

# **LIVING WITH CHRONIC PAIN – A QUALITATIVE STUDY**

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by

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## **Living with Chronic Pain - A Qualitative Study**

**Sue M Peacock**

### **Abstract**

Pain is both a medical problem and also an everyday experience for chronic pain patients. Attending to the biomedical aspects is important, but the emphasis on this can result in a failure to consider how the patients perceive and live with their chronic pain. The management of sensation over understanding emotion in traditional medical and psychological approaches has resulted in the lack of attention to the lived experience of chronic pain therefore neglecting broader issues of how culture and social factors influence pain. The UK is becoming more culturally diverse therefore there is a growing necessity to understand any influences of culture and ethnicity in pain management.

The aims of this study were to address what is the patient's experience of living with chronic pain followed by an appraisal of how or if ethnicity (White British or South Asian) influences the experience of living with chronic pain. The empirical work undertaken comprised of qualitative analysis of thirty-seven semi-structured interviews with patients attending a pain clinic in a culturally diverse city. The qualitative methodology used was Grounded Theory therefore a review of the literature was conducted after the initial empirical work. The literature itself was subjected to qualitative analysis and a narrative review was produced. The final element involved generating a synthesis of the narrative review and a theoretical model was produced from the empirical work. Important constructs of living with chronic pain were identified as affect, participants' expectations of the consultation, the reality of living with chronic pain and legitimization of chronic pain, and relationships between them were discussed.

This thesis explored patients' narratives with a view to uncovering differences between the pain experience for different demographic groups (e.g. age, gender and ethnicity). However, the data suggest that there are more similarities than differences between groups; this may be partly explained by acculturation. Research into newly arrived ethnic groups in the UK might reveal more differences in their perception of health, illness and pain.

## **Chapter 1: Introduction**

The focus of my research in this thesis is the daily experience of living with chronic pain for those attending pain clinics. These occurrences are our experiences of the everyday world, which are taken for granted, making them less available through our awareness. In the anthropological and sociological literature, this is often termed the “lived experience”. This seems an unusual phrase in that, to experience pain you must be living with the experience, and due to the nature of chronic pain being a lifelong condition, you do not cure chronic pain as such but you might be able to manage it more effectively; so to use the term “lived experience” suggests a past experience. Hence, this is the reason for me adopting the phrase living with chronic pain throughout this thesis.

In attempting to understand the daily experience of living with chronic pain I have drawn on the notion of embodiment. Embodiment is a form of experiencing and understanding the world through the body in lived experiences. The embodied experience takes place within the contextual world that each person is born into and lives. Culture, society, history and personal relationships shape the world through shared understandings, making the world a social and inter-subjective experience. Whilst we each have our own unique subjective experience what one person experiences in the world may be similar enough to another person because all of us open into the same world and therefore our experiences may be similar. Perception of others may be patterned to some extent by factors including race, gender and may be filtered by cultural understandings, meanings and general orientation. If meanings of concepts (including pain) are socially constructed (Berger and Luckman, 1967) and shared, this allows us to communicate how our otherwise subjective and private experience connects with, and overlaps with that experienced by others.

The aim of this thesis is to explore the participants' experiences of living with chronic pain by taking an in-depth qualitative approach to see how this can develop our understanding of how this impacts upon their quality of life. Although the clinical implications will be discussed, the focus of the empirical work is on getting close to and explicating the participants' experiences of living with chronic pain rather than defining the utility of any clinical interventions.

In the United Kingdom, musculoskeletal pain, including chronic pain is a frequently reported health problem, and makes up a large proportion of disability (Allison, Rogers, Symmons, Brammah, Urwin and Lowcock, 2000).

Chronic pain defies a simple description and yet I would suggest there is such a social and cultural consensus about it that if you say you have it, almost everyone you meet would know what you meant to a certain degree, despite people using the word 'chronic' in different ways. Chronic pain is typified by its idiosyncrasy, variability and a weak correlation between the pain sensation, distress, disability and any objective measures of tissue damage, this is discussed further in chapter two.

The social and economic costs to a person with chronic pain are immense, in terms of the total cost of medical investigations, loss of employment, the fact society has lost a member of the workforce, possible financial ruin of the family, financial dependence of the family upon the State and the high emotional costs of the person with pain and their families. The emphasis in the literature has been on the cost of medical interventions and the days lost from work due to chronic pain, in particular back pain. Linton (1998) reports:

*“the socio-economic impact (of chronic back pain) for the individual is often neglected....The problem then is very prevalent and has a great direct and indirect impact on society, the health care system, and above all the individual and her/ his family” (Linton, 1998 p163)*

The majority of patients in the United Kingdom presenting with chronic pain are cared for in general practice, with some requiring specialist services (Ehrlich, 2003). These specialist services are referred to as pain clinics, which provide treatments and services for patients with chronic pain. Once referred to pain clinics, patients often wait many weeks for treatments (Walker, Holloway and Sofaer, 1999). Within medicine pain is viewed as a perception as opposed to a sensation. A sensation is a direct reflection of an environmental stimulus, as opposed to perception, which begins with a stimulus, but is subject to many internal influences, some psychological, some physiological before it becomes conscious. Hence, chronic pain is deeply personal but is also universal and exists as a multidimensional phenomenon that has social, cultural, physical and historical elements. Therefore we need to understand what is happening to those living with chronic pain to gain insight into how people subjectively experience pain.

From social learning theory, it is known that attitudes and behaviours are learned, therefore are culturally influenced. Before pain can be fully understood, the health beliefs of the patient, about their pain should be investigated. These beliefs may be socially and culturally patterned. Beliefs have been defined as assumptions about reality which serve as a perceptual lens, or a 'set' through which events are interpreted, therefore shaping the patient's understanding of their environment (Lazarus and Folkman, 1984). Chronic pain patients may hold a number of beliefs about their condition, and these beliefs can impact on their adjustment to their pain in many ways. Zbrowski (1952) stated that a cultural group's expectations and acceptance of pain as a normal part of life will determine whether it is seen as a clinical problem that requires a clinical solution.

In a review of anthropological, sociological and psychological literatures, Landrine and Klonoff (1992) concluded that models of health psychology have largely neglected culture, which may account for some of the negative results from the studies. For example, it is suggested that the relatively poor

predictive value of the multi-dimensional health locus of control scale and the attributional style of questionnaire may be due to the dimensions of the health schema that it assesses. The questionnaire does not permit distinctions between health beliefs that family, witches, gods or doctors control one's health, and yet these different attributions may well predict differences in health-related behaviour and treatment outcomes (Landrine and Klonoff 1992).

Cultural diversity is becoming more visible, with an increase in the range of different cultures in the United Kingdom, and clinicians are increasingly required to meet the needs of the different cultures. Hence there is a growing interest and need to understand the influence of race and ethnicity. Cultural diversity is already evident in Leicester where this research was conducted. At the last census, 25.7% of the residents of the city of Leicester described themselves as Asian Indian or Asian British Indian (Census April 2001) making this the largest Indian population of any local authority area in England and Wales. Leicester has a lower percentage of ethnically White British people, and growing populations of other minority ethnic groups than the rest of the United Kingdom. The South Asian population has been established in Leicester for a number of generations now, and those born and educated in the United Kingdom may have undergone acculturation and so may be different culturally from more recent immigrants.

Ethnicity is a cultural term implying a group of people with a shared distinctive culture and common language, representing a shared national identity (Njobvu, Hunt, Pope, Macfarlane, 1999), although it could be argued as to whether shared identity need be national identity. In this context, classification by race is insufficient for research into pain (Turk, 1996). Reflecting the visibility of cultural diversity has led to various government white papers on Ethnicity and Health, and Inequalities in Health. The government has recognised that ethnicity appears to be a factor contributing to inequalities in health and has set government policy to address these. However along with most government health policies, chronic pain does not feature specifically in them. This is problematic, as from my personal experience of working in pain

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clinics ethnic minority patients appear to be under represented in pain clinics, however there is little published data on this, which leads to the question 'Why?' Cultural influences and inequality in treatment will be discussed in chapter two, and some practical solutions offered to address this issue in chapter nine.

Some studies have been conducted around the topic of ethnicity and pain. These studies have investigated a wide range of painful conditions that have indicated ethnic differences in the prevalence and severity of the pain, but have focussed particularly on African Americans, as can be seen in chapter two. Pain research may reveal more about the ethnocentricity of the researcher than the researched, resulting in a tendency to view one's own culture as the standard against which others are judged (Bond and Bond, 1986). The research compares and contrasts pain tolerance, pain thresholds, and utilisation of services of the 'White' (usually northern European or north American) population with other ethnic groups. The fact that the studies are 'White' versus 'Other' may influence study design, aims, method of investigation and the presentation and interpretation of results, making 'value free' observation unlikely. However scant attention has been paid to the lived experience of musculoskeletal pain amongst ethnic minorities (Njobvu, et al, 1999) which could amongst other things lead to categories of pain developed for one group of patients being uncritically applied to another group of patients (Rogers and Allison, 2004).

Focusing on living with chronic pain is an appropriate perspective for this research to take because there is little data on the subjective experience of chronic pain particularly when considering different ethnic groups. The research in this thesis looks at the 'White British' and 'South Asian' pain clinic population in The University Hospitals of Leicester Trust. It is appreciated that 'White British' and 'South Asian' are very loaded terms and are problematic research categories; this will be discussed in chapter four. Neither category is a homogenous group and will include sub-categories such as gender,

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religions, social class, educational background and occupation. This empirical investigation aims to see whether being 'White British' or 'South Asian' is actually important in determining the experience of chronic pain.

This research is timely as the Government is increasing its efforts for patients to be involved within the NHS as 'expert patients' and to take some responsibility for their own health care. The NHS Improvement Plan: Putting people at the heart of public services (2004), it states

*"The NHS should put the patient at the centre of everything it does. To embed and sustain this approach within the NHS requires not just a change in attitude among staff but also a new approach to mechanisms for patient and public involvement".*

In order for all health professionals within pain services to do this effectively, we require a much more thorough understanding of our patient groups and their beliefs and experiences of living with chronic pain. Pain beliefs are important in terms of their relationship to subsequent behaviour, including for example pain expression, consultation rates, sickness absence: consideration of these beliefs help us move towards patient centred services. To provide culturally appropriate management of the chronic pain patient in the future, clinicians and researchers need to understand that ethnic identity is dynamic and might vary due to the effects of acculturation; assessment of pain beliefs is required rather than assumptions made on the perceived ethnic identity of the patient.

Our modern understanding of pain has moved from a simple biomedical one, now viewing pain as a complex, biological, psychological, and social and existential phenomenon. According to Bendelow (2000), pain lies at the intersection of biology and culture, and for this reason, emotional, psychological, socio-political, existential and spiritual aspects of pain must be taken into account. This awareness of the multi-factorial nature of pain allows pain to be conceptualised as a lived, existential and cultural experience. How patients with chronic pain live with and understand their specific life-world

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situation requires investigating in order to more fully understand pain, and to meet the health and pain management needs of diverse populations.

The thesis presents three pieces of research, firstly my own research as the primary source of data, a qualitative study of the perspectives of people living with chronic pain. This study used semi-structured interviews to obtain a detailed description of their daily lives and the impact chronic pain has upon it, along with the meanings and representations associated with chronic pain for them. It will address what is the patients' experience of living with chronic pain followed by an appraisal of how or if ethnicity influences the experience of living with chronic pain.

Secondly, a fundamental aspect of Grounded Theory is to collect the research participants' accounts and analyse them first, in order to minimise any influence of prior literature on the researcher in how they conduct the analysis. Therefore the literature review was conducted after the research study. The qualitative literature on living with chronic pain was used as a secondary data source and reviewed and analysed and a narrative review synthesis produced.

The results from my own study are compared and contrasted with the results from the narrative review and a final set of categories synthesised to produce a proposed model of living with chronic pain. The results from these three pieces of work can inform the developing academic theories of pain, and can be applied to the development of culturally sensitive practice of pain management.

In pursuing this agenda, I adopted the Grounded Theory approach using the method of constant comparison for data analysis (Strauss and Corbin, 1998), partly as it provides a clear framework for data analysis, also Grounded Theory has been used successfully in health psychology and lastly because it not only identifies categories grounded in the participants' own accounts but

also focuses on theory development but also attempts to capture the process of living with chronic pain, This rationale is developed more fully in chapter three.

In my professional interactions with chronic pain patients, it is apparent that many health professionals, and patients expect, pain to be treated within the biomedical model focussing on its neuro-physiological aspects in diagnosis, research and treatment despite the pre-eminence of the bio-psychosocial model. It appears that the overriding conceptualisation of pain in the pain clinic focuses on sensation, with the inference that it can be objectively measured. The biomedical model refers to an exclusively “tissue or pathology based interpretation of the patient’s problem where there is an assumed linear relationship between tissue dysfunction and the loss of function” (Watson, 2000). Hence scientific medicine reduces the experience of pain to an elaborate broadcasting system of signals rather than seeing it as moulded and shaped by both the individual and their particular socio-cultural context (Bendelow and Williams, 1995).

One of the major criticisms in using the biomedical model is that it focuses on “the resolution of the dysfunction with the expectation that function will be restored and disability resolved” (Watson, 2000) rather than investigating how pain beliefs are shaped by social interaction, how emotions, perceptions of pain and social characteristics come about for that individual. Chronic pain often creates a broad array of long-term psychosocial problems and impaired interrelationships, which cannot be addressed by the biomedical model, plus by definition, chronic pain is not “resolved”.

Although pain is seen as a medical ‘problem’, pain is also an everyday experience. Whilst the medical voice is a valid one, this research addresses the voices of the chronic pain patients in the pain clinic, which are often lost in “*the neglected encounter between pain and meaning*” (Morris, 1991:p2). In order to practise within the Government’s framework, it is vital that we

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investigate new ways to understand and engage our patients in their own pain management. Only by listening to the voices of such patients can we begin to comprehend the scope of their chronic pain. An assessment of individual pain beliefs is required, rather than assumptions based on the perceived ethnic identity of the patient, only then we can begin to develop culturally appropriate pain services.

To signpost this thesis, chapter two 'The challenge of pain: a psychosocial perspective' sets the scene for this research. It discusses the challenge of pain, giving a historical overview of the development of theories and definitions of pain. It goes on to explain the differences between chronic and acute pain and the challenges this poses to the researcher, the clinician and the person with pain. The chapter then considers some of the psychosocial and cultural factors that influence chronic pain.

In chapter three 'Developing the method' the background to the qualitative approach, is provided and contrasted with the mainstream quantitative method. It is not the intention of this chapter to dismiss the value of quantitative research, which has already revealed much about chronic pain, but to develop the argument for the value and importance of using qualitative methods that offer an alternative perspective on the subject. Qualitative research methods are typified by a wide variety of methods that can be employed and some examples are described. Grounded Theory in particular is shown as an approach that can complement and relate well to the chronic pain literature.

Within chapter four, 'the method', the aims of the study are more fully explained and the application of the method of Grounded Theory is described here in as much detail as possible. In accordance with good practice in qualitative research a reflexive account is provided.

Chapter five offers the research findings. The participants' accounts revealed the complexity and variety of their chronic pain experiences. Following data analysis of these accounts, a theory is proposed. This theory is illustrated by being broken down into its individual units to highlight the key issues of the participants.

Chapter six discusses the synthesis and appraisal of qualitative research, culminating in the production of an empirical piece of research by synthesising and appraising the data from the literature on living with chronic pain, resulting in a narrative review.

In Chapter seven, I position my research within the literature critiqued in chapter six. This chapter compares and contrasts my own research findings with the current available literature and culminates in the production of a theory of living with chronic pain. This chapter concludes by highlighting gaps in the literature.

Chapter eight reviews and discusses the important themes within this thesis in relation to the literature, the strengths and weakness of this thesis, and offers suggestion for future research.

Practical implications arising from this study and the literature are reported in chapter nine; it will also discuss the unique role the psychologist has in pain management, and also how my own clinical work has evolved as a result of this study. The chapter provides conclusions resulting from this study, with references and appendices in subsequent chapters ten and eleven.

## **Summary**

This introductory chapter has outlined the focus of this thesis as being the daily experience of living with chronic pain, drawing on the notion of embodiment. This thesis aims to address what is the patients' experience of living with chronic pain followed by an appraisal of how or if ethnicity (White British or South Asian) influences the experience of living with chronic pain. Chronic pain is discussed with relation to the biomedical model, which is very briefly critiqued; and in relation to both economic and social costs. The roles of pain beliefs are briefly touched upon and it is suggested they may be influenced by culture. This leads to a short dialogue on cultural diversity in the United Kingdom, and more specifically in Leicester. Much research exploring ethnicity has been found to be of limited value and possible explanations are provided as to why this may be. This chapter argues for the voices of the chronic pain patient to be heard, thus suggesting that qualitative research methods are appropriate and may help provide responses to Government documentation. This introductory chapter concludes by signposting the other chapters that make up this thesis.

## **Chapter 2: The challenge of pain: a psychosocial perspective**

### **Introduction**

This chapter provides some background to my research, briefly discussing the challenge of pain, giving a historical overview of the development of theories and definitions of pain. It goes on to explain the differences between chronic and acute pain and the challenges this poses to the researcher, the clinician and the person with pain. The chapter then considers some psychosocial and cultural factors that influence chronic pain, and due to the changing demographic makeup of residents in the United Kingdom concludes with a discussion on the literature relating South Asian chronic pain patients.

Pain is a universal phenomenon, but also one which is subjective and private. Pain cannot be measured directly but is inferred and interpreted from the observable behaviours, self reported cognitions and affect of the person with pain. Largely pain is associated with disease processes or tissue damage. This signals the presence of damage and/or the threat of injury that triggers a range of escape or protective behaviours and affect, which subsides as the related damage heals. However, this is not always the case; in some instances pain persists after the peripheral healing process is complete or emerges in the absence of any disease process and ceases to function as a warning of an ongoing biomedical problem.

Pain presents a challenge to the biomedical model, as it does not fully conform to a model that treats it purely as an alarm mechanism. For example, pain can result from causalgia, neuralgia and phantom limb pain that can either persist for months or years after the original tissue damaged is healed or are triggered by non-aversive stimuli (i.e. that which does not cause any tissue damage). In the case of phantom limb pain, the person experiences pain in a part of the body that no longer exists. This supports the case for the importance of higher cortical processes related to pain. In 60% of cases of

low back pain there is no recognisable organic pathology (Melzack and Wall, 1988).

A challenge to pain researchers and clinicians is how to understand something so universal, so ubiquitous and yet so personal, individual and its changeable nature, yet is so difficult to describe or access. Despite the extensive list of English words that could be used as pain descriptors, those who experience chronic pain often struggle to find the words that they feel would do justice to describe their pain and its impact on their lives. It has been found that these descriptive words serve no useful or stable diagnostic function (Melzack and Torgerson, 1971).

The unpredictability of how pain is experienced provides yet another challenge to those involved in research and/or clinical work. This is highlighted in Beecher's (1956) classic study, which showed that despite having extensive tissue damage soldiers wounded in battle required less pain relief than their civilian counterparts with similar organic pathology as a result of surgery. Beecher's observations show the importance of the context and meaning of the pain as mediating factors in how pain was experienced. The psychological factors can at times be more pivotal than the biomedical variables involved. Briefly, the experience of pain symbolised a very different future to the two groups, one positive for the soldiers as they were relieved not to be dead and looked forward to returning home; and negative for the civilians as they did not feel relief or welcome their convalescence in the same way. Each group appeared to appraise their pain within a markedly different historical and social context.

### **Historical overview of the development of pain theories**

Since historical records began, pain has been recognised and written about. During the times of Aristotle, the relationship between the body and the mind

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was fundamental in medicine. Pain was considered to be discrete from the five senses and was classified as a 'passion', related to the soul (Rey, 1993). Technical and philosophical developments during the Renaissance overhauled these holistic ideas, and the mechanical approach of modern medicine emerged. This adhered to a more Cartesian and dualistic division between the mind and the body. Pain was seen as purely a response to a stimulus, and was considered to serve as a warning signal of actual or potential damage to the body. Pain was considered to be a phenomenon exclusive to the body, and it was thought that a direct and unmediated pathway ran directly from the source of damage to the brain (Rey, 1993).

Increased physiological sophistication during the nineteenth century led to the development of theories such as Von Frey's Specificity Theory, and later other theories such as Pattern Theories (Goldscheider, 1920). They both suggested that pain was a result of specific nerve impulses that culminated in a cortical event and were perceived as sensations of pain. This indicated that pain as a phenomenon involved several stages and processes of transduction, nociception and perception; it discriminated between the peripheral and the central nervous system but could not explain the presence of pain that was not caused as a direct result of injury or disease; or denied the presence of such pain and implied a psychiatric condition such as somatoform disorder.

Somatoform disorders cover a wide variety of disorders in which physical symptoms suggesting physical conditions cause significant distress or impairment, but are not fully medically explained, in that there is no evidence of a physical condition. Examples of somatoform disorders are conversion disorder and hypochondriasis. Somatisation disorders are characterised by multiple symptoms, starting before the age of 30 years and continuing for many years. Symptoms include a combination of pain, gastrointestinal, sexual and pseudoneurological complaints. This is different from 'psychological factors affecting medical condition' in which there is no diagnosable general

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medical condition to account for the physical symptoms (Main and Parker, 2000). These criteria for diagnosis are classified in the DSM-IV (First, Spitzer, Gibbon Williams, 1997)

As research developed, pain was summarised as a phenomenon that consisted of a stimulus indicating tissue damage, a sensation of hurt and a collection of behaviours designed to defend the person from further harm. This introduced the concept of pain being multidimensional in that integral to the pain experience were protective behaviours and affective components. It also established pain as a subjective, private and personal experience (Sternberg 1968). However it still could not account for the presence of chronic pain or phantom pain where peripheral damage was not present and for when disease or injury did not produce pain.

The Gate Control Theory of pain (Melzack and Wall, 1965a, 1965b) is probably the most significant development in the understanding of pain during the last century. This theory remains the most popular for our understanding of the various aspects of pain. The phenomenon of pain was seen as consisting of several components that were separate in space, time and intensity and had an essential aversive cognitive and emotional component that led to behaviour designed to escape or avoid the stimulus.

It was proposed that the action system responsible for the pain experience involved a 'gating mechanism' based in the spinal cord which, when open would transmit signals to the brain that would be perceived and interpreted as pain. When the integrating firing level of the dorsal horn T cells in the spinal cord reached or exceeded a critical threshold, the gate would be triggered to open. This threshold is mediated by the dynamic relationship between the descending central inhibitory control processes from the brain, large afferent myelinated fibres (transmitting innocuous sensory information) and small afferent nociceptive afferent fibres.

The Gate Control Theory suggested that the experience of pain is not mediated by one particular disease process or peripheral injury but partly to whether the pain gate is open or closed. It explained how certain information could be 'gated out' and the experience of pain blocked or how the gate could remain open such that the pain became chronic or magnified. This theory in particular emphasised how psychological variables could influence the experience of pain, via the descending inhibitory control pathway from the cortex. The descending efferent fibres influence afferent conduction at the earliest synaptic levels of the pain system, and suggested that it was possible for attention, anxiety, depression, anticipation and memory to exert some control either consciously or unconsciously over the contemporary experience of pain.

The concept of a 'central control trigger' based in the dorsal column projection system of the spinal cord mediated the activity of the pain gate was proposed by Melzack and Wall. This trigger defined the degree to which the gate was open and the message transmitted to a higher cortical level. In this process, signals from the body are identified and evaluated in terms of prior and contemporary experience, localised and if necessary inhibited or enhanced before the action system responsible for pain perception and response was activated.

Evidence suggests that if the gating system is subject to a particular and persistent level of nociceptive input, then the central control trigger can become sensitised or 'wound up' and activate the pain gate on a permanent basis creating chronic pain (Jessop 1993; Davies and Lodge 1987). Consequently persistent pain could occur that was resistant to medical treatment, existing in the absence of any peripheral tissue damage and changing over time independent of the disease process. The challenge is to understand which psychological factors maintain the pain system in this hypersensitive state and influence it. Recent experimental studies with fibromyalgia patients have shown that psychological variables such as stress

appear to influence the maintenance and potentially the development of chronic pain, (Thieme, Spies, Sinha, Turk and Flor, 2005).

The relationship between the pain gate and the higher cortical areas has been examined and the neuro-matrix theory of pain developed (Melzack, 1990, 1999). The theory suggested that, at a higher cortical level to the pain gate, pain was produced by a characteristic 'neuro-signature' pattern of nerve impulses that were generated by a widely distributed neural network, called the 'body-self neuro-matrix' in the brain. The particular pattern of pain that was experienced at any one time was produced, mediated and maintained by the output of a widely distributed neural network in the brain that related to the pain gate. This development reinforced the importance and relevance of psychosocial factors in the experience of pain and highlighted the sophistication and fluidity of the pain system.

### **What is chronic pain?**

The Gate Control Theory as the central theory of the pain system, appeared to be a useful way to better understand and define pain, the International Association for the Study of Pain (I.A.S.P., 1986) formally stated that:

*"Pain is an unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage." (p. s217)*

This definition of pain although still defined in relation to organic pathology, it does recognise the psychological dimensions of pain, its individual variability, but also recognises that it can occur in the absence of any ongoing peripheral tissue damage.

The I.A.S.P (1986) also made an important distinction and stated that:

*“Activity induced in the nociceptor and nociceptive pathways by a noxious stimulus is not pain, which is always a psychological state, even though we may well appreciate that pain most often has a proximate cause.” (p. s217)*

This allowed pain to be conceived as a psychological experience, not just a physiological event and represented a challenge to psychological research to help develop the understanding of pain more fully. Nowhere is this more necessary than in chronic pain, where organic pathology is notable for its absence and a medical cure is unavailable. Chronic pain is sometimes described as ‘medically resistant pain’ as it persists despite the best attention and therapies of the medical profession who have readily admitted that complete pain relief is not always possible:

*“the medical profession has had to come to the unpalatable conclusion that its innate capacity for providing analgesia is severely flawed.” (Budd, 1993, p.63)*

Definitions of pain remain heavily debated, and are likely to evolve. For some the I.A.S.P definition is too reliant on self-report and description, so could not be applied to living organisms that were incapable of communicating in such a way (Anand and Craig, 1996). For others, the I.A.S.P definition is unclear in terms of whose point of view defined the association between pain sensation and tissue damage; this ambiguity meant it was possible to declare that if an observer could not determine this relationship then the experience was not pain (Price, 1999). Therefore an alternative definition was proposed that retained the primacy of pain as a psychological experience but did not require the inclusion of the observer to determine the presence of any actual or potential tissue damage. Pain was defined as:

*“A somatic perception containing (1) a bodily sensation with qualities like those reported during tissue-damaging stimulation, (2) an experienced threat associated with this sensation, and (3) a feeling of unpleasantness or other negative emotion based on this experienced threat” (Price, 1999, p1)*

Other current definitions and models encompass the wide variety of pain phenomena and acknowledge it as a multidimensional phenomenon that involves processes of mediation, perception and appraisal that take it beyond a simple biological stimulus-response mechanism.

Chronic pain has been defined as any pain that has persisted for longer than 6 months (I.A.S.P., 1986). This is the period of time after which it is considered that all relevant peripheral tissue damage should have healed. Chronic pain refers to any pain that is not related to an ongoing disease process but is the result of the ‘wind up’ and sensitisation of the central nervous system structures related to the pain system. There is debate around the progression of chronic pain; the view that it can be related to a precipitating injury or disease but most often simply emerges over time for no acute reason, is contested, as chronic pain is not a linear progression and usually develops from recurrent pain, which eventually becomes persistent.

Different definitions exist regarding acute pain. Acute pain is often pain, which is associated with the duration of the healing process, and anything beyond this is chronic. Alternatively acute pain refers to any pain that has been experienced for less than 3 months, or 6 months (sub-acute). In acute pain the presentation and pattern of the pain often indicates the underlying organic cause in the form of an injury or disease. (IASP, 1986)

Despite such a contrast in acute and chronic pain, to the person with pain the sensation feels the same and compels them to respond in the same manner, to protect and escape from pain. It will appear to the person with pain as the

seamless persistence of their acute pain as there would have been no distinguishable discontinuity between the acute and chronic phase. This can result in confusion for patients when they hear of the distinction. If pain becomes resistant to a medical cure, it will not have responded in the manner they expected from acute pain in that rest and other protective or avoidance behaviours will not have provided pain relief. This primitive urge to seek relief and protection does not succeed and can become a constant source of frustration.

Chronic pain is a complex phenomenon. There is considerable individual variability according to its context and the meanings it holds for the person with pain (Hanson and Gerber, 1990; Holzman and Turk, 1986; Turk and Flor, 1984). The pain is unpredictable over time and it switches in intensity and quality at any time to give the person with pain a range of experiences from 'good days' to 'bad days' (Charmaz, 1991).

Using chronic low back pain as an example, the challenge is to understand the relationship between pain sensation, distress and disability, which is neither linear nor causal but dynamic and multi-dimensional (Waddell, 1987). Chronic low back pain is not synonymous with psychological and physical dysfunction as many people with frequent pain continue to work and rarely seek healthcare assistance (Turner and Romano, 1984). Even though chronic pain can cause inactivity and disability, many people learn to function fairly normally (Doleys, Crocker and Patton, 1982). However a significant proportion of the chronic pain population report high levels of pain sensation, distress and disability (Hansen and Gerber, 1990). The biomedical model is inadequate to describe the interaction between these elements, and the difference in the experience of chronic pain, as Turk and Flor (1999) explained:

*“from the biomedical model it would be predicted that there would be a highly significant if not isomorphic relationship between objective pathology and disability, yet this is patently not the case” (p19).*

The dynamic nature of chronic pain has highlighted the importance of the personal psychosocial factors involved and they have been recognised to have a major mediating influence in the person’s ultimate experience of their pain sensation, distress and disability (Waddell, 1987; Melzack and Wall, 1988; Turk and Gatchell, 1999).

The struggle to treat chronic pain successfully and explain its presentation, coupled with the development of the Gate Control Theory and other mainstream psychological research led to the development of the bio-psychosocial model as an alternative to the traditional biomedical model (Turk, Meichenbaum and Genest, 1983). It proposed that for each individual there were predisposing, precipitating and maintaining biological and psychological factors that interacted to establish and maintain chronic pain and disability. It suggested a link between affect such as fear, distress and the somato-sensory cortex and established a link between pain experience and the physiological processing of pain (Turk and Rudy, 1988). The bio-psychosocial model (Waddell, 1987; Turk, Meichenbaum and Genest, 1983) incorporated psychological, social and cultural factors and encompassed both the complexity of chronic pain, and its ever-changing relationship with disability and distress. Importantly, it provided a tool for further exploring how the processes that influence the pain gate and the chronic pain experience might operate. The usefulness of the bio-psychosocial model in relation to chronic pain will be discussed in depth during chapter eight.

## **Psychological factors**

Responding to the demands of chronic pain causes additional difficulties such as fatigue, immobility, disability, sleep problems, social isolation. Also problems within family relationships can emerge and relationships with healthcare professionals can deteriorate as the person with pain continues to seek a cure, but often receives failed medical treatments that compound their situation (Hanson and Gerber, 1990; Gatchell and Turk, 1996, 1999; Main and Spanswick, 2000).

Emotional problems are related to chronic pain as the person with pain struggles to manage their situation (Jensen, Turner, Romano and Karoly, 1991; Robinson and Riley, 1999). Emotional distress can be associated with high levels of pain-related fear and disability (McCracken and Gross, 1993), more social and interpersonal anxieties (Asmundson, Jacobsen, Allerdings and Norton, 1996), anger (Turk and Rudy, 1995) and frustration (Wade, Price, Hamer, Schwartz and Hart, 1990). Depression has strongly been associated with chronic pain and has been related to decreased pain tolerance and self-criticism (Romano and Turner 1985; Haythornwaite, Sieber and Kerns 1991; Pincus and Morley, 2001). The research suggests that although chronic pain can cause depression, depression is not a causal factor or precipitant for chronic pain (Skevington, 1995). Reviewed research indicates that 40-50% of chronic pain patients have clinical levels of depression. From a clinical perspective, it is considered that to accommodate to loss and coping with depression is a major task presented to the person in chronic pain (Hansen and Gerber, 1990).

It has been argued that the fear of pain is more disabling than the pain itself (Vlaeyen and Linton, 2000). Melzack's theory on the neuro-matrix suggested a close relationship with, and sensitivity to prolonged stress (such as fear) indicating that high levels of arousal are considered to be detrimental to functioning and general health (Melzack, 1990, 1999). This relationship



caused the related homeostatic mechanisms to dysfunction, which led to heightened pain experiences, hyper-arousal and the eventual breakdown of muscle, bone and neural tissue.

Research has provided a good understanding of the importance of the fear of movement and the fear of (re)injury in chronic low back pain (Asmundson, Norton and Vlaeyen, 2004; Verbunt, Seelen and Vlaeyen, 2004). Clinical experience shows that patients report multiple fears, which are often difficult to verbalise such as the fear of altered identity and diminished self-respect (Morley and Eccleston, 2004). In social and clinical psychology there is a long history of identity as a concept, but not so in the field of pain management.

Patients may report a range of fears, a common fear expressed to those working in pain management is the fear of the future, what will they be like in the future? Davies (2003) investigated pain patients' future possible selves asking firstly, what they hoped they would be like, and secondly, what they feared they would be like in the future. Five categories were generated in relation to what they feared they would be like in the future. 1) They feared that their pain would continue, become worse or spread to different areas of the body. 2) They feared becoming more restricted or limited and showing signs of disability such as having to use a wheelchair. 3) They feared ill health of any kind, and many fears in this category were pain related. 4). Despite a free NHS, chronic pain does have a financial impact on their lives, often due to job loss. 5) They were fearful in relation to social and relationship roles such as their position in the family, being a burden, being unable to fulfil expected roles.

Asmundson, Norton, and Norton, (1999) noted studies reporting increased fear and avoidance in chronic pain patients are not just related to physical activity and work related disability, but also provide evidence of enhanced avoidance of social activities and health related issues, such as seeking treatment for other conditions. This raises the question of whether the

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reduction of physical activity is associated with chronic pain, by reducing access to social opportunities; does it cause fear and avoidance to increase as a default, or are social fear and avoidance are attributable to some other aspects of the chronic pain experience (Morley and Eccleston, 2004)

Anger is a common emotion experienced by those with chronic pain (Fernandez and Turk, 1995; Okifuji, Turk and Curran 1999; Fernandez, 2002), and is associated with increased pain intensity, depression and other pain behaviours. The denial of anger, and self-blame is considered destructive and will increase pain and distress (Fernandez and Turk, 1995). There are many reasons for the person in pain to be angry and frustrated in response to the personal and social implications of their pain situation, the pain sensation itself is not the only source.

Chronic pain has been shown to disable cognitive functioning, resulting in difficulties with concentration, attention, short-term memory, problem solving tasks and other cognitive tasks (Kewman, Vaishampayan, Zald and Han, 1991; Smith, O'Keefe and Christensen, 1994; Schnurr and McDonald, 1995). People with chronic pain struggle to understand their pain, the reason for its presence, its unpredictability and this confusion can compound the distress and cognitive problems that arise (Williams and Thorn, 1989; Morley and Wilkinson, 1995; Eccleston, Crombez, Aldrich and Stannard, 1997).

The evidence appears to show that affective distress is an important factor in the experience of chronic pain and that it can operate within it in a wide range of ways, although precise causal or maintenance mechanisms are not well understood. Longitudinal studies indicate that affective distress is more likely to result from chronic pain than cause it (Radanov, Begre, Sturzenegger and Augustiny, 1996).

Mainstream social-cognition psychological theories of chronic pain focus on either the contribution of dysfunctional beliefs and the behaviours associated with them, or the coping or adaptation responses to chronic pain. Most research in chronic pain is applied and directed at either how to modify particular maladaptive behaviours or beliefs, or towards determining the active contribution of a particular phenomenon with the aim of achieving better therapeutic interventions and outcomes.

From various theories such as social learning theory (Bandura, 1986), it is known that attitudes and behaviours are learned, therefore are culturally influenced. Before pain can be fully understood, the health beliefs of the patient about their pain need to be investigated fully. Patient's beliefs about their health can have a profound effect on clinical care, or on how care is received, or how effective clinical care is (Flores, 2000).

Beliefs have been defined as assumptions about reality which serve as a perceptual lens, or a 'set' through which events are interpreted, therefore shaping the patient's understanding of their environment (Lazarus and Folkman, 1984). Chronic pain patients may hold a number of beliefs about their condition, and these beliefs will impact on their adjustment to their pain in many ways. Beliefs about the meaning and significance of pain, the context in which the pain occurs and the emotions associated with it can affect pain sensation as previously discussed earlier in this chapter, for example with reference to Beecher's (1956) study.

Patients' beliefs about the cause of their pain may influence treatment compliance and the likely outcome of that particular treatment (Schwartz, DeGood, and Shutty et al, 1995). Beliefs about their ability to control the pain will influence coping strategies. The greater the sense of personal control the patient has, it is expected that this will be associated with the greater use of coping strategies (Bandura, 1986); Patients who believe they have greater control over their pain may be more likely to participate in rehabilitation

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programmes (Jensen et al, 1987, 2000; Harkapaa et al, 1991). It has also been found that a reduction in disability was predicted by improvement in pain control (Woby, Watson, Roach, Urmston, 2004). Those patients who believe their pain remains unchanged are often associated with poor compliance to both physical and psychological treatments (Williams and Thorn, 1989).

### **Socio-cultural influences on pain**

Before considering socio-cultural factors, it is important to consider culture briefly because often this is where our health and pain beliefs originate. There are many different definitions of culture:

*Culture is that complex whole which includes knowledge, beliefs, art, morals, law, custom and any other capabilities and habits acquired by man as a member of society (Taylor, 1871)*

Characteristics of culture include that it is shared, it is learned, it is an adaptation, and it is a dynamic system, which is constantly changing. It is made of both macro-cultures and micro-cultures. In the United Kingdom, macro-culture is described as the universal culture with Western European roots, especially White Anglo-Saxon Protestants, however today it is not limited to this particular group, but is heavily influenced by social class. Examples of macro-culture are status based on occupation, education and wealth, particular work ethics, and values achievement over inheritance. Micro-cultures are sub-societies or sub-cultures, which exist within the context of larger societies sharing the same values, political and social institutions, but which may not be common to the macro-culture. Examples would include ethnicity, social class, gender, religion, language, age and different groups within a work place.

There are a wide range of socio-cultural influences on pain, including gender, age, ethnicity, religion, interactions with friends and family, economic / work, personal meanings of pain, difficulty in expressing pain, changing circumstances, interaction with health professionals, social isolation, limitations and restrictions that may or may not be imposed by pain, uncertainty, historical reasons and the media.

### Culture

Using back pain as an example of how socio-cultural factors influence pain and disability, Waddell and Waddell (2000) reviewed more than 6000 medical and scientific abstracts. They identified 470 studies relating to socio-cultural influences on back pain and disability. Back pain was chosen because it is not a disease, it has no single pathology, its prevalence has not changed considerably, but disability, work loss and consultation patterns have increased in most countries within the past twenty five years. These studies provide extensive evidence that the following socio-cultures influences are important, although the strength and magnitude of the effect varies.

With regard to culture, Waddell and Waddell (2000) concluded that neck and back pain are common to all societies, but different cultural groups do not seem to perceive or respond to pain in the same way. Attitudes and beliefs about the pain, expectations and meanings attached to the pain seem to vary in different societies and over time. Culture may be associated with how people express their pain and emotions, pain behaviour and whether and how they communicate their pain to others including health professionals. It may be associated with how they seek treatment or how they respond to treatment. Unfortunately despite the importance of cultural influences on pain, there is little evidence on which cultural issues are most important, how they operate or how they can be modified.

### Cultural beliefs

Culture influences attitudes and health beliefs. Specific cultural beliefs and practices in South Asia that can impact on health and health care are very diverse (Nichter, 1981; Ramakrishna and Weiss, 1992). Superstitious beliefs such as the belief in the evil eye (Najar or Drishti) are common, as are rituals to ward off perceived dangers (Ahmed and Lemkau, 2000). The illness beliefs of Southeast Asian refugees are inextricably linked with beliefs about life, harmony and energy suggesting that Western medicine, with its focus on organic causes of illness, is often deemed inappropriate by these refugees (Uba, 1992). Therefore it is suggested that their health care providers need to learn how to frame explanations in a way that is compatible with their beliefs. The South Asian culture is rich and complex, encompassing a number of languages and religions. However, as South Asians originate from the Indian subcontinent, they share many cultural practices surrounding food, dress, ceremonies and cultural norms (Johnson, Cross and Cardew, 1983). Within the South Asian culture are a number of widely held beliefs relating to health and illness. In recent years attempts have been made to outline the central components to these beliefs including the role of bodily balance and the supernatural in illness (Assanand et al, 1990; Rajwani, 1996)

### Social factors

Socio-economic inequalities in health and life expectancy have been found in many contemporary and past societies (Whitehead, 1997). While individual lifestyle decisions will have an important effect there are many other factors that lie outside of the individual's control but that can still directly influence their health, such as: poverty, social exclusion, employment, housing, education, and the environment.

Inequalities in health exist, whether measured in terms of mortality, life expectancy or health status; whether categorised by socio-economic measures or by ethnic group or gender. Although in general disadvantage is associated with worse health, the patterns of inequalities vary by place,

gender, age, year of birth and other factors, and differ according to which measure of health is used (Illsley and Baker, 1997).

At face value it would appear that in Britain ethnic minority groups as a whole have poorer health than whites. However, relatively poor health is not distributed evenly throughout ethnic minorities; overall Chinese, Indian and African Asian report their health to be similar to Whites and better than some ethnic minority groups. Caribbean, Pakistani and Bangladeshi groups were the ethnic minorities that reported poorer health than whites (Nazroo, 1997). Therefore it is suggested that members of ethnic groups cannot be considered as uniformly disadvantaged. Consequently investigations of the health of ethnic minority people need to consider carefully which ethnic group is being studied, and that the factors affecting health disadvantage may be different across the ethnic minority groups.

A number of factors may play an important role in determining ethnic variations in health. Such factors may include the way the data has been collected; they are a result of biological/genetic differences in risk; health related selection into a migrant group or the consequences of migration itself; or they are a result of the relationship between socio-economic status and both health and ethnicity (Nazroo, 1997). Therefore, it could be suggested that the influence that a person's socio-economic status has on pain and its treatment should be studied further, and separated from the race and ethnicity of the patient to better understand the causes of disparities in pain treatment.

### Gender and ethnicity

There is considerable debate about the relationships between biological, genetic and social factors for the health of men and women and members of ethnic minority groups (Cooper et al, 2002). Unequal social relations characterised by discrimination, exclusion and exploitation are thought to have profound consequences for the economic and social wellbeing of

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gender and ethnic minorities groups, that may be expressed as inequalities in health (Krieger, 2000). Minority women in particular may be exposed to adverse health consequences associated with 'multiple discrimination' on grounds of both ethnicity and gender (Cooper et al, 2002).

### Social class and ethnicity

Waddell and Waddell (2000) found in their literature review there is conflicting evidence for a relationship between the prevalence of back pain and lower social class, and any association is probably weak. They report strong and constant evidence that back pain is associated with more work loss in people in lower social classes. This relationship is most constant in men. The problem with these findings is, understanding what does social class mean? Social class is a very crude index, which deals with a host of social, educational, occupational, economic, lifestyle and psychosocial influences and corresponding attitudes and behaviours, any of which may bear a relationship to work loss associated with back pain. It is suggested that there is a relationship with back pain for men particularly as they are often engaged in manual work. It is probably also related to social disadvantage in both men and women, as those from lower social classes are more likely to be employed in manual work, although it is not exactly clear which aspects of disadvantage are important or how they affect back pain.

In a separate unpublished meta-analysis, Waddell and Waddell (2000) also reviewed 69 studies on job satisfaction and psychosocial aspects of work in relation to neck and back pain. They report that there are some theories, but limited evidence that psychosocial aspects of work affect the physical condition of the back or actually cause neck or back pain. About half the studies show that individual psychosocial aspects of work particularly low job satisfaction, high intensity and demand and low social support at work are associated with how people report neck and back pain in questionnaires. Monotonous work, low job control and low job clarity show generally non-significant or very weak associations. They conclude that there is little



evidence to support any theoretical model of demand – control interactions for low back pain. These psychosocial aspects of work may be better explained by conceptualising them as psychosocial influences rather than causal risk factors.

The most commonly quoted literature is about worker's compensation, and there is limited and conflicting evidence on litigation. Most studies are carried out on a selected clinical series, e.g. those with neck pain only, and often from highly selective referral situations, e.g. those referred to Occupational Health Departments and therefore it can be difficult to generalise from the results. There is considerable legal evidence that litigation may influence reports of increased symptoms and disability and the clinical presentation when in a medico-legal context (Waddell and Waddell, 2000). However in the clinical situation litigation does not appear to be associated with any significant increase in the severity of the pain or distress. There is insufficient evidence to assess whether, or to what extent litigation may be associated with any difference in clinical outcomes, disability or return to work (Waddell and Waddell, 2000)

#### Family support

Ethnic minority communities live not only within their social structures, but also the structures of the wider society. Some normative values may be difficult to fulfil because of their minority status within the UK. This range of issues requires an assessment of impairment and disability among ethnic minority people both in the contexts of their cultures and their minority status. It is generally well recognised that health and well-being are a function of multiple inter-related factors, including social factors and lifestyle behaviours, which are influenced by our social networks.

Within Asian families, the following characteristics are applicable to families from the Indian subcontinent, these include strong ties to the extended family, patriarchal family structure, and a sense of family pride or shame to mould

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behaviour (Sue, 1998). Often family needs are given higher priority over the individual needs. South Asian women are expected to assume domestic responsibilities, bear children, tend to the sick, and defer to the authority of men (Seagal, 1999). In rearing children, South Asian parents tend to rely on the inculcation of shame and guilt, reminding children of family obligations and the importance of bringing credit to their families. Educational and occupational success is a source of great pride for the whole family. Conversely, mental health or drug problems are sources of great shame on the family. The relationship between carer and pain patient is especially complex when dealing with people from ethnic minority groups. For ethnic minority people in pain or with a disability, their own families and communities provide vital buffers against a racist society (Ahmed, 2000). Therefore, perhaps there is a greater tendency for the stigma of impairment to be shared among family members within the often more communally orientated South Asian communities. Having a disabled family member, may, for example, affect the marriage chances of siblings or the social standing of the family in the community (Ahmed, 2000). These ingrained values affect a patient's recognition of health problems and receptiveness to recommended treatments (Ahmed and Lemkau, 2000).

Studies have shown that migrant women suffer from poorer health and long standing illness. The immigrant woman has to deal with the chronic disease and also with marginality, lack of social support, social isolation and alienation in a foreign culture (Anderson et al, 1993) It is also suggested that the lowered self-efficacy inhibits their capacity to receive information (Bandura, 1986), which might result in variations in the perceived susceptibility and severity of diseases. This may decrease the motivation to take an active part in self-care, because the person does not understand the benefits of the change according to the health belief model (Rosenstock, Stretcher and Becker, 1988) or to their health beliefs.

Stress at both home and at work, a low standard of living, unemployment, being a victim of crime, absence of a confidante and difficulty speaking English are factors that have been shown to be associated with psychological distress in South Asians (Creed, Winterbottom, Tomenson et al, 1999). In this study, psychological distress was measured using the Self-Rating Questionnaire with a cut off score of  $\geq 8$  to indicate possible psychiatric distress. The questionnaire also includes a question from the General Health Questionnaire regarding thoughts of ending one's own life. Recent life stress was measured using the brief list of threatening life events (Brugha, Bebbington and Der, 1985). Also, studies have identified different social or language groups of South Asians will show different levels of psychological distress, with Muslim and Hindus reporting a higher prevalence of anxiety/depressive disorders and suicidal ideas compared with Sikhs (Creed, Winterbottom, Tomenson et al, 1999). Another comparable study found higher levels of distress and psychosomatic symptoms among Muslims compared to Sikhs and Hindus (Williams, Eley, Hunt and Bhatt, 1997).

Much of the research investigated by Waddell and Waddell's (2000) review on the family as a socio-cultural influence was found to be methodologically weak, and many of the results were inconclusive. Most of the available evidence was related to chronic pain in general rather than low back pain. Despite these limitations, evidence suggests that family influences may be associated with treatment outcome, and the development of chronic pain and disability. For most routine patients with back pain, good family and social support may be associated with better recovery and less disability. But for a small number of chronic pain patients a history of physical or sexual abuse, or spouse related reinforcement might be associated with more chronic pain and disability (Waddell and Waddell, 2000). Despite the potential importance of family issues, there is little evidence on exactly which family influences are most important, how they operate or how they can be modified (Waddell and Waddell, 2000).

## Religion

In the Indian subcontinent, religions are diverse. Hindus dominate in India, and Muslim in both Bangladesh and Pakistan. In times of illness, people's religious beliefs and practices often become relevant to the medical encounter. Relevant practices are extensive and often specific to the religious subculture of a patient (Ahmed and Lemkau, 2000)

## Summary of socio-cultural factors

It can be concluded that there is extensive, although scientifically often poor quality evidence, that socio-cultural factors may influence the reporting of pain, pain behaviour, and disability. There is suggestive evidence that some of these interactions may be potentially powerful and at least in some situations may be more important than any physical abnormalities.

## **Ethnicity and pain**

As this thesis investigates living with chronic pain from the viewpoint of White British and English speaking South Asians, a brief discussion of the literature follows, highlighting the lack of research on pain in the South Asian community. Implications for practice both from my own research and from the literature are presented in chapter nine.

Increasing ethnic diversity means clinicians are regularly required to meet the needs of people from different cultures and offer culturally relevant health care. Hence there is a growing necessity to understand the influence of race and ethnicity in pain management. Cross-cultural differences are evident in many aspects of human behaviour and in the prevalence of illness and in healthcare usage. Cultural factors influence beliefs, behaviour, perceptions and emotions, all of which have important implications on the perception of pain. Culture influences illness behaviour in a number of ways including defining what is regarded as 'normal' and 'abnormal', determining the cause

of illness, influencing the decision-making control in healthcare settings, and impacting on health seeking behaviour.

Chronic pain affects approximately 1 in 5 adults in Europe resulting in substantial healthcare costs (Fricker, 2003). Evidence that cultural influences have an impact on pain is readily available from the UK where pain is the most common symptom encountered by the medical profession. This can be seen in the number of incapacity benefits claimed for back pain, which increased dramatically in the UK between 1979 and 1996, despite no change in the incidence of the conditions that cause back pain. This trend has reversed in recent years, leading commentators to conclude the changes were most likely a cultural phenomenon. Hocking (1996) explains this by suggesting that people cope with sub-clinical symptoms and only consult if the social environment changes and the “symptoms” become viewed as malign.

### Definitions

The terms ‘race,’ ‘ethnicity,’ and ‘culture’ are often used interchangeably, however they all represent very different concepts. Controversy exists over whether ‘race’ is a biologically valid idea, or whether it is a social concept, which serves a social purpose. Race is described as a construct, which distinguishes groups of people according to their ancestry (Edwards, Fillingim, Keefe, 2001). Furthermore, distinguishing groups of people according to behaviour, culture, biological and physical characteristics are termed “ethnicity.” Defining culture has not been straightforward; there are many definitions in the literature, including culture as “*a coherent set of values, concepts, beliefs, and rules that guide and rationalize people’s behavior in society*” (Hahn, 1995, p.66) or “*a set of learned behaviors, beliefs, attitudes and ideals that are characteristic of a particular society or population*” (Ember, Ember and Peregrine, 2002, p.217). A person’s culture determines how pain is perceived, experienced and communicated. A useful analogy of culture is described by Helman (2007) who refers to culture as an

inherited 'lens' through which the individual perceives and understands the world and as a result learns how to live within it. In previous research the two terms have been used interchangeably however, future research should focus on addressing "ethnic" rather than "racial" differences.

There are no fundamental differences in the neurological or physiological experience in the relationship between pain and ethnicity; rather it is shaped by experience, learning and culture (Zbrowski, 1952). The distinction between race and ethnicity is particularly important for pain research based on the bio-psychosocial model. This model suggests the experience of pain is derived via and the interaction of biological, psychological and social factors.

Pain response is studied in two ways. Firstly, for example pain behaviour is examined following a type of operation in a hospital or clinic setting; or secondly in laboratories, by observing painful stimuli and the responses to these stimuli. Both types of study show that people from different ethnic minority groups have different levels of pain tolerance when compared to the European population. Clinical studies have shown differences between the ethnic minority groups in terms of pain tolerance and the amount of analgesics required (Strelzer and Wade, 1981; Houghton, Aun and Lau, 1992; Ng, Dimsdale, Shragg and Deutsch, 1996)

Analgesia consumption following upper abdominal surgery was compared between Asian and European patients living in Hong Kong (Houghton et al, 1992). Results showed that Asian patients required less post-operative analgesia than European patients, and identified these Asian patients had a higher pain tolerance than European patients. This result could be attributed to psychological and cultural factors, such as the expectation of pain following surgery, or that Asian patients being prepared to tolerate more pain, or that their perception of pain differed to that of European patients. Houghton et al (1992) hypothesised that the observed difference was associated with Asian patients being more sedated by the analgesia, therefore their requirements

for additional analgesia was reduced. Unfortunately this study just classified patients into the broad categories of Asian and European. It is important to remember that there are clear distinctions between North and South Europeans in the experience and reporting of pain as indeed there are between the Asian sub-groups.

#### Laboratory pain studies

Findings from laboratory studies have suggested there are ethnic differences in experimental pain but other research has questioned this (Edwards et al, 2001; Edwards, Doleys, Fillingim and Lowery, 2001). Sensitivity to experimental pain stimuli is demonstrated to be greater among African-Americans compared to non-Hispanic Caucasians (Sheffield, Biles, Orom, Maixner and Sheps, 2000). In a study focusing on ethnic variations in pain tolerance among South Asian males and White British males the results indicated South Asian males had significantly lower thermal pain thresholds and experienced higher pain intensity than White males. This was only true of thermal pain no differences were reported for cold pain threshold or heat unpleasantness (Watson, Latif, Rowbotham, 2005).

Similarly, ethnic differences have also been reported in studies of acute clinical pain including post operative pain, low back pain and exercise induced angina where African-American patients reported greater pain intensity than Caucasians. We must treat these results with caution as some studies have failed to report any ethnic differences in acute clinical pain. Moreover, other studies have found when matching ethnic groups on selected confounding variables such as education, pain duration and work status, the differences in pain related sequelae and emotional distress may be reduced (Edwards, Moric, Husfeld, Buvanendran and Ivankovich 2005; McCracken, Matthews, Tang and Cuba 2001).

A literature review on pain-induced studies (Zatzick and Dimsdale, 1990) found generally Europeans had a higher tolerance of pain and a higher pain

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threshold than Asians (Japanese, Chinese, Malaysian and Nepalese). The conclusion reached was that there was no consistent evidence that ethnic differences existed regarding pain response, due to the distinctive differences in the populations studied and the research methods used in the studies.

Before drawing any formal conclusions about these ethnic differences several issues should be considered. Firstly, the race/ethnicity of the experimenter is rarely documented or controlled. Some studies have suggested that the experimenter's gender has been found to influence results. It could be that similar effects occur in the context of ethnic characteristics. However, it may be perceived that experimental pain is seen as irrelevant. It could be that pain resulting from injury or surgery is perceived to be more personal and relevant. Other issues that require further consideration are how do individuals in the ethnic groups being studied describe pain? How will pain response both verbal and non verbal be assessed and how will these account for inter-group differences. What is the patient's expectation of the research and/ or the researcher, what does the patient understand about the research they are involved in and the more general idea of research? Evidently, there is a need for further research to investigate potential differences in the perception of pain and the tolerance of pain in South Asian people.

### Acculturation

To aid our understanding of cultural influences on pain the notion of acculturation should be explored. Acculturation has been defined as the extent to which an individual, who migrates from the country of birth, adopts the values, beliefs, cultures and lifestyles of the country they emigrate to. It is suggested that those who are more acculturated report similar levels of pain and illness to the country they have emigrated to, in particular, second and third generation immigrants are more likely to share the beliefs and behaviours of the host nation; however this remains poorly researched (Palmer, Macfarlane, Afzal, Esmail, Silman and Lunt, 2007). The variation in health between groups could partly be explained by the idea that newly



arrived immigrants tend to be situated in lower social economic groups and there is strong evidence of the link between low social economic status and poor health including the report of pain (Nazroo, 1997).

Acculturation has been perceived to have both positive and negative health effects. It has been suggested that the greater level of acculturation, the less likely that, environmental factors will explain differences in health outcomes between immigrants and individuals born in the host country (Deyo, Diehl, Hazuda and Stern, 1985).

Investigating the effect of acculturation on the development of disability or prevalence of psychological morbidity in musculoskeletal pain found that the likelihood of reporting chronic widespread pain is related to cultural factors. Chronic widespread pain, but not pain per se, is more commonly reported in South Asians in the United Kingdom, Bengali (14%) Indian (17%) and Pakistani groups (25%). However South Asians with a high acculturation score were less likely to report chronic widespread pain. Speaking a South Asian language and wearing non-Western clothing were both associated with an increased reporting of chronic widespread pain (Afzal, Finn, Lunt, Gupta, Esmail, Silman and Macfarlane, 2002).

#### Consultation rates

Pain in one form or another, is an inseparable part of everyday life. It is probably also the commonest symptom encountered in medical practice. In the United Kingdom, musculoskeletal pains are the most frequently self-reported health problems in the United Kingdom population, and make up a large proportion of long standing illness and disability (Allison et al, 2000).

Reviewing the literature reveals that that all ethnic minority groups report attending the GP more frequently than their white counterparts (Allison et al, 2000). Studies have found adult Asians attend general practice more often

than Europeans (Balarajan, Yuen and Soni-Rayleigh, 1989; Gillam, Jarman, White and Law, 1989); and that Asian men were more than twice as likely to consult their GP, irrespective of self-assessment of health or presence of illness or disability (Atri, Falshaw, Livingstone and Robson, 1996). It has been found that Punjabis present with 'pain' more often than other symptoms. Nazroo (1997) suggests that pain may be a special type of somatic disorder that requires more understanding in terms of culture. However these studies do not tell us the consultation patterns for the different Asian groups or indeed the different religious groups within the Asian community.

Comparing the number of GP consultations amongst different ethnic groups, found a higher rate of consultations for Pakistani men aged between 16-44 years, in comparison with European men. Higher rates were also found for Pakistani women aged 16-44 years relative to European women. However the Bangladeshi community consult their GP less for musculoskeletal symptoms than the White group (Allison et al, 2000), although how significant this is, is uncertain as no statistical evidence was provided. It is unclear from these findings whether they reflect a true difference in morbidity or differing perceptions of illness in Bangladeshis that leads to the greater use of health care services.

Health seeking behaviour has also been found to differ in children and young people of South Asian origin. This group is more likely to consult a GP compared with European children and children from other ethnic minority groups (Cooper, Smjaj and Arber, 1998). Once again homogeneity has been assumed in both the European and Asian groups of children, and issues may have been missed.

Studies looking at primary care consultations in general, show that South Asians consult their GP more frequently than Europeans (Murray and Williams, 1986; Brewin, 1980). These studies suggest that whether a GP refers or decides to manage the patients themselves, could be a factor in the

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uptake and use of the psychiatric and psychological services by South Asians. From this point of view, community and primary care based studies have frequently shown that ethnic minority groups from non-Western cultures tend to express psychological distress through summarisation or somatic metaphors more often than Britons (Williams and Hunt, 1997).

Despite the frequency of primary care consultations, the use of outpatient secondary and tertiary services has been noted to be significantly lower amongst Asians (Cooper-Patrick, 1999; Johnson et al, 1983). This could suggest that GPs manage the symptoms differently possibly depending upon their ethnic group, culture and their interpretation of the symptoms, alternatively their choice of treatment could be swayed by the ethnicity of the person consulting and their interpretation of the patients' cultural identity. Other possibilities could include that the patient prefers to be treated by the GP rather than at the hospital, the reasons for this are potentially vast ranging from feeling comfortable with the GP to problems accessing secondary and tertiary services. More research is required to establish reasons for attending the GP and to establish reasons for not attending secondary and tertiary care services.

#### Occurrence of musculoskeletal pain

The occurrence of musculoskeletal pain needs to be set in the context of the possible differences in health and health seeking behaviour within South Asians compared to Europeans.

Few studies focus on musculoskeletal disorders in ethnicity minority groups living in the United Kingdom (UK). In Greater Manchester, UK, the prevalence of musculoskeletal symptoms was assessed in the ethnic minority populations. The study found the profile of musculoskeletal pain amongst ethnic minority groups differed from the White population. Ethnic minority communities' musculoskeletal pains were in multiple sites and were more prevalent than in the white community. The highest reported rates of "pain in

most joints” were among Indian and Pakistani women, whilst the lowest were among white men and women. The study concluded that these results might reflect social, cultural and psychological differences (Allison, Symmons, Brammah, Haynes, Roers, Roxby and Urwin, 2002).

In Glasgow, UK, South Asians were compared to Europeans in terms of various health measures (Williams, Bhopal and Hunt, 1993). In the month prior to responding South Asian men reported significantly less musculoskeletal pain, with 14% experiencing symptoms compared to 31% in the general population. However, it was found that South Asian women reported slightly more (35%) than the general population (26%).

The results of the occurrence of chronic pain between Asians, different groups of Asians, and Europeans are contradictory. It is suggested that this could be a result of homogeneity, but could also be attributed to the use of different research tools, different numbers in each ethnic group, how the ethnic groups were defined, and different locations in the UK.

In South Asian countries, the prevalence of musculoskeletal symptoms are mainly unknown, therefore few comparisons can be made with the UK. The rates of rheumatic symptoms between urban and rural populations in Pakistan, found that musculoskeletal disorders are more common in urban areas (Farooqi and Gibson, 1998; Finnstam, Grimsby and Rashid, 1989). In the UK a study reported that South Asians were 3.25 times (95%CI, 1.58-6.68) more likely to report back pain with disability than whites and 5.35 times more likely to have neck pain with disability than whites after adjustment for age and gender (Webb, Brammah, Lunt, Urwin, Allison and Symmons, 2003)

#### Factors influencing the clinical situation

Pain beliefs are brought to the clinical situation by both clinician and patient and can have a profound effect on care. Mistaken beliefs about the nature of

pain and disability, resistance to treatment seeking, reluctance to comply with treatment and failure to accept responsibility of the treatment outcome are not culturally or sub-culturally specific obstacles to pain management (Main and Parker, 2000).

Pain is a private experience however pain behaviour is influenced by social, cultural and psychological factors. It is these factors that influence whether private pain is translated into pain behaviour, the form this behaviour takes, and the social setting it occurs in (Helman, 2007). Part of the decision about whether to translate private pain into public pain behaviour depends on the interpretation of the significance of pain, for example, is it seen as “normal” or “abnormal”, the latter most likely being brought to the attention of others.

Each culture and social group has its own unique language of pain and distress, its own complex expressions by which ill or unhappy people make other people aware of their suffering. There is a specific, often standardized way of signalling both verbally and non-verbally, that the person is in pain or discomfort. The form that this pain behaviour takes is largely culturally determined, as is the response to this behaviour (Helman, 2007). This depends on factors such as whether their culture values or disvalues the display of emotional, postural, mobility or verbal expression in response to pain or injury. Some cultural groups expect an extravagant display of emotion in the presence of pain, but others value stoicism, restraint and playing down the pain.

Zbrowski (1952) stated that a cultural group’s expectations and acceptance of pain as a normal part of life will determine whether it is seen as a clinical problem that requires a clinical solution. This is illustrated by observations of Australian aborigines. Despite one-third of men, and half of the women reporting back pain when asked, they did not perceive it to be a health problem and consequently did not report symptoms (unless asked), display pain behaviour or seek medical treatment (Honeyman and Jacobs, 1996). Another study in rural Nepal found back pain to be common and yet when

medical facilities were available virtually no-one sought help. In this instance, it appears that the symptoms of back pain were not perceived to be a medical issue rather part of the aging processes (Anderson, 1994).

Many ethnic minority groups, whilst identifying and incorporating certain elements of scientifically-based understandings of disease and illness into their lives, nevertheless also adhere to more traditional paradigms of health and illness, or associated health beliefs and behaviours sometimes known as folk medicine. Older women, who are often more steeply versed in traditional health beliefs than men and often act as the first line of medical advice within the family, may adopt a combination of scientific and folk traditions to attempt to address the illness. This multiple approach is not necessarily harmful, rather many folk treatments (which include specific ritual behaviour, and the use of teas and other folk remedies) may, from a strictly medical view play a neutral role in terms of biochemical activities but a highly positive role in terms of psychological well-being. Folk medicine allows individuals to address their social imbalances that are considered significant in causing a particular condition within the ethnic group tradition (Helman, 2007)

Research has shown lay advice is often used extensively before consulting with a doctor, and a wide range of self-care activities have been reported amongst ethnic minority groups. Self-care strategies differ across ethnic groups; South Asians use painkillers, and praying and staying off work more frequently than the African-Caribbean group (Allison et al, 2000). South Asians appeared not to discuss individual coping strategies, but the importance of role of the family in dealing with pain was expressed. This included the transfer of everyday and domestic duties to another member of the family (Rogers and Allison, 2004). The African-Caribbean group was twice as likely to cope by thinking about something else (Allison et al, 2000), and in a general sense, containment and individualised coping strategies were more evident (Rogers and Allison, 2004). Older respondents were more likely to make extensive use of home and lay remedies from their own country

of origin, and there is some evidence of this being passed on within families, (Allison et al, 2000; Rogers and Allison, 2004). Younger respondents made greater reference to the acculturated use of products such as Deep Heat (Rogers and Allison, 2004). It was noted that self-management was not generally a substitute for, but rather complementary to the use of health care services.

The literature reviewed by Bonham (2001) shows empirical data in the USA indicating disparities in pain treatment based on the patient's race or ethnic background. The key findings of this review were specifically that Black and Hispanic patients were more likely to be under-treated for their pain across *“different types of health care facilities and treatment settings; from the emergency room to the community hospital to the nursing home”* (Bonham, 2001,p60). It is suggested that these disparities in pain treatment are a result of stereotyped perceptions of race and ethnicity, language barriers, socio-economic status, doctor – patient communication and clinical assessment of pain.

Understanding the influence of race, ethnicity and sex in the clinical decision making process is important in understanding their effect on patient – doctor communications. Ethnic differences between doctors and patients are often barriers to partnership and effective communication. Cooper–Patrick (1999) theorised that a number of doctor – patient factors might account for these problems, including that the doctors may unintentionally incorporate bias, such as stereotypes, into their interpretations of the patient's symptoms, predictions of the patients patient's behaviours and medical decision making. Doctors may not understand a patient's expression of symptoms. Patients might also contribute less to participatory medical views because of language barriers, low health literacy, little education as well as the inability or failure to advocate for one's health (Cooper–Patrick, 1999).

Policy documents argue that people should be valued as individuals: their views and experiences should be obtained and addressed. Therefore there is concern that ethnic minority communities are at a disadvantage to the host nation regarding treatment for painful conditions. It is demonstrated that people from minority ethnic groups receive less provision of preventative health care, provision of medication and secondary referrals than host nationals. Multidisciplinary research is required which integrates basic clinical and health service research methodologies into practical interventions for ethnic and minority groups to overcome barriers to accessing pain management.



## **Summary**

This chapter has provided a background to the psychology of chronic pain. It initially discussed the challenge of pain, before moving onto the challenges faced trying to define pain, by researchers, clinicians and those with chronic pain. The differences between acute and chronic pain are explored and the subsequent historical theoretical development of pain is discussed. An examination of the role that psychosocial factors play within the Gate Control Theory in terms of the development and maintenance of chronic pain is presented. Psychological factors including affective distress and pain beliefs are reviewed, along with results of a large literature review investigating the role of socio-cultural influences on back pain. As this thesis investigates living with chronic pain from the viewpoint of White British and English speaking South Asians, a brief review of the salient literature on cultural influences on pain concluded this chapter.

## **Chapter 3: Developing the method.**

### **Introduction**

The aim of this chapter is to outline the rationale for taking a general qualitative approach, and for the selection of the particular methods used in this thesis. Initially as pain is essentially a phenomenological experience, I will outline the development of the intellectual approach to phenomenology and the historical background that lead to the development of qualitative psychology. In the rest of the chapter I will discuss the strengths and weaknesses of qualitative and quantitative approaches in relation to the research aims of this thesis. I will begin outlining the historical thinking in relation to qualitative psychology, followed with a discussion of the qualitative / quantitative debate, and go on to focus on strands of qualitative research that were considered for this research. I will conclude with the rationale for the methods selected for this study.

### **The Foundations of Qualitative Methods in Psychology**

Taking a simplified historical perspective, psychological research moved from a controlled laboratory experiments that centred on manipulating observable behaviours to studying the more private, personal and subjective phenomena. This shift arose from the interest in the activity of the mind of the individual being studied. Despite this development, the epistemological and ontological approaches remained the same – logical positivism and empiricism of the natural sciences (Leahey, 1987).

The qualitative approach did not emerge as a single or unified movement; and there is considerable debate and diversity within the field (Denzin and Lincoln, 1994), which makes it difficult to define concisely.

Qualitative research is an alternate approach which values experience and seeks a way to study its richness and complexity. In rejecting positivism, qualitative psychological research favoured attending to accounts that people formulate of their reality and is interested in idiographic accounts as well as what is happening in different groups and populations. Qualitative research adopts an approach that different perceptions of reality may be equally useful and 'valid' and it rejects the logical positivists' view of there being a single objective reality in favour of other epistemological positions such as social constructionism (Leahey, 1987)

### Phenomenology and Existentialism

The logical positivist approach is rejected by phenomenology because the assumptions and methodologies of the natural sciences ignore the participant has active involvement in the research process.

The most essential feature of the phenomenological perspective is that it is committed to attending to the individual's point of view and the meanings they attribute to their actions. Human behaviour is a product of how people interpret their world in their attempts to make sense of their own experiences and it is for the researcher to examine the process of that ongoing construction of meaning or sense-making (Giorgi, 1985). Phenomenologists view experience as a system of inter-related meanings – a Gestalt, which is wrapped in a totality, which is termed the 'life world' (Husserl, 1970). This concept of the 'life world' that it is an embodied, conscious related to a personal world was emphasised by Merleau-Ponty (1962) and Sartre (1958).

Explicit attention is paid to the conscious world in phenomenology. Via subjective experience phenomenology seeks to find out how consciousness imposes itself upon and obscures reality. Through the process of interpretation a distinction is made between subjective experience and what is termed objective reality. Phenomenology questions exactly what is 'real' to the individual and what it is that the individual acts on.

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Broadly speaking, phenomenology is based on the view that real objects exist in the world independent of our conscious knowledge or awareness, which can be accessed directly via our senses. Having translated information from our senses, it is then experienced as a 'phenomenon' in the form of its appearance to us as opposed to what it is in the external world – this is a key view in phenomenology.

In phenomenology, the definition of 'the object' comprises of both the individual and meaning systems employed in the interpretation and translation process and the 'something' itself. Interpretational processes are indivisible from reality in the phenomenological approach. For example to paraphrase Giorgi (1985;p28):

*"Let's assume that I walk into an office and perceive a chair to be sat upon. The physical chair just remains there and does not move, unless moved by somebody; it does not change and it presents itself to an adult consciousness of our socio-cultural world as a product made by humans, as a cultural object. An infant or pre-modern societies who do not use chairs may not perceive the chair as a cultural object".*

Phenomenologists' believe that a basic act is to experience the world in terms of objects and what sense is made of the world is derived by intentionally reaching out to these objects' actively. It is suggested that direct or conscious access to the real world is denied because interpretation lies at the centre of our mental experience.

The theory and processes outlined above gave rise to a broadly based phenomenological method. The method aimed to remove the interpretation added to the stimuli, to arrive at an accurate knowledge of 'the object' experienced.

Regardless of the 'object', it is argued that much could also be learnt about the nature, structure and processes involved in the construction of the interpretation. Philosophical phenomenology points in the direction to a particular way of undertaking qualitative psychology, by attending to personal meanings which a situation has for that person, which is non-positivist, in contrast to positivist (explained earlier in the chapter) and focuses on the 'life world'.

### Social Constructionism

Early schools of thought encouraged the view of the individual as a perceiver. However, later schools of thought develop the idea of the individual as a conceiver or constructor with research focussing on their construction of the 'life world' or how they make sense of it, rather than their perception of the 'life world'.

A new focus emerged with the social constructionist view; language and other cultural signs and symbols gain significant importance, as the means by which the individual constructed reality. The person was seen more as a member of society with ways of conceiving reality that are typical of that particular time in history or that culture, rather than an independent individual. In terms of research the psychologist was viewed as part of this web of cultural construction, therefore meant that research had to be seen as a joint product between researcher and participant, this has been termed 'reflexivity'.

