it just happened at work, I was working on a mixer by myself lifting heavy things and there's supposed to be two of you on the job and the other lad was running another mixer which the manager had told him to, and I complained about my back and asked for a break just to rest my back, and sat down in a seat and couldn't get back out of it

Jack had a heavy manual job in a busy factory. Here he told of working by himself on a job that required two people. His manager had instructed single working and was seen, therefore, as responsible for the resulting injury, distancing Jack from any blame. To further distance himself from blame, Jack informed his manager that his back was hurting and asked for a break to rest his back so as to be able to continue with work. He was unfortunately unable to resume work as he could not get back out of the seat and was eventually taken to hospital. Jack leads us to believe that this incident occurred because he was working in an unsafe way outside of his control, and this lends authenticity to his claim for legitimacy of his problem. Alternatively authenticity can be claimed following an accident, as in this extract from Jane.

(5) 6-10

I fell off my horse and had a fractured L3 and L4, and that took me about 6 months to get over that and then I started to get a lot of pain and I got pain in my back and then I started to get pain in my legs which I hadn't had initially, erm and I had surgery

Jane was only seventeen when this accident occurred, she fell off her horse. At seventeen Jane was, and would be expected to be, pain free, and therefore the pain and subsequent

surgery are directly related to the accident. An accident confers absolute distance from blame and establishes an immediate genuine reason for pain. Fred coupled both work and an accident in the next extract.

(4) 5-8

I got injured at work, I got attacked by a patient, I worked for the NHS and I was thrown backwards very heavily, and erm, and I hit a fire extinguisher and that damaged the bottom of my back, I just took it to be more bruising as you do, I used to get knocks a lot

In the interview Fred went on to describe how he worked with adults with autism in a long term care setting. He particularly pointed out that he was attacked at work, by a patient. He detailed the mechanism of injury as being thrown backwards and hitting a fire extinguisher. Fred then qualified this description by stating how it was common to be attacked by patients, it had happened to him before and initially he dealt with it by saying it was just more bruising. Only when the pain persisted and began to get worse did he acknowledge it as a serious problem, which we find out further in the interview caused him to retire. Establishing a cause to confer authenticity and legitimacy to the problem is important and this is achieved by highlighting that the injury happened whilst pursuing his usual line of work with troubled individuals. It was normal to be in this situation.

Five participants described accidents involving work, car or sporting situations which immediately distanced them from any blame. The other stories mentioned equally credible activities or occurrences to account for their pain. Certain props were used, for example working with deaf children or adults with autism, to complete the displacement of agency, ensuring an escape from control. It also established the fact that the



participants were leading fruitful lives and did not invite pain. Thus pain depends on factors beyond their control and this facilitates the inhibition of behaviours and the depletion of active coping strategies (Torres et al 2009). These points will be discussed more fully in the next sections.

### Control / Dominance – the pain or me?

This recurrent feature of the accounts referenced the idea that at times the pain was ‘in control’ and dominant and at other times the person was ‘in control’. Related to this concept are the notions of good days and bad days, and fighting a battle. This is different to agency because this describes the person’s relationship with the pain rather than the relationship with healthcare services. Charmaz (1993) explored the fluctuations of living with chronic illness and described how this generated a day to day existence. Good days permit routine and even unscheduled events, whereas bad days force the person to focus on the present and only immediate needs can be attended to.

(8) 490-493

If I was in control I wouldn’t be here, I know I’m never going to get rid of it but I want to try and get back to some feeling of I’ve got more control than it has

The opening remark ‘I wouldn’t be here’ can be considered to mean two things; firstly that Linda wouldn’t actually be attending the pain clinic and subsequently a research interview which was where she was when the comment was made. Secondly that Linda would not be in the situation, emotionally, physically, or socially, that she finds herself in

now. She immediately stressed that she had no control, and that although she could begin to think the pain would never go she needed to feel that there was some hope of her being in control. She was acknowledging that control could shift between herself and the pain. The pain was not referred to directly in this extract, but referred to as 'it'. This could be a means of distancing from the pain, and was probably done to allow the idea of control and dominance to be explored by the person. If the pain is part of you, then it becomes a moot point to discuss control. Similarly Clare talks of control.

(9) 273-276

it's ridiculous, the only thing I would say I control now in my life is my medication, it's the only thing I seem to have control over, and everything else is just controlled (laugh) by my pain

Clare attempted a light hearted approach to the issue of control which probably belies the true depth of emotion felt. The fact that Clare stated 'everything' was controlled by her pain, suggested the overwhelming nature of chronic pain. She did not acknowledge or allude to the possibility that she could regain control in any other area of her life than medication. However she did refer to the pain as 'my pain', which seemed to suggest she owned it though was powerless to control it.

### *Bad days*

The participants all relayed stories of good days and bad days, a concept identified by Goodacre (2006). For the most part people had average days when the pain was constant but just about bearable and they could function at some capacity. Personal ability was

usually not at the same level of activity or function as prior to the onset of pain, and was very precarious in that the situation could worsen at any time.

(4) 65-68

it brings it down to a bearable level but not what I would class as a workable level, erm because you're ok, you know I can do odd things, mess about, but then I've got to change what I'm doing, either sit down or, it's an up and down existence, that's what I call it.

Here Fred was describing an average day, where the pain medication had some effect and the pain was bearable. However he then described how his lifestyle was disrupted by the pain because he could not settle to any one thing for too long. His pain was bearable and he felt 'ok' but not comfortable or pain free so that he could continue his pre-morbid activities. The pain was constantly there to remind him that he must attend to it with analgesia and regular positional changes. In contrast Jane painted a very vivid picture of her pain but did not feel the need to rely on analgesia.

(5) 117-119

A minor degree of leg pain, I have a little at the moment but I wouldn't say it was really bothering me, so I'm aware that up the front of my lower left leg that I've got a sharp sensation there but I wouldn't even think about taking something for it

Jane described quite a graphic picture of the pain in terms of severity and location. To her this was a minor degree of pain and one that she would not consider taking extra analgesia for. This description could be taken for her general level of pain, constantly present, but causes minimal interference with her everyday activities. Jane is very

familiar with her pain and easily described its presence even when it was not overtly troubling her.

Bad days were described as inevitable. They could occur unannounced or they could creep up over a few days during which time the pain was steadily increasing. Days could start 'ok' and turn into a bad day part way through.

(2) 285-287

nothing you can do, you try reading, getting into telly but on a bad day you just cannot. I try talking to the dog and playing with the dog, and you know it gets frustrating, you're fidgeting all the time and like you're not on a good day

Robert described the restlessness of a bad day, how he fidgeted and could not get interested in anything. He compared this to a good day where presumably he could settle and felt less frustrated. The implication here was that Robert was attempting to continue in his usual pursuits but was thwarted, hence the frustration, but he did not suggest he gave in to the pain and stopped trying. Linda highlighted similarities to Robert, but relied on a different coping style.

(8) 432-435

A bad day's where I feel physically I can hardly get up and stand and not be able to stand very long, sit very long, walk very long, it's that I've got the treble thing of any of them aggravate it, erm and if you do one, anyone of them for too long it's going to be lying down, I should say if I've got to go to work then I have to drag myself in, it's kind of grit your teeth and try and get on with it, but I kind of find myself huffing and puffing and like trying to control it a bit, trying to relax your back, and it is really difficult, yeah.

Linda talked of her restlessness in not being able to sit, walk or stand for too long, but in contrast to Robert she talked of her solution which was lying down if she had the opportunity. This was a very explicit account of the control pain had over her, when she stated that 'it's going to be lying down', we could hear the inevitability in this statement. Linda used vivid language to describe the struggle if she had to go to work; the difficulty in relaxing and the physical effort needed to get there and stay there. Clare, however, offered a different coping style again.

(9) 543-551

just maybe not even getting out of bed, or getting out of bed and making your way downstairs and just getting as far as the settee, and that's it, not even have the energy unless somebody came to go and put the kettle on, I have my medication set out for the day ahead, I would have a couple bottles of water, go in the sitting room and I would be on the settee all day, maybe half asleep, watch a bit of telly, never ever have the energy to read and you wouldn't think reading took much energy, but just on days like that when I try and read I just instantly go to sleep, but I mean I may as well not get out of bed.

Clare gave an account of a bad day, but again in contrast to Robert and Linda she did not even attempt any of her usual pursuits. She told us that she may not even get out of bed, and if she did then she might as well not have bothered to. Clare's day involved minimal activity due to her low energy level, however she did not directly mention the pain in this part of the extract. Clare implied these bad days are common in that she had already prepared for this eventuality by ensuring her medication was set out and water was available. Unless someone visited her, she would stay on the sofa all day and would attempt nothing.

It seemed that during a bad day pain was at the forefront of the mind and the participants could focus on nothing else. Work was very difficult to pursue and any kind of activity was severely disrupted. Most people described not being able to do anything. At these times all the participants described the pain as in control. Bad days suggested a clear inseparability of mind and body, which was in stark contrast to the mind-body duality of modern medicine (Bendelow 2006).

### *Good days*

Good days, however, were much less frequent than bad or average days, and were highly sought after. People described them as days when they felt normal again and could do anything

(3) 251-254

I mean when I go to work I usually have a good day, some days I can be sat at work and I can still be in pain but I enjoy my job so much I just work through it, I'll just sit there and work through it, erm just because it's what I like doing and I'm thinking 'I'm not letting this beat me!'.

Laura clearly enjoyed her work, and would tolerate her pain. Maybe the pain was not always present when Laura was at work, but on days when the pain was present she could work through it. Laura was able to put the pain out of her mind because she was actively engaged in something she really enjoyed, and could take control of her situation. She was not letting the pain become dominant. Going to work was important to Laura, and it was the work that allowed Laura to have a good day. For Jane going to work was routine not the means to a good day.

(5) 343-347

Getting home from work, I've had a good day, 'come on let's go here', 'let's go and do this', 'let's go to the pub' and it's just 'let's go and drown our sorrows', 'let's go for a walk', you know 'come on, come on, come on' rather than I'll go and sit down for a bit, and it is about, oh I don't know, yes wanting to do things, having the energy, not thinking about pain.

Jane however always went to work but that was not what made it a good day, having energy and enthusiasm was what made it a good day. In this extract she had been to work and still had energy to do other things, she was not thinking about the pain. Jane does not say the pain had gone, but she was not paying attention to it, she was not thinking about it. She wanted to continue in her activities whilst she could, and was very much in control of her situation. The ability to do everything was what made the day good without the distraction of pain. Not everyone worked, but good days were still achievable as Clare highlighted.

(9) 481-485

if it's a good day I'd think 'Oh my head feels different', I'm not thinking about having a crap night and I think I don't know on a good day I feel it sounds strange but you feel like I don't know there's a light in you, I don't know you're happier, like you feel happy for no apparent reason, it sounds ridiculous but I feel when I have a good day like that I feel lighter in myself, it's a funny feeling but I just feel like lighter.

Clare in contrast to the previous participants did not work. To her a good day still involved a distraction from her pain, but she described feeling light. Clare explained this as a feeling of happiness for no apparent reason. This suggested that the pain was still present, as an obvious reason for happiness would be a reduction or resolution of pain. Clare clearly stated there was no apparent reason, so we can surmise that pain was

present but she was not focusing on it. She was concentrating on the lightness and was describing a happy, positive state.

On the whole good days were good from the start, and the participants described being in control. The data suggested that average days and good days can turn into bad days, but bad days never turned into good days.

(4) 294-296

When I'm having a bad day and it's leading up to a flare up, no, nothing from the start, and it will stay a bad day, you seem as if you're constantly looking for a, for a position if you're sitting to get a little bit of relief

Fred summed this position up in this extract which was an experience mirrored in all the narratives. Fred described how a bad day was bad from the start and would remain that way. He suggested a restless existence, constantly looking for some relief from the pain, but which always remained elusive. Despite his best efforts Fred was unable to subdue the pain.

On good days everything was achievable, work and activity, with a feeling of lightness and energy. All the participants craved good days and some suggested that good days could be achieved if certain factors were fulfilled; for example taking rest days, or not over-doing it, as Susan highlighted.

(6) 136-139

you just soldier on as best as you can but it's not the best thing to do, I suffered, I suffered until about Monday with that one and then it started to



ease off again because I managed to get myself into bed in the afternoons for an hour and a half just to refresh the batteries.

Susan has previously described a very busy day involving hospital appointments, shopping and Brownie classes. She felt that she had to keep going despite knowing that her pain was becoming unbearable; she had commitments and people that she did not want to let down. Susan acknowledged this was not the best thing to do but in her words 'soldiers on'. Here Susan used a war metaphor (see below for further discussion). On one hand Susan could be describing a good day as she achieved everything she set out to do, however she suffered for the experience and had to resort to rest to overcome the intensity of the pain and recoup her energy. In this extract Susan over does it but still managed her day out, whilst in the next extract Jane described activities to avoid.

(5) 129-132

I know that sitting down triggers pain if I sit down for a long time, I know that stooping forwards so things like gardening and weeding I just can't, I absolutely can't do them, so there's that applying pressure whilst you're stooped over, so I know there are specific things that I do that can create it

Jane was able to list the activities she felt unable to do. She had had pain for all of her adult life, and had developed an awareness of what could trigger the pain. She had fine-tuned this to the degree that she was able to describe outright triggers and situations that could be tolerated for a short time. This extract in comparison to the previous one suggested that Jane was managing her lifestyle and pain in tandem, rather than Susan who appeared to meet her pain head on by not acknowledging what she could and could not do and suffering the consequences. There was a realisation over time that more good

days could be achieved by adapting lifestyle rather than struggling to maintain previous levels of activity. Pacing comes into the narratives as a possible solution, leaving behind the bust or boom approach.

### *Fighting an ongoing battle*

All participants talked of the idea of an ongoing battle between the pain and themselves. Metaphors have been used in everyday speech and language throughout history (Byrne 2008). Sontag (1988) quoted Aristotle's definition of metaphor as 'giving the thing a name that belongs to something else', and went on to elaborate that using metaphor was an ancient mental operation that spawned most kinds of understanding. The fortress image has a long pre-scientific genealogy, and John Donne (1627) described illness as an enemy that invades and lays siege to the body-fortress (Sontag 1988). Military metaphors have come to infuse all aspects of illness, whereby bodies are invaded, bodies mobilise defences and medicine responds aggressively (Sontag 1988). Military metaphors have become prominent, and are not only used by medical personnel, but by society in the wars against poverty or drugs for example, and by individual people when they fight, struggle and battle illness and disease. People use symbols and metaphors to draw attention to aspects of their experience that might be overlooked (Stanworth 2005). Therefore, given this cultural tendency it was no surprise to find that fighting was frequently mentioned in a number of contexts within the data; for example fighting for a good day, or fighting to achieve certain goals, and could be closely linked to the concept of control and dominance.

(3) 273-278

do you know I could quite honestly say I probably have more good days, not so much in the sense that the pain's not there but because I'll fight through it, so I'll fight for a good day (laugh) more, and I think that's something that's come lately really. Although it will knock me, you know, I'll fight through it and then as I say by the Friday I'll spend the day in bed, You know, sometimes I think it's worth it (laugh), you know, because then I can look forward to the weekend, You know, sometimes it knocks me for longer

In this example Laura was describing an ongoing battle. There needs to be an opponent to fight, and although Laura did not explicitly state that she was fighting the pain, she did describe fighting through what we could interpret as the challenges of pain. Later in this section there was a discussion on pain being separate to the person, and this extract provided an example of that. Laura suggested that pain was separate to her, and therefore was the opponent in her fight. She described a positive experience of fighting for a good day where pain was still present but she was in control. The idea of a battle was seen because this fight was not a one-off event but a continual encounter where control switched between her and the pain. Interestingly Laura was able to feel dominant to the pain whilst at work and at weekends, but was dominated by the pain on the other days when she clearly gave in to the pain and spent the day in bed. Similarly Susan highlighted the idea of control, and introduced the notion of consequences.

(6) 566-568

you've got to do what you've got to do, but always at the back of my mind there's this voice saying you shouldn't be doing that, you're going to pay for this and really, probably should be listening to that voice a bit more.

Susan did not explicitly mention fighting in this extract but it was included to illustrate the point of control switching from person to pain, and the feeling that it was out of their

control. Susan implied a struggle to achieve what she must do with a permanent voice telling her that there would be consequences. She acknowledged that she should attend to that voice more often but did not, and that was where the notion of fighting or resistance to the pain was suggested because she did not listen to the voice. Susan was struggling to stay in control, but knew that the pain would be dominant at times. In contrast Clare described advanced preparation to allow for an activity.

(9) 377-384

what I tend to do is if I know I'm going somewhere I'll just go to the hairdressers and get my hair done and then I know it's done and I don't have to think to myself 'God I can't hold a hairdryer' because you couldn't go out if your hair wasn't done on a night out could you? So they always give us stick, they'll go 'You're always getting your hair done when you go out', and instead of explaining it all which would bore them to death I just say 'I like to get it done like that' cos then I know I'm not giving myself the excuse of you can't go because you can't do your hair, go to the hairdressers and get it done

Clare highlighted the idea of preparing for an event. Again she did not explicitly mention fighting, but illustrated how tenuous her grasp was over the pain at times. Once her hair was done she knew she could go out, she was not allowing the pain to flare up by actually having to do her hair herself. Clare interestingly suggested that she was not giving herself the excuse of being unable to go out, when the subtext alluded to the problem being with the pain not herself. This was an example of how having to prepare in advance is perceived as unusual and related to pain, when in fact she asked for confirmation in this extract of this being a normal situation. Clare also mentioned the necessity of having to justify her actions to her friends, which she declined to do in terms of pain but puts the onus on to herself. This could be because the pain was invisible to her friends and to

make it real to them she had to describe it, which in turn reminded her of the control it held over her.

### *Paying the consequences*

The idea of fighting for a good day was expressed by many participants and this was closely associated with the idea of suffering afterwards and paying the consequences.

(4) 262-265

at times if I do anything out of the ordinary, erm, I usually say I'll pay for this tomorrow (laugh). If I've walked that little bit too far then it's going to catch us the next day, and there's no getting away from that, but I think everyone else is the same, or could be the same.

Fred introduced the concept of ordinary into the discussion. He described how anything out of the ordinary would cause the pain to flare up and he would suffer for it afterwards. He knew that it would catch him up the next day. It was almost like 'tit-for-tat' inasmuch as Fred seemed to be describing a game. Fred could be in control one day but if he overstepped the mark then the pain would be in control the next day and he would pay the consequences. Fred highlighted what all the participants described, that ordinary was redefined as anything that did not aggravate the pain. Out of the ordinary was not what it once was, but in fact referred to anything that would provoke pain, for example walking too far, or going on a long journey. These were all usual events in people's lives before pain became a problem.

The concept of fighting, as it appeared in the accounts, could be construed in two ways; firstly fighting involved doing whatever was necessary to ensure a good day for a certain

occasion, and this involved passive and dynamic elements. Secondly fighting involved doing what you would normally do and struggling through. When fighting, people perceived themselves to be in control of the pain but when consequences occurred, which inevitably meant a bad day would follow, the pain was seen to be dominant. Control shifted between the pain and the person; sometimes the person was the winner sometimes the loser.

Baszanger (1989) believed that people always seek to maintain control over the pain. This control, which is effective only in certain situations, is aimed not only at lessening pain but also at maintaining both personal integrity and the presentation of a competent self which the pain experience tends to destroy. Attempting to control the pain continues because the person believes that the pain will end. The data in the current study, however, suggested that control passed between pain and person, and whilst the person wished to be in control the pain would be dominant at times.

### Anticipating Futures – where do we go from here?

#### *The idea of time*

Before we can relate to the future, it is necessary to briefly allude to the concept of time. Consciousness cannot be without a sense of past, present or future, and the concept of time is central to the matter of consciousness (Adams 1990). Time is central to understanding the natural and social worlds, but is one of the most taken for granted aspects of human life. Adams (1990) suggested that an understanding of how we use time

and how we organise social life by time can only be undertaken once we elaborate the nature and function of time. However there lies a dilemma, as little consensus exists how to define time. McTaggart (1927) identifies two distinctive ways of talking about time, objectively (B-series), for example calendar time, and subjectively (A-series), where the A-series of time consists of statements comprised of relative terms such as past, present and future which are fundamentally context dependent. Human time always includes the dimensions of past, present and future as humans are conscious beings for whom these dimensions matter. In this case human time as an orientation to past-present-future is dependent on memory, intention, aspirations as well as growth and decay.

Heidegger (1962) thought of time as a horizon, and thus was able to distinguish from the boundary effect of time. Life is organised, regulated and structured in relation to some sense of scale, and as such living an 'in-time' sort of existence is reinforced by clocks and calendars. However, Heidegger (1962) suggested that unlike boundaries which are independent and fixed, horizons are relative to their owners and to contexts and cannot be reached. This concept recognises that time has a *dasein* element, the irreversible directionality of time from birth to death. Looking at time and horizons is particularly pertinent to stories of chronic back pain, because each story portrayed the person in the past, the present and the future. Embedded within a linear time frame each story was more than a chronology because of the context and the personal representations of time. The temporal aspects of the self were actualised in chronic pain, requiring the sufferer to rethink and reconfigure the past and future (Hellstrom 2001).

### *Looking for a cure*

The future was not always mentioned directly in the narratives, but was alluded to in three particular ways. Firstly, there was the idea of looking for a cure; which seemed to be in fact a continuation of the original aim. Irrespective of the length of time that back pain had been suffered, people could still be looking for a cure. They could pursue this vigorously and actively sought practitioners to help, or take a more long-term view that they would be ready when something curative came along.

(3) 368-373

well I saw my GP the other day and, erm, I gave him quite a hard time really (laugh). I had loads of questions to ask him, and one of the questions was 'have I been written off?' (laugh) he said 'no, but we'll tell you when we have!' (laugh) And the other one was about adhesions actually, and he said that nothing, they can't really do anything at the minute, but that doesn't mean to say that in the future it's not going to change. So maybe one day there will be a cure, who knows

Laura, like all the participants, had a continual relationship with her GP. Despite having pain for many years she still had many questions to ask him, and suggested that their relationship was harmonious and quite light hearted. This could be because the pain was so longstanding that maintaining a close relationship with her GP authenticated her situation. This and further aspects of identity with low back pain are considered below. It also reflected the fact that despite surgery and numerous investigations her pain was still undiagnosed and she remained hopeful for some help from the medical profession. Laura felt that she gave her GP a hard time because of her persistent search for help, but equally was pacified when it was stated that there was nothing to be done at present. She



continued to be optimistic for a cure in the future, even though she only pursued help from her GP now, unlike Annie.

(1) 27-33

So I had this back x-ray which came back that I had a bone slipped or slipping and arthritis. And that was that, so then my son rang up a chiropractor to see if they could.... I had to try what I thought was my last hope.

Annie in contrast to Laura was still actively seeking help from a range of practitioners. She relied on medical diagnosis but when treatment was not forthcoming from the medical profession she took it upon herself to pursue complementary therapies. Annie used quite dramatic language to convey the importance of continuing her search for a cure, when she declared that visiting a chiropractor was her last hope. It also implied that a medical route to a cure might have been what she was expecting, if her last hope was chiropractic she obviously rated complementary therapies as a second line option. Annie was still actively seeking a cure.

### *Resignation to the pain*

Secondly there was the notion of resignation in relation to the future. Bendelow & Williams (1996) interviewed chronic pain patients, who expressed the feeling that their lives were totally dominated by the pain, and that there was no hope for the future as the pain would never disappear. Bendelow & Williams (1996) suggest the group display classic features of resignation, a term coined by Herzlich (1973). In this situation people dwell upon their condition; feel psychologically cut off or isolated from others; feel hopeless or depressed as a result of their condition; indicate that they are missing out on

social activities in which they previously engaged, or which are enjoyed by other people; and express the view that illness has come to dominate their life (Herzlich 1973).

In this discussion resignation referred to the above idea that the pain was here to stay, and the data suggested that people treat that positively or negatively. An attitude of stoicism may also have a role in influencing the level of adjustment to chronic pain. Yong (2006) reported on findings from the illness coping literature and concluded that stoicism affected not only a patient's willingness to report symptoms but that it could have a positive or a negative impact on adjustment. A positive response involved a suggestion of coming to terms with the pain, and an admission to themselves that the pain was here to stay despite their best efforts. It alluded to hope that things may improve but the pain would be present. In contrast a negative response suggested that the pain would always be present and may even get worse, however coming to terms with the pain was not an option. This was different to looking for a cure, because no hope was expressed for a positive outcome, and there seemed to be no engagement in actively looking for help.

(8) 499-505

I don't want to accept that this is the level I'm at and this is where I'm going to stay or it's going to get worse, I'll only accept that it's going to improve (laugh) I haven't accepted that this is where I'm at cos I don't think this is where I'm at, I think there's an improvement to be had, definitely an improvement, there's got to be, I have to have that because if I don't then god knows what state I'll be in you know, I've got to try and focus on a positive future.

Linda was striving to focus on a positive future, she had accepted that the pain was there to stay but would not accept that it would remain at that severity. She stated that she had

to have that hope of improvement because she could not imagine how she would cope if the pain stayed the same or got worse. This seemed to be a conditional resignation to the pain; Linda was resigned to the pain being present in her future life but only on the condition that it would improve from the current level. Fred discussed resignation too.

(4) 172-176

but I know it's there and I know you've got to accept it to a point but at times you think 'why the hell should I have to put up with this?' But if you know it's not going to go away, you can't let it take over everything, it does but it's a case of fighting it. I've always been a fighter but there are days when you think I've had enough of this

Fred in contrast was resigned to the pain on the whole, but still described a struggle. He questioned whether he should have to put up with the pain, but then acknowledged that the pain was not going to go away. Fred continued to battle and stressed that he will not let the pain take over everything, he suggested that he had always been a fighter but there were days when he could not fight. Again fighting seems to be a significant aspect of identity in low back pain. Fred implied that he had resigned himself to the presence of pain in his life but would not come to terms with it, it would be present on his terms only.

The struggle to make changes in their life and not let the pain take over everything highlighted the battle with suffering, and the determination to alleviate their own suffering. Suffering occurred in the whole person as a state of distress induced by the threat of loss of intactness or disintegration from whatever cause (Arman & Rehnsfeldt 2003). Suffering is one of the oldest human experiences (Copp 1974), and can also be described as a constant struggle between hope and hopelessness, meaning and

meaninglessness, reconciliation and broken-heartedness (Rehnsfeldt & Eriksson 2004). Key features of suffering are the notions of enduring, struggling and sacrifice. People can conceptualise, analyse, attack and to some extent endure chronic pain, but its existence is potentially present in everyday life (Raholm 2008). People fight against suffering, and the sacrifice of a life that is collapsing. Frank (1995) has written extensively about suffering and illness, and described narrative surrender, which seemed to be what Fred in the above example was experiencing, and may be what Clare was experiencing too as it was difficult to determine if she had resigned to the pain.

(9) 625-627

Because when you hurt yourself you always get better don't you? And that's what I did, I was in an accident, I hurt myself, I should get better but I know I'm not, just have to wait and see.

Clare described an interesting dilemma, she stated her reference point as 'pain always goes when you get better', however, her pain had remained. She reinforced her belief that you get better after an accident by stating it twice, once in particular relation to her own scenario. Clare then acknowledged that she would not get better, but immediately questioned this when she said that she would just have to wait and see. Clare may be resigned to the pain, but because it did not fit with her belief system, which was the belief system we are socialised into, she could not fully accept that it would not get better. This notion also supported the need for continuing medical involvement.

The medical perspective frames illness in objective, depersonalizing terms, which may be indispensable and reassuring to the patient, especially in the acute phase, but can become

overwhelming when beyond medical help (Sakalys 2003). Ville et al (1994) described the importance of the prevailing historical and socio-political context on the ways that illness is experienced. Conformity to social norms is important in locating illness experiences within collective contexts that extend beyond the life of the individual concerned. Thus we can see that Clare's beliefs were conforming to the socially accepted norm that pain goes as recovery takes place, and medical help will assist this process. People use socially available themes, ideas and images, identified as 'interpretive repertoires' (Potter & Wetherell 1987)<sup>6</sup>, to provide subject positions which confer rights and obligations. One such subject position is pain patient, with the attendant right of medical management, and the obligation to keep trying to get better. Illness identity is entrenched within an individual and social context.

### *Looking Forward*

Thirdly there was the idea of looking forward to the future which captured a positive, motivated approach. Lifestyle adaptations and pacing activities featured in these narratives, with a view to what may be achieved in the future in work and social relationships. Goals could be considered, and there was talk of real hope for the future.

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<sup>6</sup> 'Interpretative repertoire' is a theoretical concept developed by Potter & Wetherell (1987). They recognised that language allows for multiple versions of an event and were interested in the way that individuals construct their versions to do things. Variations in language use can shed light on ways that people construct their accounts. Potter & Wetherell (1987) argued that a range of accounts of the same phenomenon would contain the same relatively internally constant language units which they called 'interpretative repertoires'. As such they are the building blocks speakers use for constructing versions of actions, cognitive processes and other phenomena. Any repertoire is constructed out of a restricted range of terms used in a specific stylistic and grammatical fashion, often signalled by certain tropes or figures of speech. A repertoire may be used to construct positions for ones self or others.

(2) 336-341

I know I'm not going to get any better, I know I'm stuck with it now, I can still see something positive, even as I say if I can't get to work I'll get a computer and even if I can't do that I'm resigned to what I can do. I mean, roughly, I've only worked 2 years in the last ten and I did enjoy it. I was getting out and about, but I've just got to change it and go to clubs or something, you know, join a chess club, you know you've got to start instead of sitting in the house feeling sorry for yourself

Robert was beginning to address the future. He was resigned to the pain but could see something positive and phrased this in relative terms, if he could not go out to work then he would get a computer. Robert acknowledged that he had to change and modify his expectations, there were things he could do but they would just be different to what he was managing in the past. Robert had set some short and long term goals, and indicated a positive approach to achieving them.

#### To separate or to accept

##### *Accepting pain*

Acceptance was considered here as a separate feature, but was very closely linked to the previous feature. Acceptance involved having difficult or painful experiences without functioning being influenced to any significant degree (Vowles et al 2007). Acceptance did not imply a blind pursuit of activity in spite of pain, but argued for behaving in chosen ways with pain contributing towards a full and satisfying life (McCracken 2005). Risdon et al (2003) identified eight different everyday accounts of acceptance of chronic pain, and despite the diversity all accounts shared common features: the need to focus away from pain to non-pain aspects of life, a recognition that cure of pain is unlikely, and

a rejection that acceptance is a sign of personal failure. In this discussion acceptance was a very positive statement that suggested pain had been incorporated into the person's life.

(8) 484-486

Yes it's part of me but I try to separate from it, and I think that's my coping mechanism as well because it's almost like I feel it's sitting there, sort of just to the side of you and it's you kind of push it away a little bit I suppose that's how you can look at it.

Linda felt that the pain was part of her, but continued to treat it like an unwelcome extension of herself. She acknowledged that it was part of her but tried to push it away. Linda described sitting separate to the pain and pushing it away as her coping mechanism. She then suggested that was how she could bear to consider the pain, and may be this was the first step to completely accepting pain as part of oneself. Interestingly she personified the pain by giving it the ability to sit next to her. Jane on the other hand embraced acceptance.

(5) 404-409

I think that sort of the pain and it's limitations are much more part of me, same way as big nose is and long legs are, you know it's all sort of part of the same bundle, part of the same package, it's not separate anymore, I really don't think it is, I've never really thought of it this way before, I was always really aware that pain used to be something inflicted upon me but I now I think actually the pain is just part of me.

Jane in contrast to Linda completely accepted the pain, describing it as not separate anymore. She suggested that this is a recent understanding; previously she felt that the pain had been inflicted upon her and she was trying to distance herself from it. Now she was much more aware that the pain was part of her in the same way that bodily features

were. This extract formed part of a broader discussion on acceptance of pain, and Jane was using a very positive frame of reference to discuss and describe herself with pain.

People described themselves as a person with pain, again a significant aspect of their identity which will be considered below. It seemed to form part of their identity, although not all participants were quite so accommodating. It implied the person had more control and was not dominated by the pain, and thus allowed an optimistic approach of being able to look forward and the realisation that life must be lived regardless of the pain.

### *Separating from the pain*

The stories described pain coming to the participants and taking on a form of its own, to which the participants inevitably succumbed despite trying to rid themselves of the pain via the medical and alternative therapy routes. In the previous extract Jane described pain as being inflicted upon her. Pain was described as a separate entity, it was rarely referred to in the data and when it was referred to was frequently called 'it'.

(8) 480

I don't want it (laugh), it's an 'it', it's alien.

Linda actually referred to the pain as 'it', and clearly stated that she did not want it. She went on to say that the pain was alien, and by this means the pain was not part of her but also different to the rest of her. Linda articulated how she was separate to the pain. At this stage she could not consider the pain to be part of her and used quite graphic language to describe the pain. Laura had a similar relationship to pain.



(3) 49-51

I get it slightly above my coccyx, across, it could be in the right or left side and I find that when it's in the left side it shoots down my leg, so it's a bit of sciatica, you know, when it's on the left side.

Laura again described the pain as 'it'. She, like all the participants, had a very intimate knowledge of where the pain may occur, what it felt like and what the consequences may be. Laura provided a detailed description of the pain without actually referring to it as pain, and seemed to imbue the pain with the ability to choose its area of influence, for example whether it's on the right or left side. Laura did not discuss whether the pain was part of her or separate to her, but did give the impression that it was separate because of the distance she implied when describing the pain. She suggested it was a separate entity because of the notion that it could choose where to affect her. Susan adopted a similar approach and related this to fighting.

(6) 581-583

I put up more of a fight, but it definitely takes over when I'm having a flare up, it wins that battle and then I withdraw, spend time in bed, don't go out, but I'm not giving up just recharging.

Susan very clearly depicted the pain as a separate entity. Again she described the pain as 'it', and pursued the theme of fighting a battle. The pain could be seen as her enemy, and she stated that during a flare up the pain would win, and she would retreat and recharge ready to pursue the battle. Susan implied that this situation had happened many times before, she was aware of the outcome but was ready to continue and this would suggest that she was the victor occasionally. Maybe when she was not experiencing a flare up, she could see herself as winning the battle. There was no suggestion in this extract of the

pain being part of Susan, quite the opposite in fact, the pain was certainly separate and given its own identity.

In contrast, Vrancken (1989) discussed this concept of a separate entity and suggested that pain requires an opponent and inevitably creates a split within the individual himself. The pain sufferer creates a dichotomy between that which is hurting and that which is trying to control the pain. For the sake of integrity the pain sufferer makes an 'it' of the body and an abstraction of the pain (Vrancken 1989). Furthermore the medical profession focuses on the 'it' of disease rather than the patient, which is a prevailing societal view of good doctoring (GMC 2006) and forms the 'habitus' of medicine<sup>7</sup> (Bourdieu 1990).

Despite not owning the pain, the participants talked of the pain as a powerful presence that could take over life, isolate the sufferers, reduce work opportunities and influence family and social relationships. For some participants, acceptance was the stage when pain was no longer separate to them but part of them. The male participants had a tendency to talk of loss of identity in relation to changing or lost job opportunities, whereas the female participants certainly talked of work and the impact this had emotionally but tended to relate identity more specifically to social roles.

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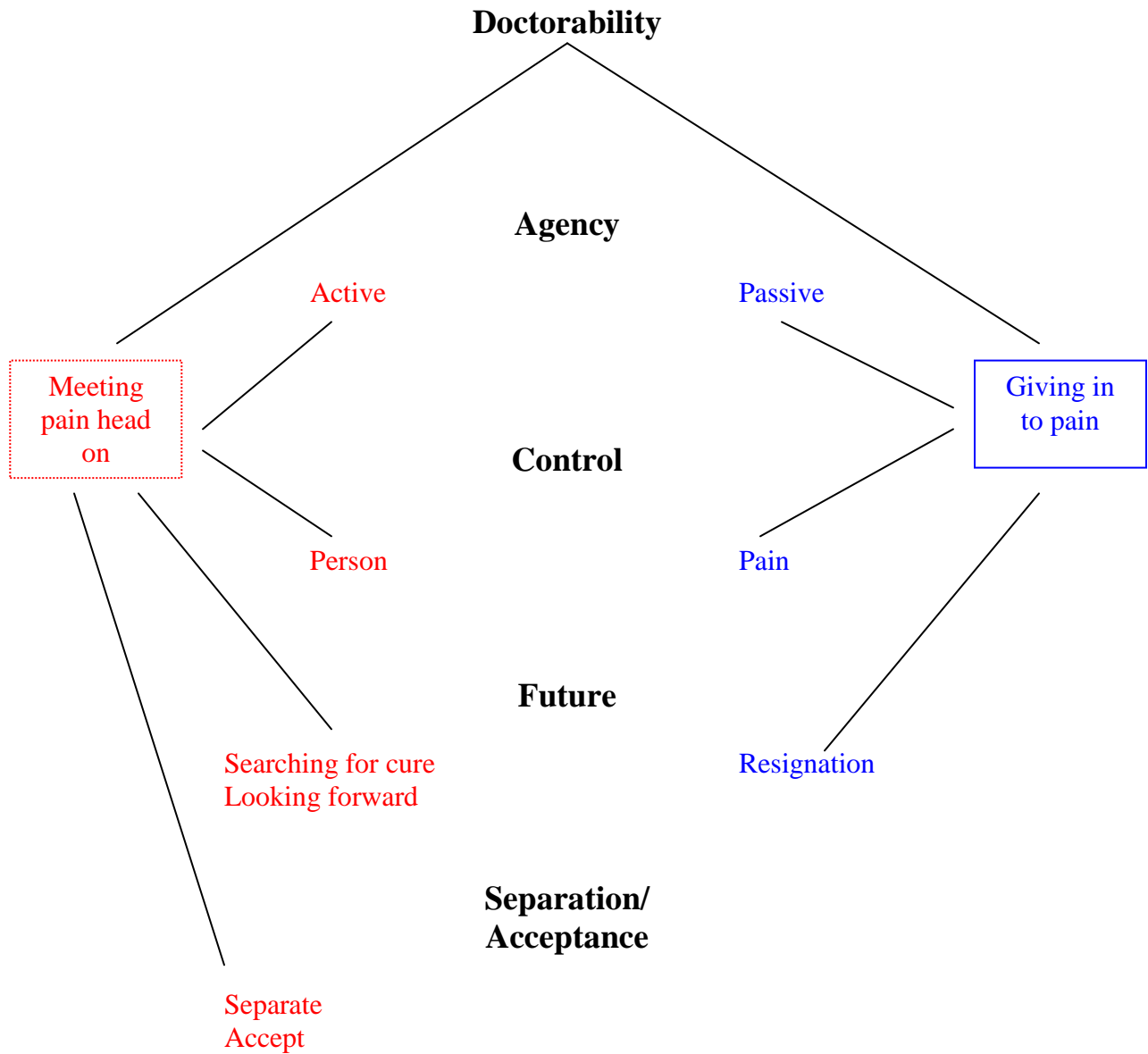
<sup>7</sup> Bourdieu (1990) described 'habitus' as the assumptions, expectations and presumptions about medicine which prevail in wider society. The medical profession are required to reproduce medicine as an abstract system which results in an objective, trustworthy, reliable, competent and fair mode of healing (Nettleton et al 2008).

## Summary of Recurrent Features and Dimensions

The features have been discussed at length within this section. All the participants described doctorability and the necessity to convince the medical profession of a genuine, legitimate problem which would authenticate their treatment and status as a chronic pain patient. The stories identified how at certain times active or passive approaches were adopted, and how control moved between the person and the pain. Closely related to this was the notion of good days and bad days, and the stories highlighted the importance of fighting and struggling. Three status claims were then discussed, describing where the participants felt they were at: searching for a cure, resignation and looking forward. The final feature was concerned with whether the pain was felt as separate to the person or whether it had been accepted by the person. Fig. 4.1 is a representation of these features and dimensions, which are listed in no particular order.

Two key strategies were noticeable throughout the stories. The first strategy was 'meeting the pain head on', where people engaged in a battle with the pain and fight for control. Here the people were less passive and continually striving for improvement. Improvement could be a cure or substantial pain relief, or could be acceptance of the pain with its associated improvement in quality of life. This strategy aimed to promote independence and enable people to do things.

Fig. 4.1 A visual representation of the relationship between the recurrent features and strategies



The second strategy was ‘giving in to the pain’, where people described a reduction in social relationships and activities, and job losses. Passivity in managing the pain was evident with a usual endpoint of resignation. Lives were ruled by what could not be achieved rather than what could. This strategy resulted from people feeling unable to implement choices and direct their own life. It would not be possible in this study to declare if these two strategies are mutually exclusive or whether people move between them. However, the stories told suggest that one strategy is adopted and movement does not occur between the strategies. The adoption of a strategy would seem to be related to the understanding and belief structures held.

How the key features were played out in the participants lives were highlighted through their stories of their daily experiences. The strategies used influence these features. The above diagram highlights the recurrent features, and indicates how certain dimensions are more aligned with the two strategies. Where no dimensions are mentioned, the feature is influential in both strategies. One could have expected differences in the stories in respect of gender, social roles, employment status and age, but the experience of pain seems to be a leveller in that there appear to be no gross differences in the stories based on biographical information, rather the differences are more subtle at the level of ‘tendency’. The focus of the next chapter is how the recurrent features are presented in terms of sequential organisation.

## Chapter 5

### Sequential Organisation of the Stories

#### Second Stage: Structural Analysis (Ricoeur 1981)

The previous chapter outlined the thematic content of accounts of living with low back pain; whilst this chapter proposes the way in which the various recurrent features or story elements are organised into a narrative sequence. The ‘whole story’ is indicative of an individual’s experience of life with pain, and gives clues to claimed identities and management of agency. The chapter begins with an overview of a theoretical model drawn from key papers. The research to be described outlines a theoretical view against which this current study will compare and contrast.

Firstly, Kotarba (1983) charted the process of adjustment to chronic pain and becoming a ‘pain-afflicted’ person. Using pain biographies he identified three stages in this process. First there is the onset stage, which is perceived to be transitory, and amenable to diagnosis and treatment. At this stage pain is diagnosed as real by doctors and classed as having a physiological basis. The second stage concerns ‘the emergence of doubt’, where there is an increase in specialist consultations, and the possibility that treatment may not work. Patients however may still feel in control by seeking care. Kotarba (1983) describes the third stage as the ‘chronic pain experience’. Following the shortcomings of treatment the patient may now be labelled as having chronic pain syndrome, and enters

the elusive search for cure, which may well dominate their life resulting in a long term process of medicalisation.

Secondly, Breen (2002) used a concept analysis to clarify transitions in the literature on the concept of chronic pain. A random sample of nursing, psychology and neurophysiology literature published over a thirty year period was used. Breen (2002) reported that by the 1990s phases could be recognised in the development of chronic pain. The first phase is linked to the sensory discrimination of pain and the individual may self treat the pain as if it were acute pain. During the second phase the person realizes that the pain is not subsiding but still believes that a cause can be found and aggressively seeks a cure. It is in the third phase that the person understands that the pain is chronic, and previous experiences influence the ability to cope. The final phase sees the modification of lifestyle and behaviours to compensate for the impact of chronic pain on living.

Breen (2002) identified two consequences of chronic pain: living with pain, and coping with pain. Living with pain adversely alters life patterns resulting in negative physical, psychological and social effects. The effects described include alterations in eating, sleeping, the need for inactivity, reduced mobility, depression, anger, hopelessness, helplessness, isolation and loneliness, and potential for loss of work and social roles. Coping with pain was seen as limiting the adverse effects by reducing stress and pain intensity. Strategies used included cure-seeking behaviours, medication use, surgery, exercise or reduced activity, distraction, meditation and seeking social support. Thus,

living with pain was construed as a negative situation, and coping with pain was seen as a more accommodative solution.