There is not an absolute distinction between the perceptual and the constructionist outlook, as discussed in 'The Social Construction of Reality' (Berger and Luckman, 1967). Qualitative research may regard language as either something that reveals the lifeworld (perceptual tendencies) or as something to be investigated in its own right (constructionist tendencies) (Ashworth, 2003).

### Symbolic Interactionism

The work of G.H.Mead (1934) is significant in the constructionist orientation of qualitative psychology, particularly his work on symbolic interactionism. Symbolic interactionism has its roots in sociological approaches to the study of human behaviour, but shares many of the assumptions of phenomenology. It puts direct attention to the social context and has a more explicit concept of the 'self' (Denzin, 1995; Blumer, 1969).

In symbolic interactionism, individuals exist within a social world and have a social self that consists of the 'I' which is a complex mixture of biological instincts; and the 'Me' which are internalised social constraints. The self is considered to be an outcome of interaction between 'I' and 'Me'. This interaction involves continually processing interpretations between how we define the situation and how we believe we would be received.

Like phenomenology, symbolic interactionism considers that action is directed towards things based on their meanings and that meanings are developed via the interpretation process. It also believes these meanings are developed much more through social interaction processes.

During the processes of social interaction, individuals respond to others and grasp their meanings through various forms of communication e.g. language, facial gestures, body language. By interpreting and defining each other's languages and actions, people can choose from an infinite variety of social roles. It is suggested that members of society affect the development of a person's self by their expectations and influences. Initially, individuals model their roles on the important people in their lives, their 'significant others'. They learn to act accordingly to the expectation of others, thereby shaping their own behaviour. Eventually the individual is able to take on a number of social roles simultaneously and can organise the roles from society, group or community,

which is termed the 'generalised other'. Mead (1934) compares this to a team game, where the members of the team anticipate the behaviour of the other players and therefore can play their own role.

Symbolic interactionists explain how individuals attempt to fit their behaviours and actions to those of others (Blumer, 1969), take account of each other's acts, interpret them and reorganise their own behaviour. People share attitudes and responses to particular situations with members of their group. Therefore members of a culture or community analyse language, appearance and gestures of others in the same setting and act accordingly with their interpretations. On these perceptions they base their justifications for conduct, which can only be understood within that context.

As explained above, the aim of symbolic interactionism according to Blumer (1969) was to discover how the process of interaction sustained and directed ways in which the participants determined their actions. In common with phenomenology, it depicts a 'stimulus to act' as undergoing interpretation processes before a response is produced. The research focus is also process orientated and intends to be able to describe the interpretation process.

In summary symbolic interaction considers that our social world and the reality of our conscious experience is complex and multi-faceted. It focuses on subjective experience and feelings rather than objective fact. Its roots are in the school of sociology based on the works of James (1907), Dewey, (1927) and Mead (1934). Symbolic interaction assumes that we create a world of phenomena and experiences for ourselves, which reflect back as we continue to experience things. Self-reflection, social interaction and the basis upon which we behave within our personal and social worlds are the products of symbolic interaction. The key elements are communication and its relationship to culture and society, social relationships, self and identity. Consequently these have assumed a central role within the broad spectrum of qualitative approaches that it has influenced.

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**Summary of historical context**

Qualitative research places an emphasis on processes and meanings using description and interpretation rather than measurement and statistical analysis. Most qualitative research stresses the social construction of reality looking at context in an holistic way, and eschews positivist notions of one objective reality. It focuses on the internal, subjective experiences and their meanings, and accepts that multiple interpretations of a phenomenon are possible.

**Qualitative versus quantitative methodology: the debate**

A simplified view of the difference between qualitative and quantitative methodologies is that the quantitative paradigm is based on positivism; in contrast, the qualitative paradigm is based on interpretivism (Altheide and Johnson, 1994; Secker, Wimbrush, Watson and Milburn, 1995), and constructivism (Guba and Lincoln, 1994). Positivist science is characterised by empirical research: all phenomena can be reduced to empirical indicators that represent the truth. The ontological position of the quantitative paradigm is that there is only one truth, an objective reality exists independent of human perception. Whereas the ontological position of qualitative paradigm is that there are multiple realities or multiple truths based on the individual's construction of reality. Reality is socially constructed so is constantly changing (Berger and Luckman, 1967). Epistemologically from a quantitative paradigm, the researcher and participants are independent entities. Therefore, the researcher is capable of studying a phenomenon without influencing it or being influenced by it. In contrast, with regard to qualitative paradigm's epistemological position, there is no access to reality independent of our minds, no external reference to compare claims of truth (Smith, 1995). The researcher and the participants are interactively linked so that findings are mutually created within the context of the situation that shapes the inquiry (Guba and Lincoln, 1994; Denzin and Lincoln, 1994). Quantitative research measures and analyses causal relationships between variables within a value-



free framework (Denzin and Lincoln, 1994) attempting to determine how much of the entity there is, what its dimensions are and how the components relate to each other in a law like manner, as in the natural sciences. Techniques to ensure this include randomisation, blinding, highly structured protocols, and written or orally administered questionnaires with a limited range of predetermined responses. The importance of internal representation and schemata that influence our experiences are acknowledged by quantitative researchers but studied in a different way, usually within the context of a controlled experiment. The quantitative approach converts the phenomena being studied into a numerical value for analysis. Sample sizes are much larger than those used in qualitative research so that statistical methods to ensure that samples are representative (Carey, 1993).

In contrast, qualitative research emphasises processes and meaning seeking to find out and express the nature of the properties forming an entity; focusing on speech and language or behaviour and attempt to describe or interpret the personal meanings within it. In qualitative research people are seen to engage in the active process of making sense of their worlds, and it is presumed that we build up a representation of it and use it as a reference, which guides action.

The aim of qualitative research is to produce a rich detailed and textural description or interpretation of the phenomena rather than quantitative measurement of the relationship between hypothesised variables. The qualitative approaches relinquish the traditional psychological variables, seeing them as dynamic and fluid constructions that are found and buried within a social and biographical context, yet in qualitative analysis we seek to form categories, thus questioning, how different are qualitative and quantitative methods? Explicit attention is paid to the social context of the research study, where meanings and interpretations are privileged over measurement and statistical analysis. (Smith et al, 1995a; Yardley, 1997; Murray and Chamberlain, 1999). Techniques for collecting data used in

qualitative research include semi-structured interviews, focus groups and participant observation. Samples are not meant to be representative of large populations instead small, purposeful samples of participants are used because they can provide important information, even if they are not representative of a larger group (Reid, 1996).

The strengths and weakness of both quantitative and qualitative research have been frequently documented and debated (Richardson, 1996, Murray and Chamberlain, 1999; Silverman, 2000; Bryman, 2001) Therefore these discussions are summarised in table 1 Some of the key issues of qualitative and quantitative research are addressed later in this chapter.

**Table 1: Strengths and weaknesses of Quantitative and Qualitative Research**

	Quantitative	Qualitative
Strengths	<p>Testing and validating already constructed theories about how and why phenomena occur.</p> <p>Testing hypotheses that are constructed before data are collected. Can generalise research findings when data are based on random samples of sufficient size.</p> <p>Can generalise a research finding when it has been replicated on many different populations and subpopulations.</p> <p>Useful for obtaining data that allow quantitative predictions to be made.</p> <p>Researcher may construct a situation that eliminates the confounding influence of many variables, allowing one to more credibly assess cause and</p>	<p>The data are based on the participants' own categories of meaning.</p> <p>It is useful for studying a limited number of cases in depth.</p> <p>It is useful for describing complex phenomena.</p> <p>Provides individual case information.</p> <p>Can conduct cross-case comparisons and analysis.</p> <p>Provides understanding and description of participant's personal experiences of the phenomena (e.g. the insider's viewpoint).</p> <p>Can describe, in rich detail, phenomena as they are situated and embedded in local contexts.</p> <p>The researcher identifies contextual and setting factors as they relate to the phenomenon of interest.</p> <p>The researcher can study dynamic processes.</p> <p>The researcher can use the primarily qualitative method of Grounded Theory' to generate inductively a tentative but</p>

	<p>effect relationships.</p> <p>Data collection using some methods is relatively quick (e.g. questionnaires).</p> <p>Provides precise, quantitative, numerical data.</p> <p>Data analysis is relatively less time consuming (using statistical software)</p> <p>The research results are relatively independent of the researcher (e.g. effect size, statistical significance)</p> <p>It may have higher credibility with people in power (e.g. administrators, politicians, funding bodies)</p> <p>It is useful for studying large numbers of people</p>	<p>explanatory theory about a phenomenon.</p> <p>Can determine how participants interpret 'constructs'.</p> <p>Data are usually collected in naturalistic settings in qualitative research.</p> <p>Qualitative approaches are usually more responsive to local situations, conditions, and stakeholders' needs.</p> <p>Qualitative researchers are responsive to changes that occur during the conduct of a study and may shift the focus of their studies as a result.</p> <p>Qualitative data in the words and categories of the participants lend themselves to exploring how and why phenomena occur.</p> <p>One can use an important case to demonstrate vividly a phenomenon to readers of a report.</p> <p>Determine idiographic causation (e.g. determination of causes of a particular event).</p>
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	Quantitative	Qualitative
Weaknesses	<p>The researcher's categories and theories that are used may not reflect participant's understanding.</p> <p>The researcher may miss out on the phenomena occurring because of the focus on theory or hypothesis testing rather than on the theory or hypothesis generation.</p> <p>Seeks knowledge of patterns in populations. Such general trends may not be useful in clinical contexts with individuals who are not 'typical' of their population.</p>	<p>Knowledge produced may not be generalised to other people or other settings (e.g. findings may be unique to the relatively few people included in the study).</p> <p>It is more difficult to test hypotheses and theories.</p> <p>It may have lower credibility with some administrators and commissioners of research programmes.</p> <p>It generally takes more time to collect the data when compared to quantitative research.</p> <p>Data analysis is time consuming.</p> <p>The results are more easily influenced by the researcher's personal biases and idiosyncrasies.</p> <p>Potential lack of transparency in method of analysis that relies on subjective interpretation.</p>

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## Critique of the Quantitative Approach

For many years quantitative research along with its epistemological and ontological foundations has been criticised by qualitative researchers who suggest that it is not an appropriate approach to study human behaviour because it is reductive and limiting (Bryman, 2001) as shown in table1. Contemporary psychological research has shifted the focus to study more complex and private processes of the mind, but despite this the dominant methodological approaches draw from quantitative methods, making it difficult to address the way we construct meanings and make sense of our experiences.

Schultz (1962) argues that scientists who employ a natural science method with treating the social world as if it was no different to the natural world, goes on to argue that this means ignoring the differences between the social and natural world. Qualitative researchers challenge the notion that experiments can take place within a value-free or neutral context and provide objective outcomes that relate meaningfully to the participant's experience. It is suggested that understanding the constructions or phenomena that emerge in the interaction between researcher and participant is more useful than measuring psychological variables, which are objectified by positivists than those measured within experimental settings. This view does not dismiss the value of the quantitative approach but maintains that the research cannot be independent of the physical and social settings. Quantitative data cannot be considered neutral, as they are value-laden, as are the theories or null hypotheses that the research study sets out to test. Any claims, therefore, that an accurate representation of external reality is 'correct' must be challenged.

The idea that the researcher remains neutral should also be challenged. During an experiment the researcher selects a theory from which to hypothesise and chose a research question, participants are then selected and interaction occurs throughout the experiment to produce data. The data is

subject to a process of selection and interpretations, such as the inclusion or exclusion of certain data. This will influence the conclusions, examples of this are the examination of particular comparisons or associations and the explanation of unexplained, ambiguous or inconsistent research findings, which will control the way the data are presented. This illustrates the potential for selectivity, therefore undermining the argument that the researcher can remain neutral or that the results are an objective record of 'reality' or 'truth' and not the product of social interaction.

The quantitative approach employs the logico-deductive model which states that theory drives research and data analysis is criticised (Smith, 2003) as it limits the development of our understanding of the processes related to private cognitions and affective phenomena because they are not accessible to quantitative measurement. Charmaz (1995a) argued that the experimental and deductive approach rarely lead directly to theory development in the same way as qualitative research; as deductive reasoning contrasts with the qualitative approach, which in general does not apply any prior assumptions and looks for theory to emerge through the inductive process.

In quantitative experiments, individual variability and personal meaning are often reduced to the status of an experimental error, or excluded as a statistical 'error' as the larger the group of participants is, the more powerful and generalisable the statistical outcome is. The results that emerge from these studies can seem unrepresentative of the individual experience of the participants involved in the study. This is because quantitative studies focus on patterns within populations, often working with mean measurements, focussing on differences between groups (e.g. males versus females; experimental condition versus control group). Little attention is paid to the variation within groups, as the aim is to identify patterns in populations and not individual variability.

Another criticism of quantitative research concerns measurement. The natural phenomena that exist in human nature are dynamic, fluid, varied and inconsistent. However in natural science, the participant involved in the study is 'frozen in time' in order to measure the phenomena being investigated. Other criticisms levelled at quantitative research are that the constraints of statistical testing take away the ambiguous, unpredictability and idiosyncrasies that characterise human behaviour. The quantitative approach is accused of elevating numbers to the status of absolute facts rather than recognising their limits and treating them as something that has evolved from a particular viewpoint (Yardley, 1997).

Human behaviour contains a capacity for intention and anticipation; this implies the presence of dynamic intra- and inter-personal processes, which give meanings. It is these processes that make sense of what is going on, what has gone on and what might happen in the future in the world around us. Therefore a research participant will be constantly appraising their situation and responding appropriately. Their appraisal processes draw on many different sources and represent a powerful process that cannot be controlled for in the experiment. Qualitative researchers believe that this in its own right is an important area to focus further study. Quantitative researchers may also share this interest but are limited in their ability to capture and explore unfolding cognitions because of the methods they prefer to use, it is therefore argued that the application of qualitative methods are required (Lyons, 1999).

Traditionally psychology has been a predominantly quantitative and positivist discipline. However psychologists are becoming increasingly aware that the gathering and analysis of data are not only inevitable features of professional practice (in clinical or counselling interviews) but it also constitutes one of the key competencies needed to conduct research. Hence in recent years there has been a development in the use of new and alternative approaches that have adopted a more constructionist, contextual or discursive epistemology (Guba and Lincoln, 1994; Smith et al, 1995a, 1995b).



This shift away from quantitative and positivist psychology towards more qualitative approaches is reflected in the number of publications emerging in general psychology (Smith et al, 1995b) and in health psychology (Morse and Johnson, 1991; Yardley, 1997; Murray and Chamberlain, 1999). It has been suggested that the acceptance of qualitative approaches was necessary for psychology to continue to develop and progress in the study of covert, multidimensional and dynamic phenomena, which requires focussing on personal experiences and meaning (Smith, 1995a).

This section has concentrated on the problems of quantitative approaches. Criticisms against this approach do not distract from its usefulness and application but illustrate its limitations and the need to develop different but complementary approaches. It has been argued that the phenomena and processes that are evident in subjectivity and in the construction of 'reality' have been neglected and should in the future be given more attention in psychological study (Yardley, 1997).

*“Rather than striving for the illusory goal of objectivity, it is more productive to examine the way in which our reality – including the particular version of reality portrayed by scientists – is shaped by the purposes and conventions, aspirations and assumptions, which form an intrinsic part of human life” (p1).*

### **Issues in Qualitative Research**

Qualitative research is often criticised because of the potential reactive effects of the interviewer's presence on the situation being studied and selective perception or bias on the part of the researcher. Some qualitative researchers have addressed these by using purposive or theoretical sampling, based on reviews of the literature and knowledge of the subject area. This has been used to select cases under study, rather than as an attempt to observe or collect data from a representative sample of respondents, who may be

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affected by the phenomena under study. The most cited criticisms of qualitative research are the presumed lack of the generalisability of findings and the reliability and validity of its findings.

In regard to field research, critics question the ability of qualitative research to replicate observations (reliability) or to obtain correct answers or correct impressions of the phenomenon under study (validity) (Kirk and Miller, 1986). Quantitative researchers are likely to address threats to validity through such techniques as random selection of participants and the use of controls. Qualitative researchers are more likely to address validity throughout the data collection and analysis processes. As qualitative researchers review more cases, seeking common themes, patterns and testing emerging hypotheses, they are in essence working to ensure validity (Maxwell, 1992).

Several stances to assimilate the goals of reliability and validity into qualitative research have evolved. One such position is to adopt the terms reliability and validity with little change to their meanings other than the playing down of the salience of measurement issues. When considering the main components of external validity, that is reliability, validity and generalisation, Mason (1996:p21) argues that these components 'are different kinds of measures of the quality, rigour and the wider potential of the research which are achieved according to certain methodological and disciplinary conventions and principles'. This view remains close to the perspective of quantitative research, where these principles have been mainly developed. Validity refers to whether 'you are observing, identifying or measuring what you say you are' (Mason, 1996:p24). Other authors write about reliability and validity in relation to qualitative research but invest the terms with a different meaning (Le Compte and Goetz, 1982; Kirk and Miller 1986), these will be explored further.

Some qualitative researchers, such as LeCompte and Goetz (1982) write about external reliability adopting the meaning of the degree to which a study can be replicated. In qualitative research, this is a difficult criterion to meet, as

it is impossible to freeze a social setting and the circumstances of an initial study to make it replicable in the sense that the term is used in the natural sciences (LeCompte and Goetz, 1982). They also suggest adopting internal reliability by which they mean, when there is more than one observer, members of the research team agree about what they see and hear. There is opposition within qualitative research to this view. In qualitative research, the researcher will ask someone to affirm that they are 'seeing what is there' and for this a second researcher is used to read and code a transcript, or to 'check' the validity of a category. This process is considered to violate the process of induction because the first investigator has a wealth of knowledge gained from conducting the interviews and from observing the participants, which the second researcher does not have. As the process of inductive qualitative research frequently depends upon insight and on the processes linking the data, both amongst categories and established theories, expecting another researcher to have the same insight from a limited data set is unrealistic, and could potentially impede the research and stunt the development of the theoretical model (Morse, 1994). Also, it is driven by a positivist epistemology assuming that there is one objective reality. Many schools of qualitative methods would say that multiple or different interpretations are possible. This does not mean that only one interpretation is 'correct', as the different perspectives can all be 'valid' and useful. It is also argued that the process of synthesizing data is similar to the cognitive process of synthesizing articles written by other authors for a literature review. During the literature review, a second researcher does not go to the library to check that the researcher is interpreting the original sources correctly, so Morse (1994) argues the necessity for anyone to have a reliability checker for their data.

Internal validity is concerned to be a key criterion, which is whether there is a good match between the researchers' observations and the theoretical ideas that they develop. This can be achieved by presenting the resulting model to the participants for confirmation of the accuracy and validity of the study. They may provide clarification or offer additional stories to confirm the model further (Glaser, 1978). Sometimes the results report on findings that are implicit in the

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setting, then even the participants are not aware of the findings and must 'check them out' themselves (Bryman, 2001). Internal validity is considered to be one of the strengths of qualitative research, as it allows and ensures a high level of congruence between concepts and observations (LeCompte and Goetz, 1982). External validity relates to the degree to which the findings can be generalised, unlike internal validity. This represents a problem for qualitative researchers because of the tendency to use smaller samples and case studies (LeCompte and Goetz, 1982).

As this brief outline suggests, some qualitative researchers have tended to imply the terms of reliability and validity in very similar ways to quantitative researchers when seeking criteria development for assessing quality in qualitative research.

Within qualitative research, a second stance has been adopted in relation to reliability and validity. It is suggested that qualitative studies should be evaluated upon completely different criteria to quantitative studies, proposing that it is necessary to specify terms and ways of establishing and assessing the quality of qualitative research that provides an alternative to reliability and validity. The two criteria proposed were trustworthiness and authenticity (Guba and Lincoln, 1994; 1994). The main reason for the objection to reliability and validity as criteria for qualitative research is that they are critical of the view that there are absolute truths about the social world and that it is the job of the researcher to reveal this, because this view presupposes that a single absolute account of social reality is feasible, and as they argue, there can be several possible accounts.

The differences in the underlying assumptions of the quantitative and qualitative paradigms extend beyond philosophical and methodological debates. These two paradigms have given rise to different journals, differences in sources of funding, expertise, different methods, and even differences in scientific language. However to represent the two approaches

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as in competition to each other would be inaccurate. Patton (1990:p39) advocates a “paradigm of choices” that seeks “methodological appropriateness as the primary criteria for judging methodical quality”. This will allow for a “situational responsiveness” that strict adherence to a particular paradigm or another will not. Some researchers believe that both approaches can be effectively combined in the same research project to gain a wider perspective on the research topic (Strauss and Corbin, 1990; Patton, 1990). For example, standardized measures might be used to collect data in conjunction with open-ended interview questions. It is possible to code interview data using both qualitative and quantitative techniques and to report the results of both the qualitative and quantitative analyses of the same data set (Daley, 1992). Qualitative strategies need not be limited to small-scale studies. Daly (1992) reported a technique for applying Grounded Theory principles in the design and analysis of a large national survey on adoption trends. Furthermore Yardley (2001) argued that the value of both approaches was recognised, there is a need, therefore, to find a theoretical framework that integrates all the approaches to enable the discipline to move forward in a pragmatic way, rather than maintain the separatist debate, with each group misrepresenting the other.

### **Justification for using qualitative research methods**

Clinical practice is more than technical knowledge and evidence based medicine; it involves intentions, meanings, inter-subjectivity, values, beliefs, personal knowledge and ethics of both the health professional and the patient (Miller and Crabtree, 1994). As qualitative research strategies best address questions that concern meanings, experiences, patterns, relationships and values; this study has adopted this approach in aiming to understand the lived experience of chronic pain patients as it attempts to gain insight into the participants’ world. Qualitative research deals with the unique experiences of the participants, by looking at naturally occurring events, (Miles and Huberman, 1994) and or social or human problems (Creswell, 1998), such as chronic pain and the participants’ reasons that they attribute to why they have

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pain. Epidemiologically pain clinics tend to have more female than male patients attending, Davis (1986) suggested that the gender of respondents should be a consideration in selecting a research strategy because many women may prefer qualitative research techniques to quantitative approaches because they prefer opportunities to discuss subjects in context. As this study is interested in cultural similarities and differences it was also felt that qualitative methods would be appropriate as Davis (1986) suggested that some members of ethnic groups, low-income populations, or others who may be socially distant from the researcher are more likely to participate in the in-depth interviews characteristic of qualitative research than to complete a structured questionnaire or survey.

The main aim of qualitative research is to understand the world of those being researched, giving a voice to those rarely heard (Jones, 1995). This study endeavours to do this, but is aware that the participants' voices are open to interpretation, therefore, due to the subjective nature of qualitative research it is important for the researcher to continually engage in self-examination to be certain that his or her own biases and stereotypes are not influencing the interpretation of the findings. This is discussed in my reflexive account in chapter four. Conversely, as qualitative analysis allows researchers to explore in depth all factors that might affect a particular issue, this strategy permits sensitive consideration of the complexities of human diversity (Marlow, 1993).

Chronic pain is complex, it involves physical, emotional, social and cultural aspects and qualitative research seeks to understand the phenomenon being researched in terms of a complex system (Pattern, 1990). The dynamic complexity of chronic pain has yet to be addressed comprehensively by psychological research, it could be suggested that this is due in part to the limits of the approaches employed until recently. Little attention beyond case study accounts of clinicians had been given to the lived experience of people with chronic pain (Carter, 1999). This was exposed in the literature review undertaken by Walker et al (1999) who could not identify any published

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studies using qualitative methods to access patients' accounts of their experiences of chronic pain in any of the journals solely directed to the study of pain. This is beginning to change, with qualitative research starting to feature in these journals. This research is discussed within the narrative review in chapter six.

Quantitative research has provided a wealth of data about the multi-dimensional nature and complexity of pain, and the argument for adopting qualitative methods does not imply the rejection or dismissal of these findings. However, there is much that still defies our understanding of chronic pain and a qualitative approach could be utilised to explore this further. In particular, qualitative methods are needed to access an account of the phenomenological experiences and meanings of pain. There is a need for a different approach not to replace quantitative methods but to complement them.

Quantitative research has made some attempt to attend to the symbolic nature of pain and the use of language. Melzack and Torgerson (1971) in their preliminary work for the McGill Pain Questionnaire were keen to develop new approaches to the problems of assessing chronic pain and wanted to use words instead of numbers to describe its many forms. They attempted to view pain as more than just a sensory perception and explore the wealth of language that was available to describe it. Although these ambitions appear limited, at the time, they aimed to explore the many different ways that pain could be described in an empirical way. Words used to describe pain were brought together and categorised and an attempt was then made to scale them on a common numeric intensity dimension. So despite some movement towards an exploration of linguistic meanings of pain, they went on to use a rich data source and reducing it to single dimensions and numbers.

The study did lend strong support to the idea that pain represents a wide variety of experiences that can be captured, expressed and accounted for in

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the chronic pain patients' use of language. This work showed that the words that were used revealed something about the nature of pain and showed it to be something that involved previous experience, attributions and meanings. Melzack and Torgerson concluded that a detailed analysis of the quality and structure of the pain experience was required but this has yet to happen in the way they identified. Their research revealed that the nature of chronic pain resists attempts to reduce it to a simple uni-dimensional phenomenon and that the language used to describe pain does not contain enough shared or consistent meaning to work successfully as a diagnostic medical tool. It is important to consider that even descriptions of pain can be problematic as neuropathic pain patients find words to be of limited use (Desouza and Frank, 2000). Perhaps this implies a future debate, which could centre on the subjective nature of our experience of pain which is so individual that it is inappropriate to even attempt to use generic scales.

### **Establishing the meaning of chronic pain**

Many explanatory theories have been developed for chronic pain. These have been criticised for being too reductive whilst suggesting the need for the development of more complex theories, which integrate the multidimensional aspects of pain (Novy, Nelson, Francis and Turk, 1995).

Aldrich, Eccleston and Crombez, (2000) proposed that such theories will need to recognise these multidimensional aspects as frequently changing rather than being static or concrete phenomena, e.g. chronic pain patients will often talk of differences in the perception of 'good' and 'bad' pain days. Qualitative methods have been shown to be useful in studying fluid, dynamic and rapidly changing phenomena that are not easily identifiable.

A major problem in the field of pain, which gives support to the suggestion for developing alternative ways of studying pain, is the inability to quantify pain or

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its related cognitions and emotions in a reliable and valid way. This suggestion is based upon the critique of the limits of quantitative research done to date but has also emerged from the conclusions formed from the research literature and recommendations for further study (e.g. Price, 1999; Pincus and Morley, 2001). It is recommended that a more idiographic approach to the study of pain be taken. In particular one that favours the description and interpretation of the personal meanings of chronic pain and the process by which chronic pain patients constructed it and made sense of their experiences.

Quantitative measures of pain exist, but arguably do not capture the meanings of pain, or the quality of subjective experience. Within the clinical field of pain, two examples of the problem of quantifying the pain phenomena that I encounter in my clinical work as a member of a pain team, are the visual analogue scale (VAS) and the 'straight leg raise' (the degree to which someone can raise their leg from horizontal). Both of these measures are widely used and accepted as quantified measures of pain sensation and disability; however it is problematic to suggest that they capture the pain experience in an objective or valid manner, these are discussed further.

The visual analogue scale can be considered a psychological measure enabling the measurement of pain severity and intensity. Despite its development as a standardised and 'objective' pain measure, it also remains subjective. Chronic pain patients are asked to indicate the severity of their pain on a 100mm line where one end signifies 'no pain' and the other the 'worst pain imaginable'. Not only is this measure language dependent, it is also based on the assumption that pain can be evaluated along one dimension and the 'worst pain imaginable' remains constant for the individual. Therefore this does not allow for the possibility that the person's experience could cause their thoughts and feelings to change over time, thus altering their pain report.

Medical and sensory conceptualisations of pain have lead to the use of measures such as the 'straight leg raise' to determine the nature and extent of pain sensation, organic pathology and disability. These findings are based on clinical judgement and the interpretation of the clinician and are poorly standardised (Jensen, Turner, Romano and Karoly, 1991). Measures such as 'straight leg raises' do not allow for the social demand characteristics of the situation. For example, a chronic pain patient may be able to raise their leg to its mechanical limit once, as long as they were prepared to endure severe pain as a result. It is possible that pain might not occur whilst carrying out the 'straight leg raise' but it would emerge the next day. Therefore it could be considered that the degree to which a person can carry out a 'straight leg raise' is not a measure of their pain but could be a function of what they hoped to do the next day, or what they wanted the person assessing them to think of them.

The quantitative study of pain will always be problematic as a person's pain can only be inferred from their behaviour and self-report. By quantifying and aspiring for an objective and stable measure will limit the extent to which pain can be viewed as a dynamic and fluid phenomenon that can change according to the context, containing within it different dimensions. The evidence suggests that pain is much more than a primitive warning signal, as discussed in chapter two, the challenge of pain, thus its complex presentation demands further study.

To date, empirical quantitative research has clarified and classified the psychological nature of chronic pain (Skevington, 1995). Despite the fact researchers have identified important constructs, beliefs and behaviours that are characteristics associated with chronic pain, they have not been able to address fully how or why such beliefs and behaviours are formed, maintained or interacted. It is suggested that further research is required to gain a greater understanding of the personal meaning of pain to chronic pain patients and to the processes involved in the development of chronic pain and subsequent

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disability (Craig, 1984; Holzman and Turk, 1986; Jensen, Turner, Romano and Lawler, 1994). It has been suggested that the nature of personal meaning needed to be given a central focus in the study of pain because

*“It has long been clear that the meaning given to a somatic (pain) experience will play a critical role in the activation of the emotional – motivational component of the pain system” (Leventhal, 1993, p142).*

Whilst acknowledging the extensive expansion of research on the pain phenomenon, it could be suggested that the developments in our knowledge have also highlighted the need to gain a greater awareness of both the meaning of the pain to the chronic pain patient and the relationship between a subjective experience and its overt expression (Craig, 1984). These phenomena could best be understood as a product of the chronic pain patient’s personal background, which lends further support to the value of adopting an idiographic approach to pain research.

### **Qualitative Methods considered for this study**

Qualitative research in psychology encompasses many different methods, many of which have been developed from the phenomenological and social interactionist perspectives. Although these approaches stand together in contrast to the quantitative approach there is still much debate within qualitative research. The debate centres on the focus of the status of the participant’s account of their experience and how much of what the participant says about ‘something’ is actually related to the thing itself. Many methods are employed in qualitative approach (Guba and Lincoln, 1994; Smith, Harre and van Langenhove, 1995; Murray and Chamberlain, 1999), I will outline the elements of qualitative research focuses on three prominent methods in health psychology that were considered for this thesis; Phenomenology, Interpretative Phenomenological Analysis and Grounded Theory which have

emerged from phenomenological and symbolic interactionist viewpoints. These three particular methods were considered because this study does not wish to reduce the phenomenon of living with chronic pain into numerical indices of identifiable variables as the aim of this study is to clarify the situation lived through by persons with chronic pain in everyday life and uncover meanings attributed to chronic pain.

### The Phenomenological Method

Phenomenological researchers collect descriptions that are exhaustive, intensive and 'thick' (Geertz, 1973) from their participants in an attempt to present the participants' perspective of the world and develop an understanding of the structures that make up that experience. Until relatively recently, phenomenology was considered to be a philosophy, however it was first addressed as a method by Giorgi (1985). It is this method that I will outline, firstly describing the rules that have to be adhered to in this approach.

The Rule of Epoche, suggests that the initial biases of the researcher are set aside (bracketed) so that an open mind can be imposed on the data, and that only primary data is attended to. This is intended to keep the prejudices of the researcher in check. Giorgi (1985) suggest focussing on the immediate and concrete impressions, this makes it possible to derive an analysis from the individual's experience, and not the researcher's or the participant's prior assumptions. The rule of scientific phenomenological reduction considers that objects or states of affairs are taken to be presences and not realities. *'They are to be taken exactly as they present themselves to be, but no claim is made that they actually are the way they present themselves to be'* (Giorgi and Giorgi, 2003:p32) The principle of horizontalism is applied to enable the researcher to remove their own prejudices and adopt a further open minded approach by treating each descriptive episode as equal and not imposing their own hierarchical structure upon it.

Briefly, the phenomenological method involves four main processes; firstly the researcher reads the participant's entire description of their experience in order to achieve an overall grasp and understanding of the statement, 'a sense of the whole'. Secondly the researcher returns to the beginning of the text, and reads it discriminating the passages or incidents in text, which act as 'meaning units' and convey something about the psychological phenomena under study. Thirdly, once all the 'meaning units' have been defined they are examined and transformed to reveal the psychological insight they offer. Lastly, each of the 'meaning units' are combined and a consistent statement is developed about the participant's experience.

In order to stay as close as possible to the participant's accounts, it is important that the discrimination of the 'meaning units' takes place in a discrete step before they are examined further and transformed into a more integrated statement.

Giorgi (1985) stated that different perspectives could be adopted within this phenomenological method he accepted the diversity but suggested a cautious manner would be required to address the conclusions drawn. However it is assumed that human experience will constantly change and be more complex than any one study or analysis could capture.

#### Interpretative Phenomenological Analysis

Interpretative Phenomenological Analysis (IPA) is an idiographic qualitative approach that has its roots in both phenomenological psychology and symbolic interactionism (Smith, 1996a). It is committed to understanding the participant's perspective, although recognises that this perspective cannot be completely accessed as their thoughts, beliefs or affect are not entirely transparent. IPA asserts that the participant's perspective can be achieved to a useful extent through the interpretative analysis of the researcher. It involves the analysis of verbatim transcriptions that are gained from in depth semi-structured interviews (Smith, 1995). The final report is seen as a co-

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construction between the participant and the researcher in that it emerges from the analysis and engagement with the data.

IPA shares with the mainstream social cognition paradigm the interest and acknowledgement of the links between someone's account, their cognitions and their physical state but has particular commitment to the importance of the participant's talk and use of language. IPA sees these cognitions as complex, malleable and dynamic entities that are formed and reformed as the participants' endeavour to make sense and talk about their condition.

Within IPA there is a considerable amount of common ground with phenomenology and Grounded Theory methods in terms of obtaining data, for example via interviews and some of the steps of analysis. Although there are clear differences between them, related to theoretical underpinnings and the way that later data analysis is carried out beyond looking for themes. For example if using Grounded Theory, a substantive theory would be produced as the endpoint of that particular piece of research. It would be inadvisable to define them by what amounts to subtle contrasts, or equally to see them in conflict with each other. They are all driven by the data and have a commitment to finding the meaning representative in a person's experience by looking at it from the person's point of view and by trying to see how they construct and interpret their world.

The phenomenological method contrasts with IPA. The phenomenological method aims to develop more of an understanding and description of the structure of the experience, whereas IPA endeavours to get as close as possible to the participant's private and personal experience with its commitment to interpretation as a means of articulating the person's view. Within IPA there is no formal attempt at 'bracketing' whereby the researcher's personal biases are set aside, instead the researcher engages immediately with the data, this is acknowledged to be key in the analytical process. The idea of bracketing is not completely rejected as steps are taken to ensure the

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analysis remains grounded in the data. The principles of equivalence and horizontalism are adhered to, so that no part of the transcript is excluded as potential data in the beginning.

In IPA, a series of steps enables the researcher to identify themes that are combined into a formal write up and statement. Currently IPA usually uses verbatim transcriptions as the primary data source whilst phenomenology and Grounded Theory can use different data sources, such as text. However this cannot be seen as a criticism in the approaches as the development and application of IPA is still at an earlier stage than the other two methods. Phenomenological and Grounded Theory methods could be adapted to look closely like IPA; it is just as possible that IPA could be applied to other data sources in the future.

#### The Grounded Theory Method

Grounded Theory is the preferred approach for this thesis; the theoretical historical background will be discussed here, the rationale for its use in this study will follow and the practical implementation will be covered in the method, chapter four.

An important principle in contemporary qualitative health psychology is that the theory generated is 'grounded' in semi-structured interviews, field-work observations, case studies or other forms of textual material. This principle is associated with the methodological approach first developed by Glaser and Strauss during their investigation of the institutionalised care of the terminally ill (1965), which they subsequently termed Grounded Theory in the book 'The Discovery of Grounded Theory' (1967). Their approach is particularly suited to the study of local interactions and meanings as related to the social context in which they actually occur, therefore it has considerable potential as a method for health psychologists, which will be discussed further in the rationale for using Grounded Theory.

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A brief historical overview of Grounded Theory will be outlined. During 1960's quantitative methods were dominant; the belief in scientific logic, objectivity and truth supported and legitimised the reduction of the qualities of human experience to quantifiable variables and simultaneously a growing division between theory and research developed. During this time, theory informed quantitative research through the logico-deductive model of research, but this research seldom led to new theory generation (Charmaz, 1995).

Glaser and Strauss (1967) confronted the popular quantitative perspective of the era, challenging the arbitrary division of theory and research. The prevailing view of qualitative research as primarily a precursor to more 'rigorous' quantitative methods was disputed as they claimed the legitimacy of qualitative research in its own right, questioning the belief that qualitative methods were impressionable and unsystematic. They challenged the separation of data collection and analysis phases of research and the assumptions that qualitative research only produced descriptive case studies rather than theory development.

By producing written guidelines for conducting qualitative research, Glaser and Strauss changed the oral tradition of the social sciences. The epistemological assumptions, logic and systematic approach of Grounded Theory methods reflect Glaser's rigorous quantitative training. The strong links with symbolic interactionism, with its focus on human reflection, choice and action stems from Strauss's training at the University of Chicago with Herbert Blumer; this influenced Strauss to adopt the pragmatic philosophical tradition with its emphasis on studying processes, actions and meanings (Mead, 1934; Blumer, 1969).

Grounded Theory contains both positivistic and interpretive elements. The emphasis on using systematic techniques to study the external world remains consistent with the positivist approach. Whereas the importance placed upon how people construct actions, meanings and intentions is in keeping with

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interpretive traditions. Some grounded theorists (Clarke, 1998; Charmaz, 2003) assume that a researcher's discipline and theoretical perspectives, their relationships and interactions with respondents all influence and shape data collection and analysis. Grounded Theory can be used to bridge traditional positivistic methods with interpretative methods in psychology and the chronic pain research that have traditionally embraced quantification. These methods allow psychologists to study aspects of human experience that remained inaccessible with the traditional verification methods. The Grounded Theory approach emphasises process, which enables psychologists to study how individual and interpersonal processes develop, are maintained or change.

Since its initial publication, the number of procedures and practices that are applied as Grounded Theory are now so intensive that there is no longer one discrete or easily identifiable method; it has become a broad term (Chamberlain, 1999). As Strauss continued to conduct, teach and discuss research methodology, his ideas of Grounded Theory evolved, in collaboration with Corbin produced the first edition of *Basics of Qualitative Research* (Strauss and Corbin, 1990), which contained differences from the original Grounded Theory, particularly in conducting data analysis. This text was designed to supplement other Grounded Theory texts as it provided a set of techniques and guidelines for those new to qualitative research questioning how to do data analysis. Glaser (1992) felt that the Strauss and Corbin (1990) version of Grounded Theory forced results rather than letting them emerge, that it asked directing rather than neutral questions and that analysis was based on preconceived ideas rather than being open to emergent categories. It is felt that this was an overstated claim as can be seen from the discussion of the differences between the two positions (Melia, 1996). It has been suggested that it may be appropriate to consider that there are two forms of Grounded Theory, Glaserian and Straussian (Stern, 1994). Grounded theory, although essentially centred on a similar set of practices are varied and contested. There is no one way of conducting Grounded Theory but there are relatively clear guidelines as to what can be considered to constitute a Grounded Theory (Chamberlain, 1999). Charmaz proposed that Grounded

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Theory methods provide a set of strategies for conducting rigorous qualitative research' (1995:p27).

The Grounded Theory approach of Strauss and Corbin (1998) means that theory is derived from the data systematically gathered and analysed through the research process. In their interpretation of Grounded Theory, data collection, analysis and eventual theory stand in close relationship with one another. Initially the researcher does not have a preconceived theory, they start with an area of interest and allow the theory to emerge from the data. It is then more likely that the theory derived from the data will resemble 'reality' than a theory derived from putting together a series of concepts based on experience or speculation (Strauss and Corbin, 1998). As grounded theories are drawn from the data, they are likely to offer insight, enhance understanding and provide a meaningful guide to action. Creativity is considered an important skill for qualitative researchers, this manifests itself in the ability of the researcher to aptly name categories, ask stimulating questions, make comparisons and extract innovative integrated realistic schemes from a mass of unorganised raw data (Patton, 1990; Sadelowski, Docherty and Emden, 1997; Strauss and Corbin, 1998).

This approach is 'theoretical' in that it demands that a theory of the phenomena under study should develop and emerge from the data as a result of a sequence of inductive and deductive thinking undertaken by the researcher (Charmaz, 1995; Chamberlain, 1999).

Grounded Theory is typified by the employment of a prescribed process of repeated data sampling and coding techniques aimed at the development of an emergent theory. Data is coded according to its content hence giving meaning to the researcher the categories are developed and inter-related until no further categories emerge. At this point data saturation is reached, indicating that it contains no further data that can be contained within any meaningful code or descriptive label. The researcher engages closely with the

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data through the ongoing and iterative process of re-reading line-by-line, coding and memo writing. Therefore abstract analyses are built up directly upon the data and refined by gathering further data to the point where the researcher can attempt to capture, describe and theorise about the experience of the participant in a meaningful way. The 'constant comparative method' of analysis is often used where instances and categories are continuously compared for similarities and differences to find out as much as possible about the relationships between them. Once the data has been coded line-by-line, questions are asked about the data that help lead to the development of abstract categories. The data are reduced and a core category is identified which relates to the other categories and unifies the resultant theory (Chamberlain, 1999). Data collection is guided by theoretical sampling whereby participants are selected on the basis of theoretically relevant constructs, rather than for their statistical representativeness within a particular population. This contrasts with IPA, which remains with the original homogenous sample throughout the study.

Grounded Theory pledges to work towards the development of theory using a sequence of inductive and then deductive reasoning and theoretical sampling (Chamberlain, 1999). This contrasts with IPA, which is more committed to elaborating the emerging themes and developing a rich interpretative account of the participant's experience.

Grounded Theory can be used to accommodate the interpretative, constructivist or a structured positivist analysis (Charmaz, 1995). Grounded Theory is not a single entity but it shares within it the adoption of a contextual perspective in the development of an understanding of how that person experiences the phenomena under study (Henwood and Pidgeon, 1992, 1994). This section has provided a brief historical overview of Grounded Theory and discussed its role within qualitative research; I will now explain the rationale of the use of Grounded Theory in this study.

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## **Rationale for the use of Grounded Theory**

This study has adopted the Grounded Theory approach as proposed by Strauss and Corbin (1998) as it provides a well-defined framework for data analysis, which is helpful for one new to data analysis. Grounded Theory has been used successfully to investigate many areas of health psychology, covering diverse issues such as how general practitioners discuss psychosocial issues with their patients (Aborelius and Osterburg, 1995); the experience of recovery after liver transplantation (Wainwright, 1995), until recently most of these type of studies had been conducted by nurses and it was rare to locate Grounded Theory research in health psychology journals, or indeed with the pain literature. However, I think that Grounded Theory can bring benefits to both health psychology and the pain literature as it focuses on theory and attempts to capture the process of living with chronic pain, it goes beyond what is said in the interview. This addresses the criticisms that have been levelled at health psychology for its entrenched ways of theorising, as well as its failure to go beyond an individual perspective and incorporate social context within the theory. Many issues of interest to health psychologists involve processes such as living with chronic pain, adjusting to chronic illness, these aspects of Grounded Theory provide potential for advancing understandings of process in our research; by this I mean examining the process, how it is experienced and the meanings of the experience, rather than documenting number of days spent in hospital or the number of complications following surgery. Until recently the pain literature was dominated by quantitative approaches, so adopting Grounded Theory with well-defined guidelines and established track record in health related research would make it more acceptable to the pain research 'establishment' and hence facilitate the dissemination of findings through pain journals and conferences.

One of the weaknesses of some published qualitative work is that sampling strategies are overlooked. In Grounded Theory, the sampling strategy is explicit therefore the researcher can provide a clear rationale for the sample

selection. Theoretical sampling is key in Grounded Theory and is a powerful technique to ensure trustworthiness or credibility (Chamberlain, 1999). Also taking this theoretical approach to sampling will extend the focus of the research from the limited individualised context in which health psychologists too often locate their research. Illness and chronic pain is social as much as it is individual, and sampling diverse participants offers one way of explaining and incorporating this context.

The concept of saturation is strongly promoted in Grounded Theory, often in published research it only receives lip service, however by attending to this, it can enhance the quality of the research and facilitate theory development. Interestingly, saturation is not always about the frequency with which categories appear but as Morse (1995) comments

*“it is often the infrequent gem that puts other data into perspective, that becomes the central key to understanding the data and for developing the model” (1995:p148)*

One of the benefits of intertwining data collection with analysis is that it gives the researcher chance to identify areas which may have been missed and use subsequent data collection to clarify issues or the emerging theory and/ or follow up new insights. As previously mentioned, using the constant comparative method of data analysis provides a framework of how to undertake data analysis and therefore is extremely valuable to those new to qualitative research. Finally Grounded Theory is important because the theory emerges from the data. The goal is to generate a theoretical framework rooted in the participants' accounts. This moves qualitative research findings beyond that of interesting accounts of a small number of participants, to form a model that can be tried, tested and developed in future research. Hence it links to a broader body of literature in a clearly defined manner.

For this thesis I have adopted the constructivist view to Grounded Theory because this view assumes that pain not only deals with reality, but also with the internal representations of reality that are constructed from moment to moment using sensory information, networks of associations and memory stores. For the person with chronic pain subjective reality is constantly changing due to feedback from sensory information, emotions, other cognitions and sense of self. This sense of self is closely related to the sense of body self (Damasio, 1994) and embodiment (Merleau-Ponty, 1962) as chronic pain demonstrates ways in which the persistence of chronic pain becomes part of the self (Chapman, 1999).

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## Summary

Chronic pain is essentially a phenomenological experience. This chapter has offered a brief historical outline of the development of the intellectual approach to phenomenology and the historical background that lead to the development of qualitative psychology. To summarise the quantitative/ qualitative debate; qualitative research is concerned with non-statistical methods of inquiry and analysis of social phenomena. It draws on an inductive process in which themes and categories emerge through analysis of data collected by such techniques as interviews, observations, videotapes and case studies. Samples are usually small and are often purposively selected. Qualitative research uses detailed descriptions from the perspective of the research participants themselves as a means of examining specific issues and problems under study. Qualitative research differs from quantitative research in that the latter is characterized by the use of large samples, standardized measures, a deductive approach and highly structured interview instruments to collect data for hypothesis testing (Marlow, 1993). In contrast to qualitative research, in quantitative research easily quantifiable categories are typically generated before the study and statistical techniques are used to analyze the data collected. Both qualitative and quantitative research is designed to build knowledge; they can be used as complementary strategies.

Living with chronic pain on a day-to-day basis involves far more than medical knowledge; it involves intentions, meanings, inter-subjectivity, values, beliefs, personal knowledge, ethics of both the health professional and the person with chronic pain. As qualitative research strategies best address questions that concern meanings, experiences, patterns, relationships and values; this study has adopted this approach in aiming to understand the lived experience of chronic pain patients as it attempts to gain insight into the participants' world. One of the main aims of qualitative research is to give a voice to those who are rarely heard (Jones, 1995), which this thesis endeavours to do but is also aware that the participants' voices are open to interpretation; this is discussed further in the reflexive account in the method chapter.

The qualitative approach encompasses a wide range of different perspectives that adopt contrasting approaches and epistemologies that lead researchers to study things from alternative perspectives. This is advantageous because there is a wide range of approaches, which reflect the complexity of the participant, which can be selected according to the focus of the researcher and the research question. Being new to qualitative research, I adopted the Grounded Theory approach (Strauss and Corbin, 1998) using the constant comparative method of data analysis because it provided a clear framework of how to undertake the data analysis, and it addressed the criticisms that are directed towards qualitative research in health psychology, which I have discussed earlier in the chapter. The other important reason for adopting Grounded Theory is that it explicitly aims to develop a theory. Another more pragmatic consideration was as until recently the pain literature was dominated by quantitative approaches, would my work be published in journals solely dedicated to pain? I would suggest that the close compatibility of qualitative research methods with health psychology practice techniques is likely to lead to greater use of qualitative strategies in practice evaluation. As more health psychology researchers network, refine and publish qualitative studies that clearly specify the techniques used, qualitative methodology is likely to receive even greater acceptance among those working and researching in the field of chronic pain.



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## **Chapter 4 – Method**

### **Introduction**

The rationale for using the Grounded Theory approach (Strauss and Corbin, 1998) and the constant comparative method of analysis are discussed in the previous chapter. A sample of White British and South Asian participants were drawn from the patients that attended the chronic pain out-patient clinic at University Hospitals of Leicester, United Kingdom. The data set for the studies consisted of transcribed semi-structured interviews. Grounded Theory (Strauss and Corbin, 1998) was used as a methodological framework.

The aims of this study were to address what is the patient's experience of living with chronic pain followed by an appraisal of how or if ethnicity (White British or South Asian) influences the experience of living with chronic pain.

As the study is qualitative, the participants were not regarded as exemplars of the 'chronic pain patient' or expected to speak explicitly for their peers, but rather to provide specific instances of the psychosocial experience of chronic pain.

### **Reflexive account**

Reflexivity directs the qualitative researcher to introspect on their own experiences, values and feelings and how these may interact with their engagement in the research process. In a Grounded Theory approach it is particularly important that emerging categories are truly grounded in participants' accounts. Reflexivity helps to guard against the personal 'agenda' of the researcher biasing the interpretation data. Given the interpretative nature of the analysis, who the researcher is will always have some influence on the process, but provision of a reflexive account of relevant information,

helps to make this more transparent to the audience. Mead (1934) described reflexivity as *“the turning back of the experience of the individual upon [her or himself]”* (p134). It requires researchers to the best of their ability, to engage in private reflection, or discussion others such as with colleagues or supervisors and seeks to challenge and self analyse their history, values and assumptions, as well as the interrelationship with their participants and sometimes, public declaration of their reflections.

With reference to research and their interpretation of the results, researchers are increasingly encouraged to become aware of their feelings and experiences and to scrutinise these closely. Griffiths (1996) summarising a British conference on qualitative research, wrote that:

*“there is a lot of feeling behind the questions we ask, they are not innocent, they are knowing and are not so much questions as statements of a point of view. All facts, all data are values”* (1996, p s27)

These dimensions of reflexivity not only acknowledge the affective component of the research, but can also be used as a source of insight for the purposes of scholarship and innovation (Ballinger, 2003). I kept a reflective diary to record my own thoughts, feelings, insights and reflections into my study to facilitate reflexivity. The following gives a summary of those reflections.

#### Positioning the self: the researcher

Working in the field of chronic pain, as a Chartered Health Psychologist, my clinical practice briefly involves the psychosocial assessment and treatment of chronic pain patients; often in relation to patients' beliefs about their pain, patients' coping strategies, adjustment to their pain or illness, and how they view their quality of life. My role in academia involves research, and teaching about the psychological aspects of pain with both medical students and health

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professionals. I recognised the need to avoid making assumptions based on this experience.

My interest in chronic pain has taken a cultural perspective for several reasons. Initially in my clinical work, a few years prior to the start of this thesis, a 'South Asian' gentleman was enrolled on the pain management programme, which I ran, which is a self- management approach to living with chronic pain. Despite our best efforts he did not grasp the concept of self- management and expected 'hands-on treatment' even at the end of the pain management programme and therefore kept returning to pain clinic. Predominantly my clinical work was at that time with 'White British' people so I began to wonder whether the notion of 'hands-on treatment' was an example of different cultural expectations of what pain management involved. However as Milton Keynes continued to expand, more ethnic minority groups moved to the area, and hence attended the pain clinic, I began to notice this trend of expecting 'hands-on treatment'. This prompted me to turn to the literature to try to find a more effective way of treating their pain not only from a psychological viewpoint but also from a medical stance to assist my pain team colleagues. It soon became apparent that there was very little literature addressing chronic pain and ethnicity in particular 'South Asian' people that is people from India, Pakistan and Bangladesh. To me this appeared to be a huge oversight in the literature considering the increasingly cultural diversity in the UK. I secured a part-time research post at the University of Leicester, which enabled me to explore my interest in ethnicity further because Leicester has a very ethnically diverse population with a high proportion of South Asian people.

Having worked in the area of chronic pain for several years, I had developed my own personal thoughts and ideas about both acute and chronic pain. I was very aware that despite having personally experienced acute pain through injury, my pain had improved and disappeared and had not developed in chronic pain contrary to the experience of the participants in this study, I wondered, "why does that happen?" I was keen to further enhance my

understanding of chronic pain by exploring the patients' experiences, which was a perspective that at the beginning of this study was not common in the pain literature. I hoped that by using a qualitative approach I could develop my ability to empathise with what it is like to live with pain on a day-to-day basis and make a contribution to the study of pain that appears to be in demand. This research has provided me with an excellent medium for continuing professional development and enhancing my interest in chronic pain and more broadly health psychology.

#### Initial steps towards reflexivity

This study is my first piece of qualitative research, and I feel it has been a “vertical” learning curve. In fact I knew very little about qualitative research at the beginning of this study, as despite undertaking research modules and undergraduate and postgraduate level, qualitative research was not on the curriculum. At the beginning of this study, I knew that I only had five years part time to complete my thesis and my original focus was on getting it done. I was too preoccupied completing tasks to think about what I was doing or my role in the research. Initially I was aware of reflexivity but unaware of its value in research despite participating in this approach in my clinical work. I am aware that in the beginning I made the classic mistake of being too keen and enthusiastic to undertake the interviews, without allowing myself enough time to transcribe and analyse them, so I was left with a large amount of transcription and analysis at the end of my first year. At this point, one of my supervisors suggested that I might like to co-facilitate a reflexivity workshop with a colleague who was an experienced qualitative researcher. I agreed (inwardly reluctantly), but in hindsight, this was a changing point, because I had to find out more about the concept of reflexivity, I began to appreciate its value through discussions with my supervisors and academic colleagues. I learnt to appreciate that reflexivity is not concrete, and that you have to let go your tight control on the research process to allow free thinking, coming from a quantitative research background this was very difficult. I had to justify to myself that it was reasonable to stop interviewing and that it was fine to return to the field once some data analysis had been carried out, otherwise this

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would compromise the iterative nature of interview and then analysis. Initially I found it difficult to write about my results, as there are no right or wrong answers, just my interpretations in contrast to quantitative research, which seeks 'objective facts'. I have used this opportunity to learn about qualitative methodology and methods and developed my ability to use them, broadening my understanding of research in general. I believe that effective reflexivity comes with practice and initially requires a huge dose of self confidence in yourself as a researcher to overcome the paralysis experienced when you realise that it is my role as the researcher, and my interpretations of the research that make up the thesis. On reflection I think I found this difficult because of my background as a psychologist, as my academic training focussed on the concept of "science-practitioner", and emphasised quantitative research methods.

#### Researcher subjectivity

For this study it was important to be seen by the participants as a researcher rather than psychologist. I felt this was very important because of the assumptions and stereotypes that people have of psychologists, that they only see people who are 'mad or bad' for example. Also from my clinical work I was very aware that some people with chronic pain felt disbelieved and reported that they had been told that it was 'all in their head', therefore I did not want to be seen as contributing to or reinforcing this belief.

I acknowledge that being a white female may have influenced participants' responses. I was concerned that perhaps 'South Asian' participants would not discuss things that entailed constructs that were specific to Asian cultural beliefs, and if they did would I understand them? If not would they mind me asking them to explain. However I hope that my understanding of different cultures and my communication skills developed in practice as a health professional and allowed me to be sensitive to these issues. I need not have worried about this, as participants were frequently happy to explain and clarify

especially around issues of culture and religion. They seemed to appreciate being listened to on topics that are perhaps not often openly discussed.

#### Reflexive strategies and practice

This section describes some of the practices and strategies I employed to ensure reflexivity in my research. I learnt to look at the research process as a whole and ask myself questions such as, is the research ethical? Does the research respect the participants? Has the research been systematic and rigorous? This type of questions provided a degree of self-monitoring. Asking questions such as, what are my presuppositions? How similar or different am I to the research participants? What interpretations have I made? What other interpretations are there? I developed a more self-critical approach to the research.

The use of the research diary had the potential to serve many functions, although initially I found it difficult to know what to write. The diary acts as chronological record of the sequence of events and the development of thinking. It was useful as a resource to note down emerging ideas pending further thought and as can be seen from the following extract, also it served as a cathartic function when things were very irritating.

#### Extract from research diary:

“The research and development office were a source of frustration in terms of accessing participants. My original ethics application contained the process of accessing and recruiting participants as described in this thesis, however initially this was rejected by the research and development office, and they advised me in order to get ethical approval I would have to make written contact with the patients attending the pain clinic. From own clinical experience I knew this would be unsatisfactory, as many people do not read all the information that is sent to them, however it was the only way forward. This involved sending out an introductory letter about the study with the letter

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from the pain clinic saying they had received their referral, and that when the patient phoned to make an appointment they had to say whether they would be willing to take part in the study. Unsurprisingly only 2 people out of 147 letters sent out were willing to take part in the study. I went back to the research and development office and discussed the predicament I was in. At this point they agreed I could resubmit to the ethics committee with the 'accessing and recruitment strategy' I originally had, which was accepted and proved to be far more successful"

Having two part time jobs provided the opportunity to present my work to different groups of people. I was fortunate to be able to present to both clinicians and academics who gave useful and often thought provoking feedback. Due to the practical difficulties of returning to the participants in the study to validate my theory, I asked the members of the chronic pain support group that I facilitate whether I could present my theory to them in order for them to make comments and as a group discuss ideas that came forth. This was particularly interesting as all the members were able to understand and apply the theory to themselves. We had long discussions about how affect is influenced by pain and ultimately how affect influences everyday living and their perceptions of their 'lifeworlds'. Although for ease of understanding, I replaced the word 'affect' with the word 'mood'. As I expected we also had long discussions around the 'visibility issue of pain' and not being believed by everyone, from family to friends, work colleagues and society as a whole and how this again impacted on the way they felt about their situations.

#### Reflexivity in the interview

Initially I found it difficult to keep to the 'research interview' as in my usual clinical practice of a 'therapeutic interview' I would address the issues that the patient talked about that were of concern to them, and in this case I had to actively refrain from doing this. I had to bear in mind that the two types of interviews had different purposes, the therapeutic interview aims the facilitation of change in the patient, and the knowledge gained is a means for

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instigating change. Whereas the purpose of the research interview is to obtain knowledge of the phenomena investigated. Therefore I wanted to

*“avoid unknowingly reproducing unequal relations with participants in which knowledge (mine) was privileged over experience (theirs)” (Ballinger, 2003, p74).*

My field notes at the beginning of the study within my diary record my sense of unease at not being able to address the opportunities throughout the interview for therapeutic interventions. Despite this feeling I deliberately did not pursue or facilitate therapeutic interventions because I thought this would interfere with my role as a researcher. One particularly challenging interview was when the patient revealed that she had tried to commit suicide in the past because of her pain. I felt that on this occasion I had a “duty of care” and had to enquire whether she still had these feelings, and be ready to address them if required or to refer to the appropriate services.

I was conscious that unlike everyday conversation, the research interview is not based on an equal partnership. The power is usually very much in the hands of the researcher, as they define the situation, introduce the topics for discussion, and through further questioning steer the course of the interview (Kvale, 1996), which is similar to the health professional’s interview in a clinical setting. However, good qualitative research does allow people to be heard and give them a voice. I think I achieved this because often when thanking the participant for their time, they thanked me for listening to them and giving them time to tell their pain stories as often they felt that they had never been asked what it is like to live with. Six of the thirty-seven interviews were carried out via the telephone the reasons for this are explained later in the chapter. Initially I was a little concerned that this type of interview would not be as rich and productive as face-to-face interviews as rapport might be more difficult to establish. However I attempted to counteract this by meeting and talking with the participants about my study whilst they were at the pain



clinic. Five of the interviews were as productive as face-to-face interviews, maybe this was because they were comfortable at home, perhaps, they felt they could talk freely about their pain whilst retaining a certain degree of anonymity as they were at the other end of the phone. One telephone interview with a South Asian gentleman I felt was particularly awkward interview as he kept saying he didn't know the answer to the question, despite me reassuring him that they were no right or wrong answers to the questions. Reflecting back I think that this may be due to a language barrier, whilst talking to him albeit it briefly in pain clinic before his appointment, he answered questions appropriately, it was only when he asked me questions that I suspected that his English wasn't very good; but by this time I had already arranged to telephone him, so from that point of view it was a learning experience. I think with hindsight, once I suspected his English was not very good, I should have chatted to him a little more after his clinic appointment before arranging a telephone interview.

#### Summary of reflexive account

I have found that qualitative methodology has completely challenged my own research background, and although at times I have found it tedious and time consuming, I fully appreciate the richness of the data it provides which is fascinating. As a health psychologist I have found the research very useful in my clinical work, in particular it has reinforced my belief in the importance of the psychology of chronic pain and of always viewing it within a personal, social and moral context; I will discuss this further in the final chapter.

#### **Ethical approval**

Ethical approval was sought and granted from Leicestershire Research Ethics Committee (see appendix 1 for copy of approval letter, appendix 2 for patient information sheets, and appendix three for the patient consent forms). This study complies with ethical guidelines set by the British Psychological Society and the British Pain Society.

Due to the subjective nature of data collection, interpretation, and analysis in qualitative research, there appears to be more ethical dilemmas and concerns with confidentiality associated with this method than with quantitative research. Data was kept on a password-protected computer, and paper copies of any data were stored in a locked filing cabinet.

Participants were informed that the aim of the study was to help us try and understand how chronic pain affects their lives on a day-to-day basis. It was stated explicitly that participation was voluntary, separate from any clinical contact that they might have at the pain clinic, that they were free to withdraw their participation from the study at anytime without giving a reason and this would have no affect on their care and treatment at the pain clinic. The measures that would be taken to ensure confidentiality and anonymity were also explained.

Participants agreed that the interview could be audio-taped. The participants' names were assigned an identification number and the names then deleted. Any identifying information was changed or deleted from the transcripts to preserve their anonymity and guarantee confidentiality. Having transcribed the tape of the interview, the tape was erased. Written participant consent was secured prior to completion of the questionnaires and conducting any interview in the study.

### **Entry to the field**

Access to the field often involves negotiating with the gatekeepers. Therefore I wrote to all the pain clinic consultants and pain nurses informing them of the study enclosing the protocol for comments. I also presented the proposed study at a pain team meeting, which provided the opportunity for feedback prior to the study. Throughout the study I maintained frequent contact with the

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clinic co-ordinator who would provide me with clinic lists, and the clinic nurse who initiated contact between the participants and me.

### **Participants - Sampling strategy**

The descriptive epidemiology data of chronic pain patients attending the pain clinic was used to provide background information on characteristics of people we could expect to attend the pain clinic, thus informing maximum variation sampling. This type of data forms the Out-Patient Commissioner Data Set, which is a mandated government return. University Hospitals of Leicester uses the HISS system to collect this information. The following tables 2–6 present the epidemiological data for Leicester General Hospital's Pain Clinic between April 2003 and end of March 2004.

**Table 2: Showing all appointments at the pain clinic**

<b>Appointment type</b>	<b>Appointment count</b>	<b>%</b>
New patient	832	18.57%
Follow up patient	3649	81.43%
<b>TOTAL</b>	<b>4481</b>	<b>100%</b>

**Table 3: Showing source of referral**

<b>Referral Source (HISS)</b>	<b>Referral Count</b>	<b>%</b>
Other Consultant in this Trust	844	70.81%
GP Referral	227	19.04%
Same Consultant this Trust	91	7.63%
Same Consultant (private patient)	21	1.76%
Other Consultant other Trust	4	0.34%
Self referral	1	0.08%
Prosthetist	1	0.08%
Medico-Legal	1	0.08%
Same Consultant other Trust	1	0.08%
Same Consultant post in-patient stay	1	0.08%
<b>TOTAL</b>	<b>1192</b>	<b>100%</b>

**Table 4: Showing gender of patients attending pain clinic appointments**

<b>Gender</b>	<b>Appointment count</b>	<b>%</b>
Female	2965	66.17%
Male	1516	33.83%
<b>TOTAL</b>	<b>4481</b>	<b>100%</b>

**Table 5: Showing ethnicity of patients attending pain clinic appointments**

Ethnic Origin	Appointment Count	%
British	2708	60.43%
Indian	718	16.02%
White	566	12.63%
Not stated	192	4.28%
African	55	1.23%
Caribbean	47	1.05%
Irish	32	0.71%
Any other Asian background	30	0.67%
Any other White background	23	0.51%
Black Caribbean	23	0.51%
Not indicated	20	0.45%
Pakistani	13	0.29%
Black African	11	0.25%
Other ethnic group	11	0.25%
Chinese	8	0.18%
Bangladeshi	7	0.16%
White and Black African	6	0.13%
Any other ethnic group	5	0.11%
Any other mixed background	4	0.09%
Any other Black background	1	0.02%
White and Black Caribbean	1	0.02%
TOTAL	4481	100%

**Table 6: Showing age of patients attending pain clinic appointments**

Age At Appointment Years	Appointment Count	%
0 - 20	9	0.20%
21 - 30	160	3.57%
31 - 40	662	14.77%
41 - 50	945	21.09%
51 - 60	1076	24.01%
61 - 70	779	17.38%
71 - 80	765	17.07%
80 +	95	2.12%
TOTAL	4481	100%

The inclusion criteria required participants to have been referred to the Pain Clinic, University Hospitals of Leicester NHS Trust; be diagnosed with non-specific chronic pain as defined by the International Association for the Study of Pain (1986, 1994), as discussed in chapter two, have no auditory deficits as it would be difficult for these people to take part in the study with the current available resources, have the ability to speak / comprehend English well enough to complete questionnaires and be interviewed, and patients must be over 18 years of age. The reasons for the last two criteria are largely pragmatic. This is recognised as a limitation of the study, however there were no funds available to provide translators for non-English speakers and a focus on adults' experience of chronic pain is a large enough topic for a PhD thesis.

The possible implications of not having enough financial resources to employ translators, revolve around first generation 'South Asians' being excluded from the study as they are less likely to speak English, therefore those recruited to the study may have adapted more to Western cultural beliefs and attitudes to their pain. This will be explored further in chapter eight.

Initially, patients were recruited opportunistically, accepting any consenting patients who met the inclusion criteria and seeking to obtain maximum variation as the sampling proceeded. The aim of maximum variation sampling is to generate as many categories as possible, therefore demographic details and where the patients had been referred from, and whether or not they were new patients or patients with follow up appointments were recorded to allow us to ensure maximum variation sampling. As the study progressed some theoretical sampling occurred, in order to test out assumptions and ideas that were being developed from analysis of earlier interviews.

Sampling in Grounded Theory is theoretical because, rather than being predetermined at the beginning of the study, sampling occurs on the basis of concepts that have emerged from the study and those that appear to have relevance to the evolving theory. It is important when exploring new ideas as it enables researchers to choose those areas of sampling that can bring about the greatest theoretical return:

*“ data gathering driven by concepts derived from the evolving theory and based on the concept of ‘making comparisons’ whose purpose is to go to places, people or events that will maximise opportunities to discover variations among concepts and to densify categories in terms of their properties and dimensions” (Strauss and Corbin, 1998: p201)*

Sampling is directed by logic and the aim of the three coding procedures. Sampling during open coding is often based on convenience as the aim is to generate as many codes, properties and dimensions as possible. Sampling during the axial coding stage proceeds on the basis of theoretically relevant concepts, but focuses on changes. During this stage the researcher will use relational and variational sampling aiming to validate relationships between the categories. The aim of selective coding is to integrate the categories along dimensions to form a theory, validating the statements of relationships. At this point discriminative sampling is employed, a direct and deliberate sampling

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which will maximise opportunities to verify the storyline. Sampling continues until theoretical saturation of each category is reached (Strauss and Corbin, 1998), that is, until there is no new conceptual information, which indicates new codes (at any level) or expands existing codes (Wilson and Hutchinson, 1986).

#### Participants - Negotiating access – recruitment strategy

The clinic nurse approached the patient and invited them to speak to me as a researcher from the Anaesthetics Department studying people's experiences of pain. If the patient agreed, I explained the study to them. An invitation letter and a patient information sheet (see appendix two) informed them that we are involved in research looking at what pain means to people and what effect pain has on their day-to-day lives. The invitation letter informed the patients that taking part in the study would require them to talk to the researcher about their pain, it was explained that the interviews would be in English, and that they would be required to complete two questionnaires, one for demographic details, (see appendix four), the other looking at acculturation, (see appendix five).

#### **The setting**

The majority of participants (n=31) were interviewed on the day of their Pain Clinic appointment; a description of these participants is in chapter five. These interviews took place in the Out-Patients Department. The small room had two comfortable chairs and no desk. A small number of interviews (n=6) were conducted by telephone. The reason for telephone interview was that often because of delays in the Pain Clinic, participants were reluctant to speak to me before their appointment with the Doctor in case they missed their appointment; and afterwards some were in discomfort or had been kept waiting for a while, so wanted to return home. I chose telephone interviews rather than visiting them at home as it is a lower cost option in terms of time, effort and money, and is safer. Telephone interviews share many advantages



of face-to-face interviewing such as correction of obvious misunderstandings, possible use of probes. Rapport may be more difficult to establish, however this was counteracted in terms that I had met the participants in Pain Clinic and discussed my study with them prior to telephoning them. Telephone interviews may have smaller interviewer effects however the lack of visual cues could make interpretation more difficult (Bradburn and Sudman, 1979). Care was taken to note whether any differences were noted between face-to-face and telephone interviews.

### **Data collection tools**

#### Demographic details questionnaire

A questionnaire collecting demographic details was devised. The data collected included age, gender, ethnicity, marital status, income, housing, educational attainment, site of pain, duration of pain and diagnosis if known (see appendix four).

#### Acculturation Scale

An Acculturation Scale (Afzal, Finn, Lunt, Gupta, Esmail, Silman and Macfarlane, 2002; Palmer, Marfarlane, Afzal, Esmail, Silman and Lunt, 2007) was administered to the participants who identified themselves as South Asian. The scale is designed to reflect the language, religious beliefs and traditions of culture and lifestyle distinctive to South Asians from the Indian subcontinent. Eight domains are identified;

Language is assessed at two levels, the use of South Asian and English languages both at home and outside the home, and the proficiency of the use of English as a language (understanding, reading and writing English).

Religion, questions enquiring about religious beliefs and practices.

Alienation and belonging, questions relating to whether the participant saw the United Kingdom as their home, and whether they felt part of British society.

Traditions and celebrations, questions relating to observance and participation in traditional South Asian cultural festivals.

Customs, questions enquiring about the participant's fear of loss of cultural identity for themselves and their families.

Media, questions enquired about preference of South Asian or English media of television, radio and newspapers.

Clothing, questions related to the participant's clothing preference (traditional South Asian or Western) at home and outside the home.

Living conditions, question asked about living with family or extended family.

This scale was used as a measure of how acculturated these participants were to the White British way of living. For each item, a participant scored 0 or 1, with 1 being the more acculturated response. Acculturation is important to consider as it may influence the results. A copy of this scale is in appendix five.

#### Semi-structured interview

The semi-structured interview procedure followed that described by Smith (1995). It involved the construction of an interview schedule that outlined the areas of interest to be discussed during the interview. The initial interview schedule was developed from a review of a wide variety of literatures encompassing different disciplines, from my own personal experience of working in a Pain Clinic, and from discussions with my supervisors. The main aim of the interview was to facilitate the participants' telling of their own pain story focussing on what it is like to live with chronic pain on a day-to-day basis. A copy of the interview schedule can be found in appendix six.

The interview schedule was developed using main questions directed towards areas of interest. Each of these main questions had several shorter questions that could be used if the participant struggled to understand and could help 'funnel' them towards the subject. The main questions would be open ended,

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not closed and would invite the participant to say whatever they felt was important about the subject in question. An example of a main question would be 'can you tell me about your pain?' perhaps this is the most obvious question to ask, but if it was too broad for the participants to answer, funnelling questions would include 'how long have you had your pain?' or 'what does it feel like?' or 'how did your pain begin?'.

Whilst devising the interview schedule, I was aware of how each question could be evaluated from both a thematic and a dynamic perspective. Thematically with regard to its relevance to the research theme; and dynamically the questions should promote a positive interaction and keep the conversation flowing, motivating the participants to discuss their experiences and feelings. The schedule was not intended to be prescriptive but to act as a guide for the interview and not dictate its exact course. Participants were asked to talk as freely as possible about their experience of chronic pain and were told that there were no right or wrong answers as it was their experiences that were important.