Thirdly, Bendelow & Williams (1996) charted the hope and despair of attenders at pain relief clinics in London, in a small scale qualitative study. They found differences in attitudes towards the overall effect on people's lives, which could broadly be divided into two categories. The first group expressed the feeling that their lives were totally dominated by the pain, in that there was no hope for the future as the pain would never disappear. Bendelow & Williams suggest the group display classic features of resignation, as defined by Herzlich (1973). The second group in Bendelow & Williams (1996) study reflected a similar sequence as above but there were marked differences in their styles of adjustment. Although the people felt the quality of their lives had been severely affected, they could still envisage a 'pain-free' future. This group employed elements of active denial, seeing their life as a battle against the pain, but they more often expressed what Radley & Green (1984) refer to as an accommodative style of adjustment. Pain was incorporated into their lives and was adjusted for in a more positive manner. The accommodation group appeared to feel less stigmatised and less defensive about being in chronic pain.

Kotarba (1983) and Breen (2002) suggest a sequential movement through the phases of the chronic pain experience. Breen (2002) talked of phases quite generally whereas Kotarba (1983) described a definite endpoint and labelled this as chronic pain syndrome. This is the position reached following adjustment. In contrast, Bendelow and Williams



(1996) did not discuss a sequence of phases, but suggested that it is the attitude of those in pain that influence coping styles and adjustment towards two particular positions – resignation or accommodation. Table 5.3 compares the three studies cited here, from which a theoretical model can be drawn. People in pain pass through phases to reach a position of accommodation or resignation, which may be closely related to chronic pain syndrome. The remainder of the chapter considers the narrative sequence of the stories in relation to this theoretical model.

Table 5.3 Comparison of key findings in relation to phases

Breen (2002)	Sensory discrimination of pain  (Phase 1)	Seek cure  (Phase 2)	Realisation chronic nature of pain  (Phase 3)	Lifestyle & behaviour modification to compensate for pain  (Phase 4)
Kotarba (1983)	Onset of pain	Emergence of doubt		Chronic pain syndrome
Bendelow & Williams (1996)	(unspecified)	(unspecified)		Resignation (chronic pain career) or accommodation

### Phases in the development of chronic pain

Each participant reflected their unique life experience in a series of phases; before the pain, the onset of pain, living with pain, adjusting to pain, and the future. Narratives, as a type of story, generally have a beginning, a middle and an end (Lillrank 2003).

As Denzin (1989: p.37) suggested:

‘A narrative is a story that tells a sequence of events that are significant for the narrator and his or her audience....A narrative as a story has a plot, a beginning, a middle and an end. It has an internal logic that makes sense to the narrator. A narrative relates events in a temporal, causal sequence. Every narrative describes sequences of events that have happened’

The phases of being in pain mirror the story structure of beginning, middle and end, and are represented in the following table 5.4.

Much literature has been written on narrative and discursive forms, on sequencing and chronology (Edwards & Potter 1992; Mishler 1986; Hyden 1997). This literature has informed the following analysis. The interviews were conversational, and the data obtained flowed between the researcher and the participants. However the participants’ voices were dominant in that most of the dialogue was theirs with minimal clarification and questioning by the researcher. The data consists of long stretches of speech interspersed with short or one word answers, and as such are considered as narratives in

this discussion. Stories offered by people as responses to interview questions are culturally acceptable ways to talk about illness (Mathieson & Barrie 1998).

Table 5.4 Phases of a journey with pain in relation to the structure of the story

<ul style="list-style-type: none"> <li>• Before the pain</li> <li>• The onset of pain</li> </ul>	Beginning	Scene Setting	Communication Effects <ul style="list-style-type: none"> <li>- Claiming legitimacy</li> <li>- Establishing doctorability</li> <li>- Linking agency &amp; causality</li> </ul>
<ul style="list-style-type: none"> <li>• Striving for diagnosis &amp; cure</li> <li>• Living in pain</li> <li>• Adjusting to pain</li> </ul>	Middle	Story Delivery 'Telling the Tale'	Making the pain 'real' <ul style="list-style-type: none"> <li>- Referencing loss</li> <li>- Ongoing struggles</li> </ul>
<ul style="list-style-type: none"> <li>• The future</li> </ul>	End	Closure	Claiming Status Anticipating Futures

### Setting the Scene – opening sequences

#### *The 'onset of pain'*

All three key papers mention 'pain onset' either directly or indirectly. Kotarba (1983) talks of the 'onset stage' and is concerned with diagnosis and treatment. Bendelow & Williams (1996) refer to onset indirectly, by stating that the people in their study had

emerged through Kotarba's (1983) first two stages. The importance of medical input, medication and other forms of treatment were directly discussed. Breen (2002) links the first phase in the development of chronic pain to the sensory discrimination of pain. Onset of pain is the beginning of the story in the above papers, and is also where the participants started their narratives.

All opening remarks within the narratives include the date of onset or the age of onset of pain. The first question asked of the participants was 'Can you tell me about your pain?', and interestingly all responded with a starting date or age followed by a chronological sequence of events and contacts to the current time. The recollection of the circumstances is significant in that it was not solicited but was produced spontaneously. Wooffitt (1992) suggests that this is not unusual, and is part of the cultural set of communicative competencies with which people are equipped to talk about their experiences. The participants provided a description of the routine circumstances of the environment at the time of their experiences and a reference to their first awareness of the actual problem. Descriptive items were selected to provide for the everyday circumstances of extraordinary events (Wooffitt 1992). The participants had a choice between verb tenses; they could employ an active present tense or they could use a passive past tense. Wooffitt (1992) suggests that the present tense preserves the active, ongoing quality of the event being described, a character that is lost when the passive tense is used. Different tenses and movement between tenses was noticeable within the stories.

The following extract, which could be taken from any of the participants, shows how precise 'factual' information is used. The actual events are not 'facts', but the categorization of the events transforms them into objects of significance (Smith 1978). If something is to be constructed as a 'fact' then it must be shown that proper procedures have been used to establish it as objectively known, and it must be seen to appear in the same way to anyone. The reader of these accounts is given an opportunity to judge for themselves, based on the presentation of a collection of events (Smith 1978).

(1) 17-47

Well the problem now which started in 2001 is, well, I got woken up and tried to get out of bed one morning, but couldn't with pain along the back you know..... so this went on for a week so I went along to see my doctor..... and so she thought it was a trapped nerve, I've been taking medication since 2001, it was the back end of 2001..... and I went on into 2002 still taking medication when the doctor decided that there was nothing more pain medication wise that she could do for me.....so I had this back x-ray which came back that I had a bone slipped or slipping and arthritis.....so then my son rang up a chiropractor to see if they could, so I went there and I had 10 weeks seeing a chiropractor, that took me up to 2003, then I had 10 weeks of acupuncture which I thought I would have to see if that would help.....but then the pain came from that side into this side, the same, and it's stayed like this since 2001.....so then I had asked my chiropodist what she thought, cos I go every month to her, and she said there's a pain clinic at the general hospital..... so I had to go back and see the doctor and I said to her, you know that I'd heard about this pain clinic and could I be referred there, maybe they could help me but she said what I'll do is I'll refer you back to the doctor that you saw about your shoulder and neck, I went back and I saw them and they sort of referred me to here, you know the pain clinic at the RVI.

This is an extensive extract to highlight the chronological sequence of events and practitioners seen. The supporting information about how Annie approached the practitioners and what interaction she had with her family has been excluded. Annie catalogues all contacts with health care practitioners in chronological order and

repeatedly mentions the date during this sequence. Wooffitt (1992) stated that emphasis is placed on locating precisely when and where events and experiences happened to establish objectivity. This suggests how important it was to engage in health care and pursue a range of therapies to relieve the pain. It also highlights how seriously Annie wanted to be pain free, and therefore how bad the pain was, in that she continuously sought help for what amounted to a number of years. Annie established her credentials of 'sharing' the medical goal of cure. The reporting of the dates and time scale not only establish the duration of the problem but highlight the length of suffering that had been endured despite all attempts at cure and relief. The onset and duration of the pain were of such significance that they were repeatedly mentioned, and remembered without any hesitation. The mechanism of injury was detailed but very little attention was paid to a description of the pain. It seemed that justifying a genuine problem and detailing the efforts to escape the pain was more important initially than describing the severity. This could be because there was an assumption that the pain was severe because of what had had to be tried to get rid of it, and the duration of the problem. The pitfall of not being able to justify the genuineness of a problem was being seen as a malingerer. Asher (1972) defined malingering as the imitation, production or encouragement of illness for a deliberate end, and suggested that the conscious, cognisant action of malingering is a rare condition, as it risks a social judgment, and places reputation at stake.

### *Seeking cure*

Breen (2002) suggests that people in the onset stage may initially choose to self-treat, but by the second phase the person in pain realises that the pain is not subsiding but still

believes that a cause can be found and aggressively seeks a cure. Both Kotarba (1983) and Bendelow & Williams (1996) recognise the importance of making contact with the medical profession. The narratives were all similar to the above example and listed all contact with health care professionals, all therapies and all changes in the pain for better or for worse, providing a potted history of the pain journey. The catalogue of events and continued attendance at health care appointments and treatments detailed the continued search for a diagnosis and cure. It might be that initially this research interview was like any other meeting with a new health care professional, and the groundwork was being laid by summarising the journey so far. As Clark & Mishler (1992) report clinical interviews are structured in ways that limit patients' opportunities to tell their stories. Although patients initiate the meeting and their problems are the central topics, doctors control the process. A clinical encounter usually begins with the doctors opening request for the patient's complaint followed by specific questions. In this study the initial request for information concerning pain may have been viewed as any other by a medical practitioner. The participants may have been attentive to medical questions and tried to respond appropriately (Clark & Mishler 1992). Stories typically begin with an introductory section that orients the listener to the events, and may include time, place, prior events and comments on the significance. Diseases are disclosed through such accounts and objectively include a problem and action taken to remedy it, without reference to personal agency initially. Thus, these encounters initially reflect the biomedical model of disease, and highlight the distinction between 'troubles telling' and service encounters (Jefferson & Lee 1981).

The underlying common denominator in these chronological sequences is failure. If a cure or adequate management had been achieved the list would have stopped at that point, but instead it contains visits and revisits to the GP, specialists, surgeons, physiotherapists and alternative therapists. The participants were managing their responsibility in that they had fulfilled the demands made of them by attending the health care practitioners. This helped to confirm their status as genuine and the seriousness of their quest. Related to this idea is the concept of heroism. In our everyday life we have the mundane, taken-for-granted routines which sustain and maintain the fabric of our daily lives, but when pain disrupts the 'everydayness' a heroic element emerges in which everyday is viewed as something to be tamed or subjugated in the pursuit of a higher purpose (Featherstone 1992). The modern day view of heroism still has a traditional emphasis on courage in the face of external danger, and emotional expression and self-sacrifice (Seale 1995), all of which can be heard in the stories. Featherstone (1992) used the phrase 'ordinary heroes' to describe how dying people fought internal and external enemies, courageously passing through stages to acceptance. This concept is equally applicable to chronic pain and will be picked up later in the discussion.

#### *Doctorability in the narrative*

Doctorability, as previously discussed, is important in the beginning of the narrative. Kotarba (1983) specifically describes the importance of doctorability within the 'onset' stage, where pain is diagnosed as 'real' by physicians and thus has a physiological basis. The process of communication through which medical diagnoses are sought and disclosed appears to be a time of congruence between the trajectories of medical course,



social career and personal narrative (Robinson 1990). A biomedical diagnosis may coincide with the legitimization of sickness and be associated with narrative reconstruction. Before and after this process the trajectories of patient and medical practitioner may be very different. The participants were trying to provide a convincing argument as to why they sought medical help initially, and subsequently, throughout their journey. They provided a detailed description of the injury or onset of pain to establish a reason for seeking medical intervention; once through the gateway into the medical domain a diagnosis would authenticate their pain and its cause.

(2) 14-16

I wasn't happy with that, so I went back to the doctors and asked for a 2<sup>nd</sup> opinion. I went to see Dr G and he told us that I'd had a trapped nerve down my right leg.

In this instance Robert described how he went back to his GP to ask for a second opinion because the initial referral was inconclusive by not providing a diagnosis. The second consultant offered a diagnosis which Robert found acceptable, and Robert translated this into lay language as a trapped nerve. The attainment of a diagnosis confirmed the genuine nature of the pain. This was the case for Fred too, though after a number of investigations.

(4) 24-26

After a lot of tests, MRI scans and what have you they found the sacroiliac joint, the right sacroiliac joint was showing signs of wear which is an unusual joint to wear, and that's what was causing the pain

Fred highlighted that the diagnosis was eventually decided upon after a lot of tests. This determined the authenticity of the pain by suggesting that the diagnosis wasn't easily established because it took a number of tests, however it was then considered to be reliable to Fred because it took that number of tests. Fred then stressed the diagnosis and qualified the tests undertaken by highlighting that he had an unusual problem. The fact that the problem was unusual was the justification for pursuing the tests and confirmed the genuine nature of the problem.

#### *Narrative construction of self-efficacy*

Breen (2002), Kotarba (1983), nor Bendelow & Williams (1996) mention the concept of 'agency', locus of control or self efficacy. Breen (2002) refers to behavioural and psychological coping strategies, and the evaluative and cognitive components of the pain experience, whilst Bendelow & Williams (1996) focus on the physical and psychological sequelae of chronic pain though do mention 'active denial strategies' in relation to an accommodative style of adjustment.

Agency featured early in the narratives within this study. The beginnings of the narratives suggested that participants either adopt an active approach by choosing to pursue medical help, or adopt a passive position by accessing health care following an accident.

(1) 21-24

when I stood up the left side from the hip down to the big toe was all pins and needles, all down from there to the toe. So this went on for a week, it went on for a week and I thought this is no good I've got to go along and see the doctor

Annie attempted to manage the pain for a week before seeking medical help, she then actively pursued going to see the doctor. She adopted an active approach to the management of her pain, by initially taking care of herself and when that was unsuccessful she approached the doctor. Again this could be a device for avoiding claims of hypochondriasis, by establishing that she did not rush immediately to the doctor. In contrast to Clare who avoided such claims by direct access to health care.

(9) 7-12

I first started getting the back pain cos I was involved in an accident in 2001 with a car accident, my car was hit from behind by an armoured truck and it pushed me underneath like another truck that was in front of us, so erm when I initially went to the hospital they just checked my neck as they do and sent us away and I started getting really, really bad back pain, lower back pain and neck pain and the doctor just kept saying 'whiplash' or 'nothing wrong with your back'

Clare delivered this dramatic account in a very 'matter of fact' way. She described being hit by an armoured truck, being taken to hospital, and being told she had whiplash without relaying any of the gravity of these situations. Having been in a car accident Clare immediately accessed health care as a passive recipient. She described the accident and in so doing established justifiable reasons for having pain. The initial opinion of the medical team was claimed to be probable neck problems, which were investigated, and she was then discharged. Clare may have been in a previous accident in view of the comment 'they just checked my neck as they do and sent us away'; it suggested prior knowledge of hospital assessment and management. When back pain started Clare continued to pursue help but was told that there was nothing wrong with her back, this diagnosis was apparently made without further investigation and relied on the previous

assessment at the time of the accident. The passive approach adopted by Clare continued although she tried to take an active position in contacting her GP when the pain developed. Clare suggested that she kept asking the GP about her back pain but was always told the same thing, and this seemed to highlight her passive role as she did not move the process along.

The journey mapped out in the beginnings of the narratives then fluctuated between active and passive approaches as further doctors or health care practitioners were sought to establish a diagnosis. Once a diagnosis was achieved the management of pain was externalized initially, and responsibility and agency were handed over to health care practitioners, and a passive approach was adopted.

### *Biomedical beginnings*

The beginnings of the stories tended to be biomedical in the language and phrasing used, ranging from highly medicalised, jargonistic speech through to a lay interpretation with minimal use of jargon. The beginnings of the stories included a lot of 'factual' data, supported by dates. The previous section on recurrent features provided examples from the data to support this claim. This links back to the notion of doctorability where there is the expectation of including factual data to generate a medical story and the dates specifically provide plausibility and a relevant time frame (Wells, Pincus & McWilliams 2003). The medicalised beginnings also help construct legitimacy of the problem and helps establish causation. Similarly Lillrank (2003) described a common story of low back pain sufferers who had been asked to write their story from initial symptoms to

diagnosis. The beginnings of the stories were told in real time, and were very biomedical in the search for bodily causes of the pain. Medical diagnosis was perceived as satisfaction and relief despite the possibility of a chronic condition. This highlights the importance of diagnosis to low back pain sufferers. By avoiding a discussion on severity in the beginning and focusing on diagnosis participants were avoiding a socially constructed, humanistic version of their pain.

A further early feature of the narratives related to agency is the tendency to link causation and culpability together; if a reasonable cause was identified then the participants could not be blamed for the pain. The narratives highlighted this management of agency by incorporating a morally credible activity, for example work, into the beginning to establish legitimacy and causation. A number of participants described accidents, which immediately established causation and distanced them from blame. A variety of props were used to displace agency and indicated how well, happy and healthy the participants were before the onset of pain. Managing agency in this way and establishing legitimacy for the pain may be ways of escaping control, but are also related to the sick role. Parsons (1951) described the sick role as a means of relinquishing decision making and becoming exempt from normal tasks, but those entering the role are obliged to view being as sick as undesirable.

Pain descriptions tended not feature in the beginning. The stories described pain as happening to them, as though the participants were passive recipients. The narratives in the beginning rarely talked of the pain directly; after the initial mention it was alluded to

as 'it', 'this' or 'that'. Kameny & Bearison (1999) suggest that distance from illness is created by replacing a possessive with a determiner, so in the example of low back pain it would be 'the' pain rather than 'my' pain. The beginnings suggest that pain was a separate entity, it was described as being inflicted upon the participants, was unwelcome and not to be tolerated. The beginning catalogued the energy and enthusiasm expelled in trying to get rid of the pain.

### Telling the tale – Narrativising pain experiences

#### *Narrating the physical and social impact of pain*

The delivery of the narratives outlined the plot and the characters involved. The 'middles' tended to be personal in the language used; they were much more expressive than the biomedical beginnings. This shift in language could be an example of code switching, and suggests a significant change in alignment between speaker and hearer (Goffman 1981). Goffman (1981) refers to this as 'footing'<sup>6</sup>. The participants used anecdotes and descriptive language to elaborate on events and situations.

(8) 290-294

my back has made it so that I always make sure I've got my car, I don't drink which is a good thing because of the tablets that I have to take, and really that's kind of a, that's been a longstanding thing because of my back, because I know that if my back is particularly playing up I can just go and I've got my car and I can just head off home and there's not a worry there, from a social point of view I make sure I'm a driver

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<sup>5</sup> Footing is present in almost all conversation. Code switching implies a shift in and out of the business at hand, a change of tone, or an alteration in the social capacities of the persons present. Footing however is code switching like behaviour that does not involve a code switch. Such that a change in footing implies a change in the alignment taken up by ourselves and others and expressed in the way we manage the production or reception of an utterance. A change in footing is another way of talking about a change in the frame of events. In the course of speaking, people constantly change their footing, and is feature of natural talk.

This extract provided an example of how social lives were implicated. Linda was describing how she always took her car when she went out socially. In this small excerpt she established that she was unable to drink because of her medication. However this was not the reason she gave for always driving when going out socially. She took her car because she needed the security of knowing that if her back became problematic she could go home, and that was one less thing to worry about. Linda insisted on being a driver. This excerpt also reminded us indirectly that Linda had longstanding pain which was severe enough to warrant strong medication. Jack recounted a similar tale.

(7) 58-63

I could hardly walk at first, I found it very hard to stand up and stuff like that, I mean my legs I did get exercise, I used to go for a walk with my wife, one leg would go dead, no feeling in it whatsoever, so I had to sit down until that one the pins and needles came back and actually start feeling it again, then you'd go for a bit further and then the other one would start going numb, they used to take turns and it was very rare that the pair of them would go together.

Here the physical difficulties encountered when Jack was first troubled with back pain are highlighted. He described how walking and standing were extremely hard. He provided a very detailed picture of the sensations felt and the consequences of physical activity. Even though pain was not mentioned directly, this extract presented a very vivid account of the limitations of physical activity and the impact of pain on everyday life. Jane highlighted the impact on her work, but particularly stressed the disruption to her personal life.

(5) 101-106

at work as much, erm because I find that I get so engrossed in something that I wouldn't move from my desk, I wouldn't move from a meeting, I could be in a 3 hour meeting and I wouldn't move at all, and then when the meeting finished I just couldn't stand up, if it was a difficult meeting I just wouldn't be aware of it throughout the meeting and it wouldn't be until the end and then that evening that it would erm really catch up with me.

In another part of the interview Jane told us how she had changed career to accommodate her back pain, but that work was very important to her and she would never miss work because of the pain, which may be a means to distance herself from a charge of malingering. In this extract she highlighted the toll that pain could take. Jane acknowledged that she could be distracted from the pain by her work and become so engrossed that she would not move. This would then lead to her not being able to stand, and the consequences would catch up with her. This implied that severe pain was the result, and her personal life was ultimately disrupted. The pain had some impact on her work life, but more so her home life.

### *The emotive reaction to pain*

The middles of the narratives tended not to be sequential with little reference to dates or a particular time-frame; rather specific examples were selected to highlight a point or an experience. The middles, though obviously located within the middle of the narrative, draw on experiences from the beginning to the end of the pain journey. The middles were very personal accounts told in the first person and frequently detail the emotions felt at the time and on reflection. The stories exhibited examples of what Hochschild (1983) called emotional labour. The concept was first developed by Hochschild in 1983 and



describes the induction or suppression of feeling in order to sustain an outward appearance that produces in others a sense of being cared for. It is frequently employed to sustain people in situations that are often demanding and difficult.

(4) 135-139

but you've just got to get on and that's it, but I felt, I felt very bitter and I still do but I don't dwell on it, I try to shove it to the back of my mind, erm which is difficult because every time you move you've got that pain and, you know where it's come from, you know, I just think if I hadn't gone in that day and if that hadn't happened then I'd be living a normal life and I'd still be working in that job.

Here Fred told of his feelings of bitterness which we might surmise are directed at the pain itself and the situation that caused it. Fred was involved in an accident at work which he described as a physical attack by a patient. Fred talked of having felt bitter at the time, but reflected that he still felt bitter because he was reminded every time he moved where the pain came from and what life might be like now if it had not occurred. There may be some bitterness towards himself for not getting better after all these years. Fred suggested that he does not dwell on the situation but the text suggested otherwise as he described the difficulty in trying not to think about it. The 'what if' thoughts mentioned in this extract are counterfactuals because they take the form of mental replays of situations where the outcome is altered to be opposite of the fact. Davis (2001) suggested that counterfactual thoughts have been linked to higher levels of emotional distress, have been known to persist for many years, and can disrupt effective coping by shattering self confidence and optimism. Annie did not talk of bitterness, but commented on the need to re-engage with life.

(1)

for me I felt a bit down when I finally got home, well I was in my dressing gown for about a week, a fortnight. I just felt, well I didn't feel right, I couldn't be bothered you know. Then after a while I had to be made bothered because my daughter and father brought in a little puppy, tucked inside their jacket. Who was going to look after the puppy? So that made me, you see, I had to get my clothes on and get with it. I think that was the hardest part, was trying to accept and I felt that I was no good in a way really.

Annie described the time immediately following surgery when she realised she was unable to return to her previous work. She described feeling down, unable to dress, and generally not feeling right which she qualified by stating she could not be bothered. This implied that Annie was previously an active lady, hard working, who got on with life. This description of her emotional self summed up the perceived losses in her life. On reflection she considered how she felt 'no good', presumably because her role and lifestyle were called in to question. Annie went on to say how her daughter and husband brought a puppy home and so she had to re-engage with life, and was made to be bothered. This suggested that her family were aware of her change in emotions and that she was acting out of character, and tried to resolve the situation for her by giving her a reason to become more active. It provided another example of adopting a passive stance, which was a feature not unknown to Laura who described the impact on her family.

(3) 224-228

It's the feeling of guilt you get from not being able to do things with your children because you're too tired or whatever, I think when they were smaller it was worse, it's quite a lot of stuff that I haven't been able to do really just because I've been so exhausted or whatever, that kills me.

In this melancholic excerpt Laura reviewed the things she could not do with her children and described how that 'kills' her. She told of the feeling of guilt because of being too

tired 'or whatever', where 'whatever' presumably meant pain. By not naming the phenomenon, and stating 'whatever', Laura is building up interest and inviting the listener to come to their own conclusion. Wooffitt (1992) would argue that by not naming a phenomenon this suggests a sensitivity to the kinds of negative assumptions that may be attributed. Laura's children were involved in the losses and impact of her pain because of the things she could not do with them. It could be that she felt guilt because she was unable to exclude them from her pain, it did not just affect her.

From a psychological perspective the above examples are suggestive of a grieving process. Grieving is what happens in response to bereavement, and allows the person to give meaning to experiences and actions. Bereavement means 'the state of being deprived', and implies suffering and the loss of wholeness (Attig 2001). Suffering and loss are common denominators to chronic pain and bereavement. Bereaved people not only have to cope with the loss of their loved one, but also have to make major adjustments in their lives because of the secondary consequences of their loss (Stroebe & Scut 2001). Bereaved people have to restructure and reinterpret aspects of their life narratives, and re-evaluate and if necessary modify their understanding of their place in the larger scheme of things (Attig 2001). CS Lewis (1976) wrote in his diary that people suffer in the sense that they feel helpless and powerless in the wake of events they could not control, and feel great anguish as losses are thought to be irretrievable, resulting in fear that their distress may never end. The stories presented above resonate with this description of grief. In this population grieving can be described therefore as the struggle to come to terms with pain and the process of putting lives back together.

### *Pain and middle adulthood*

This seems to be the part of the story where the participants ‘make the pain real’, in that they use real accounts of what the pain feels like, what it means to them, what impact it has on their life, and how important it is for them to be rid of it. Avoidance of physical and emotional suffering is a common occurrence with chronic pain, whereby people attempt to control or limit their contact with experiences perceived as pain provoking which is likely to restrict overall functioning (McCracken & Keogh 2009). The effects of pain were clearly depicted in the middle sections providing vivid accounts of the impact on personal and working life. According to Erikson (1980) work is most crucial during middle adulthood. Erikson (1980) organised life into eight stages, extending from birth to death, and he classified the age of thirty five to fifty five as middle adulthood. Middle age is when people tend to be preoccupied with meaningful work and with issues surrounding the family. People expect to be ‘in charge’, and their greatest fear at this time is inactivity and meaninglessness. Faced with major life changes can present an ‘identity crisis’ with the struggle to find new meanings and purposes. Much of this is familiar within the data.

Back pain is common in middle age (Palmer et al 2000; CSAG 2000), and all the narratives highlighted the disruption to work and careers as well as social and family life. Some participants had had to give up work or take early retirement because of the pain, which had great implications financially but also personally and socially. Other participants had had to change jobs to accommodate the pain and felt their chosen career was no longer an option for them.

(8) 329-334

It stopped the job I loved, I left college at 18 and I'd only been doing it about 4 years, maybe 5 years and it was all I wanted to do was work with children, so I'm angry that it's there and because now that I've got a bad back every application form, I'd applied for other jobs to try and get out of the school I was in because they were making life so difficult at the time, but they all had the question on 'Do you have or ever suffered from a back problem?'

Here Linda described the anger and frustration at having to leave her job which involved working with children. It was whilst working in this job that Linda sustained her back injury, and she claimed that the school was making life hard for her, though interestingly she did not acknowledge the limitations that both she and the school had suffered because of her ongoing back problem. The difficulties within the work environment were displaced onto the school not herself or the back pain. The excerpt highlighted the loss and sorrow felt at having to change career at such a young age, and the anger at being denied further employment in this field. Despite her enthusiasm for continuing to work with children she perceived that it would always be denied because she could not get beyond the question of 'Do you have back pain?' This next extract detailed a similar experience to the previous example, but highlighted the stark contrast between the before and after jobs as described by Jane.

(5) 185-193

I've changed my career and part of that was erm about my back, erm it was a decision that I made when I had the surgery. I was working in investment banking, had a very good job, very high salary, erm I worked half of my week in London and half my week in Amsterdam, I worked for a Dutch bank, so I'd leave home at 5 o'clock in the morning and fly to Amsterdam, fly to New York or fly to wherever and get back late at night, erm worked exceptionally long hours, commuted, always knocked and hassled and bustled on the train and I just thought no it's not worth it anymore, so I now work for the council,

a 5 minute drive and 37 hour week maximum, doing something very similar each day.

Jane had already sustained her back injury prior to commencing the first job but was in remission to a degree from her pain. It was during her hectic lifestyle that pain started to increase and become disabling, which resulted in further surgery. Jane provided great detail about her job and status, including salary, and described a typical week. In contrast her current role is somewhat downplayed, which suggested a perceived loss of status. Jane has acknowledged, albeit somewhat despondently, that these changes were necessary to accommodate her back pain.

Participants described loss, feelings of worthlessness and low self esteem (Gatchel et al 2002; Charmaz 1983). In these stories back pain seemed to strike at a time when people were most productive in their life with far reaching consequences. They were sad, sometimes tragic stories. A feature in many of these accounts was the loss of interpersonal contacts, within the work and social domains. One consequence of this may be to increase a person's dependence on the family as a source for sustaining self esteem (Harris et al 2003). However as Morley et al (2000) highlighted there is evidence that people in pain may regard their condition as a burden in the family and this could impact on family dynamics.

*The 'Emergence of Doubt'*

Kotarba's (1983) second stage concerns the 'emergence of doubt', where treatment may not work and there is an increase in specialist consultations, but people in pain still feel in control in seeking best care available. This is similar to Breen's (2002) finding that the second phase is based on the belief that a cause can be found and so a cure is pursued. This is the case for the participants in this study. The 'middles' expanded on the detail of the pain journey. Visits to health care practitioners and alternative therapists were outlined, and often the search for a cure was elaborated.

(3) 172-174

Well I just try and fight my cause really, I just try and see if there's anything else the medical profession can do. I found the pain classes useful, but I find it just a waiting game at the minute

Laura offered a typical scenario of staying in touch with the medical profession. Maintaining relationships with medical professionals became a source of emotional support (Carricaburu & Pierret 1995). Most participants were in regular contact with GPs and specialists for review appointments, but few were still being actively managed with new investigations or treatments. Laura suggested that it was a waiting game, occasionally checking with the medical profession for any developments or new options. Even for those participants who have come to terms with the pain, the chance of a cure remained a hope. Living hopefully in the presence of pain is probably not something that can be achieved quickly, since hope is typically thought of in the future but for people with pain the future holds the greatest risk, namely uncertainty and threat (Chesla 2005). The narratives tended to reflect the passive nature of the participants, in that they

followed guidance and referrals made by the experts they encountered, even when the hope of a cure was becoming more elusive. Bendelow (2006) described an increased emphasis on socio-cultural variables as people need the pain to be validated.

Some participants described their views on the causes of their pain which may be at variance to the medical opinion, an example of 'emergence of doubt' (Kotarba 1983). In this section of the narrative people questioned whether anything could be done to alleviate the pain, and began to disagree with the medical opinion if a firm diagnosis had not been given, or had been given but was not going to relieve the pain. Chronic pain brings uncertainty – diagnostic uncertainty, symptomatic uncertainty and trajectory uncertainty (Robinson 1989). The medicalisation of pain can be seen as the reliance on medicine to cure pain (Illich 1976), but can also be seen as a method of control by the medical profession, where ultimately the patient may feel that the medical toolbox is not being used in their favour (Seers & Friedli 1996).

(2) 148-149

and you're thinking why I've had 3 operations and you're telling me there's nothing wrong, why I know there's something wrong,

Robert described an internal conversation between himself and his consultant. The actual encounter of being told there was nothing wrong would probably have occurred, but Roberts's response was what he believed to be true but did not say at the time. He showed his incredulity at being told there was no problem, when his body and life were affected daily by the pain. However he chose to highlight medical interventions rather than personal anecdotes to strengthen his argument. Again this confirms the passive



approach adopted by participants when conferring with medical professionals. Most participants at some time question the medical view on their pain when it becomes a chronic problem, as in this extract from Linda.

(8) 32-34

I saw an osteopath who diagnosed that I'd had a prolapsed disc, I don't know whether that's actually true given the circumstances since, but at the time I believed that

Linda voiced a concern regarding the veracity of a diagnosis which she originally believed to be true. The original diagnosis by one professional was overturned by a subsequent diagnosis. Linda was unsure whether she wanted to completely give up on the first diagnosis. This could be because it was just that the first diagnosis, but the subsequent diagnosis was by a medical consultant based on radiological evidence and seemed to carry more weight. Linda was caught between two considered opinions, both by practitioners that she valued, and so added an interesting twist to her journey. Linda then had two diagnoses to question and would be at variance to one of them. Disputing a diagnosis is a contravention of the sick role, previously described, because responsibility must be handed over to the doctor to diagnose. Clare, however, highlighted the problem of a lack of diagnosis.

(9) 38-39

I've recently been for another x-ray on my back and that has come back as clear, so nobody seems to explain where my back pain's from.

This extract provided an example of how the lack of a firm diagnosis left participants wondering where their pain was from. Clare highlighted this enigma. She had had

another spinal x-ray which was reported as clear, and stated that nobody knew where her pain was from, and as such links uncertainty of diagnosis with identity, which will be considered in the next section. At this point Clare actually acknowledged the pain as hers, but was still without a diagnosis, and thus remained with all the attendant problems of perceived authenticity and responsibility. Clare referred to ‘nobody’ rather than the medical profession. This could be because Clare sees the medical profession as lacking in status as they order tests and then cannot suggest a suitable explanation, but does not directly voice this problem as belonging to the medical profession and so does not offend the sick role.

#### *Good days and bad days revisited*

The theme of control and dominance features within the middles of the narratives. The participants talked of good days and bad days. This concept was raised spontaneously by some, but when raised by the interviewer the participants related to the concept and discussed it at great length. However this concept does not seem to be captured by any of the three papers upon which the theoretical model was established. Kotarba (1983), Breen (2002) nor Bendelow & Williams (1996) directly comment on issues of control nor the day to day struggles or fluctuations in pain, though Bendelow & Williams (1996) do allude to the battle against pain.

(4) 237-244

A good day, erm one similar to today actually, yeah, yeah I feel a bit laughy (laugh), erm yeah that’s a good day when I can potter on and not have to think, oh you know it’s starting to get really stiff, but yeah and as well to sit down at lunchtime if I feel tired just drop off to sleep, you know, just for half an hour, it doesn’t hurt anyone (laugh). But a bad day is when every

movement is, it seems on a bad day as if from the top of your head to the tip of your toes it just seems as if it goes right through, but mainly the lower trunk but every time you move you can't find a resting place, you know you're not taking in what you're doing.

Here Fred summarised what all the participants described in the narratives. He contrasted a good day with a bad day, but interestingly did not actually mention the severity of the pain. In other passages pain severity was mentioned on a bad day, but rarely was a good day associated with being pain free. Fred stressed the emotional and psychological aspects of a good day, but focused on the physical aspects of a bad day. There was an element of increased severity with a bad day but not enough to suggest that this was the only factor that made a day bad. On good days the pain was still present but the person felt they were in control, they described more personal agency; activities could be achieved and work undertaken. On bad days the pain was described as being in control and nothing could be done to relieve it; the pain took on a persona and the belief expressed in the narratives was that the pain would go when it was ready.

(4) 251-253

Well it's like when I get a build up, a flare up that's it, it's like a build up to that, it seems as though nothing is going to change it until it's ready to put itself out or ease down.

Fred went on to describe how the pain was in control and it would decide when to die down again. He seemed to be describing the pain as a fire, initially flaring up and then putting itself out or easing down. He quickly tagged the option of easing down into the scenario, presumably because putting out implies a pain free state, something long out of his expectations. This notion of the pain as separate was seen here because of its ability to

control the situation. Fred saw the pain as separate because it would decide when to ease off, and he referred to it as a separate entity with its own persona. Fred was similar to the other participants in their stories of the dominance of the pain, and reflected a passive attitude; they were unable to alter the course of things and would wait it out.

The middles show how most days were average, the pain was constant but just about bearable and the participants could function in some capacity. The stories clearly highlighted that this level of activity was less than before the onset of pain, as described in the next extract from Clare.

(9) 238-244

Without a doubt it takes us out of society, it takes me out of like I was always at work I was always like the one that planned the parties, other than like my normal job that I did, I was the one that planned the parties, booked everything, if anything was happening in the store I organised it, I was right in the thick of it, I did everything, I went to everything, but when you've been such an active person, I used to work in a bar after work but I had to stop all that

Clare recalled a very busy time of her life, and the entire passage was clearly tinged with regret. She had a busy job, and on top of that organised a hectic social life plus having a second job. The purpose of highlighting life before and after pain, was to demonstrate that the pain was uninvited and this discussion continued to determine its authenticity. Clare suggested that life before the onset of pain was busy but fun, in contrast to her present life where she had had to stop all work and reduce her social life considerably. Where Clare focused on her social life, Jack described the impact on his family.

(7) 115-119

I used to take the bairn on his motorbike and do daft things with him, digging worms and all sorts, and most of that's been knocked on the head now, I mean running, if I try running with the bairn after a few minutes I can actually, I don't know if it's the bones rubbing together or just something in my back that starts grinding and making a squelching noise and that's me knackered

Jack highlighted the impact of his pain on his family life in this extract. He described a few of the activities that him and his son would do together, and with sadness stated that these had mostly had to stop. Jack provided a very vivid account of what running would induce, but did suggest that he occasionally tried to run, presumably because he did not want to stop every activity with his son, or tried periodically to see if his situation was changing. It could be that this graphic description was included to stress the seriousness of his condition and the genuine reasons why he could no longer engage in his pre-morbid activities.

Good days were highly sought after and tended to be infrequent, in contrast to bad days which were perceived to be more regular and often inevitable. Over time the narratives suggested that more good days could be achieved by adapting lifestyles rather than struggling to maintain pre-pain levels of activity. Pacing was mentioned in the narratives as a positive coping strategy, but did not tend to feature until the end of the narratives. People described being introduced to pacing in the pain clinic, which invariably occurred towards the end of their pain journey. Participants seemed to be taking more personal agency in their management decisions towards the end of the journey, and this could explain why pacing was seen as a positive coping strategy.

*The desire for an ordinary life*

The middles of the narratives described how ordinary life became a constant struggle. All the participants talked of the idea of an ongoing battle to maintain normality, between the pain and themselves because these events were uninvited. There are similarities here to the idea of heroism, where new and extraordinary circumstances occur in an otherwise ordinary life (Seale 1995; Featherstone 1992). Again this idea does not appear prominently within the existing theories.

Featherstone (1992) contrasted the everyday life revolving around the mundane and ordinary, with the heroic life incorporating the extraordinary which threatens the possibility of returning to everyday routines. The participants wanted to maintain their ordinary life, but required extraordinary trials of strength to attempt this. Ordinary pursuits became extraordinarily difficult, and the stories suggested heroic endeavours of struggle and self sacrifice. Fighting was viewed by the participants as a positive response but would incur penalties in the form of suffering afterwards and paying the consequences.

(6) 565-568

If I bend over for too long for sure that's going to start things going, sometimes you've got to, you know what I mean, you've got to do what you've got to do, but always at the back of my mind there's this voice saying you shouldn't be doing that, you're going to pay for this and really, probably should be listening to that voice a bit more.

Susan was describing an everyday experience of household tasks, nothing out of the ordinary, which would cause her pain to increase. She did not directly mention pain increasing but rather it was alluded to as 'start things going'. Susan did acknowledge that at times she could pay attention to her internal voice that told her she would pay the consequences. However, she qualified this by saying that although she knew pain increase would be the likely outcome, certain things had to be done, she could not stop everything that may trigger her pain. Fighting could be construed in this text, because there was an implied tension between Susan and the pain. In contrast to the previous example, Laura elaborated on a special event.

(3) 464-467

I did go out to the Tuxedo Princess, is that the boat? for my 40<sup>th</sup> about 3 months ago or something, 2 or 3 months ago, and had a wonderful time, danced and stuff, you know, but boy did I suffer the next day (laugh) but, you know, I had a good time and sometimes you've just got to, you can't let it rule your life totally, you know

There was no mention of pain during the party, and in fact Laura stated how she had a wonderful time, presumably unbothered by the pain. Her usual activity levels were exceeded with reference to dancing, however the 'great time' was followed by a day of suffering. Laura was able to justify the suffering by acknowledging that she had had a good time, she suggested that you could not have one without the other. Again as with Susan, Laura did not mention pain directly, but the pain was given great power as Laura suggested that it should not have total control. It must by implication have the greater share of control, and this was where fighting entered the context when Laura stated that she would not let it rule her life totally. These extracts show that fighting tended to be

construed in two ways; firstly fighting to achieve a good day for a particular reason, and secondly fighting to achieve normality.

Control moved between the person and the pain. Participants described themselves as sometimes the winner and in control, sometimes the loser and the pain was in control. This was related to the notion of good days and bad days. When the pain was dominant, participants talked of fighting the pain in different ways; some fought to stay at work, some fought to conquer it with therapies. Not being beaten was an important concern in the narratives. During discussions of fighting, pain tended to be referred to as separate to the person; it took on a form of its own. The pain took on a very powerful presence which the participants did not want to own, but must continue to fight and distance themselves from.

#### The Final Stage - Ending of the story

Kotarba (1983) describes the 'chronic pain experience' as the third stage of the model, where people may return to the lay frame of reference and seek help within the chronic pain subculture. This experience could be alternatively described as 'chronic pain syndrome', and is exemplified by the continual elusive search for cure or relief that may dominate a person's life, and relies on medicalisation of their predicament. In contrast Bendelow & Williams (1996) outline two possibilities: resignation or accommodation to the pain. Breen (2002), however, does not state a particular category, but suggests the



final stage is when lifestyles are modified to compensate for the impact of chronic pain. Features of all three are recognisable within this study, with additional elements.

*A biopsychosocial summary*

The endings of the narratives tended to be the final summary of where the participants were, in similarity to existing illness narratives (Bury 1982; Williams 1984; Kralik et al 2005). Endings were mentioned in the beginning of the narratives as the destination of the journey so far, but only in so much as they stated that fact without any explanation. The endings of the narratives were more than that; they sometimes acknowledged the medical endpoint, for example attending a pain clinic, waiting for a scan, but described where they are socially and psychologically as well.

(4) 412-417

So as I say the pain is constant but there's a lot of people who would rather be in my situation than the situations they are in, so I suppose I've got that to be grateful for, but life would have been different had it not happened, you see the thing is, as I've said, yeah I've been told it's going to get worse but one thing I don't do is look down the road and think what sort of state am I going to be in, in 10 years time, I mean because will I be here in 10 years time? I don't know, nobody does.

Fred began to summarise his condition by restating that the pain was constant and was expected to get worse. He interspersed this with comments to reflect his position in relation to other people. Firstly Fred suggested that there were people worse off than him and for that he should be grateful, but Fred gave the impression that he was not grateful possibly because this was the expected response rather than one genuinely felt. He qualified this by saying that things would have been different if the incident had not

happened, and this was the basis of his difficulty in being grateful for what he had. Here Fred was benefit finding (Tennen & Affleck 2005), where he was able to identify positive aspects to an adverse life circumstance. Benefit finding has been shown to influence mood but not pain intensity (Affleck & Tennen 1996). Secondly Fred suggested that nobody could know what the future holds, and so would not look down the road and consider how he would be. This was an attempt at a positive spin following a bleak comment on the likelihood of pain progressing. In these few sentences Fred summed up his dilemma of being grateful for an advancing pain condition, and highlighted a little of the psychological and social challenges he faced. In the next extract Susan described the range of emotions and feelings that resulted from an ongoing pain.