A good interview requires conversational characteristics yet it is characterised by a systematic form of questioning. My interview questions tended to use the main types of questions proposed by Seidman (1991). Early questions would be introductory such as "Can you tell me about.....?" It was anticipated these questions would help the participants feel at ease and become comfortable being interviewed, whilst at the same time produce spontaneous, rich descriptions about their pain and its affect on their lives in general. Often I encouraged the participant to continue with the non-verbal responses and expression of "umm". At other times I questioned directly what had been said. Often I probed for more information by saying "Can you give me any examples of that?" Sometimes I felt that I needed more specific responses so I would ask, "How did that make you feel?" or "Have you had some experience of that?" A mixture of direct and indirect questions was used to elicit participants' views, and their views on how they felt others perceived their pain. Allowing

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pauses in the interview provided the participants with time to think about their answers and often break the silence with useful information. At times, when I was unclear what the participant was saying, I would either rephrase or try to clarify it, for example “Do you mean that....?” or “..... is that what you are saying?” Active listening is a key skill in the interviewing process.

The interview was semi-structured as in the researcher followed the lead of the participants and referred to the schedule to guide the interview towards the main area of interest when necessary. The purpose of the interview schedule was not to dictate the interview, but served to ensure that as many important areas of focus were attended to. During the interview questions were adapted in response to whatever emerged and the researcher could probe any interesting issues that came to light. Therefore the interview schedule, see appendix, was emergent and reviewed frequently and refined as appropriate.

In order to maintain the flow of conversation, the interview was audio-taped. Minichiello, Aroni, Timewell and Alexander (1990:p134) state, “ *tape recording is one means of obtaining a full and accurate record of the interview. It can enhance greater rapport by allowing a more natural conversational style. The interviewer is free to be an attentive and thoughtful listener. The raw data remains on record*” Nevertheless Minichiello et al (1990:p135) warn that “*problems with tape recording include potential inhibition in the interaction, the feeling that once something is on tape it is indelible and cannot be refuted leading to a possible imbalance in the interaction because of the interviewer’s perceived greater power*”. To address this issue of power, the participants were reminded that they were able to change their minds about participating at any time, and that they will not be identifiable and the tapes will be destroyed once transcription is complete.

## Grounded Theory – the process of data analysis

Initially I chose to carry out data analysis of the interviews manually, using a word processing programme (Microsoft Word 2000) to facilitate cutting and pasting of the open codes. I found this process very cumbersome and switched to computer assisted qualitative data analysis software (CAQDAS) that would aid my analysis. I was aware of several CAQDAS packages commonly used in qualitative research, the University had NUD\*IST and NVivo available. I visited the websites of these two packages and worked through the demonstration tutorials and found them both relatively easy to navigate, and both had strengths and weaknesses, as summarised briefly below in table 7 (Lacey and Luff, 2001). I chose NVivo, a CAQDAS package that is widely used by researchers, my reason for this choice was entirely pragmatic, I found it slightly easier to use and one of my colleagues had successfully used this package before and offered to show me how to use it.

**Table 7: comparison of NUD\*IST and NVivo packages (Lacey and Luff, 2001)**

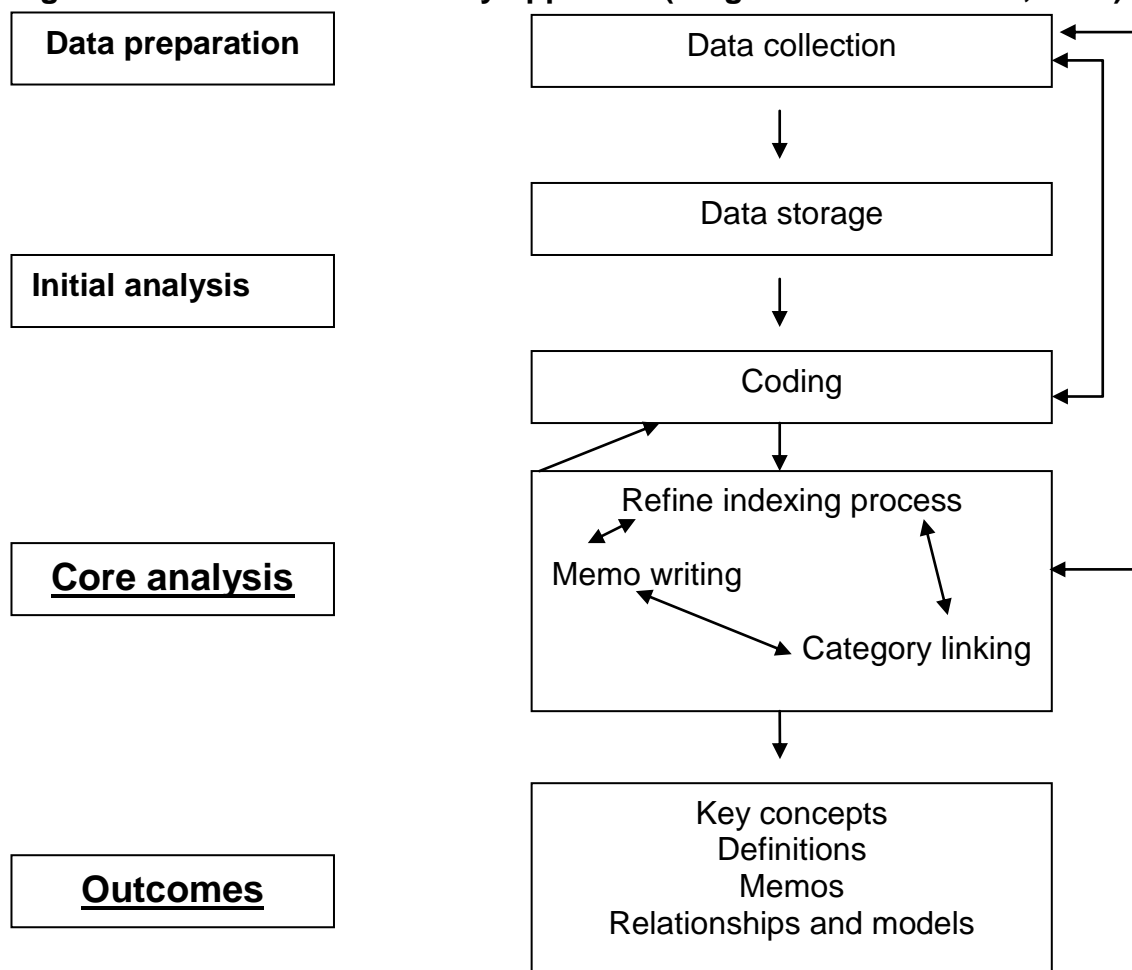
	<b>NUD*IST</b>	<b>NVivo</b>
Strengths	Widely used package, well developed Ideal for coding and sorting narrative data Interface with SPSS	Combines the best of NUD*IST with more flexibility User friendly Good modelling facility Can include hyperlinks to internet
Weaknesses	No graphical facility Limited modelling capacity Limited to hierarchical structure of analysis	Remains essentially hierarchical but more flexibility than NUD*IST
Ideal applications	Large projects needing narrative analysis, coding and organising	Projects using visual and web based as well as narrative sources

A criticism that has been levelled at CAQDAS is that it distances researchers from their data and may be a substitute for rigour of analysis (Barry, 1998), however I only used this programme to aid and record data coding. As the researcher I was responsible for the decisions made in defining emerging categories.

My methods of analysis drew on the Grounded Theory approach developed by Glaser and Strauss (1967) especially the method of constant comparison, which will be discussed more fully in this chapter. This approach was based on how to do Grounded Theory in practice (Strauss and Corbin, 1998). I chose this particular approach as I was new to qualitative research methods and this provided a structured way of analysing the data and identifying categories rooted in the participants' accounts of their lived experiences of chronic pain.

The aim of Grounded Theory is theory generation from the raw data, the researcher looks for the processes involved during interviews from which the theory emerges. The sequences of steps in Grounded Theory are different from other approaches because the process is not linear and involves simultaneous literature review, hypothesis generation, data collection and data analysis. Moreover, the ongoing analysis will direct the researcher's questions and sample selection. The constant comparison of codes and categories occurred throughout analysis using the three levels of coding to develop a theory, open coding, axial and selective coding (Strauss and Corbin, 1998), as illustrated in Figure 1. It is important to stress that analysis proceeds from data to outcomes in only a very loosely linear way. Grounded Theory is an iterative process and researchers often move between steps, or steps merge into one another as analysis progresses, also it is key to move between data collection and analysis continuously. The researcher is constantly moving between induction and deduction in qualitative research, this is summarised by Strauss and Corbin in their version of Grounded Theory as:

*“although statements of relationships or hypotheses do evolve from data (we go from the specific case to the general), whenever we conceptualise data or develop hypotheses, we are interpreting to some degree. To us, an interpretation is a form of deduction. We are deducing what is going on based on data but also based on our reading of the data along with our assumptions about the nature of life, the literature that we carry in our heads, and the discussions that we have with colleagues.....In fact, there is an interplay between induction and deduction (as in all science)” (1998:p136-7)*

**Figure 1: The Grounded Theory approach (Pidgeon and Henwood, 1996)**

In order to present this lengthy process concisely I have broken down the data analysis into four stages; preparation of the transcript for analysis, open coding and generation of preliminary categories, definition of themes and categories, and category incorporation, that is linking the themes and categories. To illustrate this method more clearly I have provided examples to help the reader understand the analytic process enhancing transparency. Providing this evidence and establishing the researcher's commitment to the project are considered to be important criteria in the evaluation of qualitative studies (Yardley, 2000).



### Preparation of transcripts

After each interview, I made notes on the conduct of the interview and what I thought were the main issues of the discussion in my reflective diary. This information was referred to throughout the process of analysis. I transcribed all the interviews verbatim and this served as the raw data for this thesis to be analysed using a Grounded Theory approach. The transcription notation that will appear in some of the extracts used in the analysis is as follows

... pause

[text] clarificatory information

I carefully checked the initial transcript against the recorded interview and made corrections as necessary, noted para -verbal cues such as laughter, tone of voice as appropriate. I made further notes on the salient issues of the interview in my reflective diary.

### Open coding and generation of initial categories

This process begins by looking in detail at the transcript of one interview before incorporating it with others. The transcripts were read and re-read closely in order to become as intimate with the account as possible, as each reading had the potential to reveal new insights, therefore open codes were applied to each one in turn. A line-by-line analysis or microanalysis (Strauss and Corbin, 1998) was undertaken and the text broken down into a multitude of codes, which I felt reflected the meaning, or considered to be important or significant in each sentence or group of sentences, these were noted down in the left margin of the transcript. Initially some of the comments were attempts at summing up or paraphrasing, some were associations or connections that came to mind whereas others were preliminary interpretations. The generation of codes proceeded sequentially. Open coding develops and identifies concepts by asking questions of the data and comparing instances of the data, for example "What is this?" "Is it the same as or different from?" As coding

progressed groups of coded instances were gathered together into categories. Throughout this stage the codes were constantly compared with each other, and memos relating to the codes and possible category generation were written as appropriate.

In the following example the notes on the left margin focus on how the participant struggled to understand chronic pain and its effect on her. The right margin was then used to document emerging concepts, using key words to capture the essential quality of what was found in the text:-

Shoulds, ideals, expectations, age appropriate, frustration, bothered, other people, restrictions/limitations, comparisons with others	"I'm only 57 and I should be doing this and that and the other cos they say life begins at 40, but I can't and it does bother me, its frustrating people of my own age are doing things and you feel as if you can't" (P5, White British female)	Limitations/ restrictions Mood Social comparison - others
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This process continued through the whole interview, making preliminary notes in the left margin first, and then proceeding to identify concepts in the right margin. All of the transcripts were treated as potential data and no attempt was made to omit or select particular passages for special attention.

Using the sequential list of open codes, an initial coding frame was set up. All of the transcripts were read and re-read many times to identify codes and

explore possible links between the codes. It became apparent that some codes were unclear therefore required either re-coding or further clarification. Memos were written linking various codes into categories as the constant comparison process continued. When the open codes had been read the process of categorisation continued with grouping linked codes together into key categories and concepts.

Example of a code note relating to open coding.

## CODE NOTE

Oct 2005

### CAUSE OF PAIN

P1 South Asian male

Asking what he thought the cause of his pain was

"well, I had this disc problem, umm, in my back umm and umm it was just it was just a freak accident basically....I was just getting out of the car"

He describes what he believes to be the cause of his pain he believes it is the result of an accident. He is giving his pain a diagnosis (label), maybe offering justification as to why he has a bad back.

Can hypothesise from this about the importance of labelling/ diagnosing the pain

- Providing genuine reason
- Proof that something is wrong
- Fear of being thought a malingerer
- More able to come to terms with it if there is a reason for it
- Needs to be taken seriously

### LEGITIMISING PAIN, DIAGNOSIS, DISBELIEF

"accident"

Can hypothesise that he has no control over the event that caused the injury, it was out of his hands, just happened. Does this reflect his feelings of no control over pain or his life with pain

### NO CONTROL (feelings/ emotion =mood)

"just getting out of the car"

Can hypothesise this is an everyday activity we take for granted

- Why/ how does this cause pain
- No reason for this to cause pain
- Accepts no responsibility for being in pain, just happened, doesn't acknowledge twist/turn whilst getting out car may have caused pain
- Does this reflect lack of understanding about pain and condition

### LIMITATIONS / RESTRICTIONS

Example of theoretical code note:

### THEORETICAL CODE NOTE

Referring to code note causes of pain P1 Oct 2005

Other possibilities of causes of pain – things to consider

Pain caused by injury v.s disease

Consider injury – does type of accident, place of accident impact on type of pain i.e. RTA – whiplash? Work (lifting) – back? Expectations that acute pain injuries get better, but haven't in this case. Is it more difficult to deal with injury pain than having pain from disease?

Consider disease – different types of pain – neuropathic, noiceptive  
If have diagnosis (label / reason) for pain is it easier to accept or not?  
Are expectations different? Can cope/ manage with pain better as having label makes it easier to get information about their condition?

Emotional pain / distress

Caused by physical pain? Caused by restrictions/ limitations to life?

Does this cause over time? How? Why?

LINK TO MY CAROUSEL IDEA – timeframe, highs and lows of mood

EXPECTATIONS, SUBJECTIVITY, MOOD

Examples of operational notes:

### OPERATIONAL NOTE

Referring to code note/ theoretical note - causes of pain P1 Oct 2005

SHOULD HAVE ASKED:

- Who gave diagnosis?
- How was it given / explained?
- What does this mean to him?
- Does he understand the diagnosis?
- How does this make him feel?
- Explore issues of labelling – think about why/ how does it help in therapeutic encounter

Consider these ideas in future interviews

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**OPERATIONAL NOTE FOR SAMPLING**

Referring to code note/ theoretical note - causes of pain P1 Oct 2005

Potentially many different causes of pain, so several areas to investigate further

- Cause – disease v injury
- Different types of disease
- Different types of accident
- Where accident occurred
- Different areas of pain
- Demographic details

**Defining themes and categories**

A summary was written of the emerging categories from the transcripts, which included detailed specifications for each category. These definitions were used to code the subsequent interviews in terms of axial coding of focussed coding (Charmaz, 1995). Axial coding uses the same processes as described above to relate categories. The process is enhanced by the use of Glaser's (1978) theoretical codes, which are often referred to as the "six c's" (Swanson, 1986) – causes, contexts, contingences, consequences, co-variances and conditions, or by what Strauss and Corbin (1998) called the 'paradigm model'. All categories were liable to analytic memos. Memo writing is a crucial part of the process as it allows exploration of categories, relationships between categories, linking in with the relevant literature and the emergence of theoretical reflection upon these.

### **Examples of axial codes**

Limitations / restrictions

Consultation process

Visibility of pain

Difficulty in expressing pain

Embodiment

Diagnosis

Gender

Social isolation

Age

Legitimisation of pain

Mood

Ethnicity

Comparison to others

Meanings

Disability

Impact on daily life

Future

Understanding of condition

Expectations

Fear

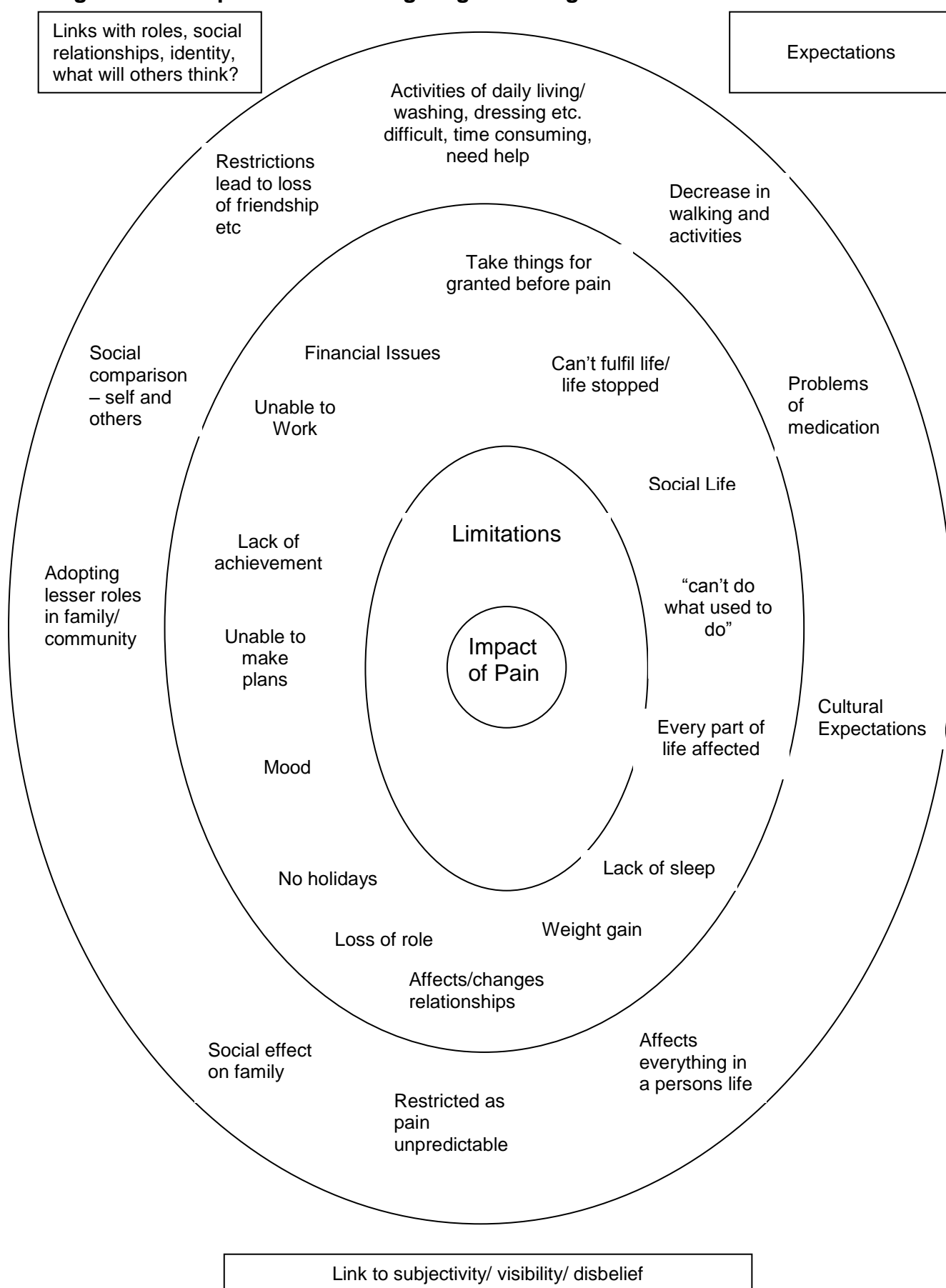
Sensation

Information seeking

Uncertainty

Treatment seeking

Returning to pain clinic

**Figure 2: Example of axial coding diagram using the code limitations:**

### Category integration- linking themes and codes

The themes, categories and memos were constantly compared and further analysis memos written linking the categories. Selective coding is the process of integrating and refining the theory. In integration the categories are organised around a central explanatory concept. Integration occurs over time, and once a commitment is made to the central idea, major categories are related to it through explanatory statements of relationships. Drawing concept maps (Miles and Huberman, 1994), writing the storyline and sorting and reviewing memos that illustrated important links between the categories aided the process.

When the theoretical scheme was outlined, the researcher is ready to refine the theory, by trimming off excess and filling in poorly developed categories until they are saturated through further theoretical sampling. Finally presenting it to chronic pain patients for their reactions validated the theory.

“A theory that is grounded in data should be recognizable to participants, and although it might not fit every aspect of their cases, the larger concepts should apply” (Strauss and Corbin, 1998)

My analysis was completed in association with my supervisors who checked codes, clusters and categories at intervals throughout the study by seeking justification and by challenging inadequacies.

### **Maintaining quality within the analysis**

Yardley's (2000) criteria for maintaining quality within the analysis were adopted in this thesis. This section highlights how they were observed in this study.



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Sensitivity to Context – Evidence for this is shown in the introductory chapters, which aim to establish the position and commitment of the researcher both to the subject that is exploring the lived experience of chronic pain patients, and the approach that was adopted. The analysis is presented in such a way as to highlight the value given to the participants' words and in each of the discussion sections care is taken to evaluate the findings in relation to the literature from a wide range of research approaches.

Commitment – Care was taken to show that this research was a serious attempt to understand to: develop our understanding of chronic pain in different ethnic groups focussing on the subjective experience; establish the case for using Grounded Theory; explain the reasons for the specific focus of the research and show evidence of an in-depth understanding of the area.

Rigour –The use of triangulation and the presentation of sufficient data to support the statements in the study were important criteria and a valuable audit tool for quality. Triangulation took the form of showing evidence for each emergent theme in the transcripts of several participants. By using the different participants' accounts the variations within each theme could be explored and articulated. The process of Grounded Theory ensured that at each point the categories could be related back to the transcripts and notes were available to my supervisors to help explain how particular categories were selected, and to provide material for an internal audit of the process.

Transparency – To ensure that the emergent categories were both coherent and grounded in the data a sample of the transcripts were looked at independently by my supervisors during analysis. During my supervision sessions we discussed our readings of the transcripts and came to agreement on the categories. My supervisors also checked on the emergent analytic account, particularly to monitor for clarity, persuasiveness and the degree to which the categories were evident in the data that was presented. Making the analytic process transparent was one of the reasons for describing the data

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analysis method in detail and providing extensive examples of the data in the results section.

Impact and Importance – To support a case for the impact of this research the emergent themes and categories were related to the findings from a broad range of approaches to chronic pain research. The aim was to show the relevance and applicability of the findings and to emphasis the degree to which it offered a new and useful perspective on the subject. The utility of the research is evident in chapters eight and nine, which discusses the implications of this study for further research and clinical work.

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## Summary

Semi-structured interviews were the method of data collection used in this thesis to provide information about the lived experience of chronic pain patients. Concurrent data analysis using the constant comparison method of Grounded Theory, incorporated literature with participants' views to provide further explanation of what it is like to live day-to-day with chronic pain. Grounded Theory was pertinent to the theoretical perspective adopted and the research question of this study. It required the selection of situations where the concepts associated with the lived experience of chronic pain would most likely be found. It also provided a clear way of analysing data, which in turn, was easily audited, on the criteria for maintaining quality in qualitative studies.

The presence of the researcher in the data means that my interpretation may well be different from that of another investigator. Grounded Theory along with phenomenology depends heavily on the researcher's use of self; *"researchers use themselves as both data elicitors and processors"* (Lipson, 1991,p74). This area of research is about people with whom I am familiar with and about whom I have a passion. Therefore it is important for me to separate what I say and what others say, but that does not mean that I leave "me" out. *"Strauss said something like: 'Everything is data, including everything that is happening in your life'"* (Stern, 1994:p212). Furthermore my interpretation is not mine alone, but one in action with the participants. *"And Glaser said: 'the best way to approach a subject is to say to the person "teach me" – so they're co-investigators as well'"* (Stern, 1994:p212)

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## **Chapter 5 – Research Findings**

### **Introduction**

The participants' accounts reveal the complexity and the variety of their chronic pain experience. Despite their struggle to understand chronic pain, they gave rich and extensive descriptions of what it is like to cope with chronic pain on a day-to-day basis, as evidenced in the extracts quoted. Following the data analysis presented in chapter four, this chapter will present a model developed from the categories that have emerged from the data: cultural expectations; consultations with health professionals; dissatisfaction with the consultation; disbelief; subjectivity of pain; identity; social relationships; impact of pain; coping strategies and information seeking, all which are overarched by affect. The model is then illustrated by being broken down into individual units to highlight the key issues the patients address.

### **Participants**

Of the 37 patients attending the chronic pain clinic at a large teaching hospital, 9 participants were new patients to the pain clinic whilst 16 were patients who had previously been seen in the pain clinic and are described as follow up patients. The majority of participants (n=30) reported back pain as their main pain, of these 5 reported back and leg pain, and 3 reported back and neck pain. Other participants reported shoulder pain (n=3) abdominal pain (n=2) diabetic neuropathy (n=1) and fibromyalgia (n=1).

Of these 37 participants, 12 were male, 25 were female, and their age ranged from 29 to 79 years (mean = 53.84 years, standard deviation = 12.80 years). With regard to marital status, 29 were married, 3 single, 4 divorced, 1 living with partner. 24 participants were not currently working, of those 4 had retired due to age rather than ill health or pain, 13 were employed.

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The participants had a wide range of religious backgrounds, they self reported as Church of England (n = 12), Church of Scotland (n =1), Roman Catholic (n = 1), United Reform Church (n =1), Methodist (n =1), Hindu (n = 6), Sikh (n = 3), Islam (n = 1), Muslim (n =1), Jain (n=1), Not religious (n = 9)

Their self-reported ethnicity indicated that 24 participants described themselves as White British, 23 of those were born in the UK, 1 was born in India; and 13 participants described themselves as South Asian, (South Asian refers to people of Indian, Pakistani or Bangladeshi origin); (Asian-Indian n = 9, Asian n = 3, British Asian-Indian n=1). 8 participants reported their birth place to be in South Asia, and had all lived in the UK for over 20 years, and 5 participants describing themselves as South Asian were born in the UK. A summary table of the demographic information can be found in appendix seven.

As theoretical sampling was used in this study, not all the demographic details were representative of those attending the pain clinic. From the data available shown in chapter four, tables 2-6, I would suggest that new patients, and in comparison to national numbers South Asian patients are over represented in this study, however as this study was looking at South Asians beliefs, they needed to be adequately represented. When comparing research data looking at pain clinic samples I would suggest that this sample in terms of age and gender seem to be representative of the clinic population. Reflecting on my own personal experience of working in a pain clinic I would suggest that this sample seemed representative of chronic pain patients in terms of their type of pain and marital status. From observations whilst sitting in the clinic waiting room and discussions with the clinic co-ordinators, and some staff involved in running the clinics, I would suggest that the sample did not exclude many potential non English speaking participant's as most 'South Asians' attending the pain clinic spoke English. However obviously some people that attended did not speak English so usually brought a family member to interpret, and these people could not be included in the sample.

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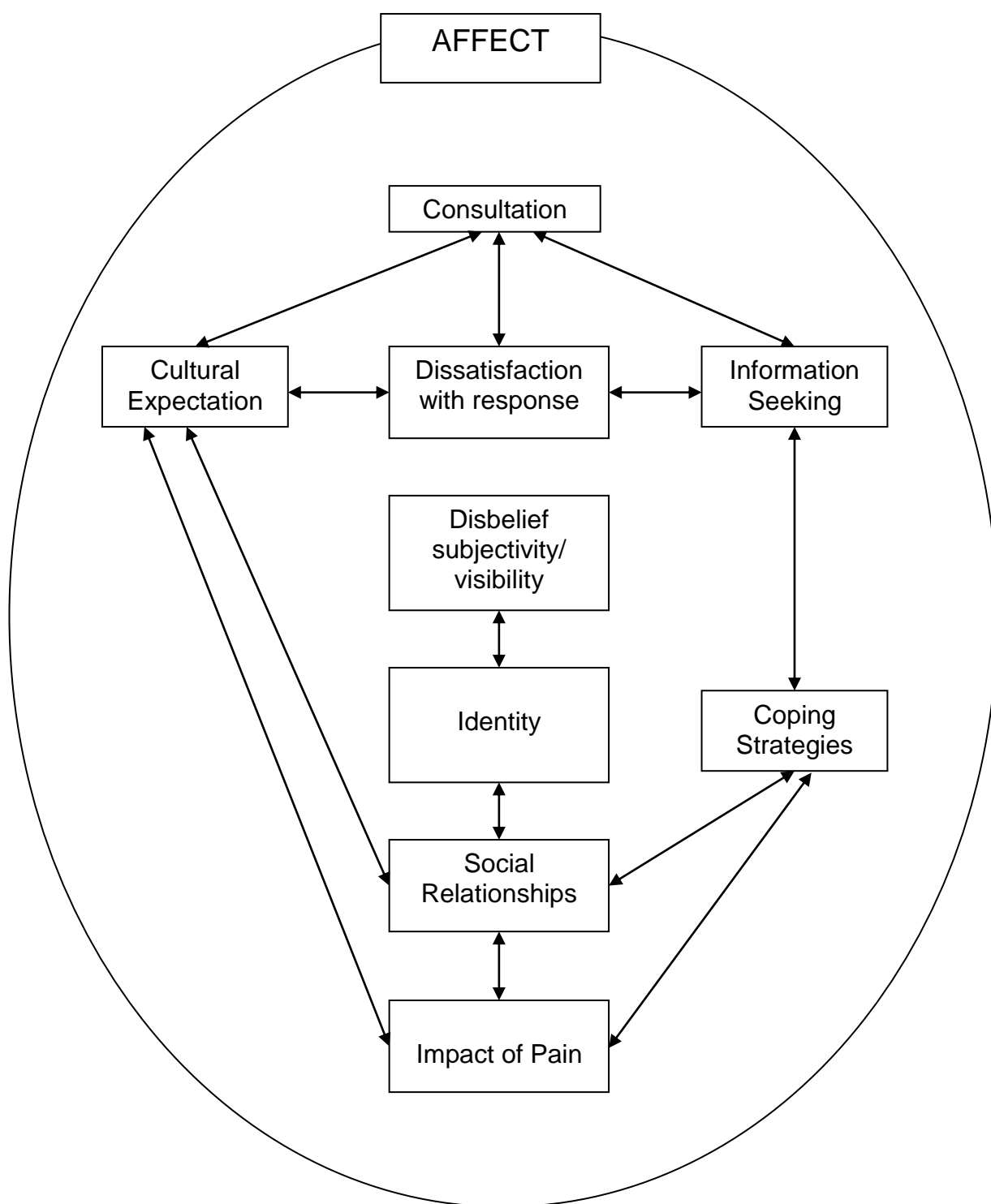
Looking at the data in chapter four, table 5, I would suggest that the clinic population is not representative of the catchment area. At the last census (2001), 25.7% of residents in the city of Leicester described themselves as Asian or Asian British, Pakistani, Indian or Bangladeshi making this the largest Indian population of any local authority area in England and Wales which is both a strength of the study and a concern, this will be discussed later in chapter eight.

Acculturation has been described as the extent to which an individual, who migrates from the country of birth, adopts the values, beliefs, cultures and lifestyles of their host country (Mavreas, Bebbington and Der 1989). Acculturation has been perceived to have both positive and negative effects on health. It has been suggested that the greater the level of acculturation, the less likely that environmental factors will explain differences in health outcomes between immigrants and individuals born in the country (Deyo et al, 1985). Looking at some acculturation factors in this sample, all 13 participants who described themselves as South Asian spoke and understood English, 12 also could read and write English. Other languages used on a daily basis to communicate at home, with friends and neighbours or at work were Urdu, Punjabi, Gujarati and Hindi, although English was the most commonly used language at work (n=8). With regard to the media, most participants (n=13) watched or listened to South Asian and English languages equally; the majority (n=12) read mostly English language newspapers. The majority (n=9) lived with their spouse, or with their parents. At home the majority (n=10) wore Western and South Asian styles of clothing equally, however the majority (n=11) wore Western Style clothing outside their homes. All 13 celebrated traditional South Asian cultural festivals. It is suggested that this sample were relatively acculturated by the criteria previously listed.

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### **The model developed from my research**

I will present an overview of the model, followed by a detailed description of each category. The model for people living with chronic pain that emerged was a mesh of nine categories that are shown in figure 3. Within these categories properties and dimensions were identified and are presented. The categories are interrelated through statements of relationship to form the theoretical framework that explains this psycho-social phenomenon, although they are presented here as separate units for the sake of graphical representation. The findings of this study and the model that emerged from the data established the theory that the key areas that influence how people live with their chronic pain on a daily basis are their perceptions of the consultation with the health care professional and the actual experience of living with pain, affect is intrinsically woven within these factors. The 'South Asian' participants reported similar experiences of living with pain on a day-to-day basis as the 'White British' participants. Therefore it appears that the experience of living with chronic pain is more important than demographic factors, acculturation may remove differences in the pain experience, or that the experience of living with chronic pain is the same irrespective of culture.

**Figure 3: Model developed from my research of living with chronic pain**



Everyone has certain beliefs and expectations about pain, these are often based upon our own experiences or experiences of others, such as the pain will go away, medicine will cure pain, there has to be a reason for pain. Sometimes our knowledge of pain is based on stereotypes. Stereotypes are a set of widely held generalisations about characteristics of a group or class of people. Examples from a 'White British' point of view could include women do not express pain as much as men, men do not cry (Bendelow,1993). Reactions, beliefs and expectations are learnt so could have potential to be culturally different. All of these beliefs and expectations are brought to the consultation with the health professional.

From the experience of the participants, the consultation is not always a successful experience as often there is a mismatch in views between what the participant expects and what realistically can be offered by the health professional. Often the health professional is not the healer that they are expected to be by the participant, as the participant is seeking treatment and a cure for their pain rather than help to live with their pain. Issues arising from consultations include the attitude of the health professional, the differences in attitude between pain clinic team members and other health professionals as perceived by the participants. Often participants reported that their treatment is ineffective and despite having prolonged contact with health professionals they still have very limited understanding about their pain. Lack of diagnosis is particularly problematic for the participant, as they believe that if they could give the pain a name or a reason, then the health professional would be able to treat it, or at the very least the participant would have a legitimate reason for not being able to take part actively in life as they had in the past. This lack of diagnosis often leads participants to feel disbelieved not only by health professionals, but their own families, friends, neighbours and work colleagues. Often participants would retreat into their own world of pain and feel able only to talk about their experiences with others in a similar situation.

The lack of visibility of chronic pain emphasised their perception of disbelief, which in turn affected their social relationships and often changed their identity in terms of changing roles. This change impacted significantly on their lives, often causing great upheaval as jobs and friends have been lost and finances become a constant source of worry and stress which in turn leads to increased pain.

With their worlds changing but chronic pain remaining, many participants try the hierarchy of coping strategies, firstly turning to learned coping strategies such as over the counter medication, hot water bottles, ice packs and rest which may have been successful in relieving acute pain in the past. As the pain remains, they try conventional Western medicine to seek pain relief. When this fails some resort to trying complementary therapies, with varying degrees of success. With the hope of finding a cure diminished, there is a realisation that nothing substantial will cure the pain some resort to using the desperate phase “I’ll try anything” and keep returning to their GP or the Pain Clinic in the hope that one day there will be a cure for their pain.

There was an overriding belief that eventually medicine will cure the pain, regardless of how long the participant had pain, even if it meant continually coming back to the pain clinic:

*“well if they can keep in touch and keep modernising things hopefully they’ll come up with something that will stop the pain or at least relieve it, take it away for at least part of the day even, but umm.....I’m not hopeful but I keep coming back” (P6, White British female).*

*“Erm I hope that they will find something that will take it away, I think you have to hold on that erm maybe next time, I come to the clinic it’s going to be effective or I’m having a different procedure, sort of pin my hopes on that, this will be it, this will take it away but I suppose on a day-to-day basis with living*

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*with it every day, its very hard to look to this time next year, I might not have the pain because I think you live with the pain and it's there all the time, its very hard having had it this length of time to think it will go away and not be there one day.... I think you do because I can't speak for other people but myself I come to clinic, I have an appointment I'd think ooh this time next week it might be better or this time next month, next time I come to clinic it will be better, then you've got to the clinic next time and you're no better than it was, so it sort of moved the goal posts again, and it's no better, and now I've just got into this is what I've got, but the dream, the little bubble far off is that one day it won't be there but I can't have I can't put any perception on to this time next year this time in 5 years it might be gone away, I suppose I don't want to pin my hopes on everything but you know it may well be looking at it in the cold hard light of day that this is what I have got to live with this is what I've got to put up with but I don't think you can lose that hope you know one day it may all be gone.” (P15, White British female).*

From the first disappointing consultation they are constantly seeking out information about their pain or any condition that they feel might have contributed to the pain in some way to try and justify their pain and their behaviour. Sources of information varied from buying magazines that had 'beat back pain' on the front cover to detailed searches of the internet and membership of support groups. This collected information is then brought back to the next consultation and discussed. Depending upon the outcome of the consultation, if the participant perceives the consultation as a negative experience, the participant goes back through the process as outlined in figure 3.

Affect was the overarching theme, this can be defined as a “general term used more or less interchangeably with various others such as emotion, emotionality, feeling, and mood” (Reber, 1985) This seems to sum up the participants better than labelling this category mood because mood can be defined as “any relatively short-lived low intensity emotional state” (Reber,

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1985). Participants talked about and reflected upon their emotions, feelings and mood in every category, see table 6. Rarely were they optimistic and hopeful, but more often desperate for a cure or resigned to having chronic pain indefinitely. Affect will influence the participants' perception of living with chronic pain and therefore how they view the consultation process, their social interaction with family, friends, employers and society in general. It will influence their motivation to seek out information about the condition in terms of treatments, 'cures' and ideas to try as coping strategies. Throughout the interviews a whole spectrum of emotions and feelings were expressed ranging from frustration, embarrassment, fear, depression, feelings of guilt and inadequacy, as may be expected from participants who have had chronic pain for many years, this will be further explored later in this chapter.

**Table 8: properties and dimensions of affect found in each category**

<b>Category</b>	<b>Properties and dimensions of affect</b>
Cultural expectations	Self blame, fatalistic, hope, frustration, bewilderment
Consultation	Initial hope, anger, frustration, dismissed, not believed, fobbed off
Dissatisfaction with the consultation	Bewilderment, disbelief, desperation, seeking justification, upset, frustration, lowered expectations, despondent, resigned
Disbelief/ Subjectivity of pain	Uncertainty, vulnerable, defensive, need to justify, frustrated, obliged to seek treatment, anger, misjudged by others
Social relationships	Misunderstood, not believed, worry, guilt, let down, rejected
Identity	Frustration, 'should', denial, loss, fear of future, despair, grief, burden, miserable, boring, irritable
Impact of pain	Catastrophising, frustration, unpredictability, decreased self esteem and confidence, worried what others think of them
Coping strategies	Frustration, hopeful, let down, desperate
Information seeking	Hopeful, fearful, frantically searching for a cure

This section has outlined the theory of how patients live with chronic pain on a daily basis. The following section presents the categories, properties and dimensions to illustrate the theory.

## Cultural expectations

Cultural expectations in this thesis refer to the pain and treatment beliefs that are adopted by pain patients and subsequently brought to the consultation. Pain beliefs can have a profound effect on clinical care, they can promote good health care but unhelpful pain beliefs can be barriers to health care. They can impede preventative efforts, delay or complicate medical care, resulting in the use of harmful or neutral remedies (Flores, 2000). Beliefs have been defined by Lazarus and Folkman (1984) as assumptions about reality which serve as a perceptual lens, or a 'set' through which life events are interpreted, therefore shaping the patient's understanding of their environment. Wide ranges of cultural expectations were discussed with the participants and commented upon, such as gender, age, cultural/ ethnic background, religion and fate, and if the pain experience such as behaviour or coping strategies are learnt. Most participants had experienced acute pain in the past, which resolved as the injury healed. Therefore because of this experience of pain they expected pain to go away, not continue way past healing time, which added to their confusion regarding chronic pain.

*"I've had lots of aches and pains, broken bones and such in the past you know, but the pain eventually went.....this (pain) is going on forever you know" (P16, White British male).*

*"...my pain usually goes after a while, but this [pain] just keeps hanging on" (P35, South Asian woman).*

Participants expected there to be a reason for their pain. Many had no answer to why their pain remained except to imagine the presence of physical damage or deterioration:

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*“well I thought you had pain to tell you there was something wrong” (P1, South Asian male).*

*“it [their back] still hurts there is something wrong with it, but doctor doesn’t know what, so that’s why I’m here [at the pain clinic] (P32, White British female).*

Participants were at a loss to explain the persistence of their pain in any manner that was meaningful to them beyond the notion that ‘there was something wrong’, something biomedical which demanded attention. Their disbelief and bewilderment prompted frustration, anger and sometimes despair:

*“... have this image that, yeah, you’ve had that done or you’ve been diagnosed with that, so you should be better now” (P32, White British female).*

*“uhh like I said people have recovered and it’s brilliant and it’s a common thing back pain and I’m wondering why I haven’t recovered” (P1, South Asian male).*

When exploring ideas and expectations about how pain is understood, whether or not we learn how to respond to pain from our parents, surprisingly one participant suggested that actual pain is passed through the generations.

*“Erm, yes, and then I thought it was because mummy died with TB, erm, you know, that had been passed, the pain was passed from one person to another, you know. Like now, that if your grandmother had cancer, then you know, it may be passed down”(P25, White British female).*

Some participants felt that the way they responded to pain was learnt from their mother's responses to pain during their childhood.

*"I actually think you learn it from childhood in a sense.*

*DO YOU?*

*You fall down, you hurt your knee, you cry. I get up, my back hurts, I cry. So, the degree might be different but the response might be the same. I don't know, I don't know whether it's inbuilt. When you're a kid, you know if you cry you get a hug.*

*SO DO YOU THINK YOU CARRY THAT ON AS YOU GET OLDER?*

*I think you do. I think you tend to revert to, er, back.....*

*WHAT MAKES YOU SAY THAT?*

*Because when you're in pain, whether emotional or physically, if somebody gives you a hug, you feel better already. It doesn't matter what the pain is, it's the emotional thing that somebody cares."(P30, White British female).*

Other participants felt that their behaviour was learned from their parents but the way they responded to their pain was different but it seemed similar to their parents, in that this participant illustrates that she states that she would not talk about her pain per se, but would talk about how the pain made her feel.

*"Err, in my case, I think my behaviour is learnt from my mother (laughs) because my mother is that sort of person who doesn't show her feelings, although she talks, you know, she talks about things but not about personal things, but in that way I am a bit different from her because I do, if I feel I can talk to someone I do talk about my feelings and things like that, but, err, in a pain wise, or if I got something wrong with me, I don't make big thing out of it, you know, I wouldn't even tell my husband that, err, you know, I got this." (P21, South Asian female).*



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The participant quoted above felt that this was because she had moved from India at the age of 20, and had adopted a more Western approach.

*“Yeah, yeah, she (her mother) still does (laughs). Yeah, you know, although she was in a pain or whatever, or she was suffering she wouldn’t say to us. Even to this day there’s things, you know, I still don’t know about. You know, I was brought up, that, umm, well that is the old way of thinking, you know, that the woman should, you know, do this and that and that sort of thing but because I moved away from that culture when I was 20 to this country, so its like part of me growing in this country. I lived there 20 years and been to this country for last 20 years plus, err, I am more educated than my mother, she wasn’t educated at all so you are different in some ways as well, and so that way I am quite broadminded so my children are the same way and, err, they talk about their feelings, you know, more often. And they have different point of view about women as well” (P21, South Asian female).*

Some participants felt that you could learn about your pain from other people, but that others could not experience pain in the same way as themselves.

*“I mean, you can learn about it, and you can try to help people with it, but I really think that until you’ve experienced it, you, you don’t fully grasp just how bad it is.” (P33, White British female).*

*“you just can’t understand how bad it is, until you get it, you’re totally unprepared for it even if you know people who have pain” (P1, South Asian male).*

*“I think it’s ..., it’s hard to understand, ‘cos unless you’re going through it, it’s er, kind of, when you’re going, you know when you’re in pain, you trying to understand, when someone else is going through it, it’s very, very difficult. To*

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*decide what kind of pain or what level of pain you're going through" (P37, South Asian female).*

*"...others in pain try and say they understand like my sister, she has arthritis, she always says I understand, but I doubt that she really does as she doesn't have the same pain as me" (P11 White British male).*

Whilst other participants reported that pain is not a learned experience and that:

*"You learn through your own experience, because everybody's got different thresholds to pain, haven't they. I mean, some people, sort of, cry over a finger ache and others will have their finger sliced off and not even bat an eyelid.....Well I think it's something you'd have to know and to learn to live with, you know. It's sort of, nothing you can condition yourself for really."* (P29, White British male).

*"everyone is different, you just deal with it yourself" (P12, South Asian male).*

Discussing the stereotype that women show, express pain less, or cope with pain better than men produced interesting responses. All the participants reported that the main reason for this was, to sum up:

*"women have babies and women's troubles" (P12, South Asian male).*

*"...women have to deal with their monthlies and childbirth so have to deal with pain" (P3, White British female).*

Most women commented upon 'man flu' often in a jovial manner, and that if men had a cold they would generally take themselves to bed and expect their wives or partners to look after them, and even the male participants commented on this.

*"Um my experience has been that men make a lot more fuss about it. Although I have to say that my husband is with his arthritis and his knee isn't so it's quite unfair to say that really, regard him as a bit of a wimp in some classic areas of pain. You know if a man's got a cold it's off to bed whereas women I think tend to get on with it a bit."* (P5, White British female).

*"Well obviously men are always in a lot more pain than women! (LAUGHS) That goes without saying. If any bloke has a cold, he's got to have a month off work. I suppose, erm..."* (P27, White British male).

Female participants reported that they felt obliged by their roles, as wives, mothers and carers and their responsibilities to keep going despite their pain. It is often the case that being unable to fulfil these roles that caused them distress, this is reported later in the chapter.

*"I think men exaggerate a little bit more than women, because it still in a way that women are seen as the carers in their family and we do three time more work than men, maybe we don't get paid for it (laughs), so, umm, yeah so just take it for a headache, you know, we just carry on take a tablet and get on with it and while men even if they take a tablet they still lay on the settee and play on it, pass me that and pass me this, I know I got a headache (laughs). I don't think it is expected by anybody. I think a women's point of view is that we are expected of doing things so we just do it without any question. It's not that somebody is telling us we should do it, we just do, we are just expected to do it."* (P21, South Asian female).

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*"If my partner had pain, she would get on with things cos she's lots to do looking after the kids and that" (P12, White British male).*

Some participants felt that it was not the actual pain experience between genders that was different but it was more related to stereotypes that exist such as the macho image and differences in coping style.

*"I don't think they experience it differently, but they handle it differently.*

*WHAT MAKES YOU SAY THAT?*

*Well I think even today, we've still got the macho image that the men, the testosterone if you want. In fact Pete (her husband) hurt his back and I said look I'll book you in to see Lizzy, er, Lily (physiotherapist) and, you know, have a look at it. I'm alright, it'll wear off. Whereas I think a woman would say, yeah I think I ought to get it looked at....yeah. And I think also men are more frightened to get medical assistance than women." (P30, White British female).*

It was reported that although initially men and women coped with their pain in different ways, over time it was considered that they had to adopt similar coping strategies to enable them to live their lives with chronic pain.

*"Yes, I think probably on the whole they (women) do (cope with pain). But I think when it initially starts, I think if erm, a woman is ill for a short while, er, then, or she has pain for a short while, she'll tend to think, well I've got to get on, I've got to do this for the kids, blah, blah. Where as I say, the guy will probably take to his bed. But I think possibly long-term, as in my case and a lot of people's cases, I think it evens out because even men being whoosies, I think you have to look at and think I've got to deal with this, otherwise I'll just be consumed by it. So I think to start off with, they may cope, women may cope better. But I think it evens out, I would say." (P27, White British male).*

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*“....initially women cope better than men despite their pain because it’s in their nature, over time it evens out cos men suddenly realise they can’t stay in bed forever they have to get on with it ....so, yeah, it (coping with pain) evens out over as time goes on” (P3, White British female).*

Some participants felt that gender did not really explain pain differences but that it was more likely to be related to attitude, social support and personality.

*“Erm....I don’t know. I don’t know whether that is purely because I have seen um, different experiences with men myself, like, because I’ve seen men react different. I mean my ex-husband couldn’t accept anything of it at all, and, or if he got a pain himself, the earth, the world was ending. And, whereas on the other hand, my dad’s like, 67, and I can see him fight with pain for as long as what I have. But he gets on with life and doesn’t let it affect him,. So, its, I think its.....like an individual thing, it closely depends on the attitude of the person” (P32, White British female).*

*“Yeah, I think so, because I think you’d get different, I think you get on the gender side of it, I think you’d get people that would battle through whatever, and people that would, you know, um, try and make the most of it. So I would definitely say personality, yeah.” (P30, White British female).*

Exploring stereotypes and pain beliefs further, discussions were brought round to the topic of culture and ethnicity. Many participants felt that they could not offer an opinion in these areas, as they had no experience of it. Others recalled pain behaviour that they had seen on the news. Both ‘White British’ and ‘South Asian’ participants shared the view that ‘White British’ people were more stoical about pain. Despite the traditional mind-body split, participants often talked of emotional pain as being the same as physical pain, in particular when discussing cultural issues as is illustrated in the following quotes.

*“Not really personally, but when you see the, erm, some of the horrific pictures and things on the news, you get people from the, erm, the er, Iraq and places like that, even the men, if they’re upset because there’s a death or something like that, they’re a lot more, their culture, they’re a lot more visual with it. They will jump up and down and tend to scream. I saw it on TV a couple of weeks ago, there was a bomb in Baghdad, and all the men were jumping up and down screaming and smacking their faces, but that’s obviously a cultural thing. I don’t understand what it means, but I don’t understand how that personally would help, erm, so as like our culture, you know, if someone dies that you feel for, erm, you tend to be, yes, you might cry and be upset, but you’re a bit more reserved with it. Not quite as, I don’t mean to be disparaging to any foreigner, but it’s more a visual thing, they wear their heart on their sleeves, you know. Whereas, like I say, we seem to be a little bit more reserved. That’s the only comparison I can think of.” (P27, White British male).*

*“Having lived abroad I’ve seen terrible things but having said that they shout more about it. They’re much more verbal about it*

*WHAT PEOPLE WOULD YOU SAY?*

*Asian people mostly....*

*IS THAT WHERE YOU LIVED?*

*Yes. They shout and scream and yell and ... you know they’re in pain but they let you know about it.....I just think it’s just how they are, the women are taught to show their emotions by crying or what have you and the men will just shout so I think even Arab countries women make noises and yell. It’s Asian way of grief you know. I think so anyway” (P6, White British female).*

Some participants drew on the knowledge of their own traditional culture and from the culture that they lived in, when considering both physical and emotional pain, responses to pain and responsibilities for those in pain.

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*"I've seen people who are in pain and I believe certain communities and cultures are more tolerant to pain than other people, I mean there are a lot of Asian girls, when they have pain, some how they just give up , and I think ok I've got this pain oh ha complaining every time, its not really going to get anywhere, I mean I it's amazing I see that, a lot of the thing is part of our Asian culture the way we live, our lifestyle umm but then I see a lot of white folk during pain but they'll still be out shopping in their buggies, I really respect that and I think to myself it's amazing , you know, that they can actually do that. Uhh a lot of elderly Asian women once they're in pain they feel that's the end, I can't do anything now so I'm just gonna sit at home umm, umm. It is a shame, I think different cultures and different races err, take err, pain and understand pain differently I think, and some people give up quite quickly when pain is there and umm, some people don't umm however I think, umm, within the Asian community because umm the kids are still around their parents, so they feel that, umm, they still have that support. However you know, but within the white community umm, obviously when the kids move out and leave them, or they have to go in homes, or they have to fend or they have to do things for themselves. While we're still always around our family, we'll always doing things for our mums and our dads, err, because we either live (laughs) nearby or we are living with them. Its one or the other, so I think that's another reason why err, they tend to take a backseat as they feel oh well, my kids are here, they'll do it for me, and that's how it is. (P1, South Asian male).*

It is suggested by this participant that particularly in South Asian families, that pain behaviour is reinforced by attention from the family resulting in a loss of independence, and promoting the sick role because of the role of extended families in their culture.

It appears from this quote that there are stronger family ties within the South Asian culture with younger members of the family supporting older members. This is linked to the 'social relationships' category.

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Some participants felt that there were no cultural differences in the pain experience, whilst others considered the differences to be due to stereotyping and expectations about different cultures

*“I don’t know everybody has the same sort of pain I don’t know if this pain is different to another. If you cut yourself, we have different colour but we have the same colour blood.” (P12, South Asian male).*

*“But erm, I think, erm, people’s perception of pain from other societies or other people within society, they think they’re not as brave as we are (laughs)”(P22, South Asian female).*

Exploring stereotypes further, the concept of how age, if at all, affected people’s pain was discussed. Some participants, in particular women suggested that if they were older they would find it easier to accept that they had chronic pain, because they would have lived their lives and pain is seen as inevitable and part of growing old.

*“Yes, because you expect your body to start giving up. As you get older, you expect to have health problems, but certainly when you are young, you don’t expect it to happen to you” (P33, White British female)*

*“(pause) perhaps it would .. I when you’re younger you probably wouldn’t think about so much pain but now I’m older probably I think well. .. I’m older and if I was younger I should probably feel more unhappy about it as I do now as I’ve had a life... and if I were younger I’d be just starting out in my life” (P10, White British female).*

*“Um yes I think it probably I think if I was older it probably wouldn’t matter so much um because I feel to an extent that I’m missing out on some things you*



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*know at the age I am there's still a lot to do and out there I want to go out but I am restricted by it whereas if I was in my 60s, 70s, 80s then I would be quite contented to sit at home with my dog or whatever it wouldn't have such an impact on my life" (P15, White British female).*

Other participants, particularly the female participants felt that to have pain when you were older would be more difficult to accept and cope with and very much focussed on lack of independence and being alone.

*"I would imagine as you get older pain would be worse because it'd stop you from doing things, especially if you haven't got a partner, it could probably get you down a lot more than a younger person would. I don't know really, it all depends on what pain they've got" (P3, White British female).*

*"I feel really old. As I was saying, I don't know how I'm going to cope as I'm getting older and older.....er how to do things, kind of, like you wouldn't, I mean I'm finding it difficult now kind of, but to get older, like to get around or whatever, I think I will find that hard" (P37, South Asian female).*

*"Older is, I think more of a worry, because I think, if you are in pain, and your body's not moving so well and going so well, it, it could be more debilitating, so I think its perhaps more scary when you are older, to be in pain, because you actually think, 'am I going to get out of this? Is it going to get better? Are, is there less I can do to help myself?' ...but I think perhaps if you're older, its harder, and then it does definitely mean perhaps more dependency, and less control, and that kind of thing. So I think it actually, the older you get, I think, pain is perhaps a bit more scary. That's the way I would see it"(P32' White British female).*

Other participants, South Asian male participants in particular felt that if they were younger they would be more able to cope with their pain, and gave various reasons around being stronger, fitter and more able to do exercise.

*“Well if I was younger it would help but I’m not,*

*HOW DO YOU THINK IT WOULD HELP IF YOU WERE YOUNGER?*

*Well you do a bit exercise, extra exercise and things like that. I don’t know people say when you get downhill it doesn’t get better but when you’re young it does help” (P12, South Asian male).*

*“I think younger, I would have coped better. I think you’ve got a lot more strength and, er, you don’t think about it much. You’re just doing things that you want to do.” (P20, South Asian male).*

*“if I was younger, I could have gone for some exercise’ (P23, South Asian male).*

Female participants also reported if they were younger they were able to be more active, which they believed would help them cope with their pain better, but also their willingness to use “mind over matter” and a sense of invincibility helped.

*“because I think when you are younger you can perhaps get more active and get involved in things, and definitely use the mind over matter” (P33, White British female).*

*“Erm, yes, because if you’re younger, erm, you erm, I don’t know what it is, but you seem to be able to face anything at all when you’re young, (P32, White British female).*

However, other participants, in particular those defining themselves as White British reported that because they perceived that when you are younger you needed to be active, this in itself was problematic, as they had to be able to work and look after the family. They compare their present situation and their current role with the past and the future in terms of providing for their family unit despite the limitations of their pain.

*"I'm grateful that I have this problem at the age that I am, a) because it was 10-15 years ago when my children were younger, if I couldn't work then, er, trying to bring up children on benefit I'm sure, well, I don't know how people do it. It's got to be a non-starter really, I just don't know how people do it. At least when I had to stop working, my children were at an age where they could work themselves. It wasn't everyday money I had to give them or everyday food or everyday clothes" (P27, White British male).*

*"I suppose if I was younger I'd be even more depressed, because I have to put up with this for the rest of my life. I get angry sometimes and think well, if I was older then I'd understand it a bit more. But then I am middle aged so. I look back and I was fortunate I could do the things I did with my children when they were young so I had those years um" (P7, White British female).*

*"Possibly as well if I was younger it would make even more of an impact on my life but I feel the stage I am at the moment with a husband with a family um I'm very active but were at that stage in our lives that were still got all children at home and were out doing things... its not even probably in 10 years time it'll be different when the children have left home or they're in a different education, at the moment I think I'm very needed as a support for the children they need me there just for pure everyday things taken here mum, I need to go there mum, I need collecting at this time when you've got 3 of 'em you put a chart on the wall and follow where ya going and if anybody takes the chart away then that's it when in big troubles I need to there and I need and I need*

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*to be able to do things but it can be very restricting” (P15, White British female).*

The participants clearly had different views about whether age influenced pain. For some participants, pain was to be expected in older life therefore they reported that they would be more accepting of it, however they reported that they would not be able to employ more active coping strategies such as exercise. Age and pain were closely related with loss of independence and being alone. With regard to being younger and living with chronic pain, this proved to be a double-edged sword as they reported if they were younger they would be able to remain more active, however this was problematic because if they were younger they perceived that they needed to be more active as they needed to be able to work and / or look after their families.

The notion that religion could in some way influence pain and pain management was discussed. Some participants refused to acknowledge any link that religion may have and poured scorn on the idea that pain could be considered a punishment regardless of ethnic background or whether they considered themselves as religious or not. The following responses resulted from the question “Some people have told me that they see pain as either a religious test or as a punishment, whereas others have used religion as a way of coping, I wondered what you thought about these ideas?”

*“what as in you’ve got a pain so you’re being punished for it? I think it’s a load of rubbish” (P18, White British female, Methodist).*

*“No. I don’t, no I don’t believe it” (P20, South Asian male, Sikh).*

*“A load of twaddle!” (P28, White British female, Church of England).*

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*“No, I don’t believe that one” (P24, South Asian male, Hindu).*

Other participants did not believe in their own religion that pain was associated with punishment, but accepted this may be the case in other religions and offered their opinions about this view, which was very often negative.

*“Erm, in truth, I think its rubbish. Um, to me, if you are going to be affected by pain, you’ll be affected by pain, whether you’re a good person or not, because it’s , I mean, it shouldn’t depend on your religion, whether you believe in this God or that God or, for somebody to actually put that on them that, you know, pain is because of what this God said, I think is completely wrong. But, I mean, ‘cos to me, if you’re going to be affected by it, you’ll be affected by it, no matter what religion you believe in. And I think in some religions that if they do blame it on certain situations that’s gone on in certain families, then I think that’s wrong, because its, you know, you shouldn’t feel that you’ve got it because you’ve been punished.....*

*UMM.....*

*Because pain itself is being hit with it, is a punishing thing to have to live with each day without being it dictated to you horribly. That’s how I feel, I think” (P32, White British female, No religion).*

These negative views exemplified by the quote above were possibly made, as in Christianity God is seen as an all-loving figure and would not cause pain.

*“Erm, no, because, you know, I mean, the Lord is supposed to be, supposed to be, is a loving, erm, person, and I don’t think he would, erm, dole out, er, pain, erm, you know, to anybody.....” (P25, White British female, Church of England).*

Some participants who were actively religious felt that it was their duty to accept pain, although they did not accept that they had pain as a punishment; they believed that their faith helped them manage and cope with their pain.

*“well I’m not, not a religious maniac but I mean when Christ suffered like he did on the cross I think well we didn’t, we’re not suffering so much as he did. We must accept it and still believe in our faith .....(pause) I really can’t understand that, really (pause) of course I mean all throughout life you do some little thing that probably isn’t right and I don’t think you should er it should be a punishment. I don’t know, I’ve never sort of come to a conclusion about that. I just think that the faith that I’ve got is helping me and....it is faith. Faith has got me through a lot. And I couldn’t go, live my life without that. About this sin I don’t know ...” (P10, White British female, Church of England).*

Others although not considering themselves religious, could see religion as a source of comfort for those with pain rather than a punishment for wrongdoing.

*“I just, all I know is that, erm, that before me dad died, well a few years before me dad died, he got religion and I couldn’t be dealing with it, but he said, you know, when I, er, if I saw him or spoke to him, he’d say we pray for you at the church every Sunday and hope, you know, to make your pain better and things like that. And I thought, well, it’s having no effect, so either he ain’t listening or, that’s the only way I can, cos it ain’t getting no better, you know (laughs). Erm, and again, I wouldn’t want to put anyone down that does believe in it because, I mean, sometimes I think I’m missing out because I don’t believe in it.” (P27, White British male, No religion).*

*“.... my mother in law she’s very Irish Catholic and she will say you better get yourself off to church for a pray and it’ll probably get better and I think I don’t think so and a 8 mile drive to the nearest church I’m not gonna get better by driving I’ll sit in thank you very much so she would put a lot of um thought into*

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*it in that way but um I don't seem to" (P15, White British female, Church of England).*

Participants with a South Asian background illustrated that their faiths did acknowledge that pain was sent as a punishment, but personally found it difficult to explain why they had pain because they felt that they were leading good lives now. Despite not knowing what they did in their past lives, they believed that in this life they had to lead a good life to be free from pain in their next life.

*"It's not a punishment, it's having a balance. Yeah, yeah, if somebody is suffering in this life, I suppose they must have done something wrong in a previous life so if we do something good in this life and, err, hopefully in the next, you know, that is what we say in our holy book says that when you go it depends what you have done in this life then according to that in next life you get born as that person not as a human being, but err, its very difficult to explain (laughs)" (P21, South Asian female, Sikh).*

*"mmm... um.. people say that in Hindu that you must have done something wrong in a previous life to deserve this but I don't know. I've been a fair good son, good brother and friend to my friends. I think according to what the wife says I'm a good husband I treat her well, and my kids adore me. So I don't know. I can't sort of say that. Whatever my previous life did then I'll have to suffer for, I'll suffer for it. The next life that I go into hopefully my good work, then he or she will be in better health, better sort of thing. I don't know, keep an open mind" (P8, South Asian male, Hindu).*

For those that knew the cause of their pain it was easier for them to be more practical rather than religious or fatalistic about the cause of their pain, however they still wished that the pain could be taken away from them by God or other higher beings.

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*“Never, never considered it in that light uh I wouldn’t say I’m a deeply religious person not by any means I do have religious beliefs but I don’t see this as a punishment for what I’ve done in a previous life or anything I suppose I’m really practical about it I know what I did I know what caused it and I know what’s happened 3 years ago and this is the problem (pain resulting from a fall) I think I have days where I say for God’s sake please take this pain away (laughs) so but you know I see that it’s a religious belief but not at all very practical on that respect” (P15, White British female, Church of England).*

Many participants had asked the question “why me?” which lead to a discussion around fate. Particularly to those of White British origin that had no explanation for their pain, fate to them seemed a plausible option.

*“Erm ... yeah, I, yeah, I mean I, I sometimes, I mean I do, er, you know, often think about fate, and I do, I do believe in it, and I think, I, there is an element of that, yeah, because, you know, my my sister is, you know, didn’t have anything, and er, and she’s never had any surgery or anything, whereas I have. And I think, you know, but that was what I’ve been dealt with. But then again, you know, there’s other people who’ve been dealt with more, with worse things, and you just don’t know. But I do feel it, because its not like something’s happened, or I’ve been in an accident and it’s a continual knock-on effect from that. It’s something that’s happened to me, and I’m like ‘well, why?’ That’s one of the things I don’t understand, because I don’t think I should have it, ‘cause I do work so hard to keep myself fit and well” (P32, White British female, No religion).*

*“Down to fate? Erm, I suppose perhaps to a certain extent it perhaps could be that, ‘cos that is perhaps where I sort of, will say ‘why was it me that got hit with it?’ you know, and perhaps, I suppose that has sort of um, made me think, ‘well perhaps sometimes it is perhaps the stronger people that get hit, that cope with it, knowing that they’d cope, but, I don’t know I’ve not, I’m not*

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*one that's very religious or stuff ” (P34, White British female, Church of England).*

*“fate does play part in it I suppose and I put it down to that, you know, going back to my GP again, that maybe, you know, it was in my fate, you know, to suffer for this long or this was my fate to get what I am suffering, so I don't know whether it will get better or worse” (P21, South Asian female, Sikh).*

Interestingly, for some participants fate seemed more plausible than religion, but when asked what they meant by fate, they often linked fate to a higher being, which could be God, whereas others considered fate to be preordained bad luck.

*“Umm, I think it is just people who believe in God they believe in fate as some sort of, I suppose, a power, you know, it is very difficult to say, I don't know how to explain it because some things you can't really explain, you just believe in. You know, it's like how you describing God, you can't say he looks like that, you know, it's something that, I suppose it is a way of living, it's just holding on to something, you know, I suppose it's like, you know, having a goal in life if you got a goal in life you keep going and if you haven't got a goal then you think that what's the point you wouldn't get up in the morning to do something, would you, so I suppose it's something like that if something is out of your reach, out of your control, you know, you put that down to fate, you know, the God thing is although I know it is not a person, that God isn't a person, it's just some kind of power, you know” (P21, South Asian female, Sikh).*

*“I suppose it is fate if you get ill or if you trip over a curb and break your leg. I mean, I suppose it is fate isn't it....It's, you know, I suppose fate means that, er, your destiny. I suppose to a certain extent, you do set out your own path in life, and yet something crops up and then all of a sudden, you're not on that*

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*main path any more, you've shot off onto another direction. And I suppose, yes, some people would say that was fate. I suppose it is fate to a certain extent, whereas you can buy a lottery ticket every week for 10 years and not win a penny, and then buy a lottery ticket every day for 10 years and then win 1 million.*

*YEAH.*

*The same as you can get on a train every day and not have a problem, and then 3 weeks ago people got on a train and got blown up, so I suppose from that point of view there is such a thing as fate.” (P27, White British male, No religion).*

*“I think it's just my bad luck! yes I do think it's (the pain) down to bad luck” (P5, White British female, No religion).*

Some participants considered medical and genetic reasons for their chronic pain, whilst others attributed it to not looking after themselves properly such as playing too much sport in their younger days, not giving injuries enough time to heal properly in the past, accidents, and being overweight rather than attributing their pain to fate.

*“No, I don't think so. I think it's just one of those things, it's either hereditary or just due to an injury in the past somewhere. Like a disease, you've picked it up. I don't know if there is any known reason for these conditions.” (P29, White British male)*

*“I think, you know, the pain is through, you know, damage to your, damage to you from an accident or, erm, you know, a health problem, you know (P25, White British female).*

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*"It's just, you know, it just happened at work. I was doing something which I shouldn't be doing and I didn't know at that time, I was doing my job. I wouldn't say that it's made by fate, no" (P26, South Asian male).*

*"Erm, I've only ever thought of the chronic pain as a result of, er, a medical problem really. (P27, White British male).*

*"I don't think it's down to fate. It's how they've looked after their bodies, probably wear and tear when they were younger, you know, things like that. If they haven't looked where they've put their foot, you know, stepped and...*

*It is their fault. I don't think it's fate" (P20, South Asian male).*

Regardless of the cause of their chronic pain, some participants took the view that you just had to get on with life and deal with it in the best way you can.

*"You can't, if you start thinking about what ifs and whys and wherefores, I think you could drive yourself pretty mad really. You have to deal with your life and your situation as it is, and do the best you can". (P22, South Asian female).*

Some participants felt that despite wanting to understand why they had chronic pain, they could not; to many it was 'unbelievable'. These were not simple accounts of ignorance but a profound state of bewilderment as they consistently fail to understand why they have chronic pain, and are suffering and being punished despite not having done anything wrong. As the best efforts of others had failed, often the participants would blame themselves.

*"I get so ... so angry with myself that its still there despite everything I do to get rid of it" (P16, White British male).*

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*"I blame myself for some of the pain, being overweigh can't help but I can't do anything about it as I can't hardly move a lot of the time as pain is so bad" (P31, White British female).*

Whilst discussing religion and fate, the topic of blame was brought up in some of the interviews. Participants' views tended to typically fall into three camps;

- participants who felt that they were to blame for the cause of having chronic pain;
- participants who reported that there was no-one to blame, and
- those that blamed themselves for continuing to have chronic pain.

Those who did blame themselves for having chronic pain, *"it was my own fault"* (P32, White British female) these participants tended to be those who injured themselves at work or felt that they were overweight, which increased their pain.

Other participants adopted a more philosophical viewpoint

*"I think there's no point in blaming somebody else or blaming a religion. Unless it's self-inflicted, the pain, I can't see the point of blaming anybody else. There are circumstances that have made your life what it is"* (P22, South Asian female).

Others blamed themselves because they could not rid themselves of pain, which is at odds to the beliefs that pain should disappear over time.

*"I don't actually blame myself cos I'm in pain, I blame myself cos at that point I can't get out of pain. Does that make sense?"*(P22, South Asian female).

Affect (Riber, 1985) was present throughout this section on cultural beliefs, particularly in terms of the highs of the promise of expectations gained from prior experience of the pain usually resolving after a short time and the lows of these expectations not being met, the lack of understanding about their pain, some adopted a fatalist view whilst self-blame relating to their pain was a feature for others.

This section has focussed upon the most popular cultural expectations expressed from the interviews that participants brought with them to all of their consultations. Considering the participants' wide-ranging beliefs and expectations coupled with the beliefs and expectations of their health care providers, it is understandable why the consultation is a difficult experience for both parties.

### **The Consultation**

Many participants spoke of unsatisfactory – at times very unsatisfactory interactions with various health professionals, including their GP, prior to attending the pain clinic. Most strongly criticised what they saw as bad medical treatment, various doctors had mislead them, *“nobody ever gave me a direct answer”* (P11, White British male) did not understand pain, provided no diagnosis, did not listen to them, demoralised them, did not do enough, responded too slowly, or prescribed ineffective, unnecessary and inappropriate treatments.

*“Erm however when I went back for the follow-up appointment she obviously hadn't listened to a word I'd said. .... Erm for a start she offered she said, 'Right. Erm the acupuncture, now when can we get you an appointment for that? I said, 'Two injections a day is more than enough needles for me; I don't want to see any other needles' (P31 White British female, diabetic injecting insulin).*

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*"It's not that he sent me back to work I was quite happy with my work and I wanted to work, it's not that he sent me back to work it's that he actually changed towards it. The way he said that to me that I just need a sick note, I haven't got this problem. I think that .....He didn't take me seriously and, err, if he thought that I was just saying it for the sake of it whatever he thought, I don't know what his thought was behind what he said that, but he should have investigated, you know, or talk to his colleague or whatever, I don't know what the practice is in the GP surgeries, but I was more annoyed with that" (P21, South Asian woman).*

*"I had to put pressure on, through the system to try to get the scan done eventually, because by that time the symptoms were really bad and it was affecting my walking badly" (P5, White British female).*

Some female participants felt that their GP was not interested in their pain and *"Put it down to being a woman of a certain age" (P15, White British female)* suggesting menopausal tendencies, whilst others related it to expectations of their culture.