(6) 416-422

I know I'm irritable but that's as far as I've ever got, frustrated yes but yes reluctant to look forward which is quite sad, to me it's quite logical the way I'm thinking but probably to anyone else they probably think I'm a complete fruit loop, you know anybody whose not trained you know what I mean, but to me it's logical not to get excited about the future, you know when this could all turn out to be rheumatoid and get worse, but then it might not and have I wasted all that time?

Susan acknowledged irritability, frustration and a reluctance to look forward to the future. Susan blamed pain for all of these feelings and realised this was a sad position to be in, though countered this with the belief that it was a logical way of thinking. Susan provided an insight into her emotional and psychological self. She initially suggested that this was a logical standpoint for her, but equally could see others may differ in their opinion, and in fact questioned her own logic at the end. However Susan only admitted that this would be the view of lay people, she suggested that trained professionals would agree with her.

Susan did not really seem convinced by her own argument, because she did acknowledge that she could be wasting her time.

### *Three status claims*

#### *- Searching for a cure*

There appeared to be three status claims in the narratives, describing where the people feel they are at. The status claims also described the future, although the future is not always mentioned directly, and can be framed in a positive or negative way. Firstly, there were those people who were still describing a constant struggle to make sense of the pain and were searching for a cure, in line with Kotarba's third stage (1983) where people were considered to have 'chronic pain syndrome' and were embedded within a process of medicalisation.

(1) 27 - 33

Is it me thinking all this pain over the years, you know you go to the doctors with one thing and you come out with two, but I think since I was 60 I think my health is all, you know I've never been away really with different things, anyway my whole body has had an MOT, so then I was referred here by Mr W and I'm just so pleased that something showed up on the x-rays and MRI and everything because, you know.

Annie was optimistic that a cure could be found. Despite having pain for a number of years, Annie continued to pursue medical help, and in this extract felt exonerated for doing so. She described a regular attendance at her GPs with a number of complaints, pain being one of them. Annie was very heartened that a problem had been identified on x-ray and scan, but did not even mention why, presumably because the answer was so obvious - that a cure could be a possibility. It authenticated her pain problem.

Annie, and to some extent Laura, found relief in the acknowledgement of physical findings, and an ongoing interaction with the medical profession. Investigations and interventions were sought after to authenticate the pain and establish a genuine cause. The pain was still described as a separate entity, and the participants continued to attempt to distance themselves from it. Biomedical language tended to be used in this type of status claim. In this particular group, the perceived status claim was similar to where the people described themselves at the beginning of their stories. There were elements of personal agency in that participants were pursuing a cure, though control fluctuated between the person and the pain.

*- Resignation*

The second type of status claim was one of resignation, where the pain was discussed as here to stay. This could be described in positive or negative ways. A more positive approach highlighted a coming to terms with the pain involving an admission that the pain would be present but that there was hope of the situation improving.

(2) 336-338

I know I'm not going to get any better, I know I'm stuck with it now, I can still see something positive, even as I say if I can't get to work I'll get a computer and even if I can't do that I'm resigned to what I can do

Jack had reached an awareness that the pain was not going to go away, a situation he was not happy about because of his description of being 'stuck with it'. However he did offer some suggestions for how he could manage his life, accommodating the pain. Jack had

clearly thought about his options and framed them in a positive though realistic way. He acknowledged there may be limits, but gave the impression that he was determined to move on, resigned to the fact that he knew what he could do rather than attempting to live life at his pre-morbid level. Jack did not see his pain improving, but did see hope for his life improving. A more negative response suggested that the pain would always be present and may even get worse, and therefore coming to terms with the pain was not an option. In contrast to the previous extract Clare offered no hope of improvement in her situation.

(9) 608-614

my main aim now cos I know I'm going to be on medication for years and years, they told us that I'm never not going to be on medication cos he says my neck, the deterioration of the discs will increase by 3% every year or something like that to give you a rough idea, so he's basically saying I'm never going to get any better and he can't operate and he said what they are looking at is maybe the long term medication so I'm going to say I would like to be able to drink and then I'll put up with whatever I need to put up with

Clare had one aim at this time, to be able to drink socially again. She had been unable to drink for a long time because of her medication, and felt that she was more likely to join in with her family and social group if she could drink alcohol. Clare framed this argument as a coping strategy, if she could drink she would put up with whatever she needed to. However it seemed that Clare had little to control in her life because the pain was so dominant, and changing her medication to allow her to drink was all she felt able to control. Clare based her argument on medical advice, the fact that her pain was expected to get worse, there were no surgical solutions, and medication was going to be longstanding. Clare was resigned to the pain when she acknowledged she would put up

with whatever she had to, but there was no optimism for an improvement in the pain or her lifestyle. This version of resignation aligns to that described by Bendelow & Williams (1996), who suggested that people in this group felt dominated by their pain and could express no hope for the future as their pain would never go. They framed this group of people as having entered into a 'chronic pain career'.

Either response featured some degree of personal agency, as participants began to describe being more in control and learning to live with the pain. The language used was personal, little reference was made to medicine or associated health care in relation to helping them manage their lives, and participants discussed how they would move on themselves. The language used implies a future orientation.

*- Acceptance*

The third status claim was very positive in contrast to the previous endings which had both positive and negative elements. This ending involved people accepting the pain and participants described looking forward, being able to control the pain and incorporating it into a description of the self. This is similar to 'accommodation' described by Bendelow & Williams (1996), where a 'pain-free' future could be envisaged whilst incorporating pain into their lives and adjusting to it in a more positive manner.

(5) 437-441

Much happier about the whole thing, I do still get days when I'm cross with having pain but those days are just so few and far between, I always used to want to turn back time to that day when I had the accident and I suppose because it was such a moment in time that changed my life, now I just don't even think about that.

Jane talked of acceptance of the pain in this section of the narrative, and this small extract revealed how she was more settled and happy with her situation. Jane had previously elaborated how the pain was now part of her, and openly acknowledged that it was part of her self and she accommodated it as she did for any other feature of herself. Here Jane was describing how she was happier now that she had accepted the pain, and the days when she was angry and frustrated were so infrequent. Jane suggested that she had accepted the pain to such a degree that she no longer thought about turning back time. It seemed Jane was no longer focused on looking back, but embracing her future and looking forward.

Lifestyle adaptations and pacing activities featured in these few narratives with a motivated, optimistic approach described. The future was referred to and participants, specifically Jane and Robert, discussed goals and what may be achieved in work and social relationships. Pain was incorporated into the discussion; it was no longer distanced but rather included as part of the person. Acceptance was achieved because pain was no longer separate and had to be factored into all aspects of the person's life. The narratives used personal language with no reference to medicine, and talked of real hope for the future. The participants had the control and were not dominated by the pain, but highlighted the realisation that life must be lived regardless of pain. McCracken et al (2004) proposed that the ineffective struggle to gain control over pain that is essentially uncontrollable should be abandoned because acceptance of pain may foster a sense of life control.

### Summary - From medicalised beginnings to personal endings

The participants constructed a narrative of their pain journey, where the opening section was framed as a well rehearsed chronological account of the landmarks of this journey. The beginnings were medicalised not only in the language used, but in the effect created. The participants were trying to establish a story of genuine pain witnessed by many health care professionals and alternative practitioners in an attempt to prove the authenticity of the pain and their response to that pain. In British culture it is not appropriate to claim ill health without a genuine reason, and the concern would be to be labelled as a malingerer (Heritage 2006).

Telling the tale was the main body of the narratives and was filled with examples of the consequences of pain. It was here that the pain was made real for the listener, and provided accounts of the struggle to remain in control and live a normal life. The participants used very personal language, giving vivid explanations of what it was like to have pain and what the pain meant to them. There was no sequence to these sections; anecdotes and experiences were recounted from any phase in their journey from beginning to end.

The endings were where the narratives were drawn to a close and the participants described in more detail where they were now in physical terms as well as emotionally and socially. Three positions or status claims were stated using personal language; there



were those who were still searching for a cure; those who had resigned themselves to having pain; and those who had accepted the pain as part of their life. The future was also addressed in the closing sections, and was obviously closely related to the perceived positions.

All of the narratives had a flow from medicalised beginnings to personalised endings. One explanation for this could be that the participants had lived with pain for a long time, and like with any chronic condition the initial optimism of a cure had faded leaving the person with the impact of the pain on their sense of self and life. Few participants were striving for a cure, most had resigned or accepted the pain at the conclusion of the narratives. Thus it would seem for some people the initial importance of naming the problem as a clinical condition with the expected conclusion of treatment had taken a back seat to the importance of addressing the problem of living with the pain. Giving the pain a diagnosis did not lessen the devastating impact on the person's quality of life, efforts to manage the pain were what became important.

In contrast to Kotarba's (1983) claims, this study proposes three stages that offer a different 'journey'. Whilst the first and second stages in both studies can be construed as similar, the third stage varies. Kotarba (1983) implies that the emergence into a chronic pain syndrome is the ultimate destination, whereas this study contends that this is not necessarily the endpoint. There is hope of moving forward into a positive, fulfilling phase. Kotarba (1983) describes a 'blanket dependence' on healthcare, whereas the data

from the current study argues that this may be true of some but not exclusively for all, as some step of the medical merry go round.

The Bendelow & Williams (1996) study differentiates two positions, in contrast to the present study where a third position is described. The accommodative group does not seem to entirely embrace acceptance of the pain, and is more akin to the idea of resignation with a positive outlook. When the two Bendelow & Williams (1996) groups were compared the most obvious differences were in pain chronicity, so that people in the resignation group were more likely to have been in pain for longer. This is in contrast to the present study, where duration of pain can result in people resigning to or accepting the pain, or in fact be still searching for a cure. This study also suggests that acceptance may be the endpoint because resignation comes first. The findings of this study mirror those of the Bendelow & Williams study in many ways, but by taking a narrative view over the whole 'journey' the model is broadened to include all status claims and relationships between them.

The stories portrayed the unique ways that people live with pain. These were intimate stories about pain, loss, personal goals and ambitions, functional ability, and the struggle to control ones own life. The stories highlighted how people work to maintain a sense of self. The next chapter examines the importance of the journey to acceptance, and outlines the features that influence the extent to which people achieve acceptance.

## Chapter 6

### Making Sense of the Stories

#### Third Stage - Critical Interpretation (Ricoeur 1981)

To recap, for the majority in this study pain arrived uninvited following a traumatic accident or incident at a time in their life when people were highly productive. For others the pain was insidious but no less uninvited. Numerous visits to health care personnel were tried to establish and maintain authenticity, and by engaging in all therapies offered people showed the seriousness and dedication with which they pursued the relief of their pain. Despite their best efforts the pain became a chronic condition, and remained. It was always unwanted and initially it was unexpected as the usual script for pain is one of a transient incapacity followed by recovery. It was precisely this deviation from the norm that resulted in difficulties for the people suffering the pain.

The stories revealed the complexity of establishing a life with pain, rather than a life in pain. The participants entered previously unknown territory, as they came from a pain free state, and consequently adopted diverse strategies to maintain relationships, work and interests from their former life as well as developing new activities and management options. The stories indicated that some were more successful than others, and constructed a life with pain. Some were less successful, and lived within severe limits and led very restricted lives. They had little influence over the way they lived, and pain dictated their day to day life. The author does not claim that the narratives actually correspond to real events in peoples lives; it is the narratives themselves which have been

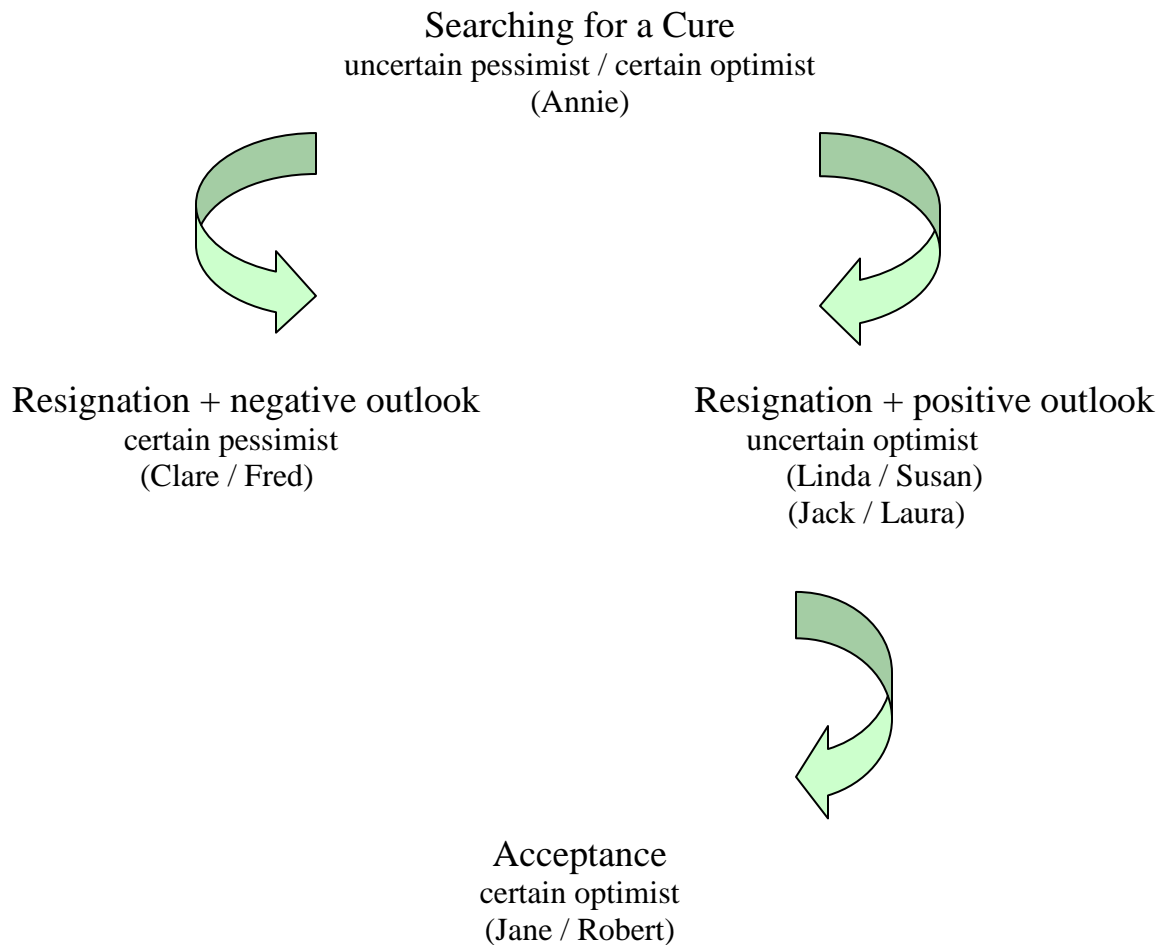
studied and these that are deemed successful or not. Comment and theory are on the content of the narratives not the relation to actual events.

Three central status claims emerged through the stories: searching for a cure; resignation; and acceptance. The following section builds a conceptual model of different ways of living with or in pain with reference to these claims.

### *From separation to acceptance*

The following diagram, fig. 6.1, simplifies the process. The data in this study suggest two cyclical processes. One route is from separation from the pain to acceptance of the pain, with occasional cycles along the way depending on influencing factors, for example if the possibility of a new treatment comes along a revisit to the initial search for a cure might be prompted. This claim is based on the stories told by the people who had accepted the pain as they had all gone through rejection of the pain, wanting to separate from it, before resigning and eventually accepting the pain, and incorporating into their life. A second route is for those who had resigned to the pain but could not see themselves moving on to acceptance, they still wanted to distance themselves from the pain. One group of people were still searching for a cure and continued to describe pain as separate to them and never mentioned resignation or acceptance as an option at this stage.

Fig. 6.1 A representation of the possible journeys with back pain



The journeys seem to indicate that people develop back pain, and depending on the cause and context they either sought medical help immediately or they did so within one to two weeks of onset. People continued to pursue medical help when the symptoms did not respond to the initial treatment, and the search for a cure became a longstanding endeavour which incorporated medical and complementary practitioners. The search for a cure continued for years for the participants, and despite one of the participants still being

at this phase, the other participants eventually reached a dichotomy. Four participants had moved onto resignation that the pain was there to stay. They described a positive outlook in that they could hope for a brighter future. However their lives continued to be disrupted, talk of change was occurring without actual lifestyle changes being evident to accommodate pain. Two participants claimed to have accepted the pain as part of themselves, and incorporated pain into a description of their identity and into their lifestyle. The stories indicated a transition to acceptance for these people, starting with a search for a cure, moving through resignation and finally achieving acceptance of the pain. The alternative route at the dichotomy leads to resignation of the pain but with a negative outlook. Two participants were at this point in their journey, and were not able to contemplate acceptance. Their lives were felt to be severely disrupted, and although resignation to the pain was voiced a constant struggle of distancing from the pain was described.

The diagram represents an interpretation of the journeys outlined in the stories told in this study, and as ever presents more questions than answers. Three status claims can be drawn from the data, but by looking at the entire journey made by each participant it is possible to relate the claims together. Such that one route begins with a search and ends with acceptance via an interim time of resignation. The other route again begins with a search but ends with resignation of a negative outlook. The questions now posed are:

- Could it be one cyclical process?
- Is it possible to move from a negatively framed resignation to a positive resignation?

The stories do not indicate that people moved from a negative resignation to acceptance, though it is not possible to categorically state this. The suggestion that a transition occurs from a search to acceptance is based only on the few stories told, and though the stories did not suggest a route from negative resignation to acceptance it may be that that story had not been told. Further investigation may clarify this question.

*The diminishing relevance of separating from the pain*

Being able to separate from the pain initially is a coping device, and reflects the fact that pain is unwanted and alien. People refer to pain as ‘it’, ‘that’ and ‘the pain’ rather than own it, and dissociate from the pain believing it to be a temporary arrangement. It is not part of them or their normal lifestyle. This may be an effective response to acute, short lived pain, however it becomes less so as pain persists. This idea of separating pain from the person can be related back to the cartesian mode of thinking where mind and body are separate. Kleinman (1988) describes a dualistic experience of a body in pain becoming distinct and alien. By separating from the pain it allows the person to fight and struggle against the pain; it allows the person to blame the pain for any lifestyle disruption and losses; and the person engages in a battle of control. To be able to separate from the pain is a powerful cultural resource, because it allows the pain to be held at a distance and assists in the claim that one is a victim of external forces (Bury 1982).

Doctorability and separation from the pain are concepts that overlap. Bury (1982) asserts that access to medical knowledge offers an opportunity to see the disease as separate from the individual’s self, and by objectifying the disease through medical science

provides a socially legitimate basis for clinical intervention. However strict separation of self and disease can lead to an imbalance between seeing the disease as an outside force and feeling it's impact on all aspects of life. The gradual realisation that medical treatment is not curative leads to a search for a more comprehensive level of explanation which may incorporate understanding that the pain is not separate.

When the pain has been incorporated into a person's life and truly accepted, the fighting and struggling stops. Low back pain thus challenges the body – mind dichotomy. By establishing a partnership with pain there is no need to constantly battle, and issues of control are no longer relevant. It would seem that people cannot or will not fight themselves, by accepting pain they are accepting it as part of their self identity. Getting accustomed to something entails reconciling oneself to the pain and acknowledging the pain as part of oneself (Delmar et al 2005). Acceptance is not an act of resignation or surrender, people who accept chronic pain are not passive (Viane et al 2004). It is reasonable to assume that despite acceptance of the pain, the pain will sometimes interfere, and it is in this situation that fighting is relinquished and a non-reactive openness and flexibility is adopted (Hayes & Wilson 1994). The future has a meaning and purpose and this group of people can be considered as certain optimists as they frame their life in a positive way.



### *The importance of optimism and hope*

The terms certain / uncertain optimists and pessimists are based on positive psychology, and seem relevant to the claims of resignation and acceptance. Here the author is implying that the narratives were narratives of optimism rather than stating that the people are displaying traits of an optimistic personality style. As human beings we are all goal focused, and our psychological well being can be influenced by whether we successfully pursue and achieve our goals (Carver & Scheier 2002). Optimists have a sense of confidence and persistence in their pursuit of goals, even when progress is slow and difficult, and believe future outcomes are likely to be positive. Pessimists have a sense of doubt and hesitancy, and are characterised by a belief that the future may be negative. As such optimists tend to cope much better with adversity assuming that it can be handled successfully, whilst pessimists tend to anticipate disaster and are more likely to give up (Linley 2002). Optimists tend to use problem focussed and positive reframing coping strategies, and are better equipped to rebuild their world following a trauma (Linley & Joseph 2003). Where optimism is about the belief that positive future goals will be achieved, hope theory expands on this and suggests that hope is a combination of finding the pathways to desired goals and being motivated to use those pathways (Snyder et al 2005). A key element of hope is the way in which it combines both the belief that good outcomes will ensue, and the way these outcomes will be achieved through a combination of pathways and agency (Linley 2002).

From a psychological perspective, optimism and hope can be classed as protective or resilience factors (Gatchel et al 2007), and in fact optimism may be one of the most important personality traits in relation to adjustment to chronic pain. It has been found to be associated with better general health, adaptation to chronic disease and recovery after surgery (Scheier & Carver 1992); and in experimental studies high hope people experience less pain and tolerate greater stimuli (Snyder et al 2005). Optimism has also been related to less catastrophising and more use of active coping strategies in chronic pain patients (Novy et al 1998), and has been associated with less depression, higher life satisfaction and less pain (Treharne et al 2005). The main mechanism of optimism may be differences in coping behaviour between optimistic and pessimistic people. In general pessimists use avoidant coping strategies whilst optimists use more problem-focussed strategies, and when that is not possible they turn to acceptance and positive reframing (Garofalo 2000). Hence Carver & Scheier (2005) postulate that it may not be the coping strategies but the flexibility of coping that protects against disability and distress.

Uncertain pessimists and certain optimists can be included in the 'separation' group, as all participants started their journey from this point of searching for a cure and wanting to distance themselves from the pain. People invest in searching for a cure, and in Western cultures the dominant solutions to persistent pain are pharmacological methods and avoidance of pain provoking activity (Davis et al 1992). These attempts are often unsuccessful for people with chronic pain, but perversely continuation with these methods persists (Viane et al 2004), and can lead to more distress, disability and preoccupation with pain (Aldrich et al 2000). In the participants for whom the elimination

of pain was the primary but unobtainable goal, movement towards other goals was blocked, and led to frustration, a sense of entrapment and depression (Morley et al 2005). Some successfully managed to negotiate a route to acceptance, certain optimists (Jane and Robert), whilst others remained at the searching for a cure stage (Annie) or moved on to resignation without any hope of improvement, certain pessimists (Clare and Fred). Some people were at a stage where they were resigned to the pain but felt there was hope for a brighter future, however the daily disruption and losses were such that there was some uncertainty, hence uncertain optimists (Linda, Susan, Jack and Laura).

#### *Acceptance as an analogy to heroic death*

The journey towards acceptance of chronic pain is analogous to the script of a heroic death as documented by Seale (1995). The script depicts a dying person struggling to know the truth, and provides the opportunity to display great courage in facing the final threat. Seale (1995) uses the ideas of open and closed awareness described by Glaser & Strauss (1965). Closed awareness is where the medical profession know the diagnosis but the patient does not. Suspicion awareness follows and represents the beginning of a series of obstacles to be overcome, initially presented by a doctor who would not tell, or told in an uncaring way, or whose telling leads to a feeling of abandonment. Open awareness is the beginning of the journey towards acceptance, and portrays the heroic script of fighting, determination, will power and putting on a brave face which are all to be admired. Telling, denying, fighting and finally accepting are particular moments in the journey towards open awareness (Seale 1995). As Featherstone (1992) argues an ordinary hero is one who fights internal and external enemies, courageously passing through

stages of anger, fear, and denial to eventual acceptance. Thus the project of self awareness is a central preoccupation, because in a climate of chronic and pervasive doubt it becomes necessary to forge meaning in the search for a stable construction of self (Mellor 1993).

If we relate this to the pain stories within this study, suspicion awareness links to the lack of a diagnosis and the continued pursuit of one. The main disadvantage of awareness concerns the capacity to continue as normal. Continuing as normal and maintaining everyday routines then becomes a heroic pursuit because it requires a constant struggle, determination, will power and self sacrifice, all depicted in the stories. However this struggle and fighting does not allow acceptance until the end of the journey, where acceptance in the case of dying is the goal of the struggle to know, and in the case of chronic pain is the goal of the struggle to know how to live with pain. All pain narratives invoke the concept of identity, which in turn invoke a number of possible theoretical interpretations. The ideas of struggle and heroism will be picked up again following the discussion on identity.

#### *The importance of a dynamic self*

From a cognitive perspective the self is a construct constantly under reconstruction and is linked to the body because both are experienced as one and the same thing (Kelly & Field 1996). With the onset of pain, the body changes and the self conception changes too. Identity, however, is the public and shared aspect of an individual as people occupy positions, statuses and social roles. To be acknowledged as a social performer we have to

have control over, use and present our bodies (Kelly & Field 1996). Thus bodies are central to social processes, and in the case of chronic pain any lack of control of the body will inhibit the capacity to enact social roles. When the pain is chronic alterations to the self and identity are substantial and permanent, though this may not be recognised at first. Living with the problems of impaired functioning will become permanent features of the self and the publicly defined identity (Kelly & Field 1996).

Traditional theorists conceptualised the self as a unitary, core and cohesive entity (Kohut 1977), more recent theorists propose a theory of the self as a process; that is multifaceted, dynamic and narrative in nature (Anderson 1995; Sampson 1996; Polkinghorne 1988). With chronic pain people compare their older, healthy self with their ill self, and separate the person in the present from the person in the past (Corbin & Strauss 1987). Perceptions of self must relinquish aspects of the self which are no longer meaningful and incorporate pain related changes to form a new image of self. This process moves people from separating and fighting the pain, to resigning and hopefully accepting a life with pain. People with chronic pain need to rethink and reconfigure the past and the future (Hellstrom 2001). Narrative reconstruction of a self-identity enables a sense of control and will require changes in perceptions and priorities. At times the pain is in control, at other times the person is in control, however since the pain is the person then in reality the person is always in control. As Williams (2000) wrote, the fashioning of self identities is a reflexive and contingent process involving a never ending cycle of biographical appraisals and re-appraisals.

People can not be understood as having a fixed identity, therefore. Identity is not to be found within a person, but rather it is relational and produced within specific contexts (Elliott 2005). Narratives can focus on the everyday practices which constantly construct and re-construct a sense of identity. Ricoeur has been influential in contributing to the concept of the narrative constitution of identity, which suggests an identity that is grounded in experience and temporality, and therefore, not static. Ricoeur (1984) uses narrative in two ways: firstly as a means of understanding of how people make sense of time; and secondly as a way of conceptualising how people have a continuous presence through time without becoming fixed. Thus identity can be seen as permanence through time without sameness through time. Smith (1994) similarly describes personal identity as a product of managing the opposing forces of change and continuity.

*The journey to acceptance is one of transition and normalisation*

The journey to acceptance of chronic pain displays affinities with other illness narratives, particularly the literature on transition and normalisation. Illness narratives can direct us to view illness as a disintegration of self, as an interruption of one's biography, and as a silencing of one's voice (Bury 1982; Charmaz 1983; Hyden 1997). Severe illness has been described as an ontological assault because of its disruptive nature; for example the human power to act is compromised, and the body becomes foreign and medicalised (Sakalys 2003), potentially resulting in biographical disruption (Williams 1984). As previously described, new perceptions of body and self are needed (Sakalys 2003), and the literature on transition and normalisation can help elaborate how acceptance may be reached when suffering long term chronic back pain.

Meleis et al (2000) define transition as a process that results of and results in change in lives, health, relationships and environments. Kralik (2002) argued that change and difference were essential properties of transition, and to understand transition it is important to uncover and describe changes and the effects of change taking place in a person's life. Transitions follow a time span and commence from first signs of change through a period of instability, confusion and distress to an eventual calming with a new period of stability (Bridges 1991). Thus, a concept very relevant to chronic pain as documented in the stories told in this study.

Another feature identified in the transition literature was a strong desire to move on (Kralik et al 2002), which resembles the experiences of the participants in this present study. Important was to know one's response to illness, to develop inner conviction, and to refrain from comparing the before and after of what could be done. Identifying and being aware of priorities formed part of the new image of self and ultimately enabled the management of illness as an ordinary part of life. Looking forward was important, as the perception of self shifted and past aspects of self which were no longer meaningful were relinquished to incorporate a new image of self identity. 'Moving on' was understanding the confines of illness and its acknowledgement, and was described as liberating. The reconstructed self accommodates the reality of living with chronic illness, where illness had been incorporated as an ordinary part of life (Stern 1993), akin to normalisation.

Normalisation is a form of coping, whereby an individual learns to tolerate or put up with the effects of chronic illness. Initially life is problem saturated, but gradually a shift occurs where people try to manage the problem and it becomes part of them, and a new story emerges (Robinson 1993). Robinson (1993) believes there is an evolution of 'as normal', and that construction of life as normal is a balancing act whereby the chronic condition must be recognised and acknowledged but in a way that deficits and difficulties are minimised and abilities emphasised. The early focus on loss and burden gradually shifts to a more positive image of normality (Thorne & Paterson 1998), but the struggle for a tolerable existence takes a long time (Paulson et al 2002).

The journey with pain and the struggles encountered are elaborated upon in the stories told in this study. Frequent oscillations of control between the person and the pain are described by the participants. The shifting perspectives model helps to clarify this oscillation, and describes living with a chronic illness as an ongoing, continually shifting process between illness and wellness (Paterson 2001). Either illness or wellness takes precedence. Illness in the foreground will result in the person focusing on sickness and suffering, whilst wellness in the foreground occurs when the person can distance themselves from the illness. This model aligns well with the present study in relation to the shifting perspectives experienced by the people; illness in the foreground may relate to the pain having control, whilst wellness suggests the person is in control. The shifting perspectives model does however contrast with this study by objectifying and placing pain at a distance from the person. This is at variance to acceptance which incorporates pain into the identity and ends the continual shift between illness and wellness.



The study of illness narratives has afforded a more general understanding of illness experiences, recognising the interdependent nature of body, self, and society. People have an ongoing identity that is discursively constructed across time (Stephens et al 2004). Chronic pain changes the foundations of someone's life because the pain creates new and qualitatively different life conditions. Chronic pain can affect every aspect of being – physical, social, psychological, financial, spiritual, and pose a threat to the person. The common fears cited by people with chronic pain are loss of control, loss of self image, loss of independence, stigma, abandonment, anger and isolation (Pollin 1984). The ultimate goal of people with chronic pain is to adapt, and somehow create a situation where the pain, though always present, does not dictate decisions and activities. Pollin (1984) suggests that adjustment occurs in ebbs and flows, and the person must learn to appreciate when integration occurs. Some people reach acceptance, others find that the limitations in their daily life make difficult the movement toward acceptance.

Kelly (1994) identified a range of possible narrative 'genres' in a discussion of the discursive representation of chronic illness, including:

- epic-heroic;
- tragic;
- comic-ironic;
- romantic; and,
- didactic.

Albeit that many of these genres could be identified within the stories told, the stories could not be themed into distinctive genres and to suggest a typology of unifying 'themes' to these accounts would be to downplay their characteristic complexity. However, one common theme was evident across the accounts: namely, those actions were in some way 'extraordinary' and therefore to be understood in contrast to the mundane concerns of day-to-day life. The predominant vehicle by which to claim an extraordinary / heroic identity was that of a 'struggles discourse'. Seale (1995) noted that themes of suffering, struggle, and redemption resonate strongly in relation to struggles discourse. Pain and distress were typically portrayed in the stories in this study, and 'survival claims' afforded the participants the status of having 'beaten the odds'.

Featherstone (1992) suggested that in contemporary terms a 'heroic life' can only be claimed in juxtaposition to 'the mundane'. A heroic life is comprised of the following features: emphasis is placed upon the extraordinary; the possibility of return to everyday routines is denied; emphasis is placed upon overt risks to future security and the 'courage to struggle'; extraordinary displays of courage, or self-sacrifice are made; the hero/heroine is driven by forces outside him/herself; the hero routinely claims to be self-possessed with an inner sense of certainty and, emphasis is placed upon a compulsion in being able to overcome the greatest misfortunes and make ones own fate. This is not an exhaustive review, but selects features that can be recognised within the stories. This characterisation shares many features with the classical conception of heroism, and the

participants did reference what they perceived as extraordinary feats of courage and strength.

Seale (1995) suggested that 'struggles discourse' provides a vehicle by which anyone can rescue meaningful identity from unfavourable circumstances. This discursive strategy resonates with the theme of identity as a dynamic concept. With the onset of pain the body changes and the self conception changes too. When the pain is ongoing alterations to the self and identity can be substantial and permanent. Kelly & Field (1996) suggest that living with pain and impaired functioning will become permanent features of the self and the publicly defined identity. Current theory proposes that self and identity are processes, multi-faceted and dynamic in nature. Chronic pain patients frequently compare their former healthy self with their ill self, when in fact they should be encouraged to relinquish aspects of the self that are no longer meaningful and incorporate pain related changes to form a new self. This process moves people from separating from and fighting the pain to resigning and, hopefully, eventually accepting a life with pain.

Commonalities between the discursive representation of heroism, death and dying and pain and suffering have been noted above. I suggest that the contemporary cultural script of 'heroic death' (Seale 1995) is very similar to the concept of 'living with pain', whereby people move from separating from the pain to accepting it as part of themselves.

- The struggle to know – the movement from mere suspicion to confirmation. In relation to chronic back pain, this is akin to seeking a diagnosis and initially a cure.
- The struggle with knowing – the struggle to cope with ‘information’, once suspicions are confirmed. In terms of pain, the ongoing search for a cure and the inability to maintain ‘normality’.
- Facing difficulties – affirmation of the self in the face of overwhelming threat to ontological security. In respect to chronic, unresolved pain, to resign and live in pain, or to accept and live with pain.

Struggles discourse is exemplified with self-defining moments in which adversity is conquered by means of acts of courage or sacrifice. Seale (2001) asserted that the principal discursive function of ‘struggle language’ is therefore in allowing unfavourable personal experiences to be represented in terms of a psychological and spiritual journey towards a satisfying resolution. However, in this study a satisfying resolution was not the only outcome.

*Living with pain (certain optimist narratives)*

Having pain was the foundation for a life that was different to that which the participants had previously known. However this was a life filled with different possibilities where pleasure and satisfaction could continue. Hard work was needed to create the life they wanted to live as a person with pain, by using a range of strategies and resources

available to them. There is no suggestion that life was without difficulty for the people who lived with pain, but life could be enjoyed despite their circumstances.

People living with pain assessed and adjusted their expectations, and could play down the negative impact and minimize the significance of what they were no longer able to do. They focused on what they could do, and negotiated strategies to allow them to plan and achieve goals. In this way they could look to the future as a positive, fulfilling experience.

*Living in pain (certain pessimist narratives)*

The people living in pain did not play down the negative impact and their stories highlighted the continuation of difficulties, frustration and despair as they put up with circumstances they perceived were beyond their control. Consequently these people struggled to lead the life they had before pain. Life became fraught with constant struggle and unfulfilled goals, which reinforced the need to seek help, and the continual search for a cure. For some the realization that pain was not going resulted in them resigning themselves to the pain. Resignation with a negative outlook could be regarded as a type of learned helplessness, where the people are helpless to change their situation and lead a life aimed at not aggravating the pain.

Whether living with or in pain, the people had moved to a situation where they could not live their life or pursue their personal aspirations without restriction. In their everyday life

the majority struggled with pain. For the minority who had truly accepted the pain, they concentrated on living. Important to both was being able to live an everyday life.

## Chapter 7

### Conclusion

#### *Why this study?*

Back pain is a relatively new disability – the problem has probably existed for as long as man has been a species, but it is only within the last 150 years that it has become a disease for which a cure will be sought. Here lies a problem as simple back pain frequently evades a cure, though the majority of sufferers within the UK will seek a cure because of the expectation of, and reliance on, the medical model. The epidemiological evidence and literature review highlight how much attention has been paid to the effect of low back pain on the population and to the increasing cost in economic and health terms. Present health care services are often seen as unsatisfactory in managing chronic low back pain, and back pain still represents one of the major challenges in health care today.

The research question posed within this study grew from an interest in the disparity between the professional and patient viewpoint of what low back pain is and means, what the expectations are, and what are suitable options and outcomes. My clinical experience told me that the lay search for a cure for low back pain was not easily reconciled with the professional recommendation of management. However, some people were able to accept this more readily than others, and this led me to consider the journey that people take from the onset of back pain. It seemed that professionals had already determined the final destination of acceptance and management, but those suffering pain had alternatives.

Low back pain has been researched across many health care disciplines, using a variety of approaches. An interpretivist inquiry was chosen for this study because clinical experience had shown that patients tell stories of their pain problem, and frequently lead the researcher on a journey through the history of their low back pain, and are thus constantly engaged in the process of interpretation. The study focused on the patient's perspective in an attempt not to overshadow the voices of the sufferers. As the researcher had observed that people readily tell stories of their life events, it was felt that a process that enabled people to tell stories of their everyday life would be most appropriate. In-depth interviews were arranged, and a series of narratives resulted. Narrative analysis complemented the research area and the wider interpretive approach as it was the experience, the meanings, beliefs and perceptions of back pain that were to be investigated.

The aims of this study focused on the patients' perspective of low back pain, and particularly addressed:

- ◆ the beliefs that study participants hold on what are the causes of their pain,
- ◆ what their pain means to them,
- ◆ the experience of living with low back pain,
- ◆ what the future might hold.



### *The causes of low back pain*

An enduring concern with all the participants was the need for legitimacy, and the necessity of presenting a ‘doctorable’ problem. The term ‘doctorability’ was adopted to define the situation whereby a patient must satisfy the health care professional that they have a problem requiring investigation and treatment, and the patient must lack the knowledge, skill or expertise to manage the problem on their own (Heritage 2006). This relies on the assumption that doctors can provide a treatment, and supports the idea of the medical model. In some situations the confirmation of a diagnosis by a positive test would be feared, but for back pain patients a positive test confirms a real problem, and is a desired outcome. All participants sought medical care and wanted to establish a genuine, physical reason for the pain. The need to attribute cause is crucial on many levels. Pain that cannot be seen threatens a crisis of meaning – having pain confirmed and diagnosed by a doctor aligns the person with medicine and the sick role, whilst an inconclusive diagnosis, or no diagnosis, alienates the person from medicine and reduces the claim to be sick.

Causation and legitimacy of the problem were attempted by the participants describing either morally credible activities or accidents. All participants used such devices, and stressed how ordinary but fruitful their lives were before the pain. The onset of pain was seen as beyond their control. Bendelow (2006) described a hierarchy of pain where some forms of pain are more socially acceptable than others. Pain with a pathological, usually a physical, cause appears to have more respectability, validity and authenticity. People were aware of this and were driven to establish a genuine cause for their pain.

Reduced activities and daily functioning led all the participants to seek a cause for their pain. Most participants retained their own views on the causes of their pain, which did not always reflect the views of the medical profession. In a study by Geisser & Roth (1998) people who were unsure or disagreed with their diagnosis tended to report a greater belief in pain being a signal of harm, and described themselves as more disabled which resulted in them using maladaptive coping strategies. Participants unsure of their diagnosis had the lowest levels of perceived control over the pain. Lack of diagnosis can lead to chronicity of pain, and the evidence suggests that it can lead to heavy use of medical services in an attempt to validate and legitimise pain.

Without proper explanation of their pain the people in this study became increasingly inactive, and frequently increased their medication use. People withdrew from activities and social interactions, focusing more and more on their pain. Proper explanation does not have to be a definitive diagnosis, but as Wells et al (2003) highlight a label may provide a name for the person's experiences through which they can more easily communicate, and give their pain a sense of tangibility, validity or control, or provide justification for suffering. Telling people earlier in their journey may go some way to accelerating the struggle, and eventual arrival at a more positive outcome.

*What does the pain mean?*

Pain beliefs are peoples own ideas about their pain and what it means to them. The participants were anxious to understand the cause of their pain, but were equally concerned about the damage that may have occurred and the potential for future damage. All the participants felt that their pain was permanent and was progressively going to get worse. The degree to which people believe that they are disabled by their pain proved to be a powerful factor in limiting their functional ability. The advice to manage pain and keep active was difficult for people to grasp, especially if they had low perceptions of perceived control and believed their pain to be a serious long term problem.

Pain was always uninvited and was described as invading a person's life, separating the person in the present from the person in the past (Corbin & Strauss 1987). People described living day by day, and not being the same as before. Fighting was a recurring theme with all the participants. At times all fought the pain either to continue as normal, or to achieve something particular. Control shifted between the pain and the person; sometimes the person was the winner, sometimes the loser in these battles. This created a continual struggle to control the pain. In order to maintain this struggle the participant had to believe the pain was separate to them. Baszanger (1989) believes that people always seek to maintain control over the pain, but this is only effective in certain situations and is aimed at not only lessening the pain but also at maintaining both personal integrity and the presentation of a competent self. Thus, from this data it becomes clear that for the majority the attempts to control the pain continue until the person believes that the pain is chronic and will not end.

Initially being able to separate from pain reflects the fact that pain is alien; it is not part of the person or their normal lifestyle. It allows the person to fight and struggle, and blame the pain for any disruption and loss. However, as pain persists this coping style is a less effective response. Separation of self and pain leads to an imbalance between seeing the pain as an outside force, and feeling its impact on all aspects of life. A socially legitimate basis for clinical intervention may be achieved by objectifying pain through continual access to medical help, but for most people at some point the gradual realisation that no cure is likely for chronic back pain will lead to a search for a more comprehensive level of explanation. Introducing the idea of chronicity and management earlier in the journey may lead to the development of a comprehensive explanation that incorporates the understanding that pain is not separate to the person. The evidence in this study suggests that those participants who had accepted the pain were no longer fighting as issues of control and struggle were no longer relevant. By accepting pain the person is accepting it as part of their self identity, and clinically this is something we could move people towards at an earlier stage.

Phases, as suggested by Breen (2002), were discernible in the stories. Breen (2002) describes four phases, but for the purposes of this study two extra phases have been added to incorporate the entire journey. This summarises the meanings held by the participants over the course of their experiences with pain. For the majority of people their beliefs may hold fast, but the meaning of the pain was changeable.

- 1<sup>st</sup> phase = before the pain = active, 'normal' life.

- 2<sup>nd</sup> phase = onset of pain = initial discrimination of pain, person self treats the pain. (Breen's first phase).
- 3<sup>rd</sup> phase = striving for diagnosis and cure = ongoing pain, person seeks medical help and a cure, and separates from the pain. (Breen's second phase)
- 4<sup>th</sup> phase = living in pain = gradual understanding that the pain is chronic, and previous experience influences ability to cope. (Breen's third stage).
- 5<sup>th</sup> phase = adjusting to pain = modification of lifestyle and behaviours to live in pain or to live with pain. (Breen's fourth phase).
- 6<sup>th</sup> phase = future = still searching for a cure, or resigned, or accepting of the pain.