*"One of the GP's that I was with, elderly lady Dr X she is brilliant, she is a gem and a half. She moved and I moved with her and then she left and I was stuck with this other Asian lady older and ..... She was like oh just get married, don't worry about it, and I was like I'm not getting married for no one mate, if I'm going through this pain what am I supposed to do after I get married, look after myself or look after them, but she was like that you see, an older Asian lady doctor ...that is what is expected, you forget the pain, forget everything, you're a young lady you need to get married and slave over them and that's it. You know, you need, it's not even marriage you need to have kids. Get married and have kids, keep your family tree running. Sort your pain out" (P13, South Asian female).*

Some charged health professionals as intimidating, dismissive, sarcastic (this comment usually applied to hospital consultants, but not consultants working in the pain clinic), did not believe the patient and fobbed them off:

*“he (GP) used to make me cry you know....one day I said to him, ‘my my, kids are older than you, and they wouldn’t dream of talking to me the way you talked to me’ And of course, um, we got more of an understanding now, and he’s not so bad, but I still dread going there” (P36, White British female).*

*“.... if it gets like that I go, I’ve walked out the door two or three times you know. There is one person that really gets me, but he winds everybody up some days he gets me at the wrong time and I just grit my teeth” (P17, White British female, discussing her GP).*

*“I think this dates back to 20 years ago I used to come and see at the Royal Dr X a consultant and he kept saying well there’s nothing wrong with you. At that time I’d be walking in town and stop all of a sudden (pause) I was seeing him every two months for four years and it was driving me mad that nothing could be found.” (P14, White British female).*

*“.... (pain and possible reasons for her pain) not explained properly, um and people who do need to explain but they don’t, its like I’m getting fobbed off a lot....I changed my doctors/GPs about 3 or 4 times and not even now am I happy with it” (P13, South Asian female).*

*“I get fed up that I never get a straight answer, it’s this then that then take more pills” (P11, White British male).*

Many participants expressed the difficulty of communicating to others including health professionals about the personal nature of pain, and felt that

only they themselves, could understand the pain they were experiencing or the effect on their own lives.

*“it’s like taste, you can’t explain taste until someone has tasted it. Pain is a four letter word that people just say” (P13, South Asian female).*

*“You can only learn pain through your own experience, ‘cause no matter how much you describe something hurting to somebody, they can’t actually understand how much that impacts into the whole of your being. If you say to someone ‘yes, the pain makes me feel so bad I feel sick’, they might think ‘oh dear, that doesn’t sound very nice’, but the actual feeling of ‘oh my God, you know, I can’t bear this’ I don’t think you can describe that to someone. (P33, White British female).*

In short the health professionals did not live up to the expectations of the participants. Quite a few participants echoed the bitter recriminations found throughout the pain literature as mentioned above. Participants often became incensed if they felt a doctor implied that their pain was ‘not real’ and they often interpreted this to mean that their claims of having a medical problem were unfounded. A female participant reported that she became alarmed when she was told that there was no medical explanation for her pain, therefore it must be psychological. But she did not believe this, as her pain was so excruciating, it could not possibly be in her head, so she concluded that she had been misdiagnosed and sought further medical opinions. One participant said that when doctors implied that pain ‘is in your head’ they should be more humble and admit they did not know what was wrong. Several participants spoke of wanting to transfer their pain for a day to their GP so that they could see exactly *“what the hell it was all about”*(P27, White British male).

In earlier coding, categories such as getting a label or diagnosis, not having a psychological diagnosis and the perceived resulting stigma were identified.



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Through further constant comparison, they became absorbed into the category of dissatisfaction with the consultation.

Importantly there seems to be a distinction between the perception of 'good' and 'bad' GPs, in that those who were perceived by the participants as dismissive and unhelpful as indicated above were seen as 'bad' GPs. In contrast some participants reported having good relationships with their GPs and other health care providers, because they appeared to listen, take the participant seriously and tried everything. These participants believed that their GP had done all that they could and should not be blamed for a failed surgical procedure or for not knowing why their pain was so severe.

*" well my GP's tried this and that (medication) and I've had physio and that, so at least she trying things that might help you know, and now she's referred me here (to pain clinic) so I'm pleased about that" (P29, White British male).*

*"...he can't do anything for my pain but at least he listens" (P32, White British female discussing her GP).*

Arrival at the pain clinic initially brought great expectations, that they would be given a diagnosis or reason why they had chronic pain and the hope of pain relief. When asked about their expectations of the pain clinic, new patients often had *"come for answers, and to get rid of my pain"* (P8 South Asian male), whereas follow-up patients were often looking for *"new treatments, other things to try"* (P17, White British female).

*"Erm I hope that they will find something that will take it away I think you have to hold on that erm maybe next time I come to the clinic it's going to be effective or I'm having a different procedure sort of pin my hopes on that this will be it this will take it away"(P15, White British female).*

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*“well if they can keep in touch and keep modernising things hopefully they’ll come up with something that will stop pain or at least relieve it, take it away for at least part of the day even you know, but um.. I’m not hopeful but I keep coming back!”(P6, White British female).*

*“I keep coming back, in case they find out what’s wrong you know or if there’s anything new, anyway my GP tells me to keep coming (to pain clinic) (P27 White British male).*

*“these people know what they are doing so I come back, one day they will have the answer so I come back and back again” (P1 South Asian male).*

Despite the pain clinic not always having the answers or being able to provide effective treatment at that particular visit, the participants valued being believed and having their condition explained to them.

*“Erm having spoken to Dr X cos I’ve been seeing him about 18 months now he said they really don’t know why it’s there it quite complex thing erm I was going for a long time going back to my GP saying this foot is killing me it’s agony and I was referred to other consultants and specialists and it was sort of oh well it’ll settle down eventually I went to see Dr X who was actually able to say you have got this condition and it was wonderful to find that somebody was actually believing that I’d got this. “ (P15, White British female).*

*“Erm I’ve had a lot of treatment with Dr X but he’s always been very honest right from day one and that’s it’s a complex problem it’s difficult and at the moment I’m having procedures that are giving me relief but it’s coming back. I can’t see the light at the end of the tunnel with it I just know that I’ve got somebody who’s actually trying to do something for me” (P15, White British female).*

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*"I can't tell you what a relief it was. Even though, erm, when the doctor said to me, erm, er, he examined me and I went through the same examination that I'd gone through probably 15 times before, and actually ironically I very nearly didn't go, because I felt quite rough and I thought, well this is going to be a waste of time just to get told the same old stuff. Anyway, I went, and he obviously went through the same routine as previous doctors, and then he said to me has anyone ever said to you about chronic fatigue syndrome. And I said no, and I said should they, I've never heard of it. He said well you've heard of ME. I said yeah, but I don't really know what it is. He explained all the symptoms and I said, yeah, I've got that, that happens to me, yes, yeah, that's exactly what happens. And when he explained it, although he explained, because I said, ok what can he do about, there's no cure, you know, it could go on for years, but there are things that we can do to help. Although he said there wasn't a cure, just to be told that it was actually a problem, well I knew it was a problem but I didn't know, the problem didn't have a name. And the doctors I've seen before, they've not seemed to believe, just really didn't take on board what I was saying. And I just thought I was losing the plot, big time. But when he explained to me what it was, and that in his opinion that was my diagnosis, it was a huge, a huge relief, and when I got home, I thought about it and I just shed a tear really, because everything fell into place, and I thought, well, yeah, it's not great but at least I know I'm not going doolally" (laughs) (P27, White British male).*

Whilst some participants sought pain relief, for others the sense of reality in terms of that perhaps the pain couldn't be cured and this honest admission from the pain clinic was welcomed.

*"I think the one thing that I am very fed up with and I got very angry with I keep seeing various doctors and they'd all say it will get better so and I just go so sick of hearing it all the time and it was actually nice to come and see Dr X who actually said I can't promise you it will get better he was actually being*

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*truthful I think on your day you think well somebody told me its is gonna get better and then it doesn't" (P15, White British female).*

The consultation process brought out a wide range of affect, in the participants, initially they felt hope as they expected treatments to cure their pain. Subsequent consultations particularly in primary care left them feeling disbelieved, angry, frustrated and fobbed off. However when they arrived at the pain clinic, there was a sense of being believed and hope. The mismatch between the expectations of the participants and that of the health care provider often lead to dissatisfaction with the consultation, for the reasons that no diagnosis could be given, and the participants' perceived ineffective treatment.

### **Dissatisfaction with response from health professional: no diagnosis**

Chronic pain is a complex phenomenon; often the participants have poorly diagnosed, complicated problems that lack the legitimacy of well established pain-causing disorders such as arthritis, some participants expressed that they:

*"would rather have cancer so they could be treated and would be taken seriously" (P13, South Asian female).*

Others were not always given a diagnosis. In the 21<sup>st</sup> Century participants felt that it was completely inconceivable that with all the medical technology available that they could not get a diagnosis that would explain their chronic pain;

*"...we can fly to the moon, clone sheep, but they can't tell me why I have this constant pain, or get rid of it... it's ridiculous" (P11, White British male).*

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*“I just don’t get it, why there isn’t a cure for my pain when some cancers are cured, it’s only pain” (P13 South Asian female).*

Participants were often desperately searching for something that would explain their experiences in their disorientating and confusing world of chronic pain; as well as to provide them with terms with which to speak about this new and confusing world, which no longer corresponds to their previous life world.

*“If you actually know what is causing your own pain, and if you turn around to someone and say it’s caused by X, Y and Z, and they’re familiar names rather than medical mumbo jumbo, if I say arthritis, well everybody knows what arthritis, alright they might not know the difference between osteo and rheumatoid, but they know what arthritis is basically. So it’s accepted.” (P30, White British female).*

*“If they told me what it was I could look on the internet and give information to my wife so she can understand. If they knew what it was they might be able to get rid of it (the pain) (P29, White British male).*

For some participants, the lack of a firm diagnosis or reasonable prognosis was a constant source of upset. One man described how frustrated he felt when the doctors said they could not find anything wrong. He would go for various tests and investigations hoping fervently that something would show up, and after a while he did not care what it was. Others reported that they had been through a lot to discover that there was *“nothing medically wrong”* (P27, White British male)

Participants felt that they needed a diagnosis, as it would tell them and the various people around them that they have X, that the pain is real, and that it cannot be willed or wished away. To some a diagnosis was considered to be more important than pain relief, *“if they can’t find a cure...just, just to know*

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*what's causing the pain would be a start, at least I would have a reason for not doing things: (P27, White British male).*

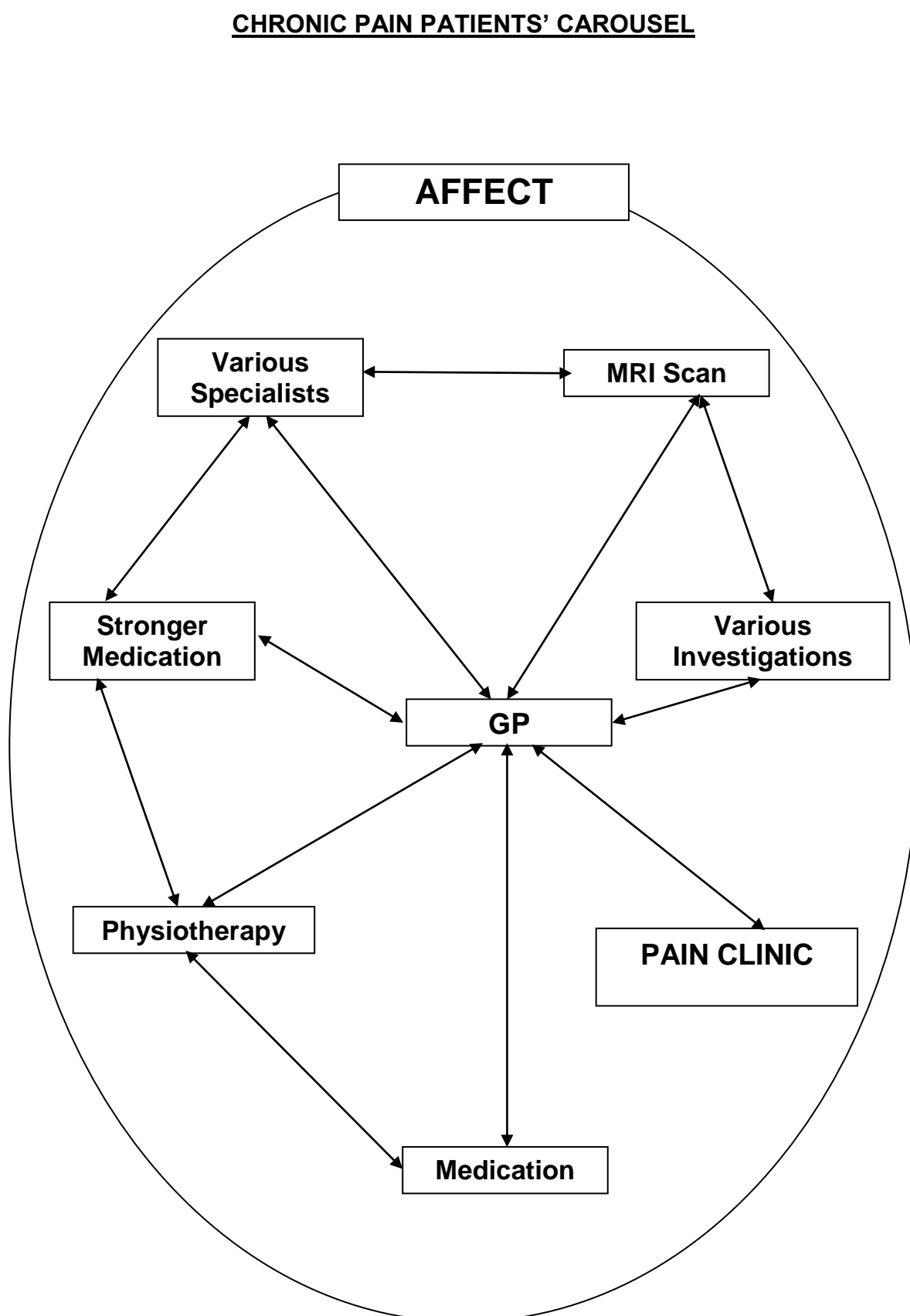
To others having a diagnosis meant that there must be a treatment or cure for their pain, *"if they can give it a name I can go away and look it up on the internet and find the treatment I need" (P18, White British female), "if they know what's wrong they must know how to cure it" (P4, South Asian male)*

Some participants felt that knowing their diagnosis would enable them to cope with their pain more effectively. They could justify their multiple visits to various health professionals and why they were unable to do things for their friends and family.

### **Dissatisfaction with response from health professional: ineffective treatment**

Chronic pain is often resistant to treatment. These patients are often described as 'revolving door patients' in the literature. Many of the participants described enduring the ineffective treatment carousel of GP, painkillers, GP, physiotherapy, GP, stronger painkillers, GP, various medical Consultants, MRI scans and various investigations, back to the GP and then finally to the pain clinic. I consider it to be a carousel rather than a revolving door because of the impact of affect, initially the participants' hope that something can be done to cure their pain, as time goes on, feelings of frustration, depression, anger and resentment come into play but with each visit to the health professional, there is a glimmer of hope, hence the up and down of affect, as shown in Figure 4 below (Peacock, 2005).

Figure 4: illustrating the participants' ineffective treatment carousel.



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*"I mean Dr X has tried to do as much as he can. I mean I'm not blaming him at all but, any problems like we'll refer you and six weeks/eight weeks after that and you'll go and see your consultant and they are supposed to be... GP doesn't want to do nothing about it, that's all they know how to do is referrals. Which is not a good thing, GP's need to know a lot more than they do." (P13, South Asian female).*

*"And, erm, but er, I, you know, had a couple of steroid injections which helped, but they didn't do, erm, you know, they're supposed to last 6 months, but mine only lasted about 2 months" (P25, White British female).*

*"I've tried everything, tablets, potions, creams, gels, TENS machine, injections but nothing has taken the pain away you know, tablets take the edge off for 'bout an hour." (P11, White British male).*

There appear to be two main issues involving dissatisfaction with treatment. One issue is side-effects. Sometimes the treatment may have been effective but the side effects were too distressing. The other issue is treatment efficacy. Participants talked openly about their past and current medications and described the side effects of taking them, which were sometimes perceived to be worse than the pain itself.

*"I mean, it's definitely constipated, one of er, one of the ones I was on that was absolutely awful. Another one completely makes your head very fuzzy, so you're kind of not, you kind of feel a bit out of yourself in a way. I suppose it must be just like being on a high you're kind of there but you're not there, a bit spaced out. And I don't think that's good either. (P32, White British female).*

*"Er, actually, you know, with taking Amitriptyline, and it was causing swelling on my nose and I've got rhinitis as well, and it was causing me nose bleed in the morning and blood clots in the nose in the morning when I used to blow*

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*my nose, all this blood it's worse than my pain which I have to deal with as well. (P26, South Asian male).*

One participant reported using cannabis rather than legalised medical drugs because she felt more comfortable and perceived that she had less side effects.

*“drugs yes they are helpful but you fall asleep and you're like a little rag doll you know just lying there, you can't even lift your own arm up. You're so drugged up. I'd rather be drugged up with cannabis and be alive and awake you know rather than dozed up properly and you don't feel like eating, you feel sick you don't want to do anything. Tablets are just horrible, horrible stuff and I'm on antibiotics, two a day for three months because of a skin condition, I don't mind taking that but sometimes I tend to forget because I don't want to take them.” (P13, South Asian female).*

Some participants expected their medications to relieve their pain, without side effects. However many participants had tried various medications therefore their expectations were less, hence had different expectations and beliefs about the medication which were brought to further consultations with various health professionals. It could be suggested that repeated treatment failures over time lower expectations, so participants hoped that the pain could be relieved rather than cured.

*“You know, I don't want pain killers that are going to do that I actually want pain killers that would help a) perhaps relax you and help a bit with the pain, but not send your head out, and also the others, you know, er, er, er things in your body, particularly like being constipated, is awful, and that can also bring other problems, particularly if it's in an area near where your pain is, anyway” (P30, White British female).*

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*"I mean my doctor's gone through um, quite a few different um, you know, these inflammatory tablets, and we've decided to go to, now to stick to the one I'm on. I mean, they don't, neither of them gets rid of all the pain. I mean I can take quite a few and I know my pain is still there, pretty bad some days, but it's enough to take that edge off of being in pain" (P32, White British female).*

Often for some participants, their medications made them feel "out of it", leading them to compare themselves with illicit drug users. They explained the concept of being "out of it" as feeling sleepy, unaware of their surrounding, 'muzzy headed' with difficulty in concentrating on everyday tasks.

*"More when I was on patches, the side effects were terrible, it was like being a drug addict, and the patches wore off, they're designed to last 72 hours, sometimes they did and sometimes they'd last 48 hours, and they start to wear off and it takes, by the time you realise they're starting to wear off and you put another patch on, your patch takes a few hours to kick in.....You can, I can be lying in bed and you're just pulling your hair out. Your whole body twitches and you don't know what to do. You just want to get up and run around the block, it literally, it takes about 3 hours I suppose and then gradually the patch would kick in. I just felt like a druggie" (P27, White British male).*

*"Couldn't take those tablets, I was like a... zombie you know, couldn't do anything" (P5, White British female).*

*"...taking these these really big tablets, they knocked me out, couldn't do anything once I'd taken them, horrid you know horrid and sleeping all the time, couldn't do anything so stopped taking them. They didn't stop the pain anyway" (P8 South Asian male).*

Participants reported that each time they tried a new treatment they hoped it would work, especially if things looked promising initially. However often after a few days of treatment, the pain would return, resulting in disappointment and misery. Failed treatment can have a profoundly demoralising effect. It may be that the participant has lost faith in the health professional, for a variety of reasons such as not feeling believed, feeling mislead over the benefits of certain treatments and as result of these iatrogenic factors, any further treatment may not be of benefit.

*“They (physiotherapist) helped me for a while, and then erm, the pain would just come back, and just go into spasm again. I’ve had, like, acupuncture, seeing if that kind of, that kind of helped me, then two or three days later it would go into spasm and the pain would be conti.....severe pain” (P37, South Asian female).*

*“I think at that point I realised that it was a case of taking painkillers and just getting on with it. Um, I had physio at the hospital and she said that there was just nothing they could do. And the fact that the chiropractor said my back was unstable, and he really didn’t feel it was a good thing to touch it, I thought oh, dear, you know, that’s it now” (P33, White British female).*

*“my GP said take these (tablets) they are stronger than the last ones so will work....well they did for a few weeks....um...think my body has just got used to them” (P8 South Asian male).*

Affect was very evident throughout the category of the consultation. The range of emotions expressed ranging from anger, frustration, annoyance, dread, resignation which were often related to a mismatch in the cultural expectations of the participants as previously discussed and the health professionals, and feeling as if they are not believed by the health professional. This contrasted with the consultation at the pain clinic where participants felt hope and

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expectation but also relief at being believed their pain was real. This section has reported upon the difficulties experienced by the participants of the consultation when patients' expectations about their pain and the treatment of their pain is not matched by their health professional, and highlights communication as a key issue.

### **Not being believed**

Apart from pain behaviour, the participants' condition revealed no visible signs that would give credence to any of their claims of suffering and disability. The participants who themselves endured a profound sense of uncertainty regarding the aetiology or legitimacy of their pain, felt vulnerable to the judgements around them

*"...what's quite evident in front of your eyes and you know that, they're in pain. When you know like they don't have a plaster or anything like that, so you don't really know what pain they've got..." (P1, South Asian male).*

*"the thing is it's one of these illnesses, it's a hidden illness that you can't see, like if somebody had an arm missing it's something you can visually see..." (P11, White British male).*

*"I've never been without pain since I can remember, 24/7 pain and sleeping I'm in pain. I need to write a diary down to help other people realise what I'm going through. What sort of pain I'm going through, but I can't wake up in the middle of the night and write down that I'm sleeping but I'm in pain and I'm moving in pain, you can't do that because it's 24 hours a day" (P13, South Asian female).*

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*“Because it’s something they can’t see. It’s like a mental illness, it can’t be seen. If you’ve got a broken leg and a pot on your leg, or a pot on your arm, it’s physically there for them to see...Yeah. Yeah. It’s like people who use a disabled bay in the car, and you get out and you’ve not got a walking stick or a walking frame or a wheelchair, and people think, why are they there.” (P28, White British female).*

*“If you are a young age and you’ve got arthritis and you’ve got the supports on your hand or something then people would be fine, people who have got to look at them and see that they are weird. With my illness not many people know about it, they are always like what the hell is that we don’t know what that is, even the doctors they don’t know fibromyalgia....if it’s older person or someone with a stick or someone with a bit of grey it’s ok you can be in pain, they will help you sort of thing.” (P13, South Asian female).*

*“Well that, I mean, it’s very hard, it’s like, er, I go to like pain clinic and talking to someone else who’s got pain the same as me, they can understand and they can relate to me. Whereas someone else, if I talk to family and friends and they see me all the time, and if I’m just saying the same thing everything is like, like ... about it kind of, you know ... ‘cos they don’t understand, ‘cos they’re not, ‘cos I look well kind of, you know? If I had like a bandage or a something else on it, they’ll think, oh yes, she’s in a pain, because they can’t see my pain, it’s very, very hard” (P37, South Asian female).*

The participants felt a continual need to justify their pain as ‘real’, that is not in any way psychogenic which was synonymous with ‘mad or bad’:

*“its embarrassing because it’s not something that you can see and I do feel guilty, I know that my back really does hurt and I’m not making it up and I feel sort of angry that I can’t do it and I think well I wish I could just prove to them*

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*that my back really is bad and that I really must not do it, because if I do I put myself back weeks (P32, White British female).*

*“...when people ask me like that you know I uh...I don’t know how to answer that to tell you the truth umm..I don’t feel that I just think that it’s there I know it’s there I’m not the sort of bloke that puts it on like or anything like that I’m a genuine straight bloke you know what I mean” (P27, White British male).*

*“it’s difficult... I had an accident at work so that’s why I’ve got pain, so that’s what I say when people ask, it’s ok unless it’s my in-laws, they always say well that was ages ago” (P37 South Asian female).*

Self-justification was important. In the absence of any recognition that their pain could persist, participants were by default required to be defensive about their condition but were often unable to make use of any credible explanatory story and as a consequence were often frustrated.

*“you feel as though no-one believes you, unless people who have got bad backs, it’s only them who believe you, you know”(P37, South Asian female).*

*“Um, everyone says ‘oh, it’s just a bad back’ unless they’ve actually experienced the pain themselves. And then, even if somebody has suffered back pain at some point, they don’t seem to accept that you’ve got it just all your life. Um, and they feel surely there’s something you can do to get better and get back out in the world.” (P33, White British female).*

*“I feel that I always have to justify my pain because no-one can see it, I feel that..um... I always have to be ready to explain about my pain when people ask...I wish they wouldn’t (ask)” (P8, South Asian male).*

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Others felt that people in pain were stereotyped and portrayed as malingerers in various forms of media such as television and magazines, reflecting the view of society as a whole.

*“Well to be honest, I think they’d make it like a Les Battersby (character in Coronation Street) skiving type of, you know, I still think people see it as a skiving problem, you know, if it’s cancer its taken seriously I really don’t think back pain is” (P11, White British male).*

*“I was in the doctors and there was an article, something like Good Housekeeping, something fairly reputable, about back pain so I read it. It didn’t mention spinal stenosis at all and it basically said to get on with it and that people skive off. I felt quite pissed off with that” (P5, White British female).*

*“...everyone says they’ve got back ache, it’s the oldest excuse in the world, so you can have a sickie” (P1, South Asian male).*

*“pain isn’t taken seriously as a whole...you know...it’s seen as an excuse to get out of doing something” (P21, South Asian female).*

One participant admitted to having disbelieved others in pain in the past, but has changed her opinions due to her own pain experience.

*“I mean, unfortunately, I was in the same boat as, er, people who dismissed pain, ‘cos my, erm, now sister-in-law, she, as a teenager, used to suffer dreadfully from headaches, and I’d never had a headache, and it’s only say in the last 3 years that I’ve had headaches, so I know, my goodness I’ve said, you said to myself, pooh-pooh, you know, to Patty, but erm, you know, I’ve had a headache, but what it must be like to have a migraine, er, which*

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*unfortunately Patty still gets, er, no. Erm, I have no idea what she's going through, but I don't pooh-pooh it any more."* (P25, White British female).

Intrinsically linked with not being believed, was the subjective nature of pain and the 'visibility issue'. The 'visibility issue' is described as looking and appearing outwardly well and having no external physical signs of illness or disability despite having chronic pain. The difficulties of feeling believed had a paradoxical effect on the behaviour of participants as a healthy appearance was considered by those around them to be incompatible with any claims of chronic pain, suffering or disability:

*"if I went round with no make up and bags hanging down my face or something you know, and and look really bad they'd probably think well yes.....but you can't see pain so they don't know do they so they automatically assume nothing's wrong with you you know"* (P31, White British female).

*"when you're trying to work and trying to explain it's like you're just lying basically....because if they could see the pain I'm going through as I said you see a person and you don't know if they've got pain or not"* (P1, South Asian male).

Appearing healthy or mobile whilst remaining in pain was problematic and often participants felt obliged to constantly seek treatment to legitimise their pain or to appear ill and disabled to satisfy the requirements of others.

*"I visit the osteopath quite often so that tells you that my back is bad and always clicking out of place"* (P1, South Asian male).

*"Ah ha, yes I think that if they can see something erm you almost you get their sympathies get their understanding it's ooh we can see that there is a problem"*

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*there it's like when you see a disabled person in a wheelchair erm somebody is likely to open a door for them.....now I go and do my shopping on a weekly basis I've got a bit of a limp but erm nobody looks twice at me to go in there so I think if people can see something very physical there then they know that you've got a problem so they respond differently to you. You almost you get the sympathy bit" (P33, White British female).*

Unfortunately, appearing ill left them facing pity from others, which was very much at odds with how some of them wanted to be treated.

*"I don't really want them to treat me any differently, so I don't really make an issue of it unless it's really particularly bad then I would rather somebody get up and answer the phone than I struggle up out of the chair (laughs) but seriously I really would prefer it if they just carried on" (P18, White British female).*

*"Hurt. It hurts. I mean, I have lost my temper in there a few times, if I don't walk round with a label on my back saying that I'm not able to manage the stairs. And I feel that I'm being victimised, it's a strong word, but yes, I suppose I am being victimised. Because there are a lot of people that don't walk round, that go round in a wheelchair or walk round with sticks that have problems. And because I don't walk round fast, you hear people tutting behind you, and I think well you can walk past. I would walk fast if I could. And I'm fed up with making excuses for the way I am". (P28, White British female).*

*"I don't use my stick like I should ...I don't want people to see me like that,...vulnerable to youth gangs who would pick on me cos I'm an easy target, if you see what I mean, I used to box in the army....that was years ago!!" (P29, White British male).*

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One participant often used her wheelchair when she went out, but saw this as a sign of stigma and felt it challenged her place in the social world and this was incompatible with how she viewed herself and how she wished to be viewed by others

*“I just want to say ‘hello’ you know, ‘how are you’ and I go ‘yeah I’m ok’, not look at me as if to say you spaz ...cos I’m not” (P33, White British female).*

The ambiguity of pain behaviour and the lack of understanding in others, both health professionals, friends, family and work colleagues left the participants feeling vulnerable to being mis-judged or rejected. This disbelief affected social relationships, and their identity. The suspicion they felt under often drove them to appear to be in more pain than they needed to and they felt their pain denied them the opportunity to relate to others free from the influence of pain.

### **Social relationships: family and friends**

Pain often caused a shift in the participants’ social roles and relationships and denied them the opportunity to be the kind of husband, wife, mother, father, grandmother etc that they, or others might wish them to be. Participants’ accounts exposed their awareness of the threat of rejection, not just because they felt they were a burden and unproductive but because they might also be disbelieved and were aware of the potential problems of being misunderstood by their families.

*“you know my daughters .. I think they thought probably because I’ve always been active and always done everything .. you know I think they would have thought that probably I wasn’t so bad (laughs) as what I was. ....well um .. my sister next door probably I should say it really .. I because I couldn’t help*

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*her and I was helping her, I think for a start that she thought I was swinging the leg (lead) as they say!" (P10, White British female).*

*"It's changed my friends say and my family they've had to learn to live with it as well it's restricting on things activities we do activities with my children erm the family have been very good they've adapted and so have closest but it is a life changing thing. I suppose I don't want to acknowledge mm that erm I think the children they know not to ask me to do certain things because I will try and do them but they have learn to realise that that can put mum into a lot of pain and they done want to see that when I thinks its also a worry especially for like my parents and my husband because they can't see an end to it it's not I've come for a clinic appointment today and oh it will be fine by next time" (P15 White British female).*

*"yeah...I couldn't go to my nephew's birthday party, he is only five and I'm ...I was ...his favourite uncle... I really hoped the pain went but it didn't ... he's too little to understand (P8, South Asian male).*

Often participants had become increasing dependent upon their partners even for day-to-day activities that they had taken for granted.

*"I'm finding difficulty getting out of bed, putting socks, that's why wife changing time going to work, she works in town, she goes to work after 10 o' clock so she get me ready. It's not very helpful you know you can't do much I got to rely on my wife, it's a bit too much for her sometimes but it can't be helped" (P12, South Asian male).*

*"well I'll be truthful with you I'll say to my husband the stupid little things I can't get on with, can't bend down and cut my toenails, I have to get somebody else to do them... I can't Hoover or clean the windows because it will set it off unbearable" (P14, White British female).*

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*“Well I’m very lucky. My husband’s very supportive towards me kind of, you know, he helps me a lot, so I’ve got a lot of help, so, you know, I’m lucky that way because being an Asian person, you do get a hard time, kind of, I think I’m very, very lucky, ‘cos my husband, he does most of the work anyway, like hoovering, ironing ... if I have visitors or whatever, he’ll help me out in the kitchen, but if I didn’t have that help I think I would be in severe chronic pain a lot, and I’d be frustrated and depressed” (P37, South Asian female).*

Sometimes the social role within the relationship of the participant changes which is difficult for both themselves and their partners, in particular for White British males.

*“Must be a bit uh ooh hard for ‘em really for my wife really cos I say she does everything she does the shopping cleaning the gardening everything like that like and I tell ya what it kills me when she has to go outside and say I’ve got to cut the lawn I’ve not cut the lawn in years (coughs) and she’s made it really that uh (sighs) we’ve got a low maintenance garden like you know and um we’ve only got one small wall about the size of this now at the back back at the top like you know must tell a fortnight ago about 3 week ago we’ve got living next door that have got high conifers and uh (coughs) they had them cut down to about 12 feet ya see and uh my wife said I’m going out to trim them ....and uh I felt ever so guilty about her having to go onto steps and going up the ladder to you know” (P16, White British male).*

*“The thing that worries me most of all is that I’m gonna hurt my wife in as much as she’s pushing me around in a wheelchair, and things like this, and she’s gonna get troubles, and that’s the last thing I want. She goes and does the gardening and things like this. Mowing the lawn, she’s never done that in her life before, you know, sort of thing” (P29, White British male).*

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*"...its not just me....my wife, she has to suffer as well" (P8, South Asian male).*

*"Well it has, yes, in as much that until, I talked to someone and understood what I was putting my wife through, I didn't understand it, and now I understand I've been able to adjust a bit. We don't argue half as much as we used to, and things like this. And almost begin to understand a bit more of what's going on and what the problems are." (P29, White British male).*

Participants reported that chronic pain had caused their partners to doubt them, hence affecting their relationships. This was reinforced by feelings of guilt and being a burden.

*"When I, when I first hurt my back, my husband could see I was in pain, and did his best to help me, but after a while, the doctors even tried to convince him that it was all in the mind, um, and he started to think 'oh my God, I've married somebody who's a bit psycho', and it, it ... It wasn't until it was finally diagnosed and sorted, and I returned more to a normal life, that he realised, that yes, I had had a really serious condition. And he could see that I was in pain, but he, nobody could account for why... Um, he feels that he also is suffering because of all the things I can't do. Um, admittedly, he has to do a lot of the hard work about, about the place, you know, lifting things and so on, and he feels that, because I can't go fast, he has to go slow. It, it messes up his life, if I don't want to go out to something, that we've both looked forward to. Um, and even if I say, you know, 'go on your own' its not the same if you go on your own.... so, certainly in the earlier stages, he used to say 'I'm suffering as much as you', and I thought, well, no you're not. (Laughs). (P33, White British female).*

*"Otherwise, I mean it's like sometimes my husband ... and I do get frustrated and I'll take it out on him, as soon as like, when they walk in, I'm like shouting*

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*and screaming, kind of, because I don't work or whatever, and feel guilty and he'll know, kind of, you know, .. and he'll tell me why have you done it? You know it, you know ... I'll suffer later and feel I'm a burden to him" (P37, South Asian female).*

*"my wife has to do so much more these days, it's not right: (P29, White British male).*

Participants reported that their families found it difficult to accept their pain cannot be cured, and kept searching for a cure or treatment, but appreciated the thoughts involved.

*"Well um my father-in-law actually he's the one that spends a lot of hours in the library and he'll see an article and say have you seen this and has your consultant read about this so I think probably from the family's point of view I they've come across something with pain they're probably more tuned in to it there's a article in the newspaper or magazine I find these snippets come through the post (laughs) I think they are very tuned in to how things are for me so yeah think ooh this might be helpful so its gets sent to me. I thinks it's a lovely thing they do I haven't come up with something and think oh wow it's really fantastic but you think well in some ways it's quite nice that they're still acknowledging that I have got a problem and they're still 3 years later well aware of it you know it hasn't been swept under the carpet by the fact" (P15, White British female).*

Whilst some participants felt that their relatives did not understand the impact of chronic pain on their lives

*"None whatsoever because I don't see them enough. Erm, my father has absolutely no concept of pain.... Erm, I I went on holiday with him, my stepmum and my little sister, and we we went to some museum somewhere*

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*that was on the side of a hill to start with, so that was bad enough... erm and he kept saying, "Oh, you know we only have to go...". No, I was I was saying, "Look, Dad, I've really had enough; I cannot do any more of this museum."... So he said, "OK, well we'll just go to the erm canteen." And the canteen we were at the bottom of the hill, and the canteen's right at the top, over loads of erm bridges and it it was a nightmare. And he just didn't have a clue" (P33, White British female).*

*"...Asian family, you know, is very, very, erm, you're expected to do things, as an Asian person, kind of, you know, as, er, and I have loads of er, friends and I used to do a lot of cooking and whatever, and now I just can't, even like my family and friends like coming over, and I know they're coming, I just get really stressed out, frustrated, even like where, my in-laws, if I know they're coming from like Scotland, wherever, I get really stressed out. But you know, like er, I don't want them to come, because I know, like when I cook, and I'll cook for later, I'll suffer a lot, all night long, kind of, and the day, and for a couple of days long, a week or two weeks" (P37, South Asian female).*

Other participants felt that their relatives were overprotective about their pain

*"my mum's always umm, watching out, or anything if I say, you know I going out, with my friends she always says watch yourself, don't do this, don't be silly, don't do that, or you know, err, watch your back, she'll always telling me to watch it (P1, South Asian male).*

*"well my son for a start he goes on about he thinks I ought to have a scan or something to see if there is anything else. So I say that if they thought there was anything else then that's what they would do" (P14, White British female).*

Some participants were concerned with being judged as 'useless' because they could no longer look after their families, this was particularly evident in

the male participants as they were unable to work and fulfil the role of the 'breadwinner'.

*"Obviously, like I said before, I'm upset by the fact, you know, last year my daughter got married and I would like to have helped out a lot more with the wedding expense than I did." (P27, White British male).*

*"I haven't worked properly for 3 years, I just can't, cos, every time if I do start a job it's unfair because I know I'll be taking a lot of time off work and urr, so I haven't really been working because of that....it's so unfair on my family" (P1, South Asian male).*

When discussing relationships with friends, often participants would talk about how they do not see their work colleagues now. When they first left work the participants received many calls inquiring after them, but these gradually dwindled.

*"they all phoned at first asking if I was ok and did I want to go out, but I never did and the phone stopped ringing after a while" (P36, White British female)*

*"when I first stopped work, the lads would still come see if I was going to the pub on Friday night with them, like what we always did...often I said no pain too bad or had no money...after a bit they didn't bother anymore" (P8, South Asian male).*

Some had supportive friends with whom they could talk about their pain or not depending upon how they felt, whilst others had helpful neighbours that would *"Do odd jobs" (P12, South Asian male).*



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*“I’ve also got a very close friend a very close female friend she’s very good as well she’s become very perceptive to the pain and she’ll say are you having a pain day today and I’ll say yes I don’t want to talk about it we’ll have a quick coffee instead” (P15, White British female).*

Other participants felt let down and rejected by their friends in an environment where they expected them to be supportive, as illustrated in the quote below when this lady’s friend took her shopping for the day

*“but when I was in, erm, in Bicester, erm, my friend there, er, she would just lose patience and I would catch up with her when she was on her way back. And I’d say to her, she’d say, I’ve done what I want to do. I said, but you know I want to go and look in Debenhams or wherever. And she’d say, well I’ve done my shopping” (P25, White British female).*

### **Social relationships: withdrawing from others**

Rather than endure their chronic pain and continue to meet the increasing demands of their social world, the participants tended to withdraw from public view.

*“I didn’t want to meet people, I didn’t want to socialise at all, umm, and even when we made an agreement to go and see somebody, I’d back out at the last minute” (P36, White British female).*

*“I don’t want to do things and go out when my pain is bad which is most of the time” (P1, South Asian male).*

They felt a burden to other people and there appeared to be no agreed way of relating to others that they could use. It was easier for them to conceal their condition than to rely on the understanding of others. For some, rather than explain that it was their pain that caused them to avoid social events, it was easier to lie and risk appearing unsociable

*“if anyone asks me out, rather than telling them about my pain, I just say I can’t be bothered, that way they’ll think I’m a misery but that’s better than going out and ruining their fun” (P13, South Asian female).*

Misery and being boring with little to talk about, except their pain, was considered to be unacceptable in company especially with those without pain, so they withdrew from social contact to avoid the potential for any embarrassment or rejections:

*“we don’t go out much.....I get too embarrassed having to try and explain my pain when I look ok, and if you’re out for a social evening the last thing people want to hear is your misery and pain, so that’s why we don’t go out often” (P31, White British female).*

There appears to be tension between the participants’ need to withdraw from other people and their fear that this would leave them isolated and abandoned. They felt that their relationships were at risk and were aware of the limits of other people’s compassion. Some participants discussed that in the past prior to their own pain problem, they would avoid contact or cut short conversations with anyone who appeared unwell as they were unable to tolerate the misery, and now felt that they had to hide their own pain and distress so as not to evoke those feelings in others.

*“Uh it’s just been a whole life changing experience for me in that I wouldn’t have thought about unless it happened to me um and an area where I know*

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*I've not been sympathetic in the past but I have a very different outlook on it"*  
(P15, White British female).

Participants reported that they not only felt easily irritable in public, but also conspicuous therefore now preferred not to go out. Often their own social worlds could not accommodate people who had chronic pain and needed to change position regularly or required supportive chairs, so sometimes their disability was mediated partly by social acceptability and appearances.

*"I didn't even go out at New Year cos I knew that it would be like packed, there'd be no seats and there's no way I could stand up and if I needed to stand someone would take my chair and I'd need it again so I can't remember the last time I went out"* (P34, White British female).

### **Social relationships: talking to others in pain**

With many participants withdrawing from society and not discussing their pain because they felt misunderstood and not believed, the discussions turned to whom could they talk to and is it easier to talk to people who have a similar condition to the participants. The participants seemed to fall into two camps, those who would value support and understanding from others in chronic pain; whereas others felt that they would have to listen to others comparing their pain in a kind of competitive way and complaining about their pain.

Those who felt that talking to others in pain made them feel that they weren't the only ones in pain therefore it cannot be in their heads so they must have something wrong despite no 'medical evidence'. They valued talking to other pain patients as they felt they could be understood and believed whereas talking to people without pain about pain was difficult as they didn't and couldn't understand the whole pain experience.

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*“Well, a lot of people have got it. You know, you say something and they say, oh I’ve got this and I’ve got this and then you think about it, oh, I’m not the only one suffering.” (P20, South Asian male).*

*“Well it is, how do you say, it is comforting, if that’s the right word, when you know, er, that somebody else is going through the same thing as you, and they understand, so you know that you’re not going loopy or, you know, imagining things. ....Erm, and then, if somebody, you know, you happen to speak to somebody and they’ve got, you know, the same thing, er, then you say to them, erm, well, this is what I do, you know.” (P25, White British female).*

*“That thing is, you know people who are in pain, they have better understanding of what we are going through, because the people who are healthy and don’t have any pain, they’ve never experienced it, it’s difficult for them to understand, and sometimes if they say something which is not very nice, that can hurt you. It’s better to keep it to yourself.” (P22, South Asian female).*

Many requested the need for support groups and thought that health professionals should set up support groups and at the very least, be proactive in providing these details

*“....there are no support groups no nothing. Since I’ve been here I’ve seen one lady who has fibromyalgia and I was so wanting to turn around and say to her do you want to stay in touch, to stay in contact. But I didn’t and I think it should be the doctor who should be saying right we’ve got a lady here who has fibromyalgia, why don’t you get together here and then arrange what you want to do later. Because there are no other support groups, I think you need to do something. If there are people coming down but I don’t know they’re*

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*here. The only common person that knows you're here are the doctors." (P13, South Asian female).*

Other participants felt that they did not want to engage with others in chronic pain because they felt they had enough dealing with their own pain that they did not want to hear about the pain experiences of others

*"Erm, well, I don't want to talk about my pain erm, because I don't want to take on board anybody else's pain... There are other people that introduce themselves: they tell you their name, and then they go straight into a list of what they suffer with....." (P31, White British female).*

*"I actually lost her as a sister. She actually became her condition. She talks about it as soon as you meet up, the telephone call or whatever is dominated with conversation about it. And then occasionally she'll ask, "Oh how's your back?" (P5, White British female).*

*"I think some people become, I know, I'm sure unaware, slightly self-centred. It's a bit like the scenario when you go and visit someone in hospital, and you go and talk about operations you've had (laughs). It's that sort of thing." (P27, White British male).*

It appears that the participants have clear ideas of who they feel understands their condition and who they are willing or not willing to engage with to discuss their pain. Some would like support groups and believe that talking to others is helpful, whilst for others this is not the case.

Affect, in particular depressed mood, is woven throughout social relationships, as relationships with both friends and family change over time, feelings of being misunderstood, guilt, rejection and the appreciation of others are evident

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with issues of the change in role and identity. Expectations from both the participant and their families, and the need for self-justification to frequently consult various health professionals introduced limitations to their life worlds. Those feeling rejected and like a burden tend to withdraw from the company of others without pain. Some participants found talking to other people in pain who understood the complexities and difficulties of living with chronic pain helpful. This often focussed around information seeking and understanding. However, for some, the need to justify their condition was felt by some participants to be *“competitive moaning”* (P32, White British female).

### **Social Identity: pain has its own identity – “pain as It”**

The participants showed a strong motivation to understand and explain their situation, to know ‘why?’ Participants regularly stated they simply could not ‘believe’ that nothing more could be done to relieve their pain. There was a marked contrast between their preoccupation with their pain and their inability to account for its chronic presence. Participants rejected the judgement that their pain was ‘unreal’ i.e. psychogenic but could not explain its reality in a manner that was meaningful to them. Their accounts revealed their attempts to cope with their pain despite a profound lack of either understanding or information. This uncertainty and ambiguity encompasses their experiences and continues to appear as an important factor throughout the themes.

Despite their long history of pain, and extensive contact with the health service they neither felt informed about their condition, nor able to influence it. They often felt that their pain acted of its own volition:

*“it just comes and goes when it wants really”* (P37, South Asian female).

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*“the pain is an all consuming thing. Basically if you do the wrong things the pain takes your life over and that rules precisely what you’re going to do, which is nothing” (P16, White British male).*

*“It’s just something I’m having to put up with and I’ll keep going with it the day I give in from it it all sounds very dramatic will be the day the pain’s won and I’m not at that level yet. It’s a battle between me and this pain” (P15, White British female).*

*“It consumes my whole life and my whole waking hours, touch wood it doesn’t affect my sleep that much unless it’s really bad. You know when you turn over it wakes you up, but it (coughs) the whole of your waking hours is consumed with a niggle or an excruciating pain” (P18, White British female).*

*“it is just there constantly, no let up” (P8, South Asian male).*

*“it’s like having an intruder in my head it’s um.. it’s been very very rare but occasional times when I’ve had no pain and it’s been a kind of complete shock to remember what it was like to have no back pain.....um (pause) it’s like an invasion. It’s like something I’m living with.” (P5, White British female).*

Interestingly, pain was considered to be a separate identity to the participants themselves, this concept of splitting originated in Freud’s description of a division of mind, as it conflicted with the ability to produce inconsistent thoughts and beliefs. Freud (1938) described the way in which the mind could adopt two separate points of view. Klein’s work on splitting the ego emphasised how parts of the self are experienced as bad and are split off through projection and usually identified as belonging to an outside person or object (Hinsherwood, 1991, p433-434 quoted in Holloway and Jefferson, 2000)

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### **Social Identity: comparing self with others**

As participants described their pain, they compared themselves with other people and with themselves both in the past and projected into the future.

*“.....(sighs) well basically I think it affects my whole lifestyle. I’ve always been an active person, I’ve always liked to do stuff whatever it be and I’m also at an age now where my children are growing up umm and possibly having children themselves in the not too distant future and I can’t see myself being an active grandmother because of my back pain, it affects my past, present and future” (P6, White British female).*

This process of comparison captured the impact of the pain. Some participants compared their present situation with selected events they had witnessed, and used these comparisons as benchmarks

*“I’m only 57 and I should be doing this and that and the other cos they say life begins at 40, but I can’t and it does bother me, it’s frustrating people of my own age are doing things and you feel as if you can’t” (P5, White British female).*

*“at my age I should be going out enjoying life having a laugh, but I’m not and all my mates are...I’m stuck at home...it’s so depressing” (P1, South Asian male).*

Some female participants felt that they could not do things that they felt that they ‘should’ do like other women of their age, who were active and enjoying life. Comparisons were not just made in terms of mobility, but also in terms of a denial of pleasure in various activities. Often descriptions of loss were



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exacerbated by the recall of the reality of their past where the participants were not only fit, but worked very hard.

*“...and you suddenly got everything (pain) like I’ve had, then I can’t understand it, because its not that I wasn’t energetic because I brought up 4 children, looked after my Mum, and my Nan, and had a full time job” (P36, White British female).*

*“I’ve always worked hard, never had a day off sick until this....never claimed anything (P12, South Asian male).*

An example of this idealised past can be summarised, one male participant who reported that he had given up playing football because of his pain, however as the interview continued, it emerged that the reason he had given up playing football was because his wife thought he was too old to play Sunday league football, and actually his pain occurred two years after he had stopped playing football.

Often participants anticipated the future, with fear, they believed their condition would get progressively worse. They could not predict the future and emphasised their pessimism by comparing themselves to others. One participant compared herself with someone she knew who died in distressing circumstances, although acknowledging that this person never had chronic pain, her own uncertainty meant that she could not guarantee that she would not share the same fate:

*“she lived down the road, she was only a few years older than me, last year it started, I don’t know what she died of she was getting lots of aches and pains I just don’t want to be any worse as I don’t want to be pushed round in a wheelchair” (P37, South Asian female).*

Participants often stated that their continual pain had eroded their mobility but made different comparisons to others:

*“when I see my friends, I saw one walking her dog the other day....I thought Oh my God, its ages since I’ve taken my dog for a good walk, you know. So for a few minutes I felt sorry for myself and then I saw someone in a wheelchair so you know, I’m not that bad” (P32, White British female).*

*“..saw me mates playing footie the other day, so wished I could ‘ave joined in...but s’ppse it could be worse I can walk at least (P1, South Asian male).*

Through comparison, participants ranked themselves against others and this served to heighten their sense of loss or disability. Some felt demoted in the family and felt the loss of their role, whilst for others feeling better off than someone in a wheelchair, they then became embarrassed when considered alongside elderly relatives

*“you say oh well I think I can make it over there. I feel so stupid especially when my mother in law who’s 81 is trotting about and I’m hobbling” (P15, White British female).*

Other participants related similar comparisons. Their sense of social order had been disturbed and in attempting to re-establish their personal status, participants took refuge in thinking about those in a worse situation than themselves. The use of others as an aid to resisting the sense of decline and loss that pain provided was equivocal and in some cases detrimental, serving only to exacerbate and define their distress. Participants’ uncertainty in their prognosis restricted any compensation that a ‘worse-world’ offered. Sometimes when witnessing those more disabled, participants questioned whether that would be them in the future

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*“I just don’t want it to be any worse as I don’t want to be pushed round in a wheelchair” (P6, White British female).*

The comparison with others less fortunate than themselves was intended as a coping strategy for enhancing self esteem but often turned into a re-enforcer of despair. Chronic pain promoted distress in the participants when they recalled how they used to be, before the pain began and often a sense of grief overshadowed their accounts.

### **Impact of pain: Limitations**

Some believed that chronic pain had caused them to lose everything by making global and catastrophic comparisons:

*“It’s stopped everything, it’s stopped my life completely” (P37, South Asian female).*

*“we go on holiday and it’s not worth going because I feel as though I can’t get round to see anything. I mean I can go in the car but then sitting in the car too long doesn’t help it .. so I think it’s a waste of time. That’s holiday-wise” (P14, White British female).*

Whereas others, were more operational and explicit about changes they had experienced and revealed the frustration caused by chronic pain

*“I can’t do what I used to do....I’m not one for staying in if I can get away with it I go out I don’t like stopping in” (P32, White British female).*

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*"I can't do anything really long term. I mean we've always had dogs all our lives, a big part of our lives and now I can't join in because I can't go for walks that far and I couldn't go up the park and take the dog for a walk up there because I couldn't walk that far. I used to go to the gym played squash but that's non-existent now. Everything I do has to be done in limitation, but I still try and do as much as I can.." (P16, White British male).*

*"um.. I find almost every action um... intense from getting up in the morning to leaning over the sink to brush my teeth to wiping your bottom even! (laughs), it does, it impacts on everything. At work I've got a sitting down job, but just getting up to move around the office grunting and groaning you sound like a 90 year old instead of 40 odd. And then all I want to do is sit down and take the weight off my back and don't want to do anything else" (P18, White British female).*

*"Well, yeah, I mean, the day-to-day living is the same really. The other thing, you can never make, you can never really make plans. If someone says shall we go and do something next Saturday or whatever, should we go out or come down the pub or shall we go for a meal or whatever, erm, you have to say yeah that'd be great, but I can only, sort of, ring you more or less on the day, cos you never really know. Yes. I mean, you can even be alright in the morning and then you can either get a lot of pain in the afternoon or you suddenly just get overwhelmed with tiredness and can't do anything. I mean, even erm, a week ago, I was going up to see my son and I phoned him the night before and said I'll come up in the morning, and I got up in the morning and I thought that's not too bad, that's okay, and I got organised, had a shower, got in the car and I literally didn't, I got to the farm gate and as I got to the farm gate, I just thought I can't do this, I am so tired I can't, I just felt that I couldn't do the drive. And I came back and I phoned him up and I just said, I'm sorry I can't do it, you know. Just lay down and went to sleep. So it's as unpredictable as that. So that has an effect" (P27, White British male).*

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## Impact of pain: Work / Financial

For many participants not being able to work, was a huge blow to their self-confidence, self-esteem, their purpose in life, and the reality that they cannot do what they did in the past, and found it incredibly frustrating that they have to pay people to do the jobs they so easily used to do.

*“It’s had a serious impact on my life. I mean, I don’t want to be a drama queen or anything like that, but as far as I’m able to work and I used to erm, be able to earn a reasonable income, and unfortunately I didn’t really save that much because you just think that once you’re able to earn a reasonable income, I suppose you just psychologically just block everything out and you just think well that’s it, I know I can always earn money.....Yes exactly, and erm, you don’t sort of, ever think that, people who get ill or have accidents, that’s other people. And you just don’t think that. And when it goes from having a reasonable earning capability to a few months trying to live on £75 a week benefit, it does have a serious impact. Not that I was ever, I didn’t ever go mad with money, but as my children got older, it’s nice to help them out and I wish I could have helped them out more really” (P27, White British male).*

*“yeah I mean I used to do car mechanics.... didn’t I? There’s no way I could do that now. I’ve got a City and Guilds in mechanics and that’s about it. I used to work for about eight dozen garages and they say why waste money when you know how to do it yourself. But now I can’t do anything can I?.....well the brain knows, it’s got the information to do it but putting it into practice are two different things .. at the end of the day it’s the physical side why I can’t do it ... and I go to the garage and pay the bills and I think ‘Oh’ (sighs)” (P11, White British male).*

Those participants who were still working, discussed if they missed work, what they thought others would be thinking about them.

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*"It affects work quite a lot actually because I work with the community so it involves me driving quite a lot it also impacts on my colleagues at work because I'm not in a situation where if I'm not in work somebody else will go and pick up load and do my work it doesn't happen like that erm we're in an office where we are desperately short staffed so I'm well aware if I have to have time off it off loads it to other people and it's gone on for a long time and they get very resentful about it which I think is quite understandable if it was me every time and again oh she's off for a week she's off for a fortnight I'd be thinking aagh she's off again so" (P15, White British female).*

The work ethic seemed particularly strong in the younger South Asian participants; one explained how she thought her peers, family and family friends would perceive her:

*"I feel that people are looking at me thinking she's lazy she's not doing much. I just keep thinking that all the time, and when especially Asians are like are you working, where is she working, is your daughter working ... its like no, I'm not working and when I say that I think they think I haven't been working for ages what is wrong with her" (P13, South Asian female).*

Some participants felt they could not return to the job they had previously had or felt that they could not work for anyone because of the unpredictability of their pain. Often working from home or setting up their own family business seemed to be a logical solution to some of the participants

*"like I said you know I haven't worked properly for 3 years, I just can't, cos, every time if I do start a job it's unfair because I know I'll be taking a lot of time off work and urr, so I haven't really been working because of that, umm hopefully we are in the process of starting our own business, so if that, as often at least, I've got my own business and I can take things uhh, you know,*

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*easily, you know my brother will be there, so every other brother always to fall back on I should be ok” (P1, South Asian male).*

The unpredictability of pain influences participants’ day-to-day lives, and to some extent determines what they do and how they feel which is reflected in the emotions and feelings they report. Some participants’ catastrophise about their life worlds, others are more pragmatic. Participants feel very vulnerable as to how they are judged by others especially in the workplace. The category of identity links with cultural expectations and social relationships, disbelief.

### **Coping Strategies**

Having to endure chronic pain on a daily basis, because of ineffective treatment or unwanted side effects, participants sought information to help them develop their own coping strategies. Coping is multifaceted and has been defined as a “purposeful effort to manage or vitiate the negative impact of stress” (Jensen et al, 1991). Coping strategies are diverse, in this thesis, they are used to describe techniques that participants had found helpful with no input from health professionals involved in perceived western medicine. Participants reported a wide range of self-management strategies that they had employed. These strategies included those with a slightly medical focus, such as TENS machines, and ‘Pain Away’ pens which had been purchased after seeing adverts in newspapers for example.

*“I’ve got a tens machine*

*HOW DO YOU THINK THAT HELPS?*

*I think it sort of numbs the area really, you know, I suppose with the numbing effect it sort of takes your mind off it a little bit ...(pause) it’s weird but it does help but then obviously as soon as you take it off again you’re back to where you were. And of course it’s a little bit difficult to use because you’ve got all*

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*the wires and you try to bend down and come out and you get all electric shocks (laughs) but no it does help um..” (P18, White British female).*

Participants, particularly females, also tried to access complementary therapies, these were successful to varying degrees for different participants.

*“I’ve done it myself at home, you know I like complementary therapies and I’ve done reflexology and aromatherapy. I can only practise on friends and family, I can’t practice on myself. I’ve only done stage 1 of it, but that is helping me, having baths with aromatherapy oils, I can’t massage myself but I can only do my hands or feet or something. I can’t do my back or anywhere. I have a bath and rub the oils in .....so it relaxes me for that bath time, but once I’m out I’ll probably fall asleep because I’ve been in it, but the pain is still there. The massage will get your circulation going and everything going quite well. I’ve been looking at complimentary therapies, natural therapies quite a lot” (P13, South Asian female).*

Cost was a big issue for those accessing complementary therapies. Those participants who returned to the pain clinic for follow up appointments thought that more complementary therapies should be available on the NHS.

*“I’ve done as much as I can on my own within the financial side of it, (discussing her visit to the osteopath) which is another aspect of living with pain, the lack of money so often you, you can’t afford to try things that might help, more should be done on the NHS” (P18, White British female).*

*“and I did actually go and see a chiropractor, and I spent quite a bit of money there, that actually had no effect” (P33, White British female).*



If none of these strategies worked participants began to find their own ways to enable them to manage and cope with their pain, often through trial and error.

*“Actually there’s only one way that I can get any relief from my feet is putting them in a bowl of cold water and I put in there for about twenty minutes and sit with ‘em there but uh it does bring a bit of relief but within twenty minutes of drying my feet off it’s back again……Oh its just sorta deadens the feet really that’s the only reason I can think cos it stops the when I say this burning buzzing tingling stinging feeling ….Well (long pause) it does a little bit yeah but uh when you sit there with your feet in a bowl of cold water you hope know one comes up” (laughs) (P16, White British male).*

*“well actually (laughs) a hot bath does ease it a bit yeah ... and go back again a couple of hours later it’s exaggerating a bit. There are times when it doesn’t ease up the pain” (P11, White British male).*

*“a nice hot bubble bath helps for a bit, although it’s a struggle to get back out again” (P30 White British female).*

One South Asian female reported that she resorted to using some forms of traditional Asian medicine, alongside Western medicine, and alludes to the humoral concept. This is that ill health may result from an imbalance of ‘hot’ and ‘cold’. Illnesses, food and medications are given ‘hot’ and ‘cold’ properties. ‘Hot’ and ‘cold’ is not related to temperature but reflects a poorly defined subjective sensation (Bhopal, 1986).

*“Dietary I think Asian spices and stuff help quite a lot.*

*HOW?*

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*Asian food ... forget chillies and spices and stuff but like turmeric, the yellow powder that is like a natural antibiotic anyway, natural healer. Warm it up in a paste with salt and slam it on.....*

#### *DOES IT HELP?*

*yes of course it does, the swelling goes down and I can't do it to my whole body... but if I'm really bad with a sore throat and coughs that sort of thing I just take honey and turmeric, natural remedy." (P13, South Asian female).*

Often participants were at the end of their tether and were willing to try anything particularly treatments, rather than positive self-directed coping strategies in the hope they could offer some relief.

*"Just I am at the stage where I think I'll try anything so it was something else let's give it a go let's try it not something that I've you know gone into mega deeply spent hundreds of pounds on it .....Just things I've picked up on I actually work with a girl who's very into herbal remedies and she sought of I've found this one try this (laughs) OK go on we'll give it a go but er I don't hold a great faith in them you know but I will give them a go.....Yes you never know one day it might just be that one" (P15, White British female).*

*"I suppose you've got to have an open mind about it. You've got to try, because you just don't know" (P22, South Asian female).*

The coping strategies reported by the participants were hierarchal, in that first, they would seek relief from Western medicine, in terms of over the counter medication, rest, hot water bottles, ice packs, visit the GP, if that had little or no effect, often they would try some of the more perceived to be acceptable complementary therapies such as acupuncture, osteopathy and chiropractors, at this point they were often referred to the pain clinic, so again tried more western medical approaches, when these failed, before trying their own self management strategies, and / or turning to other alternative medicines like

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homeopathy, or hot stones, or made use of remedies, such as spices, from their cultural background, purely as they did not know what else to do. This appears to fit with the medical model adopted by western medicine.

Their accounts of the strategies that they used to cope with the pain were littered with intense frustration around access to, and the cost of complementary therapies. The initial hope that this particular therapy may be the one that cures their pain, the disappointment when it did not live up to their expectations, which were reduced further and further, resulted in despair and desperation “I’ll try anything” and more information seeking by themselves and their families and another round of consultations, trying to justify and legitimise their on-going pain.

### **Information seeking**

Many participants were continually searching for information about their condition and various treatments that might cure or ease their pain. This category is intrinsically linked with coping strategies because often if they read about something new that offered the promise of pain relief they would try it. Sources of information other than health professionals were the Internet, patient education leaflets, magazines, charities, the media, books and others in pain.

*“when I wasn’t working I used to read everything which I could get hold of, because I wanted to get better. I wanted to find out things and... I read it in a magazine, like, err, that magazine I found on acupuncture very good and then the pain clinic so that was useful. It isn’t always you find things like that, yeah, I am not computer literate, I wish I was (laughs) and I try to read (laughs)”*  
(P21, South Asian female).

Some participants reported that if the medication they were taking did not appear to relieve their pain, then they would try alternatives that they had read about.

*“.....and I read in the book that garlic helps, so I just stopped Amitriptyline, I told Dr X about it, and just taking 3 cloves of garlic every night before I go to bed.” (P26, South Asian male).*

Despite the wide variety of information available, the perceived usefulness of the information varied between participants, some felt that the information they had found, particularly the Internet and patient education leaflets only clarified their own thoughts about their condition, whereas talking to people at support groups was found to be beneficial.

*“I read it in a magazine, umm, whilst I was sitting in the surgery at one time, the doctor’s surgery where I read it, but I always keep an eye on the leaflets and things like that but most of the time they just explain what, you know, what it is and how to start, just the normal things it’s not much more than I already knew (laughs)” (P21, South Asian female).*

*“Um its probably confirmed a lot of what I’ve been told known what the problem is um I can’t say that I found out any dynamic facts figures or anything else um I’ve gone onto various websites which in some ways has been quite reassuring where people have actually written and said how they’re feeling with it and it’s quite nice to think there’s other people in the country and other countries they are feeling the same as me there are other people out there um you know it’s not just me sitting here in Leicestershire and I’m the only person yes there are other people out and about and a long way away that are going through exactly the same thing as me” (P15, White British female).*

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*“Erm, yeah, I’ve got a book about, well back care, um, I suppose that has exercises in erm, that I got, that I looked at, but erm, God, I haven’t read a massive amount... I’d probably say bits and bobs, yeah, it was kind of what I knew, really. Yeah, I don’t know whether it was that helpful, but I think probably because the things that I probably read were like what er, physiotherapists and that and people had kind of already told me” (P30, White British female).*

*“I mean, it’s sometimes useful for example, there is a support group which I go along to, and that is very useful because that, for example, mouth ulcers, it wasn’t something I realised happened until somebody spoke to me and said we’ve got those, you know, it’s a known factor with that particular drug. ....That’s right, and erm, they try different things. Like, for example, can openers and things like this, various tools. And also we have people like reflexologists come and give us talks, you know. That was very, very useful.” (P29, White British male).*

A few participants, males rather than females did not seek information about their condition, one of the main reasons was fear of what might happen to them in the future based on the experience of others;

*“Well, I only read, er, both books were actually American and I only read the first couple of chapters really, because they’re based on what has happened to people with CFS in America. And, erm, I thought well I don’t want to read that, this is just scary. I’ve had one or two facts just off the internet. I haven’t read a great deal about it” (P27, White British male).*

For others the reason given for not seeking information was that they felt overwhelmed by it and if the Doctors did not understand it, then they would not be able to.

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*“No, I don’t, you know, it’s something, you know, the back is such a big area that even the doctors’ don’t know where it’s coming from yet” (P20, South Asian male).*

Many participants in their efforts to find ways to get relief from their pain searched frantically for information about their condition and possible treatments, some enlisting the help of family members, for others family members sought out the information. They would often go armed to the consultation with their newfound knowledge and expectations to justify the existence of their long-term pain. A few participants believed that as they thought the doctors, did not know what was wrong, and then no one would know, so did not see the point in looking for information. The quality of the information was perceived by the participants to have limited use but many found it frustrating the way that pain sufferers are perceived by society. This new knowledge was perceived to be promising but was not always expected to give relief or a cure because of their lowered treatment expectations from prior experiences. However, they often felt obliged to keep looking or to investigate further treatments or procedures that had been suggested by family and friends. For others this new knowledge caused them to feel fearful of the future by comparing themselves to the people they had just read about.

## **Affect**

Affect was the overarching theme, in every category identified, participants talked about and reflected upon their mood, emotions and feelings. As can be seen from the categories presented, initially participants were hopeful, as time moved on they became more often desperate for a cure or resigned themselves to having chronic pain indefinitely. Throughout the interviews a whole spectrum of emotions were expressed ranging from frustration, embarrassment, fear, depression, feelings of guilt and inadequacy.

Some participants, on their 'good pain days', felt able to take on tasks that they used to do. However, often during the task, their pain became severe and they were unable to complete the task in the way they wished, which left them feeling foolish and embarrassed.

*"Yeah. It's like in a shop yesterday, and I couldn't reach down to pick the things out of the basket to put on the counter, out of the trolley. And I said, I'm ever so sorry but I've got a bad back and I just can't reach down. And you get the eyes going up to the ceiling and you think I could strangle you!.... Yeah. Because as I say, you want to do it, you know you can do it but you just physically can't do it. And the number of times I get back in the car and I cry because I think, you know, you've made a fool of yourself again" (P30, White British female).*

All participants reported feeling 'down', 'low' or 'depressed', a few participants stressed that they were down rather than depressed

*"Erm, I I would a lot really. It's very miserable, and it is quite, I say depressing, but I wouldn't say that I have been depressed with it, but very close to, and makes you very down, because when it is constantly, constantly bad, you think, and you feel that you are trying to do stuff to help yourself and there is no relief and and and it just makes you so miserable" (P33, White British female).*

*"Er, stress, I mean, stress is on me and my husband, I think, 'cos I do tend, you know, 'cos I take my anger on him, 'cos he's like come from work and that's all he needs, a wife's who's a nutter, you know, you don't realise you're doing it, and after, you know, and even my son, and he's, you know, he was one when I had my injury, the poor boy's been having it since then, kind of, you know. I'm always shouting and screaming at him." (P37, South Asian female).*

However 3 participants reported feeling suicidal at times, only one reported a past history of intentional medication overdose.

*“I don’t really know, all I know is that I get this terrific pain and it radiates up into my brain and ... the pain is so bad all I want to do I curl up in a corner and die it’s that bad.....it’s I didn’t realise pain could be so bad, but when it blacks your life out, you know and there’s one thing in your head and that’s pain and all you want to do is curl up in the corner and die. It can get that bad.” (P17, White British female).*

*“Because I was quite, err, I suppose more emotionally, err, because when I am in pain I think about the children more and, err, it gets me more emotional and there are days when I cry quite a lot and there are days when umm, err, sorry I don’t know how to put it, I don’t want to get emotional but it’s like, err, you just give up on life sort of thing. You think what’s the point.” (P21, South Asian female).*

Frustration was a frequently expressed emotion, mostly focussing around the limitations imposed on participants, the realisation that the things that they could do in the past and took for granted they were no longer able to do. This coupled with the perceived disbelief about their pain from the medical profession, their family, friends and colleagues, and that pain relief or cure was not obtainable fuelled this frustration

*“Erm, because you have to, erm, no matter how frustrated you get, you have to learn that there are things that you cannot do anymore and, er, and I find that very sad (laughs). I get upset about that.” (P23, South Asian male).*

Participants often felt guilty particularly when discussing the loss of the ‘role’ or change in ‘role’, such as the husband who could no longer do his garden so his wife had to cut the trees down, the wife who could not keep the house the



way it used to be or as she perceived it should be. Others felt guilty because despite looking well they could not help out those perceived less fortunate than themselves.

*“but I always feel guilty whenever I walk in that (charity shop) uh I could cos they’ve got a notice on the window assistance required like on such a such a day I wish I could go in there and help them even if it’s only one day a week anything like that but I can’t do it and I feel guilty about it because I would like to help people more that as I say I look alright and everything like that but they don’t know what it’s like you know” (P16, White British male).*

Anger was a popular expressed emotion in the interviews, some participants felt anger about the situation they now found themselves in, and felt that the pain dominated their lives, others were angry at health professionals, whilst others were angry at themselves because they could not get rid of the pain.

*“I don’t really know how I feel about it all, I think it’s as I say .. I get annoyed with myself because it seems to have affected life in all directions ....um in as much as angry because I’ve always been active until this lot started. I’ve tried everything ....angry at myself got not being able to do things” (P14, White British female).*

Mixed in with a plethora of emotions was a feeling of inadequacy. Participants reported not being able to work, so they felt that they were letting their families down. This was not always a gender issue, in terms of traditional roles, such as the male as the ‘breadwinner’ as some South Asian females reported that they are expected to work and contribute to their families particularly if they did not have children.

*“terrible, useless and sick in myself sometimes. It upsets me quite a lot, you know, I don’t often show it but it does. It makes me feel like I really want to*

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*throw up, because one thing is sure that if I'm not working then I'm letting them down. It is one of things that you have to do. I can't do it" (P13, South Asian female).*

Other participants questioned the value of themselves, in terms of being a partner or parent.

*"But, er, it does because, especially if you're in a bad period of pain, you think I'm useless, what is the point. What good am I to me husband, to me kids?" (P30, White British female).*

*"... on my down days, I sit and cry and think what kind of mother am I?" (P21, South Asian female).*

*"...my wife doesn't really need me anymore I don't think...I can't do anything I used to do, can't take her shopping, she loves that we always used to go shopping on a weekend" (P29, White British male).*

Some participants reported feeling inadequate because they had to ask for help to do tasks that they perceived to be their tasks and could have easily done them in the past. This feeling of inadequacy often caused tension within the family as the participants hated asking for help, and often families did not really know the best way to help the participants complete the task

*"Er, because I can't get on with my work and, you know, I never wanted anybody to help me out and it was very, very painful in the beginning. It did cause a bit of problem in the family as well, cos I used to get irritated and very stressed out when I couldn't do it, and I was expecting others to understand by themselves. It wasn't my habit to ask do this for me, do that for me. I was*

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*like, I want, it's my job and just get on with it and finish it" (P26, South Asian male).*

Very few participants reported feeling selfish, those who did highlighted that they realised that others were worse off than themselves however they had become absorbed with their pain and just wanted relief from their pain.

*"I know there are a lot of people worse off, but when you're in chronic pain...you become selfish, and you think I don't give a damn, I just want it to stop"(P31, White British female).*

Fear of pain was commented on by most of the participants, for some the fear was based on fear of movement in terms that they will increase their pain intensity and associated hurt as harm. Therefore, fostering a reluctance to move, because it hurts. This reluctance was also supported by the beliefs and expectations that rest will cure pain, which participants had learnt from their experiences of acute pain in the past.

*"Well, I've always been frightened of the acuteness, cos you tend to, the general ache that's there all the time, you get used to. And in a sense it's a bit like toothache, in that if you have it for a long time, you get used to that toothache, and it seems to be less after a while, and then you'll touch your tooth or have a drink or something and you get the acute pain. Well, it's like that, and it's the acute pain that you get when you move, that you're frightened that am I doing something wrong, because all of a sudden the pain has jumped" (P30, White British female).*

*"...when my pain is really bad, I get scared to move, in case I move wrongly, the sharp stabbing pain comes...that kills me"(P12, South Asian male).*

Although many participants were fear avoidant of movement (the incorrect belief and anxiety that movement causes tissue damage and rest was required) some participants would engage in excessive and painful activities, as a result of the appraisal of the demands of their social worlds and their beliefs about themselves.