The first and final phases have been added as bookends to Breen's (2002) original phases, as a means of embedding them within a personal biography. Considering life before pain and ultimately where their life with pain may go mirrors the concept of a journey. Life did not start for the participants when they developed pain, nor does it end when adjusting to pain. Life is a continuum which features pain for these sufferers to a greater or lesser extent.

#### *The experience of living with low back pain*

Vivid stories have been told relating the impact of the pain on personal and working lives. Avoidance of physical and emotional suffering is common, whereby people attempt to control or limit their contact with anything perceived as pain provoking. Back pain strikes when people are most productive and has far reaching consequences. Participants described loss, feelings of worthlessness and low self esteem.

The concept of good days and bad days featured within the narratives. Good days were described as infrequent and highly sought after. However, bad days were more frequent and seen as inevitable. Severity of pain only partially accounted for the differences in days, which seemed to be more related to emotional and psychological factors and personal agency. Severity was mentioned on a bad day, but not on a good day, however neither were good days described as being pain free. Being in control of the pain and 'feeling different' were important features of a good day where activities could be achieved. Over the course of the journeys the narratives suggest that more good days can be achieved by adapting lifestyles rather than struggling to maintain pre-pain levels of activity. Some forms of adaptation are more positive than others; some people limit their personal, social and work life substantially whilst others alter their lifestyle with more minimal changes and pacing.

Establishing a life with pain is very complex. People came from being pain free and were thrust into a previously unknown situation. The narratives highlight how diverse strategies were adopted to initially maintain relationships, work and interests. The stories indicate that over time new activities and management options were undertaken. Some participants were less successful and lived within severe limits and led very restricted lives. They perceived that they had little influence over the way they lived and could be said to live in pain. Those telling more successful narratives described constructing a life with pain.

It is the individuals understanding of their relationship with pain that shapes that persons life. People differ in their aspirations, backgrounds and experiences, and the individual stories indicate such differences. People in pain are neither inactive, passively receiving care, nor independent and self determining in the way they manage their daily life. Some are more passive; others active in the way they attempt to shape their life and reconstruct a personal identity. However a unifying theme across all stories was being able to live a meaningful life.

### *The future*

Three status claims emerge from the narratives: searching for a cure; resignation; and acceptance. It is not intended to suggest that these are definitive positions, but more current estimations of status. The first status claim is that of still looking for a cure. This seems to be a continuation of the original aim, and can be the position irrespective of the length of time that back pain has been suffered. The participants adopting this style were either actively pursuing a cure or taking a more long term view that they would be ready when something curative comes along.

The second status claim is resignation, which can be framed positively or negatively. People relating narratives of resignation dwell upon their pain, feel psychologically cut off or isolated from others, are engaged in fewer social activities and express the view that illness has dominated their life. A more positive form of resignation narratives involves coming to terms with pain, and an admission that the pain is here to stay despite their best efforts. It is hoped that things may improve, though this is still a passive

position. A more negative response suggests that the pain will always be present, and may in fact worsen, but coming to terms with the pain is not an option. No hope is expressed for a positive outcome, and there is no active pursuit of improvement or cure.

The third status claim is acceptance of the pain. This is framed as looking forward to the future. Acceptance does not imply a blind pursuit of activity and uncompromised lifestyle in spite of pain, but features behaving in chosen ways with pain, thus achieving a full and satisfying life (McCracken 2005). Acceptance acknowledges pain and suggests that pain has been incorporated into a person's life. The participants described themselves as a person with pain as it formed part of their identity and with their optimistic approach it allowed the person to look forward. Life could be lived regardless of pain.

The data in this study suggest two cyclical processes. One route is from separation from the pain to acceptance of the pain. This claim is based on the stories told by the people who had accepted the pain as they had all gone through rejection of the pain, wanting to separate from it, before resigning and eventually accepting the pain, and incorporating into their life. This route does not appear to be related to time with pain, nor is it a linear route. Further investigation may elucidate this route more clearly. A second route is for those who had resigned to the pain but could not see themselves moving on to acceptance, they still wanted to distance themselves from the pain.

Optimism and hope are key factors in relation to adjustment to chronic back pain. Optimism has been linked to better health and less pain (Treharne et al 2005) through the



mechanism of coping strategies. In general pessimists use avoidant coping strategies whilst optimists use more problem focused strategies and turn to acceptance and positive reframing. The terms uncertain/certain optimists/pessimists were included in this study because they were employed by the participants. The idea of optimism, hope and pessimism pervaded the narratives though the author added the element of certainty or uncertainty to highlight the success, or not, of these traits in moving people on through their journey.

Having a positive and optimistic attitude to life is a key factor in managing chronic pain, and encouraging patients to have this should be part of a health care professional's role. An optimistic outlook has health and coping benefits for pain patients (Gatchel et al 2002). People want to participate, be involved and have their experiences and pain stories listened to, and being given time to do this is important at times of transition. People with chronic pain need time to retell their stories and adapt to a different way of life without losing self esteem.

### *Implications of this Study*

This study aims to make a contribution to our understanding of how people live with back pain. Contemporary literature abounds on the topic of low back pain. The stories of people suffering with low back pain are present, though limited, within the literature, and this particular research was designed to bring these stories to the fore and help to develop a greater awareness of the different phases people pass through on their journey.

Reconceptualising the status of the person with pain focuses attention on supporting people as active agents and moves them to determine their own life rather than merely living in pain. The Parsonian paradigm, with its attendant notion of the sick role, places the ill person in the position of handing over responsibility to medical professionals to alleviate their situation (Parsons 1951). Whilst the sick role is a temporary one, the impaired role is potentially permanent and one where the person faces dependency (Dewsbury et al 2004). Initially people in pain are seen as patients adopting the sick role and required to act passively seeking cure and treatment. However, chronic pain management requires people to actively address their own management and be partners not patients. This philosophical shift is the crux to successful pain management, but people frequently need help to engage in decision making and learn to be instrumental in shaping their life. For example, the discussion on control in a previous section highlighted the perception that control moves between the person and the pain; however with support choices can be made that will put the person in control. By retelling their stories and exploring their personal journey with pain a more sophisticated understanding of their construction of life with pain can be generated.

The initial questions posed in this study were answered, and as Williams (2000) suggest *moderatum* generalisations are possible. The original idea was to map out the health service contacts and events as well as the meanings and beliefs held by people in pain, to consider the possibility of service development. The study design altered along the way and became focussed on the stories and the journey. However by listening to the stories a

gap can be identified between what clinicians do and what the people in pain want, which in fact may come full circle back to the idea of service development if we ask the question could we tailor a service better. I suggest that health care is trapped in an epidemiological model, and by using narratives and the concept of identity a service could be constructed that does not just feature a 'one size fits all' approach.

The strengths of this study lie within the methodology and the findings. The methodology allowed people to tell their stories, and the data generated was analysed using a narrative approach. The qualitative framework tied together well, so that the method of data collection married with, analysis and subsequent interpretation. The findings are consistent with research on low back pain, and other chronic conditions, but expand on the theoretical models of Kotarba (1983) and Bendelow & Williams (1996) by suggesting a more comprehensive view of status claims. I think this has been achieved by taking a narrative approach. I believe that the findings of this study are relevant to other groups of people with a chronic condition. The findings resonate with the literature on illness narratives and transition which cover a number of chronic conditions including arthritis, MS, diabetes, HIV, though the extent to how generalizable it may be would require a larger study to answer.

The study could benefit from a longitudinal design which may have identified differences in stories as their chronic condition progressed. This would allow a more comprehensive view of journeys and status claims, and the relationships between them. It was not possible to undertake such an option, as it was only as the stories unfolded and were

considered sequentially that the proposed theory of a cyclical process between the stated endpoints emerged. Hindsight suggests that a further study employing a longitudinal design would be relevant to elucidate these findings. It would also be useful to interview people suffering chronic pain that are not attending a pain clinic. Issues of time, access and resources prevented this within the present study, but again could be incorporated into further longitudinal work.

*The contrasting influence of the medical model and social model of disability*

A brief consideration of two influential models may help clarify the challenges raised in this discussion in moving toward acceptance of pain, and where the above recommendations may meet obstacles. However, it is the contention of the author that although people in pain have been given the label of chronic low back pain by health care professionals, it is the people themselves who label this as an impairment and some will consider it to be a disability. The initial challenge faced by people with chronic pain is the move from a curative medical model to a patient-centred management model. Patients at this time are experiencing life with an impairment, but are being encouraged to live fully and the health care professions are actively dismissing terminology and lifestyle options associated with disability.

Historically the medical model of illness has been the basis for health care intervention, and is the standard expected and accepted by people in pain. The medical model of illness separates the body into component parts, looks for causes, and seeks to diagnose, name, define and treat specific illnesses. In relation to chronic pain the evidence supports a

move away from the medical model to a more fruitful management model. Following from the above premise that some chronic pain patients see themselves as disabled, then in terms of disability the medical model views disabled people as the problem and seeks to label people by their impairment. Disabled people are seen as needing to change and adapt, there is no suggestion that society needs to change. This forms some of the basis of pain management whereby patients are encouraged to adapt to living with pain, but the model does not acknowledge that people are steered away from labelling their condition as an impairment and as such are discouraged from adopting a disabled identity.

In contrast, the 'social model of disability' (Oliver 1990) emerged in the 1980s as a critique of medical approaches to disability. The medical view that social restrictions for disabled people were a consequence of physical dysfunction was rejected and it was forcibly argued that people with impairments were disabled by a social system which erected barriers to their participation. Disability was not an outcome of body pathology, but of social organisation, and hence presented a challenge to the medical view that the body is the 'cause' of disability. The disability movement has been happy to accept the distinction between impairment, a form of biological dysfunction, and disability, the process of social exclusion. The main achievements of this have been gained by drawing attention to the ways in which able-bodied norms have erected barriers and excluded people with impairments from the mainstream of society. The social model of disability with particular regard to learning difficulties is very clearly in support of validating people's identity and moving away from a preoccupation of the personification of stereotype (Watermeyer 2009).

The social model of disability relies heavily upon the distinction between bodily impairment and socially produced disablement, and while this approach has been of great value in establishing a radical politics of disability, Paterson and Hughes (1999) argue that it does not leave room for a full consideration of disabled identity and that a social model of impairment is possible. This is particularly relevant when considering chronic low back pain. The literature suggests that people reduce their activities, and experience loss, anxiety and depression, and frequently regard themselves as impaired. All the participants in this study felt that their pain / impairment was permanent and was progressively going to get worse. Thus impairment in itself carried real social consequences and was a significant factor in the identity and day-to-day existence of people with low back pain, and in this respect the impairment is social, and disability arises from the fact that pain curtails social activities. Those people who had resigned to the pain or were still searching for a cure, described themselves as leading severely restricted lives and many of them viewed back pain as a ‘disability’. Paradoxically this view could be considered, at times, to be antagonistic to the social model as it is conventionally conceived, since the person is disabled by virtue of the social effects of the pathology rather than due to external ‘disabling’ factors. It should be recognised that disabling barriers in the ‘world outside’ are merely part of the problem, and in fact we might do well to consider the social aspects of impairment when considering the low back pain experience.

The author does not claim that people with chronic pain, by necessity, are disabled; rather, more reasonably it can be suggested that the social effects of chronic pain impairment, can result in the attribution (or self-attribution) of disabled identity. A proposal is offered that this study points toward a biopsychosocial model of understanding chronic low back pain, incorporating an individual view of impairment. Some people will construct a 'disabled' life, others will not and by validating pain narratives and the people telling those stories we may recognise how people live with their pain in all domains of life.

The findings of this study have implications for practice, in that people need time to tell their story. History taking and story telling have different foci, and are dominated by clinician and patient respectively. History taking is the principle mode of establishing a clinical story. I contend that health care professionals should afford a detailed story more status at an earlier stage of a person's journey with pain. The importance of knowing the person in pain will benefit the relationship and help develop a more personalised supporting structure to enable people to shape their life to live with pain, rather than in pain. Packages of care could be tailored to meet the particular needs of patients, based on their understanding and perceived position with their pain, that is whether they have resigned, accepted or are still distancing themselves from pain and seeking a cure.

Narrative thinking is different to analytic thinking commonly used in clinical practice; both are ways of organising experience but as frameworks they have different purposes (Sakalys 2003). By understanding the processes by which people come to grow from

their pain and loss experiences, we learn much about the motivation for and function of narrative reconstructions of self (McAdams 1996; Neimeyer 2000). McAdams (1996) argued that one's conception of one's identity is largely based on making a coherent story of one's past experiences, present situation and future goals. Pain and loss figured prominently in these narratives and such events led to significant changes in how people saw themselves and the world in which they lived, therefore understanding the meaning making processes used by people is likely to be very informative (Davis 2001).

It is not suggested that health care professionals do not attempt to identify and respond to the needs of chronic back pain sufferers, but they do so within the scope of their profession and learned practices. Evidence, theory and value are inevitably produced from within discursive traditions (Dewsbury et al 2004). Attempts are made to help people live in a meaningful way, usually very successfully, but there can be a gap between the sufferers' views of what they need and those looking after them. Identifying where people are on their journey and identifying what strategies are available to help them move towards acceptance may prove beneficial. The current emphasis on professional, technical knowledge as key evidence underpinning practice should be balanced with the knowledge of the person in pain and their ability to accept.

Frequently health care addresses the needs of people as identified by health professionals, however this may not reflect the need as defined by the person in pain and more importantly this may not meet the outcomes they desire. Both professional and lay knowledge exist and both influence the way care is constructed and utilised. Both



perspectives are justified, but the outcomes may be very different. It remains important for professionals to draw on biomedical and patient specific knowledge, but not at the expense of the person's knowledge. People in pain have life experience and should be instrumental in managing their situation, one size does not fit all.

It was expressed at the outset of this study that the views and experiences of the participants were to be the focus, and it was important to translate this into the study design and methodology. This study indicates that narrative methods do provide the means for people to tell of their experiences and engage in a process of interpretation. This thesis provides an insight into the day to day experiences of people living in pain and with pain. The stories reveal the ups and downs of life for a selective group of people with chronic back pain, and the overriding conclusion that can be drawn is that people want to live a meaningful life and they embark upon a journey which may end with acceptance of the pain, or they may continue with the separation of pain and a life of struggle. This interpretation of life with low back pain is certainly not fully representative of the experiences of people suffering chronic back pain, but does offer one interpretation of those participants who kindly consented to the study.

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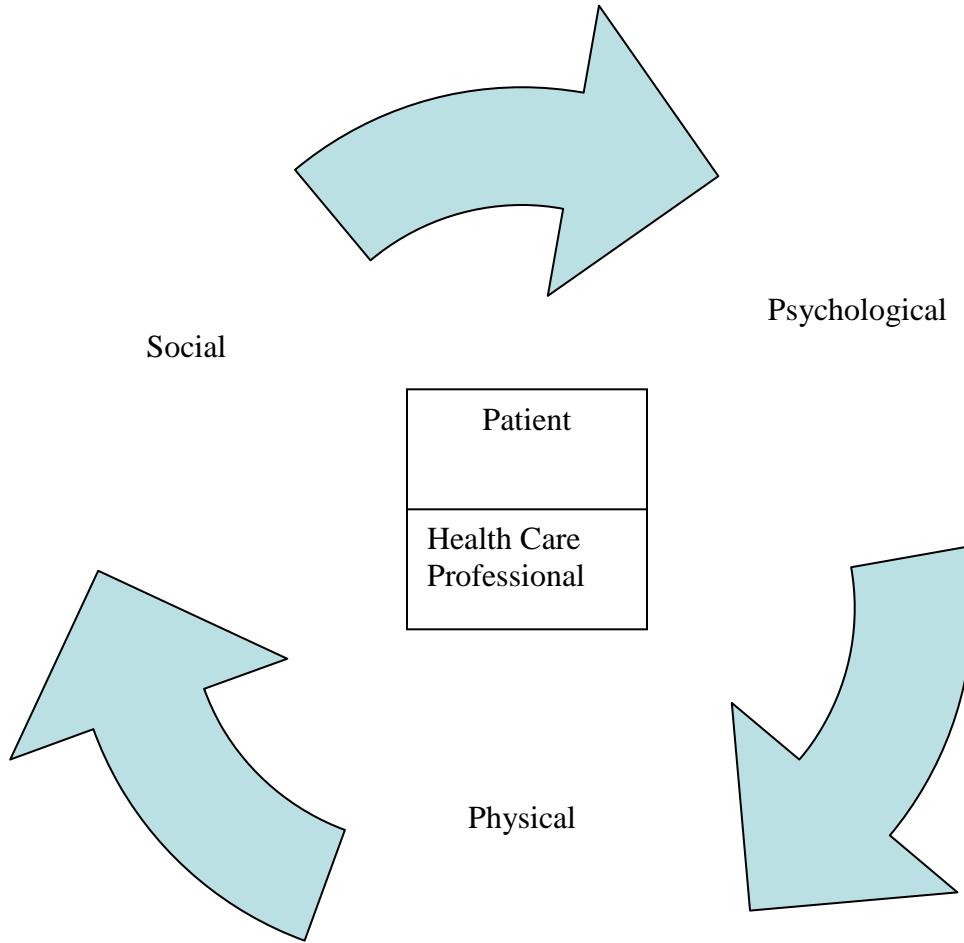
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**Appendix 1**

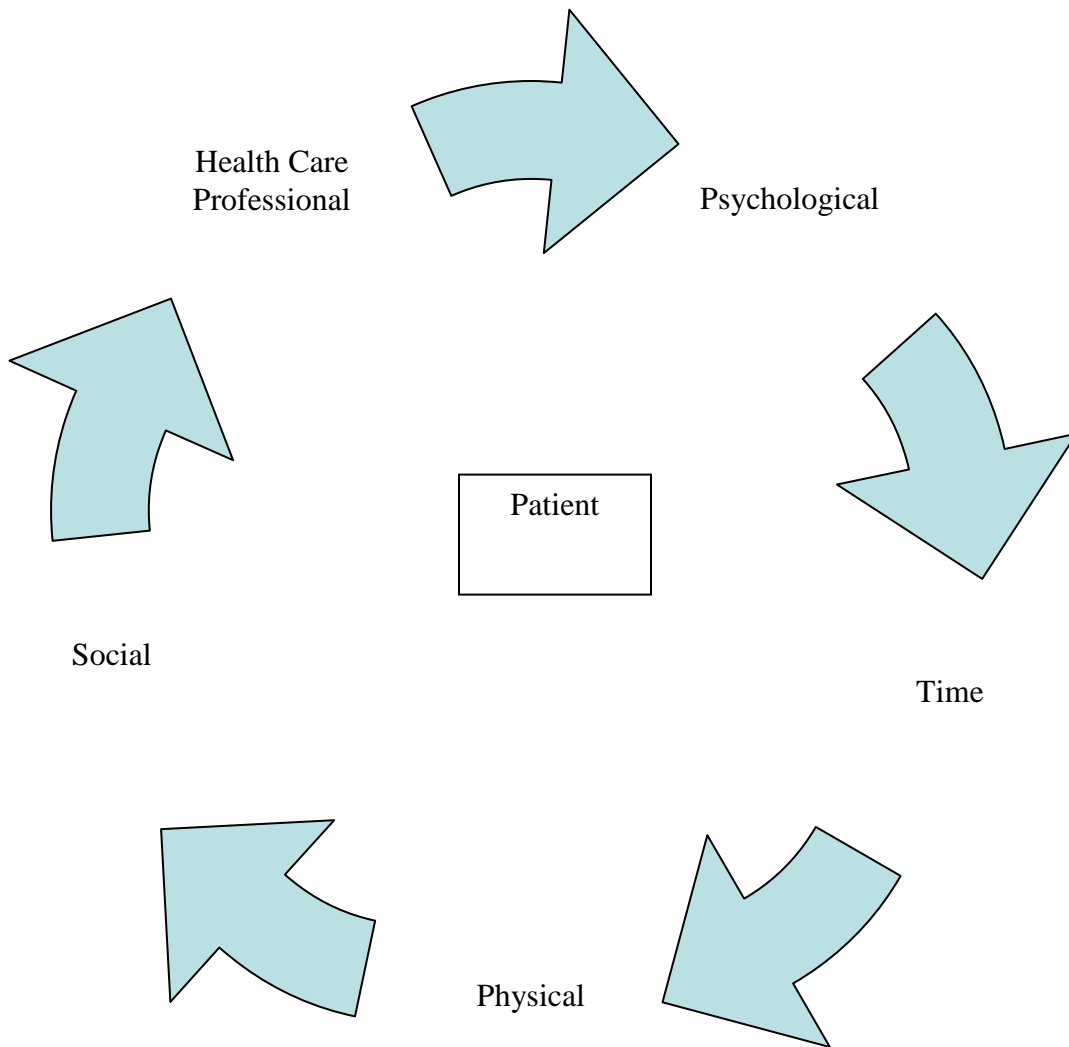
**Original Conceptual Framework**

Contextual Influences / Factors



**Appendix 2**

**Revised Conceptual Framework**



### Appendix 3

#### Sampling Matrix

<b>Name</b>	<b>Age</b>	<b>Gender</b>	<b>Occupation</b>	<b>Nerve Root Pain / Specific Pathology</b>	<b>Time since onset</b>	<b>Surgery Y / N</b>	<b>Health Care Prof.</b>

## Appendix 4

### Sample

Name	Age	Gender	Occupation	Nerve Root Pain / Specific Pathology	Time since onset	Surgery Y / N	Health Care Prof.
Annie	66	F	Housewife	LBP	16 years	Y	GP, physio, Neurosurgeon, Pain Consultant, CNS, Chiropractor, Acupuncturist
Robert	36	M	Sick Benefit	LBP, bilateral leg pain	15 years	Y	GP, physio, Orthopaedic Surgeon, Neuro surgeon, Pain Clinic
Laura	40	F	Admin Officer	LBP, left leg pain	9 years	N	GP, physio, psychologist, orthopaedic surgeon, general surgeon, pain clinic
Fred	57	M	Retired Care Assistant	Degenerative sacro-iliac joint	6 years	N	GP, Physio, Orthopaedic Surgeon, CNS, Pain Consultant
Jane	38	F	Civil Servant	LBP, leg pain	21 years	Y	GP, A&E, Neurosurgeon, physio, pain clinic
Susan	37	F	Unemployed	LBP	18 years	N	GP, chiropractor, rheumatologist, orthopaedic surgeon, psychologist
Jack	35	M	Factory Worker	LBP	3 years	N	GP, physio, A&E, neurosurgeon
Linda	37	F	Admin Officer	LBP	14 years	N	GP, physio, osteopath, orthopaedic surgeon
Clare	40	F	Unemployed	LBP Neck pain	6 years	Y	A&E, neurosurgeon, GP, physio

## **Appendix 5**

### **Dramatis Personae – populating the narratives**

#### *Getting to know the participants*

I listen to pain stories within my clinical role on a daily basis and I could hear similarities time and again between the stories. People come from a variety of backgrounds with an array of different influences, but what intrigued me was the similarity of the ‘journey’ they took and the outcomes they reached (see below for metaphorical description). The stories told by the health professionals and those told by the people with low back pain were very different, yet we rarely listen to a pain story from start to finish within a clinical setting. I wanted to listen to such stories and learn what it was like living with low back pain from the patient perspective.