*"....play with my grandson, boys' rough and tumble you know... he hasn't got a Dad, so I have to do that bit...(pause) but I'm in agony for ages afterward" (P2, White British male).*

*"I try to avoid bending or lifting as I think that makes my back worse, I get frightened in case I get stuck but sometimes I just have to do it as my husband's at work and I can't leave everything to him" (P32, White British female).*

Others were fearful of a future with chronic pain; comparing themselves in terms of pain and limitations now to previously when they did not have chronic pain, caused fear and anxiety to many who wondered how they would be physically in a few year's time, let alone the more distant future.

*"Well it's frightening cos you don't know whether you are gonna get worse over the years. I mean I'm only in the middle of the road of my age, you don't know whether it gonna be more crippling as you get older." (P3, White British female).*

*"...if it's (pain) this bad now what will it be like in 10 years?" (P12, South Asian male).*

*"there's so much I can't do now, I really worry about the future and my independence or lack of it!" (P29, White British male).*

For some who had exacerbations of their chronic pain, often the memory of returning to a 'flare up' stage made them feel fearful and depressed, the uncertainty of never knowing when they will have a flare up and what will they have to do to try and manage it.

*"I hope it will go away and settle down, and I will end up going back to where I was, and I was well and without it, and can just get on with life and not think about it. That's what I would like, and I really hope. Whether that's going to happen I don't know, I really don't know, and I find that a bit scary and a bit worrying, because the memory of it is so horrible, that when you get into that and the memory comes back, and then I can find myself slipping down into the dark hole and getting a bit down, because it brings back the memory of how awful and it seems to go on for such long periods of time, takes a long while to get to any semblance to sort of being OK. I know it's not going to be as um you know, a week thing; I know we're talking months, and that's what I hate"* (P33, White British female).

Chronic pain produces not only pain but a plethora of mixed emotions, feelings and cognitions as described here in this chapter. The mood of the participants will influence their perceptions about their pain, themselves as a person, their families, their health professionals and ultimately their life world.

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## Summary

To summarise the research findings, all participants' accounts reveal the complexity and the variety of their chronic pain experience. Despite their struggle to comprehend their pain they gave extensive descriptions of what it is like to cope with pain on a daily basis. Interestingly the South Asian patients in this study reported similarly to White British patients in many of the categories, the majority of differences being in the category of cultural expectations. This chapter has presented a model of living with chronic pain on a daily basis. The categories that emerged from the data, cultural expectations, consultations with health professionals, dissatisfaction with the consultation, disbelief, subjectivity of pain, identity, social relationships, impact of pain, coping strategies and information seeking, all which are overarched by affect.

Cultural expectations refer to pain beliefs that are adopted by the chronic pain patient and subsequently brought to the consultation by the participants. Both South Asian and White British participants had experienced acute pain in the past, which had resolved and had a reason for the pain, which added to their confusion and distress regarding chronic pain.

Exploring ideas and expectations about how pain is understood and whether or not it is learnt from our parents, the findings were mixed. Some participants felt that you could learn about your pain from other people, but that others could not experience pain in the same way as themselves.

However some participants felt the way they responded to pain was learnt from their mother's responses during childhood. Some South Asian females reported that they had learned from their parents but responded differently which was attributed to a move to a different culture suggesting cultural differences which may be reduced by acculturation.

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Both South Asian and White British participants shared the stereotypical view that women coped with pain better than men. Most men believed this was because “women have babies and women’s troubles”. Most women commented on ‘man flu’ in a jovial manner “You know if a man’s got a cold it off to bed whereas women I think tend to get on with it a bit.” Female participants reported they felt obliged by their roles as wives, mothers, carers and responsibilities to keep going despite their pain. Some participants felt it was not the actual pain experience between genders that was different, but it was more related to stereotypes that exist such as the macho image and differences in coping style. Initially, both men and women reported that they coped with their pain in different ways, however, over time they felt that they had to adopt similar coping strategies.

Both South Asian and White British participants shared the view that White British people were more stoical about pain, and that Asian women were more vocal about their pain.

Exploring stereotypes further, the concept of age and how, if at all, it affected people’s pain, was discussed. Some participants felt if they were older they would find it easier to cope accept their pain, as pain was seen as inevitable and part of growing old. For female participants it would be more difficult to cope with pain if you were older focusing on the lack of independence and being alone. South Asian males reported that if they were younger, they could cope better with chronic pain and gave reasons around being stronger and more able to do exercise. However both White British and South Asian males perceived that when you are younger, you needed to be active, this in itself was problematic, as they had to work and look after their families. They compared their present role to past and future roles in terms of providing for the family despite the limitations of their pain.

Both South Asian and White British participants reported dissatisfaction with their consultations outside the pain clinic, and many felt that they were disbelieved and hence judged by family, friends, health professionals, the media and society as a whole, leading to complications in social relationships

and issue of self identity. This perceived outcome of the consultation also affected coping strategies and information seeking behaviour. Intrinsically woven within these categories was affect, which influenced the patients' life - world.



## **Chapter 6: A narrative review of the qualitative literature on living with chronic pain.**

### **Introduction**

The aim of this chapter is to provide a review of the qualitative research on what it is like to live with chronic pain on a daily basis. Consistent with Grounded Theory, this review was undertaken after my own data collection and analysis. It aimed to explore the literature and to observe the contribution of my own research to the qualitative field in the area of chronic pain. A discussion of the relationship between my research and the literature is found in chapter seven, positioning my research within the literature. This review chapter starts by discussing the methods of synthesis, addressing key questions around synthesis. It goes on to discuss the problems in appraising qualitative research, culminating in the production of an empirical piece of research by analysing and synthesising the data within selected qualitative literature, using the constant comparative approach of Grounded Theory (Strauss and Corbin, 1998) resulting in a narrative review.

Policy documents argue people should be valued as individuals; their views and experiences should be obtained and addressed (Department of Health, 1998). Good research practice would suggest that qualitative research would be the most appropriate way to give voices to the people who are rarely heard. However, policy documents are often informed by systematic reviews, which often fail to include qualitative research. Recognition is growing that neglecting the qualitative body of research potentially could lead to inaccurate conclusions (Sheldon, 2005). Methods to incorporate qualitative research evidence remains under developed, hence the recent development of methods to incorporate qualitative research into systematic reviews (Dixon-Woods, Fitzpatrick and Roberts, 2001; Dixon-Woods, Agarwal, Jones, Young and Sutton 2005; Dixon Woods et al 2006).

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## Possible methods for synthesising qualitative evidence

Noblit and Hare (1988) propose two types of reviews, integrative and interpretive, which have been further developed by Dixon-Woods et al (2005). Noblit and Hare (1988) suggest that integrative methods for synthesising qualitative research are useful when combining or amalgamating data, such as in meta-analysis. They suggest that there needs to be a basic comparability between the phenomena so that data can be aggregated for analysis. Dixon-Woods et al (2005) propose elaborating this concept; stating that they do not wish to identify integrative synthesis with quantitative research. Instead they suggest that integrative synthesis focuses on summarising data, where the concepts under which the data are summarised are well specified. Despite the focus of integrative synthesis not being on the development of concepts or their specification, it still allows theoretical or interpretive functions to be fulfilled as all synthesis involves interpretation. Integrative synthesis could produce theories of causality and include claims around generalisation (Dixon-Woods et al, 2005).

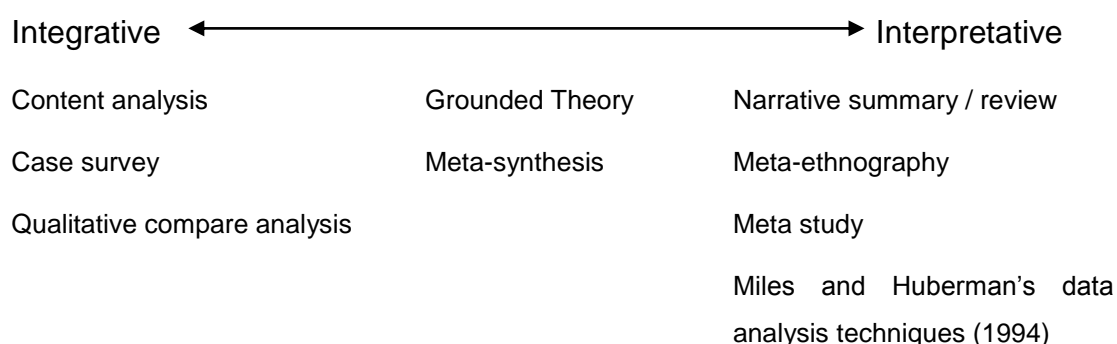
Interpretative reviews according to Noblit and Hare (1988) involving both induction and interpretation, achieving synthesis through subsuming the identified concepts into a higher-order theoretical structure, which is useful in qualitative research. Dixon-Woods et al (2005), argue that interpretative synthesis can be used on both qualitative and quantitative data. They expand on Noblit and Hare's (1988) concept described above by suggesting that the defining characteristic of interpretative synthesis is the development of concepts, with theory development that integrates the concepts. In contrast to integrative synthesis, the concepts emerge and are not fixed at an early stage; a theory is the main product of an interpretative synthesis. It is vital that the interpretative synthesis is grounded in the data drawn from the studies. It is proposed that interpretative syntheses can generate middle-range theories and therefore address questions that are difficult to answer using integrative synthesis. The characteristics of both integrative and interpretative synthesis are summarised below in table 9:

**Table 9: characteristics of integrative and interpretive synthesis of literature.**

	<b>Integrative</b>	<b>Interpretive</b>
Noblit and Hare, (1998)	<p>Concerned with combining or amalgamating data.</p> <p>Achieve synthesis through techniques such as meta-analysis.</p> <p>Require basic comparability between the phenomena studied.</p> <p>Useful for quantitative research.</p>	<p>Concerned with induction and interpretation of data.</p> <p>Achieve synthesis through subsuming identified concepts in primary studies into higher order theoretical structures.</p> <p>Useful for qualitative research.</p>
Dixon-Woods et al, (2005)	<p>Not identifiable with positivist or quantitative research.</p> <p>Focus on summarising data where concepts are assumed to be well specified.</p> <p>Can fulfil theoretical or interpretive functions.</p> <p>Can produce theories of causality, and may include claims of generalisability.</p>	<p>Concerned with the development of concepts, and development and specification of theories that integrate the concepts.</p> <p>Avoids specifying concepts in advance of the synthesis.</p> <p>Main product is a theory, not the aggregate of data.</p> <p>Must be grounded in the data reported in primary studies.</p> <p>May be able to address questions that are difficult to address through integrative synthesis.</p> <p>Concerned with generation of middle range theories.</p> <p>Can be carried out on both qualitative and quantitative data.</p>

As can be seen from looking at table 9, there is overlap between the two methods of synthesis, as they both include an element of interpretation. Ultimately the choice of the method of synthesis has to be related to the research question. Methods of synthesis can be broadly grouped by their epistemiological and ontological foundations, and whether the aim of the synthesis is primarily interpretive or integrative, see figure 5.

**Figure 5: Showing the overlaps of possible methods of synthesis**



Within the groupings shown in figure 5, the elements of some methods show overlap. In the integrative grouping all methods involve quantification and systematic integration of data. Whilst the integrative groupings involve a creative process where new constructs are developed by identifying related concepts in primary studies, these are then reworked and reformulated to extend theory. In practice, many approaches to synthesis involve both integrative and interpretive elements.

I have chosen to use the narrative review because I feel it is appropriate for synthesising the qualitative evidence. Whilst quantitative data does contribute to the understanding of living with chronic pain, qualitative methods are more appropriate for investigating experiences. The narrative review is interpretative yet can be critical. To develop my narrative review I have used the constant comparative technique of Grounded Theory (Strauss and

Corbin, 1998) as used in my own research discussed in previous chapters. I particularly like the recent technique of critical interpretative synthesis (Dixon Woods et al, 2006), which synthesises all types of evidence, both qualitative and quantitative from peer reviewed journal articles, to policies, however this was impractical to complete within the time constraints.

### **Issues in synthesis**

There are no evaluated synthesis studies that are applied to the chronic pain literature, and few in the whole healthcare literature. There needs to be a development of existing approaches by incorporating, extending, adapting and evaluating the most successful elements of these methods. This would offer the provision for capitalising on what is already been accomplished in the field rather than the intervention of new approaches. However before this work can move forward key questions proposed (Dixon-Woods et al, 2004) need to be addressed. These are discussed below.

Is it acceptable to synthesise studies? There are arguments for and against conducting the synthesis of qualitative research (Sandelowski, Docherty and Emden, 1997) and surrounding whether or not it is acceptable to conduct synthesis of qualitative studies derived from different traditions, these distinctions, tensions and conflicts are well documented by Barbour (1998). Some argue that in order for successful synthesis, the methodology of the studies should be similar therefore suggesting that when similar themes are identified across all studies, the mixing of methods leads to difficulties in theory development because of epistemological differences. (Jenson and Allan, 1996; Estabrooks, Field and Morse, 1994). Others take a more pragmatic view and deal with the problem of different approaches in part through their techniques of meta-method and meta-theory (Patterson, Thorne, Canam and Jillings, 2001). Within this developing field, more controversially attempts are being made to synthesise both qualitative and quantitative research to produce a review. As there is little research within the

area of living with chronic pain on a day-to-day basis, I have taken a pragmatic view and included all relevant papers, for this review, as discussed later in this chapter.

Should reviews start with a well-defined research question? Estabrooks et al (1994) argue that the review question should be selected to focus on similar properties or themes. In contrast, others suggest that in primary research definitions of phenomenon emerge from the data (Glaser and Strauss, 1967). Therefore whether or not the research should start with an a priori definition of the phenomenon for purposes of a secondary synthesis remains an important question, and often centres on the research question itself. My research had a broad review question, to synthesise findings from qualitative empirical research in chronic pain, which was developed as the data analysis progressed in line with the constant comparative approach of Grounded Theory

How many papers are required? For practical reasons the number of papers for the review potentially need to be limited. This can be achieved either by narrowing the focus of the question, or alternatively by using theoretical sampling as in primary studies aiming for concept development. As in primary studies sampling continues until theoretical saturation is reached (Strauss and Corbin, 1998). It has been suggested that this approach would be suitable for selecting papers to be included in the reviews (Schreiber, Crooks and Stern, 1997; Booth, 2001; Patterson et al, 2001). Others express anxiety as this form of sampling has not been empirically tested which may result in the omission of relevant data, therefore the understanding of both the phenomenon and its context will be limited (Jensen and Allen, 1996; Sherwood, 1999). As discussed later in this chapter, there was very little literature found, so all studies were included despite some of them being methodologically weak.

How are studies appraised for inclusion?

This question continues to receive a great deal of attention. The NHS CRD (2001) guidelines stressed the need for a structured approach to assessing quality in qualitative studies to be included in reviews, but does also recognise the difficulty of achieving consensus on the criteria that might constitute quality standards. As expected views in this area vary considerably, some argue that methodologically weak papers should be excluded from the review (Campbell, Pound, Pope et al, 2003; Yin and Heald, 1975; Estbrooks et al, 1994). However others argue that papers should not be excluded for reasons of quality where this might result in the synthesis discounting important studies which contribute considerably to the themes of the review for the sake of minor flaws (which are distinguished from 'fatal flaws' that invalidate the results) (Jensen and Allen, 1996; Sandelowski et al, 1997). Fatally flawed papers are those, which evoke strong concerns over their methodology, reporting or content, thus being unable to make a useful contribution to the review. Interestingly this debate continues as some published studies include reviews that have adopted a formalised approach to assessing papers (Campbell et al, 2003) and those that have not chosen to appraise the papers (Garcia, Bricker, Henderson et al, 2002). It is clear that some form of quality appraisal is necessary the problem that arises is how can this be done.

Within a narrative review, synthesis would include the inclusion of methodologically weak papers because even procedurally weak papers may have useful findings and make a theoretical contribution (Dixon Woods, Bonas, Booth et al, 2007; Mays, Pope and Popay, 2005; Sandelowski et al, 1997; Jensen and Allen, 1996; Noblit and Hare, 1988). However, this inclusion would need to be in the context of explicit critical evaluation of the weakness. The weak papers could contribute to development of hypotheses rather than as evidence.

### Problems of appraising qualitative research

The valuable contribution of qualitative research to understanding what it is like to live with chronic pain on a daily basis is increasingly becoming recognised and starting to be illustrated in some of the publications devoted solely to the study of pain. Both practitioners and policy makers need to have confidence in the quality of this type research (Guba and Lincoln, 1994). However there is disagreement not only about what constitutes good quality research but also whether criteria for qualitative research should exist at all.

Some researchers argue that a set of distinctive criteria that is different from the criteria applied to the natural scientific quantitative approaches should be designed for assessing the quality in qualitative research (Guba and Lincoln, 1994; Searle, 2002; Popay, 1998). In contrast, others have called for an end of “criteriology” (Schwandt, 1996) arguing that this leads to privileging of method rooted in positivist philosophical traditions, whilst stifling interpretive and creative aspects of qualitative research. Whilst others suggest that criteria are best regarded as guides to good practice, (Henwood and Pidgeon, 1992) rather than rigid requirements in appraising papers. Clearly some means of determining the quality of qualitative research is essential (Dixon–Woods et al, 2001) as including poor quality studies may distort the synthesis, which may result in difficulties with interpretive aspect of the review (Campbell et al, 2003).

Over a hundred proposals for quality criteria for assessing qualitative research have emerged (Dixon-Woods et al, 2004), which have wide ranging diversity but little common ground. Illustrating this point, Searle and Silverman (1997) stressed the need for detailed transcriptions, support of generalisations with counts of events and use of computer software. Whilst others recommend that qualitative studies should be reproducible and that multiple coding is a good means of assessing quality (Engel and Kuzel, 1992; Strauss and Corbin, 1998). These views contrast with other researchers who deem such criteria as meaningless when conducting research within a relativist paradigm involving multiple realities, subjectivity, and the negotiation

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of meaning (Yardley, 2000; Morse, 1994). Popay, Rogers and Williams, (1998) proposed the priority of subjectivity, flexibility, and adequate description; they argued that quasi statistics and computer programmes are not required. However developments of wide ranging proposals have been useful in identifying possible criteria that could be used to assess quality in qualitative research. (NHS Centre for Reviews and Dissemination, 2001). Attempts to produce consensus on the criteria has proved difficult, the UK National Centre for Social Research has produced a framework (Spencer, Ritchie, Lewis and Dellon, 2003), which is useful in that it describes the tensions and diversities in the field but it is lengthy and potentially unwieldy because it involves over 18 separate domains.

It appears that the key problem when trying to develop appraisal criteria for qualitative research is the tendency to treat all qualitative research as a unified field (Dixon-Woods et al, 2004); both at the level of data collection (e.g. interviews) and at the methodological approach (e.g. Grounded Theory). This flawed approach will produce criteria that fit some cases but not others.

Another key concern is what actually does 'quality' mean in qualitative research. This is more than a procedural consideration, because some of the most important qualities in qualitative research are some of the most difficult to measure. An example to illustrate this point is that a study may have been judged to have followed particular procedures for a certain approach, gave appropriate information on participant selection, provided a clear method section, yet the study might have very poor interpretation and offer little new knowledge into the phenomena studied, and vice versa. Often it is not clear how judgements of quality are made, however it is crucial to take into account the particular features of qualitative research when considering the appropriate way to evaluate it (Dixon-Woods et al, 2004).

## **Method**

### **The Narrative Review**

This narrative review adopted the definition that a narrative review is used to *“describe reviews that combine broadly systematic approaches to searching and appraisal of the literature, but offer a textual (rather than quantitative) summary of the evidence”* (Miller, Bonas, Dixon-Woods, 2007)

In this chapter I take the process beyond a descriptive narrative review and attempt to produce a synthesis by conducting qualitative analysis of the findings in the published literature to develop a new model.

The aim of this narrative review was to offer a theoretically sound and useful account of the lived experience of chronic pain that was demonstrably grounded in the evidence.

### **Formulating the review question**

Initially this study used conventional systematic review methodology (NHS CRD, 2001; Alderson 2004) producing a narrow research question which focussed on the experience of living with chronic pain, initially looking at similarities and differences in White UK British and South Asian populations, as reported in qualitative studies. However, this produced very little evidence (n=2), so it was decided to broaden the research question to investigate the experience of living with chronic pain to conduct this synthesis. Upon further investigation into review methods, the narrative review approach was uncovered and is an appropriate method to use to draw together the evidence and stimulate debate within the field of pain management. Taking a qualitative approach seemed particularly appropriate as the synthesis was of qualitative literature from different disciplines, such as psychology, sociology, nursing and anthropology. Often it is neither possible nor desirable to specify

the precise review question, a priori definitions or categories under which data can be summarised in advance. Hence one of the aims of this review was to allow the definitions to emerge from the data analysis (Jensen and Allen, 1996). The broad question focussed on the experience of living with chronic pain, but did not have a specific hypothesis in mind. The approach used to further specify the research question was highly iterative; and the question was modified in response to the search results and findings from retrieved articles. Eakin and Mykhalovskiy (2003) provide an interesting analogy, in that they treat the research question as a compass rather than an anchor and suggest that the review question is not finalised until the end of the study.

### Search strategy

The method of searching for qualitative research is becoming increasingly important as interest in incorporating qualitative research into systematic reviews grows (Dixon–Woods et al, 2001). Conducting a thorough search is distinguishing feature of systematic review, as there is a need for reviewers to be able to demonstrate the comprehensiveness and reproducibility of their searches (NHS Centre for Reviews and Dissemination, 2001). However it is important to be aware of problems of literature searching for qualitative research. Some of these issues include, electronic databases do not cover all the more popular qualitative journals, the acceptability of qualitative research means that it is published in an ever widening field of journals, and the transferability of qualitative research skills and their capacity to both address a wide variety of substantive topic areas and cross disciplinary boundaries, qualitative research has found its way into a wide array of journals (Barbour and Barbour, 2003). Strategies that use thesaurus terms, free-text terms and broad based terms used as Shaw et al (2004) found that using any of the search strategies could potentially identify relevant qualitative studies. However relying on one strategy, made it more likely to miss relevant records. Therefore Shaw et al (2004) suggests a combination of the three search strategies is required to maximise the number of potentially relevant articles retrieved.

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Considering the problems outlined, searches for papers for inclusion in this narrative review were conducted using structured search strategies on Medline, Embase, Cinahl, PsylInfo, Social Science Citation Index and Science Citation Index, Assia, Amed, Campbell Collaboration, Cochrane Library, Centre for Research in Ethnic Relations, National Library for Health Specialist Library for Ethnicity and Health, to cover the disciplines of medicine, psychology, nursing and the social sciences. Initially the search was conducted using the key words as shown in appendix eight, reported in the English language and went back as far as each database allowed up until March 2007 and repeated in June 2007.

### Sampling the literature

Conventional systematic review methods limit the number of papers included in the review by having a narrow research question. Interpretive reviews have a broader research question but there is still a need to limit the number of papers in the review. Sampling is also required theoretically because the focus on interpretive synthesis is the development of concepts and theories rather than producing an exhaustive summary of all data known to date. Some researchers suggest drawing on the sampling techniques of primarily qualitative research, including the principles of theoretical sampling and saturation when conducting an interpretive synthesis of qualitative literature (Schreiber et al, 1997; Booth, 2001; Patterson et al, 2000). Due to the lack of literature in this area, this narrative review used all available papers. However if more literature were available, initially purposive sampling would be used to select papers that were clearly concerned with aspects of living with chronic pain, and later theoretical sampling (Strauss and Corbin, 1998) would be used to add, challenge, modify and elaborate the emerging analysis.

### Appraisal of evidence

The appropriate means of appraising the quality of qualitative research for inclusion in a systematic review remains deeply contentious, often reflecting some of the tensions within qualitative research itself. The debate

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surrounding the appraisal of the evidence for inclusion in reviews has been discussed above.

For the purpose of this narrative review, and being a fairly inexperienced qualitative researcher, I used the criteria adapted from those proposed by the NHS Electronic Library for Health to inform judgements on the quality of papers and to identify fatally flawed papers (Dixon-Woods et al, 2006), see table 10

**Table 10: appraisals prompts for informing judgements about the quality of papers (Dixon-Woods et al, 2006)**

1	Are the aims and objectives of the research clearly stated?
2	Is the research design clearly specified and appropriate for the aims and objectives of the research?
3	Do the researchers provide a clear account of the process by which their findings are reproduced?
4	Do the researchers display enough data to support their interpretations and conclusions?
5	Is the method of analysis appropriate and adequately explicated?

This study aimed to prioritise relevant qualitative papers. Abstracts that were identified through the searches were screened to exclude papers that clearly did not use qualitative methods, or were irrelevant to living with chronic pain. Abstracts and papers were screened to ensure that they were relevant to the topic of living with chronic pain, used qualitative methods; papers that were primarily quantitative were excluded, however mixed method papers reporting substantial qualitative data were accepted. This study prioritised the likely relevance over the methodological quality (Edwards, Elwyn, Hood and Rollnick, 2000) as it was felt that for an interpretive review that a low threshold should be applied to maximise the inclusion and contribution of a

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wide range of concepts. Therefore only fatally flawed studies were excluded, and the synthesis itself crucially involved judgements and interpretations of credibility and contribution, which will be discussed later.

### Synthesis of evidence

Narrative review does not claim to offer a series of pre-specified procedures for the conduct of the review, and there is no consensus on what a “narrative” synthesis might involve (Miller et al, 2007). As someone new to the process, I decided to use the proforma of published example of narrative reviews where the synthesis takes the form of an account of the evidence organised within broad themes with summary tables (Miller, Bonas and Dixon Woods, 2007) and the relationships between the themes are developed. The broad review question was formulated at the outset, but remained open to modification throughout the synthesis. Initial sampling used a broad search strategy, see appendix eight and included purposively selected material such as papers considering different conditions other than back pain causing chronic pain such as fibromyalgia or rheumatoid arthritis to see the similarities and the differences in living with chronic pain. The analysis aimed to develop a synthesising argument, which took the form of a theoretical framework comprising of a network of constructs and the relationships within them. The synthesising argument connects the synthetic constructs with existing constructs in the literature. As with all qualitative research, there was a need for reflexivity to inform the emerging constructs, and to guide theory development. Searching, sampling, critique and analysis proceed together, and further selection of literature is guided by the emerging theory. This narrative review has used papers with the maximum relevance and theoretical contribution despite methodological weakness only those fatally flawed (as defined earlier in this chapter) were excluded.

### Data analysis

As with my own research data, my methods of analysing the research literature drew on the Grounded Theory method of constant comparison

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(Strauss and Corbin, 1998). My rationale for using Grounded Theory is discussed in chapter three; the actual method of Grounded Theory is presented in detail in chapter four. As the same process was used but applied to the literature, a brief outline of the process will be given in this chapter. Quality was maintained within the analysis using the criteria; sensitivity to context, commitment, rigour, transparency, impact and importance suggested by Yardley (2000), which are reported upon in chapter four, and by regular consultation with my supervisors and for clarification over interpretation throughout the analytic process.

The data analysis as before was broken down into four stages; preparation for analysis, open coding and generation of preliminary categories, definition of themes and categories, and category integration. To illustrate these processes I have provided examples, ensuring transparency. However, it is important to consider as with any other type of qualitative research, complete transparency is not always possible due to the creative and interpretive processes involved.

Preparation of data: In this review I made detailed notes on each paper in the review, and the themes reported as findings in each of the papers were assembled into a tabular form, see table 11.

Open coding and generation of initial categories: Thematic analysis was used to identify dominant and recurrent themes within and across the papers. Initially codes were generated using the themes explicitly identified by the papers. Memos were written linking various codes into categories as the constant comparison process continued, for examples of code notes, see chapter four.

Defining themes and categories: Summaries were written of the emerging categories, which included detailed specifications for each category. Using the 'paradigm model' (Strauss and Corbin, 1998), analytic memos were

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written to explore the relationships between categories and linking in with the literature and aiding theoretical reflection.

Category integration – linking the themes and codes: The themes, categories and memos were then constantly compared, contrasted and critiqued and used to develop synthetic constructs that served to provide a structure within which to organise the research evidence. This part of the process was aided by the use of drawing concept maps (Miles and Huberman, 1994), writing the storyline, sorting and reviewing memos that illustrated the important links between the categories.

In reporting the analysis, it is important to acknowledge the influence and potential limitations (Hausmann, 2003) that may derive from the background of the researcher. This is discussed in chapter four, the method under the reflexivity heading.



**Table 11: Articles selected for the review**

	Reference	Qualitative approach or method used	Participants	Themes /headings labelled explicitly within each paper	Comments
1	Baker, T.A., Wang, C.C. (2006) Photovoice: Use of participatory action research method to explore the chronic pain experience in older people. <i>Qualitative Health Research</i> , 16, p1405-1413	Sampling strategy: non clinic sample recruited from existing database, clinic based sample, recruited volunteers via posters Method of data collection: Participatory action research, involves individuals photographing their every day health and pain realities and providing a commentary, and open ended questions Method of data analysis: not explicitly mentioned. Reflexivity: not mentioned	27 participants agreed to participate (26% clinic based, n=7; 74% non clinic based, n=20) Mean age 65 years (SD=6.32 years) 67% female, n= 18; 33% male, n=9 Mean level of education = 15 years (SD = 1.44 years) Self identified ethnicity, Black, n=10; White, n=14, Others, n=3 Clinic based sample entirely White. Non-clinic sample, n=13 self-identifying as Black. 5 completed Phase 1 only. 13 participants completed the whole project. Country where study took place: USA	Not explicitly mentioned however I would suggest these headings Realities of living with chronic pain Difficulties revealing emotion	Authors report small sample – not enough data for meaningful analysis Authors report that they deviated from the photovoice protocol of group discussions and presentations of images due to participants physical limitations, transport problems and small clinic based sample

	Reference	Qualitative approach or method used	Participants	Themes /headings labelled explicitly within each paper	Comments
2	Bates, M. S., Rankin-Hill, L., Sanchez-Ayendez, M. (1997) The effects of cultural context of health care on treatment of and response to chronic pain and illness. <i>Social Science and Medicine</i> , 45 (9) p1433-1447	Sampling strategy: not specified, other than study took place in outpatients' departments Method of data collection: Formal and informal interviews: open-ended questions. Observations at treatment sessions. Method of data analysis: Content analysis Reflexivity: not mentioned	Social demographics of the 4 groups reported elsewhere: 3 groups (Anglo-Americans n= 100, Latinos n= 44, Polish-Americans n= 28) from New England study represented by 5 case studies, 2 case studies represented the Puerto Rico study (n= 100) Most common diagnosis- back pain, arthritis or neuropathies Similar medications Similar in types of treatment they have had in past for pain Intensive Case study (6 from each ethnic group) Country where study took place: USA	Language barrier and linguistic expression of pain. Cultural differences in standards for expressing pain. Differences in medical setting world-views on mind-body relationships. Cultural differences in the doctor – patient relationship. Health care provides as patient advocates and counsellors. Differences in views on responsibility for pain.	Doesn't say how participants were selected Based on 2 studies, one in New England, the other in Puerto Rico Not supported by extensive quotes Difficult to understand if data was drawn for this paper from the seven case studies reported on page 1434, or the intensive case studies as reported on page 1435, or if there were combined Good idea about the use of advocates within the chronic pain setting, but not sure how this would work beyond the medical setting.

	Reference	Qualitative approach or method used	Participants	Themes /headings labelled explicitly within each paper	Comments
3	Bates, M. S., Rankin –Hill, L. (1994) Control, Culture and Chronic Pain. <i>Social Science and Medicine</i> , 39 (5) pp 629-645	Sampling strategy: not specified, other than study took place in outpatients' departments Method of data collection: Quantitative - questionnaires Qualitative - Formal and informal interviews: open -ended questions Case study (6 from each ethnic group) Observations at treatment sessions. 6 case studies reported Method of data analysis: content analysis Reflexivity: not mentioned	Quantitative study: New England Study: Old Americans n=100, Puerto Ricans n=44, Irish n=60, Italians n=50, French Canadians n=90, Polish n=28 Puerto Rican Study; n= 100 Puerto Ricans Puerto Rican population was older (mean age 60 years) than New England study (mean age 45 years) Both populations similar in socio-economic status and education Qualitative study Case study (6 from each ethnic group) Country where study took place: USA	Locus of control	Not supported by extensive quotes Qualitative data suggests that the style of locus of control may be fluid and altered by pain experience

	Reference	Qualitative approach or method used	Participants	Themes /headings labelled explicitly within each paper	Comments
4	Becker, B. (1999) Narratives of pain in later life and conventions of story telling. <i>Journal of Aging Studies</i> . 13 (1) pp73-87	Sampling strategy: not mentioned: Method of data collection: Interviews Methods of data analysis: Narrative analysis (Labov (1972) Reflexivity: not mentioned	1 female with chronic pain in the "later half of her eighties" 1 male with chronic pain in the "later half of his eighties" No other demographic details given Ethnicity: not mentioned  Country where study took place: UK	I never used to say anything You don't forget it in a hurry Little girls should be seen and not heard You are no longer you in your entirety Now how did I get this pain	Looking at way stories are told, the author sees the ways of speaking as integral to the way both individuals make meaning of their pain and their lives. Paper explores the violation of narrative conventions, as author felt if used Labov's (1972) linear analysis, the nature of the accounts would be lost by only extracting core information that follows narrative conventions. Interesting in that through their life stories how this has influenced the way they deal with their pain.

	Reference	Qualitative approach or method used	Participants	Themes /headings labelled explicitly within each paper	Comments
5	Bendelow, G. (1993) Pain perceptions, emotions and gender. <i>Sociology of Health and Illness</i> , 15 (3) pp273-294	Sampling strategy: not specifically mentioned other than it took part in a health centre: Method of data collection: Questionnaire and interviews, during interviews selection of visual images of people in pain shown Method of data analysis: not stated Reflexivity: not mentioned	53 male and 54 female Ethnicity: "experiences of people in an English multiracial inner city area which has a mixture of both deprivation and gentrification, in housing and other services, and a varied ethnic mix" not reported beyond this. Country where study took place: UK	No explicit themes identifying, however quotes to support ideas of stigma attached to emotional or psychological pain, and seeking explanations for their pain	Physical pain was reportedly more frequently than emotional pain. Gender difference shown in relation to the importance of emotions in the pain experience. Men are more likely to incorporate the mind/body splits in conceptualising pain. Twice as many men did not complete the questionnaire as women. Questionnaires revealed that majority of the sample believed that women are better able to tolerate pain than men as reported in other literature. Do people attending the health centre have different views from those attending pain clinics, or those without pain?

	Reference	Qualitative approach or method used	Participants	Themes /headings labelled explicitly within each paper	Comments
6	Bendelow.G., Williams, S.J. (1996) The end of the road? Lay views on a pain relief clinic. <i>Social Science and Medicine</i> , 43 (7), pp1127-1136	Pilot study Sampling strategy: everyone attending a pain clinic attached to a teaching hospital was asked to take part in the study over a two month period. Method of data collection: Semi-structured interviews Method of data analysis: not stated Reflexivity: not mentioned	34 participants, 22 female, 12 male. Age range 20-80 years, 12 'working class' 10 'middle class' Ethnicity: 6 described themselves as either Pakistani, Iranian or Greek Cypriot Country where study took place: UK	Pain carers Experiences of the pain clinic	Most important factor in differentiating between the 'resignation' group and the 'accommodation' group appeared to be the chronicity of the pain condition. Mind/ body dualism, does treatment reinforce or overcome this division? Chronic pain seen as 'low status' in our increasingly technologised world, serves as a reminder of the limits of modern medicine.

	Reference	Qualitative approach or method used	Participants	Themes /headings labelled explicitly within each paper	Comments
7	Borell, L., Asaba,E., Rosenberg, L., Schult, M-L., Townsend, E. (2006) Exploring experiences of “participation” among individuals living with chronic pain. <i>Scandinavian Journal of Occupational Therapy</i> , 13, p76-85	Sampling strategy: not specifically mentioned other than occupational therapy practitioners selected the sample based on treatment history and reports related to pain. Method of data collection: Open ended Interviews Method of data analysis: Constant comparative Reflexivity: reflection mentioned but not explicitly described	6 participants, 3 male, 3 female both of Swedish and non-Swedish descent living in Sweden. Age range 41-56 2 participants had lived with their pain for over 20 years Participants were being treated for pain at time of interviews Country where study took place: Canada	Taking initiative and making choices Doing something physical Doing something social Doing something for others	Indicates need to look at the subjective experience in order to understand social forces that influence pain, and ideas of participating in life. ICF undervalues the role of personal meaning or individual life experiences as it focuses on a person’s identifiable and observable capacity to perform certain activities.

	Reference	Qualitative approach or method used	Participants	Themes /headings labelled explicitly within each paper	Comments
8	Carson, G.M., Mitchell, G.J. (1998) The experience of living with persistent pain. <i>Journal of Advanced Nursing</i> , 28 (6) pp1242-1248	Sampling strategy: participants identified by healthcare professionals Method of data collection: Open-ended interviews Method of data analysis: Descriptive exploratory method (Parse et al, 1985) Reflexivity: not mentioned	17 participants, 10 female, 7 male. 12 lived in long stay hospital, 3 short stay hospital admissions, 2 outpatients. Age range 54 – 93 years old. Short stay and acute patients had back pain and arthritis. 11 of the 12 living in long-term care had chronic illnesses such as arthritis, stroke and heart disease, 1 of the 12 had chronic pain linked with a diagnosis of cancer. 2 participants were outpatients diagnosed with fibromyalgia and rheumatoid arthritis, Ethnicity: not mentioned. Country where study took place: Canada	Forbearance surfaces with the drain of persistent anguish Isolating retreats coexist with comforting engagements Hope for relief clarifies priorities of everyday living	All participants reported the difficulties of living with long-term pain, yet all indicated that they had found the strength to bear with and endure their discomfort.



	Reference	Qualitative approach or method used	Participants	Themes /headings labelled explicitly within each paper	Comments
9	Closs, S.J., Staples, V Innes Reid,Bennett, M.I., Briggs, M. (2007) Managing the symptoms of neuropathic pain: an exploration of patients' experiences. Journal of Pain and Symptom Management, 34, pp422-433  (Accessed on-line prior to publication)	Sampling Strategy: purposive sampling (recruited from existing database from previous study, sent information packs, 12 responded, 10 took part) Method of data collection: focus groups Method of data analysis: thematic analysis Reflexivity: professional roles i.e. psychologist, and experience of working / researching pain stated.	10 participants, 4 male, 6 female Age range 24 to 60 years Ethnicity: not mentioned Country where study took place: UK	Use of medications Alternative Strategies Adjusting to the situation	Little support was offered when told to live with their pain as pain management programmes are thought to be ineffective for neuropathic pain, although scarce evidence for this. Highlights the need for psychological support

	Reference	Qualitative approach or method used	Participants	Themes /headings labelled explicitly within each paper	Comments
10	Cunningham, M.M., Jillings, C. (2006) Individuals' descriptions of living with fibromyalgia. <i>Clinical Nursing Research</i> , 15 (4) pp258-273	<p>Sampling Strategy: Purposeful sampling, and theoretical sampling later in the study, thus allowing maximum variation in sampling</p> <p>Method of data collection: In-depth semi structured interviews</p> <p>Method of data analysis: constant comparative analytic process (Glaser and Strauss, 1967)</p> <p>Reflexivity: kept a reflexive journal to ensure rigor (Guba and Lincoln, 1994)</p>	<p>8 participants, 1 male, 7 female</p> <p>Age range "early 30s to late 70s"</p> <p>Ethnicity: not mentioned</p> <p>Lived with fibromyalgia between 18 months and 13 years.</p> <p>6 participants were unable to work, 1 was retired and living on a pension, 1 engaged in occasional casual work with part time hours</p> <p>Country where study took place: Canada</p>	<p>Living with symptoms of Fibromyalgia</p> <p>Management of Fibromyalgia</p>	<p>Participants felt more accepted by alternative therapies rather than health professionals</p> <p>Stigma, the need for validation of their illness</p> <p>Delicate balance between helpful social support and that which result in alienation and isolation.</p> <p>Groups that were "lead by knowledgeable facilitator were less likely than self help groups to deteriorate into depressing venues for the venting of rage and misery"p269</p>

	Reference	Qualitative approach or method used	Participants	Themes /headings labelled explicitly within each paper	Comments
11	De Souza L.H., Frank, A.O. (2000) Subjective pain experience of people with chronic back pain. <i>Physiotherapy Research International</i> 5 (4) pp207-219	Sampling strategy: purposive sampling from new referrals to rheumatology outpatient clinic Method of data collection: Unstructured interviews Questionnaires at later date Method of data analysis: Thematic content analysis (Ritchie and Spencer, 1994) Reflexivity: not mentioned.	11 participants, 5 male, 6 female Mean age: 49.3 years Mean duration of pain: 10.4 years 10 of the participants had low back pain, 1 had neck pain None of the men were working, all but one of the women were working except one who had retired. Ethnicity: not explicitly stated but the paper suggested that 2 participants were Indian Country where study took place: UK	Pain descriptors Use of simile Positive and negative descriptors Loss of words Intensity and quantity	Participants provided in-depth accounts of their pain experience but these bore little resemblance to commonly used pain assessment tools, therefore challenging the appropriateness of such instruments.

	Reference	Qualitative approach or method used	Participants	Themes /headings labelled explicitly within each paper	Comments
12	Dickson, G.L., Kim, J.I. (2003) Reconstructing a Meaning of Pain: Older Korean American Women's Experiences with the Pain of Osteoarthritis. <i>Qualitative Health Research</i> , 13, pp675-688	Sampling strategy: not explicitly stated, recruited via advertisement in physician's office Method of data collection: Interviews (2 face to face, + telephone call, observations and interactions) Method of data analysis: constant comparison method of Grounded Theory Reflexivity: maintained a reflexivity log	Participants: 7 Korean women Age range 63-80 years Diagnosed with osteoarthritis Mean time since immigration: 23 years Religion: 3 Protestant, 4 Roman Catholic 4 lived with spouses, 3 with their children Country where study took place: USA	Suffering with pain Struggling to remove the pain Stumbling along with the pain Striving to reduce pain Managing and tolerating pain	Interesting to note that depending upon the country where the research is conducted defines different definitions of Asian. Participants conceptualise pain as part of aging process. Ageing process does not have same negative connotations as it does in USA or UK. Clinicians need to understand the role of culture so can advocate pain relief methods that are acceptable and/or consistent with the patient's worldview.

	Reference	Qualitative approach or method used	Participants	Themes /headings labelled explicitly within each paper	Comments
13	Garro, L.C. (1994) Narrative representations of chronic illness experience: cultural models of illness, mind, and body in stories concerning the temporomandibular joint (TMJ) <i>Social Science and Medicine</i> , 38 (6) pp 775-788	Sampling strategy: not explicitly stated Method of data collection: Interviews, open-ended semi structured 2 <sup>nd</sup> part McGill Pain Questionnaire Narratives Method of data analysis: not explicitly stated but seems to compare the cultural model applicable to North Americans of European heritage to the narratives obtained Reflexivity: not mentioned	Participants: members of support group for TMJ 32 agreed to participate, 27 female, 5 male. Duration of TMJ: minimum one year Age range 23 to 69 years Ethnicity: not described fully –“all but one were Caucasian of European heritage” Country where study took place: Canada	Narrative Structure TMJ: a problem of mind or body? Individual models, shared models and cultural models Relationship with the ill body: control or harmony	Anthropological perspective Important point – illness stories are built around what the participants judge to be worth talking about, and often try to convince the listener of the merit of their story (legitimising their pain)

	Reference	Qualitative approach or method used	Participants	Themes /headings labelled explicitly within each paper	Comments
14	Gibson, J.M.E., Kenrick, M. (1998) Pain and powerlessness: the experience of living with peripheral vascular disease. <i>Journal of Advanced Nursing</i> , 27, pp737- 745	Sampling Strategy: convenience sample selected from patients attending a specialist vascular outpatients' clinic Method of data collection: Interviews Method of data analysis: constant comparative approach of Grounded Theory (Strauss and Corbin, 1990) Reflexivity: not mentioned	9 participants, 6 male, 3 female Age range 62 to 75 years Length of time since diagnosis of PVD ranged from 18 months to 10 years Ethnicity: not mentioned Country where study took place: UK	Pain Someone else's problem – patient-hood Someone else's problem – expectations Someone else's problem – playing by the rules Shrinking of horizons Control, choice and changing outlook	Participants with PVD appear to view their situation in the acute medical model, leading to unrealistic expectations. Emphasis the need for patients to be able to share control of decision making about treatment.

	Reference	Qualitative approach or method used	Participants	Themes /headings labelled explicitly within each paper	Comments
15	Glenton, C. (2003) Chronic back pain sufferers – striving for the sick role. <i>Social Science and Medicine</i> , 57 (11) pp2243-2252	Sampling strategy: not explicitly stated, used contributions from Norwegian Back Pain Association's website. For interviews health professionals were asked to refer patients with acute or chronic low back pain, (n=9) or back pain sufferers or carers through the Back Pain Association (n=10) Method of data collection: On-line discussion list and In-depth interviews Method of data analysis: Content analysis of online data and interview data Reflexivity: not mentioned	Participants: Most had several years of back pain and should be defined as chronic. 5 were close family members of those with back pain. Age range: 24 to 65 years "as many women as men" Ethnicity: not mentioned Country where study took place: Norway	Medical diagnosis as a proof of suffering Psychosocial and psychiatric diagnoses Access to health care as proof of suffering Visible disabilities and consistent symptoms as proof of suffering Access to sick role benefits when proof of suffering is not fully achieved Feelings of worthlessness	Stigma – suspicion that pain does not exist. Patients try to live up to the expectations of the sick role – justification of pain

	Reference	Qualitative approach or method used	Participants	Themes /headings labelled explicitly within each paper	Comments
16	Haugli, L., Strand, E., Finest, A. (2004) How do patients with rheumatic disease experience their relationship with their doctors? A qualitative study of experiences of stress and support in the doctor – patient relationship. <i>Patient Education and Counseling</i> , 52 pp169-174	Sampling strategy: not stated Method of data collection: Focus groups using an interview format Method of data analysis: “the researchers applied principles of qualitative analysis in looking for themes or trends in the patients’ perceptions” (p170/1) Reflexivity: professions noted	12 patients had diagnosis of inflammatory disease (Rheumatoid Arthritis or ankylosing spondylitis) Age range 20 to 80 years Disease duration ranged from 1 to 30 years 14 patients had symptomatic diagnosis of non inflammatory widespread chronic pain condition such as fibromyalgia All female Age range: 35 to 57 years Disease duration not specified Ethnicity: not mentioned Country where study took place: Norway	Rheumatoid Arthritis or ankylosing spondylitis patients: being seen being believed experience of availability Non inflammatory widespread chronic pain condition such as fibromyalgia diagnosis being believed shared understanding	Parallels and differences between doctor-patient relationships depending upon diagnosis Emphasises the need for better communication to acknowledge the patients’ need to be seen as a whole person



	Reference	Qualitative approach or method used	Participants	Themes /headings labelled explicitly within each paper	Comments
17	Honkasalo, M-L. (2000) Chronic pain as a posture towards the world. <i>Scandinavian Journal of Psychology</i> , 41 pp 197-208	Sampling strategy: not explicitly stated other than “picked for the interview through cooperation with the pain clinic of a university hospital” (p201) Method of data collection: Interviews Method of data analysis: Content analysis initially and then narrative analysis to bring out the meaning Reflexivity: not mentioned	Total of 20 interviews, 10 with idiopathic pain, 10 neurogenic chronic pain Age range 35 to 65 years “All had suffered chronic pain for years” (p201) Ethnicity: not mentioned Country where study took place: Finland	*Disruption *Misunderstandings with healthcare *Not to be trusted *Meaning of diagnosis *The abject body Reasons for the pain *Longing for the past *Peace and solace	3 stories presented rather than themes as the author states “this form justifies the original way of representing pain in the interviews” (p201) Discusses pain as an embodied relation to the world, “a posture to the world” (p205)

	Reference	Qualitative approach or method used	Participants	Themes /headings labelled explicitly within each paper	Comments
18	Hwang, E.J., Kim. Y.H., Jun, S.S. (2004) Lived experience of Korean women suffering from rheumatoid arthritis: a phenomenological approach. International Journal of Nursing Studies 41 pp239-246	Sampling strategy: theoretical sampling Method of data collection: unstructured interviews Method of data analysis: Colaizzi's (1978) 9 procedural steps method Reflexivity: not mentioned	5 Korean women living in Korea diagnosed with rheumatoid arthritis Age range: 34 to 61 years (mean =48) Disease duration: 4 to 12 years (mean = 7) All housewives having more than one child Country where study took place: South Korea	Severe pain Self esteem Negative feelings Reflect the past life Concentrate on recovery from disease A comfortable mind in pain Support of the family and others New life	Female patients have more difficulty than male patients because of family responsibilities such as childcare Women suppressed in man-orientated society such as Korea so are reluctant to disclose illness to their family Authors report limitation of study is possibility of mistranslation of the meanings of the statements of the participants from Korean to English.

	Reference	Qualitative approach or method used	Participants	Themes /headings labelled explicitly within each paper	Comments
19	Kodiath, M. (1998) Cultural influences on the assessment and treatment of chronic pain. <i>Home Health Care Management and Practice</i> , 11 (1) pp46-51	Sampling strategy: not mentioned Method of data collection: not mentioned other than “talk with the nurses” Method of data analysis: not mentioned Reflexivity: states profession and expertise in pain management in both USA and India, provides reason for her interest in this area.	No demographic details given	Meanings	Interesting views on the differences of meanings and treatments of those in USA compared to those in India. Most significant difference in experience had to do with the meaning of pain for each person Outlines potential conflicts when assessing pain between the two cultures

	Reference	Qualitative approach or method used	Participants	Themes /headings labelled explicitly within each paper	Comments
20	Kugelman,R. (1999) Complaining about pain. <i>Social Science and Medicine</i> , 49 pp1663-1676	Sampling strategy: not explicit, introduced to participants at end of stress management session by the psychotherapist who ran the group. Method of data collection: Interviews Method of data analysis: analysis of discourse and phenomenological analysis Reflexivity: not mentioned	14 people attending stress management programme, 7 male, 7 female Age range: 20 to 50 years Had suffered work related injuries to necks and backs except one whose neck pain started after a car accident Reports all but one are working class Ethnicity: 11 Anglo-Americans, 2 African Americans, 1 Hispanic Country where study took place: USA	<i>Analysis of discourse</i> Stress and relaxation Physical and emotional pain Positive and negative thinking Pain invisible and visible <i>Phenomenological analysis</i> Pain and existence: loss and grief Pain and being-in-place A cry for justice	Contradictions found in that pain is seen as personal with “little cash value”, but it is not private because of pain expression and the need to approach it by considering moral and ethical dimensions. Invisibility and the difficulties of producing evidence to prove they have pain such as X-rays. Pain becomes visible when entering into the narrative about the pain

	Reference	Qualitative approach or method used	Participants	Themes /headings labelled explicitly within each paper	Comments
21	Lillrank, A. (2003) Back pain and the resolution of diagnostic uncertainty in illness narratives. <i>Social Science and Medicine</i> 57 pp1045-1054	Sampling strategy: not explicitly stated Method of data collection: Autobiographic writing competition "The Back Bone in Your Life" Method of data analysis: narrative analysis Reflexivity: not mentioned	30 females Age range 20 to 66 years Majority of narratives (n=24) were written in Finnish, and 6 were written in Swedish 17 were in the workforce and/or on temporary sick leave. 13 were retired, 10 of these were on early disability pension Majority seemed to have pink collar or manual work and belonged to the working or lower middle classes (p1046) Ethnicity: not mentioned Country where study took place: Finland	Initial scenes Initial help seeking contact Coping with puzzling body pain Seeking specialists' knowledge It's all in your head Turning points Solving the riddle	Both men and women entered the competition, in this theme, the author included only the women's accounts because "they make up a coherent unit of analysis" (p1046) Author notes that the participants are not a representative sample of back pain sufferers. Paper shows the journey from initial back pain symptoms to obtaining a diagnosis.

	Reference	Qualitative approach or method used	Participants	Themes /headings labelled explicitly within each paper	Comments
22	McHugh, G., Thoms, G. (2001) Patient satisfaction with chronic pain management. <i>Nursing Standard</i> , 15 (51) pp33-38	Sampling strategy: not mentioned Method of data collection: Focus groups Method of data analysis: Content analysis Reflexivity: not mentioned	8 focus groups were run, number of participants ranged from 5 to 8 in each group. No demographic details provided Ethnicity: not mentioned Country where study took place: UK	Living with chronic pain Support groups Communication Pain services Range of services and treatments	First part of the paper was more concerned with how to run a focus group.

	Reference	Qualitative approach or method used	Participants	Themes /headings labelled explicitly within each paper	Comments
23	McPhillips – Tangum, C.A., Cherkin, D.C., Rhodes, L.A., Markham, C. (1998) Reasons for repeated visits among patients with chronic back pain. <i>Journal of General Internal Medicine</i> 13, pp289-295	Sampling Strategy: random sample of those pre-selected ICD-9 codes (p290). Letter sent re purpose of study offering incentive to take part, followed by telephone call from researchers. Method of data collection: Interviews, and questionnaires designed to valid qualitative results Method of data analysis: Content analysis Reflexivity: Not mentioned	54 interviews, 37% male, 63% female Age range: 25 to 65 years “Had 3 or more medically attended episodes of low back pain during the 3 years preceding the study”(p289) Marital status: Married or living as married 72.2%, never married 5.6%, widowed 5.6%, divorced 14.8%, separated 1.9% Current employment: employed 68.6%, homemaker 11.1%, student 3.7%, unemployed 1.9%, retired 7.4%, sick leave 3.7%, disability 3.7% Ethnicity: White/ Caucasian 72%, Black/ African American 18.5%, Asian or Pacific Islander 7.4%, Hispanic/ Chicano 1.9% Country where study took place:USA	Activity limitations Desire to discover the cause Increase in pain Desire for diagnostic test Unanswered questions Desire for new treatment	Many have back pain complicated by emotional, social and family difficulties, and often his connections are not recognised Keep seeking treatment because past care failed to answer fundamental questions about cause of pain, diagnostic tests or specialist referrals.

	Reference	Qualitative approach or method used	Participants	Themes /headings labelled explicitly within each paper	Comments
24	Miles. A., Curran, H.V., Pearce, S., Allan, L. (2005) Managing constraint: the experience of people with chronic pain. <i>Social Science and Medicine</i> , 61 pp431-441	Sampling strategy: Theoretical sampling Method of data collection: Pain measures and open ended interviews Method of data analysis: Grounded Theory (Glazer, 1978) Reflexivity: not mentioned	29 participants, 20 female, 9 male attending outpatient pain clinic Age range: 21 to 84 years 38% primary pain site in lower back or lower back and legs, 28% had pain in legs (not back), 21% had more than 2 sites of pain, 7% had head pain, 3% chest pain, 3% neck pain. 21% said cause of pain was unknown; a further 7% described it as wear and tear. Ethnicity: not mentioned Country where study took place: UK	Constraint: Bodily constraint Speed at which things can be done The contracting social world The split between mind and body The loss of comfort Activity restriction Challenge to identity: Actions and judgments of other people Ones own ability to do things Physical changes Surrounding environment Evaluating the impact of pain Assimilation Accommodation Subversion Confrontation	Key issue that emerged for participants was the inability to do the things that they wanted to do



	Reference	Qualitative approach or method used	Participants	Themes /headings labelled explicitly within each paper	Comments
25	Ong, B.N., Hooper, H., Dunn, K., Croft, P. (2004) Establishing self and meaning in low back pain narratives. <i>The Sociological Review</i> pp532-549	Sampling strategy: not explicitly stated Method of data collection: Interviews Method of data analysis: not explicitly stated other than “using open coding and in vivo coding. Through iterative discussions the 2 researchers identified and agreed categories and themes” Reflexivity: not mentioned	16 participants, 6 male, 10 female 2 participants were jointly interviewed with their spouses Ethnicity: not mentioned Country where study took place: UK	Establishing oneself as a moral person Locating pain Pain vocabulary Patterns of pain Clinical encounters	Authenticity of the pain experience is central to their stories

	Reference	Qualitative approach or method used	Participants	Themes /headings labelled explicitly within each paper	Comments
26	Osborn, M., Smith, J.A. (1998) The personal experience of chronic benign lower back pain: An interpretative phenomenological analysis. <i>British Journal of Health Psychology</i> , 3 pp65-83	<p>Sampling strategy: not mentioned</p> <p>Method of data collection: semi structured interviews</p> <p>Method of data analysis: Interpretative Phenomenological Analysis (Smith, 1995)</p> <p>Reflexivity: not mentioned explicitly</p>	<p>9 female participants attending an out-patient back pain clinic</p> <p>Age range 25 to 55 years</p> <p>Duration of pain: at least 5 years</p> <p>Ethnicity: not mentioned</p> <p>Country where study took place: UK</p>	<p>Searching for an explanation</p> <p>Comparing this self with other selves</p> <p>Not being believed</p> <p>Withdrawing from others</p>	<p>Use of biomedical model to understand their pain is ineffective</p> <p>Multidimensional experience of living with pain</p>

	Reference	Qualitative approach or method used	Participants	Themes /headings labelled explicitly within each paper	Comments
27	Osborn, M., Smith, J.A. (2006) Living with a body separate from the self: The experience of the body in chronic benign low back pain: an interpretative phenomenological analysis. <i>Scandinavian Journal of Caring Sciences</i> , 20 pp216-222	Sampling strategy: purposive sample Method of data collection: Semi structured interviews Method of data analysis: Interpretative Phenomenological Analysis (Smith and Osborn, 2003) Reflexivity: not mentioned	6 participants, 4 male, 2 female Age range: 36 to 52 years Range of pain duration; 5 to 15 years Working class background Ethnicity: European Caucasian Country where study took place: UK	Living with body separate from self	Focuses on the embodied experience of the participants chronic pain Complex relationship between bodies, chronic pain and sense of self.

	Reference	Qualitative approach or method used	Participants	Themes /headings labelled explicitly within each paper	Comments
28	Peolsson, M., Hyden, L-C., Satterlund Larsson, U. (2000) Living with Chronic Pain: A dynamic learning process. <i>Scandinavian Journal of Occupational Therapy</i> , 7 pp114 - 125	Sampling strategy: consecutive flow of patients to the clinic were sent invite letters, and followed up by a telephone call couple of days later. Method of data collection: Interviews Method of data analysis: not specified Reflexivity: not mentioned	37 participants (14 males, 23 females) Age range 21 to 56 years 33 had professional training, 2 were students, 2 were of unknown professional background Ethnicity: All participants were native speakers of Swedish except one Country where study took place: Sweden	Describing pain Pain as Gestalt Prototypes of pain Pain Management	Legitimisation of pain
29	Peolsson, M., Saljo, R., Satterlund Larsson, U. (2000) Experiencing and knowing pain – patients' perspectives. <i>Advances in Physiotherapy</i> , 2 pp146-155	Sampling strategy: as above Method of data collection: Interviews Method of data analysis: analysis not specified Reflexivity: not mentioned	37 participants (6 in pilot study, 31 in main study) Demographic details as above in Peolsson, M., Hyden, L-C., Satterlund Larsson, U. (2000) Country where study took place: Sweden	Making discriminations Pain transformations – pain phases Pain phases as resources for pain accommodation	Use of language and communicating about pain

	Reference	Qualitative approach or method used	Participants	Themes /headings labelled explicitly within each paper	Comments
30	Rhodes, L.A., McPhillips – Tangum, C.A., Markham, C., Klenk, R. (1999) The power of the visible: the meaning of diagnostic tests in chronic back pain. <i>Social Science and Medicine</i> , 48, pp1189-1203	Sampling strategy: random sampling of patients meeting the inclusion criteria Method of data collection: Interviews Method of data analysis: Thematic analysis Reflexivity: not mentioned	54 participants (20 male, 34 female) Age range: 26 to 65 years Majority (72%) were married Majority were employed (69%) Ethnicity: majority were white (72%) Country where study took place: USA	Diagnostic testing and the invisibility of back pain The anatomical body and the body in pain Seeing it in black and white: patterns of alignment or alienation	Also present 2 case histories to show narratives of testing for chronic back pain to illustrate cultural and historical assumptions Fear of de-legitimation

	Reference	Qualitative approach or method used	Participants	Themes /headings labelled explicitly within each paper	Comments
31	Rogers, A., Allison, T. (2004) What if my back breaks? Making sense of musculoskeletal pain among South Asian and African Caribbean people in the North West of England. <i>Journal of Psychosomatic Research</i> , 57 pp79-87	Sampling strategy: "a quota sample of patients from a postal survey, ...were selected according to age, gender, site of pain and severity of symptoms to attend a research clinic for clinical assessment"(p80). Of 114, 32 participants selected on age, gender, ethnicity, extent of primary care usage Method of data collection: in-depth interviews (12 conducted by same language interviewer) Method of data analysis: thematic analysis Reflexivity: not mentioned	Of 114 patients attended for clinical assessment, 32 participants were interviewed (13 men: 19 women) Ethnicity: men 4 Afro Caribbean, 9 South Asian, women 6 Afro Caribbean, 13 South Asian Country where study took place: UK	Causes of symptoms – beyond wear and tear The relationship between psyche and soma: Fragile bodies? Coping with and managing pain	Linked with large scale quantitative study Authors report limitation in the way the classification of ethnicity was used Suggestion of differences between and within the two ethnic groups Biomedical framework unlikely to consider different conceptualisations of pain, the body and role of family members in the experience and management of chronic pain as reported by Asians in this study.

	Reference	Qualitative approach or method used	Participants	Themes /headings labelled explicitly within each paper	Comments
32	Raak, R., Wahren, L.K. (2006) Health experiences and employment status in subjects with chronic back pain: a long term perspective. <i>Pain Management Nursing</i> , 7 (2) pp64-70	Sampling strategy: convenience sample Method of data collection: semi-structured interviews Method of data analysis: Content analysis Reflexivity: not mentioned	10 participants, 6 male, 4 female) Age range: 39 to 58 years Marital status: 9 were married or living as if married, 1 was divorced Ethnicity: not mentioned Country where study took place: Sweden	Coping Root causes Control/ influence Pain Sleep Employment Status and Well-being	Pain experience had not changed over years, but participants at work changed the way they coped and used coping strategies related to their work Acceptance of pain Highlights differences in pain expression between males and females

	Reference	Qualitative approach or method used	Participants	Themes /headings labelled explicitly within each paper	Comments
33	Smith, A.A. (2003) Intimacy and Family Relationships of Women with Chronic Pain. <i>Pain Management Nursing</i> , 4 (3) p134-142	Sampling strategy: purposeful sampling of volunteers for the study Method of data collection: Interviews Method of data analysis: Coding procedure outlined by Strauss (1987) Reflexivity: not mentioned	25 women with chronic pain Age range: 37 to 72 years Marital status: 18 married or living as married, 6 divorced, 1 widowed Range of pain duration: 1.5 months to 46 years Ethnicity: 20 (80%) White, 5 (20%) African American 13 family members also interviewed Country where study took place: USA	Cycle of close involvement and isolation Focus directed towards others Loss of sexual intimacy	Women felt guilty about having chronic pain and burdened by responsibilities Family need help to respond to pain effectively



	Reference	Qualitative approach or method used	Participants	Themes /headings labelled explicitly within each paper	Comments
34	Smith, J.A., Osborn, M. (2007) Pain as an assault on the self: An interpretative phenomenological analysis of the psychological impact of chronic benign low back pain. <i>Psychology and Health</i> , 22 (5) pp517-534	Sampling strategy: purposive sample Method of data collection: semi-structured interviews Method of data analysis: Interpretative Phenomenological Analysis (Smith and Osborn, 2003) Reflexivity: not mentioned	Same participants as used in Osborn, M., Smith, J.A. (2006) 6 participants, 4 male, 2 female Age range: 36 to 52 years Range of pain duration; 5 to 15 years Working class background Ethnicity: European Caucasian Country where study took place: UK	The negative impact of pain on the self Continuum or trajectory The public arena makes it worse Directing it at others The sting in the tail (fear of social judgement)	Illustrates the debilitating impact of chronic pain on self Concept of shame

	Reference	Qualitative approach or method used	Participants	Themes /headings labelled explicitly within each paper	Comments
35	Sofaer, B., Moore, A.P., Holloway, I., Lamberty, J.M., Thorp, T.A.S., O'Dwyer, J. (2005) Chronic pain as perceived by older people: a qualitative study. <i>Age and Aging</i> , 34 pp462-466	Sampling strategy: not mentioned Method of data collection: unstructured interviews Method of data analysis: Grounded Theory approach Reflexivity: not mentioned	63 participants, 21 male, 42 female Age range 60 to 87 years Ethnicity: not mentioned Country where study took place: UK	Independence and control Adapting to a life with pain	Highlights the usefulness of "just talking" about pain Information leaflet developed from interview data (Pain in Later Years: Practical Ideas to Help You Cope)

	Reference	Qualitative approach or method used	Participants	Themes /headings labelled explicitly within each paper	Comments
36	Sofaer-Bennett, B., Walker, J., Moore, A., Lamberty, J., Thorp, T., O'Dwyer, J. (2007) The social consequences for older people with neuropathic pain: a qualitative study. <i>Pain Medicine</i> , 8 (5) pp263-270	Sampling strategy: not specified other than patients who had taken part in another study, contacted in writing, on receipt of agreement to participate were telephoned to arrange interview. Method of data collection: Semi structured interviews Method of data collection: Interpretative Phenomenological Approach (Smith, 1996) Reflexivity: not mentioned	16 participants, 6 male, 10 female All over age of 60 years All had confirmed diagnosis of neuropathic pain Ethnicity: not mentioned Country where study took place: UK	Pain related limitations Pain related uncertainties Social isolation	Highlights social withdrawal and isolation for both patient and spouse/partner leading to loss of confidence Findings not unique to neuropathic pain Support group set up following research

	Reference	Qualitative approach or method used	Participants	Themes /headings labelled explicitly within each paper	Comments
37	Sofaer-Bennett, B., Holloway, I., Moore, A., Lamberty, J., Thorp, T., O'Dwyer, J. (2007) Perseverance by older people in their management of chronic pain: a qualitative study. <i>Pain Medicine</i> , 8 (5) pp271-280	Sampling strategy: not specified, other than invitations issued by Consultant at 3 pain clinics Method of data collection: unstructured in-depth interviews Method of data analysis: constant comparative method (Strauss and Corbin, 1998) Reflexivity: not mentioned	63 participants, 33% male, 67% female 27 significant others were present and participated in the interview Mean age: 72.2 years Marital status: married or with permanent partner 57%, divorced or separated 16%, Widowed 22%, single 5% Main type of pain: Spinal 60.3%, knee 7.9%, shoulder 6.5%, post surgery/ trauma 7.9%, other 18% Ethnicity: not mentioned Country where study took place: UK	Perseverance (main theme) Keeping occupied Focus on social activities	Despite the presence of pain, older people who consciously persevere in planning ways to lead meaningful lives can do so Perseverance is an important element of older adults' successful coping with chronic pain. Did not mention how or if the significant other's contribution changed the interview in any way.

	Reference	Qualitative approach or method used	Participants	Themes /headings labelled explicitly within each paper	Comments
38	Thomas, S.P. (2000) A Phenomenologic Study of Chronic pain. <i>Western Journal of Nursing Research</i> , 22 (6) pp683-705	Sampling strategy: not explicit apart from recruited via a newspaper advert and network sampling Method of data collection: In-depth interviews Method of data analysis: Phenomenological approach of Pollio et al (1997) Reflexivity: not mentioned	13 participants, 4 male, 9 female Age range: 27 to 79 years Marital status: 10 married, 3 single or divorced Range of pain duration: 7 months to 41 years Ethnicity: 12 White, 1 Black participants (8 White women, 1 Black woman, 4 White men) Country where study took place: USA	The altered, recalcitrant body: Invisibility of pain Separation from other people: Isolation Trust and Mistrust of physicians Lack of support Moments of time, existential crisis, and thoughts of death: Hope and hopelessness	These participants report that their pain cannot be managed. "In contrast to healthy individuals' relative lack of consciousness of their bodies, the body is the main focus of the chronic pain patient's existence" (p696) Psychological pain of being disbelieved and stigmatised is as devastating as bodily pain.

	Reference	Qualitative approach or method used	Participants	Themes /headings labelled explicitly within each paper	Comments
39	Tse, M.M.Y., Pun, S. P.Y., Benzie, I.F.F. (2005) Pain relief strategies used by older people with chronic pain: an exploratory survey for planning patient-centred intervention. <i>Journal of Clinical Nursing</i> , 14 pp315-320	Sampling strategy: not explicit, residents of a local nursing home were invited to take part in the study Method of data collection: Interviews, and visual analogue scale Method of data analysis: "organised into 4 themes" Reflexivity: not mentioned	44 participants, 7 male, 37 female Age range: 65 to 82 years 93% had lived in a nursing home for 3 years or more Ethnicity: not mentioned Country where study took place, Hong Kong, China	Prevalence and intensity of pain Areas of pain and onset of pain Pain relief measures used Non prescription intervention: types, frequency and perceived effectiveness	Does not clearly say whether themes emerged or the interviews were put into pre-selected themes. Older people reluctant to request pain relief, seeing it as part of the aging process, more likely to self medicate than use prescription drugs.

	Reference	Qualitative approach or method used	Participants	Themes /headings labelled explicitly within each paper	Comments
40	Walker, J., Holloway, I., Sofaer, B. (1999) In the system: The lived experience of chronic back pain from the perspectives of those seeking help from pain clinics. Pain, 80, pp621-628	Sampling strategy: consecutive patients, then criterion based sampling Method of data collection: interviews Method of data analysis: phenomenological analysis Reflexivity: not mentioned	20 participants, 12 male, 8 female Age range: 28- 80 years Range of duration of back pain: 2 to 50 years. Ethnicity: not mentioned Country where study took place: UK	Reported theme – In the system Medical process Waiting Feeling insignificant Getting nowhere Losing faith All in the mind Challenging the medical model Battling for benefits Establishing a legitimate claim Your life isn't your own Compensation claims Damned if you don't, but damned if you do Passing the medical test	Those with back pain are rendered passive and powerless, entrapped by the systems designed to help them Anger is a salient feature of chronic pain patients, but often suppressed as no-one to direct it at. Highlights the importance of communication and management issues, which need to be addressed by both clinicians and policy-makers.

	Reference	Qualitative approach or method used	Participants	Themes /headings labelled explicitly within each paper	Comments
41	Walker, J., Sofaer, B., Holloway, I. (2006) The experience of chronic back pain: Accounts of loss in those seeking help from pain clinics. <i>European Journal of Pain</i> 10, pp199-207	Sampling strategy: initially consecutively, then purposively Method of data collection: interviews Method of data analysis: Interpretative Phenomenological Approach (Smith, 1996) Reflexivity: not mentioned	20 participants, 12 male, 8 female Age range: 28 to 79 years Range of duration of pain: 2 to 50 years All had experienced variety of treatments for back pain prior to their referral to the pain clinic. Ethnicity: All white British Country where study took place: UK	Loss of abilities and roles Employment- related losses Financial and related losses Relationship losses Loss of identity Loss of hope	Loss is reported as one of 5 themes that emerged Life changes were reported as facts, however loss is a perception



	Reference	Qualitative approach or method used	Participants	Themes /headings labelled explicitly within each paper	Comments
42	Werner, A., Steihaug, S., Malterud, K. (2003) Encountering the continuing challenges for women with chronic pain: recovery through recognition. <i>Qualitative Health Research</i> , 13, p491- 509	Sampling strategy: purposeful sample Method of data collection: Semi structured interviews Method of data analysis: phenomenological analysis – Giorgi (1985) Reflexivity: not mentioned	6 female participants Age range: 31 to 53 years 2 women were living in marital relationships 3 women had children (2 had adult children, 1 had children at home) 4 women were employed Range of symptom duration: 1 to 16 years Ethnicity: not mentioned Country where study took place: Norway	What did the women acquire in the group –for better or worse? Applying the competence in the context of everyday life Why can't she just do it?	Based on their experiences of treatment group Discussed of the gendered way the term coping has frequently been used

	Reference	Qualitative approach or method used	Participants	Themes /headings labelled explicitly within each paper	Comments
43	Werner, A., Malterud, K. (2005) “The pain isn’t as disabling as it used to be”: How can the patient experience empowerment instead of vulnerability in the consultation? <i>Scandinavian Journal of Public Health</i> , 33 (Suppl 66) pp41-46	Sampling strategy: purposeful sampling Method of data collection: semi-structured interviews reported in 4 studies previously published Method of data analysis: Analysis supported by Code’s (1995) work on rhetorical spaces Reflexivity: not mentioned	10 female participants Age range 26-58 years 5 were married 6 had children 3 had college degrees, 7 had education below this level 5 had paid work, 6 received social security benefits Average symptom duration was 9 years 5 had diagnosis of fibromyalgia Ethnicity: not mentioned Country where study took place: Norway	The struggle for credibility The medical consultation: symptoms appraised as legal evidence? Marginalised, yet strong, narrators in pain The medical narrative: “Unexplained” pain understood as hysteria Recognition: a foundation for ‘recovery competence’	Doctors should take the responsibility to transform patients’ experienced vulnerability into strength instead of increasing feelings of disempowerment by both doctor and patient. Suggested that Doctors take on the professional responsibility for acknowledging the shortcomings regarding diagnosis and treatment for chronic pain, so the blame can be put onto the discipline of medicine rather than the person with chronic pain.

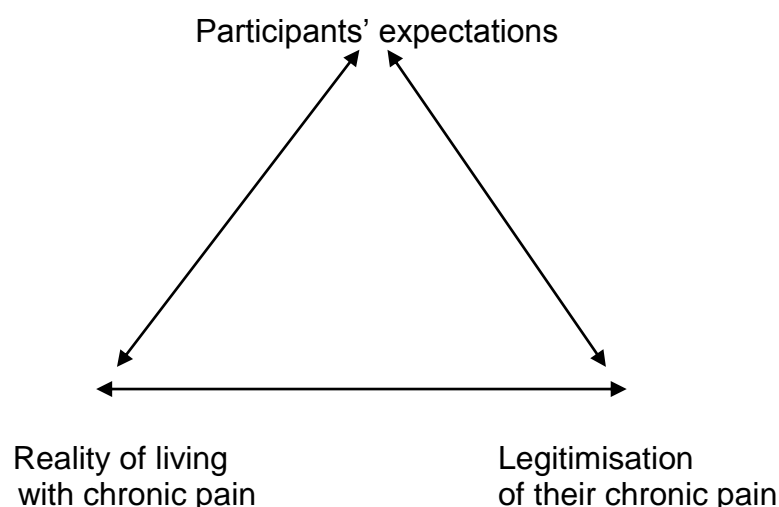
	Reference	Qualitative approach or method used	Participants	Themes /headings labelled explicitly within each paper	Comments
44	Wiener, C.L. (1975) The burden of rheumatoid arthritis: tolerating the uncertainty. <i>Social Science and Medicine</i> , 9 pp97-104	Sampling strategy: not stated Method of data collection: observations, interviews Method of data analysis: “were coded into categories and their properties” (p97) Appears to use Grounded Theory although not explicitly stated Reflexivity: not mentioned	21 participants No other demographic details given Ethnicity: not mentioned Country where study took place: USA	Social-Psychological Tolerating Strategies: Psychological strategy of hope Social strategies of covering up and keeping up Social strategy of pacing Re-normalising: the adjustment to reduced activity: Re-normalisation Eliciting help	Living with chronic pain requires coming to terms with uncertainty

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## Findings

The initial phase of searching identified 106 potentially relevant papers, and screening these on the basis of ethnicity and living with chronic pain yielded 17 papers, whilst removing ethnicity from the search, yielded 44 papers inclusive of the 17 mentioned. Following appraisal of quality and assessment of relevance to the topic of living with chronic pain and the use of qualitative methods, as discussed earlier in this chapter under the method section; all 44 studies were deemed suitable for inclusion in the review, see table 11. Analysis of these papers suggested that 'saturation' (Strauss and Corbin, 1998) was achieved. As the synthesis evolved, tentative early analytic categories became more highly specified. This synthesis involved a critique of what it is like to live with chronic pain on a daily basis. From the data analysis previous discussed, it also involved the generation of a synthesising argument that illustrates the interplay of the synthetic constructs of expectations, legitimisation and reality experienced by chronic pain patients. Synthetic constructs are described as such because they are the product of the transformation of the evidence into a new conceptual form.

**Figure 6: Model of living with Chronic Pain developed from the narrative review**



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The synthesising argument around living with chronic pain is organised around the interplay of patients' expectations of chronic pain, their need to legitimise their chronic pain and the reality of living with chronic pain. The expectations and beliefs, that people with chronic pain hold will influence both their attempts at legitimising their pain and how they experience the reality of living with chronic pain. Equally their attempts at legitimising their pain, and the reality of how chronic pain impacts on their lives, will cause them to review and redefine their expectations. This section has briefly outlined the model of living with chronic pain developed from the narrative review. The next section presents the categories, properties and dimensions and a critique of these to illustrate the proposed model developed from the narrative review.

### **Patients' expectations associated with chronic pain**

The chronic pain literature suggests that it is key to understand people's cultural beliefs in terms of their health (pain) beliefs, their own personal and societal beliefs, hence the development of the synthetic construct of expectations. From social learning theory, it is known attitudes and behaviours including the expression of pain, are learned from the observation of others, therefore is culturally influenced. As people mature responses are 'shaped' by the social world. Through observation it is learned how others react to pain and in turn develop individual pain beliefs and behaviour patterns; through social learning processes people become more skilled and effective in communicating their pain so needs can be met (Main and Parker, 2000). The patient's beliefs about their health can have a profound effect on clinical care, in terms of seeking access to various types of treatment, treatment expectations and outcomes. Pain beliefs help people gain a stable understanding of the events they have, or may experience in the future (Williams and Thorn, 1989).

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The difficulty in expressing chronic pain is not necessarily restricted to language barriers but our perceptions and expectations of pain expression both verbally and non verbally, this was usually considered in the literature to be by both male and female chronic pain patients and health professionals in terms of gender stereotyping with women being perceived to cope better with their pain because their biological and reproductive functioning, but were under-pinned by cultural expectations of roles and socialisation (Bendelow, 1993).

*“Women are made to suffer pain because we have periods and childbirth. Whatever the social climate, women end up child-rearing therefore they don’t have the ‘privilege’ of giving in to pain and sickness” (Bendelow, 1993, citing Female, fulltime childcare, 36, White British, UK study)*

*“Nature has built women that way to cope with everyday pressures – raising a family, running a home and so on” (Bendelow, 1993 citing Female, full time childcare, 33, black British, UK study)*

*“I do think with pain, when it’s your mum or other women, you do find yourself thinking she can cope with it. The impression I get is that women aren’t supposed to feel pain. Now, I would, but as a kid I never felt any sympathy whatsoever – it’s a man’s world really...(Bendelow, 1993, citing Male, double glazing salesman, 26, white Irish, UK study)*

Equally stereotyping of men was evident in that it is not seen as socially acceptable for men to cry or vocalise their pain (Bendelow, 1993; Bates et al, 1997)

*“Men are not allowed socially to express pain as much they’re supposed to be stronger. We’re allowed to cry and they’re not...although women have more*

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*breakdowns than men, men don't allow it to come out, they hide it until it's unbearable whereas a woman will usually say 'I can't cope' long before"* (Bendelow, 1993, citing Female, student, 18, mixed race, UK study)

*"The average man always thinks he's tougher than he is but is not so good when it comes to coping with pain when it happens"* (Bendelow, 1993, citing Male, interior designer, 38, white British, UK study)

It is interesting to note the distinction between what people report they expect of themselves, and what they feel others expect of them in terms of managing their pain:

*"Men will sort of try and battle it out, whereas women will give in and take a pain killer. As a boy I was always told that the good Indian suffers in quiet but in fact the feeling is that women actually cope better, have a bigger threshold"* (Bendelow, 1993, citing Male, freelance copywriter, 24, white British, UK study)

### **When discussing treatment for pain**

One nurse said, *"He starts to yell when I apply the alcohol swab – even before I put in the needle (for I.V.). He looks so macho but acts like a baby."* (Bates et al, 1997; p1437, USA study)

Seventeen studies mentioned the ethnicity of their participants, however cultural perceptions and expectations in terms of ethnicity were rarely considered in the literature (n=3), despite some of the papers reporting different ethnic groups within their studies. Bates et al (1997, p1436) provide an example of what type of pain expression is seen as acceptable and unacceptable by both patients and health professionals working in pain clinics

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in New England, USA, and in Puerto Rico. Yolanda, a Puerto Rican immigrant to the mainland attended the pain clinic in New England, was able to speak enough English to be able to communicate her condition to the staff, however her “open expressions of pain intensity, depression, anger and frustration made her unpopular with the N.E. pain center nursing staff because she did not meet their cultural expectations for appropriate behavior”, as this contrasted to their own stoical approach to pain. Rogers and Allison (2004) in their UK study, suggest differences between South Asian and African Caribbean respondents. They found similarities in reasons for reporting their pain, however the experience and management of widespread pain differed. Accounts from some South Asian participants suggest a lack of separation between pain and broader social and personal concerns, and an unwillingness to recognise ‘depression’ or psychological distress. In contrast, descriptions from the African Caribbean participants coincided with the traditional medical model of psychogenic pain that is adopted in Western cultures.

The learned expectations that pain is time limited often resulted in a visit to the general practitioner and various consultants when the pain remained; this visit entailed a myriad of expectations, surrounding both the consultation and treatments available and the expectation that their pain will be cured. Initially patients assumed that the health professionals treating them are competent and knowledgeable.

*“The likes of [surgeons], they know what they are talking about, they don’t say things unless they are sure so I accept what they want to do” (Gibson and Kendrick, 1998 citing participant 1, UK study)*

Often patients placed an unquestioning faith in the medical system despite its shortcomings, and a common feature was the expectation to see ‘clear results’ (Cassell, 1992; Gibson and Kendrick, 1998, Lillrank, 2003), and often



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perceived surgery as the only cure (Leavitt, 1990). There was an implicit trust in the accuracy and appropriateness of the health advice given. There was also the desire to be seen as a good patient,

*“I decide to visit the doctor to know the reason for my pain. Now I take the doctor’s medicine to try to relieve the pain” (cited by Dickson and Kim, 2003, Korean women living in USA)*

Reasons for attending medical consultations included the difficulty in carrying out normal activities, which defies social norms. Limited activity was cited more frequently than an increase in pain as to why people sought further medical consultations. McPhillips-Tangum et al, (1998) use the following quote to illustrate this.

*“I’ve been living on pain pills. I leave [work] in the afternoon, and I can barely walk to my car. When I do get there, I have to sit for a little while before I can drive the car home. I cannot cook. I have to sit on a stool to do any cooking because if I try to stand for more than 5 minutes at a time, well, you wouldn’t believe the pain” (Cited by McPhillips-Tangum et al, 1998, USA study)*

The consultation is not always a successful experience as often there is a mismatch in views between what the participant expects and what realistically can be offered by the health professional. Many found the long lasting, complicated help-seeking process to be ineffective, and found that the specialist’s moral judgements and personal attitudes were not that different from those already evident in the general practitioners explanations (Lillrank, 2003).

*“I went again to the specialist. Since he did not really want to listen to me I had written on paper what I wanted to say. He thought I was fixated on my*

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*symptoms, that I stressed the importance of wellbeing and that I was disappointed when physical exercise did not work. Of course I was disappointed when the physical exercises were not helpful. But I was most of all disappointed with not being taken seriously. And by the way, is there anybody who does not want to feel well?" (cited by Lillrank, 2003, study involving Finnish women)*

Many participants expressed frustration over not receiving any diagnosis, as one man described,

*"The initial diagnosis was just – well, you know, there really wasn't one. I had some x-rays, and they said they weren't really certain what was going on. All they told me was to lie flat on my back for four days and see what happens" (McPhillips- Tangum et al, 1998, USA study)*

Even when a diagnosis was provided, it was sometimes seen to be inadequate by the patient, especially when it was a symptomatic descriptive diagnosis,

*"The diagnosis from my primary care provider was back pain. He then referred me to an orthopedic doctor. [He] took a series of x-rays, and asked me to do some movements, such as bend over to see how far I could reach before the pain kicked in. He tested my muscle strength, and so on, and so on. Then his diagnosis was back pain too" (cited by McPhillips-Tangum et al, 1998, USA study)*

Often the health professional is not the healer that they are expected to be by the participant. Often the patient is upset and disappointed that their hopes or expectations are not met as the participant is seeking treatment and a cure for their pain rather than help to live with their pain.

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*"I just can't cope with it, I mean I had such high hopes of coming here, that finally they'd make me better. I don't want to learn to manage it, I want to get rid of it. Now I just feel I might as well give up, its going to be there for the rest of my life" (Bendelow and Williams, 1996 citing Female, shop assistant, 33, UK study)*

Some patients saw referral to the pain clinic as the 'end of line'

*"I wish I'd lied and said that they were working, that the pain had gone, I just feel like they've given up on me here, sending me to that other place (pain management clinic) I've heard bad things about that..." (Bendelow and Williams, 1996 citing Female, living alone on benefits, 57, UK study)*

*"Well, they don't know what else to do with me do they? That's why I'm here so they can stick needles in me, experiment. Like I'm no good for nothing else am I?" (Bendelow and Williams, 1996, citing Male, ex HGV driver, 51, UK study)*

Whilst others reported that their treatment is ineffective and inappropriate, but wanted to comply to be seen as a 'good patient', with others hoped for a miracle,

*"It's a complete waste of time (acupuncture), if you really want to know. I don't know why I bother coming. You might as well start saying magic spells or do some voodoo. I don't know, it's all a big con but I don't like to tell her, she's such a nice lady. I was so pleased about coming here, I can't tell you, but I'm still in as much pain as ever." (Bendelow and Williams citing Female, retired machinist, 62, UK study)*

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*“I was so scared at first, the sight of those great big needles, I nearly passed out I was that scared, but I have to say I think it worked...nothing else ever has apart from painkillers. I couldn’t see any point in coming here or in anything really, but if this, if the feeling lasts then it’s a miracle”. (Bendelow and Williams 1996, citing Female, living alone on benefit, 40, UK study)*

Issues arising from consultations include the attitude of the health professional, the differences in attitude between pain clinic team members and other health professionals as perceived by the participants, as expressed below who was referred to the pain clinic.

*“8 years I’ve had this pain... I’ve been through literally everything you could possibly think of trying to get to the bottom of this. My GP told me I was imagining it, that I was being neurotic because the kids had left home. He sent me for X-rays, all sorts of specialists, nothing worked. I even tried an osteopath, that was useless...I’d given up completely just lived on painkillers...then I got the appointment for here. I couldn’t believe it, it’s the only place that’s taken me seriously” (Bendelow and Williams 1996, citing Female, 48, ex florist, UK study)*

In Western medicine, despite the introduction of the bio-psychosocial model of chronic pain, mind / body dualism remains, both in views of health professionals and in chronic pain patients. When clinical investigations and examinations continue to show no physical cause, health professionals may turn to psychological or psychosocial models of explanation for pain, but to receive a psychological diagnosis or explanation of one’s problems is a huge source of distress and frustration for many patients and their families (Glenton, 2003; Lillirank, 2003; Cunningham and Jillings, 2006)

*“And at the hospital when they couldn’t find anything they send him to the psychologist, and it was over in fifteen minutes, and he was completely*

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*shattered after that. And what it said in his notes, it didn't make sense at all, not for us who knew him, but he apparently knew him after quarter of an hour. It seemed like when they didn't find anything wrong then just to have something to say they sent him to the psychologist. So then it was his head that there was something wrong with and not his back. But it's things like that that (hurt) so much, you don't know what to do. And if you ask to go to some other place and the doctors there (get a copy of the) notes, well, everything becomes a mess then" (Glenton, 2003, citing Informant 2, Margrethe, 60 year old housewife and mother of chronic back pain sufferer, Norwegian study)*

*"I went to the hospital, and I have never been so angered in my life when one of the nurses walked by and somebody asked, "What's wrong with this lady?" "Oh!...the usual...menopause..."We are called complainers. I have one document from one of the doctors that said I have psychological problems...I simply told him that if I needed to see a psychologist, I will see a psychologist, I am here to ask you a medical question...The medication profession does not take it seriously. I know there are doctors who will absolutely not sign disability papers for you" (cited by Cunningham and Jillings, 2006, Canadian study)*

Despite having prolonged contact with health professionals chronic pain patients often still have very limited understanding about their pain. However attempts to legitimise their pain often suffered from the harsh reality of living with chronic pain and enforced a redefinition of their expectations and assumptions based on previous and current knowledge, leading to the perception of an unsatisfactory consultation for both the patient and the health professional.

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## Legitimisation of chronic pain

Most people have experienced acute pain as defined in chapter one, leading them to expect pain to serve a protective function for limited period of time, but usually the patient had control over it by taking medication or using another type of coping strategy. During this time, they are able to express their pain and for it to be understood and sympathised with by significant others. As pain persists beyond the expected time of healing, it becomes more and more difficult to express pain. Communicating pain becomes a complex challenge for those with chronic pain who need to operate at different levels, expressing pain for themselves and others (for example family, friends, employers, health professionals) because from past experience of communicating about pain they have been understood and so now expect to be understood. It is important for the patient to express their pain and be understood as it links with seeking legitimisation of their pain. Bickerton (1996) argues that to communicate, we have to have something to communicate about. This, in some sense trivial, yet provocative statement points to a fundamental dilemma for patients suffering with chronic pain. For patients, accounting for their pain implies bridging the gap between making sense of a complex, maybe limiting, set of experiences and finding adequate correlates for these experiences in language (Peolsson et al, 2000). When asking what is the pain like, answers vary from 'it hurts' to rich linguistic offerings with in-depth descriptions of burning, dull, achy, stabbing pains. One of the most common ways of trying to express pain was the use of the simile identifiable by the use of the word *like* (De Souza and Frank, 2000)

*"Now, I really can't tell you anymore because, how you describe pain, you can always say it's like something else" (Becker, 1999, citing Andrew:85, UK study)*

Descriptions of pain would often emphasis both what the pain is like and not like,

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*"it's not a burning pain...it's a stitching pain" (De Souza and Frank, 2000:213, table 4, citing subject 3, UK study)*

*"It's like toothache, it started to come on and then got worse...." (Ong et al, 2004: 541 citing Christine, UK study)*

Often chronic pain patients were at a loss to describe their pain,

*"I think pain is an individual thing really...In my mind I know what sort of pain it was, but in your mind you might interpret in a different way" (De Souza and Frank, 2000:213 citing subject 1, UK study)*

*"I don't know how I can differentiate the pain. I can't put any specific words to describe it" (De Souza and Frank, 2000:213 table 5, citing subject 5, UK study).*

The synthetic construct of legitimisation incorporated the struggle for credibility, in terms of dealing with consultations and the need to access services despite difficult consultations because it proved proof that there was an explanation for their pain. The literature addresses the problem of chronic pain being both visible and invisible, and the need for diagnostic test as proof that there was a real reason for their pain.

Lack of diagnosis is particularly problematic for the participant, as they believe that if they could give the pain a name or a reason, then the health professional would be able to treat it, or at the very least the participant would have a legitimate reason for not being able to take part actively in life as they had in the past. This lack of diagnosis often leads participants to feel

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disbelieved not only by health professionals, but their own families, friends, neighbours and work colleagues, but also causes the patient to try and legitimise their pain with repeated medical visits, this is discussed further under the section legitimising their pain.

*“My life is just hell, complete misery, I don’t know why someone can’t just put me down, if it was a dog it wouldn’t suffer...and these bloody doctors, I could swing for them, I don’t know why they can’t find out what causes it. I can’t do my job for the pain in my belly, I’m just about to be made redundant and I bet I’ll lose my pension. The wife and kids are fed up with me moaning and yelling at them all the time. The only pleasure I’ve got is the bloody whisky and beer, but of course they tell you off and say I’ve to stop smoking. I’ve had the big intestine cut four times you see. Its all very well for them, that’s all I’ve got...”*(Bendelow and Williams, 1996, citing Male, school caretaker, 58, UK study).

The identification of an objective, physiological sign of disease is central to the legitimisation of chronic pain, however for many with pain, there is a lack of objective physical signs, hence spend varying amounts of time without any diagnosis. Throughout the literature the achievement of a medical diagnosis was a common theme (for example Glenton, 2003; Lillrank, 2003, McPhillips-Tangum et al 1998). Diagnoses were seen as important because they could lead to explanations of cause and suggestions for treatment, as well as access to welfare benefits. Some patients associated their lack of diagnosis with their perceived unpopularity as patients:

*“they’re so sick of us ladies who come along with this sort of thing! There are so many of us and they don’t know what to do with us, do they? One doctor has written about me “she complains so much...” He could have written “she has so many problems” but it was the complaints that were the problem! Of course I was a pretty hopeless case when they couldn’t figure out what it was.*

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*I heard from a friend of mine that her daughter, who's a doctor, is training to be a radiologist now because she can't stand all these women who hurt all over!" Glenton, 2003, citing Informant 1, Arnhild, 55 year old teacher, Norwegian study).*

The person with chronic pain is expected to display a visible attempt to get well and a desire to co-operate with those seen as appropriate. To be undergoing health care treatment can be seen as such an attempt and is also a visible sign to one's social surroundings that medical approval of one's suffering has been received. (Glenton, 2003) Even when treatment was sought and received, it was sometimes perceived as unsatisfactory, causing the patient to seek out a new type of treatment.

*"At first my back felt better with the brace on it, but after a while it didn't work. So I went back to the doctor, and I said, 'What else can we do, doc?'" (cited by McPhillips-Tangum et al, 1998, USA study).*

Apart from pain behaviour, in particular in the inability to carry out certain activities, the patients' condition revealed no visible signs that would give credence to any of the claims of suffering and disability. This was often seen as a cause of a number of problems amongst friends, families and work colleagues, as chronic pain patients' fear that those around them will display similar reactions of disbelief and de-legitimisation to their lack of visible disabilities as health professionals (Glenton, 2003).

*"I'm so healthy, and [people] look at me and they don't understand the severity of this problem I have" (Cited by Rhodes et al, 1999, USA study).*

*"I will have friends that will come up to me, "Hey, you're looking good." And I'm feeling absolutely the pits...Can you identify somebody who has*

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*diabetes? I can't...We can say that with a whole variety of illnesses...though they may have the appearance of being invisible, can be tested and there's something concrete...blood tests, X-rays, MRI, CT scans...they can make a definite diagnosis...[But with FM] nothing shows up. So what does a doctor conclude? ...does that mean that the person is lying? Does it mean that the person is imagining it? Does that mean that the test results are wrong?...that's a dilemma. And I think a lot of people with fibromyalgia end up having to face that doubt" (Cited by Cunningham and Jillings, 2006, Canadian study).*

*"...people have a problem talking to their doctors. Because they (doctors) just don't pay them much attention. They don't, they're not listening to what you say...[they] try to tell you back aches are psychosomatic and your back couldn't be hurting, [that] there's nothing, no reason for it to hurt. X-rays don't show anything and you don't really have a back ache. Oh yes I do, yes I do...but back aches are hard to see. Unless there's something that's a visible thing, it's kind of your word against who's looking" (Cited by Rhodes et al, 1999, USA study).*

The inconsistency of their symptoms is problematic, in terms of having 'good and bad pain days'. They were often fearful that this lack of consistency would harm their credibility

*"Don't let grumpy neighbours who only see you on good days get you down. Who hasn't heard them say more than once: "Oh yes, she can paint (or mow the lawn, hang up the clothes) so she can't be that ill!" In other words: social security sneaker" (Glenton, 2003, citing a web based discussion list contributor, Norwegian study).*

The lack of visibility of chronic pain emphasised their perception of disbelief, which in turn affected their social relationships and often changed their

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identity in terms of changing roles. This change impacted significantly on their lives, often causing great upheaval as jobs and friends have been lost and finances become a constant source of worry and stress which in turn leads to increased pain. For most patients, onset of increased pain signalled a need to seek medical care (McPhillips-Tangum et al, 1998).

Minimisation of the seriousness of their pain by doctors, families and employers led some chronic pain patients to seek diagnostic tests as proof that some physical cause was underlying their pain (McPhillips-Tangum et al 1998; Glenton, 2003, Lillrank, 2003, Werner and Malterud, 2005; Cunningham and Jillings, 2006).

*“I know doctors are just hesitant because of the expense and I know insurance companies are trying to cut costs...but if someone is truly in pain, the MRI is the only thing that is going to tell them what’s wrong, where the root of the problem is.” (cited by Rhodes et al, 1999, USA study).*

The identification of objective physical signs of disease was often met with relief and was satisfyingly concrete.

*“I am a 21 year old girl who has suffered from back pain for ten years. They have now found a slipped disc with stenosis. I have spent six years not knowing what is wrong with me because they ignored my symptoms. I knew that something was wrong with my back! The worst thing about not having a diagnosis is that a lot of people treat you like a drug addict. I hate those people! People like that don’t know what it means to be in pain” (Glenton, 2003, citing a web based discussion list contributor, Norwegian study).*

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*"I felt relieved. I felt like, well, here's proof. It's not just me going crazy or complaining. It's in black and white and anybody can see it" (cited by Rhodes et al, 1999, USA study).*

The constant attempts at legitimising their pain for fear of not being believed and fear of stigma are immersed within their expectations of chronic pain, be it a trajectory, consultation and treatments expectations and expectations of significant others; and the day to day reality of living with chronic pain.

### **The reality of living with chronic pain**

The synthetic construct of reality encompasses the limitations in a life with chronic pain, acceptance of pain for some, control (or lack of) over their pain, seeing themselves as different people from the past, being taken over by pain, coping with difficult consultations and problems, and the use of various coping strategies including medication.

Balancing the unexpected communication difficulties and differing expectations of the health professionals, with the perceived insult of being given a psychological diagnosis or reason for the pain, as discussed above and in chapter five, in both expectations of the consultation and legitimising their pain, often results in the patient spending time thinking about what may have caused the pain, and sometimes questioning the reality of their pain.

*"Interviewer: Why do you think you have the pain?"*

*Interviewee: I don't know, maybe it's because I work hard. I had all the children and my husband worked all the time so I had to do a lot for his family as well. All the time I am in the house looking after the children and family children, doing lots of cooking. When I got married in Bangladesh I went to live with my husband's family and always there are lots to do. My mother-in-*

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*law she needed lots of help and [I] was like her daughter so I had to do it but it was hard. It was a big family and lots of brothers. Even now we sent them money to help them. They think we have lots of money but they don't know how much things cost here. Even to go and visit takes lots for the airfare" (55 year old Pakistani woman, cited by Rogers and Allison, 2004, UK study).*

*"I just keep asking myself why the pain is there and I haven't got an answer. I don't know how I should feel really it's just that I don't think it should be there why should I have it? I would have thought that after all this time it should have eased up and gone away but it hasn't" (Linda, cited by Osborn and Smith, 1998, UK study).*

*"I also began to believe that I imagined my pain. Even many doctors "helped" me in that [belief]" (cited by Lillrank, 2003, Finnish study).*

Most report having no control over the pain, it affects their whole lives, and the experience of living with the unpredictability of sensation and intensity of chronic pain is expressed in the literature.

*"my everyday pain feels like someone is stabbing me with a knife. The pain would stop for a bit and then I would get a surprise attack (of pain) again. Sometimes my pain is so bad that I feel like taking that sharp knife and chopping both hands off...and what is so disappointing is that there is not one pill that I have taken that has helped" (Cited by Baker and Wang, 2006, USA study).*

*"Pain is nerve-racking. My pain is worse when I sit, and I sit this way trying to hold the spot where the pain is and rub my back. You can't relax at all. I can't sit down and listen to anything, 'cause I'm always having to move around...It's an ache, it isn't a sharp stabbing pain or anything, it's just a constant ache. You just have to go along with it. You have to try and ignore it*

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*as much as you can. I've gotten used to it...Sometimes I'm getting ready to go somewhere if my back isn't too bad, then all of a sudden it starts again and it's just like a cloud coming down. Where it was so bright, now it's cloudy and, it takes your energy away and so spoils everything" (Cited by Carson and Mitchell, 1998, Canadian study).*

Chronic pain often becomes its own entity, and many patients report the feelings of being taken over by pain, and fear for the future,

*"pain is a unwanted guest in your body. No one can see that it's with you. After so many surgeries and doctors visits, it (pain) just won't leave. The drugs are the only things that keep you at peace with the pain. Is this all modern medical science has to offer? Pills and patches...little electrical gadgets...a surgeon's knife? Cover it up or cut it out? Aren't there any other choices? I wonder what I will be like in the years ahead with my body's exposure to all this drugs?" (cited by Baker and Wang, 2006, USA study).*

Participants report paying little conscious attention to their bodies prior to their pain and normal functioning was taken for granted,

*"I suppose it's made me think about it, before I thought about what it looked like, whether I was putting on weight or what make-up to wear, but never about what was going on inside, never gave that a thought, I still don't about the bits that don't hurt, but I know I've got a back now and a bum and left leg, because it hurts and you can feel it like a solid thing like something that has gone wrong" (Lynette cited by Osborn and Smith, 2006, UK study).*

*"I never thought about my body before, I just abused it I suppose, now I feel it and bits of it feel really weird, as if they're not part of me anymore [...] the numb bits and down the leg where it hurts and I can't move it like I could,*

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*they're somehow separate now" (Simon cited by Osborn and Smith, 2006, UK study)*

The literature provides evidence of pain interfering with the performance of important relationships, social roles and activities,

*"my wife even turned on me, thinking it was all put on. She came in the bedroom one morning to find me flat on the floor, unable to move, and she naturally assumed that I was putting it on. From that point on I've just lived on my own" (Colin aged 46 cited by Walker et al, 2005, UK study).*

*"Well, even in relationships. I mean, I can't even perform all my wifely duties. I mean there's a lot more to a relationship but they certainly expect that too. We're close, we're always been close. But it's different." (Hannah cited by Smith, 2003, USA study).*

*"We haven't lost friends but [FM] interferes with relationships...you'd make a plan to go someplace as a foursome and then...end up having to cancel...an hour before...we'd be ready to go for a dinner...the day comes and we get into the car...and I'm feeling terrible...I just get back into the apartment, lie on the couch and just drop" (cited by Cunningham and Jilling, 2006, Canadian study).*

Participants expressed frustration with their inability to perform crucial household tasks and their work.

*"...Previously, I enjoyed my job now, one could say, I'm like a child. In the mornings, when it wakes up, so it plays, or then I go walking here around my house. At noon I try to do some housework. I can do it only standing. Such as making lunch, and so on. But I can't do vacuum-cleaning, I can't take wash*

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*from the washing machine, nor put it there, I can't...during the mornings I take a walk, then I come home, then we'll have lunch, then I take naps. Then during the afternoons I am a child again, a child that tries to find a position to be able to read at least, watch TV, or do something else. In the evenings I go to sleep early" (cited by Honkasalo, 2000, Finnish study).*

*"I'd like to do many things, but I can't do anything because of rheumatism. When the 'phone was ringing, I'd like to run to answer it, but I was unable to have my own way, because of knee pain" (cited by Hwang et al, 2004, South Korean study).*

*"when you walk round the shops and things like that you take it for granted but when you can't do it, it's hard work" (Miles et al, 2005 citing S9; 65 year old man, UK study).*

Both men and women talked of their distress when the pain interfered with the ability to care for or play with children or grandchildren:

*"I got to the point where I couldn't pick up my grandchildren. I could not lift those kids because of my back. I couldn't even hold the baby. I wouldn't dare walk while holding the baby. I was afraid I'd stumble and fall" (cited by McPhillips-Tangum et al, 1998, USA study).*

*"I can't wash dishes and clean the house. Sometimes. I can't help my son wearing socks, because of decreased muscular strength of both arms" (cited by Hwang et al, 2004, South Korean study).*

*"I can't do some things I would really love to do with [my son]...I can't really get out there and teach him the things I would like to teach him" (truck driver cited by Kugelmann, 1999, USA study).*

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Many activities were only achieved if they were done more slowly than in the past, to prevent pain increasing. This slowing down meant that participants could no longer engage in family events as before:

“...my children will sort of say ‘oh we can this and that’ and I don’t keep up with them when they walk. I’m the one lagging behind shouting to them at saying what’s the point of me coming with you if you’re not going to wait”.  
(cited by Miles et al, 2005)

As well as disruption to daily life are financial losses often due to loss of employment and these are mainly reported in those of working age:

*“There is so many ways life’s changed. Well the obvious one, we used to have a three storey town house, a nice pine kitchen, fitted carpets everywhere, now we’re in a council place with unfitted carpets and not very nice furniture” (Bill, aged 42 cited by Walker et al, 2005, UK study).*

*“I’ve been off sick for so long we’ve used all our savings, virtually nothing left, that’s why we’re moving downwards, putting a few thousand pounds in the bank” (John, aged 60 cited by Walker et al, 2005, UK study).*

When treatment seeking, financial constraints also become apparent, even if they found a treatment that seemed to be of benefit, the requirement for the regularity of treatment was restricted by cost.

*“For my body, none of these treatments work unless they are done regularly. Massage, for example, is very helpful if I get it on a regular basis, but if I scrounge the money for a treatment here and there, it will often make me*

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*worse, just stirring up muscle spasm without resolving them” (cited by Cunningham and Jillings, 2006, Canadian study).*

In order to try and maintain some normality in their lives, and cope with their pain, many patients relied on many different forms of medication, but frequently acknowledged ineffective medication or unwanted side effects.

*“...I was four years trying all different types of medication to try and control the pain...they weren’t any good...” (Q3 cited by Closs et al, 2007, UK study).*

*“I’m glad you said that about the gabapentin with the memory...when I first started taking it I’m thinking I can’t concentrate I couldn’t read a book, I still can’t read a book really and it’s a bit blurry...and I had to make a decision at one point to sort of reduce the gabapentin a little bit and have more pain just to be able to...A bit more clarity I won’t say brilliant, but a little more clarity, yeah.” (Q8 cited by Closs et al, 2007, UK study).*

Many participants continue treatment seeking, which as previously mentioned links to expectations and the need to legitimise their pain, and well as addresses the issue of the need to manage and cope with their pain on a day-to-day basis. Others move to an acceptance phase:

*“...it’s no good you know, fussing over what you can’t do ...so you learn to live with what you can’t do and cope with what you can ... otherwise I think you make a rod for your own back” (Marjorie, in her 60’s cited by Sofaer et al, 2005, UK study).*

*“And it’s got to, where I am at the moment that, I’ve got to just sort of admit to myself that I can’t do what I could do before and just accept you need to take the tablets and you need to readjust your life around this pain and so I’ve got to manage it” (Q31 cited by Closs et al, 2007, UK study).*

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*“Pain is tiring...it makes you want to snap at the world. It’s demoralising, it’s depressing, it colours your whole existence. It affects me day and night; it restricts everything and governs my life. It can be in every joint and all down the spine and legs. The pain is as if someone is putting a screwdriver and turning it. You just have to learn to rise above it, to carry on in spite of it. You have to do the best you can” (Cited by Carson and Mitchell, 1998, Canadian study).*

Often by adopting acceptance, participants report that an important self-management strategy is to balance the limitations of the pain with activities and expectations of themselves.

*“you cannot always have a spotless, clean house...[or] keep your commitments, you have to understand that you do what you can...and not feel guilty when you can’t....You do have to learn to cut stresses out of your life because this is also a stress activated condition....You cannot keep up a normal life. But you have to not be hard on yourself” (cited by Cunningham and Jillings, 2006, Canadian study).*

Participants often compared themselves to other people, some felt that they ‘should’ be able to be active and enjoy life:

*“I’m only 50 and I should be doing this and that and the other cos they say life begins at 40 but I can’t and s’ppose it does bother me, it’s frustrating that people of my age are you can see them flying their kite and you feel as if you can’t.” (Linda, cited by Osborn and Smith, 1998, UK study).*

Other participants compare themselves to others they considered less fortunate than themselves:

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*"I try to tell myself I'm luckier than a lot of people, you know I haven't got cancer" (Ruth, cited by Osborn and Smith, 1998, UK study).*

*"You get to wake up miserable every day, but at least you get to wake up. There are many people who get illnesses, cancers, and things where they die in accidents, and some days you just consider yourself fortunate that you get to wake up in the morning...you get to see your children, your family, and the sunshine; and many people don't get that opportunity. So...at least you're not going to die in six months....You get to live, but you get to be challenged while you live. And you have to accept that too." (Cited by Cunningham and Jillings, 2006, Canadian study).*

Participants felt that when they were in public, they could not show their distress, the need to look 'normal' was especially strong for women.

*"People stop me in the street and say when I've got makeup on, "oh you do look well Mrs A"...if I don't wear makeup they say "you don't look at all well Mrs A" and I don't like that, so I'd rather put a bit of makeup on..." (Peggy A aged 76 cited by Sofaer et al, 2005, UK study).*

Male participants reported the dislike of other people seeing them in pain, perhaps reflecting the fear of stigma: "I don't show it to other people because they shun you" and "I'm not going to let them know the amount of pain I am in or how distressed I am about it" (cited by Sofaer et al, 2005, UK study)

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## **Summary of narrative review**

This narrative review aimed to produce an interpretation of the evidence that could create new insights in understanding the phenomenon of living with chronic pain. Using the constant comparison method of Grounded Theory (Strauss and Corbin, 1998) my synthesising argument was developed from the evidence of living with chronic pain is organised around the dynamic interplay of patients' expectations of chronic pain, legitimisation and reality of living with chronic pain. In the conceptual model developed from the reviewed literature proposed that expectations and beliefs that people with chronic pain hold will influence both their attempts at legitimising their pain and how they experience the reality of living with chronic pain. Equally their attempts at legitimising their pain and the reality of living with chronic pain will cause them to review and redefine their expectations. A discussion critiquing the reviewed literature is presented next, followed by a discussion around this narrative review. I will position my own research in light of this review in chapter seven.

## **Critique of the literature on living with chronic pain**

Methodologically, much of the qualitative research on living with chronic pain is weak. As can be seen in table 11 earlier in this chapter, the common methodological problems were the lack of reporting upon ethical issues, no reflexivity or use of reflexive journals, did not provide detailed accounts of how the data was analysed, and little discussion of emerging themes.

Much of the evidence on the lived experience of chronic pain has relied on self report of chronic pain patients from interviews (n=38), this research is often only as good as the researcher's skills and abilities to obtain rich interview data. 7 of the 38 studies used interviews in conjunction with another research method. Other possible methods of obtaining data would be observation (Bates et al, 1994, 1997) and ethnography. The use of reflexivity

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and reflexive journals to set the scene, for the reader to understand how the researcher's background, ideas and values might have contributed to the way they interpreted and analysed the data; 38 studies did not have reflexive accounts, 3 studies mentioned reflexivity such as maintaining a reflexive log, and 3 studies gave details of reflexivity. A source of frustration for the reader is often the lack of explanation of how the data was analysed, the technique of Grounded Theory was frequently cited but it was not mentioned which form of Grounded Theory was used i.e. Glaser and Strauss (1967) or Strauss and Corbin, (1998). Another criticism of some studies purporting to use Grounded Theory is that they only used the constant comparative part to describe themes arising from the literature, but failed to discuss the relationships between the categories and develop these into a theory. Important information surrounding ethics such as where and how researchers' gained ethical approval, which guidelines were used to ensure ethically appropriate treatment of research participants were omitted in many studies (n=24). This could be due to the word limits set by journal editors particularly in the fields of medicine and psychology. However such low word limits leads to the omission of important information and this contributes to the criticisms of qualitative research discussed in chapter three.

Examining this literature more broadly, the majority of research focuses on chronic pain patients attending for treatment, and ignores those who have either disengaged from the healthcare system or those who choose not to seek medical consultations or treatment. To expand the pain knowledge base it would be useful to compare and contrast the expectations and the need (or not) to legitimise pain and the reality of living with chronic pain. Perhaps the majority of published work in this area involves patients because pragmatically it is much easier to access chronic pain patients who are often willing to share their experiences. An alternative view would be that perhaps there is a bias in the published material in that in an ever-changing healthcare system, this group of patients are considered difficult or problematic and there is a tendency to need to know what we can achieve with these patients in an efficient and cost effective way to meet health care targets.

Many of the themes identified by the literature were self evident in terms of medical or psychological concepts such as locus of control (Bates and Rankin–Hill,1994); pain carers, accommodation (Bendelow and Williams,1996); meanings (Kodiath, 1998); bodily constraint (Miles, Curran, Pearce and Allan, 2005); living with a body separate from the self (Osborn and Smith, 2006); the relationship between psyche and soma (Rogers and Alison, 2004); continuum or trajectory (Smith and Osborn, 2007); social-psychological tolerating strategies (Wiener,1975). Much of the literature reported themes that had been extracted from the participant's accounts, for example; realities of living with daily pain (Baker and Wang, 2006); now how did I get this pain (Becker, 1999); additional burden for family members, unable to make and stick to plans, medication, financial constraints (Cunningham and Jillings, 2006), loss of words (De Souza and Frank, 2000); suffering with pain, managing and tolerating pain (Dickson and Kim, 2003) stress and relaxation (Kugelman,1999); living with chronic pain, support groups, communication (McHugh and Thoms, 2001); coping, pain, sleep (Raak and Wahren, 2006); the struggle for credibility (Werner and Malterud, 2005). Going against the suggestion of Pollio et al (1997) who recommended staying close to the participants words rather than moving to highly abstract language; some of the literature tended to report abstract themes such as subhuman, (Becker, 1999); forbearance surfaces with the drain of persistent anguish, isolating retreats coexist with comforting engagements, hope for relief clarifies priorities of everyday living (Carson and Mitchell, 1998); the abject body (Honkasalo, 2000); turning points, solving the riddle (Lillrank, 2003); the sting in the tail (Smith and Osborn, 2007); the altered, recalcitrant body (Thomas, 2000). All of the themes result from the researcher's interpretation; and the lack of reflexivity is problematic as it is unclear to see how these abstract themes were developed. Therefore it is difficult to see how these can be defended as being 'grounded' in the patient's experience of living with chronic pain.

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This analysis suggests that it is key to understand people's cultural beliefs in terms of their health (pain) beliefs, their own personal and societal beliefs as this will influence pain sensation, coping strategies, consequent behaviour including consultations, compliance and eventual treatment outcome (Jenson et al 1991), the need or not to legitimise their pain and the day to day reality of living with chronic pain. However a major omission in much of the data is not reporting the demographic details collected to help explain similarities and differences between different cultures, gender, age and socio-economic groups for example. Pain research may reveal more about the ethnocentricity of the researcher than the researched, resulting in a tendency to view one's own culture as the standard against which others are judged (Bond and Bond, 1986). The majority of the research evidence reviewed is carried out on White North Americans, and White Northern Europeans (n=41), which is useful to a certain extent, but neglects the issue of ethnic diversity despite a growing interest in the dynamics of social meaning and ethnic identity in understanding health status (Fenton and Sadiq-Sangster, 1996; Bhopal, 1997) and very little attention has been paid to the experience of pain amongst ethnic minority communities. With the absence of an in-depth exploration of acculturation factors, conceptualisation of symptoms, conditions and pain amongst groups of people with differing socio-economic and cultural backgrounds there is the danger of a nosological category of pain is developed for one group in the population, which is uncritically applied to another group (Rogers and Allison, 2004). The use of these demographic details would improve our knowledge, particularly in the field of pain beliefs, leading to improved consultations and possibly more satisfactory or realistic treatment expectations.

In reporting their findings, the studies tend to concentrate on one main theme without acknowledging the wider picture of chronic pain and the interplay of various factors such as demographic details, medical, psychological, social and cultures factors, which influence the chronic pain experience. Some papers just produce accounts of what the people with chronic pain are reporting which in itself is interesting and useful, but we need to go a stage

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further and develop this information into theories that can be used to inform and improve practice. Therefore this analysis addressed the need to bring all this information together by synthesising the evidence to produce a conceptual model of living with chronic pain.

## **Discussion**

Good practice should allow qualitative research to inform and influence policy and practice as it is the most appropriate way for people's subjective experiences to be heard. Both practitioners and policy makers need to have confidence in the quality of this type of research (Guba and Lincoln, 1994), which has led to the increased development of methods that can synthesise a wide range of diverse evidence (Sheldon, 2005).

Conventional systematic review methodology is useful in that it is able to synthesise evidence that requires the testing of theories rather than the development of theories (Greenhaugh, Robert, Macfarlane, Bate, Kyriakidou and Peacock, 2005; Greenhaugh, Robert, Bate, Kyriakidou, Macfarlane and Peacock, 2004). Most current approaches for conducting an interpretive synthesis of the literature are considered to be lacking in critique (Dixon-Woods et al, 2006). The critique within interpretive synthesis tends to be limited to the appraisal of the methodological specificities of the individual papers; this could be attributed to the use of checklists when appraising qualitative literature. With the exception of Greenhaugh et al (2005), studies using interpretive synthesis rarely reinterpret the phenomenon to challenge the way it is represented in the literature, nor question the epistemological or normative assumptions surrounding the literature (Dixon-Woods et al, 2005). This research has reviewed, critiqued and reinterpreted themes within the literature, producing a conceptual theory of living with chronic pain.

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The synthesising argument developed from the evidence of living with chronic pain is organised around the dynamic interplay of patients' expectations of chronic pain, legitimisation and reality of living with chronic pain. In the conceptual model proposed the expectations and beliefs that people with chronic pain hold will influence both their attempts at legitimising their pain and how they experience the reality of living with chronic pain. Equally their attempts at legitimising their pain and the reality of living with chronic pain will cause them to review and redefine their expectations. The conceptual model derived from the reviewed literature may be further developed if the same literature was synthesised by a multidisciplinary team, or as additional studies added to the current knowledge.

Criticisms that could be levelled at this study are that unlike traditional systematic review methodology (transparency, comprehensiveness and reproducibility of search strategies) are not strictly adhered to, in terms of the selection of papers for inclusion, by including methodologically weak papers. Methodologically weak papers were compensated for by being considered critically and as a hypothesis rather than evidence, so rather than placing too much confidence in the findings per se, the themes arising were explored for their contribution; this is reflected as fewer quotations were used to illustrate the analysis. It could be suggested that too few papers have been synthesised, however traditional systematic review methods limit the study types included, which might result in only a proportion of the papers being reviewed. If the literature had been vast, this study would have used purposive sampling initially and theoretical sampling in selecting the papers, and it is acknowledged that a different research team using the same approach could acquire a different sample, as sampling would be guided by emerging theories. It is not claimed that the list of qualitative research papers on living with chronic pain is exhaustive. However I am satisfied that the major themes that have been identified and reported upon reflect those found generally in the literature.

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The need to bring together a diverse body of evidence in terms of academic backgrounds (psychology, nursing, medicine, sociology and anthropology) and diverse epistemological and methodological viewpoints, into a format that is useful to inform practice and is empirically and theoretically grounded in the data, has lead to the development of the critical interpretive synthesis (Dixon-Woods et al, 2006). Future research could use the technique of critical interpretive synthesis, which investigates the literature in ways that are distinctive from approaches to interpretive synthesis; it would treat the literature as an object of scrutiny in its own right.

To date a narrative review focussing on the qualitative literature has not been published in the pain field. An important future piece of research should involve a critical interpretative synthesis to be undertaken combining both qualitative and quantitative research to produce an interpretation of the evidence that could create new insights in understanding the phenomenon of living with chronic pain, discussed within the broader context of healthcare policy and practice, and employment and legislation.

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## Summary

This chapter has discussed the appraisal of qualitative research, investigated some of the possible methods of synthesising qualitative research, addressed some of the key questions around synthesis, and culminated in the production of an empirical piece of research by synthesising and analysing the data within selected qualitative literature, resulting in a narrative review and a conceptual model of what it is like to live with chronic pain on a daily basis.

Looking through the published literature, a narrative review has not been published in the pain field. I aimed to produce an interpretation of the evidence that could create new insights in understanding the phenomenon of living with chronic pain. My synthesising argument developed from the evidence of living with chronic pain is organised around the dynamic interplay of patients' expectations of chronic pain, legitimisation and reality of living with chronic pain. In the conceptual model developed from the reviewed literature proposed the expectations and beliefs that people with chronic pain hold will influence both their attempts at legitimising their pain and how they experience the reality of living with chronic pain. Equally their attempts at legitimising their pain and the reality of living with chronic pain will cause them to review and redefine their expectations. Criticisms of this study have been considered and defended.

## **Chapter 7: Positioning my research in the literature**

### **Introduction**

The aim of this chapter is to position my research within the context of the literature critiqued within the narrative analysis. This chapter will initially briefly summarise the model developed from my research findings, and the model developed from synthesising the qualitative literature. I will then compare and contrast my findings with those in the literature, to develop a proposed theoretical model combining my model with the model developed from the literature, and discuss this in relation to the literature.

### **The model developed from my research**

Briefly, this model for people living with chronic pain that emerged was a mesh of nine categories that are shown in figure 3 (chapter five). These categories, (affect, cultural health expectations, consultation, dissatisfaction with the consultation, disbelief, identity social relationships, impact of pain and information seeking) their properties and dimensions were identified and are presented in detail in chapter five (research findings). The categories are interrelated through statements of relationship to form the theoretical framework that explains this psycho-social phenomenon. The findings of this study and the model that emerged from the data established the theory are that the key areas that influence how people live with their chronic pain on a daily basis are their perceptions of the consultation with the health care professional and the actual experience of living with pain, affect is intrinsically woven within these factors.

### **The model arising from the narrative review**

The synthesising argument developed from the literature around living with chronic pain is organised around the interplay of expectations, legitimisation and reality of living with chronic pain. The expectations and beliefs, that people with chronic pain hold will influence both their attempts at legitimising their pain, and how they experience the reality of living with chronic pain. Equally their attempts at legitimising their pain and the reality will cause them to review and redefine their expectations, see figure 6 in chapter six.

### **Positioning my research**

With regards to participants, the papers examined in the narrative review either reported participants with one diagnosis such as fibromyalgia, (Cunningham and Jillings, 2006) or participants had varying diagnosis or type of pain (e.g. back pain) as would be expected at an outpatient chronic pain clinic (for example, Bendelow and Williams, 1996), all participants met the criteria for chronic pain as described in chapter one. Only one paper in the narrative review included a condition that was not present in my sample, which was severe peripheral vascular disease (Gibson and Kenrick, 1998). Therefore I suggest that my sample in terms of reason for pain or type of pain is consistent with this body of literature. The majority of studies used an age range similar to the range I used, which is indicative of the age of the general chronic pain population, apart from the research investigating exclusively older people (Dickson and Kim, 2003; Sofaer et al, 2005; Sofaer-Bennett et al, 2007a, 2007b). Most studies reported including both male and female participants as my study did, however four studies included only female participants. My study focussed to some extent on the similarities and differences of the pain experiences between White British and South Asian people with chronic pain. Very few studies (with the exception of Bates and Rankin Hill, 1994; Bates et al, 1997; Rogers and Allison, 2004) reported on ethnic similarities and differences despite nine studies reporting participants

from different ethnic backgrounds, 19 studies made no explicit mention of their participants' ethnicity. This either indicates a large gap in the literature, or that the experience of living with chronic pain is universal.

Considering the data collection method, the majority (n=40) of published papers used interviews, other methods used were case studies (n=2), website discussion list n=1), autobiographical writing competition (n=1). Three studies used observation in addition to interviews. The method of data analysis varied considerably, two studies reported using Grounded Theory explicitly (Dickson and Kim, 2003; Miles et al, 2005), whilst two described their analysis as "based on Grounded Theory" (Sofaer et al, 2007a, 2007b). The majority of studies (n=13) reported using either content or thematic analysis, others used interpretative phenomenological analysis (IPA) (n=4), the rest of the papers were either vague or did not report in detail how they conducting the analysis. My choice of data collection method, the semi-structured interview appears a standard technique within the published field; however my choice of data analysis method, Grounded Theory, seems to be lacking in popularity. For me Grounded Theory brings benefits to both the health psychology and chronic pain literature as it goes beyond what is said at the interview and focuses on the development of a theory and attempts to capture the process, (rather than for example, days admitted to hospital or number of treatments) of living with chronic pain, see chapter three for a more detailed rationale for using Grounded Theory. Perhaps other researchers are deterred by this method because of its complexity due to the different versions of Grounded Theory (Glaser and Strauss, 1967; Strauss and Corbin, 1990), or due to the excessive amount of time it takes to analyse data and produce a theory.

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## **The theoretical model of living with chronic pain developed from my research and the narrative review**

When undertaking a constant comparative approach of Grounded Theory (as described in chapters five and six), of my research findings and the narrative review, it appears that many topics raised are evident in both pieces of research, but depending upon their context may feature in different categories. For example, cultural health expectations in the model developed from my research included the properties and dimensions of pain beliefs, treatment beliefs, gender, age, stereotypes, ethnicity, attitude, learned behaviour, religion, fate, pain expression, reasons why people thought they had pain. Whereas in comparison, the category of expectations in the model developed from the narrative review included the properties and dimensions of expressing pain, gender stereotypes, ethnicity (in three papers), and reasons for attending appointments with health professionals regarding their pain, diagnosis, ineffective treatments, and the bio-psychosocial model. In the model developed from my research, consultation and dissatisfaction with the health professionals' response were separate categories. The properties and dimensions under the consultation category included reasons for attending appointments, attitudes of health professionals, chronic pain patients' perceptions of 'good versus bad' GP's, attendance at pain clinic, being believed at pain clinic. Dissatisfaction with the health professionals' response included no diagnosis, ineffective treatments, side effects of treatment, not being believed by health professionals. In the model developed from my research, disbelief, subjectivity and visibility was a key category, with the properties and dimensions of not being believed by health professionals, friends, family, work colleagues; the fact that you and others cannot see pain, reaction of other people, seeking legitimisation.

Many of the properties and dimensions of cultural expectations and of expectations from the two models can be developed into categories of health expectations, patient's expectations, and societal expectations, all these



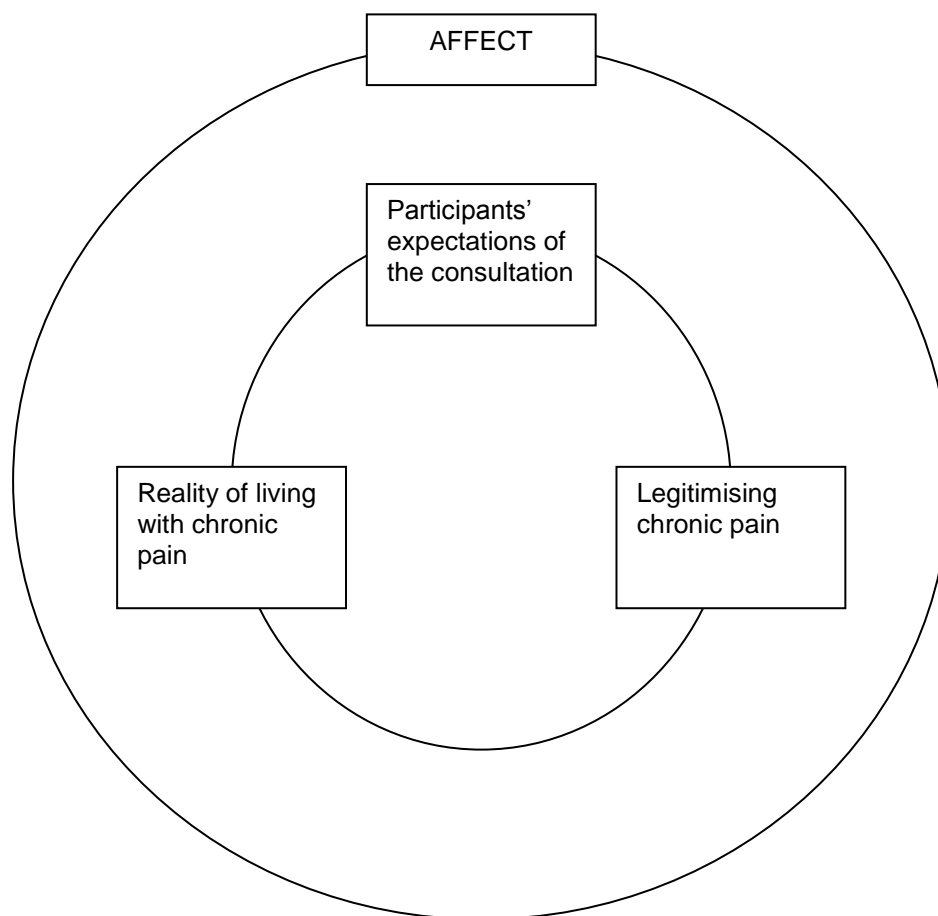
expectations feed into what is expected in the consultation and will influence the perceived outcome of the consultation. Legitimation is linked closely with the consultation and the outcome of the consultation. Legitimation is a key category in the model developed from the narrative review, encompassing the properties and dimensions of the importance of having a diagnosis, the consultation process, and the subjectivity of pain, and the issue of 'visibility' as described in chapter four.

The last category within the model developed from the narrative review was living with the reality of chronic pain, the properties and dimensions for this included living with chronic pain, finding meaning, acceptance for some, control (or lack of) over pain, seeing themselves as different people to who they used to be in the past, being taken over by pain, coping with difficult consultations, and coping strategies. The categories in the model developed from my research of impact of pain (physical, financial, social, emotional limitations), information seeking (Information gained from magazines, newspapers, TV, radio, patient education leaflets, internet, support groups, those who do not seek information), coping strategies anything not initiated by health professional, (e.g. Asian medicine, complementary therapies, hot or cold packs), social identity (comparing self to others, pain as 'it') and social relationships (change in roles, families not accepting there is no cure, continuing to treatment seek on behalf of people with pain, employment, withdrawing from others, talking to people in pain). Therefore these categories could fit into super ordinate category of the reality of living with chronic pain.

The impact of the category of affect appeared to be neglected in much of the literature, however it was the overarching category in my research because rarely were the participants optimistic and hopeful, but more often desperate for a cure or resigned to having chronic pain indefinitely. Affect can either increase or decrease expectations or make people indifferent therefore, affect will influence whether the participants hold positive or negative expectations about their pain and its consequent treatment. Affect influences the

participants' perception of living with chronic pain and therefore how they view the consultation process, their needs to legitimise their pain, their social interaction with family, friends, employers and society in general. It will influence their motivation to seek out information about the condition in terms of treatments, 'cures' and ideas to try as coping strategies. Throughout the interviews a whole spectrum of emotions and feelings were expressed ranging from frustration, embarrassment, fear, depression, feelings of guilt and inadequacy as may be expected from participants who have had chronic pain for many years.

With the hindsight of my own research findings (chapter five) and the narrative review (chapter six), a combined theoretical model of living with chronic pain can be proposed, see figure 7. This has been developed by extended the constant comparison technique and comparing and contrasting themes from the empirical study and the review. A summary of this theoretical model includes the key themes of the consultation versus the experience, legitimisation of their pain, and the reality of living with chronic pain daily. Depending upon the outcome of the consultation, this is often perceived as negative, because it does not match the participants' expectations, which are drawn from their schemas. This brings into play the process of legitimising their pain, as does the reality of living with chronic pain on a daily basis. Equally their attempts at legitimising their pain and the reality of living with chronic pain and how pain impacts on their lives will cause the participants to review and redefine their expectations and schema. Affect would be the overarching theme as it is intrinsically woven throughout each category.

**Figure: 7: Theoretical model of living with chronic pain.**

When the participants talk about experiences with chronic pain they rely on autobiographical memories (Rubin, 1986). Like other memories processes, autobiographical memory processes are best understood as reconstructions rather than reproductions of past events (Bartlett, 1932) as reported throughout the participants' interviews in both my research and the narrative review. As the participants talk about their experiences, past events are reconstructed in a manner congruent with current understandings. The present is explained with reference to the reconstructed past. Schemas mediate autobiographical memories like other cognitive processes. Schemas are guidelines for perceiving, organising, interpreting, representing, making inferences about and acting in the world (Neisser, 1976), and influence expectations that the participants have.

Schemas may be shared or individual. Cultural models are schemas, which are generally shared in a particular setting (D'Andrade and Strauss, 1992). Cultural models for chronic pain or other illness as well as shared understandings about specific conditions (e.g. cancer, arthritis, high blood pressure) help individuals to make sense of episodes of illness and provide the basics for action to be taken in response to illness (Garro, 1994). As a representation of shared understandings about the world, illness or chronic pain, cultural models may invoke simplified worlds where events unfold and people's actions occur in an understandable and expectable fashion (D'Andrade and Strauss, 1992). Whether individual or shared schema, are not static, they are created through experience and are modified by new experiences hence influencing expectations.

An example of such schemas and their influence on expectations from both my research and the narrative review are that older people are often reluctant to request pain relief, attempting to endure pain as 'normal' part of ageing and wishing to avoid being seen as a 'complainer' (Ferrell, 1995). Instead they self medicate with non-prescription and non-pharmacological measures, such as analgesic oils, gels and creams, massage and medications, the oils and gels often being purchased and supplied by visitors and family members.

These types of expectations are brought to the consultation with the health professional. During the consultation the participant tells a story of what it is like to live with chronic pain. It has been suggested that story telling is seen as a social action embedded in a social world as a symbolic interaction and political process that fulfils some roles in our social life. These stories can be generated by social and political conditions, which enable the story to be told (Plummer, 1995). The sociologist Frank (1995) claimed that restitution stories are what we all want to hear, whether we are health professionals, patients or members of society. He argued that restitution stories reflect how we have learned to talk about illness from institutional stories, which provide a model of

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how sickness should be described in our culture (Frank, 1995). In various studies illness has been shown to be experienced as a moral event concerning shame, blame and responsibility (Jackson, 1992; Eccleston, Williams and Rogers, 1997; Kugelmann, 1999; Osborn and Smith, 1998; 2006)

Throughout my research and the narrative review, participants talk more frequently about their encounters with various health professionals than their friends or family. Despite their perceived repeated experiences of unkind or impersonal health professionals they remained hopeful that there was a caring health professional out there so continued to keep various appointments with health professionals.

Initial appointments with the general practitioner were usually the beginning of a long period of distrust and doubt for the participants. Following frustrated visits to the general practitioner, pain increases its control over the participants so a specialist was seen to be a more reliable option to cure their pain. However, the participants found the specialists' moral judgements and personal attitudes towards chronic pain were similar to those already encountered in general practice (Lillrank, 2003). Participants experienced a wide variety of appointments, which involved using a broad range of painkillers, physiotherapy, chiropractor and acupuncture in order to reduce or manage their pain (see patient's carousel in chapter five). Even when suggested treatments were not successful participants continued to seek understanding and expert knowledge, at the same time becoming more frustrated about random treatments (McPhillips-Tangum et al, 1998; Lillrank, 2003).

Health professionals are trusted and mistrusted, with the pendulum swinging towards greater mistrust and alienation after repeated experiences of being unheard and unhealed (Thomas, 2000). Participants perceiving that they are not being listened to are well documented in the literature. Only by talking

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about their pain and their experiences can the participant explain their subjective experience, but many claim the health professionals did not listen to them when they tried to explain their pain and its impact on their daily lives (Crabtree and Miller, 1994). Research suggests that health professionals have a different understanding of listening they hear words as diagnostic cues, rather than placing words in the context of the participants' lifeworld (Crabtree and Miller, 1994), which suggests some implications for practice that will be considered in chapter nine.

The identification of objective and physiological signs of disease is central to the legitimisation of illness; a lack of objective physical signs that something is wrong is characteristic for many chronic pain patients who may spend long periods of time without a diagnosis. Issues of validation and legitimisation were important to participants. For chronic pain patients, these issues are intensified by the fact that the problem may be invisible both externally (in terms of physical appearance) and internally (as negative or inconclusive diagnostic tests) (Jackson, 2000). This is at odds with the participants' expectations that inside the body will correlate to visual images, so often they will continue searching until they find the evidence that it does. They often believe it is the job of the health profession to 'look', and if the pain remains, the health professional cannot have run all the possible available tests. Participants expect that the body can be measured against objective norm and standards they hoped that diagnostic tests will see where this deviation is that is causing their pain and expect it to be repaired (Rhodes et al, 1999). It is a struggle for the participants to understand that pain is subjective and that diagnostic tests do not always reveal the answers they are looking for. The literature reports the great lengths that participants will go to find a diagnostic test that can identify objective signs of disease, both pressing their health professionals for tests that have not been carried out as well as paying privately for tests not available within the National Health System (Glenton, 2003). For participants if no objective signs were found, there was the fear that health professionals, friends and family would distrust the participants' motives and question the reality of their pain. The identification of objective

signs of disease were often met with relief and were seen as proof to the participants' health professionals and their social surroundings that there are truly in pain (Glenton, 2003).

The need for legitimisation of their pain is an integral part of the search for meaning and the acceptance of an individual's pain by others, both socially and clinically (Bendelow and Williams, 1995). Drawing on the chronic illness literature, it can be proposed that while the actual bodily limitations resulting from the chronic illness must be recognised, it is also important to understand the social change and diversity within which illness is conceptualised (Williams, 2000), meaning can be located within socio-economic relations, within gender structures (Williams, 1984). Achievement of a medical diagnosis was also considered important as it can lead to an explanation of cause and suggestions for further treatment, as well as access to welfare benefits and social services. The need not to be seen as a malinger and the fact that medico-legal and compensation including incapacity benefits require "objectification" means people "need" a label in the United Kingdom. The need for legitimisation is made clear in the compensation rules and regulations that consider *"pain ... the basis of a finding of disability only when medical signs...show a medical condition"* (Osterweis, Kleinman and Mechanic, 1987). Thus in other conditions a positive test may be feared, for a person with chronic pain a positive result affirms the problem as real and allows their suffering to become *"an acceptable illness, one that can be handled"* (Coulehan, 1985, p370)

When clinical tests and examinations continue to show nothing, health professionals may turn to a psychological or psychosocial model of explanation for the participants' pain, but for the participant to receive a psychological diagnosis or explanation is a source of despair and frustration (Glenton, 2003)

The ambiguous status between mind and body makes chronic pain difficult to understand. According to the definition of chronic pain as suggested by the International Association for the Study of Chronic Pain (1986) “an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage”. Therefore, chronic pain can be considered to be both physical sensations and aversive feelings that must be correlated with physical damage (Lillrank, 2003). To separate sensation and emotion into distinct categories seriously distorts the nature of pain, IASP’s definition emphasises pain as an emotional experience rather than sensations, since pain without unpleasant emotions would not be pain (Jackson, 2000)

The division between physical and mental health did not correspond to the participants’ own expectations or experiences. Whilst some patients were unwilling to accept psychological explanations for their pain, some did report psychological problems they saw as a result of long-term pain. Fear of the stigma of mental illness as well as fear that a psychological diagnosis would lead to the de-legitimisation of their pain resulted in some participants not reporting psychological difficulties.

Many participants feel disappointed and insulted when experienced pain was not taken seriously and their urgent need for pain relief did not seem to come true. Since the specialists were not able to confirm any bodily cause of pain they morally invalidated it by discrediting the experienced pain as imagined and reduced their ability to define their bodily condition, an essential part of their self (Lillrank, 2003).

Health professionals’ understandings of pain varied, depended partly upon their medical speciality but also on the specifics of an individual case. Encounters in the Pain Clinic were generally seen as more favourable because the participants felt believed.



Consultations can be viewed as social encounters where participants construct themselves as believable narrators of their pain experience, in their attempt to communicate and legitimise their pain (Ong et al, 2004). Key to the participants was to communicate both in the consultation but also in the research interviews the authenticity of their pain experience by attempting to use clinical categories. They used strategies such as retelling the drama of pain and / or by calling on shared experiences and knowledge these are common reference points within their cultural contexts. The participants tended to draw the interviewer (health professional or researcher) into their own life-worlds, or at least present their accounts and interpretations incontestable.

It is argued that to communicate we have to have something to communicate about (Bickerton, 1996), this trivial, yet provocative statement points to a fundamental issue for chronic pain patients. For patients in clinical practice, and research participants, accounting for their pain implies bridging a gap between making sense of a complex, and possibly disabling set of experiences and finding adequate correlates for these experiences in words (Peolsson et al, 2000). When asking patients or participants what their pain is like, some will say 'it just hurts' whilst others will give rich linguistic accounts with in-depth discriminations of burning, shooting or stabbing pains and describe the implications of these.

Perhaps we should explore what resources are involved in such discriminations. From the biological perspective, which inspired the McGill Pain Questionnaire (1975), it is argued that natural kinds of pains are generated by the action of internal brain structures (Melzack, 1973). Melzack argues that *"there are no external equivalents to stinging, smarting, tickling, itch; the qualities are produced by built in neuro-models whose neuro-signatures innately produce the qualities. We do not learn to feel qualities of experience; our brains are built to produce them"* (p624). The discrimination between pains, thus, is assumed to result from ready-made biochemical

processes, which are automatically released when the person hurts themselves (Peolsson et al, 2000).

In contrast, Harre (1991) argues from a socio-cultural perspective: *“In the case of pain, one is inclined to say that there are no natural kinds, and that the complex array of discriminable discomforts is the product of the cultural assimilation of a range of legitimated displays and lexical items, united through wittenstein process of the playing of physiognomie language games”* (p103).

It is argued that although pain is very real to people by virtue of what is often labelled a biological substrate, pain involves a discursive element (Peolsson et al, 2000), *“Human pain is a conceptual as well as sensory experience because of our contact with our pain is mediated by the conceptual structure of our language”* (Sullivan, 1995:p3). Therefore adopting a socio-cultural model emphasising *“how discourse enters into our perceptions and thinking and how conceptualisations of phenomena reflect distinctions that are discursive in origin rather than present in objects as such”* (Saljo, 1995:p85), this view alters the role of language from that of a representative devise to a constitutional tool (Poelsson et al, 2000).

It is claimed that language allows pain to emerge *“from utter privacy into dialogical context”* Morris (1986, p1). As an alternative to Melzack, Peolsson (2000) argues that experiencing pain is part of a learning process. As a consequence the development of linguistic discriminators maybe of significance when developing knowledge about pain and coping strategies, this is illustrated by some of the participants in my research.

One of the fundamental problems of pain is that it is a private experience and does not have a focus outside the body. It is argued that pain is resistant to language because tensions exist between the highly personal internal physical sensation of pain and the interactional socially acceptable categories of language where people connect to each other (Scary, 1985). Participants

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are aware of the dilemma they face when presenting pain to health professionals. They are aware that the scientific approach of medicine demands precision and measurement; however pain patterns, locations and pain severity were often variable, thus it is a challenge for them to provide reliable and measurable information. It is suggested that participants either adopted biomedical terminology or juxtaposed lay knowledge with scientific expertise (Ong et al, 2004).

The increased recognition of the interplay between biological, social and psychological aspects of chronic pain has resulted in some acceptance of the bio-psychosocial model (Engel, 1997). However this model creates its own contradictions whereby health professionals attempt to gain acceptance in the participants of this approach, with participants resisting this model in the case of indeterminate problems such as chronic pain.

In most accounts of the healthy individual, the body is silent in performing its functions without a compelling moment-to-moment awareness (Thomas, 2000). Whilst chronic pain may be an invisible condition, and the reality of living with chronic pain is in stark contrast to the healthy body, as the participant is perpetually aware of their body. For most of the participants in my research and the narrative review, every movement of the body produces twinges, aches spasms or unpleasant consequences. The participants do not have the luxury of moving the body spontaneously and thoughtlessly, and the body cannot be ordered to perform the desired movements. Even simple taken for granted activities such as cleaning teeth become carefully planned and calibrated; sharp reminders of disability (Thomas, 2000). The pain experience alters the perception of their bodies, and rather than their body being the enabler as it was, it has become an obstacle. Often the body is seen in terms of damage, or is inert or useless in contrast to the body that was previously active. Pain levels and variations in these are described in great detail with extreme precision. This embodied experience of chronic pain is discussed further in the next chapter.

The person with chronic pain is expected by society to display visible attempts to get well, therefore to be accessing health care and receiving treatment is a visible sign to the participant's social surroundings that medical approval of their suffering has been received, hence treatment seeking and receiving treatment becomes part of the reality of living with chronic pain. Perhaps this is one of the reasons why people engage in treatment they know will be ineffective and that a cure is not so much the reason for treatment seeking, but the legitimisation of their pain with an outside hope of help. For participants the lack of effective treatments and long waits between pain clinic appointments mean periods without treatment, which is often frustrating and expressed as a fear because lack of treatment could be seen as a sign that they were not trying to cure or relieve their pain (Glenton, 2003).

Communicating pain is a complex challenge for participants who need to operate at various levels, expressing pain for themselves and for others who inhabit a range of social worlds (e.g. family, friends, employers, colleagues and health professionals). Establishing pain as a recognisable experience requires a repertory of words that are framed by culturally accepted concepts and ideas (Kleinman, 1988). Perhaps this is why there is a frequent use of similes and metaphors when participants try to explain their pain.

Participants ruefully acknowledged that chronic pain was not readily apparent to others despite the profound changes they felt in their bodies. As chronic pain is invisible, the participants' inability to carry out certain activities is the only indication that something was wrong. As their bodies looked healthy in the eyes of others, they frequently reported both in my research and the narrative review, this was the cause of numerous problems amongst family, friends, and neighbours and at work. They became accustomed to hostile glances when they got out their cars parked in disabled bays (Thomas, 2000). Many participants fear their social surroundings will display similar reactions of disbelief and de-legitimation to their lack of visible disabilities as the health professionals (Glenton, 2003). Many participants longed for a diagnosis

to give a reason for their pain, or an external manifestation of disability to increase the social legitimacy of their pain (Thomas, 2000). Another example of their divergence from the acute model of sickness is the fact that people with chronic pain may experience inconsistency in their symptoms, leading to the problem of having 'good and bad pain days', and the fear that this lack of consistency may harm their credibility.