The participants who agreed to take part in this study were a diverse group. In common they all attended a pain management clinic within the North East of England because of difficulties with low back pain. In this section the stories of nine people are summarized, to elaborate the perspectives of those suffering pain. The participants told stories about their life before and after the onset of pain, they told of themselves and the events that happened to them. Through the retelling we hear of their experiences.

All the participants claimed to have had a pain free life prior to the onset of their low back pain. What the participants did and how they reacted to the pain are at the same time similar and diverse. Similar because they all access health care and describe lifestyle



changes; diverse because they react and experience such changes differently. Table 4.2 gives an overview of their ‘journey’, and is based on the key areas spoken of in their stories. All the names are pseudonyms to preserve confidentiality.

Table 4.2 Summary of events depicted in the stories

<b>Participant</b>	<b>Onset &amp; duration of pain</b>	<b>Contact with health care professionals</b>	<b>Family &amp; friends</b>	<b>Work life</b>	<b>Activities</b>
Annie Age 66	Pain started whilst at work 18 years	GP, chiropractor, acupuncture, orthopaedic surgeon, neurosurgeon, pain clinic	Reduced contact with friends, same contact with family but visiting her at home usually	Retired after initial surgery in 1987 aged 48	Declines holidays, and babysitting for family. Unable to attend line-dancing, stopped gardening.
Robert Age 36	Insidious onset 15 years	GP, orthopaedic surgeon, physio, pain clinic	Sees friends less	Had to stop engineering work and carpet fitting. Currently unemployed, looking towards retraining with computers	Had to stop sports – participation and spectator. Less holidays. Watches TV, walks dog.
Laura Age 40	Insidious onset 10 years	GP, gynaecologist, colorectal surgeon, psychologist, physio, pain clinic	Less contact with friends, actively involved with young family	Stopped work to have children, now working part time in charity	Doesn't meet friends in bars or clubs, had to stop badminton, can't play sports with children. Enjoys reading/puzzles

<b>Participants</b>	<b>Onset &amp; duration of pain</b>	<b>Contact with health care professionals</b>	<b>Family &amp; friends</b>	<b>Worklife</b>	<b>Activities</b>
Fred Age 58	Work injury 6 years	GP, physio, rheumatologist, pain clinic	Limited contact with friends, reduced contact with family	Retired after injury, unable to work since	Can't play active games with grandchildren, or baby-sit. Had to give up walking and cycling. Watches TV, collating memoirs, dog walking.
Jane Age 38	Fell off horse 21 years	Neurosurgeon, GP, physio, pain clinic	Different group of friends now, moved closer to family	Was going to join army. Used to work in busy city job involving extensive travel, now quieter desk job	Left TA, stopped riding and active sports. Meals out, cinema, golf.
Susan Age 37	Insidious onset 18 years	GP, rheumatologist, chiropractor, physio, orthopaedic surgeon, psychologist, pain clinic	Close contact with father and one brother. Frequent contact with one friend	Worked with children but had to stop. Library work and had to stop. Currently unemployed	Brownies and church events. Single parent, occasional night out with friends. Had to stop swimming, frequent alternative therapies
Jack Age 35	Work injury 3 years	A&E, physio, GP, neurosurgeon, occupational health pain clinic	Regular family contact, reduced contact with friends	Factory work, recently changed employers because of health issues	Had to stop fishing, going out with mates. Occasionally goes out walking. Stopped physical games with son

<b>Participants</b>	<b>Onset &amp; duration of pain</b>	<b>Contact with health care professionals</b>	<b>Family &amp; friends</b>	<b>Worklife</b>	<b>Activities</b>
Linda Age 37	Work injury 14 years	Physio, GP, osteopath, orthopaedic surgeon, pain clinic	Close to mother and stepfather, frequent contact with nephew. Limited contact with friends	Used to work with children but had to stop. Now works in admin, has recently had a lot of sick leave	Occasional nights out with friends, no hobbies, likes her own company
Clare Age 40	Car accident 6 years	A&E, neurosurgeon, GP, physio, acupuncture, pain clinic	Less family and friend contact	Had to stop shop work because of pain, now unemployed	Has large family and occasionally will socialize with them. Hobby is shopping which she manages occasionally. Very infrequent socializing with friends.

Metaphors have been used throughout history to shape our understanding and to help us make sense of situations (Sapir 1977; Barker 1998). Metaphors are constructive mappings from one domain of human experience to another, and enable the description of elusive, intangible experiences (Arvey 2001). Particularly relevant to this study is the idea of a journey. The metaphor of the ‘journey’ was used by Cicely Saunders, founder of the modern hospice movement, as a means of pointing to ways of finding acceptance, fulfilment and meaning in life (Saunders 2000). She suggests that metaphor is central to description, and description is central to any full understanding of dying, pain and death.

The journey metaphor imposed by serious illness demonstrates that there are still opportunities for personal growth, hope, discovery and change (Byrne 2008). The metaphor of the journey has a definite place in palliative care, and can be construed as relevant to stories of chronic pain. Carson & Mitchell (1998) describe the isolating journey of suffering when living with pain. The patient story of their 'journey' is recognized as a research method, and although we cannot accompany them on their journey we can recognize the experience through language (Stanworth 2005).

I asked people attending a pain clinic to tell me their story. In practice I find people are happy to share their stories, and recruited nine willing participants. I interviewed the participants and recorded the dialogue. The following pen portraits are summaries of the stories told.

*Annie*

Annie was a 66 year old widow, who had a long history of low back pain. Her original problem started when she was 48 and employed as a carer; she leaned over to place a plug into a socket and was overcome by a severe back pain. This pain resulted in her being off work for a number of weeks, and was initially treated with surgery. However Annie was unable to return to work which caused her great despondency and frustration, and at this time she became a housewife.

Annie suffered with back pain on and off over the subsequent years and was told by her GP that she had arthritis. In 2001, fourteen years after the surgery, Annie developed more

severe back pain and pain in her leg. Another visit to the GP confirmed her own belief that the pain was sciatica, but Annie was only offered pain killers and felt that she needed to try to sort the problem out for herself. Over the next two years Annie regularly attended a chiropractor and an acupuncturist. The pain had a great impact on her lifestyle, preventing her from looking after her grandchildren and going away on family holidays. She could not garden or take part in dancing that she had previously enjoyed. Annie revisited the GP on many occasions and referrals to orthopaedic surgeons and the pain clinic were arranged. Ultimately a referral to a neurosurgeon was scheduled which resulted in a new diagnosis and the possibility of surgery. This was the stage that Annie was at during the interview, and she felt that finally she could be hopeful of a positive outcome, specifically complete pain relief.

During the interview Annie maintained a cheery disposition and suggested that you just have to get on with your life whatever comes your way. However Annie's life was compromised by her back pain, as she attempted to lead her normal day to day life and just hoped that the pain would not get in the way. Inevitably it did which frustrated her very much. Annie suggested that she would put up with what she had to, but was still searching for a cure.

### *Robert*

Robert was a 36 year old man who was unemployed and received sickness benefit due to his back problem. Robert was born with a congenital deformity of his legs, and as a

young boy had corrective surgery and was required to wear a brace for many years. As a young man he went to work in an engineering job, but was unable to sustain this due to the onset of back pain which steadily worsened. It was agreed by Robert and his GP to go back to his original orthopaedic surgeon as Robert thought his pain could be related to his previous problems. The surgeon did not think this was the case and offered a course of physiotherapy. Robert requested a second opinion and was diagnosed with a spinal problem which resulted in three operations over the period of two years. The resulting pain was considered by Robert to be worse than initially, and persisted over the subsequent years. Ten years after the surgery, Robert was finally referred to a pain clinic.

Robert had very firm beliefs about the causes of his pain and the management offered to him, and suggested that he would not have had the surgery if he had been given the information that he now knew. His life had been severely disrupted by back pain, such that he had not been working since his surgery other than a few weeks as a carpet fitter, which he could not tolerate because of his pain. Robert rarely socialized with his friends, he described being very moody and could not tolerate a social group. He had a dog because it made him leave the house, otherwise he watched TV all day. His marriage was close to failing because of his coping style and impact of the pain, but Robert believed that he had turned the corner after hitting rock bottom and could now see a future. He was determined to work again and felt that he could begin to incorporate his life around the pain.

*Laura*

Laura had a problem with back pain though her original presenting problem was gynaecological in nature. She had suffered low back pain since 1995 and underwent gynaecological surgery in 2000, which resulted in her pain worsening. Laura was a 40 year old married woman with two children.

Laura had been referred to a gynaecologist who referred her on to a colorectal surgeon after the surgery did not resolve her pain. She attended her GP regularly, and had also seen physiotherapists, a psychologist and been referred to two pain clinics. Laura frequently asked her GP if she had been written off, and in her own words 'fights her corner' in the pursuit of finding a cure.

Laura's life had been very disrupted by pain. Her relationship with her husband had been affected, and this was complicated by him working away from home. Laura was solely responsible for childcare during the week, but did manage to work for a charity three days a week. This was a recent occupation and something she thoroughly enjoyed. Although the week's activities exacerbated her pain and tiredness she would not give up her job, but instead spent a day a week in bed. Laura described her life as a series of losses and found it difficult to come to terms with not being able to play with her children. She was resigned to having pain, but continued to search for a cure.

*Fred*

Fred was a jolly 58 year old man with a great sense of humour, though he did have a serious side. He sustained a back injury whilst at work as a carer, a patient attacked him and threw him backwards. He continued working for three days despite extreme pain because he knew he had a holiday thereafter and expected to recover during this time. Unfortunately he did not recover and his condition deteriorated, which resulted in him being retired on health grounds.

Fred was referred by his GP to a rheumatologist and diagnosed with a degenerative arthritic condition, and was told at this point that it would only get worse and he could not work again. Other than frequent visits to his GP for analgesics, Fred has seen only a physiotherapist.

Fred felt very angry and resentful of what happened to him, and felt that as a relatively young man he had lost all of his former life. He was able to laugh and joke, but it was tinged with great sadness and frustration. Fred outlined all the things he could never do at his time of life, but added all the things he now felt unable to do. He had to limit his involvement with his grandchildren and sorely missed the physical games they enjoyed. Fred rarely planned any visits, but occasionally he and his wife would spontaneously visit family or friends. Fred had a dog which he suggested was a life saver in that without him he would rarely go out, because his previous hobbies of cycling and walking had to be curtailed. Even quieter pursuits of reading and collating his memoirs were restricted by his back pain. Fred was resigned to having pain but would never accept it.



*Jane*

Jane had a traumatic accident aged 17 when she was thrown off a horse and sustained a spinal fracture. She initially had surgery, and following that was able to go to university where she led a very sporty and active life. Unfortunately the pain recurred and she required further surgery three times over the next ten years. Although she had constant pain it improved following the final surgery. Jane had been told that more surgery would be needed in the years to come as her spine degenerated.

Initially Jane lived as if she had never had a spinal problem. At university she played many sports and joined the officer training corps with the expectation of joining the army on graduation from university. After the second operation she couldn't join the army, and instead went to work in a stable. This job had to be curtailed because her medication interrupted her working day too much. Jane then went to work in high powered banking job and also joined the TA. Again her lifestyle was hectic and in tandem her back pain was worsening but she would not give in to it, and chose to keep her problems to herself. Eventually the pain was so severe that she went on to have further surgery, followed by a move closer to her parents home and a change of job.

Jane continued to work, and stressed that she always went to work even if the pain was severe. Her lifestyle was more sedate and she accommodated her needs by pacing and thus achieved a broad range of activities. Jane was looking forward to getting married in the near future and starting a family, though she expected her pain to worsen it did not

frighten or upset her anymore. Jane had accepted the pain and could see a positive future as a person with pain.

### *Susan*

Susan was a 37 year old single mother, who had a long history of neck and back pain. Aged 19 she developed neck pain whilst working as a children's rep for a holiday company. This resolved, but she then developed back pain two years later and had to give up her job. She subsequently went to work in a library. After the birth of her daughter she had been left with constant low back pain, and again had to give up her job in a library. She was unemployed due to health reasons.

Susan was initially referred to a rheumatologist because her mother had rheumatoid arthritis, and Susan was exhibiting similar problems at a young age. She was told that she was in a low risk group for developing rheumatoid arthritis. Susan had also seen an orthopaedic surgeon, and more recently been referred to a psychologist and a pain clinic. Susan had spent many years going to a chiropractor, and engaged in many alternative therapies.

Susan was very angry at having pain and felt that her life was constantly compromised by it. She could not shop alone but relied on the help of her elderly father, who also looked after her eight year old daughter one night a week so that she could rest. Susan was antagonized by her brothers because she felt that they did not understand her problems and demanded of her to act 'normally'. She compared herself to her mother and struggled

to get others to see how similar they were. Susan was an active member of church and took on voluntary work there; she also ran a Brownie group. Both activities left her exhausted and she felt frustrated that any spare time was dependant on what the pain would allow her to do. Susan stated that she spent a lot of time explaining to her daughter why she could not always play. Susan constantly battled with her pain and although she expressed that the pain would never go, she could not accept it.

### *Jack*

Jack was a 35 year old man, married with one son. He sustained his back pain following an accident at work. He worked in a factory and a heavy piece of equipment caused him to fall and take the weight. He was immediately taken to hospital but discharged a few hours later with no apparent injury. He had a brief course of physiotherapy with no benefit and was allowed to return to work. Further visits to his GP resulted in a referral to a neurosurgeon and subsequently to a pain clinic. Another accident at work left him with worsening pain.

Jack talked extensively about his job and place of work. He had been compensated for his injuries but was required to leave that employer and had recently started work at a new firm. Jack was very positive about this new job and the personnel, and how his pain was accommodated. However he was clearly very angry and resentful of his time and treatment at the previous employer. All lines of questioning would return to this issue.

Jack was unable to play with his son and could not engage in any physical activities. He had to stop fishing and walking, and hardly ever socialized with his friends. He refused to go out regularly and drink orange juice whilst his friends drank beer. Jack felt saddened that he could not be good father, and was aware that at times he could be moody and would keep away from his family at these times. Jack believed he had a very understanding wife who knew more about his condition than he did. Jack knew that he would have pain forever, but was beginning to come to terms with that.

### *Linda*

Linda was a 37 year old woman who had a long history of back pain. Linda worked with children with special needs and her pain started whilst at work doing an activity expected of her. Despite initially consulting her GP and attending physiotherapy her pain was getting progressively worse, and Linda visited an osteopath with no success. The osteopath gave her a very specific diagnosis. Unfortunately Linda was forced to give up her job because the physical demands were too great and her absences were substantial. She took a job in administration because she could not secure another job in childcare.

Linda attended her GP regularly; she was referred to an orthopaedic surgeon who gave her a conflicting diagnosis and did not recommend surgery. Finally she was referred to a pain clinic. The alternative diagnoses caused her frustration because it called her to question her treatment and choices that she had made based on the initial diagnosis.

Linda lived alone, and led a quiet life severely compromised by her back pain. She rarely socialized with friends and if she did would always take the car so she could leave at her discretion. Linda freely admitted that she was poor at maintaining contact with people, because she could not commit to anything. Linda devoted a lot of her time to her nephew but stated that she would like to be able to play more with him. Her family was close but she had a tough relationship with her mother at times, who thought she should just learn to get on with life and stop giving in to the pain. However her stepfather also suffered from back pain and they seemed to have formed an alliance to support each other. Linda acknowledged that her pain was not going to go away but would only accept that fact if there was some improvement.

### *Clare*

Clare was a forty year old single woman, involved in a long term relationship. She had no children. Clare was involved in a car accident where her car was shunted between two other vehicles, and claimed that she was not responsible for the accident. She was taken to hospital but shortly discharged with advice on neck care. Clare continued to have neck pain which resulted in a referral to a neurosurgeon and surgery.

Clare continued to have neck pain, though she felt she could manage that pain. Her ongoing problem for which she had received little attention from the health care professionals was low back pain. Clare felt that each time she mentioned back pain it was dismissed as inconsequential to her neck pain, though she stated that she never

complained of neck pain. It was the back pain that disrupted her life and caused her to stop working.

Clare described herself as the life and soul of the party, and the one to organize regular social events. Clare had two jobs, and was constantly busy with work, family and friends, until the pain took hold. Clare had to stop working, and now rarely socialized with family or friends. She had a big family and occasionally went out with them, but she knew that they hardly asked now because she usually said no. Her friends would take her out but she resented not being able to drink and frequently asked to go home early.

Clare was unable to do any activity for most of the week, mostly lying on the sofa watching TV, she could not concentrate to read. On good days she would go shopping with her mother and sister, which was a former passion of hers. If Clare did go out she would always get her hair done, as she could not imagine anyone knowing that she could not manage to appear normal. She constantly compared herself to others, and despaired at ever leading a normal life again. She would like to get a voluntary job where she could come and go depending on the pain. Clare could see no end to the pain, and stated that she was going to have to accept it.

### *My Biography*

At the beginning of the research I had been a registered nurse for twelve years. I had worked in a regional neurosciences centre for ten years within a variety of roles, which had culminated in a research post. This post had given me experience of clinical trials,

but more importantly had allowed me the opportunity to pursue a master's degree in research methods. After completion of this qualification I changed role, leaving neurosciences to join an acute pain service. I have been in this post during the entire study.

My clinical role featured daily management of trauma and surgical pain, though a substantial element was focused on patients who had been admitted for investigations into ongoing low back pain. These patients were frequently regarded as having acute problems, though in fact the majority would have had low back pain for many months, possibly even years. It was this group of patients that fascinated me, and spurred me into asking what it must be like to live with back pain, and what does their journey look like. I developed a research proposal, which was accepted and undertook the research on a part time basis whilst continuing to work within a large teaching hospital.

Personally, I have limited experience of pain, though do have family members who suffer chronic joint pain and hence I have an awareness of the potential effects to the person and to the family. However, by working within a pain service I have the experience and practical knowledge of an expert practitioner. I am aware of the literature base, clinical evidence and guidelines that surround the management of low back pain.

I am married and have two young children and as my extended family live away juggle home and work life. I enjoy the sporting and other social activities of my children, and

together as a family enjoy walking and cinema trips. Reading, quizzes and meals out with friends are regular features of my life.



## **Appendix 6**

### **Interview Guide**

Tell me about your pain?

When did it start?

What does the pain mean to you?

What is it like having chronic pain?

What are your expectations?

Is everyday the same?

How does the pain make you feel?

How do others see you / treat you?

Does the pain change over time?

What is a typical day like?

What is important to you?

What is a good day?

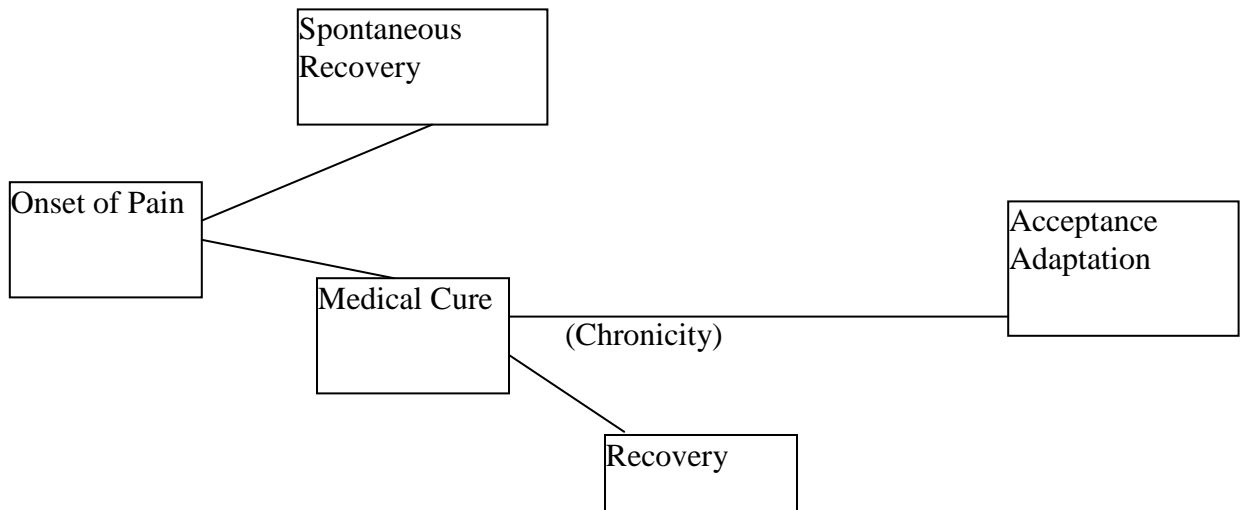
What is a bad day?

What does the future hold?

(Added after initial interviews)

## Appendix 7

Typical Timeline for Back Pain.



## Appendix 8

### Data Collection & Analysis - an iterative approach