Pain has the potential to disrupt all aspects of social life for the participants, their spouses/partners, friends and family members. Within my research and the narrative review participants reported that being aware of and needing to make adjustments to their own capacity and their limitations in their daily lives, this was closely linked to permitting or allowing oneself to adapt to their own needs and desires (Werner et al, 2003). For female participants in particular, making adjustments to their bodily limitations meant they had to leave some of their workload of family life to their partners. Sometimes this caused unpleasant reactions from partners who had not necessarily understood or accepted their responsibility for family duties (Werner et al, 2003). In both my research and the narrative review the women felt they should remain responsible for family duties such as housework and childcare despite their pain. Many participants faced pain related limitations and uncertainties that lead to social withdrawal for themselves and social isolation for their partners (Sofaer et al, 2007a). These are familiar concepts to those working in pain management however; the processes of social withdrawal and isolation are poorly addressed in the literature with the exception of Roy (2001). Physical limitations are a major problem for people with chronic pain however; it is clear from my research and the narrative review that the inability to go out to meet family or friends is not solely a consequence of reduced physical functioning or mobility. The uncertainties imposed by the potential for pain, imposed almost as many restrictions as the actual presence of pain (Sofaer et al, 2007a). This led to loss of confidence and consequent withdrawal from social engagements, perhaps this could be investigated further to see if this is a reason some people with chronic pain feel unable to return to work.

Fear is expressed throughout the categories, often in relation to doing activities, or their changing roles and identity. It has been suggested the key issue in any threat to identity is whether repeated interference with major life goals will impact on the person's self schemata hence their identity (Leventhal et al 1999). Chapman and Gavin (1990) provide this example *"Painful arthritis in the fingers would have a minor impact for most middle aged people, but could be devastating for a professional concert musician because it affects what he or she is and can hope to be in the future"* (p.2234). Identity is complex and dynamic, and is maintained by the person's interaction, reflection and appraisals of their social and material environments (Morley and Eccleston, 2004).

The biographical disruption (Bury, 1988) changes the person's perceptions of themselves with respect to past and present; it is this that challenges and threatens the sense of self (Schmitz et al 1996). Throughout clinical practice, my research and the narrative review, people often make reference to aspects of their past. Chronic pain disrupts the participants' expectations of the future, often because they feel as if they have been moved into the future in terms of developmental time and is often expressed as "old before my time" in both my research, the narrative review and the broader pain literature. Another aspect to this is was that participants found themselves in a situation, which did not fit with their imagined possible self which enhanced their psychological distress (Morley and Eccleston, 2004)

Often the participants' active efforts to alienate themselves from the reality of living with pain added to the confusion, particularly in the early stages. To be able to continue everyday life they remained in a limited medical status as 'in-between' patients to secure access to prescriptions and occasional sick leave (Lillrank, 2003).

The reality of living with chronic pain forced them to develop coping strategies to endure pain and bend inevitable social restrictions. Practically doing things

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sometimes helped the participants to come to terms with their pain and attempt to gain some control over it. Usually it was difficult to know what would help, so it became an individual process or trial and error.

This reality of living with chronic pain striving for legitimisation of pain from both health professional and the social world, being acutely aware of the body, restrictions and limitations causes the participants to revised their schema and hence their expectations which they will bring to their next consultation. As can be seen affect is intrinsically woven through the accounts in both my research and the narrative review. Change in lifestyles and health will cause changes in participants' thoughts, moods and other characteristic behaviour patterns.

Hope is often invested in diagnostic tests for example, which is a double edged sword, when health professionals are unable to locate a problem or express doubt about the possibility of a solution, participants feel that their pain is disconfirmed and not believed. They feel de-legitimised, which in fact is to experience a series of negative consequences, from not being seen, not being heard, not being believed to a sense of deficiency and shame (Rhodes et al, 1999). Participants are often faced with the disjunction between the cultural model of the visible body and the private problematically 'quiet' experience of chronic pain. Participants are not only alienated from the health professionals but from important aspects of the symbolic world of medicine (Rhodes et al, 1999).

Participants often reported trying to deal with their concerns by trying to conceal them from themselves and other people. Uncharacteristic thoughts, feelings and behaviours may be a product of the adaptation process. Adaptation is a dynamic process, and individual's resources may be overstretched until they adjust to the new 'norm' or the stressor is removed. The difficulty in reaching adaptation is when the process overwhelms the individuals' resources, resulting in a retreat from the situation. It may manifest

itself as depression or withdrawal, 'containment' of the seriousness of the situation (Leavitt, 1990) or a move to an external locus of control (Schroder and Miller, 1983) in order to conserve personal resources (Gibson and Kendrick, 1998)

As can be seen from the theoretical model drawn from the narrative review and my research, expectations are brought to the consultation, depending upon the outcome of the consultation will influence both the need to legitimise their chronic pain as well as living with it on a daily basis. The need to legitimise pain and manage it on a daily basis will influence expectations over time. The categories within this process constantly reflect and report changes in affect and show how affect influences the themes.

It is interesting to note that in contrast to the pain management beliefs of the healthcare professional, these participants believe and report their pain cannot be managed. Data from both my research and the narrative review call into question the idealised positive depiction of chronic illness that is prominent in the contemporary literature. A review of fifteen years of qualitative work on chronic illness experiences concluded that the early focus on themes of loss, and burden had shifted by the mid 1990's to positive images of normality, courage and self-transcendence (Thorne and Patterson, 1998). Researchers increasingly depicted participants as strong, powerful and competent. But few participants in my study or in the narrative review perceived their position as one of strength or described any personal benefit of their suffering. The transformative elements within the chronic illness experience may have been over-emphasised in the optimistic literature of the 1990's (Thomas, 2000). Alternatively there may be substantial differences between chronic pain and other chronic illness, precluding their comparison. It may also be that there are substantial differences in using a pain clinic population compared to a non-treatment seeking pain population.



Having produced three pieces of analysis (chapters five, six and seven), which are generally consistent with the literature, however there are gaps in the “lived experience” of chronic pain literature, which are highlighted by my research, and will be discussed in the next chapter.

## **Summary**

Throughout the research, the complexity and difficulties with living with chronic pain on a daily basis are revealed. However few papers report on the totality of living with chronic pain, choosing to just focus on one aspect. It could be suggested that this is due to the restrictive word limit placed by many journals. This chapter has positioned my own research within the field; it has compared and contrasted the models developed my research and the narrative review, resulting in a combination of models leading to the development of the theoretical model of living with chronic pain. This chapter has not reported upon the process of the development of the model as it is extensively reported in chapters four and five. The chapter concludes discussing the literature in relation to the proposed theoretical model.

## **Chapter 8: Discussion**

### **Introduction**

To recap from previous chapters, pain is both a medical problem and also an everyday experience for chronic pain patients. Attending to the biomedical aspects is important, but the emphasis on this can result in a failure to consider how the patients perceive and live with their pain. The prioritization of management of sensation over understanding affect in traditional medical and psychological approaches has resulted in the lack of attention to the lived experience of chronic pain therefore neglecting broader issues of how culture and social factors influence pain. The UK is becoming more culturally diverse therefore there is a growing necessity to understand any influences of culture and ethnicity in pain management. The aim of this qualitative study was to address what is the participant's experience of living with chronic pain followed by an appraisal of how or if ethnicity ('White British' or 'South Asian') influences the experience of living with chronic pain. The participants' accounts reveal the complexity and the variety of their chronic pain experience. Despite their struggle to comprehend their pain they gave extensive descriptions of what it is like to live with pain on a daily basis as evidenced in the extracts in the results chapter. Using the Grounded Theory technique of constant comparison, this thesis has produced three models, firstly from my own research, secondly using the qualitative research literature as data, and thirdly a model drawn from a combination of the two based on living with chronic pain. The categories that emerged have been discussed extensively in the previous chapters.

In this chapter, the biomedical and the bio-psychosocial model are considered, as it appears they could help to explain the mismatch of expectations between participants and health professionals, which leads the participants to need to legitimise their chronic pain. Expectations and the need to legitimise their pain influence the reality of living with chronic pain, which in time may change their expectations producing a vicious cycle, whilst affect

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influences and is woven throughout the categories. A critique of the biomedical and the bio-psychosocial models lead to a discussion around embodiment and how this approach can further develop our understanding of the experience of living with chronic pain. The strengths and weaknesses arising from this research are presented. Methodological issues, including the need to rethink ethnicity and consider acculturation as factors that may influence the experience of living with pain are discussed and suggestions for future research are offered. The chapter concludes with my personal reflection on the production of this thesis.

Each culture has its own system of beliefs about health and illness, which underpin its health related behaviours. The values and customs associated with ill health are part of the wider culture, and cannot be studied in isolation from it. Beliefs and practices relating to ill health are linked to beliefs about the origin of a wider range of misfortune including accidents, interpersonal conflicts, natural disasters, and loss. One cannot really understand how people react to illness, death or other misfortune without understanding the type of culture that they have grown up in (Helman, 2007).

Following on from Helman's analysis that health and illness are culture bound, it could be safely deduced that beliefs about chronic pain are also culture bound. This study found that cultural expectations differed to some extent between the White British and South Asian participants, however the actual experience of living with chronic pain on a day-to-day basis was similar across the two cultures in the participants in this study, as seen in the findings chapter. Pain behaviour is influenced by social, cultural and psychological factors. Pain is a private experience however, it is these factors that influence whether private pain is translated into pain behaviour, and the form this behaviour takes, and the social setting that it occurs in (Helman, 2007). Part of the decision about whether to translate private pain into public pain through pain behaviour depends upon the interpretation of the significance of pain, whether for example it is seen as 'normal' or 'abnormal', the latter being most

likely to be brought to attention of others. All participants bring to the consultation, their own general health expectations, and their expectations as a result of living with chronic pain, and their expectations gained from society, which will in turn, influence their expectations of the consultation

This study suggests that both White British and South Asian participants had the learnt expectations that pain is time limited. This often resulted in frequent visits to the general practitioner and various consultants when the pain remained. These visits entail a myriad of expectations surrounding the consultation, the treatments available and the expectation that their pain will be cured. Despite being in chronic pain as defined in the introductory chapter, participants' attitudes to treatment often corresponded to the sick role adopted in acute illness (Parsons, 1966) in which the individuals' responsibilities are simply to seek and co-operate with treatment. This research suggests that patients often believed that their best chance of recovery lay in the hands of the health professionals. Their own role was to 'play by the rules' laid down by the health professionals, this could perhaps explain why participants continually returned to their health professional which may encourage passive coping strategies. Initially there was an implicit trust in the accuracy and appropriateness of the health advice given, which seemed to diminish over time, yet there was still the desire to be seen as a good patient (Dickson and Kim, 2003). This suggests the dominance and the essential weakness of the application of the biomedical model in their attempts to understand their situation. Such medicalisation of our bodies is referred to extensively in the medical sociology and anthropological literature (Bendelow and Williams, 1995; Frank, 1990).

### **The biomedical model**

Technical and philosophical developments during the Renaissance overhauled holistic ideas, and the mechanical approach of modern medicine emerged. This biomedical perspective likened the human body to a machine

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and the doctor or surgeon is the mechanic who fixes it when something is wrong. This view dominated the study of disease during the nineteenth and much of the twentieth century. The biomedical model can be characterised as one in which the study of disease is reduced to narrowly defined biological, chemical, cellular or genetic factors which cause physical changes in the body. This narrow definition has spread in methods of treatment that focus solely on the changing physical state of the body such as surgery, radiotherapy, or drug interventions; as found in the participants' responses around their expectations of treatment for their pain. In this biomedical model psychological factors have very little role to play in the disease process, in this study some White British and South Asian participants did not see the association between pain and psychological factors, suggesting their expectations were linked to the biomedical model. They adhered to a more Cartesian and dualistic division between the mind and the body. This assumes that mind and body function independently of each other, and is often referred to as 'mind – body dualism'. Within the biomedical model pain was seen as purely a stimulus and a response, and was considered to serve as a warning signal of actual or potential damage to the body. Pain was considered to be a phenomenon exclusive to the body, and it was thought that a direct and unmediated pathway ran directly from the source of damage to the brain.

Insight gained from research quoted throughout this thesis, this study and my own clinical experience show that the histories of chronic pain patients commonly reveal that there has been excessive and unnecessary utilization of various diagnostics and invasive procedures in order to prove the somatic cause of pain. This is not only unproductive but also detrimental to the relief of pain (Innes, 2005). This approach and lack of identifiable source of pain leads to a faulty conclusion that patient's pain is all in the head or in other words unreal; the participants in this study frequently expressed this view. This conclusion leaves pain patient frustrated, angry, depressed, and in feeling the need to legitimise their pain. Hence biomedical model adds to iatrogenic morbidity and pain and can cause pain to become chronic. The patient

becomes unwilling rider on the never-ending chronic pain carousel forever in search of pain relief, as discussed in chapter five.

The biomedical model, despite the severe historical constraints of Cartesian thinking, has served medicine well, in terms of gathering information regarding nociceptive transmission and its modulation within the biomedical model, which has provided a basis to expand our pain knowledge (Chapman, 1999). However, the view that psychological processes were not important to the onset of disease and/or disease progression began to be challenged during the twentieth century as disciplines such as psychosomatic medicine, behavioural health medicine and most recently health psychology emerged (Ogden, 2000).

Recent research is beginning to show links between the biomedical and the bio-psychosocial model, it has been demonstrated that a reorganisation in the central nervous system is implicated in pain suggesting that the brain and psychological factors seem to have a profound effect on symptom report in the absence of major structural abnormality. Experimental studies have shown that when people anticipate back pain, there is a change in the strategy by which the central nervous system attempts to control the spine during the perturbation caused by limb movement. (Moseley, Nichols and Hodges, 2004). This strategy serves to protect the trunk by stiffening the spine. The main implications of Moseley et al's study is that the alteration of postural strategy observed in recurrent back pain patients may be caused by the anticipation of back pain, and that the anticipation of back pain predisposes the person to actual back pain.

### **The bio-psychosocial model**

As medicine improved, acute and contagious disease has diminished and chronic illnesses have become more prevalent; there has been an increasing appreciation of the need to consider social and psychological influences on

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health and disease. Cognitive behavioural psychologists offered a different perspective on pain. They suggested that pain was not a simple alarm system, rather sensory messaging were bound with complex associations that embedded it in personal and social constructs which gave it meaning (Chapman, 1999).

This study supports the suggestion that the perception of pain involved a mixture of unpleasant bodily sensations, health and pain beliefs, fears and uncertainties, interpretation of vocational, family and social implications of possible disease (Chapman, 1999). Attitudes, beliefs, mood state, social factors and work all appear to interact with pain behaviour as do coping strategies (Ax, Gregg, Jones, 2001), sense of control (Woby, Watson, Roach, Urmston, 2004), personality type (Radnitz, Bockian, Moran, 2000), faith and religious beliefs (Koenig, 1997), have been reported in literature (for a comprehensive review see Keefe, Rumble, Scipio, Giordano, Caitlin, Perri, 2004), the most significant and reproducible factors have been mood / depression and to a lesser extent somatization / anxiety (Pincus, Burton, Vogel, Field, 2002; Fayad, Lefevre-Colau, Poiraudau, Fermanian, Rannou, Wlodyka Demaille, Benyahya, Revel, 2004). Depression has been associated with decreased pain thresholds and tolerance levels, reduced physical ability, general withdrawal and mood disturbance such as irritability, anhedonia (loss of enjoyment of good things in life), frustration and reduced cognitive capacity. Participants in this study expressed all of these emotions and moods; hence affect was the overarching theme. In relation to occupational factors, job dissatisfaction has repeatedly demonstrated itself to be a significant factor in disability / persistent pain studies. The most recent literature has implicated such factors as support from supervisors at work and low job control (i.e., inadequate power to make decisions and utilize one's skills), which can create distress, and, when perpetual, may result in ill health (Kaila-Kangas, Kiviraki, Riihimaki, Luukkonen, Kironen, LeinoArjas, 2004).



Although undoubtedly the bio-psychosocial has been of value, in building a conceptual framework that can account for chronic pain at the psychological level, and it has without a doubt advanced the knowledge within the field of pain. The appeal of the bio-psychosocial model is somewhat limited because it tends to generalise. A major criticism of the bio-psychosocial model is that it was derived from quantitative measures of psychological variables such as observable behaviours, beliefs, attitudes and perceptions gained from laboratory based experiments and structured questionnaire. However this streamlining of psychosocial measures enabled psychological research to gain acceptance from clinicians and medical researchers (Yardley, 1997).

In the 30 years that have elapsed since Engel (1977) first proposed the bio-psychosocial model, we can move beyond the problematic issue of mind-body duality by recognizing that knowledge is socially constructed. To some extent, such categories as “mind” or “body” are of our own creation. These categories are useful to the extent that they focus our thinking and action in helpful ways (e.g, they contribute to health, well-being, and efficient use of resources), but when taken too literally, they can also entrap and limit us by creating boundaries that need not exist, and disappointingly, the bio-psychosocial model is often presented as separate factors that exist in a fragmented way, rather than the more complex interplay of the biological, psychological and social factors (Borrell-Carrió, Suchman and Epstein, 2004).

Bio-psychosocial models are integrated theories of disease, not models for health professional-patient interactions, therefore there may be an explanation for the mismatch of expectations in the consultation frequently expressed by participants in this study which leads to the need to legitimise their pain which influences the reality of living with chronic pain which in turn influences expectations and feed the vicious circle. There are at least two distinct strategies for working with bio-psychosocial understandings of disease. In an instrumental approach, the health professional strives to change the patient's perspective to adapt to the health professional's bio-psychosocial

understanding of disease and illness care. In a dialogical approach, the health professional interacts with the patient to understand the bio-psychosocial disease and co-construct the approach to illness care over time. Both strategies can claim to be directly applying bio-psychosocial models, and both might be successful in various clinical contexts. The misunderstandings, mistrust, and constrained interactions found in the research suggest difficulties with the way knowledge is formed in clinical practice (Bartz, 1999). It has been suggested moving beyond the multidimensional and multi-factorial linear thinking to consider complexity theory as a more adequate model for understanding causality, dualism, and participation in care. Complexity theory shows how, in open systems, it is often impossible to know all of the contributors to and influences on particular health outcomes. By describing the ways in which systems tend to self-organize, it provides sign posts to inform the health professional's actions. It also buffers the tendency to impose unrealistic expectations that one can know and control all of these contributors and influences (Stacey, 2001).

Health professionals construct their understanding of disease in individual patients through patient-specific narratives that combine knowledge of disease, patients, and clinical context (Bartz, 1999). Adopting the stance of critical health psychology which is keen to explore the qualitative nuances of meaning and inherent value in human experiences of health and illness, this research was qualitative and was interested in understanding the processes involved in the experience of living with chronic pain from the participants' narratives, rather than prediction and control of chronic pain.

Through qualitative research, health psychology can start to understand the character and evolution of the various narratives the participants use to order illness or disability in our societies (Murray, 1999). The narratives provided by the participants offer the opportunity to engage with the body. "Our lives, including our health, hinge upon our bodies; we depend upon them; engage with the world and the people around us with them; live in and through them;

do things with and to them; exist as and for them; experience having them and being them; feel them and are them” (Smith and Sparkes, 2007). It is argued that narratives are embodied (Frank, 1995; Sparkes, 1996).

## **Embodiment**

Merleau-Ponty’s (1962) phenomenological philosophy can be foundational to any qualitative study. Embodiment challenges the mind-body split, and is a form of experiencing and understanding the world through the body in lived experiences. The embodied experience takes place within the contextual world that each person is born into and lives. Culture, society, history and personal relationships shape the world through shared understandings, making the world a social and inter-subjective experience. What one person experiences in the world may be similar to another person’s because all of us open into the same world and therefore our experiences may be similar? Perception of others varies by race, gender and it entails cultural understandings, meanings and general orientation. If meanings of concepts (including pain) are socially constructed and shared, this allows us to communicate how or otherwise subjective and private experience connects with, and overlaps with that experienced by others. Lived experiences are experiences of the everyday world, which we take for granted, making them less available to our awareness. Understandings of lived experiences are thought to be separated from our conscious understanding and therefore require a qualitative approach, as language and perception provide a tool to access the experience.

The pain experience is a dynamic process in which certain events stand out whilst others recede into the contextual background. The figure that stands out at one particular time is never independent of its background and vice versa (Thompson, Locander and Pollio, 1989). Munhall explains, accounts of experience must be situated in “space, (where we are); the time we are in, our

past, present and future; the body that enables us to be in the world; and where and when we are interpersonally connected” (Munhall, 1994, p55).

One of the most interesting areas in the embodiment literature is about meanings of illness; one of the challenges of chronic pain is to find meaning. Understanding the unique meanings of pain and disability brings the health care professional into the everyday world of people with chronic pain, making it possible to provide more culturally sensitive and knowledgeable care. The literature about embodied meanings of pain can prompt many new questions for health professionals such as what happens when the body no longer functions in pain as it ordinarily does in health? How is this experienced? What can be done about it? How does the health professional help someone adjust, cope or live with the experience of chronic pain? What kind of skills can the body be expected to possess and how can these be solicited? What makes the transformation of the body as adversary to skilful and how can health professionals help people make these changes? (Wilde, 1999).

Embodiment is important in the study of pain because embodied knowledge could provide the much-needed theoretical links in practices in daily living with chronic pain. Approaches using the philosophy of Merleau-Ponty (1962) have been used to discover new embodied meanings and practices in daily living in other health conditions so could be applied to chronic pain. Such approaches can help elicit practical and largely inarticulate skill from patients, skills learned by living with chronic pain everyday. Research findings developed from embodied approaches can then be used to generate new middle range theories to understand the processes of living with chronic pain and in assisting people with everyday living in chronic pain.

### **Strengths and weaknesses of the research**

The particular strength of the empirical work in this thesis is perhaps the perspective it provides into the process of daily living with chronic pain. The

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participants were able to give rich accounts of their experiences of pain and these highlighted and reinforced its multi-dimensional and personal nature in a way, which complements quantitative research and addresses some of the gaps in the qualitative literature.

This study is one of only a few qualitative studies that explores the role of ethnicity and acknowledges the possible influence of acculturation in the experience of living with chronic pain. Adopting the notion of embodiment, a theoretical model of living with chronic pain was produced from my research data, and refined accordingly after the narrative review to form a comprehensive theoretical model, which looked at the processes of living with chronic pain and provided possible explanations for the interaction between categories, and the role of affect on these categories. This adds to the knowledge base in both the health psychology and the chronic pain literature.

The narrative review brings together for the first time, a comprehensive review of the qualitative literature on living with chronic pain, and has highlighted gaps in the literature.

The study was limited in various ways. To begin with the research focussed on those attending pain clinics for pragmatic reasons, therefore does not capture the experience of living with pain from those who have either disengaged with the healthcare system or those who have chosen not to access it. This criticism is also aimed at the qualitative pain literature.

It is interesting that the anticipated findings that ethnicity would play a role in the experience of chronic pain were largely unfounded, as from my clinical work in Milton Keynes, often during our consultations it became apparent that ethnic minority groups of patients did have different beliefs regarding their pain, such as beliefs in gods and witchcraft, and traditional remedies from their homelands. This could be explained by several factors, firstly, my sample were of South Asian participants all spoke English and had been living in the United Kingdom for at least twenty years, so it could be suggested that they

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were acculturated, and have adopted the majority of pain beliefs of White British participants living in the U.K. It could also be suggested that the South Asian participants in this study were acculturated because other research (Patel et al, 2008) reports that GP's rarely refer first generation South Asians to the pain. Also from the hospital data obtained in this study, it appears that if you are a South Asian female you are twice as likely not to be referred to the pain clinic.

It appears that there are more similarities than differences between the groups, which may be partly explained by acculturation. Research into newly arrived ethnic groups in the UK might reveal more differences in their perceptions of health, illness and pain. It can only be speculated how much the themes identified in this thesis apply to those not speaking English or those participants who have lived in the United Kingdom for a shorter length of time. At the beginning, when developing my research proposal, I wished to include Gujarati speaking participants as that was the dominant language of the South Asian population in Leicester. However as this PhD had no funding attached to it, this idea had to be forfeited, as an interpreter and translator could not be employed. On the other hand, using an interpreter and a translator might well incur other difficulties such as the reliability of the translator, the difficulty of not being able to translate certain words back into English without obscuring their actual meaning, and organisational logistics within the available timeframe.

In this study, the definitions of the ethnic categories White British and South Asian were self-assigned, this in itself is controversial. This was for reasons explained later in this chapter when investigating the need to rethink ethnicity.

My research study used a rather narrow source of data. It was drawn from one interview so was limited in some respects, and like quantitative research in that it is a snapshot of that particular time. A useful approach for future research could be to adopt the use of the ethnographic method, which often would involve collecting data over a longer period of time with the opportunity

to revisit the participants. Additional sources of data, perhaps using repeated interviews with a selection of the participants or the use of diaries could have added strength to the study. With regard to the narrative review, the main issue of contention would be the use of data as a primary source, especially as the majority of papers did not have any reflexive account, therefore my conclusions drawn from the data should be interpreted as hypotheses rather than conclusions.

The interviewer was a white female and the majority of the interviews took place in the hospital setting. While it is possible that the cultural background of the researcher as well as their professional status may have influenced the interviewer-interviewee relationship and the responses obtained, the impact of this is hard to gauge. Although the participants made no explicit reference to this factor during the interview, it cannot be something that is ignored as it could have influenced and inhibited the participants' accounts. However the combination of reflexivity, and the multi-professional composition of the research team contributing to the analysis and interpretation of the data decrease the risk of misinterpretation of the findings. Reviewing this issue specifically at some point within the interview may have contributed towards addressing or evaluating the nature of its effect on participants.

In hindsight, the question around seeing pain as a form of punishment in religion was rather clumsy, and much more could have been explored from that theme such as the use of religion in coping strategies, as mentioned in the literature (Ang, Ibrahim, Barrant, Siminoff and Kwoh, 2002; Rippentrop, Altmaier, Chen, Found and Keffala, 2005); and to find out whether they took an active role in religious practice and consider similarities and differences between those who have a religion in comparison to those who practice their religion.

## **Methodological considerations**

### Telephone verses face-to-face interviews

The main differences between face-to-face and telephone interviewing are the channels of communication and the physical presence of the interviewer. The physical presence of the interviewer means that ranges of non-verbal channels of communication are available. The interviewer may detect signs of waning motivation or misunderstanding and frustration on the part of the respondent and react to these more easily than over the telephone. Finally, face-to-face respondents are less likely to be engaged in other activities while answering questions and interviews are typically carried out at a slower pace than over the telephone. As a result of these differences between the two modes, telephone respondents are likely to make less effort in answering questions (referred to as satisficing, resulting in different response distributions (Jäckle, Roberts and Lynn, 2006)). However, in my study, the quality of the interviews was not compromised by using telephone rather than face-to-face interviews, I believe this was due to the fact that I had spoken to the participants whilst they were in pain clinic and started to develop a rapport with them. On average the length and content of the interview were very similar regardless of method, as is discussed in the method chapter. The most notable finding from a study looking at the efficacy of face-to-face interviews versus telephone interviews was that telephone respondents were more likely to give socially desirable responses across a range of indicators. This suggests that the advantages of trust built up in the face-to-face interview outweighed any disadvantages due to the lack of anonymity. In order to mitigate this effect, more research is, however, needed to understand the cognitive processes underlying social desirability bias (Jäckle, Roberts and Lynn, 2006).



### Quality in qualitative research

As discussed in the method chapter, it is important that the criteria by which a qualitative study is judged are appropriate. The rejection of the stable, measurable truth means that the outcomes of qualitative research cannot be validated using constructs from the natural sciences and different criteria are required to establish the value and quality of qualitative work (Smith, 1996b; Yardley, 1997, 2000). It is explained in the method chapter how this study observed the following broad criteria as defined by Yardley (2000), sensitivity to context, commitment, rigour, transparency, impact and importance.

### Rethinking ethnicity

Heath has emphasised the emerging view that ethnicity is fundamentally a matter of self-perception (Heath, 1991). Voluntary self-classified ethnicity is acceptable (Department of Health, 1990); and this principle guided the classification used in the 1991 census, and has been advocated by the Council for Racial Equality. The concept will guide the introduction of ethnic monitoring in the NHS (Department of Health, 1990). However, self assessed ethnicity is changeable over short periods and is not subject to the control of the investigator, characteristics that are counter to the principles of scientific measurement.

From reviewing the literature, it becomes apparent that there are difficulties with the classification of ethnic group. Ethnicity may be defined by country of origin or by a wider geographical area such as European or African. For example, India is a culturally diverse country with many distinct ethnic groups, a complex caste system, at least eight major religions and fifteen official languages (Cruickshank et al, 1989). Yet Indians are often grouped as one. Classical, early studies in pain responses defined differences between white European populations, demonstrating the fallacy of grouping together culturally diverse peoples in experimental research, but this persists in ethnicity research. Throughout this thesis I have referred to South Asians participants as a group for ease of data analysis. It is important to note that

when talking about South Asian participants, I have grouped a large number of faiths and cultures together as one, and within this large group there are significant language and cultural variations. If there had been more differences within the South Asian group, this issue would need to have been addressed.

In Europe there is a stereotypical view of stoical northern Europeans, which was supported by both White British and South Asian participants in this study, and more emotionally expressive Southern Europeans in reaction to pain. What is not clear is whether pain expression is a product of different beliefs about pain and injury or that one kind of expression is more acceptable than another in different cultures regardless of the pain beliefs. Therefore in research, it is unwise to adopt general classifications (European, African, Asian) without an understanding of the underpinning beliefs about pain and the cultural norms for the expression of pain.

As an example of the questionable validity of classification in scientific research, results from the study of South Asians can prove illuminating and are relevant to the UK. Within this group there are a wide range of genetic backgrounds, cultures, lifestyles and health related behaviour affected by country of origin, (duration of residence) when the group or its ancestors arrived in the country, religion and current social class. Often conflicting research results are evident, for example, results, which are attributed to South Asians, might not be generalisable to the Bangladeshi community specifically. In some research Bangladeshi people would be classified as South Asian as they originate from the Indian subcontinent, but they have different languages, religions and practices from other people from different parts of the subcontinent. Research has demonstrated significant differences in the self perception of health between Bangladeshi's and other South Asian ethnic groups which are lost if all are grouped as South Asians (Nazroo, 1997).

Some studies have used religion to define ethnicity (e.g. Hindu, Sikh, Muslim), whilst others have used linguistics (e.g. Hispanic, Cantonese). Early studies demonstrated differences between religion and pain responses when comparing Jews and Christians but these were context specific and feedback on performance eliminated differences. Culture is a fluid and dynamic concept; it would be unlikely that Zbrowski's (1952) results could be replicated because they apply to a cultural world that has undergone a total transformation. Social responses to pain will continue to change because society rarely stands still, however stereotypes will inevitably emerge if our response to pain is always a "socio-cultural artefact" (Morris, 1991).

Pain report is often assessed using written information that may place the non-native speaker at a disadvantage or differences may be attributable to translation of instruments. After extensive work with pain assessment it was noted that the usefulness of basic pain tools across cultures was not sufficient enough to ensure high quality of care for clients of different ethnic and cultural backgrounds. A wide variety of valuable information about the participants' pain was obtained via the interview, suggesting that skilled clinical interviews can perhaps reveal a great deal about living with chronic pain, than measures such as questionnaires. Health professionals need to work more closely with the patient and their families to obtain accurate pain information in order to provide culturally competent care (McCaffrey and Pasero, 1999).

With migration, intermarriage and genetic polymorphism, populations are rarely homogenous, and there are often wider genetic differences within groups rather than across groups (Morris, 2001). Furthermore, the effect of acculturation, adopting the host country's cultural norms, may influence pain reporting and subsequent disability making it more akin to the host country, as this study and others have suggested that this is the case (Palmer et al, 2007). In Leicester those participants accessing the pain clinic were second and third generation South Asians therefore are more likely to be acculturated. Newly arrived immigrants rarely enjoy the same standard of

living of those already established in the host country. There are strong links between poor socio-economic status and poor health, which must be considered (Nazroo, 1997). In addition to socio-economic status, differences in lifestyle and between generations should be considered (Senior and Bhopal, 1994). A wise researcher would assess these factors before making pronouncements based on ethnic origin alone. Studies of broad, heterogeneous groups such as Asians have value as exploratory studies, from which deeper understandings can evolve.

Finally, pain research may reveal more about the ethnocentricity of the researcher than the researched, resulting in a tendency to view one's own culture as the standard against which others are judged (Bond and Bond, 1986). The research compares and contrasts pain tolerance, pain thresholds, and utilisation of services of the 'White' (usually northern European or north American) population with other ethnic groups and may influence study design, aims, method of investigation and the presentation and interpretation of results, making 'value free' observation unlikely.

To improve ethnic research, it would be helpful if it was appreciated that ethnicity is complex and fluid in nature, as this means that research may rapidly become out of date and therefore may differ between generations. It should be acknowledged that there are limitations in the current methods of classifying ethnic groups, and research should explicitly state how classifications were made. It may be that definitions of ethnicity were devised to suit the needs of a particular project (Senior and Bhopal, 1994).

Researchers need to recognise the potential influence of their personal beliefs and values, including ethnocentricity on scientific research and policy making (Senior and Bhopal, 1994) this could be addressed by reflexivity. As discussed in depth in chapter four, reflexivity directs the researcher to introspect on how their own experiences, values and feelings interact with the

research process, hence assisting with the prevention of personal bias in the results.

In conclusion, broad definitions of ethnicity make assumptions about homogeneity, which are not supported. Difference between groups must be considered in the light of, not only ethnic origin, but also control for the effects of socio-economic influences and acculturation. Further research needs to focus on ethnic classification; and the information gained should be used to develop appropriate culturally sensitive pain services.

### Acculturation

Acculturation is the extent to which an individual who migrates from their country of origin adopts the values, beliefs, culture and lifestyle of their host country (Mavreas, Bebbington and Der, 1989). Although acculturation is usually in the direction of a minority group adopting habits and language patterns of the dominant group, acculturation can be reciprocal- that is, the dominant group also adopts patterns typical of the minority group. Assimilation of one cultural group into another may be evidenced by changes in language preference, adoption of common attitudes and values, membership in common social groups and institutions, and loss of separate political or ethnic identification (Berry, 1997).

With greater cultural diversity it is important to understand the process by which immigrants adapt to the values and customs of a new country and how that process, affects issues such as mental and physical health and family function. Research over the past two decades implies that a person's level of acculturation is strongly related to their mental and physical health. However, problems with how researchers have traditionally conceptualised and measured acculturation limit these findings.

The traditional model of acculturation is linear, assuming that people take on the values, customs and language of a new culture, and drop the values, customs and language of their old culture; it is argued that this a model of assimilation, and the most commonly used measures of acculturation are based on this model (Berry, 1997). Language usage is often a major marker of acculturation. In populations other than South Asians, language usage and familiarity with the language of the host culture have been shown to be the most important measures of acculturation (Olmedo and Padilla, 1978; Deyo, Diehl, Hazuda and Stern, 1985; Cheng and Hsu, 1995) however, this cannot replace the formal measure of acculturation. Some attempts at measuring acculturation have been restrictive in their content, choosing focus on certain aspects of acculturation while ignoring others (Deyo et al, 1985) or combining language and ethnic identification (Solis, Marks, Garcia, and Shelton, 1990). Many studies (Suinn, 1998) have been limited to students from university settings and consequently are not representative of the vast majority of immigrants. Other studies have tended to aggregate culturally or linguistically different individuals into one category, e.g. viewing all Asians as a culturally homogeneous group (Anderson, Moeschberger, Chen, Kunn, Wewers, and Guthrie, 1993). There appears to be a consensus brewing among researchers that change must occur in dominant theories and methodologies of acculturation in order to develop a deeper understanding of acculturation and how it impacts people's lives (Berry, 1997).

Some researchers suggest that the construct of acculturation may be too broad, and for research purposes, general definitions or general measures are not very useful and instead; it might be more valuable to measure individual aspects of acculturation, such as ethnic identity, social networks and acculturative attitude, (Phinney, 1992). Other researchers prefer general measures of acculturation, but agree that they may need to supplement such measures with assessments of specific elements of acculturation (Suinn, 1998). Multidimensional models allow more refined analysis of people's experiences, such models allow for four types of acculturation

Assimilation - where people replace their native culture and customs with the culture and customs of mainstream society;

Separation - where people choose not to take on the customs and culture of mainstream society and remain segregated;

Marginalization - where people fail to fit into either their native society or mainstream society, and

Integration/biculturalism - where people maintain values and customs of their native culture and take on the values and custom of mainstream society that allow them to become full participants in society (Berry, 1997).

But although many researchers agree with this type of multicultural approach to acculturation, too many continue to slip back into the ease of a linear model (Trimble, 1996).

Attempts to produce acculturation questionnaires for South Asians (Anderson, Moeschberger, Chen, Kunn, Wares and Guthrie, 1993; Suinn, 1998;) but most have focussed in United States of America where they have different definition of South Asian to what is used in the UK. Minority ethnic groups of South Asian origin, specifically Indians, Pakistanis and Bangladeshis, constitute the largest ethnic minority population in the UK, but both within and between these communities there are large differences in the level of acculturation. To date, there remains very little work focused on the role of cultural factors in explaining differences in musculoskeletal pain in South Asians (Palmer et al, 2007).

### **Future research**

This study proposes a model of the experience of living with chronic pain and offers suggestions of that process. Like so much other research it also opens up a whole new research remit.

Early in this study it was clear that the participants were often very unhappy about their experiences in primary care. Looking at referral patterns, it appears that fewer people of South Asian origin are referred to the pain clinic, and it could be supposed those that attend pain clinics are more acculturated. This led my colleagues and I to consider whether those who are less acculturated are more likely to remain in primary care, and what was their experience of primary care, and what was the experience of these, often difficult consultations from the viewpoint of the General Practitioner. Funding was obtained for a study to investigate this and the General Practitioner's experience of managing chronic pain in a multicultural community was investigated using qualitative methods. Several themes emerged including the consultation process, clinical management of pain, patient expectations and acculturation. Overall, General Practitioners find managing South Asian patients with chronic pain can be challenging as a consequence of the way in which the patients present with their condition at the consultation. There was a perception amongst General Practitioners that this group of patients use pain as a proxy for mental health in the non–acculturated group (Patel, Peacock, McKinley, Clark-Carter and Watson, 2008)

From my own personal clinical experience of working in pain management in a rapidly expanding new town – Milton Keynes, I have observed differences in the pain beliefs and expectations between the South Asian patients I see in my clinic in comparison to those who took part in my research. It could be speculated that as the South Asian community is well established in Leicester, the South Asians participants are more likely to be acculturated than the South Asian patients I see in my clinic who are relatively new to Milton Keynes, and as Milton Keynes is a new town, the South Asian community, or indeed any other ethnic minority communities are not well established. Ideally it would be of interest to compare and contrast the experience of living with chronic pain in the two communities using a qualitative approach. It also needs to be remembered that the immigration of South Asians into Leicester continues, but they are often from other areas of South Asia such as



Bangladesh. The Gujarati people are also moving into a well-established community even if they are newly arrived. This may mean that we would see these people in Leicester but they would be smaller in number relative to the size of the South Asian population. However, now I am working full time in the NHS, for me to undertake this would possibly be unrealistic. Considering that from my study, the results indicated that there was some differences in pain beliefs and cultural expectations rather than the actual experience of living with chronic pain a more quantitative approach could be adopted to examine this. With regard to investigating pain beliefs, the Pain Beliefs and Perceptions Inventory (Williams and Thorn, 1989; Herda, Siegeris and Basler, 1994) could be used and perhaps correlated with the acculturation questionnaire used in this current study. This data collected on the Pain Perceptions and Beliefs Inventory could also be analysed to see if it was a suitable instrument for measuring pain beliefs in the South Asian community.

Both my research and the literature have reported the negative aspects of some consultations regarding chronic pain, as mentioned previously throughout this thesis. It could be speculated that one of the reasons for this, could be a mismatch of expectations, in terms of locus of control. In my clinical work, I have observed that the South Asian patients expect a 'hands on' approach rather than self-management approach to their pain. Although locus of control was not examined explicitly in this study, this concept has been explored in the pain literature (for example, Crisson and Keefe, 1988; Harkapaa, Jarvikson, Mellin, Hurri and Luoma, 1991; Coughlin, Bandura, Fleischer and Guck, 2000) but not in association with acculturation or ethnic factors.

It would be interesting to examine health care seeking in South Asian patients, as it may be that the people in this study were those who were willing to accept Western medicine. It is possible that the results would be different in a different environment such as all types of alternative medicine practices. Questions that spring to mind are who accesses alternative

medicine and why? Does acculturation play a role in access? What are the similarities and differences in the experience of living with chronic pain between people accessing various forms of alternative therapies and 'Western medicine'?

One of the criticisms of my own research and that in the literature is the failure to address those people living with chronic pain, but not accessing the National Health Service 'medical system' or those who have chosen to disengage with the system. With the increasing use of the internet to seek health information, advice and psychological support (Powell and Clarke, 2002) and popularity of 'chat rooms' and message boards dedicated to those with different medical conditions, this might provide a starting point for exploring the experiences of living with chronic pain, however clearly there are ethical issues involved in using message boards such as is informed consent required, how to obtain it, and respecting privacy and confidentiality (Coulson, Malik and Kit Han Mo, 2007). An alternative method would be the use of narrative inquiry as health, illness and disability exist outside the narrative, but we can only begin to understand them through narratives (Murray, 1999). Narrative inquiry has the potential to contribute to an embodied health psychology that deals with the inherently embodied character of psychological practices that includes rather than excludes emotions, experiences, history, culture and communal practices (Smith and Sparks, 2007). Perhaps this approach could begin to unlock the answer to the million-dollar question; why do some people with chronic pain cope and rarely or never consult whereas others do not cope and consult frequently.

One of the most interesting themes from my research was the concept of public self-consciousness, which appears to be neglected in the pain literature, although addressed in some of the health literature, coronary artery disease and stroke (Scheier and Carver, 1985). Public self-consciousness refers to the tendency to think about those self aspects that are matters of public display, qualities of the self from which impressions are formed in other

people's eyes, for example, one's overt behaviour, mannerisms, stylistic quirks and expressive qualities (Scheier and Carver, 1985). Examples to relate it to the experience of living with chronic pain could be the 'good day bad day cycle', using a neck collar or walking aid. It is suggested that public self-consciousness has a role to play in social anxiety; awareness of the public self by itself is not enough to produce social anxiety, but the addition of a sense of apprehensiveness over being evaluated by the other person in one's social context, or doubt about being able to create adequate self presentations (Schlenker and Leary, 1982) will cause social anxiety. This leads to speculation that public self-consciousness will encourage people with chronic pain to withdraw from their everyday social life because of the unpredictability of their pain and their fear of what others will think of them. It would be interesting to pilot the use of the Self-Consciousness Scale with those living with chronic pain, and perhaps investigate this concept further using qualitative research methods.

### **Personal reflections on the thesis**

I have included a reflexive account in the method chapter and in the narrative analysis chapter so other researchers can see the angle from which I approached this research, and therefore understand how I came to my results. This section provides general thoughts on the process of the production of this thesis. I found the experience of researching chronic pain in this way invaluable and challenging in ways I had not anticipated. Gaining a working knowledge of qualitative research that helped to demystify it was satisfying but applying it showed me how much more in contrast to statistical analysis, it constituted a test of self-confidence. The researcher's personal interpretations are integral to the analysis rather than relying on statistical properties of the data to establish its power and quality, it was my ability to produce a coherent and selective interpretation that was tested. This felt much more personal and intimidating to begin with and was replaced in time with confidence in the method and the data. It took time to develop confidence that themes would emerge and suppress the urge to look for things based on

my clinical experience. This was quite difficult, in terms of the South Asian participants, as from my clinical experience with South Asian people less well established communities had different pain beliefs and cultural expectations from White British communities.

At the time of starting my thesis it felt as if qualitative research still had to prove that it was both psychological and scientific. I approached the data initially in this way and found it quite restricting as it felt there was a pressure to produce something exceptional immediately. This feeling receded as the richness, and value of the participants' accounts became clearer. With hindsight many of the difficulties of this thesis may have been avoided if I had appreciated the demands of qualitative work prior to starting the research. If I were to start again, I would spend more time at the beginning developing my expertise in qualitative research methods rather than focussing on the subject. Although I would have found this extremely frustrating, a much stronger grounding in qualitative research methods and methodology earlier in the process would have been valuable. On reflection, it was not wise to change jobs and move fulltime into the NHS with 6 months left until the submission date, however such opportunities never seem to come along at exactly the right time.

Although I consider Grounded Theory is an appropriate method for my research, I wonder whether I was caught up in my quantitative scientific background and the awareness of the type of literature published in journals solely dedicated to the study of pain at the onset of this study, therefore was subconsciously influenced to use an approach that provided steps to go through to produce a model. With my newfound confidence in my ability to undertake qualitative research, I might consider using different methodology such as IPA or narratives in future research.

Having a clinical background was helpful to a certain degree, but not as helpful as I initially envisaged, because I found a qualitative health psychology

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research interview to be very different from a health psychology clinical interview. It had been suggested to me by some colleagues that their psychology experience and training qualifies them as a qualitative researcher, I would not agree with this. I found that your clinical instincts have to be contained and you have to learn to develop a different style of enquiry, particularly at the beginning of the interview, that facilitates story telling rather than being too focused on single questions.

I am looking forward to collaborating with colleagues on some of the research ideas presented in the section on future research. Having completed this thesis, my first piece of qualitative research, I am now more confident with qualitative methods I feel that I do not need to use a prescriptive model for my own research. Although I think models and theories are at present more likely to be published in journals dedicated solely to the study of pain as this type of research is seen as more scientific. However the qualitative approach can offer much to the health professional working in pain management by listening to the unheard voices both in the pain clinic and primary care.

## Summary

In this chapter, has discussed and critiqued the biomedical and the bio-psychosocial model as it appears they could help to explain the mismatch of expectations between participants and health professionals, which leads the participants to need to legitimise their chronic pain. Expectations and the need to legitimise their pain influence the reality of living with chronic pain, which in time may change their expectations producing a vicious cycle, whilst affect influences and is woven throughout the categories. The notion of embodiment has been discussed and its potential role outlined in developing our understanding of the experience of living with chronic pain. The strengths of this research are that it has added to chronic pain and health psychology literature because it is one of very few qualitative studies that considers ethnicity. The narrative review brings together for the first time, a comprehensive review of the qualitative literature on living with chronic pain, and highlights gaps in the literature. The main weaknesses of the study are presented and include that the study focussed on people attending chronic pain clinics, and that the South Asian sample spoke English. Methodological issues, including the need to rethink ethnicity and consider acculturation as factors that may influence the experience of living with pain are discussed. As with most research, this thesis opens up new research remits, ideas for future qualitative and quantitative research are suggested. The chapter concludes with my personal reflection on the production of this thesis.

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## **Chapter 9: Implications for practice and conclusions**

*“The provision of skilful psychosocial care to patients suffering from chronic illness starts with an appreciation of what it is like to live with a chronic condition...Getting inside the experience of such illness may be key to understanding patient motivation, non-compliance with therapy and altered patterns of social engagement” (Price, 1996, p275).*

### **Introduction**

The findings of this thesis both from my research and those reported in the narrative review have revealed important insights into the experience of living with an invisible and poorly understood condition such as chronic pain. It has been well documented repeatedly over the past three decades that chronic pain is under-diagnosed and under-treated. (Marks and Sachar, 1973; Donovan, Dillon and McGuire, 1987; Zalon, 1993; Merskey and Teasell, 2000). Many factors have been cited as reasons for its under-treatment such as lack of access to health care for patients or lack of training for health professionals. Other studies have suggested that for example back pain sufferers are not a popular group of patients for health professionals to treat because of the difficulties involved in diagnosis and treatment (Cherkin, Deyo, Berg, Bergman and Lishner, 1991, Sears, 1996; Walker et al, 1999,). It is also suggested that health professionals find this patient group difficult because health professionals are unwilling to reveal their uncertainty and limitations (Skelton, 1998). However it could be suggested that the subjectivity of pain is the main reason for its under-diagnosis and under-treatment. As a subjective experience, often without a clear diagnosis or a clear path of diagnostic tests, pain is primarily assessed through patient – health professional interactions. In comparison to other medical conditions, the lack of consistent and objective diagnostic criteria and the reliance on social interaction make pain assessment uniquely dependent upon the patients’ subjective experiences, and how their accounts are perceived by the health professional. This chapter aims to use insights arising from my thesis to suggest implications to improve

the consultation experience, pain management practice, and education and training. It will also discuss the role the psychologist has in pain management, and concludes with how my own clinical work has evolved as a result of this thesis.

### **The consultation process**

The medical encounter constitutes only a minor proportion of the life of the chronic pain patient, yet is the most talked about in both my research and the narrative review. However, the way in which the consultation is perceived by the patient, and the way the health professional perceives the pain and handles the pain may be of vital importance for the patients' understanding of their pain, their self and their ability to accept and come to terms with living with chronic pain and engage effectively with self management.

Comprehensive and individualised assessment is key for a good health professional – patient relationship. However in clinical practice, there is a tendency to rely on measures because they are easy to use or are widely used (e.g. Visual analogue scales for pain rating, McGill Pain Questionnaire). Often health professionals expect that formal assessments provide clear and succinct information of the individuals' pain. This thesis, in particular within the narrative review has shown that this view of formal pain assessment tools is erroneous. It has highlighted the depth of perception and understanding the patient has about their pain, and the degree of insight they had into the nature of the pain and how it affected their lives. Health professionals treating those with chronic pain need to emphasise the subjective part of their diagnostic assessments and allow the experiences and insights of those with chronic pain to inform treatment (DeSouza and Frank, 2000). Health professionals need to encourage patients to describe their symptoms in depth, what factors aggravate or relieve their pain (Cunningham and Jillings, 2006). With the development of the 'yellow flags' (Kendal, Linton and Main, 1997), to identify psychosocial factors that may be barriers to effective treatment, it was hoped



that patients would also be encouraged to share their beliefs and attributions about the cause of their pain, expectations about their pain and treatment. Cultural models should be explored alongside the perceived beliefs of the patient regarding their family, friends, colleagues, employers and health professionals in addition to the patients perceived actions of these other people; of course time is a factor in the consultation process, therefore maybe this thorough assessment should be the domain of the psychologist who is able to spend more time during consultations, this is discussed later in this chapter. By demonstrating an understanding of the individuals' pain and incorporating their view into treatment plans, the health professional may be able to enhance communication with their patients.

Those who repeatedly seek medical care for their pain bring more than pain to the consultation; they also bring the consequences of chronic pain for example, emotional issues, financial and social worries, relationship problems, and experiences and expectations resulting from previous consultations.

Health professionals need to recognise that patients who repeatedly consult, may need more time for their underlying needs to be made clear. Eliciting the patient's views about the underlying causes of their pain and of possible solutions may assist the health professional – patient relationship as it will help the health professional focus on the patient's primary concerns, therefore increasing the chance that the patient will feel that their concerns are heard and their needs met (McPhillips-Tangum et al, 1998), and therefore may be satisfied with the consultation.

Within my own research and the narrative review, there is clear evidence that the patient needs to be understood and their experience validated, as even patients with a well-defined diagnosis, do not always experience being 'seen' or 'being believed' particularly by their general practitioners (Haugli et al,

2004) and other specialists outside the pain clinic. It seems important to acknowledge the patient's subjective experience as valid information.

It is possible as the biomedical model is dominant in the public perception, that some of those experiencing chronic pain do not recognise the connection between overall health and emotional, family and social difficulties. In some cases these have to be pointed out by the health professional, in others the patient is aware of this but the health professional is working to a biomedical model. Often patients expect a biomedical model and not to present one might be difficult for them to accept at least in the early stages of the patient-health professional relationship. Therefore maybe for some patients adopting a phenomenological approach in the early stages of any consultation or intervention that enabled the patients to recognise their own experience could promote engagement, rapport in the consultation and reduce attrition in the intervention or treatment phase (Smith and Osborn, 2007).

Ideally, the consultation experience could be improved in primary care by either adopting the consultation style of health professionals at the pain clinic used in my research, or having the pain clinic team hold clinics within primary care, as the majority of patients in this study were satisfied with the consultation even if there were no straight forward answers to their pain, because they felt their experience of living with chronic pain was validated and they felt believed. Pain clinic teams undertake careful inquiry into the patients' expectations of diagnosis and diagnostic tests, which may help clarify the misconceptions about the value of the test, this would be a useful practice to adopt in primary care. By suggesting several of the numerous reasonable options for treatment and letting the patient choose which one to try might help dissipate the sense of lack of control and helplessness reported by the participants in this study. Hence it is the responsibility of the health professional to recognise the suffering of the patient, and their strengths and use this to empower patients to believe that they can take control of their pain and their lives, (Malterud, 2000). The patient can then concentrate on dealing

with living with chronic pain instead of struggling to maintain their human dignity (Multerud, 2000). Achieving agreement between the health professional and the patient about the nature of the problem is a stronger predictor of outcomes than clinical measures (Bass, 1986), therefore improving the consultation experience as expectations will be managed more effectively.

Any consultation or treatment should take into account the larger socio-cultural structure that surrounds the person with chronic pain, and emphasising support, empowerment and acknowledgement of the patients' own resources. Clear attention should be paid to the individuals' needs rather than their ethnic background as this study suggests that acculturation may result in an absence of any clear patterning of pain experience by ethnicity. For those less acculturated, culturally appropriate and language appropriate health care and psychological services must be co-ordinated with more effective long-term strategies for rehabilitation.

### **Pain management**

There is no real linear progression of chronic pain, as explained in chapters one and two, chronic pain develops out of an initial three-month period of acute pain (IASP, 1986, 1994). Better patient information and good counselling may help people understand the multi-dimensional and disruptive nature of the experiences that constitute chronic pain this could be beneficial in the earlier stages of chronic pain. This would be important as my research and the narrative review suggest that patients' expectations are brought to the consultation. The need to legitimise their pain and the reality of living with chronic pain will cause participants to re-evaluate and redefine their expectations as they live with their chronic pain.

Teasdale, Seagal and Williams (1995) described this as helping the patient to cope with their situation as well as possible by developing and nurturing their

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'mindfulness' or therapeutic appraisal of their experience. In this way, the manner in which those with chronic pain felt and thought about their situation would be as constructive as possible. Patients would not pathologise their own experiences or see them as an indication of a weak or inferior self, but as the product of an individual doing their best to manage an unpleasant and unfortunate situation. This approach has been described as the development and application of a 'normal psychology of pain' (Eccleston, 1997), which accounts for the inherent disruptiveness and unpleasantness of pain. This approach could be used to help the patients understand that their pain experience is not a personality flaw, and therefore not something to be ashamed of or criticised. Instead it is an integral part of the chronic pain experience which cannot be controlled, ignored or cured but which could be accepted, managed and worked with (Smith and Osborn, 2007) enabling them to take a more compassionate self-view. To do otherwise would be a reflection of a type of 'victim blaming' that Kortaba (1986) described whereby the cause of someone's misfortune or adversity is attributed exclusively to that person. However I think this approach is more helpful for patients at a later stage in their pain history, as patients in the early stages may not find it acceptable as they continue to try to legitimise their pain.

Evidence from my research and the narrative review supports the development more 'contextual' or mindful approaches to chronic pain management (McCracken, 2005), which not only addresses the context of patients' thoughts, but also helps them re-contextualise and make sense of the experience in a helpful way, which is perhaps less threatening and shameful and more accepting of living with chronic pain (Smith and Osborn, 2007).

It has been acknowledged that whilst pain management programmes are effective, our understanding of what works for whom, and what the most active ingredients are in general is limited and in need of further study (Morley et al, 1999; Gatchel and Epker, 1999). To improve the experience of living

with chronic pain, focussing on the patients' therapeutic appraisal of the situation may guide, inform and change expectations so they become more realistic, and can be tackled in partnership with the health professional. By developing assertiveness skills to deal with perceived difficult consultations or relationship difficulties with family, friends, colleagues, employers and health professionals; and empowerment through knowledge and skill acquisition would complement the focus on pacing, goal setting and fear avoidance that typify the pain management approach.

Werner et al (2003) found the concept of recovery more fruitful than coping in their study. The term recovery is coined from mental health but they did not imply that the chronic pain experienced by the women in their study originated from emotional problems. They propose that the interface between pain and mental illness is concerned with living life with a disability rather than a related aetiology. They suggest that recovery does not mean cured, that the suffering has disappeared, or all the symptoms have been removed and or functioning is completely restored (Anthony, 1993; Deegan, 1996). Recovery is a way of having a satisfying, hopeful and contributing life even with the limitations caused by chronic pain; this concept requires further investigation, as it has the potential to have a positive impact on those living with chronic pain.

Patients who have strong supportive networks appeared to have a more positive outlook, and those with few or no social links are more likely to experience pain that interferes with their daily lives (Peat et al, 2004).

From my own clinical experience I have observed that often family members share similar frustrations and expectations as the person with chronic pain, therefore it is important to include family members where possible in the treatment process, and to develop a therapeutic relationship with each member of the family (Nichols and Minuchin, 1999). Families should be educated about chronic pain and its impact on the life of the person with pain and the family unit as a whole; specialist advice should be give to support the families. This is crucial because the pain patient only has limited contact with

health professionals, from my clinical experience I would suggest it is often the attitudes and beliefs of the family that can either help or hinder the person with chronic pain, as they seek to develop strategies for managing their chronic pain, they are often met with further resistance and misunderstandings on the part of family, friends, colleagues and employers.

Communication is vital to the family, and each member of the family should be taught communication strategies in which they are able to express their thoughts and feelings clearly, and assist families in listening to each other without becoming defensive and to talk without being critical (Kerns, 1999; Nichol and Minuchin, 1999). This will help to lessen the need for family members to try and guess what others are feeling and need, and can help clarify boundaries (Smith, 2003).

Many participants in my research and the narrative review felt guilty about their limitations around what they could do with their families. Communication skills could be taught to facilitate discussions around the meaning of the perceived changes and the losses occurring in the family and the fears and anger associated with financial burdens, decreased intimacy and increased responsibility. The family could be encouraged to engage in activities that promote enjoyment and bonding. Parents could be encouraged to seek support from their peers, thus shifting some of the emotional responsibility from their children (Smith, 2003). As part of the intervention involving partners, sexual intimacy could be considered.

As chronic pain is such a complex dynamic process, it may be useful to look at other chronic illness such as diabetes in terms of provision of services and long-term support, as many studies suggest that continuity of care is highly beneficial for chronic pain patients (Tait et al, 1990). An approach suggested by Bates et al (1997) could be useful, cost effective and warrants further investigation; they propose that chronic pain patients have a case manager who could co-ordinate medical and psychological services, or assist the

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patient in obtaining services and co-operation from the multiple agencies and institutions involved (for example, disability employment advisors, former/current employers, citizens advice bureau, health professionals in primary care, family members). The case manager approach could be a cost effective way of providing the co-ordination of services whilst at the same time providing the chronic pain patient with a long-term supportive advocacy relationship. Due to the health professionals' frustrations when dealing with chronic pain, many chronic pain patients have experienced significant distress from unsatisfactory relationships with health professionals, so the importance of a sensitive, knowledgeable and supportive advocate is clear. This idea of a case manager requires further investigation, it has the potential to work whilst the patient is under the care of the pain clinic, but may be difficult to implement outside this setting.

Health professionals are instrumental in providing support to their patients during diagnosis and treatment phases of chronic pain. By providing validation of the pain experience serves to legitimise them and may set the tone for a constructive approach to the management of their chronic pain. Strategies that encourage empowerment can also help to reinforce the credibility of the patients' experience. A problem solving approach allows them to contemplate and choose ways of dealing with their pain and its physical challenges rather than be given a list of 'things to do' from the health professional (Cunningham and Jillings, 2006).

### **Education and training**

Despite the existence of the bio-psychosocial model, and the acute model, some studies suggest that the acute model of illness is still the dominant model of illness amongst today's medical professionals and in medical education (McPhillips-Tangum et al, 1998; Davis, Nelson, Sahler, McCurdy, Goldberg, and Grenberg, 2001; Geyman and Bliss, 2001, Glenton, 2003). Where medical evidence appears to be lacking, the literature reports that

health professionals give less weight to the patient's self reported levels of pain (Turk, 1996; Tait and Chibnall, 1997). Therefore it can be suggested that neither health professionals nor patients are being taught effective coping strategies to manage chronic pain.

Patients who have chronic pain that has impacted upon their lives need something different to the standard primary care approach of brief visits and medication reviews (McPhillips-Tangum et al, 1998). Perhaps health psychology models incorporating self-management should be considered early on in chronic pain management, ideally in primary care, as all too often psychological treatments are only suggested after the biomedical model has failed. Therefore those with chronic pain interpret this suggestion as meaning that the doctors no longer believed the pain as real (i.e. physical). Hence adding further complications to the already complex and dynamic world of chronic pain, which they bring to the pain clinic.

### **Contribution of the psychologist**

Psychologists have an important contribution to the treatment of chronic pain, being charged with addressing psychosocial factors that contribute to pain related suffering and disability or that affect response to treatment. Consequently, psychologists often confront issues that relate to disparities in treatment such as socio-economic factors that can impact access to care, educational factors that effect a patient's health management, and obstacles to patient – health professional communication that interfere with case management.

Disparities in the management of chronic pain involve the social dynamics that create and maintain these disparities. Although a number of factors contribute to the problem of inadequate pain treatment, pain assessment is arguably the most crucial, as it is central to both treatment planning and monitoring treatment progress. Pain assessment can be considered to be an

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exercise in social cognition (Tait and Chibnall, 1997), a field study that considers how people think in interaction with their social world, including judgements, attitudes, attributions and inferences (Fiske and Taylor, 1991; Macrae and Bodenhausen, 2001), as all these aspects need to be considered at the initial consultation to ensure the patient feels believed and that their experience of living with chronic pain has been validated. This is important in terms of developing conducive therapeutic relationships to optimise treatment outcomes. Adequate attention has not yet been brought to the study of social psychological phenomena applicable to pain, psychologists are uniquely positioned to explicate the social dynamics of disparities in pain treatment and to propose approaches to remedy them.

Psychologists should be sensitive to issues reflecting patient distrust of health professionals, as distrust has been identified as a factor that can militate against effective treatment. Although medical economics often limits the amount of time that physicians are able to allocate to the clinical encounter, psychologists usually are able to spend substantially more time interacting with patients. Not only does this provide them with more opportunity to thoroughly evaluate patient adjustment to pain (including their interactions within the health care system), but also provides them with a venue wherein they can build trust in the process. Aside from the trust building angle of a thorough psychosocial assessment, the information collected regarding the impact of pain on adjustment puts psychologists in a good position with a treatment team to provide input on pain related interference with activities. Such information can offset tendencies of health care professionals to discount pain reports, which is often a concern when assessing chronic pain in minority ethnic patients, as pain is sometimes perceived by the health professional as a proxy for a mental health condition in those who are non-acculturated (Patel, Peacock, McKinley Clark-Carter and Watson, 2008).

## **Clinical practice within my workplace**

Being aware of the importance of psycho-social issues, and that they have the potential to influence treatment outcomes, our initial consultation process involves all new patients seen by psychologist on first visit to pain clinic. This offers those with chronic pain the opportunity to discuss any psychosocial issues that they may have. It provides an opportunity for me as the psychologist to assess any psychological difficulties they may be experiencing, the impact of their pain, levels of social support, and experiences of health professionals on the journey to the pain clinic. With this information in conjunction with my medical colleagues we can develop a comprehensive treatment plan right from their first visit to the pain clinic. Therefore removing the stigma of being referred to the psychologist and its associations of being 'mad or bad' as the psychologist is seen as part of the team.

As most pain clinics, we subscribe to the philosophy of "pain is what the patient says it is" (McCaffrey, 1989) and hence very much pay attention to the subjective experience of the patient. We are aware that many of our patients feel as disempowered as those people in this study. Therefore where practical we do try to give different treatment options and if possible allow patients to make choices. We are also aware that some patients feel unable to make choices about treatment, as particularly our older patients may believe that the doctor knows best.

With regard to long-term support, all of our patients who attended the pain management programme are invited to join the support group. The support group run by the Pain Team at Milton Keynes General NHS Hospital Trust was initially set up to try to resolve a waiting list problem. It was found that four to five years after completing the pain management programme, patients were returning to pain clinic. On questioning the main reasons were not that their pain had become worse, but because of issues of isolation, wanting to

know if there had been any new developments in treating chronic pain, the need to legitimise their ongoing pain and benefit problems. The support group aimed to provide long-term support and manage the pain clinic waiting list. The support group is based in a community setting (the same as the pain management programme), meets monthly and each session is approximately 90 to 120 minutes in duration. The chairs are laid out in a circle formation. The psychologist will start the session by asking “what’s the best thing that has happened to you since we last met?” or “anyone have any news to share?”; each person takes a turn at sharing their stories. Following this, usually there is a guest speaker from a non-medical perspective such as gardening, community transport, sudoku, volunteering opportunities, origami, local history etc. The session draws to a close with refreshments. Any time during the guest speaker or refreshments, the participants have access to either the psychologist or sometimes the nurse. The literature suggests that support groups can provide the basis for people with chronic pain to come together and share their experiences and concerns. This study supports the importance of the validation of the experience for people with chronic pain, both self-validation and by others for assisting towards the progression of living with chronic pain.

It has been observed that since the introduction of the support group, pain management programme patients rarely return to pain clinic, hence controlling this aspect of the waiting list. However, further work is needed to investigate this pattern. Observation at the support group suggests that outcomes such as activity levels, pacing ability, cognitive restructuring and goal setting continue to improve following completion of the pain management programme; this requires further research to gain the data to support this. Whilst support groups are not a panacea for all chronic pain patients, the high rate of continued membership indicate that pain support groups are helpful for those who choose to join (Peacock, Cascone and Porter, 2007).

The result from this thesis and observations from my own clinical experience, lead to the conclusion that self-management strategies should not be taught as a last resort as the medical intervention has been unsuccessful. Therefore

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in my workplace we have introduced pain management seminars, which are two, sixty-minute sessions teaching the basics of self-management; activity pacing, relaxation, stretching and posture. The patient attends these sessions within a month of attending their first appointment at pain clinic, often whilst on a waiting list for medical treatments such as injections. In addition to teaching these skills, it is aimed to start putting the patients back in control of their lives, increase self confidence and self-esteem, to provide the opportunity for those with chronic pain to meet others in a similar situation, and to address the issue of being believed, therefore improving communication with health professionals and treatment outcomes.

Resulting from this thesis, we have implemented a drop-in clinic to improve access to our pain service. This is to address the issue reported by my own patients and those with chronic pain in this thesis, that often it is so long between treatment and a follow up consultation back to the pain clinic that they feel left in limbo, particularly if the suggested treatment wasn't effective, and they end up feeling frustrated, angry, depressed, and let down again by health professionals. The drop-in clinic provides the opportunity for the patient to be listened to, these feelings to be explored, patient and family education and possible treatment alternatives discussed. The effectiveness of the drop-in clinic is currently being evaluated.

Resulting from my research and the narrative review in the thesis, future plans for the chronic pain service include the development of a pain network for GP's / Practice Nurses to provide them with appropriate education and support in dealing with the challenges of chronic pain patients.

## **Summary of practical implications**

This chapter has presented some implications for practice arising from this thesis, focussing on the areas of improving the consultation, pain management interventions and education and training both for health professionals and patients. This chapter has also discussed the contribution of the psychologist in pain management, and also how my own clinical work continues to evolve as a result of this thesis and my practical clinical experience.

## **Conclusions**

The participants' accounts reveal the complexity and the variety of their chronic pain experience. Despite their struggle to comprehend their pain they gave extensive descriptions of what it is like to cope with pain on a daily basis. The South Asian patients in this study reported similarly to White British patients except a few differences in cultural expectations. In this study it can be concluded that, ethnic differences were found in the cultural expectations surrounding learnt behaviour and age. Both South Asian and White British participants reported dissatisfaction with their consultations outside the pain clinic, and many felt that they were disbelieved and hence judged by family, friends, health professionals, the media and society as a whole, leading to complications in social relationships and issue of self-identity. This perceived outcome of the consultation also affected coping strategies and information seeking behaviour. Intrinsically woven within these categories was affect, which influenced the patients' life-world.

The narrative review brings together for the first time, a comprehensive review of the qualitative literature and has highlighted areas for future research. By positioning my research within the field, it can be concluded that aspects of my research are consistent with the literature. However it contributes to the research literature, by proposing a model developed from my research and

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the research literature and has explored the role of ethnicity in the experience of living with chronic pain, and has acknowledged the possible influence of acculturation. This thesis has highlighted possible areas for future research and suggested implications to improve practice in the key areas of communication, interventions and education of both health professionals and those living with chronic pain.

In conclusion, pain is both a medical problem and also an everyday experience for chronic pain patients. Attending to the biomedical aspects is important, but the emphasis on this can result in a failure to consider how the patients perceive and live with their chronic pain. The management of sensation over understanding emotion in traditional medical and psychological approaches has resulted in the lack of attention to the lived experience of chronic pain therefore neglecting broader issues of how culture and social factors influence pain. The UK is becoming more culturally diverse therefore there is a growing necessity to understand any influences of culture and ethnicity in pain management. This thesis explored patients' narratives with a view to uncovering differences between the pain experience for different demographic groups (e.g. age, gender and ethnicity). However, the data suggest that there are more similarities than differences between groups, and the individual narrative is needed in order to begin to understand how people live with chronic pain.

## **Appendices**

## Appendix 1

### Letter of ethical approval

## University Hospitals of Leicester

### DIRECTORATE OF RESEARCH AND DEVELOPMENT

NHS Trust

Director: Professor D Rowbotham  
 Assistant Director: John Hampton  
 Co-ordinator: N Patel  
 Direct Dial: 0116 258 8246  
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Leicester General Hospital  
 Gwendolen Road  
 Leicester  
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13 September 2004

Mrs Sue Peacock,

Dear Mrs Peacock,

ID: 07829

**The meanings of pain: an exploration of similarities and differences of the descriptions of pain between the South Asian and White population in Leicester, U.K.**

LREC Ref: 6873

We have now been notified by the Ethical Committee that the proposed amendment to this project listed below has been given ethical approval (please see the attached letter from the Ethical Committee).

Ethics Approval letter dated 3 September 2004,  
 Protocol Amendment Form dated 19 July 2004,  
 Letter of Invitation Version 3 dated July 2004,  
 Patient Information Sheet Version 3 dated July 2004,  
 Patient Consent Form Version 3 dated July 2004,  
 Protocol Version 2 dated July 2004.

I can therefore now re-confirm the full approval of this project on behalf of the University Hospitals of Leicester NHS Trust.

This approval means that you are fully authorised to proceed with the project, using all the resources which you have declared in your original notification form (and subsequent amendments).

The project continues to be covered by Trust Indemnity, except for those aspects already covered by external indemnity (e.g. ABPI in the case of most drug studies).

We will be requesting annual and final reports on the progress of this project, both on behalf of the Trust and on behalf of the Ethical Committee.

In the meantime, in order to keep our records up to date, could you please notify the Research Office if there are any significant changes to the start or end dates, protocol, funding or costs of the project.

I look forward to the opportunity of reading the published results of your study in due course.

Yours sincerely



Professor David Rowbotham  
 Director for Research & Development

Trust Headquarters, Glenfield Hospital, Groby Road, Leicester, LE3 9QP  
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 Chairman Mr Philip Hammersley CBE Chief Executive Dr Peter Reading



## Appendix 2

### Patient information sheet

The meanings of pain: an exploration of similarities and differences of the descriptions of pain between the South Asian and White population in Leicester.

**Principal Investigator:** Mrs Sue Peacock, Research Associate

**Supervising Clinicians:** Dr Paul Watson, Senior Lecturer in Pain Management & Rehabilitation,

**Contact Details:** Department of Anaesthesia & Pain Management, University of Leicester, Leicester General Hospital, Gwendolen Road, Leicester  
Telephone (0116) 2584611

#### **PATIENT INFORMATION SHEET**

We invite you to take part in this study looking at what pain means to you and how it affects your daily life. This information sheet explains the study but please do not hesitate to contact us for further information at any time. Thank you for taking the time to consider our request.

#### **What is the purpose of the study?**

The purpose of this study is to find out about what pain means to you and how it affects you, so we can begin to develop a service that is appropriate to your pain needs.

#### **What will be involved if I take part in the study?**

In addition to completing the questionnaires it would be very helpful if you could talk to the researcher, about pain and how it affects your life. The talk with the researcher will be conducted in English and will last about 40 minutes. It will be tape- recorded. The questionnaire and the tape recording will be treated with the same confidence as your medical records.

#### **Will information about the study be confidential?**

Yes. The questionnaires and the tape recording will be treated with the same degree of confidentiality as your medical records. Your personal details will be held separately from the research data and you will not be identified in any documents relating to this study.

#### **What if I am harmed by the study?**

Medical research is covered for mishaps in the same way, as for patients undergoing treatment in the NHS i.e. compensation is only available if negligence occurs.

#### **What happens if I do not wish to participate in this study or wish to withdraw from the study?**

If you do not wish to participate in this study or if you wish to withdraw from this study you may do so at any time without justifying your decision, and your future treatment will not be affected.

If you have any further questions or you wish further explanations please do not hesitate to ask. Thank you for taking the time to consider our request.

Version No 3/P-T-P/July 2004

### Appendix 3. Patient consent form

The meanings of pain: an exploration of similarities and differences of the descriptions of pain between the South Asian and White population in Leicester, U.K

**Principal Investigator:** Mrs Sue Peacock, Research Associate

**Supervising Clinicians:** Dr Paul Watson, Senior Lecturer Pain Management & Rehabilitation

**Contact Details:** Department of Anaesthesia & Pain Management, University of Leicester,  
Leicester General Hospital, Gwendolen Road, Leicester  
Telephone (0116) 2584611

#### PATIENT CONSENT FORM

**This form should be read in conjunction with the Patient Information Leaflet version 3/P-T-P/July 2004**

I agree to take part in the above study as described in the Patient Information Sheet.

I understand that I may withdraw from the study at any time without justifying my decision and without affecting my normal care and medical management.

I understand that members of the research team may wish to view relevant sections of my medical records, but that all the information will be treated as confidential.

I understand that the talk between the researchers and myself will be tape -recorded and I agree to this. I understand that I may have a copy of the tape recording if I wish.

I understand medical research is covered for mishaps in the same way as for patients undergoing treatment in the NHS i.e. compensation is only available if negligence occurs.

I have read the patient information leaflet on the above study and have had the opportunity to discuss the details with .....and ask any questions. The nature and the purpose of the tests to be undertaken have been explained to me and I understand what will be required if I take part in the study.

Signature of patient ..... Date.....  
(Name in BLOCK LETTERS) .....

I confirm I have explained the nature of the research, as detailed in the Patient Information Sheet, in terms, which in my judgement are suited to the understanding of the patient.

Signature of Investigator ..... Date.....  
(Name in BLOCK LETTERS) .....

Version No 3/P-T-P consent/July 2004

## Appendix 4

### Demographic details questionnaire

Age:

☐ Male

☐ Female

Please tick the box which you feel best describes your ethnic origin

☐ White

☐ White-British

☐ White – Irish

☐ Other White background

☐ Asian or Asian British – Indian

☐ Asian or Asian British – Pakistani

☐ Asian or Asian British- Bangladeshi

☐ Other Asian background

☐ Mixed – White and Asian

☐ Other ethnic background

☐ Not known

☐ Information refused

What is your religion?.....

How long have you lived in the UK?.....

Are you married?

☐ Yes

☐ No

Are you working at present?

☐ Yes

☐ No

What is your current job?.....

We are aware that income influences health, therefore we would be grateful if you would answer this question.

What is your family income for the year?

☐ below £7500

☐ £7500 - £9999

☐ £10,000 - £14,999

☐ £15,000 - £19,999

☐ £20,000 - £29,999

☐ £30,000 - £49,999

☐ £50,000 - £99,999

☐ Over £100,000

At what age did you leave school?

What is your highest level of educational achievement?

☐ GCSE or equivalent

☐ A levels or equivalent

☐ Degree

☐ Higher degree

How long have you been in pain?.....

Where is your pain?.....

## Appendix 5

### Acculturation questionnaire

1. Are you able to understand, speak, read or write the language. (please tick all that apply)

	understand	speak	read	write
English	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Urdu	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Punjabi	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(Bengali) Bengla	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sylheti	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Gujarati	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hindi	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Please specify	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

2. What is the main language you use at home (please tick all that apply)

	At home?	With friends?	With neighbours?	At work?
English	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Urdu	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Punjabi	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(Bengali) Bengla	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sylheti	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Gujarati	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hindi	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Please specify.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

3. Which of the following best describes your religious affiliation? (please tick only ONE box)

- |    |                        |                          |
|----|------------------------|--------------------------|
| 1. | <i>Not religious</i>   | <input type="checkbox"/> |
| 2. | Christian              | <input type="checkbox"/> |
| 3. | Muslim                 | <input type="checkbox"/> |
| 4. | Hindu                  | <input type="checkbox"/> |
| 5. | Sikh                   | <input type="checkbox"/> |
| 6. | Buddhist               | <input type="checkbox"/> |
| 7. | Other (please specify) | <input type="checkbox"/> |

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4. In the past year have you celebrated any traditional South Asian cultural festivals?

Yes ☐ No ☐

5. In what languages are the television/ videos/ films you usually watch and the radio stations you regularly listen to? (please only tick ONE box)

- |    |  |                          |
|----|--|--------------------------|
| 1. | Don't watch television/ videos/ films or listen to the radio | <input type="checkbox"/> |
| 2. | South Asian languages only                                   | <input type="checkbox"/> |
| 3. | Mostly South Asian languages                                 | <input type="checkbox"/> |
| 4. | South Asian and English languages equally                    | <input type="checkbox"/> |
| 5. | Mostly English language                                      | <input type="checkbox"/> |
| 6. | Only English language  | <input type="checkbox"/> |

6. In what languages are the newspapers you regularly read? (please tick only ONE box)

- |    |   |                          |
|----|---|--------------------------|
| 1. | Don't read newspapers                     | <input type="checkbox"/> |
| 2. | South Asian languages only                | <input type="checkbox"/> |
| 3. | Mostly South Asian languages              | <input type="checkbox"/> |
| 4. | South Asian and English languages equally | <input type="checkbox"/> |
| 5. | Mostly English language                   | <input type="checkbox"/> |
| 6. | Only English language                     | <input type="checkbox"/> |

7. What type of clothing do you usually wear at home? (please tick only ONE box)

- |    |  |                          |
|----|--|--------------------------|
| 1. | Traditional South Asian clothing         | <input type="checkbox"/> |
| 2. | Western style clothing                   | <input type="checkbox"/> |
| 3. | Western and South Asian clothing equally | <input type="checkbox"/> |

8. What type of clothing do you usually wear outside the home? (please tick only ONE box)

- |    |  |                          |
|----|--|--------------------------|
| 1. | Traditional South Asian clothing         | <input type="checkbox"/> |
| 2. | Western style clothing                   | <input type="checkbox"/> |
| 3. | Western and South Asian clothing equally | <input type="checkbox"/> |

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9. Thinking about where you are living at the moment, please indicate below who you live with (please tick as many boxes as apply)

- |    |   |                          |
|----|---|--------------------------|
| 1. | I live alone  | <input type="checkbox"/> |
| 2. | I live with my parents                                    | <input type="checkbox"/> |
| 3. | I live with my friends                                    | <input type="checkbox"/> |
| 4. | I live with my partner / spouse                           | <input type="checkbox"/> |
| 5. | I live with my children                                   | <input type="checkbox"/> |
| 6. | I live with my in –laws                                   | <input type="checkbox"/> |
| 7. | I live with my grandparents                               | <input type="checkbox"/> |
| 8. | I live with other members of my family (not listed above) | <input type="checkbox"/> |

## **Appendix 6**

### Semi structured interview questions

Can you recall when your pain first started? Tell me about it.....

Prompt: How long have you had your pain?

Where is your pain?

Is the pain always there but does the pain vary in intensity? How?

For how much of the day do you have pain?

Do you have any ideas/ thoughts as to what the cause of your pain is? Can you tell me about them?

Has anyone been able to tell you exactly why you have pain?

Who told you?

How did they tell you? How did they explain your condition?

Why do you think you are still in pain?

Do you think someday you will be 100% pain free?

What do you think medicine/ health services can do for you/ your pain?

Is your pain curable?

Can you remember what your pain was like when it first started, how has it changed?

Prompt: If so, can you explain the differences to me? Intensity, pain site, impact on life

What do you think caused this episode of pain?

If you are in pain, do you think it's your own fault? A bit of a tough question – how about – do you think you cause or worsen your pain. Perhaps I don't get the exact reasons for the question  
Why?

What do you do when you feel that your pain is getting worse?

How do you know it's getting worse?

What do you do when you feel that your pain is getting a little better?

How do you know it's getting better?

Today, how typical/ different is your pain to your usual pain?

Prompt – Why

Does it seem that you go to bed with pain and wake up with pain?

What makes you say that?

What impact, if any, has the pain had on your life?

Prompt- family, friends, daily functioning, hobbies, relationships, pleasurable events (birthdays, celebrations) or sad events

How has this changed over time?

How do you usually attempt to control your pain?

---

Prompt – medication, relaxation, go to bed, traditional medicines, diet, exercise

What do the different medications do to you?

Prompt – pain relief, make sleepy

Do they affect you in any way?

Prompt – look for side effects

Look at each coping strategy in turn and ask why they use that method and how does it help?

Prompt- relaxation, go to bed, traditional medicines, diet, exercise

Which of these do you have most belief in?

Prompt – why?

Is it better to use tablets, injections, acupuncture or complimentary therapies to control pain?

Prompt – look for beliefs about medication use and traditional remedies

Is it better to take medication for pain regularly or only when you get pain?

Prompt- look for beliefs about medication use and adverse effects, why take in this way? fear of addiction to tablets?

Does the medication affect your lifestyle in any way?

Prompt – makes sleepy so takes before bed, takes before journeys, hospital appts

How sympathetic are the general public towards people in pain?

Prompt – what about your experiences

How do the general public know someone is in pain?

Prompt- pain behaviour, stick etc

Do you think that if you had an aid that might indicate you have something wrong (like a walking stick or neck collar) that people would be more sympathetic or understanding about your pain?

Prompt – have you had any experience of this?

Do you think that pain is a temporary problem in your life or is it here to stay?

Why?

What do you think will happen to your pain in the future?

Prompt: why?

Do you find your pain confusing?

Why?

Do you know enough about your pain condition?

What information would you like?

What if anything eases your pain?

Do you have anyone to talk to about your pain?

Prompt- Who is this person?

How do they help? talk to you, do activities for you, rest, medication

What do they suggest you do to ease the pain?

Do you do this?

Have you read about your pain condition?



---

Prompt – what have you read? Where did you get this information? How did it make you feel during/ after you had read it? Did it change your views/ thoughts about your pain?

Do you think that chronic pain is portrayed in the media?

Prompt – TV, radio, -do you think it should be? Why? How would this help?

Are there any songs or pieces of music that you associated with chronic pain?

Prompt? why

How would you like your family to react to your pain?

Prompt – why? How could they help you more? what do they do that makes the pain worse?

What would you think are the pressures of living with someone in chronic pain?

Prompts- what would your response be?

Which do your family think it better to use tablets, injections, acupuncture or complimentary therapies, traditional remedies to control pain?

Prompt – look for beliefs about medication use and traditional remedies

Does your family think it is it better to take medication for pain regularly or only when you get pain?

Prompt- look for beliefs about medication use and adverse effects

How does your family know that you are in pain?

How does being in pain affect your role within your family?

Prompt- relationships, different roles within

Do you talk to your friends/ family about your pain?

Prompt: If yes – does this help?; If no, why not?

Does what your friends/family say about you pain influence it at all

Prompt- what you use to cure it, whether you show/ tell someone you are in pain or not

What do you talk about when meeting others with / without pain?

Prompt- why don't talk about chronic pain

How does being in pain affect your role within the community?

Prompt – job, social networks, feel can't take part? Standing on the sidelines?

What does the word pain mean to you?

Prompt- living life, functionality, experience of emotions, depression

Do you think you understanding of the word pain has been learnt from others, or thorough your own experience?

Do you think reactions to pain are learnt?

Prompt: who from- from parents, people with acute pain, others in chronic pain, people without pain

Do you think that we learn how to cope with pain (stop here and then ask how do we learn to cope?..... can we learn from others )from these people also?

Do you think that reactions, coping strategies and meanings are passed down through generations?

If you were (older, younger, male, female etc) do you think your experience of pain would be different?

---

Can you explain how it would be different? Why would it not be different?

Prompt: different members of the family, older, younger, male, female, different cultural groups

Apart from injury, why do you think that people get pain?

Why is it do you think that some people end up having chronic pain?

Why do you think you have chronic pain?

Prompt: -anything you have done? (not taken medication/ treatment, didn't look after self properly)

- do you think you are the cause of your chronic pain?

actions of others have caused me to have chronic pain?

actions of a greater being / force?

Do you blame yourself when you are in pain?

Prompt: Who and why?

Do you blame other people that you are in pain?

Prompt: Who and why?

Where do you think responsibility lies for the management of your pain?

Some people I have spoken to say that their pain is down to fate, what do you think about this comment?

What do you understand by the word fate?

Do you think that pain experience is associated with religious, spiritual or cultural beliefs?

Prompt- Which? Why? How?

In some religious beliefs, pain is sometimes associated with punishment, or that you have been chosen to bear pain what do you think about this?

Prompt - examples

How do you think being in pain can make you disabled?

Prompt- examples

Anything else you want to tell me about pain?

**Appendix 7**  
Participants' demographic details

	<b>New/ old pt</b>	<b>Gender</b>	<b>Age</b>	<b>Marital status</b>	<b>Ethnicity</b>	<b>Place of birth</b>	<b>Religion</b>	<b>Current Occupation</b>	<b>What is the cause of your pain?</b>
1	New	Male	29	Married	Asian -Indian	Blackburn, UK	Islam	Not working	Back and leg pain
2	New	Male	79	Married	White -British	UK	Church of England	Retired	Shoulder pain
3	New	Female	58	Married	White	UK	None	Not working	Longstanding back pain
4	New	Male	59	Married	British Asian - Indian	Bombay	None	Weaver	Back pain
5	New	Female	57	Married	White -British	Stockport,UK	None	Head of consultancy service	Spinal stenosis
6	Old	Female	72	Married	White- British	India	Roman Catholic	Housewife	Back and neck pain
7	Old	Female	56	Married	White -British	UK	None	Retired –ill health	Arthritis
8	Old	Male	42	Married	Indian	Keyna	Hindu	Not working	Arthritis
9	Old	Female	61	Married	White	Loughborough,UK	United Reform Church	Retired – ill health	Acute sciatica
10	Old	Female	79	Married	White-British	Leics, UK	Church of England	Retired	Osteoporosis
11	Old	Male	47	Single	White -British	Scotland	Church of Scotland	Unemployed	Following pancreatic surgery
12	Old	Male	63	Married	Asian -Indian	Kenya	Hindu	Not working	Accident at work- stomach, groin, left leg

	<b>New/ old pt</b>	<b>Gender</b>	<b>Age</b>	<b>Marital status</b>	<b>Ethnicity</b>	<b>Place of birth</b>	<b>Religion</b>	<b>Current Occupation</b>	<b>What is the cause of your pain?</b>
13	Old	Female	29	Single	Asian	Kenya	Jain	Not working	Doesn't know, pain all over (Fibromyalgia)
14	Old	Female	53	Married	British	U.K	None	Not working	Back pain
15	Old	Female	52	Married	British	U.K	None	Not working	Back pain
16	Old	Male	74	Married	British	U.K	Church of England	Retired	Diabetic neuropathy
17	Old	Female	56	Married	British	U.K	Church of England	Not working	Back pain
18	Old	Female	46	Married	White-British	Leicester, UK	Methodist	Accounts	Back pain
19	Old	Female	53	Partner	White	UK	Church of England	Hairdresser	Arthritis
20	Old	Male	51	Married	Asian -Indian	India	Sikh	Milling machine operator	Back pain
21	Old	Female	44	Divorced	Asian -Indian	India	Sikh	Nursing	Back and leg pain
22	Old	Female	53	Married	Asian -Indian	India	Hindu	Not working	Back pain
23	New	Male	56	Married	Asian- Indian	India	Sikh	Not working	Back pain
24	New	Male	38	Married	Asian	UK	Hindu	Not working	Back pain
25	Old	Female	63	Married	White British	UK	None	Not working	Back and hip pain
26	Old	Male	43	Married	Asian	UK	Hindu	Self employed	Back pain
27	Old	Male	62	Divorced	White British	UK	None	Not working	Shoulder pain/ CFS

	<b>New/ old pt</b>	<b>Gender</b>	<b>Age</b>	<b>Marital status</b>	<b>Ethnicity</b>	<b>Place of birth</b>	<b>Religion</b>	<b>Current Occupation</b>	<b>What is the cause of your pain?</b>
28	Old	Female	55	Married	White British	UK	Church of England	Children's nanny	Back pain
29	Old	Female	69	Married	White British	UK	Church of England	Retired	Back pain
30	Old	Female	56	Married	White British	UK	Church of England	Not working	Back pain
31	Old	Female	38	Married	White British	UK	Church of England	Not working	Neck/back pain
32	New	Female	52	Divorced	White British	UK	None	Manager	Back pain
33	Old	Female	46	Married	White British	UK	Church of England	Not working	Back/ leg pain
34	Old	Female	48	Divorced	White British	UK	Church of England	Not working	Back pain
35	New	Female	34	Single	Asian	UK	Hindu	Not working	Shoulder/back pain
36	Old	Female	66	Married	White British	UK	Church of England	Not working	Back /leg pain
37	Old	Female	37	Married	South Asian	UK	Muslim	Not working	Neck pain

## Appendix 8

### Literature Search Summary

Search: Lived Experience of chronic pain

March 2007

Database	Date Searched	Date Range	Results	Notes
Medline (Ovid)	22.3.07	1950-	13	medline chronic pain
Embase (Ovid)	27.03.07	1980-	0	
Cinahl (Dialog datastar)	22.3.07	1982-	40	cinahl chronic pain
PsycInfo (Ebsco)	27.03.07	1887-	24	psycinfo pain
Social Science Citation Index & Science citation index (ISI WOS)	27.03.07	1970-	20	wos pain
Assia - CSA	21.3.07	All 1987-	4	assia pain
Amed (Dialog datastar)	21.3.07	All 1985-	5	amed chronic pain
Campbell Collaboration (web)	21.3.07	ALL	0	
Cochrane Library Wiley	21.3.07	ALL	0	
CRER Centre for research in ethnic relations	22.3.07	All	12	<a href="http://www.warwick.ac.uk/fac/soc/CRER_RC/search.html">http://www.warwick.ac.uk/fac/soc/CRER_RC/search.html</a> crer.doc
National library for health specialist library for Ethnicity and Health	22.3.07		0	<a href="http://www.library.nhs.uk/ethnicity/">http://www.library.nhs.uk/ethnicity/</a>

**Search Strategies**  
**Cinahl**

No.	Search term	Results
1	(qualitative OR ethnon\$ OR phenomenol\$).TI,AB.	19081
2	(grounded ADJ theory OR grounded ADJ study OR grounded ADJ studies OR grounded ADJ research).TI,AB.	2680
3	(constant ADJ compar\$).TI,AB.	1086
4	(purpos\$ ADJ samp\$).TI,AB.	1218
5	(focus ADJ group).TI,AB.	4869
6	data NEAR saturat\$.TI,AB.	114
7	(participan\$ ADJ observ\$).TI,AB.	1371
8	(lived ADJ experience).TI,AB.	1490
9	(narrative ADJ analysis).TI,AB.	216
10	discours\$ NEAR analysis.TI,AB.	399
11	(life ADJ experience).TI,AB.	808
12	1 OR 2 OR 3 OR 4 OR 5 OR 6 OR 7 OR 8 OR 9 OR 10 OR 11	26769
13	chronic ADJ pain	8375
14	CHRONIC-PAIN#.DE. OR LOW-BACK-PAIN#.DE.	8197
15	qualitative ADJ studies	23387
16	QUALITATIVE-STUDIES#.DE.	27888
17	ethnographic ADJ research	2412
18	ETHNOGRAPHIC-RESEARCH#.DE.	2144
19	phenomenological ADJ research	4148
20	ethnonursing ADJ research	175
21	ETHNONURSING-RESEARCH#.DE.	109
22	grounded ADJ theory	7277
23	GROUNDED-THEORY#.DE.	4254
24	qualitative ADJ validity	303
25	QUALITATIVE-VALIDITY#.DE. OR PHENOMENOLOGICAL-RESEARCH#.DE.	4473
26	purposive ADJ sample	7747
27	(purposive ADJ sample#).DE.	0
28	purposive-sample#.DE.	7620
29	observational-method#.DE.	0
30	observational ADJ method	5152
31	OBSERVATIONAL-METHODS#.DE.	7729
32	content-analysis#.DE.	7856
33	thematic-analysis.DE.	9414
34	constant-comparative-method#.DE.	2695
35	field-studies.DE.	915
36	theoretical-sample.DE.	627
37	discourse-analysis.DE.	667
38	phenomenology	4404
39	PHENOMENOLOGY#.W..DE.	1270
40	ethnography	3331
41	ETHNOGRAPHY#.W..DE.	629

42	ethnological	1081
43	ETHNOLOGICAL-RESEARCH#.DE.	1039
44	15 OR 16 OR 17 OR 18 OR 19 OR 20 OR 21 OR 22 OR 23 OR 24 OR 25 OR 26 OR 28 OR 30 OR 31 OR 32 OR 33 OR 34 OR 35 OR 36 OR 37 OR 38 OR 39 OR 40 OR 41 OR 42 OR 43	49895
45	(12 OR 44) AND (13 OR 14)	781
46	(race ADJ factors).TI,AB.	3
47	RACE-FACTORS#.DE.	7638
48	whites.TI,AB.	9971
49	WHITES#.W..DE.	9217
50	caucasi\$.TI,AB.	1909
51	(south ADJ asians).TI,AB.	282
52	ASIANS#.W..DE. OR ETHNIC-GROUPS#.DE.	30448
53	ethnic\$.TI,AB.	8761
54	(indian OR pakistani OR bangladeshi).TI,AB.	2050
55	46 OR 47 OR 48 OR 49 OR 50 OR 51 OR 52 OR 53 OR 54	43600
56	45 AND 55	40

**Assia**

((chronic pain) or (DE="chronic pain")) and ((DE="asian people") or (asian\* or indian\* or pakistani\* or bangladeshi\* or punjabi\*) or (DE="white people") or (white people or caucasian\*) or (ethnic\* or ethnology))

**Amed**

Search history:

No.	Search term	Results
1	chronic ADJ pain	1241
2	PAIN#.W..DE.	13070
3	1 OR 2	13319
4	whites	877
5	ETHNIC-GROUPS#.DE. OR CULTURE#.W..DE.	2330
6	asians	238
7	asian	238
8	caucasian	230
9	indian OR pakistani	500
10	ethnicity OR ethnology	281
11	4 OR 5 OR 6 OR 7 OR 8 OR 9 OR 10	3807
12	3 AND 11	120
13	qualitative ADJ research	282
14	qualitative ADJ studies OR ethnographic OR phenomenological OR grounded ADJ theory	1053
15	content ADJ analysis OR thematic ADJ analysis OR theoretical ADJ sample OR focus ADJ groups OR purposive ADJ sampl\$	1150
16	lived ADJ experience	130
17	life ADJ experience	137
18	13 OR 14 OR 15 OR 16 OR 17	2447
19	12 AND 18	5



**Web of Science**

TS=((pain and (chronic or "long term" or back or arthritis) and (asian\* or white\* or caucasian\* or indian\* or pakistani\* or bangladeshi\* or punjabi\* or ethnic\*) and (qualitative or ethnograph\* or "phenomenological research" or "grounded theor\*" or purposive or "content analy\*" or "discourse analys\*" or "lived experienc\*" or "life experienc\*"))))

PscylInfo

as web of science

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## Appendix 9

### Examples of transcripts

I have included transcripts from the beginning and towards the end of the study to show my development as a qualitative researcher

#### TRANSCRIPT P1

I = INTERVIEWER

R = respondent

I: HOW LONG HAVE YOU HAD YOUR PAIN?

R: Eh, I had it since umm... year 2000 a yeah, I think it was November some sorry December 99 no January 2000 sorry...

I: JANUARY 2000?

R: ...yeah sorry January 2000

I: WHY DO YOU THINK YOU HAVE PAIN?

R: Well, I had a disc prolapse umm in my back umm and umm it was just, it was just a freak accident basically...

I: UMM

R: I think, I used to play football quite regularly and that and things like that. I remember having a crunch tackled us, but that was like 3, 4 years before the actual disc prolapse. I did feel a right niggles in the back and at that time but I just ignored it thinking that its one of those back pains you get, you know when you are going to tackle or something,

I: UMM, YEAH

R: umm and then like I said umm in January 2000 I was in the Shires car park (coughs) in Leicester, just getting out of the car and I felt a sharp pain while I was in the car. I thought oh god something is not right here and, err, that was it, I couldn't get out of the car, err, so the ambulance had to come in to the Shires car park and err, get me out of the car had to put a board to make me sleep in the car, (leans backwards as if to lie down) to put a board underneath me and err take me to the hospital, umm as far as I actually ... I remember when I went into the hospital they didn't even know what it was. And I knew that something seriously is wrong, I couldn't walk couldn't do anything, umm they were saying oh no get on your feet, it's better if you walk. You know (laughing)...it will help it, and I was thinking well I can't even move, was saying no, ok love, got my leg and I put it down and that was just it ...some serious pain, I was screaming, I was angry at them,

I: UMM

R: are you happy now?? Can you see? (laughs) and put my leg back up that was it, but and since then, to now umm I know a lot of sports people have had this back problem, a lot of people have had this back problem and they've recovered and umm I'm thinking why haven't I recovered? And I have put on a lot of weight since it happened, I have put on about 2 and a half, to three stone, its something but that might be a factor there because I'm not active anymore, I'm not, and when I do exert myself umm it gets very painful, very painful. Every morning I wake up I wake up with a stiff back and I have pain, err, it does get painful and err, I visit the osteopath quite often so that tells you that what my back is always clicking out of place, here or there, so that about it

I: SO WHAT DOES THE WORD PAIN MEAN TO YOU?

R: The word pain, means to me, umm, I suppose there is many meanings to it but, umm ... can't really put my finger on it, saying it really is this or that umm what it does mean is discomfort umm immobility and many other factors. You know it just, its horrid you, I, wouldn't bless, I mean you wouldn't curse it on anyone and you wouldn't want anyone to have the same pain umm, I think umm but like I said when, uhh, I can't really explain it really, but its not nice, lets put it that way, (laughing)

I: DO YOU THINK YOU WILL EVER BE FREE FROM PAIN?

R: Uhh I doubt, no I think its hereditary in our family umm our family my cousins and my first cousins umm we all are suffering from back pain and my brother suffers from back pain, my first cousins, 2 of them suffer from severe back pain so I think its something that's within the, our family uhh, my brother, poor guy, his back always coming up and makes all his joints ache, now his shoulders so I think he's just falling apart (laughs). But yea I think it's hereditary within our family I don't know if it's a gene problem or what

I: SO DO THINK ANYTHING CAN BE DONE TO MAKE YOU FREE FROM PAIN?

R: (sighs) I think its all in the hands of the gods, I think, err, I don't know, I don't know, if medication can go that far, I hope it can, you know, or some sort of pain management and like I said I do try and do exercise

I: THAT'S GOOD

R: I try my best, you know, to feel mobile because, like I said you know I haven't worked properly for 3 years, I just can't, cos, every time if I do start a job its unfair because I know I'll be taking a lot of time off work and urr, so I haven't really been working because of that. Umm hopefully we are in the process of starting our own business, so if that, as often at least, I've got my own business and I can take things uhh, you know, easily, you know my brother will be there, so every other brother always to fall back on I should be ok.

I: WHO IN YOUR FAMILY (IF ANYONE) HELPS YOU MANAGE YOUR PAIN?

R: Yes, I try my best to manage it myself, umm, umm, they are there to help me, but uhh (pause)

I: MANAGE BY YOURSELF?

R: like I said, I try to help myself but I like my mum usually, (laughs) but they will help me, like sometimes if it gets unbearable they will bring me the food to uhh where I am, you know to help my mum or you know whatever if it gets really excruciating, but umm, like I said I try my best to do everything myself so I don't really rely on anyone. When its really severe that's the only time, then I ask for help or otherwise its just pain, I do everything myself.

I: DO THEY GET ANNOYED WITH YOU BECAUSE OF YOUR PAIN?

R: No, they're actually quite concerned more than anything at all,

I: QUITE SUPPORTIVE?

R: yea, I know, they are very concerned about it really

I: DO YOUR FAMILY WORRY QUITE A LOT ABOUT YOUR PAIN?

R: yes, they do, my mums always umm, watching out, or anything if I say, you know I going out, with my friends she always says watch yourself, don't do this, don't be silly, don't do that, or you know, err, watch your back, she'll always telling me to watch it

I: HOW DO THEY HELP?

R: Yes they do, my mom always watch my back, if I say I haven't got a pain when I go out with my friends --- don't do this, don't do that, watch your back, she'll always----

I: HOW DOES BEING IN PAIN AFFECT YOUR ROLE WITHIN YOUR FAMILY?

R: Yes it has, yea it has definitely, uhh like I said people have recovered and its brilliant and it's a common thing back pain and I'm wondering why I haven't recovered cause I can't do half the things I used to do, uhh were you know I could do the shopping, I could run around, I could do this for the family, that I can't do half these things. I can't play cricket, try to play football, umm sooner I played it the pain was there, you know, I went to the doctor, but when I came here last time, last year. Umm, what I'll try to do is just manage the pain myself, thinking I'm not going to the hospital and I'm going to do something, and I do exercise and I do walk, I've been doing that umm, it has helped to a certain degree, but the pain is still there. And I did say you know, exercise, you should, should try and play sports, you know should try and play sport, and I have tried, I used love playing badminton, I used to love playing cricket, football, tennis and I used to play everything, and I can't do any of the them, you know and, umm, it is, you know, quite saddening for me, because I just love playing, and when I do exert myself in doing that, the pain just comes, comes back and I don't, I don't know what it is, but it just comes back, you know, really strong, next day I do really suffer. Only just recently, I'll give you an example, just 2 months, not even, no, about 2 months ago when I was sleeping in bed, I must have turned my body and upped my legs and at that, it clicked out of place and my body was here and my legs were here. You know, it was actually that if you looked in the mirror, when I was looking in the mirror and there were just like, well my body was like this till I went to the osteopath and she clicked it back into place until then I couldn't even walk properly.

I: SHE SOUNDS PRETTY GOOD

R: She is, she is fantastic, Lindsay is brilliant, umm, like I said I only go to her when I need to, but when I do go to her err, she does sort it out, sort of the thing.

I: HAVE YOU STILL GOT LOTS OF FRIENDS STILL, DESPITE YOUR PAIN, THAT YOU CAN TALK TO?

R: Oh yes my friends are still there, you know

I: THAT'S GOOD

R: Oh yes my friends are still there, you know, nothing's changed like that, my dad if not they are actually more supportive,

I: THAT'S GOOD

R: My friends, are very, I mean, I'll still tag along if they are going to do something less active, but, I won't do it, I'll only do to a certain, I just say like, but they are really good, and I always go along wherever. I won't try and not go, beats sitting at home, not getting anywhere, and not feeling sorry for yourself

I: THAT'S NO FUN IS IT?

R: Exactly, exactly that's true

I: SO HOW DOES YOUR WIDER COMMUNITY SEE PEOPLE IN PAIN, DOES IT AFFECT YOUR ROLE IN THE COMMUNITY?

R: Err, within the community, well, like I said, we used to have these err, umm, organising associations that I used to be part of. Umm, I used, used to organise the activity for the kids within the community, used to take them on excursions, you know

I: SOUNDS GOOD

R: Yeah, and trips and you know, to football tournaments and I can't even do that. I used to do that a lot, and I still do go but I don't have the same role, I don't have the role of the organiser or that anymore, I just I'm there in the background. Well it is quite difficult, within the community as well, they are helpful, and when they know you have a pain they are quite helpful, and quite understanding.

I: THAT'S GOOD ISN'T IT,

R: Yeah

I: DO YOU THINK PEOPLE IN PAIN WHO HAVE THEIR LEG IN PLASTER OR WALK WITH CRUTCHES OR WHATEVER YOU CAN SORT OF SEE THAT THEY HAVE SOME KIND OF INJURY, ARE PEOPLE MORE SUPPORTIVE TO THOSE PEOPLE? AS ONE OF THE PROBLEMS WITH PAIN, IS THAT YOU CAN'T REALLY SEE IT.

R: No, I mean exactly, what's quite evident in front of your eyes and you know that, they're in pain. When you know like they don't have a plaster or anything like that, so you don't really know what pain they've got, umm people who do know I have got pain can tell from how I used to walk to how I walk now and that I used to be quite upright and now can't walk and sometimes it gives me a pain just walking

I: YES

R: umm my cousin is actually a back specialist in South Africa he came, to England, to visit umm and he looked at me with all the postures and all that and said straight looking at me and I said I'm not walking anymore away (laughing) they can see your discomfort, I've been moving around in the chair like I have been doing actually so much or uhh they'll know that when you know you pick up ohh something you'll make this facial expression then they know that you are in pain, and they do ask you are you if you're alright or so, I tend not to say all, its like having to give my life history, so I just don't say anything.

I: SO DO YOU HAVE GOOD DAYS AND BAD DAYS - I KNOW THAT YOU HAVE PAIN ALL THE TIME - BUT ARE SOME DAYS BETTER THAN OTHERS?

R: Oh yeah, I mean, like, some days, it just won't be there I think ok, alright this is good and I'm thinking oh right well I can do sometime now then I feel really good then I think yeah ok then with day two still not there and then day three I think right I think its finally I've got it now. I think I can do some exercise and you know as soon as I do something (laughs) hello it comes back out again, yeah, yeah, just when I think its gone its still there, still hiding, waiting to come out.

I: DO YOU AND YOUR FAMILY NOTICE THAT YOU CAN DO MORE ON SOME DAYS AND LESS ON OTHER DAYS AND DO THEY MAKE ANY COMMENTS ABOUT THAT?

R: Yes, yes they do, I mean umm, while theirs is quite different because when they know I'm feeling better I like to do things and then I feel right I can do some more, a little bit more I hope, come on you know

I: PACE YOURSELF?

R: Pace yourself cos that then I feel really good and I think ok now I can do things so, I'll be doing this and doing that and then I know its, the pains going to come back but I think I've just learned to ignore it, I've learnt to umm, err learned to realise it is going to come any moment so might as well make the most of the time that it isn't there (laughs) before it does come back, you know (laughs)

I: HOW DO YOU THINK PEOPLE REACT TO SEEING YOU DO LOTS OF CHORES WHEN THEY KNOW YOU HAVE PAIN?

R: Yes they do I mean, while theirs is quite different because when they know I'm feeling better, I like to do things enough you know I can do something now, I'll be oh come on you know pace yourself, because that's enough – you're really good acting. OK I can do things I'll be doing this or doing that, I mean I know that's its gonna the pain is going to come back but I think I've just learnt to ignore it, and I've learnt to, learnt to realise that he's gonna come anymore, so might as well make most of the time when it's not there. (Laughing) ... Before it does come back you know.

I: DO YOU THINK PAIN MEANS DIFFERENT THINGS TO DIFFERENT GROUPS OF PEOPLE, BETWEEN MALE AND FEMALE? CULTURAL GROUPS? OLDER, YOUNGER PEOPLE?

R: I think, umm, pain, is specifically is pain, can be in any form mentally or physically. uhh I personally believe, I've seen people who are in pain and I believe certain communities and cultures are more tolerant to pain than other people, I mean there are a lot of Asian girls, when they have pain, some how they just give up, and I think ok I've got this pain oh ha complaining every time, its not really going to get anywhere, I mean I its amazing I see that, a lot of the thing is part of our Asian culture the way we live, our lifestyle umm but then I see a lot of white folk during pain but they'll still be out shopping in their buggies. I really respect that and I think to myself its amazing, you know, that they can actually do that. Uhh a lot of elderly Asian women once they are in pain they feel that's the end, I can't do anything now so I'm just gonna sit at home umm, umm. It is a shame. I think different cultures and different races err, take err, pain and understand pain differently I think, and some people give up quite quickly when pain is there and umm, some people don't umm however I think, umm, within the Asian community because umm the kids are still around their parents, so they feel that, umm, they still have that support. However you know, but within the white community umm, obviously when the kids move out and leave them, or they have to go in homes, or they have to fend or they have to do things for themselves. While we're still always around our family, we'll always doing things for our mums and our dads, err, because we either live (laughs) nearby or we are living with them. Its one or the other, so I think that's another reason why err, they tend to take a backseat as they feel oh well, my kids are here, they'll do it for me, and that's how it is.

I: THANK YOU VERY MUCH.

R: That's alright.

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**TRANSCRIPT P30**

I = INTERVIEWER

R = Respondent

I: ... SO CAN YOU RECALL WHEN YOUR PAIN FIRST STARTED, AND TELL ME SOMETHING ABOUT IT?

R: Gosh, that's a difficult question. Erm, erm, can I ask you a question?

I: YES.

R: Am I thinking like first time ever?

I: YES.

R: Oh right.

I: THE JOURNEY TO WHERE YOU ARE NOW.

R: Right. Erm. It's quite a difficult thing because with the back, it was odd things that happened, a long, long time ago.

I: YES.

R: I started having odd er, odd, odd things, erm, and then it would clear up. Erm, and then erm I remember, oh God, and this is, oh God I'm trying to think – this must be about, 1, 2, 3, it could be about 16 years ago, I'm thinking that's the first time I had odd bits with my back, particularly gardening I found very difficult, bending down like that, and I did actually go and see a chiropractor, and I spent quite a bit of money there, that actually had no effect, and then I eventually went to the doctor, who gave me some tablets, and er – is it OK if I go on like this?

I: YES.

R: And I remember then, it cleared up, and that was, and then that was OK, and I think that must have been almost like for a couple of years. Then I moved, I remember moving house and I suppose that must have been quite stressful, and then I remember one day, just bending down and picking a towel up off the floor, and a pain that I just, was just so horrendous, I felt sick and faint, all in one go, which was just really awful. Shooting, shooting. I remember then being laid up for a while and then that time just on and off cleared up. And then the big episode, that's really interesting, I can't remember how it just suddenly started happening, and then it was just absolutely horrendous, a constant, awful pain all the time, that no pain killers or anything would erm, do, and then I was like that for about nine months before, then, I had the first operation. Erm, and in between that I had erm, did I have Physio then? I'm not sure if I did, erm, but then I, I remember it was like? for that nine months, it was absolutely awful, erm, trying to rest and just taking painkillers and it not helping, and everything, and then I did have the surgery, and then, and then I've had a great long period of time where its been great. Erm, until last year, when it flared up again, erm, and starting to settle down now. I don't know, is that any sufficient for you?

I: YES, THAT'S FINE, THAT'S FINE. SO WHAT DO YOU THINK CAUSED YOUR FLARE-UP LAST YEAR?

R: What do I think? Oh God, that's another difficult question, because I just sort of turned and it just went, and it was this horrible feeling when it, its not like just 'oh dear, whoops I've like just had a little pull there'. I just find it very difficult to describe, the feeling, that its like 'oh my God' you know, it hasn't just gone, its something serious, and it kind of takes me back to where I was, knowing that its not going to be a little thing, but its going to clear up, and then it's a horrible, horrible pain, erm, a sort of a very, not just erm, sort of stabbing or acute pain,

its kind of, what I would say, a kind of all-consuming pain, a drawing, that kind of just absolutely, well for me, how it kind of just pulls me down, and that's kind of what happened last year, it went on for ages, but, you know, its obviously, obviously clearing a bit now.

I: SO DO YOU HAVE ANY IDEAS OR THOUGHTS TO WHAT THE CAUSE OF YOUR PAIN IS?

R: Erm, well I suppose only in as much as what I've been told by the, you know, the experts, is it the disc?

I: RIGHT.

R: And erm, but erm, you know, it was like the disc's protruding between the vertebrae and, and that, that's what, you know, was causing the problem.

I: SO, WHEN YOU SAW THEM, DID THEY EXPLAIN YOUR CONDITION QUITE WELL SO YOU UNDERSTOOD IT?

R: Funny enough, no. (Laughs) I probably should have asked more questions, because even now, I suppose I've really kind of don't have a really good understanding. I think I perhaps should have more. When people say to me 'is it difficult?' you know, and I – well I'm not totally sure. So, probably not, no.

I: NO. SO IN YOUR OPINION, WHAT DO YOU THINK THAT THE MEDICINE OR THE HEALTH SERVICES COULD DO FOR YOUR PAIN?

R: Do more?

I: YES. WELL, DO YOU THINK THEY CAN DO MORE FOR YOU?

R: Yes, I, I think they could, because I think if you understood the condition more, erm, it might help you to think about your lifestyle, and, and what you could do, other than just taking tablets to try and cure the pain, which actually doesn't do it, I think for, for chronic and long-term pain and things like that, I don't actually think they, they're always a good thing. They might be, at certain times you might need that, but there are probably other things that you can do.

I: SO, ARE THERE OTHER THINGS THAT YOU DO?

R: Erm, I have found, 'cause I think you can get so pulled down with it, and the pain, and I think sometimes you do need distraction, can help you get it in perspective, and perhaps do things to help try and relax you, because I am aware, that when I get tense my pain gets worse, and I do think that sometimes, if you are feeling awful and everything, you get so bogged down in it, and sometimes you perhaps force yourself to go out or force yourself to do something, because once your mind is taken off of it, it does help. That's one of the things that I have really, really noticed, particularly more so this time than I think before. I have to say, when I was really bad before, that did not work – it was just so awful all the time, that that didn't work, but this time I think it has kind of helped a bit more.

I: GOOD. SO IS THERE ANYTHING YOU DO THAT YOU, THAT CAUSES YOUR PAIN TO BE WORSE?

R: Erm,

I: YOU TOLD ME THAT STRESS MAKES YOU WORSE.

R: Well, yeah, I think all my stress and that - I don't know, I don't know whether there is really, because sometimes I feel so awful, and I think well, you know, I might as well just do some housework, or do something, 'cause it actually doesn't make it any worse, worse even, that's not the right word, but that's the only thing I can think of, 'cause sometimes you think, you



think, well I might as well get on, and after you've done it, its actually, well like, you don't feel any worse off, so I might as well have done, you know, because you just get so fed up with it, so it is quite a difficult one to answer. You know, if there is anything I could do, I think sometimes you do have to get on, but it is very, very frustrating.

I: SO, APART FROM THE FRUSTRATION, WHAT IMPACT HAS IT HAD ON YOUR LIFE, THE PAIN?

R: Erm, I, I would – a lot really. It's very miserable, and it is quite, I say depressing, but I wouldn't say that I have been depressed with it, but very close to, and makes you very down, because when it is constantly, constantly bad, you think, and you feel that you are trying to do stuff to help yourself and there is no relief, and the painkillers aren't giving you any relief, you do wonder where it's all going. And I think the other thing I find too, and I know it's difficult, is I think people don't understand how much pain you're in, and you don't like to go on, because its so boring.

I: ARE YOU TALKING ABOUT FRIENDS AND FAMILY?

R: Yeah, and work colleagues and that, because people will ask you, and in the end, you know, I think, I don't know if you want to talk about it, because it then kind of reminds you, do you know what I mean? Its nice that people ask you, but you actually don't want to be because, particularly this time, I kind of felt like there's Pam, bad back pain, people are seeing you like that, and you actually, for God's sake, I found I was so bored with it, its like, for God's sake, just go and let me move on, because I am just so fed up with it. But you know, you kind of can't help it, because it's such a big thing on your mind.

I: YES. SO DOES IT STOP YOU DOING ANYTHING?

R: Yes, I think it does, yeah, definitely.

I: WHAT KIND OF THINGS DOES IT STOP YOU DOING?

R: Erm, er, well, I think going out and doing lots of, because actually because physically I can't stand for that length of time, very long, so that means, say you want to go out, even say to the pub with people, you know, 'cause its not always acceptable to be able to sit down.

I: NO, NO, THAT'S TRUE.

R: You stand to be kind of social. So that restricts me. Erm, and when you really are in awful pain, not feeling that well, sometimes, you don't want to go out, or you don't want to go that far from home, in case you feel so awful, you do need to come back, so I think it does, it, well it definitely does restrict you. I think it makes life for people around you so boring (laughs) and, and, and it just makes you so miserable, especially if you are struggling to get to work all the time, like I was, 'cause I really didn't want to get into it, but then it was like I was collapsing at the weekend and in my own time. I'd try and build myself up, either for the evening or for the next day, and then come the weekend, you know, I'd fall apart. It was a struggle to keep going.

I: IS WORK QUITE IMPORTANT TO YOU?

R: Yes, absolutely, yeah, absolutely, yeah, because I think if I don't, if I don't keep my mind active, I'd, I'd go to pieces, and I think it, it really would take over. So it's very important for me to try and keep back and through and doing that.

I: SO, WE'VE TALKED A LITTLE BIT ABOUT MEDICATION, YOU SAYING, YOU KNOW, IT DOESN'T ALWAYS HELP. IS THERE ANY OTHER SIDE EFFECTS THAT YOU HAVE HAD WITH MEDICATION?

R: Yes. I mean, I tell you, that's interesting, because that question you asked about experts – one of the things I think they could talk to you about a lot more, is medication. Because I

think the doctors have certain pain killers that they prescribe for certain things, they don't tell you enough about the side effects or what they are going to do, and actually may be totally not right for you, and there is a huge number out there, that could be tried, and I think in some ways it's a process of elimination – you try some that are absolutely awful and then you start going back and then you try another one, but it, its such a long task, and I think they shouldn't prescribe the first major one to you. I mean, its definitely constipated, one of er, one of the ones I was on that was absolutely awful. Another one completely makes your head very fuzzy, so you're kind of not, you kind of feel a bit out of yourself in a way. I suppose it must be just like being on a high – you're kind of there but you're not there, a bit spaced out. And I don't think that's good either. You know, I don't want pain killers that are going to do that – I actually want pain killers that would help a) perhaps relax you and help a bit with the pain, but not send your head out, and also the others, you know, er, er, er things in your body, particularly like being constipated, is awful, and that can also bring other problems, particularly if it's in an area near where your pain is, anyway.

I: YEAH, YEAH, YEAH. SO WHAT ARE YOUR VIEWS ON SORT OF COMPLEMENTARY THERAPIES?

R: I am very, very pro them, I and I really erm, I think they're the only thing that have actually really got me through this, although I think I did need the first surgery, but I think erm, if it hadn't been for complementary therapies like physiotherapy and swimming, and doing those sort of things for myself, I, I don't know whether I'd even be where I am today, and erm, and I'm really pro them and I would encourage people to do them even before say, perhaps had to er, consider surgery and acupuncture, er, perhaps medication, erm, you know, all those kind of things definitely, definitely I would be very, very pro them.

I: SO DO YOU HAVE MORE BELIEF IN THOSE WILL WORK FOR YOU THAN MEDICATION AND SURGERY, AND ALL THOSE KIND OF THINGS?

R: I definitely think with, like, medication, pain killers, perhaps, it may be that people do need surgery, and then I think um, if they do need that, then I think they will need some other alternatives to help them get better, to a complete recovery, which I think the surgery is just one small part for your body, and then I think there is other things you can do to help yourself. So I would say, I think there is definitely a place for surgery, but I am not sure it is always the answer, and that is particularly what I have been trying to avoid this second time round, and really struggling to fight that. Erm, whether I, myself I don't know, I suppose only the future will tell, but at the moment I feel I have achieved that, but I definitely think people erm, should do that, and I think its bad really, 'cause I do know it's cost me a lot, a lot of money, painful alternative treatments, and also if you think about paying a subscription to a health club, you can go somewhere decent to swim and that kind of thing, and that's an awful lot of money, and obviously people aren't in a position to do that, but I think I've sacrificed a lot, because that was so important to me.

I: SO HOW SYMPATHETIC DO YOU THINK THE GENERAL PUBLIC ARE TOWARDS PEOPLE IN PAIN?

R: Ahh. I would, I think generally they're not, and I, one of the main things I think for back pain is, because over the years, people have always used that as an excuse – er, if anything's wrong they will go for back pain when they haven't got it, and it really, really winds me up, because I think people have no, really have no understanding. I mean, some people might get an odd twinge in their back and they might say 'oh, I've got terrible back pain' and I think, you know, unless you've really, really been in awful pain, in any area of your body, you actually don't know what its like, and I get really angry at people who are flippant about it. But I suppose in some ways that's society, because people will often say they are in pain. I think people do have different levels of pain, but I generally think that people aren't that sympathetic, Because sometimes, and I know, that I can be in terrible pain, but actually not look it. They tell me I look great.

I: DO YOU THINK THAT'S AN ISSUE, THAT YOU CAN'T ACTUALLY SEE PAIN, SO PEOPLE DON'T UNDERSTAND IT?

R: Yes, yeah I do, and it is so difficult to actually quantify, because, what, and, and I do believe that some people have, you know, um, can endure different levels of pain, so there is an element of that in it, but um, yeah, I think because you can't see it, I mean sometimes I think you can see it in people's faces, and I think now, because I know that my face changes when I am in pain, it doesn't hide it, and I think if you are a person that really is in true pain, your face does show it, and I think now, perhaps because of what I've been through, that if I do meet people, I am actually able to see that they don't look well and can see it, but sometimes people can't pick that up.

I: NO. SO APART FROM IN THEIR FACES, HOW, HOW ELSE DO YOU THINK THE GENERAL PUBLIC WOULD KNOW SOMEBODY WAS IN PAIN?

R: From, um, from the way that they would, their posture, definitely, erm, and the way they moved, and that kind of thing.

I: SO DO YOU THINK, IF SOMEONE HAD A WALKING STICK OR NECK COLLAR OR SOMETHING LIKE THAT, THAT PEOPLE WOULD BE FAR MORE UNDERSTANDING AND SYMPATHETIC ABOUT PAIN?

R: I suppose to an extent, yes, I hadn't thought of it like that, actually, you know, if you are walking with an aid, does that mean that you're, you know, you're in more pain than a person who's walking without one? Um, I hadn't thought about it like that, 'cause I suppose, if you, you've got something like that, you look at someone, you think, oh, you know, they're unwell. And even for myself, I don't know whether I consciously think, 'oh, are they in a lot of pain?' You know, I hate pain so much, ...  
(she is laughing and talking, so cannot catch what she says here).

I: TRUE, TRUE.

R: But yes, perhaps there is an element of that, and I think, you know, you can't see it, so it is difficult for people to understand it, yeah.

I: SO WHAT DO YOU THINK WILL HAPPEN TO YOUR PAIN IN THE FUTURE?

R: I hope it will go away and settle down, and I will end up going back to where I was, and I was well and without it, and can just get on with life and not think about it. That's what I would like, and I really hope. Whether that's going to happen I don't know, I really don't know, and I find that a bit scary and a bit worrying, because the memory of it is so horrible, that when you get into that and the memory comes back, and then I can find myself slipping down into the dark hole and getting a bit down, because it brings back the memory of how awful and it seems to go on for such long periods of time, takes a long while to get to any semblance to sort of being OK. I know its not going to be as um, you know, a week thing; I know we're talking months, and that's what I hate.

I: SOME PEOPLE HAVE SAID TO ME, IT'S THE UNPREDICTABILITY OF PAIN, THAT YOU DON'T KNOW WHAT YOU ARE GOING TO BE LIKE FROM SOMETIMES DAY-TO-DAY, EVEN HOUR-TO-HOUR.

R: Yeah, that's quite interesting, yeah, definitely um, yes. That's quite true, I think er I've become more aware of that this time and I don't know why. Before, it was so constant the whole time and so awful I didn't have that, but this time I have noticed that one day I can feel absolutely OK and go to bed and have a great night's sleep, and I can get up in the morning and feel absolutely terrible. And also other times as well, I've felt absolutely terrible and I've dragged myself into work, and thinking 'I don't know how I'm going to manage it', and come a few hours later I actually feel better, and I'm really pleased that I dragged myself in.

I: SO, BECAUSE ITS UNPREDICTABLE, IS IT DIFFICULT TO PLAN SORT OF YOU'RE LIFE IN GENERAL, SOCIAL THINGS?

R: Yeah, yeah, definitely, that has been very difficult over the last 12 months, to try to make any plans, because you think, I am always worried, as actually when you have made a commitment, especially if you're paying out money to organise things, um, you know, um 'cause certain arrangements are OK I think, and you know, you can perhaps go along and people will understand, but that has actually, has happened to me this time because I have said to friends when they have asked for things, um, the way I am at the moment, I would love to come and that would be great but, I have to say to you, I may have to cancel at the last minute.

I: AND ARE YOUR FRIENDS QUITE UNDERSTANDING ABOUT THAT?

R: Yes, they have been, yeah, yeah, but that is the first time now I have actually had to warn, over the last couple of months ago, I had to do that, and it was, I found it very difficult to make um, you know, plans.

I: YEAH. SO DO YOU HAVE ANYONE THAT YOU CAN TALK TO ABOUT YOUR PAIN?

R: I, I probably would, in, in pieces, yes, but probably not in depth, no. I think its something that I do really keep to myself.

I: AND IS THAT HOW YOU PREFER IT, TO KEEP IT TO YOURSELF AND ... ?

R: I don't know whether its what I prefer; I think particularly for immediate family and things, I don't actually want to burden people with actually how awful I'm feeling, because then I think they can worry.

I: YEAH.

R: And also then perhaps extended out from that, people you kind of don't want to burden them with it, and sometimes you are so bored with it anyway, you don't want to keep talking about it. It, it can be quite lonely - I have found that this time, its quite a lonely thing.

I: SO DO YOU THINK IT WOULD BE EASIER TO TALK TO PEOPLE OR OTHER PEOPLE IN CHRONIC PAIN, RATHER THAN PEOPLE WITHOUT PAIN?

R: That's quite an interesting question because I, I hadn't really done that, with er, talked to people about it, so whether um, I, I don't know whether it ... it would help or not. I think people with different types of pain ...

I: I'M ONLY ASKING THAT BECAUSE PEOPLE I HAVE SPOKEN TO IN CHRONIC PAIN CLINICS, SAY IT IS EASIER TO TALK TO PEOPLE WHO ARE IN PAIN, BECAUSE THEY UNDERSTAND, WHEREAS THEIR FAMILIES OR WHOEVER HAVEN'T GOT THE PAIN, SO THEY DON'T HAVE A CLUE WHAT THEY ARE GOING THROUGH ...

R: Yeah – yeah, I don't know whether that would be good or not, I suppose because I have never had that, um, I must admit, this time I have um, got to know someone at work who has got an awful back pain, and I, I just wanted to give out all the things to try, 'cause they had done so little to try and help themselves, well I felt they had, and I, I suddenly, you know, wanted to give them this great big 'have you tried X, Y, Z?' I think if I was in a group like that and there were people sitting around that hadn't done or tried things that I would probably get frustrated and say 'why didn't you try, why didn't you try that?' 'cause that's the kind of person that I am, so they probably wouldn't like it. 'Cause I mean, I do try to help myself with it. So I'm not sure (laughing).

I: HAVE YOU READ ANYTHING ABOUT YOUR PAIN CONDITION?

R: No, very, very limited, I have to say, very limited.

I: THE BITS THAT YOU HAVE READ, WHERE DID YOU GET THEM FROM? WAS IT MAGAZINES OR LEAFLETS OR ... ?

R: Erm, yeah, I've got a book about, well back care, um, I suppose that has exercises in erm, that I got, that I looked at, but erm, God, I haven't read a massive amount – I'd probably say bits and bobs, yeah,

I: BUT THE INFORMATION THAT YOU DID READ – WAS IT USEFUL, OR DID IT CHANGE YOUR MIND ABOUT THINGS?

R: It was kind of what I knew, really. Yeah, I don't know whether it was that helpful, but I think probably because the things that I probably read were like what er, physiotherapists and that and people had kind of already told me.

I: YES, SEE WHAT YOU ARE SAYING. UM – DO YOU THINK THAT CHRONIC PAIN IS PORTRAYED IN THE MEDIA AT ALL?

R: Is it portrayed?

I: YEP.

R: Erm – I suppose it well, you do see certain, I mean, or, do you mean like in a film or just articles, and ...?

I: GENERALLY.

R: Generally. I suppose it is a bit. I mean you often see erm, things about chronic pain, perhaps in the paper, erm, and they might go through different types of thing, and then you get to the back, and, and often I, you know, I read the stuff and I, I often think its quite bland, what they are telling you, and I'm not sure, probably could be more helpful to people, 'cause I think what I've ever read has never kind of told me anything I don't know.

I: NO. SO WHAT ABOUT TELLY OR RADIO – DO YOU THIK ITS EVER ON THERE?

R: I um, aah yeah, oh, I'm just trying to think. It was on the, I'm sure, it was on the radio recently actually, on Radio 2, 'cause I remember driving along with Jeremy Vine, and there was a bit on, and I wanted to stop the car and ring in, 'cause I had so much to say. (Laughs). And I can't remember what it was, how, what the whole programme was about, but I remember it was, and whether it was about that pain, it, there was actually a discussion about it. As for the tv, I can't really think that I have ever really seen anything.

I: SO DO YOU THINK, IF A CHARACTER IN ONE OF THE SOAPS, FOR EXAMPLE, HAD CHRONIC PAIN, HOW DO, HOW DO YOU THINK THAT WOULD IMPROVE SOCIETY?

R: I think it could be quite good, actually, especially if the person did some very sensible things, like um, trying alternative treatment, and were actually um, perhaps seeing the medical profession and having some input, but they were actually trying to do things themselves, and looking for things.

I: YEAH.

R: Um, I think that would be excellent, because I think it may open up people's eyes. And also, it would be interesting to see how the people operate around them you know, and you know, adapt and cope with that pain, and, and which they are all trying to work and that kind of thing. So I think it would probably be quite useful. It would raise an issue that, um, you know, and that's not just back pain but I think any sort of pain.

I: BUT DO YOU THINK THERE WOULD BE A DANGER THAT IT WOULD TAKE ON SORT OF THE STEREOTYPICAL VIEW FROM SOCIETY, OF SORT OF LES BATTERSBY-TYPE PEOPLE, SKIVING, RATHER THAN DOING ...

R: That would worry me, that would worry me, yes, particularly the way our soaps are, erm, because I think erm, that, that's the sort of line that they would take, erm, but if they could

open it up to being something more than that, I think it could be useful, because I'm sure, actually it's a way of helping a lot of people, and it could be a good opportunity to do that.

I: OK. SO HOW WOULD YOU LIKE YOUR FAMILY TO REACT TO YOUR PAIN? IS THERE ANYTHING THAT THEY COULD DO THAT WOULD HELP YOU MORE, OR THINGS THAT THEY DO THAT ANNOY YOU, AND MAKE YOUR PAIN WORSE, OR ...

R: I think I cry very, very rarely, but I think the odd times that I did, it would be better if people could deal with that in a way of not saying 'oh don't cry, don't cry', you know, its awful, because actually to cry can relieve a lot of tension.

I: VERY MUCH SO, YEAH.

R: And this time, it has made me want to do that, and I think if they could behave in a way that, yeah, OK, well, you know, 'let her do that', and just perhaps be with her rather than say, 'don't', because they don't like you crying, do you know what I mean?

I: YEAH I DO, YEAH.

R: Because its all like, its all helpless and everything, and I think to allow you to do that, in a comfy environment, would be good. I'm not saying I would want them to be, talk about it more, or whatever ...

I: NO, JUST BE SUPPORTIVE WHILE YOU CRY ...

R: Yeah, but I think that would be one thing, is to allow you to cry or be ?? odd times – not all the time, because I think self-pity is an awful thing, but I do think an odd time that would help me.

I: SO, HAS BEING IN PAIN AFFECTED YOUR ROLE IN THE FAMILY AT ALL?

R: Yeah.

I: HOW WOULD YOU SAY IT HAS CHANGED, OR AFFECTED IT?

R: Erm, in some ways vulnerability I think really. You, you, you know, there's an element of sort of insecurity and uncertainty, erm, there, but um, and kind of makes things a bit, yeah – an uncertainty, sort of a slightly unstableness, that, that I think could probably be a worry.

I: YEAH, OK. SO, WHAT DOES THE WORD 'PAIN' MEAN TO YOU?

R: Horrible, horrible, horrible, horrible, it's a horrible word. Erm, I suppose a bit of fear as well. Definitely fear ...

I: AND WHAT ARE YOU FEARFUL OF?

R: ... and vulnerability, erm, dependency, it means to me. And erm, and that is something that I hate, that you could end up being dependent erm, on people, and not in control of your life, and it could affect your life and the standard of living, and everything around you, so it, er, lots of horrible, negative things, oh, everything negative, nothing good.

I: YEAH, OK. SO DO YOU THINK THAT YOUR UNDERSTANDING OF THE WORD 'PAIN' IS LEARNT FROM OTHER PEOPLE, OR IS IT SOMETHING THAT YOU CAN ONLY LEARN FROM YOUR OWN EXPERIENCE?

R: I think, from my experience of it, has helped me under ..., to be a bit more understanding of other people's. I don't think I had an understanding of pain before, and its what I've learnt through my own experience.

I: AND DO YOU THINK THE WAY PEOPLE REACT TO THEIR PAIN IS A LEARNT THING, EITHER FROM ... YOU KNOW WHEN YOU ARE A KID, YOU LEARN THINGS FROM YOUR PARENTS, OR WHATEVER, OR WHEN YOU SEE OTHER PEOPLE IN A CHRONIC PAIN - CAN YOU LEARN FROM THEM, OR IS IT SOMETHING THAT YOU JUST HAVE TO LEARN AND GET ON WITH YOURSELF?

R: Umm ... Well, I well, definitely from my experience its something that I just learnt for myself. I mean, if you were around someone that is in pain, erm, its quite difficult, erm, because then I, I, it, I, I think, you know, its probably, yeah, I, I think there's an element that people could learn it, erm, so that if they are around people that are in pain and its something that's always been talked about since you've grown up, you, in some ways you might have a lower threshold of pain, because you might think, you know, 'cause, it, it, it's something that's always around. I think for my own experience of it though, I haven't lived around it as I was growing up, its only something that I've experienced now, in my adulthood.

I: OK. SO DO YOU THINK ITS POSSIBLE THAT THE WAY PEOPLE REACT TO THEIR PAIN, AND THEIR COPING STRATEGIES, AND THEIR MEANINGS, CAN BE PASSED THROUGH GENERATIONS?

R: Yeah, I, I, I definitely think there could be an element of that, yeah, yeah, definitely, I think you can. People could learn from it, and not, so their, its not their own judgement and their own personal view of it, because actually, 'cause they, I mean they, obviously, people go through their lives and everybody has certain pain, but it, it, actually how you quantify it, 'cause if they've been around people that have been in awful pain, they might just have a little pain or for a short period of time, but they may put that out of proportion ...

I: YES.

R: ... and perspective, because they've been surrounded. And also, perhaps it is dependent on how the family operates. If someone is in pain, it means they get lots of sympathy and that kind of thing, erm, it may be like, 'well, you know, I'd quite like to be in that, 'cause I get ignored if I'm not in pain'. I don't know, but I'm just saying that is something that I think perhaps could, perhaps could be, 'cause I think that people perhaps use pain to get attention and that kind of thing. But I mean, if you've genuinely experienced it, and it is so awful, I can't for the life of me see why people would want to exaggerate it or be in it, or pretend they're in it if they're not, because I just think, why would you even want to go down there, because if you genuinely have experienced it, it is so, so horrible.

I: OK. SO, IF YOU WERE OLDER OR YOUNGER, DO YOU THINK YOUR EXPERIENCE OF PAIN WOULD BE DIFFERENT?

R: Sorry, could you say that again, please?

I: IF YOU WERE OLDER OR YOUNGER, DO YOU THINK YOUR EXPERIENCE OF PAIN WOULD DIFFERENT? OR DO YOU THINK IT WOULD JUST BE AS IT IS NOW?

R: Um ... what never having experienced it before, or having ...?

I: YEAH. IF YOU THINK OF HOW YOU ARE NOW, DO YOU THINK IT WOULD BE BETTER IF YOU HAD HAD IT WHEN YOU WERE YOUNGER, OR BETTER IF YOU HAD IT WHEN YOU ARE OLDER, AND HOW YOU'D, HOW, WHAT WOULD BE DIFFERENT ABOUT IT?

R: Oh, um, well when I did have it when I was younger, um, if I was really young, yeah, I think it would impact on your life, the way you are. Older is, I think more of a worry, because I think, if you are in pain, and your body's not moving so well and going so well, it, it could be more debilitating, so I think its perhaps more scary when you are older, to be in pain, because you actually think, 'am I going to get out of this? Is it going to get better? Are, is there less I can do to help myself?' because I think when you are younger you can perhaps get more active and get involved in things, and definitely use the mind over matter, but I think perhaps if

you're older, its harder, and then it does definitely mean perhaps more dependency, and less control, and that kind of thing. So I think it actually, the older you get, I think, pain is perhaps a bit more scary. That's the way I would see it. The younger, I think it, generally, and you had a bout of it, you'd try and rise above it, and move forward. Well, I personally would, and try and get out of it, and, and move forward. But I, I think from where I am now, and I had this when I'm older, erm, I, er, more worrying.

I: YEAH, OK. SO DO YOU THINK MEN AND WOMEN HAVE DIFFERENT EXPERIENCES OF PAIN?

R: Erm ...

I: OR IS IT JUST THAT THE EXPERIENCE MAY WELL BE THE SAME, BUT DO YOU THINK THEY REACT TO IT IN DIFFERENT WAYS?

R: Yeah, yeah, I think, I think they do, 'cause I think that some men probably have quite high pain thresholds and erm, and really keep going, and then I think some women do. But then again I think there's some that would probably perhaps, because of the environment that they live in and that kind of thing, they, they'd benefit from perhaps exacerbating it more. And that would be different personalities and that kind of thing.

I: SO YOU THINK IT'S PERSONALITY TYPE RATHER THAN SORT OF GENDER?

R: Yeah, I think so, because I think you'd get different, I think you get on the gender side of it, I think you'd get people that would battle through whatever, and people that would, you know, um, try and make the most of it. So I would definitely say personality, yeah.

I: YEAH, OK. WHAT ABOUT DIFFERENT CULTURAL GROUPS?

R: That's interesting. I hadn't really thought about that, because I, I don't think I've ever spoken to anyone from a different culture that has experienced pain.

I: OK. SO, APART FROM INJURY, WHY DO YOU THINK PEOPLE GET PAIN?

R: Apart from injury? Erm ... well, I, I, this is, is an interesting thing. I, I don't know. I think that the body does weird things. I think hormones can cause pain, definitely for women, and erm, I'm sure, I'm sure probably for men to an extent. Erm, stress can cause pain.

I: OK.

R: Erm ...

I: SO DO YOU THINK THERE'S A DIFFERENCE BETWEEN PHYSICAL PAIN AND EMOTIONAL PAIN, OR DO YOU THINK THEY ARE LINKED?

R: I th ... erm ... I think if you get physical pain, you can get emotional pain. Erm ... yes, I think they definitely are linked, yeah. Definitely.

I: SO DO YOU EVER BLAME YOURSELF WHEN YOU'RE IN PAIN?

R: Um ... (long pause). Actually no, I don't think I do actually, no, no.

I: SO DO YOU EVER BLAME OTHER PEOPLE, THAT YOU ARE IN PAIN, OR ...

R: I do, I do sometimes think yeah, why me, why have I got this? You know, because I think I do a lot to keep myself fit and well, and particularly from this last erm, bout of it – I, I kind of feel short changed, 'cause I think for the last ten years, I have worked so hard to keep myself fit and well, I think I don't deserve this, yeah, and I think its, I, its unjust.



I: SO WHERE DO YOU THINK YOUR RESPONSIBILITY LIES FOR THE MANAGEMENT OF YOUR PAIN?

R: With me.

I: YEAH.

R: Yeah, I do.

I: I KIND OF GOT THAT IMPRESSION, 'CAUSE YOU WERE SAYING ALL THE THINGS THAT YOU DID AND IT WAS VERY MUCH ANTI ...

R: Yeah, with me, yeah, definitely with me, yeah.

I: THERE'S SOME PEOPLE THAT I HAVE SPOKEN TO THAT SAY THAT THEIR PAIN IS DOWN TO FATE, SO I WONDERED WHAT YOU THOUGHT ABOUT THAT?

R: Sorry - down to?

I: FATE.

R: (Laughs). Erm ... yeah, I, yeah, I mean I, I sometimes, I mean I do, er, you know, often think about fate, and I do, I do believe in it, and I think, I, there is an element of that, yeah, because, you know, my, my sister is, you know, didn't have anything, and er, and she's never had any surgery or anything, whereas I have. And I think, you know, but that was what I've been dealt with. But then again, you know, there's other people who've been dealt with more, with worse things, and you just don't know. But I do feel it, because its not like something's happened, or I've been in an accident and it's a continual knock-on effect from that. Its something that's happened to me, and I'm like 'well, why?' That's one of the things I don't understand, because I don't think I should have it, 'cause I do work so hard to keep myself fit and well.

I: OK. SO - DO YOU THINK THE PAIN EXPERIENCE IS ASSOCIATED WITH ANY RELIGIOUS OR SPIRITUAL CULTURAL BELIEFS AT ALL?

R: No, I don't, no.

I: AND, YOU PROBABLY KNOW THIS, THAT IN SOME RELIGIOUS BELIEFS, PAIN IS ASSOCIATED WITH PUNISHMENT, OR TO THE OTHER EXTREME, THAT YOU HAVE BEEN CHOSEN TO BEAR PAIN. SO I WONDERED WHAT YOU THOUGHT ABOUT THOSE COMMENTS?

R: I think, I, in that, I suppose in dark moments, like, you do think 'why me?' But I have to say that those views kind of aren't part of my makeup and my being, so in particular dark moments I might think about that, but that wouldn't be something that would be on my mind, no.

I: OK.

R: I'd get, I'd probably get miserable and down and, and that kind of thing, but no, I wouldn't spend a lot of time thinking about that because it, that isn't kind of, the sort of thing that I would generally live by or think about.

I: NO, OK. SO, HOW DO YOU THINK BEING IN PAIN COULD MAKE YOU DISABLED?

R: Because you don't act ... you can't move as well.

I: SO IT'S ALL RESTRICTIONS ?

R: Yeah, it does restrict you in cert ..., in certain ways, yeah. And I suppose if you allowed that to continue, you'd kind of sort of seize up a bit really.

I: OK. SO THEY'RE ALL MY QUESTIONS. IS THERE ANYTHING ELSE THAT YOU WANT TO TELL ME ABOUT PAIN, THAT WE HAVEN'T COVERED, THAT YOU THINK MIGHT BE USEFUL OR IMPORTANT?

R: Um ... just something came to me, just at the end there, that I was thinking about, is, is limitations. I suppose this particular bout has actually started making me think about, because I think I've, I, I haven't wanted to er, change my lifestyle at all, I think, that's me, its like, you know, I work, I do this, this, this and this, and I, you know, I look after myself, family. I've always run a home. And, and that's the way I, I always want it to be, so when I have been in pain before and that, that's kind of had to fall by the wayside, and then I've got myself back to it again, but this time, I'm noticing that I'm perhaps having to adapt my lifestyle and know my limitations, and in, one, I give an instance, its like I know that Hoovering is terrible, for me, so I've actually got a cleaner now.

I: EXCELLENT.

R: And, and is that necessarily a bad thing? Do you know what I mean? I don't know, because um, perhaps, and, and also I'm wondering that perhaps its because I am older, and the pain is being different, but I'm looking now, you know, its like, why struggle and wash the car and Hoover it out, when you can just drive somewhere and they do it for you? Why keep pushing and pushing and pushing yourself the whole time? So I've noticed that I've had to get my limitations and its OK, you know, its acceptable.

I: AND DO YOU THINK THAT'S PART OF IT, LEARNING TO ACCEPT WHAT YOU CAN AND CAN'T DO, AND THAT MAKES IT MORE BEARABLE?

R: Yes, I think so, and I would imagine that's what its like if you suddenly had a disability, 'cause you wouldn't, some people wouldn't want to accept it, and they'd be fighting all the time, and its perhaps, well, you've got to learn to adapt a bit here. But you can have a lifestyle, but it, it may need, you know, some er, er, sort of accommodation in different ways, and I, and I think this time I've, I'm kind of learning, well I can do X and feel OK, but Y might make me feel a little, you know, is not so good.

I: YES, YES, I SEE WHAT YOU'RE SAYING.

R: So I don't know whether that's useful.

I: NO, THAT IS USEFUL. BUT IS THERE ANYTHING ELSE YOU WANT TO SAY?

R: No. Just - there's some very interesting questions, that made me think, you know ...

I: OK, WELL, THANK YOU VERY MUCH AND I'LL SWITCH THE TAPE OFF. THANK YOU VERY MUCH.

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